The Development and Evaluation of the Preparedness for Employment Scale for people with Personality Disorders

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Thesis submitted for the Degree of Doctor of Philosophy

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Declaration

I, [redacted] [redacted] confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

The following work was carried out at the Research Department of Clinical, Educational and Health Psychology, University College London, under the supervision of [redacted], [redacted] and [redacted]. This thesis has not been submitted, in whole or in part, for any other degree, diploma or qualification at any other University.

My work was funded by the National Institute for Health Research (NIHR) Programme Grant for Applied Research (RP-PG-1212-20011) as part of the EMPOWER programme.

This thesis does not exceed the limit of 100,000 words specified by the Degree Committee.

Correspondence concerning this thesis should be addressed to [redacted], [redacted].

Signed, 16th September 2019
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I am looking forward to spending some quality time with you all!

I am so grateful for my immediate family, Mum, Dad, who would always be there to distract or support me with a phone call, funny photos, videos, and kind words of encouragement. I would like to give special thanks to my Mum with her amazing delivery of Malaysian food, and my sister who proofread my work endlessly. Last but not least, I would like to give my absolute thanks to my wonderful fiancé, who has been with me from the start of this journey until now. I am forever grateful.
Abstract

People with Personality Disorders (PD) often experience challenges to employment. Being prepared for work may be an essential part of overcoming these challenges. Identifying the obstacles and the extent one is ready for work may help in the planning of employment support for people with PD. The purpose of this thesis was to develop and evaluate the psychometric properties of the Preparedness for Employment Scale for people with Personality Disorders (PES-PD); the first employment-related scale for measuring preparedness for employment for PD.

Chapter 1 presents background literature on PD and employment, including PD employment interventions and the importance of validated measures. The first study was a systematic review (Chapter 2) assessing the literature for PD and employment scales; the results showed a lack of appropriate PD scales. Consequently, this thesis conducted two studies; focus groups and an e-Delphi to develop the underlying construct of preparedness for employment and explore potential content to inform a new scale (Chapter 3). A 57-item version of the PES-PD was produced and then piloted (n=109) for its content and face validity in Study 4 (Chapter 4). The results of the pilot study provided a 35-item PES-PD. The final study conducted construct validity and internal consistency on the 35-item PES-PD (n=650) (Chapter 5). The results demonstrated a 3-factor model: Interpersonal (IV), Emotional Regulation (ER), Vitality (V), with good construct validity and internal consistency (Cronbach’s $\alpha = .74$ [full scale], $\alpha = .85$, $\alpha = .74$, and $\alpha = .77$ [subscales respectively]).

These findings suggest a promising self-report scale demonstrating promising psychometric properties. The PES-PD should be considered for use as an outcome measure, in the planning of employment treatment for PD, and to identify appropriate timing into work. Future research will involve further psychometric evaluation and assessing the clinical utility of the PES-PD.
Impact Statement

My key contribution to knowledge is the conceptualisation of preparedness for employment for people with personality disorders. The work presented in this thesis presents a novel employment scale; the preparedness for employment scale for people with personality disorders (PES-PD).

The work presented in this thesis was part of a National Institute for Health Research funded programme (NIHR) called Enabling and Motivating People (with a Personality Disorder) in Occupation, Education and Responsibility. EMPOWER’s overall aims is to develop, evaluate, and implement an intervention (Dialectical Behavioural Therapy-Skills for Employment: DBT-SE). The intervention will teach clients the skills they need to obtain and retain employment. DBT-SE aims to improve emotional, interpersonal and physical functioning and also benefit the family and social network of the participant.

One key objective of EMPOWER was to develop and evaluate the PES-PD, for use in treatment, planning, and outcome measurement. Another objective is to disseminate the PES-PD, alongside the DBT-SE treatment manual and training package to both specialist and non-specialist audiences.

The studies in this thesis have gained the interest of clinicians across different mental health services in North East London NHS Trust (NELFT), employment specialists at third party organisations, Mind in City and Hackney and Richmond Fellowship and Department for Work and Pensions JobCentre work coaches.

A version of the systematic review (Chapter 2), and pilot study (Chapter 4) was prepared and presented as a poster at NELFT’s Research and Development Conferences titled: “The Art of Asking Questions: A Systematic Review of Personality Disorder and Employment Scales” and “The Preparedness for Employment Scale: a Pilot Study”.

A version of Chapter 2, 3, and 4 have been submitted for publication but were not accepted. I have considered reviewers comments and revised the papers. The revised versions will be resubmitted for review in the next six months.
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<td>APA</td>
<td>American Psychiatric Association</td>
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<tr>
<td>APD</td>
<td>Antisocial Personality Disorder</td>
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<td>AMHOCN</td>
<td>Australian Mental Health Outcomes and Classification Network</td>
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<tr>
<td>ANOVA</td>
<td>Analysis of Variance</td>
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<tr>
<td>APQ6</td>
<td>Activity and Participation Questionnaire</td>
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<td>AVP</td>
<td>Avoidant Personality Disorder</td>
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<tr>
<td>BDI-II</td>
<td>Beck Depression Inventory-II</td>
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<td>BIGSPD</td>
<td>British and Irish Group for the Study of Personality Disorders</td>
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<td>BPD</td>
<td>Borderline Personality Disorder</td>
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<td>BECES</td>
<td>Barriers to Employment subscale</td>
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<td>BSI</td>
<td>Brief Symptom Inventory</td>
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<td>CAS</td>
<td>Change Assessment Scale</td>
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<td>CHOICE</td>
<td>CHoice of Outcome In Cbt for psychosEs Scale</td>
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<tr>
<td>CIPD</td>
<td>Chartered Institute of Personnel Development</td>
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<tr>
<td>CFA</td>
<td>Confirmatory Factor Analysis</td>
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<td>CFI</td>
<td>Comparative Fit Index</td>
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<td>COSMIN</td>
<td>COnsensus-based Standards for the selection of health Measurement Instruments</td>
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<tr>
<td>CRO</td>
<td>Clinician-Reported Outcome</td>
</tr>
<tr>
<td>CTT</td>
<td>Classical Test Theory</td>
</tr>
<tr>
<td>DBT</td>
<td>Dialectical Behaviour Therapy</td>
</tr>
<tr>
<td>DBT-ACES</td>
<td>DBT- Accepting the Challenges of Exiting the System</td>
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<tr>
<td>DSM</td>
<td>Diagnostic and Statistical Manual of Mental Disorders</td>
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<tr>
<td>DTPD</td>
<td>Decision Tool Personality Disorder</td>
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<tr>
<td>DWP</td>
<td>Department for Work and Pensions</td>
</tr>
<tr>
<td>EFA</td>
<td>Exploratory Factor Analysis</td>
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<tr>
<td>EMPOWER</td>
<td>Enabling and Motivating People (with a Personality Disorder</td>
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<tr>
<td>ER</td>
<td>Emotional Regulation</td>
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<tr>
<td>ES</td>
<td>Employment Support</td>
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<tr>
<td>FFM</td>
<td>Five Factor Model</td>
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<tr>
<td>HCP</td>
<td>Healthcare Professionals</td>
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<td>HEXACO</td>
<td>Health</td>
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<td>HoNoS</td>
<td>Health of the Nation Outcome Scal</td>
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<td>IAPT</td>
<td>Increasing Access to Psychological Services</td>
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IRT  Item Response Theory
ICD  International Classification of Diseases
IP  Interpersonal
NHS  National Health Service
NIHR  National Institute for Health Research
NPD  Narcissistic Personality Disorder
OAPS  Occupational Abilities and Performance scale
OFS  Occupational Functioning Scale
OCPD  Obsessive Compulsive Disorder
PD  Personality Disorder
PPD  Paranoid Personality Disorder
PES-PD  Preparedness for Employment Scale for people with Personality Disorders
POD  Patient Owned Database
PRO  Patient-Reported Outcome
PSY-5  The Personality Psychopathology Scale-5
QOLI  Quality of Life Interview
RA  Research Assistant
RCT  Randomised Controlled Trial
RMSEA  Root mean square error of approximation
SAPAS  The Standardised Assessment of Personality – Abbreviated Scale
SAS-SR  Social adjustment scale
SCID  The Structured Clinical Interview for DSM-IV
SRMR  Standard root mean square residual
STAXI  State-trait anger inventory
TA  Therapeutic assessment
TSSES-PMI  Task-Specific Self-Efficacy Scale
URICA-VC  University of Rhode Island Change Assessment for Vocational Counseling
V  Vitality
VSSAS  Vocational Social Skills Assessment Scale
WBC  Work Behaviour Checklist
WBI  Work Behaviour Checklist
WHO  World Health Organisation
WEIS  Work Environment Impact Scale
WoRQ  Work Readiness Questionnaire
<table>
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<td>WORQ</td>
<td>Work Rehabilitation Questionnaire</td>
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<td>WRI</td>
<td>The Worker Role Interview</td>
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<td>WRSES</td>
<td>Work-Related Self-Efficacy Scale</td>
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<td>WSES</td>
<td>Work-related Subjective Experiences Scale</td>
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<tr>
<td>WVQ</td>
<td>Work Values Questionnaire</td>
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<tr>
<td>ZAN-BPD</td>
<td>Zanarini Rating Scale for Borderline Personality Disorder</td>
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Chapter 1  Introduction

The overall focus of this thesis relates to the development and evaluation of a ‘Preparedness for Employment Scale for people with Personality Disorders (PES-PD)’. The thesis outlines the complex relationship between personality disorder and employment and explores the challenges to work that impact on preparedness. Chapter 1 presents background information about personality disorders and employment. It begins with the general literature on employment and mental health and expands to personality disorders, treatments, and psychometric scales. Chapter 2 discusses a systematic review of employment scales for personality disorders. Chapter 3 describes a qualitative study that examines the concept of preparedness for work for personality disorders and an e-Delphi study, with the anticipation of devising items for a new employment scale, the PES-PD. Chapter 4 consolidates the results of both Chapter 2 and 3 and selects items for the PES-PD based on the findings of a pilot study. Chapter 5 presents a psychometric evaluation of the finalised PES-PD and Chapter 6 leads the reader to a general discussion of the thesis.

1.1 Employment

Employment is defined as paid or competitive work, full-time or part-time, and can be measured by the number of paid hours (Bond, Drake, & Becker, 2008). Employment status is often described as dichotomous ‘unemployed’ or ‘employed’ and is a common outcome in employment intervention studies (Rogers et al., 2001; Tsang & Pearson, 2000). Employment is known to be part of ‘social inclusion’, whereby people with mental illnesses can recover by gaining meaningful and satisfying lives through social inclusion activities such as employment (Repper & Perkins, 2003).

Employment tends to enhance several positive social, clinical, and economic benefits. Some people who work experience a decrease in social isolation, increase in self-esteem, and improved quality of life (Gary R Bond & Drake, 2012; Dunn, Wewiorski, & Rogers, 2008). Financial rewards may also be gained from employment (Dunn et al., 2008), as well as an increase in personal growth and improved mental health (Honey, 2004; Marwaha, & johnson, 2004
The opportunity to grow personally and the experience of returning to work (e.g. starting again and getting through any initial stages) may contribute to positive changes in oneself. Some people view employment as a way to get well and stay well by exercising one’s improved mental health.

Identity formation was found to mediate employment in young adulthood (Luyckx, Schwartz, Goossens, & Pollock, 2008) suggesting that work may be associated with identity in young people. Identity, however, is argued to change across the lifespan (Erikson, 1959) and thus may mediate employment at various ages. For some, identity at middle adulthood between age 35 to 65, centres around work and career (Erikson, 1959; Fras, 1968). The individual typically builds their identity towards stability and aims to create a meaningful change in society. It is important to note that employment may not be central to everyone’s identity. Sickness, disability, age and retirement may potentially threaten employment; thus, identities built on personal relationships, are argued to be more fundamentally important (i.e. sister, brother, friend, husband) (Fryers, 2006). Nonetheless, deficits in identity and self-worth are known to be critical markers for mental illnesses (e.g. Abramson, Metalsky, & Alloy, 1989; Beck, 1967), and as employment and identity may be associated, vocational difficulties may be prevalent for some people with mental illnesses.

1.2 Mental Health and Employment

1.2.1 Theories of Mental Health and Employment

Several theoretical models have dominated employment and mental health; the Latent Deprivation Model (Jahoda, 1982); the Vitamin Model (Warr, 1987) and the Agency Restriction Model (David Fryer, 1986). These models offer approaches to understanding the deterioration of people’s psychological wellbeing due to unemployment, ensuing an ongoing debate between manifest versus latent benefits (Jahoda 1992), as well as between contextual or situational factors and individual differences.

Jahoda’s model (1982) argues that employment brings both manifest benefits such as financial gains and latent benefits such as Time Structure, Social Contact, Collective Purpose, Status and Activity, with a true emphasis on
social institutions. Time Structure refers to the idea that employment brings organisation to a persons’ days and weeks. Unemployment deprives people of structure to their daily lives and often time is experienced as ‘dragging’. Social Contact concerns the interaction with other people. Collective Purpose involves the ability to feel connected to any community where people have common goals. Status refers to the extent to what a person does is valued and important. Finally, Activity relates to things that a person usually or rarely does. Unemployment is considered to lead to the loss of both manifest and latent benefits, but it is thought that the deprivation of the five latent benefits is what leads to psychological unwellness (Feather & Bond, 1983; Jahoda, 1992).

Numerous studies have provided evidence for Jahoda’s model (1982). In earlier studies, unemployed people demonstrated fewer Social Activities than those who were employed (Underlid, 1996). Less Social Contact in people who were unemployed was also associated with poorer mental health (Haworth, 1991). Furthermore, unemployed people were found to have less Time Structure compared to people who were employed (Jackson, 1999), and that having reduced access to Time Structure was linked with poorer well-being (Evans & Haworth, 1991). Status was found to be the most important latent benefit predictor of well-being in an unemployed sample, Time Structure was second, followed by Collective Purpose (Creed & Macintyre, 2001). In addition, Collective Purpose and Social Support were both found to be the most important latent benefits associated with psychological distress (Creed & Klisch, 2005). Overall, differences have been shown between employed and unemployed people in being able to access combined latent benefits, where people who are unemployed have less access to latent benefits and consequently have poorer mental health (Creed & Macintyre, 2001).

These studies also suggest that it is likely that people who are in different stage of unemployment may be psychologically distressed by deprivation of different latent benefits. For instance, it is possible that Status and Time Structure may be more prominent at the initial stages of unemployment, whereas deprivation of Collective Purpose and Social Support may be more important in prolonging mental health difficulties in the long term. Longitudinal
studies have provided some support for this idea of different stages of unemployment and different associations between deprivation of different latent variables (Mckee-Ryan, Song, Wanberg, & Kinicki, 2005; Selenko, Batinic, & Paul, 2011; Stiglbauer & Batinic, 2012).

The Vitamin Model (Warr, 1987), like the Latent Deprivation Model in which situation and context is integral to the theory, depicts nine (and later 12) environmental features that are argued to influence mental health and employment. The nine environment features are: opportunity for control, opportunity for the use of skill, externally generated goals, variety, environmental clarity, availability of money, physical security, opportunity for interpersonal contact, and valued social position. The analogy behind this model is that these ‘vitamins’ influence mental health like vitamins to physical health. A deficit in any of these ‘vitamins’ may cause impairment to mental health and well-being. It is thought that after the initial increase of vitamins the positive impact of mental health would plateau, and that excess of certain vitamins may lead to decreased levels of mental health and well-being.

Evidence for this theory is limited (Klehe & van Hooft, 2014). Older studies found conflicting results and partial support for the theory between job characteristics such as demands of the job, social support, autonomy, and employment in mental health (De Jonge & Schaufeli, 1998). While there may not be so much evidence for this theory, there is considerable evidence for these individual factors in relation to mental health. For instance, a combination of high demands at work and low control, and high efforts and low rewards were found to be risk factors for development of common mental illnesses (Stansfeld & Candy, 2006). Similarly, those who lacked control over their work tasks and had high job strain were more likely to develop depressive symptoms (Theorell et al., 2015). More recently, a meta-analysis demonstrated job strain and level of control were risk factors for the development of depression (Madsen et al., 2017). Specifically, the amalgamation of excessive amounts of work, conflicting demands, or insufficient time to complete tasks and the lack of decision freedom or opportunities to learning new things at work was associated with increased risk of clinically diagnosed depression.
Both the Latent Deprivation theory and Vitamin Model are concepts that are situational-centred. This means individuals’ motivational levels are largely determined by the situation; latent benefits and the environment respectively. The Agency Restriction model (Fryer 1986) emerged as a reaction to these theories. Individuals are considered central agents in society, where they strive for purposeful meaning in line with personal values. The author argued that the main negative consequence of unemployment was not the loss of latent benefits but the loss of manifest benefits. It is the loss of income that places restrictions on the individuals’ ability to exercise personal agency, making it difficult to create a life with purpose, thus, negatively impacting mental health. Although the authors acknowledged that deprivation in levels of latent benefits contribute to poor mental health, they argued that it did not fully explain the reduction of well-being experienced by the unemployed (Fryer & Payne, 1984).

Evidence for the Agency Restriction model (Fryer, 1986) has been reported. In a study comparing one group of people who were permanently dismissed and another group who were made temporarily redundant, it was found that those in the latter group had arranged more active and structured lives and appeared to be more psychologically well than people who were permanently removed from this employment (Fryer & McKenna, 1987). The latent deprivation model argues that people who are unemployed will have equal deprivation of latent benefits and thus equal levels of psychological distress. This was not the case; the finding highlights the importance of manifest benefits. The unemployed people who were made temporarily redundant were able to maintain latent benefits outside of the work environment. They were more positive about their future and were returning to work to gain manifest benefits, as opposed to latent benefits. Other studies have also found that financial hardship has a substantial role in people who are unemployed. Unemployed people reported more financial stress than people who were employed and students (Jackson, 1999). Furthermore, manifest benefits have been found to be the most important predictor of well-being amongst those who were unemployed (Creed & Macintyre, 2001).
More recently, studies have provided evidence that suggests that psychological unwellness is linked to the deprivation of both benefits as opposed to one benefit being more dominant than the other (Selenko et al. 2011). In fact, Jahoda (1982, p 365) did not directly reject the Agency Restriction model as an opposing theory but approached the concept as “a greater emphasis on the study of poverty in unemployment, making economic hardship a central explicator of the psychological impairment”.

Other debates have focused on whether latent benefits should be considered as a whole construct or as five individual constructs (Hoare & Machin, 2010; Waters & Moore, 2002). Studies have found variations in the separate latent benefits and their associations with mental well-being. For example, it was found that Collective Purpose, Activity, Social Contacts, and Time Structure (as well as manifest benefits), but not Status contributed to better psychological well-being for employed people compared to unemployed (Selenko et al., 2011). Similarly, it was found that people who were re-employed were found to gain both Financial benefits and Latent benefits, however, being employed was only attributed to two of the five factors; Social Contact and Time Structure, which lead to better mental health (Hoare & Machin, 2010).

These theories are helpful to guide research, in which subsequent empirical studies can then provide further support or limitations to the models. Studies can focus on situational and macro-level context whilst also incorporating individual differences. The underlying theme is how mental health relates to changes in employment status and how people cope with short-term and longer-term unemployment. There are still questions concerning the sort of interventions required to support these people, and how might it impact their ability to work. However, one thing is clear, unemployment has negative effects that vary in magnitude depending on variables that relate both to the individual and the wider situational context. Having financial support lifts people out of relative poverty which safeguards from these negative effects. However, financial benefits alone may not solely improve mental health and well-being. Certain employment can also provide good psychological well-being due to these latent elements and ‘vitamins.’ Research also provides evidence that
people are not passive in the face of unemployment; individuals can make active choices and plans. However, further research may need to address the importance of work and its place in ensuring a healthy and fulfilling life for people with mental illnesses. Perhaps the key issue is to produce targeted interventions that consider not only psychological well-being but individual differences and environmental factors - essentially individualised support that involves both the individual and environment over time (Feather, 1990; Klehe & van Hooft, 2014).

1.2.2 Mental Illness and Employment

As it has been established in the review of mental health and employment theory, there is a complex bidirectional relationship between mental health and employment. Consequently, there has been an increase in research in mental illnesses and employment to better understand this two-way association (Harvey, Henderson, Lelliott, & Hotopf, 2009; Henderson, Harvey, Øverland, Mykletun, & Hotopf, 2011). Therefore, identifying when the right time is to return to employment may be important due to the causal complexities of employment and mental health.

Unemployment is recognised to be a cause of poor mental health (Herbig, Dragano, & Ärzteblatt, 2013; Paul & Moser, 2009) and is detrimental to health and well-being (Lelliott et al., 2008). Unemployment is also linked to higher levels of psychological morbidity and mortality (Mclean, Carmona, Francis, Wohlgemuth, & Mulvihill, 2005), associated with a significantly higher cardiovascular risk (Noelke & Avendano, 2015), and when accompanied by poverty and social exclusion, will contribute further to poorer mental health (Ritsher, Warner, Johnson, & Dohrenwend, 2001).

For others, however, unemployment can improve one’s mental health. For example, in some work settings, being out of work may recuperate a person’s mental health, especially if work conditions were stressful (Cox, Leka, Ivanov, & Kortum, 2004). Stressful jobs or tasks have been argued to be problematic for mental health (Cox, Griffiths, & Rial, 2000; Gabriel & Liimatainen, 2000). Similarly, it was found that employment that had negative
psychosocial factors contributed to poor mental health, as would unemployment (Butterworth et al., 2011).

Nonetheless, employment is generally accepted to increase good mental health (Waddell & Burton, 2006). Some people with mental illnesses found that employment created personal meaning and promoted recovery, consequently improving their mental health (Dunn et al., 2008). People with mental illnesses also reported that contributing to society, gaining a sense of achievement, social contact, and financial rewards generated positive benefits to their mental health (Boyce et al., 2008). Furthermore, work created satisfaction, which consequently leads to a sense of achievement.

A recent systematic review found that when some people with mental illnesses worked, it increased their well-being, particularly if good-quality supervision was present, and there were favourable workplace conditions (Modini, Joyce, et al., 2016). Supervision that provided task assistance, social and emotional support, and had good supervisor-supervisee interpersonal interaction helped to decrease levels of anxiety and depression (Mor Barak, Travis, Pyun, & Xie, 2009). Thus, it is not surprising that for many people who are out of work due to mental illness, returning to work may be a key factor in their recovery (Goldberg, Killeen, & O’Day, 2005; Krupa, 2004), especially if positive supervision resources were available, and a level of preparedness was attained.

1.3 Preparedness for Employment

1.3.1 Theories of Preparedness for Employment

Although there is no specific concept of ‘preparedness for employment’ there are some theories that explore general concepts of readiness for work. Work ‘readiness’ has been described as individuals who engage in preparation to obtain and retain employment (Anthony, 1994). Preparedness for employment may also be described as the psychological capability and tolerance to challenges related to employment. For example, reaction to unknown situations during the process of seeking and gaining employment, the tolerance of failure to obtain work for a period of time, the ability to tolerate the
stress of starting a job and the stress of keeping a job (Vuori & Vinokur, 2005).
It may also comprise of the readiness to act on opportunities, as well as the
competency to manage barriers and setbacks when following chosen
employment goals (Sweeny, Carroll, & Shepperd, 2006).

Other concepts that have been used to explore preparedness for
employment is the Model of Human Occupation (MOHO) (Bellg et al., 2004).
Although not a theory of preparedness per se, the MOHO model theorises the
reasons for engagement in meaningful occupation. It describes the process of
changing occupational performance. Studies have demonstrated it has
construct validity (Neville-Jan, 2008; Sue Parkinson, Chester, Cratchley, &
Rowbottom, 2008), and clinical assessment tools have been developed based
on the model. MOHO provides a framework to explain the relationship between
a person’s motives for occupation, habits and roles, and physical and cognitive
performance capacities in the context of their environment (Bellg et al., 2004).

Previous research exploring people with mental illnesses’ perspectives
on readiness to return to work found three themes based on the MOHO that
impacted readiness for employment: volition, habituation and environment (Prior
et al., 2013). ‘Volition’ was defined as ‘personal causation’ in which service
users were found to have a lack of self-belief that they can return to work or find
employment. People with mental illnesses described perceiving paid work as
overwhelming as they could not imagine returning to work after being
unemployed for an extended amount of time. Other studies have demonstrated
that people with mental illnesses believed their own sense of whether they are
ready for work is a strong predictor of successful paid employment (Tsang et
al., 2010; Tsang, Fung, & Chung, 2010). ‘Habituation’ was defined as the
process of organising routines and plans. Prior et al. (2013) found that
participants perceived vocational rehabilitation programmes to provide routine
and structure, as well as flexibility for reasonable adjustments. However,
concerns were raised regarding whether flexibility would be available in real
competitive employment. This often led to a sense of hopelessness (Tsang et
al., 2010) and that paid employment would never be a realistic option. In this
situation, exposure to more real work environments would allow individuals to
gain experience in expectations of employers as well as their own needs, thus increasing hopefulness. The third theme, ‘Environment,’ referred to co-workers, employers and health and how they have a positive or negative influence on their readiness for employment. Participants spoke of stigma and discrimination from colleagues and employers, which resulted in a fear of the workplace that added to beliefs concerning their inability to cope. Disclosure of a mental illnesses is ideal in order to receive appropriate support. This finding suggests individuals with mental illnesses should be supported in partnership with employers as well as healthcare professionals (HCPs).

1.3.2 Population-level and Community-level factors that influence Preparedness for Employment

This section explores several factors that may impact preparedness for employment at a population level as well at the community level. Namely focusing on social, economic, family and environmental as elements in shaping whether an individual is ready to take up employment.

Socioeconomic determinants

Significant associations have been demonstrated between socioeconomic factors and psychosocial factors and mental health (Andrade, 2000; Fryers, Melzer, & Jenkins, 2003; Hudson, 2005; Wang, Schmitz, & Dewa, 2010). For example, in the U.S., women and ethnic minorities report worse mental health than Caucasians and men (Franks, Gold, & Fiscella, 2003). Being in a stable relationship or happily married is associated with positive mental health. Those who are in high quality relationships have better mental health than people who are single or unhappily married (Holt-Lunstad, Birmingham, & Jones, 2008). Poor mental health due to lower socioeconomic status may further impact ‘preparedness for work’ as it influences the ability to remain in paid employment (Bartley & Owen, 1996). Moreover, this impact increases as unemployment rises. For example, a meta-analysis suggested that individuals with low socioeconomic status have lower levels of self-esteem (Twenge & Campbell, 2002). These effects were found to be significant for occupation and education, which suggests low socioeconomic status may impact preparedness. Furthermore, downward social mobility in employment status was demonstrated
to be linked to a sense of low control and mastery (Pearlin, Lieberman, Menaghan, & Mullan, 1981). In addition, people with low socioeconomic status often report low decision-making latitude, low control, job task variety, and poor work support and high demands in their jobs (Marmot & Theorell, 1988; Stansfeld, Bosma, Hemingway, & Marmot, 1998), possibly having implications on their preparedness for work. People with lower socioeconomic status also report a greater number of stressors related to relationships, finances, and employment than those of higher socioeconomic status (Gallo & Matthews, 2003; Lantz, House, Mero, & Williams, 2005). Again, this suggests potential implications on preparedness for employment.

In a recent study, people with low socioeconomic status perceived their status to negatively affect the treatment provided by their HCPs, their access to health care, and the relationship they had with their provider (Rosenbaum, Arpey, & Gaglioti, 2017). This suggests that access to any potential mental health and employment support may also be affected, thus influencing the likelihood to take up employment.

Other socioeconomic factors such as educational attainment may also impact preparedness for employment in people with mental illnesses. In the U.S., a positive association between educational attainment and employment outcomes and higher employment status with people with psychiatric disabilities was demonstrated (Mechanic, Bilder, & McAlpine, 2002; Mueser, Becker, & Wolfe, 2001). Similarly, in Australia, there was a significant link between educational attainment and present employment and retention in people with mental illness. There was a rise in employment proportion for each hierarchy of educational level attained, with employment increasing between primary, secondary and tertiary education levels (Jablensky et al., 1999; Waghorn, Chant, & 2002; Waghorn, Still, Chant, & Whiteford, 2004). Integrating educational training as part of an intervention may help increase preparedness for work, therefore improving employment outcomes and mental health.

Overall, research shows that socioeconomic factors impact individuals’ readiness to take up work. Low socioeconomic status increases exposure to stressors related to employment (Businelle et al., 2014), subsequently
increasing levels of low self-esteem and low control. Reducing exposure to
stressors related to employment may improve mental health and preparedness
for work (Thoits, 2010). In addition, increasing an individual’s levels of mastery,
self-esteem, social support may lessen the negative stress on mental health
and well-being, thus enabling their ability to return to work or gain employment.

Community-level determinants

Family may affect readiness for employment in individuals with mental
illnesses. Receiving support either at work or in the family is argued to be a
source that generates positive impact in one area that enhances the quality of
life in the other (Grzywacz & Marks, 2000). In other words, if family support is
poor, then this might have a casual sequence on individuals’ preparedness for
work. Likewise, the emotional support from family members is shown to impact
positively on the person with mental illnesses attitudes and behaviours in the
workplace (King, Mattimore, King, & Adams, 1995; Russo, Shteigman, &
Carmeli, 2015). In addition, improving family support can buffer potential
stressors of work on mental health (Grzywacz & Bass, 2003). It was found that
having family support while unemployed helped reduce psychological distress
(Huffman, Culbertson, Wayment, & Irving, 2015). More research is needed to
examine the mechanisms involving family support to increase preparedness for
employment in people with mental illnesses who are unemployed or on long
term sick leave.

Other community-level determinants such as low expectation of returning
to work from HCPs may be a factor that explains low rates of employment in
people with mental illnesses (Marwaha, Balachandra, & Johnson, 2009; Rinaldi
et al., 2010). Mental health symptoms often interfere with readiness for
employment (Lam, Filteau, & Milev, 2011), thus lowering HCP’s expectations of
the individual’s ability to return to work. The current discourse for mental health
and employment should consider the fact that some people can work in spite of
symptoms and that employment can be positive in terms of their recovery
(Rinaldi et al., 2010). Historically, employment needs would often be addressed
secondary to psychological symptoms or much later in the illness. For example,
it was found that only 22% of services had vocational rehabilitation woven into
care plans at a later stage (Lehman & Steirwachs, 1998). In the U.K. only 8% of people with mental illnesses in community mental health teams documented vocational needs within their care plan (Bertram & Howard, 2006). This suggests that preparedness for employment is not addressed in current community practices. More recently, due to U.K. government initiatives recognising that work is good for mental health (Waddell & Burton, 2006), there has been an increase in employment support aimed at helping people with mental illnesses into employment (Centre for Mental Health, 2016; NHS England, 2019).

Other community-level factors that may affect whether individuals with mental illnesses are ready for employment is disclosure of a mental illness. Both HCPs, employers, and individuals may be required to enable preparedness in the workplace during the disclosure stage (Ralph, 2002). The disclosure stage involves the individual informing the workplace of their mental illness for employers to make reasonable adjustments to address their mental health needs. People with mental illnesses report a fear of the workplace and an inability to cope, partially due to stigma and perceived expectation that employers will be inflexible concerning their needs (Prior et al., 2013). It is this stage that needs to be considered first, before people with mental illnesses can move onto the implementation stage; putting employment support in place where necessary (Schultz & Rogers, 2010). However, due to stigma and discrimination, readiness to disclose may be minimal in the workplace (Brohan et al., 2014), thus impacting people with mental illnesses readiness to take up employment.

The decision to return to work is typically beyond the person with mental illnesses’ control, as authorities such as case workers or HCPs are often responsible for assessing work capacity. This includes the power to refuse or extend the individual’s sick leave. Consequently, the power to return to work is often not within individual’s control who are on long term sick leave (Hillborg, Svensson, & Danermark, 2009; Millward, Lutte, & Purvis, 2005). Some studies showed that it is this lack of control that feeds into anxiety and stress-levels of a
person on sick leave (Hillborg et al., 2009; Saint-Arnaud, Saint-Jean, & Damasse, 2006), often impacting their ability to return to work.

**Employment Interventions**

Participating in employment interventions may affect preparedness for work. Examining current employment interventions may also provide further insight into what factors may help improve employment outcomes for mental illnesses. In the U.K., there has been an increased focus supporting people with mental health difficulties in preparing to return to work. The British Psychological Society and Royal College of Psychiatrists recognise that employment has both clinical and social benefits for the person with mental health difficulties (Khan & Boardman, 2017; Weinberg & Doyle, 2017). As part of the “Five Year Forward View” plan for mental health (Centre for Mental Health, 2016) and NHS Long Term Plan (NHS England, 2019), employment interventions, vocational rehabilitation, and employment support programmes have been established to support people with mental illnesses into employment.

The Individual Placement and Support programme (IPS), originally from the U.S., is an intervention designed for severe mental illnesses such as schizophrenia, Major Depressive Disorder (MDD) and Bipolar Disorder (BD) (Becker & Drake, 2009). There are eight IPS principles: eligibility based on client choice, a focus on competitive employment, integration of mental health and employment services, individualised job support, attention to client preferences, work incentives planning, systematic job development, and rapid job search (direct approaches to obtaining jobs rather than slower pre-employment assessments) (Drake, Bond, & Becker, 2012).

Support for IPS has been well documented in the literature. It is effective in helping people with mental illnesses gain competitive employment (Gary R Bond & Drake, 2012). IPS schemes double the likelihood that people with severe mental health illness attain employment (Centre for Mental Health, 2011). Seventeen randomised controlled trial (RCT) studies have documented the effectiveness of IPS in the U.S. (Marshall et al., 2014). Eleven systematic reviews comparing IPS vs Treatment as Usual (typically mental health services, traditional vocational training, pre-vocational, sheltered workshops and halfway
houses) have further demonstrated effectiveness for IPS in attaining competitive employment (Bond et al., 2008; Crowther, Lim, & Crowther, 2010; Crowther, Marshall, Bond, & Huxley, 2001; Heffernan & Pilkington, 2011; Kinoshita et al., 2013; Marshall et al., 2014). Singular studies have also found other employment benefits of IPS such as increased wages, job duration, and the number of hours worked (Boardman & Rinaldi, 2013). One limitation of IPS is its sensitivity to macroeconomics, factors concerning economy-wide phenomena such as the rate of economic growth and change in unemployment. This is because one of the fundamental principles of IPS relies on attainment of competitive employment. However, a more recent meta-analysis concluded that IPS can be generalised to countries other than the U.S. (Modini, Tan, et al., 2016).

IPS employment rates, however, indicate that IPS is not effective for everyone (Bond et al., 2001; Drake et al., 2012; Marshall et al., 2014). Average competitive employment rates were 58-60% compared to treatment as usual at 23-25%, suggesting there may be some limitations to IPS (Marshall et al., 2014). It was found that three quarters of people receiving IPS also received additional support in cognitive functioning, psychosocial skills, and symptom management (Loveland, Driscoll, & Boyle, 2007). This supplementary support is known as augmented IPS and effectiveness studies relative to standard IPS have been conducted (Dewa, Loong, Trojanowski, & Bonato, 2018).

Support for augmented IPS is mixed. A meta-analysis study found cognitive remediation using software to be effective (Chan, Hirai, & Tsoi, 2015). Chan et al. found when cognitive remediation was added to supported employment it was more effective than standard IPS in terms of increasing employment rate, duration of work, and wages earned. These findings suggest that cognitive remediation may improve benefits from supported employment programmes. Education programmes integrated with IPS services have also been implemented as augmented IPS. For example, one study introduced IPS after education training (Hutchinson, Anthony, Massaro, & Rogers, 2007; Rudnick & Gover, 2009) and another study incorporated education as one of the goals of IPS (Nuechterlein et al., 2008). However, there is a lack of
substantial evidence that these educational augmented IPS interventions were effective (Becker, Swanson, Reese, Bond, & Mcleman, 2015).

More research is required to first distinguish the different types of augmented IPS, which form works for whom, and the timing of when to implement them. For instance, at two years, augmented IPS groups relative to standard IPS groups were found to have attained more competitive employment among those who were rated as having low community functioning (Bell, Choi, Dyer, & Wexler, 2014). However, those who were measured to have high community functioning did not receive this outcome. This suggests that there may be sub-populations that could benefit from augmentation. Moreover, augmented IPS for people recently employed was found to be less effective than standard IPS (Mueser et al., 2005). This suggests the timing of implementing augmented IPS should also be considered, especially given that employed people may be associated with greater access to latent benefits such as Social Contact, Collective Purpose, Time Structure, Status and Activity (Creed & Macintyre, 2001; See Section 1.3.1).

Implementation barriers to IPS may suggest potential areas for research and contemporary interventions. These interventions may highlight the type of support required for preparedness for employment. Three barriers to implementation of IPS include attitudinal factors (employers, service users and clinician’s perspective on ability to return to work) (Larson, Sheehan, Ryan, Lemp, & Drandorff, 2014), contextual factors (current economic status and welfare system), and organisational factors within mental health services (Boycott, Schneider, & Osborne, 2014; Williams, 2015). These barriers are similar to the population and community-level determinants described earlier. It is thought that organisational barriers derive from the division between employment support services and mental health services (OECD, 2012). The delivery of IPS may benefit from an amalgamation of both, where the use of clinical skills from mental health services could be applied in an employment support setting. These types of interventions are emerging in the U.K (NHS England, 2019; Shiels et al., 2013).
Although the effectiveness of IPS has been well evidenced, the key components that contribute to its ability to aid preparedness for competitive employment is unclear. In a qualitative study assessing an employment workshop, Mee and Sumsion (2001) found generating motivation, building competence, and developing self-identity, were essential in readiness for employment. In an RCT examining the effects of two vocational interventions on the employment in people with mental illnesses, the Change Assessment Scale found that ‘contemplation’ was a key factor (Rogers et al., 2001). More studies are required to further understand the underlying mechanisms of IPS that enables preparedness for work.

1.4 Personality Disorders

1.4.1 Concepts of Personality Disorder

There are several approaches that contribute to concepts of personality disorders (Ekselius, 2018), including clinical features in the form of diagnostic descriptions, dimensional traits, neurobiological, and genetic contributions. By exploring these concepts, this thesis may begin to understand the relationship between employment and personality disorder.

Diagnostic Concept

Personality Disorder is defined by the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, [APA], 2013) as personality dysfunction (both self and interpersonal) and the presence of certain pathological personality traits, specific to the type of personality disorder (see Appendix 1: DSM-5 Criteria for Personality Disorders). Pathological personality traits are defined as negative affectivity, detachment, antagonism, disinhibition, and psychoticism. The 11th edition of the International Classification of Diseases (World Health Organisation, 2016) classifies personality disorders in levels of severity, mild, moderate or severe and provides a separate description of five stylistic domain traits: Negative, Affectivity, Detachment, Disinhibition, Dissociality and Anankastia (Obsessive-Compulsive). Both diagnostic models describe the
presence of personality disorder when impairments are pervasive and stable across time and occur across both personal and social situations.

Traditionally, the DSM and ICD definitions of personality disorders were based on categorical models. Categorical models of personality disorder establish mental illness as a set of discrete characteristics, with boundaries between normality and illness (Trull & Durrett, 2005). Whilst it is important to recognise the advantages of existing categorical diagnostic models of personality such as ease of communication and access to clinical treatment and research (Casey et al., 2004; Gonzalez-Pinto et al., 2004), they are somewhat undermined by comorbidity (Hopwood, Zimmermann, Pincus, & Krueger, 2015; Stinson et al., 2008), and excessive within-diagnosis heterogeneity. For example, there are 126 ways to meet the diagnostic criteria for Borderline Personality Disorder (BPD) (Trull & Darrett, 2005). Consequently, in contemporary clinical practice, the overall approach to classifying personality disorders is departing from traditional categorical approaches towards dimensional trait models of personality. The evolution we have seen between DSM-IV to DSM-5, as well as the trait focused definitions in the ICD-11, demonstrates this movement (Hopwood et al., 2018; Skodol, 2012; Tyrer, Crawford, Mulder, 2011).

**Dimensional Trait Concept**

Dimensional models offer an alternative approach to personality disorders by focusing solely on personality traits. Perhaps the most popular and well researched is the Five-Factor Model (FFM: Costa & McCrae, 1990). The five domains of personality traits include neuroticism versus emotional stability, introversion versus extraversion, closedness to experience versus openness to experience, antagonism versus agreeableness, and negligence versus conscientiousness. Table 1. presents the FFM traits. The FFM incorporates some DSM-IV diagnostic characteristics and provides a profile of personality disorder traits (Costa & McCrae, 1990). There is also evidence to suggest that the FFM can help discriminate between different personality disorders (Trull, Widiger, Lynam, & Costa, 2003). In the newer, updated version of the diagnostic model DSM-5, the personality disorders criteria were found to be
associated with domains in the FFM (Kajonius & Dåderman, 2017; Trull & Widiger, 2013). This is not surprising as a section of the DSM-5 includes a five-domain dimensional model that coordinates closely with the FFM (APA, 2013; Widiger, 2011).

Table 1. *Five-Factor Model Traits.*

<table>
<thead>
<tr>
<th>Big Five Dimensions</th>
<th>Facet (and correlated trait adjective)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extraversion vs introversion</td>
<td>Gregariousness (sociable) \ Assertiveness (forceful) \ Activity (energetic) \ Excitement-seeking (adventurous) \ Positive emotions (enthusiastic) \ Warmth (outgoing)</td>
</tr>
<tr>
<td>Agreeableness vs Antagonism</td>
<td>Trust (forgiving) \ Straightforwardness (not demanding) \ Altruism (warm) \ Compliance (not stubborn) \ Modesty (not show-off) \ Tendermindedness (sympathetic)</td>
</tr>
<tr>
<td>Conscientiousness vs lack of direction</td>
<td>Competence (efficient) \ Order (organised) \ Dutifulness (not careless) \ Achievement striving (thorough) \ Self-discipline (not lazy) \ Deliberation (not impulsive)</td>
</tr>
<tr>
<td>Neuroticism vs emotional stability</td>
<td>Anxiety (tense) \ Angry hostility (irritable) \ Depression (not contented) \ Self-consciousness (shy) \ Impulsiveness (moody) \ Vulnerability (not self-confident)</td>
</tr>
<tr>
<td>Openness vs closedness to experience</td>
<td>Ideas (curious) \ Fantasy (imaginative) \ Aesthetics (artistic) \ Actions (wide interests) \ Feelings (excitable) \ Values (unconventional)</td>
</tr>
</tbody>
</table>

*Note.* (John & Srivastava, 1999)
Personality disorder has also been found to be associated with other dimensional models such as the PSY-5 (Trull, Useda, Costa, & McCrae, 1995), the 18-trait dimensional model (Livesley & Jackson, 2009), and the HEXACO (Lee & Ashton, 2004). Livesley and Jackson’s (2009) 18-trait dimensional model has been used to describe each DSM categorical personality disorder (Pukrop et al., 2009), while the PSY-5 is also linked to personality disorder symptoms and low agreeableness, as measured in the HEXACO, are in line with BPD features (except honesty-humility) (Hepp et al., 2014). There is growing evidence for dimensional models to explain personality disorders.

**Neurobiological Concepts**

The earliest attempts in conceptualising personality disorders from a neurobiological approach involved a model based on clinical features of Axis I disorders relevant to personality disorders and conjoining them with neurological evidence (Siever & Davis, 1991). Siever and Davis (1991) associated each clinical characteristic to biological correlates and indicators. It was assumed some were causal and some were biomarkers. For instance, eye movement dysfunction in schizophrenia, which was also seen in individuals with schizotypal personality disorder and in nonpsychotic relatives of people with schizophrenia. Furthermore, there is evidence to suggest neurotransmitter functioning that may link Axis II disorders with Axis I disorders (Krueger & Markon, 2006). More recently, neurological studies have focused on BPD which may provide some evidence for associations between underlying neurobiology of specific dimensions such as impulsivity and affect instability (Crowell et al., 2012; Fonagy, Luyten, & Strathearn, 2011; New & Siever, 2003; Stepp, Burke, Hipwell, & Loeber, 2012).

The seven-factor model of personality is a proposed model based on trait and neurobiology (Cloninger, Svrakic, & Przybeck, 1993). It involves four dimensions of temperament and three dimensions of character. Temperament includes harm avoidance (avoidance and sensitivity to punishing stimuli), novelty seeking (a penchant towards exhilaration, impulsive decision making, and avoidance of frustration), reward dependence (a tendency to respond to positive signals and maintain rewarded behaviour) and persistence (a tendency
to persevere in spite of fatigue or frustration) (Svrakic, Whitehead, Przybeck, & Cloninger, 1993). The three dimensions of character include self-directedness (the extent to which individuals are goal-oriented and resourceful), cooperativeness (the ability for individuals to relate to one another), and self-transcendence (the degree the individual is spiritual, idealistic, and transpersonal). Cloninger et al. (1993) proposed that temperaments, novelty seeking, harm avoidance, and reward dependence are heritable and correlate with low basal dopaminergic activity, high serotonergic activity and low basal noradrenergic activity, respectively (Cloninger, 1986). From this model, an empirically derived seven-factor model for all personality disorders was proposed (Cloninger & Svrakic, 1994).

The model has influenced psychiatric and psychological research, although empirical support for its conceptualisation and links between personality disorders has been mixed (Widiger, 2005). Some studies have queried the seven-factor structure in general (Ball, Tennen, & Kranzler, 1999; Herbst, Zonderman, McCrae, & Costa, 2000), suggesting a lack of evidence for the temperament and character dimensions (Herbst et al. 2000; Ando et al., 2004). Furthermore, current understanding of neurobiology appears to be insufficient in terms of supporting this model (Paris, 2005). In terms of personality disorder, the Temperament and Character Inventory (TCI; Cloninger, Przybeck, Svrakic, & Wetzel, 1994), a measure of the seven-factor model, has been found to be useful to predict the presence of a personality disorder (De La Rie, Duijsens, & Cloninger, 1998). Moreover, low scores of self-directedness and cooperativeness have demonstrated to predict all personality disorders (Svrakic et al., 1993). Similarly, harm avoidance and novelty seeking was found to be associated with all personality symptoms, suggesting these domains reflect general aspects associated with all personality disorders (Bagby et al., 2005). The seven-factor dimensions, however, is argued to lack the ability to distinguish between different personality disorders (Kantojarvi et al., 2008; de la Rie et al., 1998).

Genetic and Genetic-Environment Concepts
Genetic approaches may to some extent explain the etiology of personality disorders. There has been a wealth of gene related in personality disorders, such as quantitative genetic studies (including gene-interaction studies), molecular genetic studies, behaviour-genetic studies, and epigenetic studies. In general, the evidence from these studies suggests that personality disorders are modestly to moderately heritable. This is partly due to genetic factors across all personality disorders in the same cluster and partly by disorder specific effects (Reichborn-Kjennerud, 2008). Furthermore, environmental effects are mainly limited to nonshared effects, meaning environmental effects that are unique to the individual, rather than the shared environment contribute to almost all the environmental influence on the individual. Shared environmental influences are not significant except for antisocial behaviour and criminality (Livesley & Jang, 2008).

Quantitative genetic studies refer to family, twin, and adoption studies. They typically involve investigating the extent to which individual liability to a disorder is derived from familial effects. Twin research studies are most popular and allow more definitive answers in relation to genetic risk factors to developing personality disorders (Ted Reichborn-Kjennerud, 2008). However, these studies lack information about causality between environment and genes. In general, the quantitative genetic studies focus mainly on subsets of personality disorder such as schizotypal, antisocial (ASPD) and BPD (Blonigen, Carlson, Krueger, & Patrick, 2003; Ferguson, 2010), as well as gene-environment interaction.

Some of these twin studies show that schizotypal traits are a feature of personality disorder and suggests a strong link to genetic influences (Jang, Woodward, Lang, Honer, & Livesley, 2005; Torgersen et al., 2008). In a review investigating the etiology of ASPD and gene-environment interactions, the study found that 56% of the variance in ASPD and behaviour were explained by genetic factors and 11% were due to non-genetic factors (Ferguson, 2010). More recently, in a longitudinal twin study of BPD and ASPD traits from early to middle adulthood, ASPD was found to be linked to both gene and environmental factors (Reichborn-Kjennerud et al., 2015). Furthermore, ASPD
and BPD traits were also demonstrated to be stable from early to adulthood, mainly due to genetic risk factors that did not change over a 10-year follow up. This finding suggests that genetic liability factors are shared between ASPD and BPD traits. Overall, these studies suggest that genetic factors are associated with the development of personality disorders.

Molecular genetic studies aim to identify genes associated with a disorder, and to determine critical DNA variants in order to link and trace the biological pathways from DNA to disorder (Kendler, 2005). There are substantial studies in the area of genetics of personality traits during the last 10 years. A review of this literature is beyond this thesis. However, in summary, most studies are hypothesis-driven candidate gene association studies (Reichborn-Kiennerud, 2008). These have indicated that genes linked to neurotransmitter pathways, especially in the serotonergic and dopaminergic systems, are involved in the development of personality disorders (Reichborn-Kjennerud, 2010).

Behaviour-genetic studies tend to focus on normal personality traits (Oldham, Skodol, & Bender, 2005) and importance is placed on establishing the links with proposed phenotypic model of personality traits. There is evidence to suggest some individual genes may be related to personality modulation in traits and behaviour such as neuroticism (Lo et al., 2017), anxiety, and impulsivity (Balestri, Calati, Serretti, & De Ronchi, 2014). Studies in personality disorders are rare relative to studies on personality traits (Oldham et al., 2005). For example, there has been a recent analysis of the Big Five personality traits that demonstrate specific patterns of genetic correlation with psychiatric disorders. However, personality disorders were not included in this study (Lo et al., 2017). Most established research mainly focuses on schizotypal personality disorder and nonpsychotic biological relatives of schizophrenic people which demonstrate a link to genetic factors (Nuechterlein et al., 2002). In general, genetic and environmental influences are not independent but rather are closely intertwined (Livesley & Jang, 2008).

Gene-environment (G X E) studies explore how interactions between genes and environment may lead to the development of personality disorders.
For example, GXE correlation studies have found that people who had a polymorphism in a gene (GABRA2), a gene linked to alcohol dependency, were less likely to be married, partly due to an increase likelihood of developing ASPD, and were less likely to be motivated by a desire to please others (Dick et al., 2006). Likewise, it was demonstrated that there was no main effect of the gene monoamine oxidase A (MAOA) in ASPD on behaviour, but a main effect for maltreatment, and significant interaction between gene and adverse environment (Caspi et al., 2002). In other words, maltreated children who had low levels of MAOA expression were more likely to develop ASPD than children with high MAOA expression. Several studies have replicated this association with MAOA in BPD and other Cluster B personality disorders (Ni et al., 2007). Whereas others have found mixed results (Huizinga et al., 2006), suggesting a need for further research in this area.

Epigenetic studies examine how environmental conditions affect gene expression and are increasingly being considered a promising avenue for exploring the cause of personality disorders (Livelsey & Jang, 2008). Several studies showed significant links between personality disorders and methylation abnormalities in genes, suggesting support for epigenetic modifications in the development of personality disorders (Gescher et al., 2018). For example, people with BPD have significantly higher DNA methylation (a biological process by which methyl groups are added to the DNA molecule, thus changing the activity of a DNA segment without changing the sequence) (Groleau et al., 2014; Perroud et al., 2016). Similar findings have been found in ASPD (Checknita et al., 2015; Philibert et al., 2011). Furthermore, environmental factors of which childhood trauma demonstrated a significant impact, interfered with mainly HTR2A, HTR3A, NR3C1, and MAOA genes (Gescher et al., 2018).

These studies provide insight on understanding genetic determinants of behaviour in personality disorders. However, further research is needed to establish how genetic-environment information is useful in the diagnosis of personality disorder. It is clear that genetic evidence alone is insufficient to fully address psychiatric issues, let alone personality disorders and other factors should be taken into consideration (Reichborn-Kjennerud 2008).
Other Contemporary Concepts

More recently, there has been an interest in considering a model that includes a single general psychopathology factor (p factor) that reflects a common variance across all psychopathology (Caspi et al., 2014). The idea behind the p factor is that there is a parsimonious model of psychopathology as opposed to separate and distinct classifications of mental disorders. Emerging evidence is suggesting that this single p factor may also underpin personality disorders and include exclusive variances that represent more specific forms of psychopathology. For example, in a personality disorder comorbidity study, Jahng et al. (2011) explained that one general personality psychopathology factor and specific BPD factors best described personality disorder co-occurrence with substance dependence. Sharp et al. (2015) provided further evidence that a general psychopathology factor ('g' factor) underlines personality disorders, with BPD, avoidant, and antisocial factors also fitting this one latent variable, although the study did not include all personality disorders. Nonetheless, the ‘g’ factor was confirmed again, building credence to the dimensionality model for personality disorders (Polek et al., 2018). The authors found a ‘g’ factor that linked several personality traits, suggesting that all personality disorders were associated with interpersonal and social dysfunction, a finding which is in line with the ICD-11 evaluation of the disorder.

The evidence from these studies poses clinical implications on the models of personality disorders. It is understood that there may be a singular ‘g’ factor that explains all personality disorders; however, the precise clinical nature of this ‘g’ factor is yet to be defined. The Biosocial model of BPD (Linehan, 1993) may help to explain these clinical features and address areas of dysfunction, given that there is some evidence that BPD factors align with the ‘g’ ‘factor latent variable that underpins all personality disorders (e.g. Jahng et al., 2011; Sharp et al., 2015). For instance, a possibility is that at the centre of the ‘g’ factor lies a biological vulnerability, which may manifest itself in emotional dysregulation. Difficulties in managing emotions may result in problematic behaviours such as avoidance or aggressive behaviour, as well as self and interpersonal problems (Swales, Heard, & Williams, 2000; Gunderson & Lyons-
Ruth, 2008; Bateman & Fonagy, 2010). Therefore, it may be ideal for clinicians to implement interventions focusing on managing personality disorder pathology such as self and interpersonal, and emotional dysregulation, with other treatment approaches, including CBT strategies to target social avoidant behaviour and impulsivity.

In conclusion, the current literature on personality disorder models is moving away from the original categorical 10 personality disorders stipulated by DSM-IV (APA, 2000) and more towards a dimensional approach including a general factor with some specific additional subtypes. Emerging genetic and gene-environment studies also contribute to the understanding of the etiology of personality disorders. The Biosocial theory of BPD may help to explain clinically and psychologically the features that underpin the ‘g’ factor, the latent variable that reflects a common variance across all personality disorders. This thesis will draw on this model throughout the subsequent Chapters.

1.4.2 The Biosocial model of Borderline Personality Disorder

The Biosocial theory of BPD argues that people with BPD have an inherent sensitivity (biological vulnerability) to emotional stimuli compared to others (Linehan, 1993). The development of BPD stems from the continuous interaction between invalidating family environments and emotional (biological) vulnerability, which leads to emotional distress and difficulties in emotional regulation. An invalidating environment is associated with the unmet emotional needs of the child, whereby the family’s environment rejects or dismisses the child’s emotional expressions. The invalidating environment inadvertently reinforces these extreme emotional expressions. For instance, a child’s negative outburst may serve a function to prompt emotional support from family or allow the child to delay or avoid the parents demand. Over time this parent-child interaction is repeated, and patterns of overdeveloped problematic behaviours and emotional responses are created (Crowell, Kaufman, & Beauchaine, 2014). Figure 1. presents a diagram of the Biosocial model of BPD.
Figure 1. The transactional relationship between emotional dysregulation and BPD patterns; the Biosocial Model of BPD (Linehan, 1993).

Evidence from empirical studies have generally supported these fundamental principles of the Biosocial model (Arens, Grabe, Spitzer, & Barnow, 2011; Sauer & Baer, 2010). However, there are continuing debates around whether trait impulsivity, emotional dysregulation shaped within invalidating family contexts, and biological and environment interactions, lead to the development of BPD or borderline traits (Crowell et al., 2014).

Trait Impulsivity

Results from recent longitudinal studies provide some support for the Biosocial model, where trait impulsivity leads to an increased risk of developing BPD. In a study that investigated BPD characteristics in children from birth to 12 years, it was found that borderline related features were highly heritable and were more common in children who showed early behavioural and emotional problems, poor cognitive function and impulsivity (Belsky et al., 2012). In another prospective study following children to adolescence, borderline traits were associated with early life impulsivity (Hinshaw et al., 2012). Moreover, it was demonstrated that girls with combined ADHD (features that included both inattention and hyperactivity/impulsivity characteristics) showed higher rates of
behavioural impulsivity such as self-inflicted injury, a behaviour often but not always associated with BPD. Similarly, it was found that girls at age 14 that had ADHD and Oppositional Defiant disorder (ODD) scores predicted BPD symptoms. More specifically, an increase in ADHD scores from age 10-13 years and ODD score from age 8-10 years predicted BPD symptoms more so than depression or conduct disorder (Stepp et al., 2012). Likewise, adolescents who self-harm had higher scores on measures of borderline traits, externalising psychopathology, and psychophysiological biomarkers of trait impulsivity, compared to depressed adolescents (Crowell et al., 2012). In addition, self-injuring adolescents are found to have lower peripheral serotonin levels, a biomarker of trait impulsivity, than typically developing adolescents (Crowell et al., 2005).

Emotional Dysregulation

There are promising results in self-report studies that capture emotional dysregulation in BPD, demonstrating support for the conceptualisation of the Biosocial model (Chapman, Leung, & Lynch, 2008; Chapman, Dixon-Gordon, Layden, & Walters, 2010; Cheavens & Heiy, 2011; Domes et al., 2006; Glenn & Klonsky, 2009; Links, Eynan, Heisel, & Nisenbaum, 2008). Self-report, however, is not without limitations and is argued to be unreliable due to report bias and reliance on mood states (Mauss, McCarter, Levenson, Wilhelm, & Gross, 2005). Furthermore, the self-reported information is derived from people who are thought to have difficulties in emotional regulation and awareness (Cole, Llera, & Pemberton, 2009; Mauss et al., 2005). Therefore, psychophysiological measures of emotional dysregulation have emerged to overcome these limitations. Despite the rise of these biological studies measuring emotional response in people with BPD, recent reviews have concluded that the results of these studies are inconsistent, and that further research is required in this area (Cavazzi & Becerra, 2014; Rosenthal et al., 2008).

Emotional Dysregulation and Invalidating Family Environment

Some studies have shown that an invalidating family context shapes the development of emotional dysregulation. Parents with psychiatric disorders may intensify the impact of the environmental context, increasing the risk of
developing personality disorders (Wilson & Durbin, 2012). Furthermore, child abuse and neglect are predictors of BPD, especially amongst those with genetic vulnerabilities (Cox et al., 2012; Zanarini, Laudate, Frankenburg, Reich, & Fitzmaurice, 2011). Cross-sectional studies provide further evidence for the interaction between biological vulnerabilities and environment. For example, in self-injuring adolescents a combination of biological and environmental variables accounted for more variance in self-inflicted injury than either factor alone (Crowell et al., 2008).

**Biology-Environment Interactions**

It is argued that biology and environment interactions lead to the development of BPD (Belsky et al., 2012; Linehan, 1993). There is growing literature on Gene x Environment (G x E) interactions, however, G x E research in BPD is limited with research focusing on borderline traits such as impulsivity, emotional regulation, anger and self-harm (Carpenter et al., 2013). The largest G X E interaction study found a link between having experienced traumatic life events and severity of BPD traits, reporting a G X E correlation effect for certain life events (Distel et al., 2011). The finding suggests that genes associated with risk in developing BPD traits also increase the likelihood of being exposed to some types of stressful life events. In other studies, it was found that the gene TPH1, an enzyme involved in the creation of 5HT, combined with childhood abuse predicts BPD and self-harm in adulthood (Wilson et al., 2012). Similarly, it was found that the 5HTR2A gene interacts with sexual and physical abuse histories to predict later suicidal behaviour, impulsive behaviours characterised in BPD (Brezo et al., 2010). There is further emerging evidence that suggests a genetic involvement of the hypothalamus–pituitary–adrenal (HPA) axis in the development of BPD, in combination with environmental factors such as childhood trauma (Martín-Blanco et al., 2016). The HPA axis is one of the primary neurobiological stress response systems (Lightman, 2008) and is responsible for coordinating the body’s physiologic response to stress, referred to as the “fight or flight”. A dysfunction in the HPA axis is thought to be related to BPD (Zimmerman & Choi-Kain, 2009). Similarly, significant associations between genetic variations in the HPA axis genes were found to contribute to
the development of BPD (Amad, Ramoz, Peyre, Thomas, & Gorwood, 2019). There was also a G X E interaction in environments including childhood emotional abuse.

The causal relationship between G X E interaction and the development of BPD is still unknown. A longitudinal study examining causal relation between abuse in childhood and genetic factors found no causal effect of childhood abuse in BPD (Bornovalova et al., 2013), despite the widely held epidemiological research that 30-90% of people with BPD have some form of childhood trauma history (Battle et al., 2004; de Aquino Ferreira, Pereira, Benevides, & Melo, 2018). In a recent review of the empirical literature, although individual relationships between specific types of trauma and outcomes in adulthood are inconsistent, it was found that overall links between childhood trauma and the development of BPD are consistently identified (Macintosh & Godbout, 2015). The complexity of interrelated factors such as heritable personality traits, affect regulation and trauma symptoms are still widely accepted as mediators in the relationship between childhood trauma and BPD.

Overall, numerous studies have provided evidence supporting the Biosocial model of BPD, stemming from self-report studies to biological and genetic studies, making this model ideal for use in this thesis. Future research should focus on more longitudinal studies that follow adolescents with BPD into adulthood in order to improve the understanding of key protective and risk factors for the development of BPD. Other implications may refer to how this theoretical model is applied clinically and in research for people with BPD and other personality disorders. Linehan’s model has been widely accepted as a theory for understanding BPD. It has also been extended to people who experience pervasive emotional dysregulation and accompanying behavioural and cognitive patterns, often found in other personality disorders (Lungu & Linehan, 2016).

1.4.3 Personality Disorder Prevalence

In a recent systematic review examining worldwide prevalence of personality disorder in the community, it found that there was a pooled global
prevalence rate of 7.8% (Winsper et al., 2019). In addition, high income countries showed significantly higher prevalence estimates compared to low income countries and Cluster A personality disorders had a higher prevalence in the community compared to Clusters B and C in clinical settings (Soeteman, Roijen, Verheul, & Busschbach, 2008). Research in Cluster A is underdeveloped, with current research mainly focused on BPD and antisocial personality disorder (ASPD) (Bateman, Gunderson, & Mulder, 2015). Given that global rates are high for cluster A, the findings suggest that there is a need for research treatment trials for these less studied disorders.

In the U.K it is apparent that there is limited published work on personality disorder prevalence for over 10 years. The paucity of information may be due to the recognition challenges and evolution of diagnostic criteria for personality disorder outlined previously. Cross-sectional, community-based surveys found a personality disorder prevalence of 4-15% in Western Europe and Northern America, with a 6% prevalence in the UK population (Coid, Yang, Tyrer, Roberts, & Ullrich, 2006). In a more recent systematic review, it found that in Western countries, prevalence rates were high for any personality disorder (12.16%). Obsessive-compulsive personality disorder (OCPD) had the highest prevalence of 5.53%, and the lowest was for dependent personality disorder (0.78%) (Volkert, Gablonski, & Rabung, 2018). McCrone, Dhanasiri, Patel, Knapp and Lawton-Smith (2008) estimated in the UK that the total number of people with personality disorder in 2007 was 2.46 million, and by 2026 there will an increase of 9.3% to 2.69 million. The prevalence of personality disorders is important in the mental health and employment literature, as the condition is found to seriously impair the life of the affected individual, including employment functioning.

1.5 Personality Disorder and Employment

There is a body of evidence that demonstrates that having a personality disorder poses a challenge to seeking, obtaining and maintaining employment. McClone et al. (2008) estimated that in 2007, 1 in 4 (24.3%) men with personality disorder and 1 in 13 (7.5%) women were unemployed but would probably be employed if they did not have this mental health condition. People
with personality disorders have a higher likelihood of being unemployed, more frequent job changes, and worse work functioning when compared to people without personality disorders (Sansone, & Sansone, 2010; Sansone & Sansone, 2012; Skodol et al., 2011). Past studies have linked personality disorders to other poor employment outcomes such as absenteeism (Dewa, Loong, Bonato, & Hees, 2014), and low earnings (Frank & Gertler, 1991).

Furthermore, people with a diagnosis of personality disorder were found to be associated with a higher probability of being fired, receiving ‘cash in hand’ jobs, and being employed for a shorter period (Sansone & Wiederman, 2013). Patients with BPD were also found to be three times more likely to receive Social Security Disability Income over 10 years compared to the OCPD comparisons (Zanarini, Jacoby, Frankenburg, Reich, & Fitzmaurice, 2009) and less likely to occupy a higher income group (Niesten, Karan, Frankenburg, Fitzmaurice, & Zanarini, 2016). In a comparison study between people with BPD, other personality disorders and MDD, it was found that people with BPD were significantly less likely to be in full-time employment than people with OCPD and MDD (Gunderson et al., 2011).

The proposed ICD-11 criteria for personality disorders offers a similar description of employment difficulties reflected in these studies; “people with mild personality disorders are capable of sustaining and willing to sustain employment, given appropriate employment opportunities..”. The proposed diagnostic manual also describes people with moderate personality disorder: “…May exhibit little interest in and efforts toward sustained employment when appropriate employment opportunities are available…”; and people with severe personality disorders: “…Unwilling or unable to sustain regular work due to lack of interest or effort, interpersonal difficulties, or inappropriate behaviour (e.g., irresponsibility, fits of temper, insubordination), even when appropriate employment opportunities are available. Conflict with or withdrawal from peers and co-workers.” (Tyrer, Reed, & Crawford, 2015, p. 277). The majority of personality disorders and employment literature has focused on BPD patients, as opposed to other personality disorders, and personality disorder traits and their contribution to employment dysfunction (Skodol, 2018).
Behavioural factors may be one possible reason to explain challenges people with personality disorders experience in employment. In a study assessing DSM-IV BPD criteria on vocational outcomes, it was found that amongst the spectrum of personality disorder features, impulsivity was the only feature to have a consistently negative impact (Sio, Chanen, Killackey, & Gleeson, 2011). Impulsivity has also been found to be problematic in the workplace for other personality disorders, such as Antisocial Personality Disorder (APD) (Unterberg, 2003). Other personality disorder associated behaviours such as substance abuse, promiscuous behaviour and reckless driving, may also lead to failure in meeting societal norms and expectations, such as gaining vocational and academic achievements (Bagge et al., 2004).

Avoidance and other anxiety-related behaviours may also be contributing behavioural factors. People with BPD identified behaviours such as avoidance of going into work, anxiety about going back to work, and avoidance in taking risks (such as taking a job) as barriers to recovery in vocational functioning (Carmel, Torres, Chalker, & Comtois, 2018).

Interpersonal dysfunction may also contribute to challenges in employment. People with personality disorders were found to experience interpersonal problems such as intolerance of aloneness and conflicts regarding dependency, despite improvement in other interpersonal features (Choi-Kain, Zanarini, Frankenburg, Fitzmaurice, & Reich, 2010). This suggests that employees with personality disorders who may be expected to work in teams as well as independently and alone may find this problematic in the workplace, as their ability to tolerate separation and the acquisition of an ability to be alone may be compromised. Unsurprisingly, people with personality disorders tend to create great distress and burden on not only friends and family, but also colleagues and clinicians as well (Dunne & Rogers, 2013; Miller, Campbell, & Pilkonis, 2007; Skodol, 2018; Zanarini et al., 2010).

Social functioning is another factor that may also negatively impact employment functioning in people with personality disorders (Sansone & Sansone, 2010). Social functioning is defined as a person's interaction with their environment and their ability to fulfil their social role within it. It includes the
ability to engage in social activities, and maintain relationships with family, friends, and colleagues. It is important as people with personality disorders are found to have greater social dysfunction compared to other mental illnesses (Newton-Howes, Tyrer, & Weaver, 2008).

Personality disorder symptoms and personality traits have both been shown to prospectively predict psychosocial functioning (Hopwood et al., 2007; Zanarini, Frankenburg, Reich, & Fitzmaurice, 2010b), although the effects are stronger for traits. In a prospective study following people with personality disorders compared to people with MDD, personality disorder symptoms were found to have significant impact on psychosocial functioning and more so than depressive symptoms in people with MDD (Skodol et al., 2005). Moreover, it was found that more than half of personality disorder patients showed ‘remission’ across 12 consecutive months (no more than two symptom criteria of the baseline disorder were present at 2 years of follow up). The findings suggest that diagnosis of personality disorder in patients that were treatment-seeking or recently been in treatment, was not stable over 2 years. Conversely, the study also found that dimensional traits of personality disorder stayed stable over course of 7 years. Taken together, the studies suggest that dimensional traits contribute to impairment in psychosocial functioning. Furthermore, personality disorder may be regarded as stable dimensional traits but may express varying severity of personality disorder symptoms over time.

Similar impairment in psychosocial functioning is found in BPD. This difference in psychosocial functioning was demonstrated even in the context that 85% of those with BPD were in remission from their condition (Zanarini et al., 2010). In other words, symptomatic remission continued in people with BPD after receiving treatment, but impairment to occupational functioning remained. Acute symptoms, symptomatic behaviours that involve self-harm and impulsive behaviours, were quick to resolve. Whereas temperamental symptoms, such as chronic experiences of anger and paranoid ideation, types of dimensional traits are more stable in nature (Zanarini et al., 2005; Skodol et al., 2005). The findings suggest that this impairment in psychosocial functioning in people with
BPD, may be due to something temperamental in nature such as personality disorder dimensional traits that can remain stable over the course of time.

There is some evidence to show that pathological personality traits impair occupational functioning. In a study examining people with personality disorder dimensions and vocational functioning in the general population, the authors found that those with traits of paranoid, schizoid, schizotypal, antisocial and BPD were associated with low levels of education (Hengartner, Müller, Rodgers, Rössler, & Ajdacic-Gross, 2014). The authors also found conflicts in the workplace were linked to most personality disorder traits, except schizoid avoidant. Dismissals or demotions was significant for people with avoidant, dependent, borderline, paranoid, schizoid and schizotypal, and unemployment was associated with having paranoid, schizoid, schizotypal, borderline, and avoidant personality disorder traits.

A review of personality traits and life outcomes, including occupation, emphasised that personality is associated with occupational interest, satisfaction, and performance (Ozer, Ver´, & Benet-Martínez, 2006). For example, Neuroticism, stemming from the FFM, is not associated with any occupational interest, whereas extraversion is related to enterprising and social occupational interests, and openness to investigative and artistic interest (Barrick & Mount, 2003). Conscientiousness predicts performance and extraversion and emotional stability were connected with job satisfaction and negatively associated with burnout and longing to change jobs (Thoresen, Kaplan, Barsky, Warren, & de Chermont, 2003). Similarly, other studies have shown that the degree of neuroticism and disagreeableness contributes to employment dysfunction (Michon et al., 2008).

It is important to emphasise that these findings are not suggesting that other trait variables outside of FFM are unhelpful in the prediction of occupational outcomes, nor that each FFM trait definitely predicts these employment outcomes, but that simply personality traits play a role in work.
Personality traits and personality disorders have been well evidenced in the literature. In a longitudinal study examining FFM with a sample of people with personality disorder and major depressive disorder (Hopwood et al., 2009), the authors found that higher neuroticism was generally and moderately associated with worse functioning (social, work, and recreational) compared to other personality traits. Openness was moderately and negatively related to general dysfunction. Agreeableness was suggested to be the least predictive trait, and conscientiousness was found to be negatively related to work dysfunction. The findings suggest that individuals with different personality traits may benefit from targeted treatments that address those traits. For example, to work on areas related to conscientiousness, such as effectiveness and managing impulsivity, to boost work functioning.

People with personality disorder tend to show high levels of neuroticism and disagreeableness, especially people with BPD, NPD, Paranoid Personality Disorder (PPD), and OCPD (Saulsman & Page, 2004). High levels of neuroticism and low levels of agreeableness are linked to negative urgency; acting impulsively in response to emotional distress and interpersonal conflict (Settles et al., 2012). Both personality traits neuroticism and agreeableness has been associated with employment dysfunction (Sansone & Sansone, 2010). Thus, if interpersonal conflicts arise in the workplace, those with higher levels of neuroticism may be more likely to react in a way that is problematic for them in employment.

Collectively, these findings contribute to the debate around models of personality disorders discussed in Section 1.3.1. There is growing evidence showing the limitations of categorical diagnostic frameworks for personality disorders. Prospective studies have demonstrated dimensional traits to be stable across the lifespan of personality disorders (Skodol et al., 2005; Zanarini et al., 2005). Perhaps personality traits, more so than categorical diagnostic

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1 Please refer to Section 1.4.1 Concepts of Personality Disorder for further discussion.
features of personality disorders, can better explain the reasons people with personality disorders still present with vocational dysfunction post-treatment.

Dimensional traits may help us to understand specific areas that impact occupational functioning and preparedness for employment. Specific traits in personality disorders such as neuroticism and disagreeableness, appear to mediate employment functioning (Sansone & Sansone, 2010). Furthermore, manualised treatments focus initially on reducing the severity of acute personality disorder symptoms, rather than addressing the temperamental symptoms. For instance, treatments tend to focus first on reducing self-harm and suicide attempts, rather than modulating psychosocial impairments such as persistent experiences of anger and intolerance of aloneness (Zanarini et al., 2007). Future treatment programs may wish to make improving the psychosocial functioning a primary or even secondary focus of treatment, in order to increase preparedness for work.

1.5.1 Preparedness for Employment and the Biosocial Model

The concept of preparedness as described in Section 1.3.1 involves the psychological capability and tolerance to challenges related to employment (Vuori & Vinokur, 2005). The individuals readiness to act on job opportunities and competence to manage barriers and setbacks when following chosen goals is key to preparedness (Sweeny et al., 2006). These descriptions draw parallels with personality disorder treatments, such as Dialectical Behavioural Therapy (DBT). DBT aims to build a meaningful life through recovery processes by striving towards a balance between achievements, such as vocational goals, and setbacks (Katsakou & Pistrang, 2018). DBT was developed based on the principles of the Biosocial model of BPD and as empirical evidence for the model to explain the psychological features people with personality disorders has been demonstrated, the biosocial model may also be ideal in explaining preparedness for employment².

² Please see Section 1.4.2 The Biosocial model of BPD for detailed discussion.
The cognitive, behavioural, interpersonal and self-instabilities mentioned in the Biosocial model may apply to people with personality disorders and employment. For example, people with personality disorders were found to lack self-belief (cognitive instabilities) in being self-sufficient regarding work (Carmel et al., 2018; Comtois, Kerbrat, Atkins, Harned, & Elwood, 2010). Furthermore, problem-solving skills and negative emotions such as anxiety were factors found to impact employment for people with personality disorders (Comtois et al., 2010; Hopwood et al., 2009; Michon, Have, Kroon, & van Weeghel, 2008).

According to the Biosocial model of BPD, an invalidating environment can reinforce problematic behaviours. Friends, family, or HCPs often reinforce avoidance behaviours, reliance on negative coping strategies, and setting low expectations in people with BPD (Carmel et al., 2018). For example, the reinforcement of the person with BPD not going into work due to the family member being flexible. Another example is where friends raise concerns or express worries when receiving news of the person with BPD taking a new job (e.g. by suggesting they might lose their benefits). Consequently, the friends’ reaction would reinforce the person with BPD to avoid taking risks such as taking on a new job. Carmel et al. further reported that both friends and family members also reinforced reliance on negative coping strategies by encouraging substance use as a way of managing difficult situations. Likewise, HCPs implicitly reinforced the challenges of leaving the disability benefits system by lowering expectations. Comments such as “most people in the disability system will stay on disabilities,” subsequently reinforced the low sense of self-belief and self-sufficiency in getting off benefits.

If people with personality disorders return to work too early, the lack of preparedness may lead to the inability to react to unknown situations and leave them incapable of dealing with setbacks and barriers. Ultimately, this may result in relapse and leaving a job prematurely (Nielsen, Yarker, Munir, & Bültmann, 2018). Future research may benefit from focusing on the timing of when individuals return to work or enter vocational rehabilitation programmes (Noordik et al., 2013), especially given the complex bidirectional relationship between mental health and employment (Henderson et al., 2011). A scale that
can identify the most appropriate time to return to work may be beneficial for people with personality disorder. This is important, as many people with a personality disorder consider employment as a large part of their recovery (Katsakou et al., 2012). However, to the best of our knowledge, it appears that few measures capture factors related to preparedness for employment for people with personality disorders. A more robust review of the literature is warranted to gain a better understanding of what scales are available and how ‘preparedness’ has been defined in the literature.

1.5.2 Personality Disorders Employment Interventions and Measures

Studies of supported employment interventions and personality disorders are limited, as the majority of IPS studies target schizophrenia and mood disorders (Drake & Bond, 2011; Burns & Catty, 2008; Vázquez-Estupiñán, Durand-Arias, Astudillo-García, & Madrígal de León, 2018). However, other employment interventions designed for people with personality disorders have been examined to address employment attainment. Studies in the U.S. have adapted versions of DBT to assist those with a personality disorder into employment (Comtois et al., 2010; Elliott & Konet, 2014; Koons et al., 2006). Koons et al. (2006) tested an adapted version of DBT and found a significant improvement in mental wellbeing and a small increase in hours worked in people with personality disorders within a vocational rehabilitation sample (n=8). The intervention targeted problem behaviours that prevented seeking and attaining employment, including interpersonal conflict, leaving on time, saying no to overtime, difficulties in asking for time off and asking for help. These problematic behaviours are in line with previous literature that reports behavioural and interpersonal dysfunction in people with personality disorders (Swales et al., 2000; Linehan, 1993; Polek et al., 2018). The authors believed the main challenges to employment for people with personality disorders within a vocational rehabilitation population were interpersonal, behavioural, emotional, and concentration skills deficits, which may influence preparedness for employment.

The authors assessed levels of social adjustment, depression, hopelessness, and anger using the Beck Depression Inventory-II (BDI-II: Beck,
Steer, & Brown, 1996), the Beck Hopelessness Scale (BHS; Beck & Steer, 1988), the State-trait anger inventory (STAXI: Spielberger, Jacobs, Russell, & Crane, 1983) and Social adjustment scale—self-report version (SAS-SR: Weissman & Bothwell, 1976), as outcomes measures. These variables suggest that people with personality disorders may experience depressive symptoms, feelings of hopelessness, anger problems, and difficulties with social adjustment in employment that may impact their preparedness for work.

In a larger study (n=30), ‘DBT-Accepting the Challenges of Exiting the System’ (DBT-ACES) demonstrated at post-intervention, a significant increase in employment, although this did not remain significant at one year follow up despite a continual increase in employment overall (Comtois et al., 2010). Like Koons et al. (2006), the authors believed that the main challenges to employment were interpersonal skills and emotional regulation, which were also targeted as problem behaviours in DBT-ACES. Furthermore, they felt that negative emotions and limited problem-solving skills also contributed to poor employment outcomes; however, the study did not examine this empirically. Thus, the extent to which this population was affected by these psychological factors is reliant on the author’s qualitative report.

Interestingly, despite DBT-ACES targeting interpersonal and emotional dysregulation difficulties, scales measuring these areas were not implemented. The authors used the Quality of Life Interview (QOLI: Lehman, 1988) to measure employment status, the number of hours paid and life satisfaction as outcomes for this study as opposed to psychological outcomes.

More recently, another DBT employment-based skills intervention study also demonstrated a lack of relevant employment measures. Elliot and Konet (2014) showed efficacy for DBT-based skills for personality disorders and employment. They found almost half of the people who completed at least one month of the programme obtained and retained full-time employment. The authors considered factors such as interpersonal effectiveness and emotional regulation to be vital in improving employment readiness. However, they only measured vocational interest and possible career choices. The authors did not use any psychological measures assessing interpersonal and emotional
regulation, despite targeting these areas as part of this DBT-based skills intervention.

Another personality disorder treatment emphasised the environment as a challenge to employment for people with personality disorders. Nidotherapy (Tyrer, 2002) involves changes to the environment as opposed to the person. The therapy is argued to be a potential intervention for people with personality disorders in the workplace (Tyrer, 2014). The treatment involves a collaborative approach that includes changes to the environment to minimise the effect of mental health difficulties that arise from a personality disorder (Tyrer, 2009; Tyrer, 2002). While there has been some evidence for treatment effectiveness (Ranger et al., 2009), the current evidence for employment preparedness for personality disorders is limited, let alone measurements assessing environmental change in this context.

In summary, the current literature on employment interventions and measures for people with personality disorder suggests that interpersonal, emotional, environmental, and problem-solving skills are important factors to consider regarding preparedness in attaining and retaining employment in people with personality disorders. And yet, these areas were not directly measured as part of the evaluation of employment readiness in these intervention studies. Overall, the primary outcomes for these DBT-adapted employment interventions were “employment status” and “number of hours” worked. Although these outcomes are important, as the fundamental aim was for people with personality disorders to gain and increase employment, they may not be adequate in measuring the specific psychological factors targeted by DBT-adapted interventions.

When we consider this failure to assess this dynamic, it is also interesting to put it into the context of current psychological intervention assessment. Assessing the outcomes of interventions in mental health care has changed in recent years. Outcome assessments traditionally focus on symptomatology, service use, and social disability (Thornicroft & Slade, 2014). This approach is apparent in the national and regional usage of clinical outcome measures such as the Health of the Nation Outcome Scale (HONOS; Wing et
al., 1998), the Clinical Outcomes in Routine Evaluation – Outcome Measure (CORE-OM; Evans, Connell, Barkham, & Margison, 2002), and Camberwell Assessment of Need, (CAN; Phelan et al., 1995) across Australia, Canada, England, Netherlands and New Zealand (AMHOCN, 2005; Drukker et al., 2010; HM Government, 2011; Slade, 2012; Trauer, 2010). This approach is also apparent in the DBT adapted for employment interventions, such as measuring “employment status” and “number of hours” worked.

There is an emerging shift in focus toward recovery-oriented services in mental health (Slade et al., 2014), and to include measures that capture outcomes that are important and relevant to the patient (Thornicroft & Slade, 2014). Thus, a scale that captures psychological aspects of employment preparedness that is imperative in recovery for people with personality disorders may provide a better understanding of the challenges to employment, and therefore, a better indicator of employment readiness for people with personality disorders.

For instance, consider the following scenarios: a person with personality disorders is unable to increase the number of working hours post-intervention or a person at pre-intervention is successful in finding work but frequently loses their job. The person with a personality disorder may arrive at their anecdotal reasons; however, these subjective rationales lack scientific confirmation of the underlying contributing factors. Furthermore, hard outcomes such as “number of hours employed” and “employment status” measured in intervention studies fail to capture these aspects.

To conclude, a validated scale that captures both the psychological factors that are important to that person’s recovery and also captures DBT-adapted intervention goals would be of benefit to people with personality disorders. Such a scale could inform clinicians and individuals in the planning of employment support, and better prepare them for work, as well as gauge the timing of readiness for employment for people with personality disorders. Such a measure is important as people with mental health difficulties often lack the psychological support to overcome barriers in obtaining and retaining employment (Butterworth et al., 2011).
1.5.3 Recovery and Employment for People with Personality Disorders

Despite the challenges people with personality disorders experience in employment, it is considered an important part of recovery for some. Individuals with personality disorder described that although dealing with symptoms of their disorder and learning new skills was important; it was not necessarily a key element in their interpretation of recovery (Castillo, Ramon, & Morant, 2013). Learning to work alongside their mental illness, while embarking on new activities and achievements such as meaningful employment, was more important to patients than waiting a long time for their illness to subside. Similarly, people with BPD recognised that symptom reduction is very much an important part of recovery, but they were also aware that recovery was more about learning to live and cope with symptoms while discovering ways to achieve a life worth living goals such as employment (Gillard, Turner, & Neffgen, 2015).

It is clear from the literature that employment dysfunctions are problematic for people with personality disorders. It is imperative to address these employment difficulties because people with personality disorders often want to work (Gillard et al., 2015) and consider finding employment and career progression to be a key part of their recovery (Katsakou et al., 2012).

The challenges involved in employment for people with personality disorders include a range of psychological and social factors relevant to their recovery. Service users frequently mentioned that appropriately identifying when one is ready for employment, by focusing on these factors, was the most desired back-to-work support (Mind, 2014). There are methods to help identify factors; one that is commonly used in the field of psychology is psychometric scales. Psychometric scales may help to address challenges to employment by highlighting areas of preparedness that can overcome these difficulties.

1.6 Psychometric Scales

The methodological approach selected to develop a scale is psychometrics. Psychometrics is an area of psychology concerned with the objective measurement of the topic of interest, various measurement theories
and general construction and validation of scales (Ginty, 2013). The origins of psychometric testing derived from interests in individual differences, moving towards intelligence and personality. Modern usage of psychometric scales include other areas of psychology, such as attitudes, beliefs, and readiness to change (Kaplan & Saccuzzo, 2013).

Psychometric scales are especially crucial in psychological assessments as they can be used to quantify ‘unobservable’ or ‘hard to measure’ concepts such as ‘working memory’, as one cannot directly observe ‘memory’ (Furr & Bacharach, 2008). Thus, they are popular in clinical psychological practice where they can be used to measure typical ‘unobservable’ ideas such as ‘readiness to change’, ‘motivation’, and even preparedness for employment.

Often in psychological practice, to capture ‘unobservable’ concepts, researchers need to create tasks that can produce observable behaviours to assess them (Michell, 2013). Keeping with our concept of working memory, early research found its measurement difficult to measure without creating a task that involves presenting a series of digits to two subjects and asking them to remember and recall them in a given time. The time differences between the subjects suggest differences in working memory (Wilhelm, Hildebrandt, & Oberauer, 2013). The pitfall of this method lies in the requirement to infer from observable behaviour to unobservable psychological attributes. Thus, while researchers can infer that the differences between the two subjects indicate a difference in working memory, this may represent, either wholly or partially, some as yet unmeasured phenomenon. These are aspects researchers should consider when developing a psychometric scale.

Some psychometric scales may take the form of Patient-Reported Outcomes (PROs), or Clinician-Reported Outcomes (CROs). PROs are direct assessments of the patients’ experience, without any interpretation of the patient’s answers by clinicians (Powers et al., 2017). This is the approach adopted in this thesis. On the other hand, CROs are an indirect evaluation of the patients’ experiences determined by a person who has received relevant training to perform the assessment. Both PROs and CROs are considered clinical outcome measures. PROs shown are now an essential tool in clinical

Psychometric scales may also be of benefit to the therapeutic process in psychological practice. Instruments are often used to make informed care decisions (Ahmed et al., 2012) and to devise treatment plans during psychological assessments (Beutler, Clarkin, & Bongar, 2000). They provide information on the planning, implementation, and evaluation of treatment, as well as help to determine treatment duration and intensity (Groth-Marnat, 2009; Kubiszyn et al., 2000). For example, assessments of symptoms via measures helps to determine appropriate treatments for people with mental health problems, including personality disorders (Routh & Reisman, 2003; Weiner & Greene, 2007). The Structured Clinical Interview for DSM (SCID; First, Williams, Karg, & Spitzer, 2015), a measure used to assess the severity dimensions of psychopathology, is shown to have excellent reliability and validity (Shankman et al., 2018).

Providing clients with measure feedback can also result in significant therapeutic advantages (Ackerman, Hilsenroth, Baity, & Blagys, 2000). Patient-centred assessments that view patients as collaborators are associated with positive readiness to change in people with personality disorders (De Saeger et al., 2014). The use of measures in these assessments may help to describe the clients’ situation, refine clinical impressions of the client, monitor treatment processes, and be used as an intervention itself (Meyer et al., 2001).

Therapeutic assessments (including the use of assessment questionnaires) are thought to have a clinical impact that is equivalent to a similar period of therapy or counselling (Poston & Hanson, 2010). Perhaps it is within the joint discussions about client questionnaire responses and behaviours that occur during the therapeutic assessment (TA) that contribute to active co-operation and motivation for treatment in people with personality disorders (Fonagy, Luyten, & Allison, 2015). TA provides an opportunity to label and structure the client’s internal working model, thus allowing clarity for the client. These questionnaires used in TA also encourage both top-down and bottom-up learning for the client with personality disorders. Service users
frequently mentioned that appropriately identifying when one is ready for employment, by focusing on specific barriers and needs, was the most desired back-to-work support (Mind, 2014). Thus, developing a psychometric scale to gauge preparedness for employment may echo some of these therapeutic benefits, especially given that people with personality disorders are known to be resistant to change (Clarke, Kingston, James, Bolderston, & Remington, 2014; Kamphuis & Finn, 2018).

1.7 Development of Psychometric Scales

As part of their development, psychometric scales should undergo rigorous tests of validity and reliability (Streiner, Norman, & Cairney, 2015). These validation methods set them apart from other non-validated instruments that also involve obtaining data from participants. Streiner et al. (2015) stipulated that the basic concepts involved in scale development are: i) searching the literature and critical review; ii) devising the items (content validity); iii) selecting the items (content and face validity); iv) psychometric evaluation (reliability and empirical forms of validity); v) feasibility; and vii) reduction of measurement error. The COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN; (Mokkink et al., 2012; Mokkink, Terwee, Knol, et al., 2010) is a standardised checklist that specifies design requirements and statistical methods required in scale development). An international Delphi method was used to create the COSMIN, and subsequently, a four-step procedure was established to guide researchers to evaluate the methodological quality of studies evaluating measurement properties (Mokkink et al., 2006). The COSMIN is a risk of bias tool to assess the methodological quality of scales and is a recommended guideline for health measurement development (Streiner & Kottner, 2014). Figure 2. presents the study consort diagram and the different stages of scale development.
Figure 2. Development of the PES-PD Consort Diagram.
1.8 Summary

In summary, this introduction outlines the reasons a preparedness for employment scale for people with personality disorders is warranted. Firstly, mental health and employment are known to have an intricate bidirectional relationship; therefore, a scale that identifies when the right time is to return to work may be important to prevent unnecessary stress and premature job loss.

Secondly, employment is considered to be a vital part of recovery for some people with personality disorders (Katsakou et al., 2012), despite the various challenges to employment for people with this mental health disorder. Some people with personality disorders have successfully reduced their symptoms after receiving psychological treatment; however, these people still experience vocational difficulties (Zanarini et al., 2010). This finding suggests there are underlying employment difficulties that may get in the way of work for people with personality disorders. Given the evidence for difficulties in employment for people with personality disorders, it is imperative first to identify the areas of employment challenges in order to address them. The scale may then inform what employment supports, such as employment interventions, may be appropriate for people with personality disorders to return to work.

Thirdly, people with mental health difficulties have reported that identifying specific barriers and needs is what is required for back to work support (Mind, 2014). To recommend the necessary employment interventions and supports, clinicians need to first identify the needs and challenges of the individual. This approach is not dissimilar to typical psychological approaches of formulation (Onyett, 2007) and usually involves several measures during assessment and formulation stage, before treatment recommendations.

Lastly, some studies on personality disorder interventions adapted for employment use “employment status” and “number of hours of paid employment” as core outcomes. Other outcomes related to recovery are not measured. A preparedness for employment scale may be necessary, not only as an outcome measure alongside the intervention, but to also focus on more recovery-oriented aspects of employments. This approach is in line with current
thinking that outcome measures are beginning to adopt recovery-oriented elements, as opposed to traditional outcomes such as symptom reduction in mental health care.

1.9 Aims

This thesis aims to establish whether an adequate employment readiness scale currently exists for people with personality disorders. If such a tool is lacking, this thesis will aim to develop and evaluate a new Preparedness for Employment Scale for people with Personality Disorder (PES-PD), based on an underlying construct of preparedness for employment, reflecting the Biosocial model of BPD (Linehan, 1993) and personality disorder literature. A new scale will be designed to not only identify challenges to employment, but gauge when one is ready to return to work, measure the extent of one’s preparedness for employment, and to help inform the planning of employment support.
Chapter 2 Searching the Literature and Critical Review: A Systematic Review of Employment Scales for Personality Disorders

2.1 Introduction

The development of a psychometric scale is a major task. In order to avoid duplication of effort and to ensure scientific benefit, it is important to establish that there is not an existing employment scale that could suit the needs of people with personality disorders. Therefore, when developing a scale, the first step is to conduct an initial search in bibliographic references such as MEDLINE and PsycINFO to critically review current scales (Streiner et al., 2015). Researchers need to consider that in order to justify the development of a new scale; there should be evidence of insufficient conceptual framework or insufficient psychometrically sound scales to service the area of concern (Turner, Quittner, Parasuraman, Kallich, & Cleeland, 2007).

If a review of the literature identifies relevant scale(s), researchers need to decide whether they are appropriate for use or whether to develop a new instrument (Streiner et al., 2015). There is limited concrete guidance as to how to conduct this process, but it is generally accepted that a judgement of relevant items in the scale is required and accompanied by a critical review of evidence that supports the instrument.

Searching online is becoming increasingly popular to find evidence for clinical care and continuous research (Westbrook, Gosling, & Coiera, 2004). MEDLINE was designed for finding therapy and review articles (Robinson & Dickersin, 2002; Shojania & Bero, 2001; Wong, Wilczynski, & Haynes, 2006) and PsycINFO for finding specific interventions and study types (e.g. randomised controlled trials of cognitive therapy for depression [Watson & Richardson, 1999]).

PsycINFO is ideal to search content covering behavioural components in health care, including mental health, behavioural causes and effects of physical disorders, behavioural treatments and health promotion (American Psychiatric
Association, 2019), consequently providing access to unique articles. MEDLINE was found to index 47% of leading psychiatry journals, with PsycINFO providing a larger breadth of 73% (Mcdonald, Taylor, & Adams, 1999). Reviews that have a psychological focus may benefit from using PsycINFO to search the literature. However, the requirement of searching more than one database is key to ensure the inclusion of all relevant studies, and thus increasing the validity of the systematic review (Brettle & Long, 2001).

Searching the literature may include a literature review or systematic review. Studies that have developed scales for mental health populations utilise these methods frequently (e.g. Gratz & Roemer, 2008; Lohss, Forsyth, & Kottor, 2012; Hector Tsang & Pearson, 2000).

2.1.1 Systematic Reviews

Systematic reviews are considered the strongest form of evidence in clinical research and can involve both a meta-analysis or narrative synthesis (Melendez-Torres et al., 2017). They enable refinement of large amounts of information into manageable summaries through systematic critical exploration, evaluation and synthesis (Mulrow & Cook, 1998). Systematic reviews help researchers and clinicians to identify, justify, and refine hypotheses (Haynes, Devereaux, & Guyatt, 2002). Sound clinical decisions are made based on available evidence, and clinicians need to be able to understand the differences between studies and then integrate information from systematic reviews into clinical practice (Garg, Hackam, & Tonelli, 2008).

Systematic reviews, however, are not without limitations. Studies have shown systematic reviews were unreliable and that the application of standardised guidelines could improve reporting and subsequently improve reliability (Moher, Tetzlaff, Tricco, Sampson, & Altman, 2007). Publication bias is also common, and reviews are argued to be lengthy and present outdated results (Roberts et al., 2015). Furthermore, there are issues with methods where the inclusion of studies in a review is likely to be influenced by the knowledge of the results of the set of potential studies (Egger, Smith, & Altman, 2008). A fundamental critique of systematic reviews are that they tend to omit
context and process, elements that are fundamental in the understanding of social sciences (Mallett, Hagen-Zanker, Slater, & Duvendack, 2012).

Nonetheless, supplementing the systematic review process with a more flexible approach that includes these elements (e.g. qualitative synthesis), may help to cover some of these limitations. Considering that systematic reviews are the strongest form of evidence, and the absence of alternative approaches, this thesis conducted a systematic review to evaluate whether a suitable preparedness for employment scale for people with personality disorder exists.

2.2 Aim

This Chapter presents a systematic review that assesses current employment scales for people with mental health difficulties, with a focus on personality disorders. This study aimed to establish whether there is an existing employment scale appropriate for measuring preparedness for employment for people with personality disorders. It explored the content of variables measured in the reviewed scales and evaluated their applicability to personality disorders and employment difficulties. This study also assessed the psychometric properties of the scales to evaluate their validity and reliability.

2.2.1 Search Methods

The electronic databases MEDLINE, PsycINFO, Health and Psychosocial Instruments (HAPI), and Cochrane Database of Systematic Reviews, were searched, combining search terms for Mental Health and Employment Scales and filtered for randomised controlled trials, systematic reviews, and grey literature from 1946 to January 2018. The study also searched for grey literature in PsycEXTRA (as part of PsycINFO) and the UK Department for Work and Pensions (DWP) database.

The use of several different databases follows the convention to use more than one database and other sources to adequately identify all literature relevant to the interested topic (Lemeshow, Blum, Berlin, Stoto, & Colditz, 2005; Levay, Raynor, & Tuvey, 2015; Stevinson & Lawlor, 2004; Zheng, Zhang, Ye, & Chen, 2008). Single databases are often not sufficient on their own (Bramer, Giustini, Kramer, & Anderson, 2013; Bramer, Giustini, & Kramer, 2016). Search
strategies that combine methodologic search strategies (e.g. combination of search terms designed to identify studies that have used a specific research method [Harbour et al., 2014]) have shown to achieve high sensitivity and specificity for retrieving mental health content from MEDLINE. For example, this study combined terms such as “Employment”, “Scales” and “Validity” in the MEDLINE search strategy. The study used PsycINFO due to the unique content area of psychological and psychiatric topics that are often not found in other databases (Brettle & Long, 2001; Stevinson & Lawlor, 2004). Other databases were also used because they were deemed relevant to the study topic.

The study used index terms and subject headings in electronic searches. A search strategy for MEDLINE was developed (Appendix 2), which three independent reviewers then further agreed. The search terms were amended as required for searching other databases (see Appendix 3-5). For example, some subject headings such as “Career Mobility” created from the MEDLINE search strategy did not work in PsycINFO; therefore, the researcher changed the subject headings to another term that was as similar as possible to the original search strategy (Services, 2019). Thus, in this study, the researcher (PhD student) changed “Career Mobility” to “Occupational Mobility”.

The DWP database does not extend itself to advanced search tools such as index terms, search strategies, or truncation. Therefore, to search systematically, free texts and keywords in the PsycINFO search strategy were used to search for articles. The free texts and keywords were employment, mental health, readiness or preparedness, vocational, questionnaires, scale or scales, measures. Further studies were identified by manually hand searching the reference lists of all relevant studies. Emails were sent to authors of the identified papers and experts in the field of mental health and employment, requesting any psychometrically evaluated work-readiness scales.

All retrieved articles were searched for duplicate studies and subsequently removed. Each article was screened first by title and abstract, and second, by the full reading of the article, using the inclusion and exclusion criteria described below. All remaining articles were included in the systematic review (see Figure 3).
**Figure 3. Consort Flow Chart**
2.2.2 Inclusion and Exclusion Criteria

This systematic review included studies that had samples of working-age adults (aged 18 to 60 years) with a diagnosis or comorbid diagnosis of mental health disorders. The review also included any study assessing employment-related patient-reported outcomes (PRO) or clinician-reported outcomes (CRO), together with studies developing or evaluating the psychometric properties of an employment scale. Only publications published in English were included. The review excluded studies involving individuals with solely physical health problems, university students, or retired people. Instruments assessing the fidelity of a programme, system or intervention were also excluded.

2.2.3 Narrative Synthesis

This thesis adopted a narrative synthesis approach (Ryan, 2013). This method is recommended when studies are too heterogeneous clinically and methodologically to extract data for a meta-analysis (Akers, Aguiar-Ibáñez, & Baba-Akbari Sari, 2009; Light & Pillemer, 1984). The first step was to develop a preliminary synthesis; the second step was to explore relationships in the data; and the final step was to evaluate the robustness of the synthesis. Figure 4 presents the structure of a narrative synthesis and the technique used to conduct each step.
Figure 4. Narrative synthesis process.
1) Developing a Preliminary Synthesis

The following tools and techniques to develop a preliminary synthesis were used: textual descriptions of studies, groupings, and tabulations. These methods helped to make sense of how and why the scales in the studies had the results that were reported and to start to test the robustness of the results of the synthesis. Textual descriptions of each study were provided in a systematic manner using this format: Authors, Country of Study, Scale, Scale format and Construct, participant type, sample size, psychometric tests (and sample size), and methodological quality. The studies were then grouped in line with our research aims:

1) existing employment scale for mental health population, with a focus on personality disorders;

2) the content of variables measured in the scales and the extent of their applicability to preparedness for employment for people with personality disorders, using the biosocial model (Linehan, 1993) and;

3) the psychometric properties of the scales in the reviewed studies.

The groupings were displayed in tabulation form as this format is considered a good technique commonly used in systematic reviews; it provides fundamental structure for future elements of the synthesis process (Evans, 2002; Mulrow & Cook, 1998).

This study used the biosocial model of BPD (Linehan, 1993) to inform a deductive approach to summarise the content of the questionnaires (see Figure 5). As models of personality disorders are moving away from discrete categorical approaches towards an explanation of dimensionality and more recently a general factor (with some additional subtypes) (Tyrer et al., 2015), this model may help characterise the clinical features that reflect the general factor of personality disorders.³ The biosocial model identified the extent the

³ See Chapter 1 Section 1.3.1 Models of Personality Disorder for further discussion.
reviewed scales are appropriate for people with personality disorders and employment.

Table 2. presents each model component definition. The study changed “Invalidating environment” to “Environment” as the authors felt that the former was used to explain the pathological development of BPD, but this explanation may not appropriate in this context. Nonetheless, the authors acknowledged that the environment may still have an impact on the individual. Thus, items that included any external factors were deemed appropriate. A research assistant (the PhD student) coded the underlying scale constructs using this model and subsequently searched for any occurring patterns. A senior clinical researcher (primary PhD supervisor) then cross-checked the codes separately, before the codes and themes were jointly finalised by both the senior clinical researcher and research assistant.

![Figure 5](image_url). The transactional relationship between emotional dysregulation and BPD patterns; the Biosocial Model of BPD (priori theory used for thematic deductive approach) (Linehan, 1993).
<table>
<thead>
<tr>
<th>Model Component</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioural Instability</td>
<td>Any items in the scale that relates to actions, e.g. crying, shouting, leaving work, sick leave, self-harm, substance abuse.</td>
</tr>
<tr>
<td>Interpersonal Instability</td>
<td>Any items in the scale that relates to interpersonal behaviours, e.g. resolving conflicts, assertiveness, social skills.</td>
</tr>
<tr>
<td>Self-Instability</td>
<td>Any items in the scale that includes items that reflect a sense of self and self-awareness.</td>
</tr>
<tr>
<td>Cognitive Instability</td>
<td>Any items in the scale that reflect type of thoughts, thought content, beliefs.</td>
</tr>
<tr>
<td>Biological/Emotional Vulnerability (Affective Instability)</td>
<td>Any items in the scale that reflect emotions or affective components.</td>
</tr>
<tr>
<td>Environment</td>
<td>Any items in the scale that reflect external factors such as demands of the workplace, stigma, and support network.</td>
</tr>
</tbody>
</table>
2) **Exploring Relationships in the Data**

Once the study established the preliminary synthesis, it explored the influences of heterogeneity by examining the relationships in the data. The aim was to try and understand the differences between the characteristics of individual studies and across all studies. Variations between studies may be due to methodological differences, interventions, and differences in baseline characteristics of studied populations (Petticrew & Roberts, 2006). This thesis displayed this step by presenting potential moderator variables and subgroup analyses in table form. The research aims guided the potential sources of heterogeneity: variations in the type of scale, populations, context and setting, sample size, variations in psychometric tests, variations in the constructs being measured, about personality disorders (using the biosocial model).

3) **Robustness of Synthesis**

The COnsensus-based Standards for the selection of health Measurement INstrument checklist (COSMIN: Mokkink et al., 2010). The COSMIN was used to conduct robustness of synthesis and assessed the methodological quality of the included studies. Two independent reviewers (LS & JF) used the 4-point COSMIN. The COSMIN has been recommended for use in systematic reviews (Veenhof et al., 2006) and can also be used to assess the psychometric properties of the scale (Terwee et al., 2012). The psychometric properties evaluated were internal consistency; reliability; content validity (including face validity); construct validity (structural validity; hypotheses testing, cross-cultural validity); criterion validity; and responsiveness. Each psychometric property contained a checklist items of standards, in which the reviewers rated a quality level per item; ‘Excellent’, ‘Good’, ‘Fair’, and ‘Poor’ (Terwee et al., 2012). The overall methodological quality of the property is awarded by taking the lowest rating of any item in the checklist box, once agreed by the two reviewers. Full details of the COSMIN checklist can be found in the manual (Mokkink et al., 2012; Mokkink et al, 2018).

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4 At the time of this study the COSMIN 2010 version was the most updated version available. A newer version of the COSMIN has since become available (see Mokkink et al., 2018).
The COSMIN was developed through an international Delphi study, in which the panel agreed that in all measurement properties (except content validity), missing values should be reported and how they were handled, as well as sample sizes. Small sample sizes were considered an aspect of poor methodological quality according to the COSMIN. This is important as the statistical analysis used to assess structural validity (i.e. Classical Test Theory [CTT] and Item Response Theory [IRT]), require large sample sizes. The recommended sample size for a CTT (i.e. factor analysis) is \( n = 5 - 7 \) responders x the number of items in the scale (Kline, 2013) with a minimum of 100 (item 6, box A and item 4 box E) (de Vet, Adèr, Terwee, & Pouwer, 2005). For IRT, depending on the IRT model used, sample size recommendations vary from 100 subjects to 500 subjects for models with more parameters (Edelen & Reeve, 2007). It is generally accepted that a sample size of \( > 100 \) is excellent, 50 as good, 30 as fair, and less than 30 as poor (Pituch & Stevens, 2015).

2.2.4 Levels of Evidence

Levels of evidence refer to the overall evidence of quality on the measurement properties of the different questionnaires. The level of evidence combines the scales results, the number of studies, and methodological quality of the studies, and the consistency of their results into account. It is recommended to conduct levels of evidence because "...in applying levels of evidence, the methodological quality of the studies is taken into account, as well the number of studies and their results. As the results of studies with poor methodological quality cannot be trusted, they do not contribute any evidence, while excellent studies provide strong evidence" (Terwee et al., 2012, p. 655). Thus, levels of evidence were used to rate the quality of the scales overall, similar to how randomised controlled trials (RCTs) are handled in terms of level of evidence in systematic reviews (Furlan, Pennick, Bombardier, van Tulder, & Editorial Board, 2009).

Table 3. presents the different levels of evidence awarded to the overall quality of the measurement property. The possible overall rating for a measurement property is “positive (+)”, “indeterminate (?)”, or “negative (-)”,

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accompanied by levels of evidence, as was proposed by the Cochrane Back Review Group (Furlan et al., 2009; van Tulder et al., 2003).

Table 3. *Levels of Evidence for the overall quality of the measurement property* (van Tulder et al., 2003)

<table>
<thead>
<tr>
<th>Level</th>
<th>Rating</th>
<th>Criteria</th>
</tr>
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<tbody>
<tr>
<td>Strong</td>
<td>+++ or ---</td>
<td>Consistent findings in multiple studies of good methodological quality OR in one study of excellent</td>
</tr>
<tr>
<td>Moderate</td>
<td>++ or --</td>
<td>Consistent findings in multiple studies of fair methodological quality OR in one study of good methodological quality</td>
</tr>
<tr>
<td>Limited</td>
<td>+ or -</td>
<td>One study of fair methodological quality</td>
</tr>
<tr>
<td>Conflicting</td>
<td>±</td>
<td>Conflicting findings</td>
</tr>
<tr>
<td>Unknown</td>
<td>?</td>
<td>Only studies of poor methodological quality</td>
</tr>
</tbody>
</table>

*Note. + positive results, - negative result*
2.3 Results

2.3.1 Employment Scales

The review found eighteen studies that evaluated employment scales for mental health populations. Table 4. presents a description of each employment scale in terms of the number of items, response format, the country of which it was developed, whether it is PRO or CRO and the construct it purported to measure. The construct measured in the scales were Behavioural and Cognitive Scales (n= 6); Self-Efficacy and Motivation Scales (n=3); Combination Scales (n=3); Readiness and Change Scales (n=3); and Other (n=3). The Work Rehabilitation Questionnaire (WORQ; Finger, Escorpizo, Bostan, & De Bie, 2014) was the longest measurement, containing 52 items and the Occupational Functioning Scale (OFS; Hannula, Lahtela, Järvikoski, Salminen, & Mäkelä, 2006) was the shortest scale with a one-item anchored rating scale.
<table>
<thead>
<tr>
<th>Study &amp; Country</th>
<th>Employment Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tsang &amp; Chiu (2000)</strong> H. K.</td>
<td><strong>Work Behaviour Checklist (WBC);</strong> a 3-part scale containing 30 items and three domains: General Behaviours, Vocational Behaviours, &amp; Social Behaviours. Part 2: four graphs which reflect the three domains. Patients are rated by plotting the scores against the date of the rating. Response option for part 3: a 4-point rating scale where 4 points represent normal performance when compared with an average worker in the normal population, 3 points represents performance with minor impairment, 2 points indicates performance with moderate impairment and 1 represents severe impairment in performance. CRO.</td>
</tr>
<tr>
<td><strong>Tsang &amp; Pearson (2000)</strong> H. K.</td>
<td><strong>Vocational Social Skills Assessment Scale (VSSAS);</strong> Part 1: 10 items measuring particular social skills for job acquisition and job tenure. Response option: 6-point scale, 1 represents “always difficult”, and 6 represents “not difficult at all”. Part 2: Role-play exercise, rating option: 5-point scale where 4 represents normal performance, and 0 represents poor performance. Part 1: PRO, Part 2: two role-plays where clinician plays the interviewer and then a job supervisor in the second.</td>
</tr>
<tr>
<td><strong>Bryson et al. (1997)</strong> U.S.</td>
<td><strong>Work Behaviour Inventory (WBI);</strong> 36 items of five subscales; Social Skills, Cooperativeness, Work Quality, Work Habits, and Personal Presentation, each with 7 items. Response option: 5-point scale on a continuum of behaviour, 1 = ‘Consistently inferior performance’, 2, 3, 4 = intermediate points on the performance continuum and 5= ‘Consistently superior performance’. Each sum of the subscale is totalled to create a one global score of overall vocational functioning. CRO. Includes a 15 minute observation of client.</td>
</tr>
<tr>
<td><strong>Bull et al. (2015)</strong> Sweden</td>
<td><strong>Work Behaviour Inventory (WBI) – Norwegian Version;</strong> same items as the original WBI (Bryson et al., 1997) except the response option worded slightly differently: 5-point scale, 1 = ‘Consistently an area needing improvement’, 2 = ‘Occasionally an area needing improvement’, 3 = ‘Adequate performance’, 4= ‘Occasionally an area of superior performance’ and 5= ‘Consistently an area of superior performance’. CRO. Includes a 15 minute observation of client.</td>
</tr>
<tr>
<td><strong>Hannula et al. (2006)</strong> Finland</td>
<td><strong>Occupational Functioning Scale (OFS);</strong> a one-item, anchored rating scale. The scale ranges from 0 to 100, the higher the score indicating higher functioning. The scale is anchored along with a 10-point interval, in which a detailed functioning description accompanies each interval. The rater rates the point most suitable to the patient using a 1-month time frame. CRO.</td>
</tr>
<tr>
<td>Study &amp; Country</td>
<td>Employment Scale</td>
</tr>
<tr>
<td>----------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Self-Efficacy and Motivation Scales</td>
<td></td>
</tr>
<tr>
<td>Chou et al. (2007) H. K.</td>
<td><strong>Task-Specific Self-Efficacy Scale (TSSES-PMI)</strong>; 35 items. Response option: 6-point Likert scale, 1 = not confident at all and 6 = totally confident. PRO.</td>
</tr>
<tr>
<td>Australian</td>
<td><strong>Work-Related Self-Efficacy Scale (WRSES)</strong>; 37 items. Response option: 11-point scale (0-100) in intervals of 10, rating the confidence for performing a specified activity. CRO.</td>
</tr>
<tr>
<td>Corbière et al. (2004) Canada</td>
<td><strong>Barriers to Employment subscale (BECES)</strong>; 43 items (of the coping subscale) measuring Self-Efficacy and Coping of Barriers to Employment. Response option: 7-point Likert Scale, 1 represents “not likely at all”, and 7 represents “completely likely”. PRO.</td>
</tr>
<tr>
<td>Combination Scales</td>
<td></td>
</tr>
<tr>
<td>Waghorn et al. (2005b) Australia</td>
<td><strong>Work-related Subjective Experiences Scale (WSES)</strong>; 38 items. Seven symptom domains; Cognitive, Negative, Attention and Memory, Affective, Delusional, Social and Medication/drug use. Response option: a visual analogue scale, to record the frequency of experience, relative severity, manageability, and whether each description would be a problem when employed. CRO: face-to-face.</td>
</tr>
<tr>
<td>Finger et al. (2014) U.S.</td>
<td><strong>Work Rehabilitation Questionnaire (WORQ)</strong>; Part 1: 17 items, Part 2: 36 items evaluating work functioning of individuals in vocational rehabilitation over the last week (Behaviour and Cognitive functioning). Response option to each item: a visual analogue scale, from 0 to 100, 0 represented no problem, and 100 represented a complete problem. PRO.</td>
</tr>
<tr>
<td>Lohss et al. (2012) U.K.</td>
<td><strong>The Worker Role Interview (Version 10.0; WRI)</strong>; 16 items on perception on values: Volition (considered in one’s own values, interests and belief in their own work capacity); Habituation (where forming habits brings routines which impact work capacity); One’s own perspective of their social and physical environment; and Performance capacity. Response option: 4 point scale; strongly supports (SS) = 4, Supports (S) =3, Interferes (I) =2, Strongly Interferes (SI) = 1 and Not Applicable (NI). CRO.</td>
</tr>
<tr>
<td>Study &amp; Country</td>
<td>Employment Scale</td>
</tr>
<tr>
<td>----------------</td>
<td>------------------</td>
</tr>
<tr>
<td><strong>Readiness and Change Scales</strong></td>
<td></td>
</tr>
<tr>
<td>Gervey (2010) U.S.</td>
<td><strong>University of Rhode Island Change Assessment for Vocational Counseling (URICA-VC);</strong> 32 items, 4 sub-scales: Pre-contemplation, Contemplation, Action and Maintenance. A 4-point scale was used for agreements and eight items are totalled and averaged for each of the 4 subscales. Twelve of the items were linked to dissatisfaction across Pre-contemplation, Contemplation, and Action stages. Response option: 5-point Likert scale; 1 = ‘strongly disagree’ and 5 = ‘strongly agree’. The item scores are summed to produce three subscale scores, transformed into T-scores which indicate the individual’s Stage of Change as ‘Pre-Contemplation’, ‘Contemplation’, ‘Preparedness’ or ‘Action.’ PRO.</td>
</tr>
<tr>
<td>Rogers et al. (2001) U.S.</td>
<td><strong>Change Assessment Scale (CAS);</strong> 32 items; 4 sub-scales: Pre-contemplation, Contemplation, Action, and Maintenance. A 4-point scale was used for agreement, and the eight items are totalled and averaged for each of the 4 subscales. PRO.</td>
</tr>
<tr>
<td>Potkins et al. (2016) U.S.</td>
<td><strong>Work Readiness Questionnaire (WoRQ);</strong> 7 items measuring work readiness: 1) Adherence to medication; 2) Ability to conduct daily activities; 3) Ability to keep appointments; 4) Impulse control; 5) Patient’s behaviour; 6) Patient’s appearance; 7) Patient’s current symptoms. Response option: 4-point Likert Scale where 1 = Strongly agree, 2 = Agree, 3 = Disagree and 4 = Strongly disagree. There is also a final clinical judgment question: Is this patient ready to work? Response option: Yes/No. This is a global judgment, not the sum of the previous items, but 7 items used to inform clinical judgment. CRO.</td>
</tr>
<tr>
<td>Study &amp; Country</td>
<td>Employment Scale</td>
</tr>
<tr>
<td>----------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Other Corner et al. (1997) U.S.</td>
<td><strong>Work Environment Impact Scale (WEIS)</strong>; 17 items were measuring how the environmental feature influences the worker’s performance or needs, satisfaction and emotional/physical well-being. Response option: a 4-point Likert scale where 1 = Strongly interferes and 4 = strongly supports. CRO: Semi-structured interview</td>
</tr>
<tr>
<td>Stewart et al. (2010) Australia &amp; New Zealand</td>
<td><strong>Activity and Participation Questionnaire (APQ6)</strong>. 6 items; 1) Employment; the number of hours worked in paid employment; 2) Seeking Employment; the extent the individual is seeking employment in the past week; 3) Unpaid Work; participation in any unpaid work; 4) Education and training; participation in schools, university or informal settings; 5) Social and community participation; visiting relatives or friends going out for a meal or entertainment, or participating in organised religious, sporting, arts or other interest group activities; 6) Readiness to change. CRO: Telephone and face-to-face.</td>
</tr>
<tr>
<td>Zaniboni et al. (2010) Canada</td>
<td><strong>Work Values Questionnaire (WVQ)</strong>: 30 items; 5 subscales: Status (personal success and social recognition) 14 items; Climate (acceptance and understanding by others) 10 items; Risk (competition, possible difficulties, and obstacles to overcome) 12 items; and Freedom (independence, self-determination, and autonomy) 11 items. PRO.</td>
</tr>
</tbody>
</table>

*Note. CRO = Clinician Reported Outcome scale; PRO = Patient-Reported Outcome scale*
2.3.2 Relevance to Personality Disorders

The study also categorised the scales into the components of the biosocial model of BPD (see Table 5). The majority of the studies developed scales that had some items relating to at least one or more component of the biosocial model (n=13). One study contained some items that reflected all the components of the biosocial model (WORQ; Finger et al. 2014). Twelve studies developed scales that captured Behavioural elements, and nine studies developed scales that had items that reflected Interpersonal aspects of the biosocial model. The biosocial model components of Cognitive instability (n=4), Environment (n=4), Affect (n=4) and Self (n=3) were the least reflected in the scales developed in the reviewed studies. Four studies did not report the full scale; therefore, the authors were emailed for the full scale, but the scales were unable to be obtained.
Table 5. *Components of the biosocial model of BPD and TBM-PD in the included studies (n items): results of a thematic analysis.*

<table>
<thead>
<tr>
<th>Study</th>
<th>Scale</th>
<th>Behavioural Instability (n items)</th>
<th>Interpersonal Instability (n items)</th>
<th>Self-Instability (n items)</th>
<th>Cognitive Instability (n items)</th>
<th>Biological/Emotional Vulnerability (Affective Instability) (n items)</th>
<th>Environment (n items)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tsang &amp; Pearson (2000)</td>
<td>VSSAS</td>
<td>✓ (3)</td>
<td>✓ (7)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tsang &amp; Chiu (2000)</td>
<td>WBC</td>
<td>✓ (8)</td>
<td>✓ (6)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Potkins et al. (2016)</td>
<td>WoRQ</td>
<td>✓ (7)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bryson et al. (1997)</td>
<td>WBI</td>
<td>✓ (12)</td>
<td>✓ (14)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bull et al. (2015)</td>
<td>WBI</td>
<td>✓ (9)</td>
<td>✓ (13)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hannula et al. (2006)</td>
<td>OFS</td>
<td>✓ (1)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Finger et al. (2014)</td>
<td>WORQ</td>
<td>✓ (1)</td>
<td>✓ (2)</td>
<td>✓ (1)</td>
<td>✓ (3)</td>
<td>✓ (2)</td>
<td>✓ (2)</td>
</tr>
<tr>
<td>Corbière et al. (2004)</td>
<td>BECES</td>
<td>✓ (2)</td>
<td>✓ (3)</td>
<td>✓ (1)</td>
<td>✓ (1)</td>
<td>✓ (1)</td>
<td>✓ (13)</td>
</tr>
<tr>
<td>Waghorn et al. (2005b)</td>
<td>WSES</td>
<td>✓ (1)</td>
<td>✓ (5)</td>
<td>✓ (10)</td>
<td>✓ (4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lohss et al. (2012)</td>
<td>WRI</td>
<td>✓ (2)</td>
<td></td>
<td>✓ (1)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Zaniboni et al. (2010)</td>
<td>WVQ</td>
<td>✓ (4)</td>
<td>✓ (1)</td>
<td>✓ (30)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Karidi et al. (2005)</td>
<td>OAPS</td>
<td></td>
<td></td>
<td>✓ (7)</td>
<td></td>
<td></td>
<td>✓ (1)</td>
</tr>
<tr>
<td>Stewart et al. (2010)</td>
<td>APQ6</td>
<td>✓ (5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Corner et al. (1997)</td>
<td>WEIS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chou et al. (2007)*</td>
<td>TSSES-PMI</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Waghorn et al. (2005a) *</td>
<td>WRSES</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gervey (2010) *</td>
<td>URICA-VC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rogers et al. (2001) *</td>
<td>CAS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* *Unable to attain items*
Table 6. presents the sample descriptions of each study. None of the studies included a scale that was personality disorder specific. Ten studies used a sample with mixed mental health disorders and physical health problems, of which personality disorder was included (n=4). Eight studies included participants with a diagnosis of psychosis. The scale that included some items (n = 13, of 52 items) that reflected components of the biosocial model (WORQ; Finger et al., 2014) included psychiatric patients (n=9), for which a diagnosis breakdown was not available. Thus, it is unknown whether personality disorders were included in this study. Psychiatric patients were 9.5% of the overall sample; the rest were patients with Neurological (n=34) or Musculoskeletal problems (n=33). In 13 studies, clients took part in some form of vocational rehabilitation programmes or supported accommodation, four studies included patients from psychiatric services, and one study included clients from the community.
### Table 6. Sample Description of Studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Employment Scale</th>
<th>Participants</th>
<th>Sample size n (%)</th>
<th>Context/Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mixed Mental Health Disorders Scales</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tsang &amp; Chiu (2000)</td>
<td>WBC</td>
<td>PS, PD, MD/AD</td>
<td>113; PD = 14 (112%)</td>
<td>VRP (in PsyS)</td>
</tr>
<tr>
<td>Hannula et al. (2006)</td>
<td>OFS</td>
<td>PD, MDD, SP</td>
<td>150; PD = 37 (24.7%)</td>
<td>PS (C and P)</td>
</tr>
<tr>
<td>Corbière et al. (2004)</td>
<td>BECES</td>
<td>MD, SZ, AD, Other (PD)</td>
<td>254; PD = 80* (31%)</td>
<td>CVRP</td>
</tr>
<tr>
<td>Lohss et al. (2012)</td>
<td>WRI</td>
<td>SZ, DP, PD, BP, NseP, AN</td>
<td>34; PD = 5 (15%)</td>
<td>CVRP</td>
</tr>
<tr>
<td>Zaniboni et al. (2010)</td>
<td>WVQ</td>
<td>MD, SZ, AD, Other (PD)</td>
<td>254; PD = 80 (31.5%)</td>
<td>CVRP</td>
</tr>
<tr>
<td>Finger et al. (2014)</td>
<td>WORQ</td>
<td>PsD, NL, MSC</td>
<td>Fl: 74; PsD = 9 (12%); Sl: 52; PsD: 4 (8%)</td>
<td>CVRP</td>
</tr>
<tr>
<td>Chou et al. (2007)</td>
<td>TSSES-PMI</td>
<td>SZ, BP, DP</td>
<td>n = 156</td>
<td>PsyS</td>
</tr>
<tr>
<td>Corner et al. (1997)</td>
<td>WEIS</td>
<td>BP, MDD</td>
<td>20</td>
<td>CVRP</td>
</tr>
<tr>
<td><strong>Psychosis Scales</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Potkinds et al. (2016)</td>
<td>WoRQ</td>
<td>SZ</td>
<td>200</td>
<td>Outpatients</td>
</tr>
<tr>
<td>Gervey (2010)</td>
<td>URICA-VC</td>
<td>SZ</td>
<td>R: 80; SE: 110; OSC:106</td>
<td>CVRP</td>
</tr>
<tr>
<td>Waghorn et al. (2005a)</td>
<td>WRSES</td>
<td>SZ/SZA</td>
<td>104</td>
<td>CVRP</td>
</tr>
<tr>
<td>Waghorn et al. (2005b)</td>
<td>WSES</td>
<td>SZ/SZA</td>
<td>104</td>
<td>Community</td>
</tr>
<tr>
<td>Karidi et al., (2005)</td>
<td>OAPS</td>
<td>SZ/SZA</td>
<td>Pa: 80; NP: 30</td>
<td>VRP</td>
</tr>
<tr>
<td>Stewart et al. (2010)</td>
<td>APQ6</td>
<td>SZ</td>
<td>(Q: 62; NSW: 63)</td>
<td>NSW: PR &amp; CMHS; Q: C &amp; PsyS</td>
</tr>
</tbody>
</table>

*(table continues)*
<table>
<thead>
<tr>
<th>Study</th>
<th>Employment Scale</th>
<th>Participants</th>
<th>Sample size n (%)</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tsang &amp; Pearson (2000)</td>
<td>VSSAS</td>
<td>SZ</td>
<td>SZ: 80; Ctl: 60</td>
<td>Sheltered Workshops &amp; HH</td>
</tr>
<tr>
<td>Bryson et al. (1997)</td>
<td>WBI</td>
<td>SZ/SZA, SA</td>
<td>105</td>
<td>CVRP and HH</td>
</tr>
<tr>
<td>Rogers et al. (2001)</td>
<td>CAS</td>
<td>SZ</td>
<td>130</td>
<td>Housing programme, ESS and CVRP</td>
</tr>
</tbody>
</table>

Note. AD= Anxiety disorder; AN= Anorexia Nervosa; BP= Bipolar disorder; C = community; CMHS = community mental health services; Ctl=Control Sample; CVRP = community vocational rehabilitation programmes; DD = Delusional Disorder; DP= Depressive disorder; ESS = employment support service; FI= First Interview; HH = Halfway Houses; MDD= Major Depressive disorder; MD= Mood disorder; MSC= Musculoskeletal; NeP= neurotic disorder; NL= Neurological disorder; NP= Non-Patients; NSW = New South Wales; OSC= One-Stop Centre; P = private; Pa= Patients; PD= Personality disorder; PR= Psychiatric Rehabilitation; PS = Psychosis; PsD= Psychiatric Disorder; PsyS = psychiatric services; Q = Queensland; R= Residential; SA = Substance Abuse; SE= Supported Employment; SI= Second Interview; SP= Social Phobia; SZ= Schizophrenia; SZA= Schizoaffective disorder; VRP = vocational rehabilitation programmes; *approximate number; **Bold** = studies that included people with PD in their sample.
2.3.3 Reliability and Validity of the Employment Scales

Sixteen studies used Classical Test Theory (CTT; Novick, 1966), two studies used Item Response Theory (IRT: Lord, 1980), and one study used both methods. Reliability and internal consistency results using the CTT method are presented in Table 7. Cronbach’s alpha was described as $\alpha \geq 0.9$ Excellent, $0.9 > \alpha \geq 0.8$ Good, $0.8 > \alpha \geq 0.7$ Acceptable, $0.7 > \alpha \geq 0.6$ Questionable, and $0.6 > \alpha \geq 0.5$ Poor (Cohen, 1960; Cronbach, 1951; George & Mallery, 2003). Of the 16 studies using the CTT method, six studies reported acceptable, good, and excellent internal consistency (Cronbach’s alpha $\geq 0.7$ and above) of the overall scale (study 1, 2, 5, 7, 10, & 18) and five reported the same for internal consistency for subscales (study 3, 4, 8, 9, & 11). One study found poor and questionable internal consistency within a subscale of their measure (study 13). One study found questionable internal consistency within a subscale of their measure (Study 14). Of the three studies that used IRT method (see Table 8) all studies conducted internal consistency tests, two of which reported acceptable and excellent internal consistency; and one study said they conducted internal consistency but did not report it.

Nine studies conducted reliability tests (see Table 7.) Six studies reported the ICC; three studies reported reliability using Pearson’s correlations and Spearman rho. Three of the nine studies showed excellent reliability of the total score of the scale (study 1, 6, & 7), based on these interpretations: $< 0.40 =$ poor, $0.40 - 0.59 =$ Fair, $0.60 - 0.74 =$ Good, and $0.75 - 1.00 =$ excellent (Cicchetti, 1994). One study at the item level found the majority of items also showed excellent reliability except for Q3a, Q5a in the Queensland sample (.43 and .69 respectively) and Q5a in the NSW sample (.71) (study 12). Another study at the item level found the items showed fair to good reliability (.42-.64), with one
<table>
<thead>
<tr>
<th>Study</th>
<th>Employment Scale</th>
<th>Internal Consistency (Cronbach’s alpha unless otherwise stated)</th>
<th>n</th>
<th>COSMIN Quality Rating</th>
<th>Reliability (ICC)</th>
<th>n</th>
<th>COSMIN Quality Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Tsang &amp; Chiu (2000)</td>
<td>WBC</td>
<td>.84</td>
<td>112</td>
<td>Fair</td>
<td>Inter-rater: GB = .57*; VB = 72*; SB = .44*; Total = .81* (WH is missing). Test-retest: 84*-94*</td>
<td>113</td>
<td>Poor</td>
</tr>
<tr>
<td>2. Tsang &amp; Pearson (2000)</td>
<td>VSSAS</td>
<td>Self-report = .80. Role play rating = .96</td>
<td>33</td>
<td>Poor</td>
<td>Test-retest r = -.35 -.78 Inter-rater for role-play r = .77 -.90</td>
<td>33</td>
<td>Fair</td>
</tr>
<tr>
<td>3. Bryson et al. (1997)</td>
<td>WBI</td>
<td>Subscales: .85-.95 Individual items: .80-.93 (study did not list items individually)</td>
<td>105</td>
<td>Poor</td>
<td>Inter-rater: Individual items: .85-.95 (study did not list items individually) Subscales: SS = .92; C = .91; PP = .94; WH = .88; WQ = .94</td>
<td>32</td>
<td>Fair</td>
</tr>
<tr>
<td>4. Bull et al., (2015)</td>
<td>WBI</td>
<td>Three Subscales: WQ = 0.92, SS = 0.93, C = 0.77</td>
<td>141</td>
<td>Poor</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>5. Finger et al. (2014)</td>
<td>WORQ</td>
<td>.89</td>
<td>74</td>
<td>Poor</td>
<td>Test-retest: $r_s = .79$</td>
<td>52</td>
<td>Fair</td>
</tr>
<tr>
<td>6. Hannula et al. (2006)</td>
<td>OFS</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>Interrater reliability: .91 (95% CI 0.86-0.95)</td>
<td>4</td>
<td>Poor</td>
</tr>
<tr>
<td>Study</td>
<td>Employment Scale</td>
<td>Internal Consistency (Cronbach’s alpha unless otherwise stated)</td>
<td>n</td>
<td>COSMIN Quality Rating</td>
<td>Reliability (ICC)</td>
<td>n</td>
<td>COSMIN Quality Rating</td>
</tr>
<tr>
<td>-------</td>
<td>------------------</td>
<td>---------------------------------------------------------------</td>
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</tr>
<tr>
<td>7. Karidi et al. (2005)</td>
<td>OAPS</td>
<td>First assessment = .962; Second assessment = .976</td>
<td>174</td>
<td>Fair</td>
<td>Test-retest reliability: .96 (95% CI: 0.807-0.985)</td>
<td>30</td>
<td>Fair</td>
</tr>
<tr>
<td>8. Chou et al. (2007)</td>
<td>TSSES-PMI</td>
<td>Four factors: SMS = .95; WRS = .86; HSS = .75; ERS = .81</td>
<td>156</td>
<td>Poor</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>9. Waghorn et al. (2005a)</td>
<td>WRSES</td>
<td>CPSE = .89; JSSE = .85; WRSSSE = .86; GWSSE = .94</td>
<td>104</td>
<td>Poor</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>10. Waghorn et al. (2005b)</td>
<td>WSES</td>
<td>.93</td>
<td>104</td>
<td>Poor</td>
<td>Test-retest: (28-25 days) $r_s = .02-.93^{<strong>}$ Test-retest reliability (1-8 days) $r = .025—1.00^{</strong>}$</td>
<td>21</td>
<td>Fair</td>
</tr>
<tr>
<td>11. Corbière et al. (2004)</td>
<td>BECES</td>
<td>Five Subscales: S-C/S-C = .90, EF = .85, A/Am = .83, H = .77, WA = .79</td>
<td>254</td>
<td>Fair</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

(table continues)
<table>
<thead>
<tr>
<th>Study</th>
<th>Employment Scale</th>
<th>Internal Consistency (Cronbach’s alpha unless otherwise stated)</th>
<th>n</th>
<th>COSMIN Quality Rating</th>
<th>Reliability (ICC)</th>
<th>n</th>
<th>COSMIN Quality Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. Gervey (2010)</td>
<td>URICA-VC</td>
<td>Three factors: P-C = 0.54, Con = 0.66, A = 0.89</td>
<td>296</td>
<td>Fair</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>With BCJ = 0.91</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Rogers et al. (2001)</td>
<td>CAS</td>
<td>P-C = .67, Con = .78; A = .85, M = .76</td>
<td>163</td>
<td>Fair</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Zaniboni et al. (2010)</td>
<td>WVQ</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Potkins et al. (2016)</td>
<td>WoRQ</td>
<td>0.89</td>
<td>200</td>
<td>Fair</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Note. *(p<0.01); **(p<0.001); A= Action; A/Am= Anxiety/Amotivation; BCJ = Based on your clinical judgment question; C= compliance with work norms; CI = Confidence Intervals; Con= Contemplation; CPSE= Career planning self-efficacy; EF= External Factors; ESRS= Emotional Self-Regulation skills; GB = General Behaviour; GWSSE= General work skills self-efficacy; H= Health; HSS= Help-seeking skills; ICC = Intraclass Correlation Coefficient; JSSE= Job securing self-efficacy; M= Maintenance; NSW = New South Wales; P-C= Pre-Contemplation; PP = Personal Presentation; QL = Queensland; r = Pearson’s correlation; $r_s$ = Spearman correlation; S-C/S-C= Self-Competence/Self-Confidence; SC = Social Behaviour; SMS= Symptom management skills; SS= Social skills, VB = Vocational behaviour; WA= Work Adjustments; WH = Work Habit; WQ= Work quality, WRS= Work-Related skills; WRSSSE= work related social skills self-efficacy.
Table 8. *Psychometric Properties for Scales that used Item Response Theory (IRT).*

<table>
<thead>
<tr>
<th>Study</th>
<th>Scale</th>
<th>Psychometric properties</th>
<th>Internal Consistency</th>
<th>n</th>
<th>COSMIN Quality Rating</th>
<th>Construct Validity</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. <em>Finger et al.</em> (2014)</td>
<td>WORQ</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>NR</td>
</tr>
<tr>
<td>4. Lohss et al. (2012)</td>
<td>WRI</td>
<td>Item fit: MnSq values .44-1.28 (one item’s MnSq value was above the cut off (1.56)), Index of Subject Separation = 3.7 (reliability 0.93) Rater leniency: MnSq values 0.59 to 1.29, Index of Subject separation = 1.56 (reliability of 0.71)</td>
<td>34</td>
<td>Poor</td>
<td>NR</td>
<td></td>
</tr>
<tr>
<td>17. Corner et al. (1997)</td>
<td>WEIS</td>
<td>MnSq values = 1.0, Index of Person separation = 1.63 (reliability .73) MnSq values = 1.02, Index of Item separation = 1.57 (reliability .71)</td>
<td>20</td>
<td>Poor</td>
<td>NR</td>
<td></td>
</tr>
</tbody>
</table>

*Note.* *Finger et al.,* (2014) used both IRT and CTT to develop and evaluate the WORQ; MnSQ = Mean Square; NR = Not reported.
dichotomous item found to have good reliability (.73) (study 18). One study did not report the reliability tests for all subscales (Work Behaviour Checklist: study 1). Two studies purported to show strong reliability (.79) and weak to strong reliability (.02-.93 & .025-1.00) using Pearson’s correlations and Spearman rho (study 5 & 10). None of the studies reported measurement error.

Sixteen studies conducted validity tests (see Table 9). Eleven studies conducted structural validity. This study used the following interpretations for criterion validity: \(0.10 < r < 0.29\) = weak or small association; \(0.30 < r < 0.49\) = moderate correlation; \(0.50 < r\) or larger = strong or large correlation (Cohen, 2013). Eight studies reported criterion validity of which 6 studies found a moderate to large association (study 3, 6, 7, 9, 10 & 12). Study 5 and 15 found small associations. Six studies conducted hypothesis testing (Study 2, 8, 11, 14, 16 & 18), 10 conducted content validity (study 1, 2, 3, 6, 7, 8, 10, 11, 13, & 18), and three conducted cross-cultural validity (Study 5, 6, 8).

Overall, the employment scales showed fair to excellent reliability, acceptable to good internal consistency (with a few exceptions of subscales showing poor and questionable internal consistency). For validity, some of the scales showed good structural validity, and a medium to large association for criterion validity was found in the majority of the scales. Over half the studies conducted content validity and less than half conducted hypotheses testing. None of the studies conducted measurement error, and three studies conducted responsiveness (9, 10, & 12).
<table>
<thead>
<tr>
<th>Study</th>
<th>Employment Scale</th>
<th>Content and Construct Validity Tests</th>
<th>n</th>
<th>COSMIN Quality Rating</th>
<th>Criterion Validity (r)</th>
<th>n</th>
<th>COSMIN Quality Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Tsang &amp; Chiu (2000)</td>
<td>WBC</td>
<td>Content Validity</td>
<td>11</td>
<td>Excellent</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Structural Validity (EFA): 4-factor model, 67.2% of the total variance</td>
<td>112</td>
<td>Good</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>2. Tsang &amp; Pearson (2000)</td>
<td>VSSAS</td>
<td>Content Validity</td>
<td>3</td>
<td>Fair</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hypothesis Testing</td>
<td>SZ: n = 80; Ctl: n = 60</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Bryson et al. (1997)</td>
<td>WBI</td>
<td>Content Validity</td>
<td>47</td>
<td>Excellent</td>
<td>WPP-TO &amp; WBI-WQ = .89**</td>
<td>27</td>
<td>Poor</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Structural Validity (EFA): 1st PCA; 5-factor model, 79% of the total variance. 2nd PCA: 5 factor model, SS = captures least variance, WH, WQ, C = captures variance (study does not report % of variance).</td>
<td>1st PCA: n = 47</td>
<td>Poor</td>
<td>WPP-WM &amp; WBI-WH = .84**</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2nd PCA: n =59</td>
<td></td>
<td>WPP-SS &amp; WBI-SS = .83**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Bull et al. (2015)</td>
<td>WBI</td>
<td>Structural Validity: 3-factor model, 54.5% of the total variance</td>
<td>141</td>
<td>Poor</td>
<td>.19*</td>
<td>140</td>
<td>Fair</td>
</tr>
<tr>
<td>6. Finger et al. (2014) U.S.</td>
<td>WORQ</td>
<td>Content Validity</td>
<td>NR</td>
<td>Excellent</td>
<td>EQ5D = -.42*</td>
<td>74</td>
<td>Fair</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cross-Cultural Validity</td>
<td>NR</td>
<td>Fair</td>
<td>BDI = .51*; SF-36 = -.35; WHOQoL = -.44*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Employment Scale</td>
<td>Validity Tests</td>
<td>n</td>
<td>COSMIN Quality Rating</td>
<td>Criterion Validity (r)</td>
<td>n</td>
<td>COSMIN Quality Rating</td>
</tr>
<tr>
<td>-----------------------</td>
<td>------------------</td>
<td>----------------------------------------------------</td>
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</tr>
<tr>
<td>7. Hannula et al.</td>
<td>OFS</td>
<td>Content Validity</td>
<td>5</td>
<td>Good</td>
<td>SAS-work = - .47**; WAI = .43**</td>
<td>119</td>
<td>Poor</td>
</tr>
<tr>
<td>(2006)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Chou et al.</td>
<td>TSSES-PMI</td>
<td>Content Validity</td>
<td>4</td>
<td>Fair</td>
<td>156</td>
<td>Poor</td>
<td></td>
</tr>
<tr>
<td>(2007)</td>
<td></td>
<td>Structural Validity: 4-factor model, 63% of the total variance</td>
<td></td>
<td></td>
<td>Hypothesis Testing</td>
<td>Fair</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cross-Cultural Validity</td>
<td></td>
<td></td>
<td></td>
<td>Poor</td>
<td></td>
</tr>
<tr>
<td>9. Waghorn et al.</td>
<td>WRSES</td>
<td>Structural Validity: 4-factor model, 20.5% of the total variance</td>
<td>104</td>
<td>Poor</td>
<td>HoNos = -.49*; CGI = -.41*</td>
<td>104</td>
<td>Poor</td>
</tr>
<tr>
<td>(2005a)</td>
<td></td>
<td>Responsiveness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Waghorn et al.</td>
<td>WSES</td>
<td>Content Validity</td>
<td>21</td>
<td>Excellent</td>
<td>HoNoS = -.54*; CGI = -.50*</td>
<td>104</td>
<td>Poor</td>
</tr>
<tr>
<td>(2005b)</td>
<td></td>
<td>Structural Validity (CFA): 5-factor model, 16.2% of the total variance</td>
<td></td>
<td></td>
<td>Hypothesis Testing</td>
<td>Fair</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Responsiveness</td>
<td></td>
<td></td>
<td></td>
<td>Poor</td>
<td></td>
</tr>
<tr>
<td>11. Corbière et al.</td>
<td>BECES</td>
<td>Content Validity</td>
<td>50</td>
<td>Excellent</td>
<td>254</td>
<td>Fair</td>
<td></td>
</tr>
<tr>
<td>(2004)</td>
<td></td>
<td>Structural Validity (EFA): 5-factor model, 60.9% of the total variance</td>
<td></td>
<td></td>
<td>Hypothesis Testing</td>
<td>Fair</td>
<td></td>
</tr>
<tr>
<td>12. Karidi et al.</td>
<td>OAPS</td>
<td>Structural Validity: 5-factor model, 72% of the total variance</td>
<td>174</td>
<td>Good</td>
<td>GAS = .38**</td>
<td>80</td>
<td>Poor</td>
</tr>
<tr>
<td>(2005)</td>
<td></td>
<td>Responsiveness</td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

(Table continues)
<table>
<thead>
<tr>
<th>Study</th>
<th>Employment Scale</th>
<th>Validity Tests</th>
<th>n</th>
<th>COSMIN Quality Rating</th>
<th>Criterion Validity (r)</th>
<th>n</th>
<th>COSMIN Quality Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. Stewart et al. (2010)</td>
<td>APQ6</td>
<td>Content Validity</td>
<td>29</td>
<td>Excellent</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>14. Gervey (2010)</td>
<td>URICA-VC</td>
<td>Structural Validity (CFA): 3 factor model, $\chi^2/df = 1.66$, GFI = .95, RMSEA (90% CI) = .05***</td>
<td>296</td>
<td>Fair</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>15. Rogers et al. (2001)</td>
<td>CAS</td>
<td>Structural Validity: 4 factor model, 43.5% of the total variance</td>
<td>163</td>
<td>Fair</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>16. Zaniboni et al. (2010)</td>
<td>WVQ</td>
<td>Structural Validity (CFA): $\chi^2/df = 1.77$, CFI = .95, RMSEA (90% CI) = .05***</td>
<td>254</td>
<td>Poor</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>18. Potkins et al. (2016)</td>
<td>WoRQ</td>
<td>Content Validity</td>
<td>47</td>
<td>Fair</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Note. *(p<.01); ***(p<0.001); ***(significant chi-square); A= Action; BDI = Beck’s Depression Inventory (Kühner, Bürger, Keller, & Hautzinger, 2007); C = Cooperativeness; CFA = Confirmatory Factor Analysis; CFI = Comparative Fit Index; CGI= Clinical Global Impression scale (Busner & Targum, 2007); CI = Confidence Intervals; Con= Contemplation; Ctl = Control; EFA = Exploratory Factor Analysis; EQ 5Q (EuroQol Group, 1990); GAS = Global Assessment Scale (Endicott, Spitzer, Fleiss, & Cohen, 1976); GFI = Goodness of Fit Index; HoNoS= Health of the Nation Outcome Scale (Wing et al., 1998); M = Maintenance; P-C= Pre-Contemplation; PCA = Principal Components Analysis; r = Pearson’s correlation; RMSEA = Root Mean Square Error of Approximation; RSA = Substance Abuse; RSES = Rosenberg Self-Esteem Scale (Rosenberg, 1965); SAS-work = The Social Adjustment Scale (Weissman, 1976); SS = Social Skills; SZ = Schizophrenia; TO = Task Orientation; WAI = Work Ability Index (Tuomi, Ilmarinen, Jahkola, Katajairinne, & Tulkki, 1998); WBI-SS = Work Behaviour Inventory- Social Skills; WBI-WH = Work Behaviour Inventory-Work Habit; WBI-WQ = Work Behaviour Inventory-Work Quality; WH = Work Habits; WHOQOL= World Health Organisation Quality of Life Questionnaires (Skevington, Lotfy, O’Connell, & WHOQOL Group, 2004); WPP = Work Personality Profile; WPP-WM = Work Personality Profile-Work Motivation; WQ = Work Quality; WPP-SS= Work Personality Profile-Social Skills; WPP-TO- Work Personality Profile – Task Orientation; $\chi^2/df = $ chi-square; NR = Not reported.
2.3.4 Methodological Quality of Studies (Robustness of Synthesis Results) – COSMIN Checklist

Results of the methodological quality of the 18 studies evaluating employment scales are presented in Table 7-9. Overall, the review found the methodological qualities in the studies varied. The methodological quality of tests of internal consistency was rated poor (n studies = 9) the rest of the studies were rated as fair (n=6). Of the nine studies that conducted reliability, the majority of studies were rated fair (n=7) and the rest were rated poor (n=2). Of the 10 studies that conducted content validity, six were rated as excellent, three were rated as fair, and one was rated good. Of the 11 studies that reported construct validity (structural validity), six were rated poor, three were rated fair, and two was rated as good. Six studies conducted hypothesis testing of which five were rated as fair and one study as poor. Of the eight studies that conducted criterion validity, six were rated as poor and two as fair.5

In summary, the methodological quality for content validity was rated excellent in most of the studies that conducted it. For the majority of studies that conducted internal consistency and structural validity, methodological quality and criterion validity were rated as poor. The majority of studies that conducted reliability and hypothesis testing; the method was rated fair.

2.3.5 Levels of Evidence

The level of overall evidence of the quality of measurement properties of the different scales is presented in Table 106. With regards to internal consistency, the results suggested that the overall methodological quality for eight scales (out of 14 scales) were unknown (VSSAS, WBI, TSSES-PMI, WRSES, WSES, WORQ, WRI, & WEIS), and six scales had limited evidence for internal consistency (WBC, OAPS, BECES, URICA-VA, CAS, & WoRQ).7 Seven out of nine scales had limited evidence for overall methodological quality

5 See Appendix 6 for COSMIN ratings between raters.
6 Please refer to Table 3 in Section 2.2.3 Narrative Synthesis.
7 See Appendix 7 for items
for reliability (VSSAS, WBI, OAPS, WSES, WORQ, WoRQ, and APQ6), and two had unknown evidence of quality (WBC & OFS).

On the other hand, with regards to content validity, the evidence for overall methodological quality for six out of ten scales was strong (WBC, WBI, BECES, WSES, WORQ, & APQ6), one was moderate (OFS) and three were limited (VSSAS, TSSES-PMI, & WoRQ). For structural validity, the overall evidence of quality was unknown for seven scales out of twelve (WBI, TSSES-PMI, WRSES, WSES, WRI, WEIS & WVQ), three had limited evidence (BECES, URICA-VA, & CAS), and two had moderate evidence (WBC & OAPS). The evidence of the overall quality for hypotheses testing was limited for five out of six scales (VSSAS, TSSES-PMI, BECES, URICA-VA, and WVQ), and unknown for one scale (WoRQ).

The evidence of the overall quality for cross-cultural validity was unknown for two scales out of three (WBI & TSSES-PMI) and limited in one scale (WORQ). For criterion validity, the evidence of quality for one scale was conflicting (WBI), five was unknown (OFS, OAPS, WRSES, WSES, & CAS), and one was limited (WORQ).

The level of evidence for responsiveness for three scales was unknown (OAPS, WRSES, & WSES). No evidence of overall quality of measurement error was given as none of the studies conducted this test of reliability. Table 10 also highlighted which measurement properties were not conducted (labelled NA). Overall, internal consistency, reliability, content validity, and structural validity were conducted by most of the scales. A few reported hypotheses testing, criterion and cross-cultural validity and responsiveness.

In summary, there were few studies that assessed the same scale (except WBI). Therefore, the majority of the levels of evidence of overall quality of measurement properties were deemed towards the lower levels; the level of evidence was limited or unknown (except content validity). For example, for internal consistency of the TSSES-PMI (Chou et al., 2007) the level of evidence for quality was limited because there was only one study of fair methodological quality for the scale.
Table 10. Quality of measurement properties per questionnaire

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Internal Consistency</th>
<th>Measurement error</th>
<th>Reliability</th>
<th>Content Validity</th>
<th>Structural Validity</th>
<th>Hypothesis testing</th>
<th>Cross-cultural Validity</th>
<th>Criterion Validity</th>
<th>Responsiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td>WBC</td>
<td>+</td>
<td>NA</td>
<td>?</td>
<td>+++</td>
<td>++</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>VSSAS</td>
<td>?</td>
<td>NA</td>
<td>+</td>
<td>+</td>
<td>NA</td>
<td>+</td>
<td>NA</td>
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<td>NA</td>
<td>?</td>
<td>+</td>
<td>NA</td>
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<td>NA</td>
</tr>
</tbody>
</table>

Note. +++ or --- strong evidence positive/negative result; ++ or -- moderate evidence positive/negative result; + or - limited evidence positive/negative result, ± conflicting evidence, ? unknown, due to poor methodological quality, NA no information available.
2.3.6 Process Results

Cohen’s Kappa was calculated for inter-rater reliability of the COSMIN checklist between the two reviewers that rated the 18 studies. Values \( \leq 0 \) indicates no agreement, .01–.20 as none to slight, .21–.40 as fair, .41–.60 as moderate, .61–.80 as substantial, and .81–1.00 as almost perfect agreement (Cohen, 1960; Landis & Koch, 1977). The interrater reliability for the methodology quality ratings for internal consistency were \( \kappa = .79 \) (\( p < .001 \)), 95\% CI (-0.261, 0.610), \( \kappa = .87 \) (\( p < .001 \)), 95\% CI (-0.051, 0.132) for reliability. Content validity was \( \kappa = .38 \) (\( p < .001 \)), 95\% CI (-0.315, 0.464), structural validity \( \kappa = .85 \) (\( p < .001 \)), 95\% CI (-0.085, 0.213), hypothesis testing \( \kappa = 1 \) (\( p < .001 \)), 95\% CI (-1.092, 3.370), and criterion was fair \( \kappa = .28 \) (\( p < .001 \)), 95\% (-.203, 0.271). Kappa values were not calculated for cross-cultural validity or responsiveness due to a small number of studies.
2.4 Discussion

This systematic review found that none of the scales included in the reviewed studies were created specifically for people with personality disorders. Of the studies reviewed only one scale (WORQ; Finger et al. 2014) had some items that reflected aspects of preparedness for employment, concerning all components of the biosocial model (Linehan, 1993). Self-instability, cognitive instability, affective instability and environment were components that were captured the least in the scales in the reviewed studies. The review also found that despite some of the employment scales showing good psychometric properties, the methodological quality of some of the psychometric tests was questionable.

The extent to which the WORQ (Finger et al., 2014), the only scale that contained items that reflected all aspects of the model, is appropriate for measuring preparedness for employment for people with personality disorders is worth discussing. A scale that assesses these aspects (cognitive, behavioral, affective, interpersonal, and self-dysregulation) may be useful as these difficulties are often present in people with personality disorder in the workplace (Sansone & Wiederman, 2013; Unterberg, 2003; Langan-Fox, Cooper, & Klimoski, 2007; Scott, 2005). However, only thirteen out of thirty-six items reflected the model, with the majority of the items in the WORQ measuring general physical health parameters or items that may not be relevant to personality disorders. For example, there were items that captured vestibular functioning and protective functioning for the skin. Although people with personality disorders often experience physical health problems (El-Gabalawy, Katz, & Sareen, 2010), it is not necessarily a core feature of personality disorders (APA, 2013; WHO, 2019).

Furthermore, the WORQ is the longest measure reviewed in the studies. The length may have implications in response burden, where long questionnaires leads to lower response rates and reduced data quality from clients (Diehr, Chen, Patrick, Feng, & Yasui, 2005; Snyder et al., 2007). Given that people with personality disorders are found to have difficulties engaging in treatment have reported high dissatisfaction with services (Levy, Johnson,
Clouthier, Scala, & Temes, 2015), and are more likely to drop out from treatment prematurely (Ben-Porath, 2004a, 2004b; Chiesa, Drahornad, & Longo, 2000), the use of a lengthy measure, may not be ideal. In addition, clinicians are often restricted for time, therefore, short questionnaires tend to be favoured (Williams, 2015).

This study also evaluated the psychometric properties of the reviewed scales. Regardless of some of the scales displaying good validity and reliability, the quality of the underlying methods used to evaluate psychometric properties were problematic. The WORQ was an example of this; good internal consistency was achieved; however, the test of internal consistency was undermined due to a small sample size; thus, the quality was rated as poor as judged using the COSMIN checklist (Mokkink et al., 2010). Furthermore, the authors also only performed test-retest validity on 34 out of 36, omitting item 36, the only item that reflected ‘self-instability’ according to the biosocial model. Thus, taken together, the WORQ did include items that reflected the biosocial model but not all items were included in assess the scales reliability. This suggests implications on the WORQ’s appropriateness as a validated scale, as well as an appropriate scale for personality disorders.

Poor methodology may have implications on the overall psychometric validity and reliability of the scale (Mokkink et al., 2012). In other words, inadequate quality in methodology may lead to inaccurate scores from the scale or the scale not measuring what it purports to measure. Subsequently, in clinical practice, the use of such scales may lead to misinformed clinical decisions in the planning and support for those with personality disorders towards employment. As measures are considered essential in both clinical practice and research (Ahmed et al., 2012; Deshpande, Rajan, Sudeepthi, & Nazir, 2011), there is an increasing emphasis on not only considering the measurement properties of scales, but also the quality of methods used to assess the measurement properties (Mokkink et al., 2012). Based on these findings, the study felt that the practical utility of WORQ with people with personality disorders was limited.
2.4.1 Strengths and Limitations

A strength of the study is the systematic approached used to navigate the complexities of scale development. The COSMIN checklist used to review the quality of the psychometric methodologies is a robust quality rating tool for psychometric property evaluation (Mokkink et al., 2010; Winser et al., 2015).

A limitation of this systematic review was that some of the studies included in this review were developed before the COSMIN checklist, and were, therefore, created before such robust guidance was available. Another limitation is the interpretation of the results of the retrieved studies. Although the study followed key recommendations for conducting a systematic review, in the form of a narrative synthesis, the findings do not report statistical analysis (e.g. effect sizes). This was mainly because there were limited studies that evaluated the same employment scales and the studies were heterogeneous.

2.4.2 Future Directions

Future studies may involve the development of a new employment scale for people with personality disorders that also incorporates areas that the reviewed scales did not cover; cognitive, affective, self-functioning aspects and environmental factors. Furthermore, the poor methodology quality in the new scale may be prevented by using systematic guides such as the COSMIN checklist (Mokkink et al., 2010). Many people with personality disorders regard working as a key aspect of their recovery (Gillard et al., 2015; Katsakou et al., 2012). Therefore, the development of a new scale may contribute to the recovery process by gauging the extent of preparedness for employment and identifying areas of support required to return to work.

2.5.3 Conclusion

This systematic review found that there is a lack of scales addressing employment difficulties that are specific for people with personality disorders. The existing employment scales for other mental health populations covered areas including behavioural and interpersonal aspects of employment preparedness but lacked other pertinent areas for people with personality disorders, such as affect, self, cognitive and environmental factors. There was
also a need to improve the quality of methods used to conduct psychometric testing. The next step is to develop a personality disorder specific preparedness for employment scale that will identify challenges to employment for people with personality disorders. This will involve devising and generating an item pool. This review also provided potential items to use in this new scale.
Chapter 3  Devising the Items (Content Validity): Challenges to Employment for People with Personality Disorders, a Focus Group Study and e-Delphi Study

3.1 Introduction

An initial search of the literature and critical review demonstrated that current employment scales are insufficient conceptually and psychometrically to measure preparedness for employment for people with personality disorders. Therefore, the development of a new scale was warranted. This chapter discusses several methods that are commonly used to construct and devise items: focus groups and expert opinion and presents two studies.

3.1.1 Qualitative methods

The application of qualitative methods with the target population is imperative to determine that a measure captures all the essential aspects of a concept from the participants’ viewpoint. These insights are collated to help create items that can form a new measure. Focus groups and expert opinion are frequently used approaches for this purpose (Streiner et al., 2015).

Focus groups generally involve a collection of people who are guided by a facilitator to talk freely and spontaneously about a topic of ‘focus’ (Powell, Single, & Lloyd, 1996). The researchers seek different opinions, attitudes, and perspectives. They are frequently used to develop questions or concepts for scales and interview guides (Hoppe, Wells, Morrison, Gillmore, & Wilsdon, 1995; Turner et al., 2007). Kitzinger (1994) describes focus groups to have four distinctive elements. The first is that attention is paid specifically to the participant and not the researcher, whereby the participant is considered the expert. The second is focus groups provide richer insight into subjective ideas and beliefs than individual interviews. Third, focus groups are conducted by a facilitator as opposed to an interviewer, and the fourth element is the information derived from the group depends on the dynamic interaction of the participants. It is within the fourth element that researchers gain insight into the
focused topic by creating an opportunity for participants to discuss, agree, and disagree with other participants’ opinions (Kitzinger, 1995).

Focus groups are low in cost and are highly efficient, collecting information from several people in one setting (Marshall & Rossman, 2014). Furthermore, as they tend to involve more than one participant, focus groups provide perspectives that a single person may not have and allow a more in-depth understanding of the research topic (Streiner et al., 2015). This advantage is ideal when generating content for a new instrument.

A limitation of focus groups may be the number of resources required. Finding multiple participants, as opposed to one for an interview, may be time-consuming. Also, managing several perspectives at one time may take up time. As a result, the time constraint may limit the number of questions asked and, therefore, impact the opportunity to ask more in-depth questions (Farr, 2008). Furthermore, a skilled facilitator may be required to handle any possible conflicts between participants (Streiner et al., 2015). Given that people with personality disorders often experience interpersonal and self-dysfunction (APA, 2013; Swales et al., 2000), a concern would be that interaction with other participants in a focus group may lead to challenging situations for the facilitator.

Additionally, focus groups may also be problematic for certain types of participants, such as those with avoidant personality disorder (AVPD) or those who experience social anxiety who may not wish to engage in this setting. Consequently, facilitators ideally need to be experienced enough to guide sensitive topics in a manner that encourages people to speak freely and be encouraging of those who are less likely to speak up. The skill of the facilitator will be dependent on their style of facilitation. They need to strike a balance between being direct and non-direct to manage any conflict, dominant group members, and sensitive topics (Stewart & Shamdasani, 2014). Alternatively, providing online focus groups or semi-structured interviews for people with personality disorders may help to overcome social anxiety (see Blanchard, 2018). Online focus groups, compared to face-to-face focus groups, have demonstrated an increase in ideas and disclosure (Fox, Morris, & Rumsey, 2007). In this thesis, face-to-face focus groups were conducted, and facilitators
had at least one year’s experience working with people with personality disorders and running group therapy sessions, where dynamics are similar to a focus group.

Another qualitative method used to construct items for a new scale is Expert Opinion. There are no concrete rules on conducting expert opinion; however, both informal and formal discussions may be acceptable. Informal methods range from a few experts discussing their opinions to more formal approaches such as a Delphi method and other consensus techniques (Grant & Davis, 1997; Linstone & Turoff, 1975). For example, the Decision Tool Personality Disorder (DTPD) gathered opinions from a small working group to inform measure design (Goorden et al., 2017). In the development of the CHOICE questionnaire, a Delphi method was used to gather expert opinion (Greenwood et al., 2010).

The Delphi technique, originally developed by the RAND corporation (Dalkey & Helmer, 1963) is defined as an interactive process between researcher and expert panel member. The Delphi method aims to seek and explore an understanding of a topic of interest through the process of seeking consensus from a group of identified experts. The key elements of a Delphi involve: an expert panel, anonymity, rounds and analysis (Hsu & Sandford, 2007; Keeney, Hasson, & McKenna, 2001). The approach has evolved, with modifications and adjustments made (Hasson & Keeney, 2011), becoming an increasingly popular approach within mental health research (Clibbens, Walters, & Baird, 2012; Crawford, Mackway-Jones, Russell, & Carley, 2004; Greenwood et al., 2010).

An advantage of the Delphi method is it allows for experts to express views and opinions freely due to anonymity (Hsu & Sandford, 2007). Anonymity is achieved by researchers corresponding with experts individually and sharing the anonymous responses to the group. It allows an opportunity for experts to adjust their responses by comparing their own to the groups in a more non-invasive manner, unlike focus groups that are limited due to potential dominant contributors inhibiting responses or group dynamics that may well create
conformity to adopt a certain viewpoint (Adams, 2001; Keeney et al., 2001; Powell, 2003).

Another advantage of a Delphi method is that gathering opinions from experts generally ensures that the items reflect the patient’s perspective and that the language used is acceptable for both clinicians and patients (Turner et al., 2007). The information gathered may encapsulate the most recent thinking on the topic and researchers can build upon the experiences of experts to accumulate a range of perspectives (Streiner et al., 2015).

The Delphi method is not without its limitations. Some authors have argued that the technique lacks empirical rigour (Keeney et al., 2001; Powell, 2003; Sackman, 1974; Williams & Webb, 1994). The Delphi method is also considered to be time consuming which consequently leads to poor attrition (Hsu & Sandford, 2007). The loss of panel members may also be due to the lack of rapport between the panel and the research team. Attrition could therefore be reduced through maintaining the panel’s level of involvement, increasing autonomy over the results and motivation (Keeney et al., 2001).

Another limitation is the issues of the overall choice of experts and selecting expert panels (Baker, Lovell, & Harris, 2006). A selection of specific experts can lead to a skew in the opinion of item selection (Keeney, 2010). If the expert group is too homogenous, then limited opinions may be provided. However, if the expert group is too heterogeneous, it will be difficult to come to any consensus (Streiner et al., 2015). The issues regarding the choice of expert selecting experts evolves around what constitutes an “expert” (Keeney, 2010). Experts may include professionals with the relevant qualifications; however, these criteria deny experts by experience, an important point to deliberate, given the current climate of service user co-production and involvement (Shippee et al., 2015). “Informed individual”, “specialist in the field”, “someone who has specialist knowledge about a specific subject” and “informed advocates” are a few examples of definitions of an “expert” (Baker et al., 2006; Crisp, Pelletier, Duffield, Nagy, & Adams, 1999; Keeney et al., 2001; Mead & Moseley, 2001). It seems that regardless of whether they are a professional
expert or expert by experience, it is essential their peers regard them as experts.

Purposive sampling is a non-random sampling method which involves identification of people or groups of people who are proficient and well-informed about the phenomenon of interest (Creswell & Piano Clark, 2007). This sampling method is recommended to select expert panel members for a Delphi method, as people are chosen not to represent the general population, but instead for their expert opinions regarding the topic of interest (Fink, 2009). It is also recommended that an initial identification from PhD supervisors may be beneficial (Skulmoski, Hartman, & Krahn, 2007) and then a snowballing sampling technique to generate subsequent participants (Hartman & Baldwin, 1995). Thus, this thesis addressed issues of selecting expert panels by using purposive and snowballing sample.

A final limitation is that expert opinion is also thought to be the lowest form of validity (also known as “grade of evidence”) (Jordan, Lockwood, Munn, & Aromataris, 2019), and argued to lack reliability and empirical rigour (Keeney et al., 2001). Therefore, in this thesis, subsequently, empirical tests of validity and reliability were conducted in Chapter 5.

3.1.2 Data Triangulation

In this study, data triangulation was used. The views of healthcare professionals, supporters, occupational professionals who are connected to the patient population, and the target population were considered. Taking into account the views of the target group and those closely connected to them will help generate items on a valid questionnaire that may be informative to both the person with personality disorders and clinicians providing employment support (Jordan et al., 2019). In addition, generally including the target population ensures that a scale is relevant for the target population (Rose, Evans, Sweeney, Wykes, & Evans, 2011). Clinicians and researchers have increasingly recognised that involvement of service users is an important factor in the development of measures (Staniszewska et al., 2011; Trujols et al., 2013; Turner et al., 2007).
In summary, in scale development, it is unusual for only one method to be used to generate an item pool. Often researchers will use more than one approach in the design of a measurement (Streiner et al., 2015), especially given that expert opinion alone is thought to be of low validity and reliability (Jordan et al., 2019). Thus, this thesis conducted a systematic review, focus groups, and an e-Delphi study to develop the underlying concept and item generation for a preparedness for employment scale for people with personality disorders. This Chapter now presents two studies i) a focus group and ii) an e-Delphi study.

3.2 Study i) Focus Groups – Devising the Items

3.2.1 Aim

This study aimed to explore the challenges to employment as a means to describe items for a preparedness for employment scale for people with personality disorders. The primary objective of this study was to enable people with personality disorders, supporters of those with personality disorders, healthcare professionals, employment advisors, and occupational health professionals to identify areas that they considered important and relevant to challenges in employment for people with personality disorders, with the anticipating it will generate items for a new preparedness for employment scale for people with personality disorders.

3.2.2 Method

Ethical Approval

The study received ethical approval from West Midlands - South Birmingham National Health Service (NHS) Research Ethics Committee (REC) (ref 15/WM/0466) (See Appendix 8).

The study conducted 10 focus groups. The study also offered semi-structured interviews as an alternative to participating in the focus groups, but none were conducted. Research assistants (RAs) (including the PhD student) recruited four different participant groups for the focus groups; clients with personality disorders (4 groups), supporters of those with personality disorders (2 groups), Healthcare professionals (HCPs) with experience of working with
people with personality disorders (2 groups), and Occupational Professionals (2 groups). Table 11. presents the demographics for all participant groups.

Table 11. *Focus Group Demographics*

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<th>HCP (n=14)</th>
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</table>

*Note. *Age range missing data; PD n=1; Supporters n=1; Employers n=1; HCP n=1; **Ethnicity missing data; Occupational Professionals n=6. NR = Not reported.*
Personality Disorder Focus Groups

Four focus groups with clients with a diagnosis of personality disorder were conducted (n=5, n=6, n=7, n=3). A purposive sampling and snowballing method were used to recruit participants. Purposive sampling is a popular method since focus group discussion relies on the ability and capacity of participants to provide relevant information (Morgan, 1988). Our study recruited participants from personality disorder services two NHS Trusts. All participants met the DSM-5 (APA, 2013) criteria for personality disorders.

Supporter Focus Groups

Two supporters focus groups were conducted (n=8; n=3). The study defined supporters as people who emotionally or financially help a person in their social network (primarily family members, partners, and close friends) with a personality disorder. Purposive sampling method was used to recruit supporters from a personality disorder specialist service at an NHS Trust. The study reimbursed supporters for travel expenses only.

Occupational Professionals Focus Groups

Two employers focus groups were conducted. The study used purposive sampling and recruited participants from two large UK based companies (n=5 & n=8). The authors contacted the Chief Medical Officers and heads of departments to recruit participants who would be interested in taking part in the focus group. There were no exclusion criteria; the participant needed to express an interest in personality disorders and employment to take part. In the focus groups, there were psychotherapists (n=2), occupational health consultants (n=2), a nurse, a team leader, an employment support assistant, and an occupational/HR manager (n=5 job role were missing).

Healthcare Professionals (HCP) Focus Groups

The study used purposive sampling to recruit HCPs. Two HCP focus groups were conducted, one in each NHS Trust (n=8 and n=6). The focus groups consisted of clinical psychologists (n=7), a psychological therapist (n=1), and other HCPs (n=3) (n=3 HCPs job roles were missing). HCPs who had no experience of working with people with personality disorders were excluded.
The researchers advertised for HCPs in the team meetings of the personality disorders services in both NHS Trusts.

**Procedure**

Interested participants were given an information sheet describing the study. Consent forms were subsequently completed, and participants were asked to complete a demographics form before the focus group began (see Appendix 9-14). Each focus group lasted for 1 to 1.5 hours. Participants in the personality disorder focus group were a £15 gift voucher for their time and travel expenses. Supporters were reimbursed for their travel expenses, and occupational professionals and healthcare professionals were not given compensation. Two RAs (including the PhD student) conducted the focus groups.

**Data Collection**

Researchers guided the focus group participants with questions about the challenges to thinking about, seeking, gaining and retaining employment (see Appendix 15-18 for focus group questions). The research team audiotaped and transcribed the information from the focus groups (see Appendix 19-28).

**Analysis**

The study used a framework analysis (Krueger & Casey, 2014; Ritchie & Spencer, 1994; Ritchie & Lewis, 2003) to analyse information drawn from the focus groups. It involved the following steps: familiarisation; identifying a thematic framework; indexing; charting; mapping and interpretation.

**Step 1: Familiarisation**

The study team began to immerse themselves with the data by listening to tapes and reading the transcripts. The aim was to get a sense of the focus group holistically before moving onto identifying smaller parts. The team involved three Ras (including the PhD student) and the primary PhD supervisor. Listening and reading the transcripts enabled the RAs to gain an understanding of what difficulties people with personality disorders faced in employment. The RAs worked on the transcripts individually, from the beginning to the end and noted anything of potential interest and other thoughts. From these initial notes,
the study team developed preliminary codes to reflect different aspects of participants’ experiences and matched them with quotes from the transcripts. This process was repeated for each transcript, and after each one, the study team met, and the preliminary codes were revised.

**Step 2: Identifying a Thematic Framework**

The PhD student identified a thematic framework to organise the data in a meaningful way that was conducive to exploration and examination during the final mapping and interpretation step. Ritchie and Spencer (1994) stipulated that framework categories are ideally formed through a combination of a priori concepts and emerging information that arises from the familiarisation stage. To inform the framework categories, the study used priori concepts derived from the literature on the biosocial model of BPD\(^8\) (Linehan, 1993) and the systematic review in Chapter 2. Emergent issues arising from step one also informed the framework.

The three RAs met weekly, where they tested the framework on a different transcript. The RAs individually coded the transcripts and used the meetings to compare and discuss how the framework categories were applied. Any differences were marked and highlighted as a potential adjustment to the framework. The study team made continuous iterations of the framework through this procedure, and the thematic framework was discussed monthly with the primary PhD supervisor. Parkinson, Eatough, Holmes, Stapley and Midgley (2016) stressed the importance of several iterations, as it tends to lead to a “fruitful” process in developing a framework (p. 118). Once finalised the 10 transcripts and together with the framework categories were then uploaded into NVivo (QSR International Pty Ltd, www.qsrinternational.com, 2015), and the PhD student began the process of indexing and charting. Appendix 29 presents the full framework.

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\(^8\) Please refer to Chapter 1 Section 1.3.1 Models of Personality Disorders for further discussion.
Step 3: Indexing

Indexing involves coding the data by systematically applying the framework to each transcript and organising the data into categories (Ritchie & Spencer, 1994). The PhD student was responsible for indexing and charting the data. Figure 6. presents a screenshot from NVivo. It shows the indexing process; a list of framework categories on the top half and a focus group transcript in the bottom half. The RA worked through the transcripts and highlighted sections of text before dragging and dropping them into the relevant categories. Indexing allows the researcher to extract all data and code them into categories, consequently facilitating exploration in the later stages of data analysis. After indexing the transcripts, the study was able to gather all codes under a framework category and use it for further analysis.

Figure 6. A screenshot from NVivo to highlight the indexing stage.

When indexing, the RAs were aware that the framework might not be perfect, and that it was likely that some of the data that occurs, will not fit into the framework categories (Parkinson et al., 2016). Consequently, the RAs coded these sections of data under “Other”.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sources</th>
<th>Reference</th>
<th>Created On</th>
<th>Modified On</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Cognitive Factors</td>
<td>7</td>
<td>159</td>
<td>01/07/2016</td>
<td>30/09/2016</td>
</tr>
<tr>
<td>10. Life Events</td>
<td>0</td>
<td>0</td>
<td>30/09/2016</td>
<td>30/09/2016</td>
</tr>
<tr>
<td>11. Financial Matters</td>
<td>0</td>
<td>0</td>
<td>30/09/2016</td>
<td>30/09/2016</td>
</tr>
<tr>
<td>2. Supports</td>
<td>0</td>
<td>0</td>
<td>07/07/2016</td>
<td>07/07/2016</td>
</tr>
<tr>
<td>3. Emotions</td>
<td>0</td>
<td>0</td>
<td>07/07/2016</td>
<td>07/07/2016</td>
</tr>
<tr>
<td>4. Behavioural Consequences</td>
<td>0</td>
<td>0</td>
<td>07/07/2016</td>
<td>07/07/2016</td>
</tr>
<tr>
<td>5. Demands of the Workplace</td>
<td>1</td>
<td>1</td>
<td>12/07/2016</td>
<td>04/10/2016</td>
</tr>
<tr>
<td>6. Common Physical Vulnerab</td>
<td>1</td>
<td>2</td>
<td>12/07/2016</td>
<td>02/02/2017</td>
</tr>
<tr>
<td>7. Interpersonal Conflict</td>
<td>0</td>
<td>0</td>
<td>12/07/2016</td>
<td>30/09/2016</td>
</tr>
</tbody>
</table>

LS: Uh-huh, what kind of things comes to mind when you think of an interview, like what kind of thoughts?

01010: I won’t know what to say or anything.

LS: Won’t know what to say?

01010: Yeah.
Step 4: Charting

Charting involved presenting the data in a more accessible format to aid data analysis. The indexed data were summarised for each category and placed in chart form. Figure 7 shows an example of charting. The rows present the focus groups, and the columns show the categories from the framework. This process allows the researchers to view the summaries to be read across within the focus group, as well as downwards across themes or categories (Ward, Furber, Tierney, & Swallow, 2013). The primary PhD supervisor checked the final charting to reduce risk of losing details through summarising, and to ensure summaries were not repetitions of sections of interviews. This step aimed to reduce the data to more manageable forms for analysis.

![Figure 7. A screenshot of the PES-PD Framework and transcript in NVivo](image)

Step 5: Mapping and Interpretation

Mapping and Interpretation draw essential characteristics of the data to map and interpret the data as a whole (Ritchie and Spencer, 1994). It involves one’s own sense of the data while bearing in mind the research question. In this study, the concept of preparedness for employment to overcome challenges to employment for people with personality disorders was held in mind. It is a
creative process that involves both an intuitive and imaginative stance (Ritchie & Spencer, 1994). As the RAs (including the PhD student) were closer to the charting and indexing data as well as running the focus groups, the PhD student took on the primary responsibilities for the initial interpretation of the data. The primary and secondary PhD supervisors oversaw the interpretation of the analysis. Their clinical and academic expertise helped to check that the interpretations were in line with the literature, to enable intersubjective consensus and to cast critical judgement upon the framework.

There is always a risk of interpretation bias, as humans are skilled meaning-finders and can typically find meaning in large data sets (Miles & Huberman, 1994). Thus, it was essential to involve both creativity in interpretation but also ensure willingness and acceptance by external examination and cross consensus. When the research team solidified the interpretation, and established meaning behind the data, the team reviewed the other nine transcripts to test whether these interpretations had reached “saturation” (Hennink, Kaiser, & Marconi, 2017).

3.2.3 Results

Dominant Themes

Eight dominant themes reflecting the challenges to employment for people with personality disorders emerged from the focus groups. The dominant themes were: 1) Cognitive Factors; 2) Emotions/Biological Vulnerabilities; 3) Behavioural Consequences; 4) Interpersonal factors; 5) Stigma; 6) Demands of the Workplace; 7) Vitality; and 8) Supportive Factors. Table 12 presents all dominant themes and subthemes. RAs coded some subthemes under different dominant themes. Table 13 presents examples of quotes coded in interrelated subthemes in different dominant themes.
Table 12. Dominant Themes and Subthemes

<table>
<thead>
<tr>
<th>Dominant Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive Factors</td>
<td></td>
</tr>
<tr>
<td>Cognitive Distortions(^a)</td>
<td>Thoughts of burden</td>
</tr>
<tr>
<td>Fears</td>
<td>Lack of commitment</td>
</tr>
<tr>
<td>Worry thoughts</td>
<td>Difficulties in understanding other</td>
</tr>
<tr>
<td>Lack of Self-Belief</td>
<td>people’s thoughts</td>
</tr>
<tr>
<td>Judgements (self and from others)</td>
<td>Feelings of hopelessness</td>
</tr>
<tr>
<td>Lack of self-identity</td>
<td>Validation thoughts</td>
</tr>
<tr>
<td>Poor goal generation</td>
<td>Feeling ‘sick’ at the thought of work</td>
</tr>
<tr>
<td>Feelings of worthlessness</td>
<td>Feelings of frustration</td>
</tr>
<tr>
<td>“I don’t fit” thoughts</td>
<td>Feelings of emptiness</td>
</tr>
<tr>
<td>Differences in values</td>
<td>Challenges about thinking of how to problem solve</td>
</tr>
<tr>
<td>Previous expectation</td>
<td>Thoughts of being victimised</td>
</tr>
<tr>
<td>Blocked ambitions</td>
<td>Lack of sense of responsibility</td>
</tr>
<tr>
<td>Poor concentration</td>
<td></td>
</tr>
<tr>
<td>Emotions/ Biological Vulnerabilities</td>
<td>Overwhelmed by emotions</td>
</tr>
<tr>
<td>Negative Emotions(^b)</td>
<td>Positive Emotions</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Embrassed</td>
</tr>
<tr>
<td>Mixture of emotions</td>
<td>Emotionally tired</td>
</tr>
<tr>
<td>Transient psychotic symptoms</td>
<td>Inability to tolerate emotions</td>
</tr>
<tr>
<td>Emotional Sensitivity</td>
<td>Anxious temperament</td>
</tr>
<tr>
<td>Emotional Reactivity</td>
<td>Quick emotional response</td>
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<tr>
<td>Emotional Volatility</td>
<td>A slow return to baseline</td>
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</tbody>
</table>

(table continues)
<table>
<thead>
<tr>
<th>Dominant Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioural Consequences</td>
<td>Difficulties in using assertiveness skills</td>
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<tr>
<td></td>
<td>Avoidance&lt;sup&gt;c&lt;/sup&gt;</td>
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<tr>
<td></td>
<td>Self-harm</td>
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<tr>
<td></td>
<td>Behavioural reinforcement (i.e. home, workplace).</td>
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<tr>
<td></td>
<td>Impact on manager’s time supporting employee with a PD</td>
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<tr>
<td></td>
<td>Aggressive behaviours (i.e. angry outbursts, argumentative)</td>
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<td></td>
<td>Inability to structure the day</td>
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<td></td>
<td>Leaving work early</td>
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<td></td>
<td>Going from job to job</td>
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<tr>
<td></td>
<td>Suicide attempt</td>
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<tr>
<td>Interpersonal Factors</td>
<td>Conflict at Work with Supervisor</td>
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<td></td>
<td>Conflict with others</td>
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<td></td>
<td>Stigma towards Personality disorders</td>
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<tr>
<td>Demands of the Workplace</td>
<td>Excessive Work Expectations</td>
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<tr>
<td></td>
<td>Difficulties serving customers</td>
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<td>Performance issues</td>
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<td>Uniform</td>
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<td></td>
<td>Overtime requests</td>
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<td>‘Pressures to attend work.’</td>
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<tr>
<td>Vitality</td>
<td>Physical Health sick leave</td>
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<td></td>
<td>Mental Health and Physical Vulnerabilities</td>
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<td></td>
<td>Poor Sleep</td>
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<td>Tiredness</td>
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<td></td>
<td>Amotivation</td>
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<tr>
<td></td>
<td>Impulsive Behaviour (i.e. fleeing/sick leave/resigning)</td>
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<tr>
<td></td>
<td>Excessive Working</td>
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<tr>
<td></td>
<td>Being signed off sick</td>
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<tr>
<td></td>
<td>Resigning from work</td>
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<tr>
<td></td>
<td>Difficulties with social interaction</td>
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<tr>
<td></td>
<td>Crying</td>
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<td></td>
<td>Fired</td>
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<tr>
<td></td>
<td>‘Freezing’ due to anxiety</td>
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<tr>
<td></td>
<td>Lying</td>
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<tr>
<td></td>
<td>Dependent on others</td>
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<tr>
<td></td>
<td>Social relationships outside of work</td>
</tr>
<tr>
<td></td>
<td>Inappropriate interpersonal skills&lt;sup&gt;d&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>Discrimination towards PD</td>
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<tr>
<td></td>
<td>Noisy work environment</td>
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<td></td>
<td>Other environmental influences</td>
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<td></td>
<td>Chaotic lifestyle</td>
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<td></td>
<td>Size and type of organisation</td>
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<tr>
<td></td>
<td>Stigma and Discrimination</td>
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<tr>
<td></td>
<td>Being on time</td>
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<tr>
<td></td>
<td>Feelings of exhaustion</td>
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<tr>
<td></td>
<td>Lack of energy</td>
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<tr>
<td></td>
<td>Medication</td>
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<tr>
<td></td>
<td>Alcohol reliance</td>
</tr>
<tr>
<td>Dominant Themes</td>
<td>Sub-themes</td>
</tr>
<tr>
<td>------------------------------</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Support Factors</td>
<td>Employers level of understanding personality disorders</td>
</tr>
<tr>
<td></td>
<td>Helpful support from Employers</td>
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<tr>
<td></td>
<td>Lack of support from Employers</td>
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<tr>
<td></td>
<td>Reasonable adjustment</td>
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<tr>
<td></td>
<td>A need for more mental health service support</td>
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<tr>
<td></td>
<td>Support from Health Care Professional</td>
</tr>
<tr>
<td></td>
<td>A need for more one-on-one support</td>
</tr>
<tr>
<td></td>
<td>Support from friends and family/Lack of Support from friends and family</td>
</tr>
<tr>
<td></td>
<td>Holistic approach</td>
</tr>
<tr>
<td></td>
<td>Normalising experiences</td>
</tr>
<tr>
<td></td>
<td>Clients’ requirement for reassurance</td>
</tr>
<tr>
<td></td>
<td>A need for flexibility at work from employers</td>
</tr>
<tr>
<td></td>
<td>Support from colleagues</td>
</tr>
<tr>
<td></td>
<td>Astute managers</td>
</tr>
<tr>
<td></td>
<td>Phased return</td>
</tr>
<tr>
<td></td>
<td>Lack of knowledge from GP’s</td>
</tr>
</tbody>
</table>

*Note.*

a i.e. over generalising, jumping to conclusions, catastrophizing, future predicting, paranoid thinking, perfectionism, depressive, mind-reading, personalisation, all or nothing thinking, irrational thinking, rumination); b i.e. Anxiety, Anger, Sadness, shame, self-disgust); c i.e. not going into work, avoid going to the jobcentre, avoid talking about own emotions, avoiding interviews, avoiding preparation for interviews, avoid applying for jobs, staying in one’s room all day, hiding, not going back to work [due to fear of others seeing self-harming scars], avoid working on CV; d (i.e. staring at people, avoid eye contact, inability to use assertiveness skills, interpersonal difficulties, difficulties with social interaction, poor sense of limitation in others and themselves, masking facial emotional expression); PD = personality disorders.
<table>
<thead>
<tr>
<th>Dominant Theme</th>
<th>Subthemes</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotions and Behavioural Consequences</td>
<td>Anger</td>
<td>“…they actually expected like people to work from like 7 in the morning to 7 at night on like weekends, I’d like to get emails from her on a Saturday asking for things to be done by Monday and just like they…no respect for the work/life balance. And I couldn’t like, negotiate that I just flipped out one day and was like, “I’m not doing this anymore” and left….” (HCP participant 5).</td>
</tr>
<tr>
<td>Behavioural Consequences, Cognitive Factors, and</td>
<td>Excessive Working</td>
<td>“…because I was working [excessively]. I ended up in and out of the hospital because of it… I kept on with it because I got this job… I knew I wouldn’t get another one. And in the end, I was persuaded to cut down to two afternoons…” (client with a personality disorder 03009)</td>
</tr>
<tr>
<td>Supportive Factors</td>
<td>Fear of not getting another job</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Reasonable adjustment</td>
<td></td>
</tr>
<tr>
<td>Interpersonal Conflict and Behavioural Consequences</td>
<td>Conflict at work with supervisor/manager</td>
<td>“…I can think of at least three cases where I’ve had line managers being threatened by the individuals… whether it’s by email, whether it’s ‘I know where you live’… ‘I know your family’… we’ve had all those (F3 Occupational Professional)”</td>
</tr>
</tbody>
</table>
**Theme 1: Cognitive Factors**

Cognitive Factors was a clear dominant theme when participants recalled their experiences of challenges to employment. When participants were asked to elaborate on their thoughts about challenges to employment for individuals with a personality disorder, participants expressed several cognitive distortions such as negative predictions and catastrophising. One participant described “It was just the thought ‘I won’t get the job’ or ‘I’ll be terrible’ or ‘what if I don’t get the job” (client with a personality disorder 02012). Another participant stated “ ‘Yeah, I’ll be terrible’, ‘I’ll be crooking over my words’, ‘I won’t answer’, ‘What sort of questions are they going to ask me?’ ” (client with a personality disorder 02001). Also, participants recalled a lack of self-belief, perfectionistic and self-critical thoughts/negative self-judgements following the interview process:

At the interview, I thought, ‘Oh they probably just gave me the job because I’m like the only person who applied’ or something like that, then I put myself down a lot, so people don’t have expectations on me. Whereas if I think, ‘Oh I did really well to get that job’ I’m like, oh my god I’ve got to be perfect. But either way, I get into being ‘I’ve got to be perfect’… (client with a personality disorder 01012).

An HCP participant recalled an ‘all or nothing’ belief of a client with a personality disorder who expressed two extreme polarising thoughts. For example;

On one hand…‘I [person with a personality disorder] can do this, I can do anything, I’m bloody amazing’ and then on the other side, when it actually comes down to it, ‘I’m so scared that I won’t survive, that I will either sabotage it for reasons why’ ‘I won’t do that’…(HCP 01108).

**Theme 2: Emotions/Biological Vulnerabilities**

Emotions/biological vulnerability was another dominant theme. Participants often described primary emotions (emotions that are people’s ‘immediate, first reactions’) (Linehan, 2015, p. 345) and secondary emotions, emotions that are reactions to our primary emotions (Dimeff & Koerner, 2007).
Sometimes the experience of emotions was triggered by external events, and often difficult to tolerate, subsequently leading to certain reactions and behaviours.

Participants with personality disorders often described a mixture of emotions, mostly negative, and experiences of difficulties in tolerating these emotions. For example:

I’m very good at covering my emotions...But sometimes you know, you just can’t. And it can also result in anger...I avoid my emotions, and by avoiding it, I’m actually feeling really anxious...but it results in me being angry... (client with a personality disorder 03008).

I walked out to the car...I kicked my wheel...not the best idea in hindsight. Then I built myself up, and I was so angry, I was physically sort of shaking...I took myself off to have a cigarette to try and calm myself down...and I burst into tears...and part of me was crying because I think I realised I screamed at my boss...Part of me was crying because I then felt stupid for not watching every child, which then made me feel angry because it wasn’t actually my fault...(client with a personality disorder 03010).

Also, I’ve got a client....He is terrified because of his anger, so he just keeps away from people. He used to have a really high powered job, but now he can’t even contemplate going to work because he is scared that someone’s going to wind him up and he’s going to attack them...(HCP 05006).

Participants described experiences of biological vulnerabilities. A participant with personality disorder described a level of emotional volatility, experiencing ups and downs in their emotions, which made it difficult for them to go to work:

...So if they were to call me up and be like, you need to work today...but I don't know how I'm going to be feeling. I have no idea. And with the sudden changes, it could be straight before work,
and I just can’t go in. (client with a personality disorder 03008).

Other participants also recalled emotional sensitivity:

If someone fails an interview, and other people hear about it, people just take the piss, because it's something to joke about…most people take it quite well, whereas (clients names) and my other friend, they’re both very…even though they'll play along to the joke at the time, it will really affect them later on…(Supporter 03562).

**Theme 3: Behavioural Consequences**

Participants described specific behavioural consequences from situations and extreme emotions, that lead to challenges in employment. Examples of individual subthemes were avoidance, shouting, impulsive behaviour, self-harming and masking emotional facial expressions.

One participant with a personality disorder recalls both avoidant and impulsive behaviour:

…it was so stressful for me, like dealing with the customers and the hot environment. And I’m basically dripping with sweat, my face is so red, and it’s like those symptoms I cannot cope with. And I don’t know how to function anymore…And what ends up happening is I just don’t turn up again. I just walk out and never come back. And I can’t call them; I can’t do that, definitely not. So yeah, I just walk out; and it looks like shit on me, like I was just unreliable, a shitty worker… (client with a personality disorder 01006).

An HCP participant describes another avoidant behaviour:

…I mean just from my experience, they [people with personality disorders] do tend to go off sick quite a lot which affects them. In the mornings when they feel really helpless, they don’t want to and can’t just go to work and then that impacts on their position and their reputation with other people at work as well… (HCP 05005).
Participants with personality disorders often recalled self-harm as a behavioural consequence of emotions, which leads to challenges in employment:

One thing that does put me off getting back into work is my scars...You can't miss them if I've got my sleeves up...I reckon I could work the whole way throughout the cold months...wear long sleeves if I can under a uniform...But as soon as it gets really hot, I don't even see my family, never mind go to a job... (client with a personality disorder 01003).

In some transcripts, the RAs coded subthemes under Behavioural Consequences as subthemes in other dominant themes such as ‘Emotions’ and ‘Cognitive Factors’. For instance, how a person with personality disorders reacted to a situation was often accompanied by certain emotions and thoughts. See table 13 for examples of interrelated subthemes and themes.

Theme 4: Interpersonal Factors

Another challenge to employment theme that was described was interpersonal factors. Examples of individual codes were disagreements, difficulties in resolving differences, and difficulties in being assertive. Some of these codes were coded across other subthemes in different themes, such as Behavioural Consequences and Emotions/Biological Vulnerabilities (see Table 13. Example of Quotes coded in interrelated Subthemes across different Dominant themes

One participant with personality disorder described their experience of interpersonal conflict:

What I do is I jump from job to job...like most jobs I've left because I've fallen out with the people. I just hate it, and then I leave...I've never tried to like resolve it in a good way, I don't think. I always just try and like, become difficult...basically at work with whoever is causing me problems, I just start causing problems back... (personality disorder client 01012).

An HCP participant recalled a similar experience of interpersonal conflict at work:
...in the past [client with a personality disorder] walked out of jobs because, I mean it’s to do with emotional regulation...she maintains that her problems were to do with home, related to her family, but then she was actually able to tell me that she walked out because of relationships at work...(HCP 05004).

Often HCP participants described people with personality disorders as experiencing difficulties in assertiveness. Consequently, people with personality disorders would work long hours and often work more than is helpful for them.

For example:

...I think one problem can be a lack of assertiveness and the inability to say no. So I had a client who got a job as a carer, and she ended up working incredibly long hours and then she just couldn’t cope with the stress, and she just fell apart really...because she wasn’t able to maintain any boundaries to look after herself... (HCP 05006).

**Theme 5: Stigma**

Stigma towards people with personality disorders were frequently recalled across by all participants as a challenge to employment. The sub-themes were stigma towards people with personality disorders and discrimination towards people with personality disorders. Participants frequently described that having a label of personality disorder had negative connotations.

I think if employers were educated about it, we wouldn’t feel so stigmatised...and being able to actually say that yeah, we’ve got personality disorders. It’s a horrible word, because of whatever way you, you know ‘emotionally unstable’...or ‘personality disorder’...(client with a personality disorder 03564).

I think parts of the stigma as well with personality disorders...when you compare that with common mental health problems like anxiety and depression... personality disorders quite often...the stigma of being you know...how do you say...that personality disorders [the label] can be quite a significant barrier...(Occupational professional 04002).
**Theme 6: Demands of the Workplace**

Workplace demands were found to be a common dominant theme in challenges to employment for people with personality disorders. The subtheme of excessive work expectations often overlapped with other dominant themes, such as behavioural consequences and emotions. For example, participants described difficulties in saying no and consequently receiving extra work, which led to feelings of being overwhelmed. “And I wouldn’t say no to anything, so they’ll give you extra stuff to do, and I’ll just keep doing it ‘till it got too much, and then I’ll be off for like three, four months…I’ll be completely overwhelmed” (client with a personality disorder 01010).

Participants described performance issues as a potential barrier to employment, whereby workplace pressures may impact attendance.

…he’s had a period of absence recently...there were some performance issues, and then he would just seem to struggle with the performance issues and being asked about them...he was trying to...raise his game...And he found that incredibly distressing...at times he’s on his headset [at the call centre], and his emotions when he was talking to customers was quite, quite different to the other colleagues...(Occupational Professional 04500).

**Theme 7: Vitality**

Vitality issues was another emerging dominant theme. Participants often described a combination of mental and physical health problems that would contribute as a challenge to employment for people with personality disorders. For example:

I feel like my mental illness; my anxiety literally has caused me physical problems...it’s like telling someone I’ve got a mental disorder, ‘well you can still do this though, you can still work, you can still do that, it’s just in your head, right?’ But it affects me physically...and that’s the main problem I have... (client with a personality disorder 01802).

Subthemes such as tiredness and low energy were also described as having an impact on an individual’s motivation regarding work:
You see staying at work for me, when I had the care home job, I enjoyed it but I struggled to get there because I was always so tired, I had no energy, no motivation, and it’s still part of my mental health… (client with a personality disorder 03001).

…and the hardest bit for her is going out the door in the morning. That’s where she has to make the decision, like the very conscious decision ‘I’m just going to go for it even though I don’t feel like life today’… (Supporter 02010).

Reliance on alcohol and drugs, although infrequently mentioned across the focus groups, was described as a coping mechanism for dealing with interpersonal difficulties. When participants were probed further, it became apparent that reliance on substances would often lead to job loss or strain. A participant describes, “Yeah, I had a client lose her job because she was actually a waitress it was like a pub restaurant, and she was drinking on the job and lost her job because of that…” (HCP 01101).

Theme 8: Supportive Factors

The analysis found 16 subthemes under the dominant theme of supportive factors. Employers’ ‘level of understanding about the difficulties employees with personality disorders experience’, was a common subtheme that was described by participants. It was coded under supportive factors because participants described that if employers had a better understanding of personality disorders, then people with the condition were more likely to disclose their difficulties and receive the help they needed. One participant with a personality disorder explained:

“…I saw three psychiatrists… and each one I asked them to tell me what this diagnosis was and what it meant for me… they all struggled… if they don’t know what they’re talking about then what hope do I have to get an employer to know what they’re on about. An employer that understands what is going on… I’d probably be more open with them… And if they understood that then maybe… they would be more helpful in the workplace…” (client with a personality disorder 03010).
Similarly, having a supportive manager who made reasonable adjustments at work was found to be helpful in the workplace.

…usually you’re not allowed to have as many bracelets….but she’s quite happy for me to have a lot of bracelets because she knows it covers it up [in relation to self-harming scars]…she does do these little things that on the surface don't really seem huge, but it does like help you so much…when somebody comes up to your till and they’re looking at your arms….Feels like they're judging you instantly, it just lowers your confidence. So, actually, that was one of the things that I found very helpful with my employer…(personality disorder client 01005).

…We had…a lucky circumstance that he had a very supportive manager who was interested in psychology as a subject. So, he [manager] went and researched and found his niche and found how he’s going to support him, cos he was acting as the buffer in between him and the colleagues, in between him and the passengers…” (Employer 04006)

3.2.4 Discussion

The study found eight dominant themes including behavioural consequences, emotions/biological vulnerabilities, cognitive factors, interpersonal factors, supportive factors, demands of the workplace, vitality, and stigma that all contributed to challenges to employment for individuals with personality disorders. The majority of subthemes were coded across different dominant themes suggesting that the dominant themes may be interrelated. The findings build on the current literature on personality disorders and employment and help to inform the content of a preparedness for employment scale for people with personality disorders.

Emotions/biological vulnerabilities, presented as negative emotions (such as anxiety, anger, sadness, shame and disgust), were found to be common challenges to employment for people with personality disorders. These intense emotions tended to overwhelm the person and often when accompanied by biological vulnerabilities, lead to problematic reactions and actions in the
workplace. These findings are in line with presentations shared in people with BPD, Narcissistic PD, Histrionic PD and Antisocial PD who are more likely to encounter earlier work age disabilities, and are less likely to return to work (Lang & Hellweg, 2006). Neuroticism (the tendency to experience negative emotions) and disagreeableness (being unconcerned with others' well-being, being uncooperative, unfriendly, and suspicious) are common amongst people with personality disorders (Bagby, Sellbom, Costa, & Widiger, 2008). Neuroticism and disagreeableness have been found to underpin employment problems in those with a personality disorder (Sansone & Sansone, 2010).

The findings of this study also provided insight into interpersonal factors as a challenge in employment for people with personality disorders. The interpersonal conflict between colleagues and supervisors involved disagreements, difficulties in resolving differences, and lack of assertiveness. Interpersonal functioning is found to be associated with social functioning and is argued to be greater in severity in those with a personality disorder (Newton-Howes et al., 2008). When those with personality disorders experience interpersonal problems in the workplace, there tends to be a greater likelihood to have time off sick (Gordon, Eisler, Gutman, & Gordon, 1991), and to lose a job on purpose (Sansone & Wiederman, 2013). This study also reflects these findings.

Behavioural consequences was also a theme. Impulsivity (i.e. walking out of a job, shouting), being signed off sick, avoidance, aggression, and crying were reported. These behaviours were similar to what is already known in the literature regarding personality disorders. People with personality disorders tend to experience behaviour dysfunction (Swales et al., 2000) including non-suicidal self-injury (T.A. Widiger, 2011) and other Maladaptive behaviours such as substance use, risky driving, unhealthy eating, suicide, and violence (Bogg & Roberts, 2004).

Cognitive factors such as a lack of self-belief and self-criticism were also prominent in people with personality disorders in this study. Beliefs such as ‘not being good enough’ to get the job, or beliefs that ‘I should do better at work’ or ‘what is wrong with me’ were often expressed. These thoughts lead to feelings
of anger, shame, and sadness. Although self-criticism, the cognitive precursor to shame, is common across all mental health disorders, there is evidence that self-criticism may be more prevalent in people with personality disorders (Southwick & Yehuda, 1995). Fearful thoughts, another cognitive factor, may also be a significant challenge to employment. These worry thoughts contained negative predictions that captured negative emotions such as anxiety and anger about oneself (e.g. “I’ll be terrible”, “I won’t get the job”) and about others (e.g. fear of others judging them negatively).

The study also found that stigma was linked to the fear of disclosure of a personality disorder. Stigma was also considered a theme in challenges to employment for people with personality disorders. Participants recalled that disclosure could lead to the possibility of colleagues or managers judging them, rejecting them, or firing them. A report similarly reflected this finding that employed service users had fears of being dismissed if they disclosed their mental health problem (Mind, 2014). Disclosure has also been shown to be associated with fear of failure and rejection at work, consequently creating potential career damage (NHS, 2009). More recently, in a YouGov survey, it was reported that 15% of employees faced dismissal, disciplinary action or demotion after disclosing a mental health issue at work (Business in the Community, 2017). is therefore understandable, and sometimes justifiable, to have this ‘fear’ around disclosure. Individuals with personality disorders felt that having a diagnostic label impacted, or influenced, them negatively in the workplace, thereby preventing them from seeking appropriate support at work. This finding is reflected in a previous study that found that people with personality disorders were likely to change their behaviour due to fear of the cost of disclosing outweighing the benefits, such as seeking support in the workplace (Elaine Brohan et al., 2012).

The use of unhelpful language to describe people with personality disorders may also contribute to this stigmatisation. For example, in a case study, leaders with BPD were described as creating “toxic behaviour” and may serve as a “systematic contaminant for an organisation” (Goldman, 2006). Even if leaders with BPD presented with some problematic behaviours as described
by Linehan (1993), the language used to define people with BPD may be inflammatory for all stakeholders involved in the workplace. Non-disclosure, in this instance, can, therefore, be a very rational decision based on the service user’s knowledge of the advantages and disadvantages of the disclosure.

The environment, which incorporated thematic aspects such as supportive factors and demands of the workplace, were also deemed to be challenges to employment for people with personality disorders in this study. Adjusting the situation is central to the well-being of a person with personality disorders in the workplace (Tyrer, 2002). This changing of environment differs from other approaches in supporting the individual by emphasising a change around the person, rather than change within the patient (Tyrer, 2009). In this study, we identified that having a supportive manager helped with job retention. A report by the Chartered Institute of Personnel Development (CIPD) (CIPD, 2016) indicated that a supportive, compassionate manager, competent in understanding and working with mental health, may help dissipate barriers to retaining work for the individual with a mental illness. The report also found that management leadership-style was the third leading cause of work-related stress. This suggests that how managers approach their job can impact employees’ mental health in both directions.

In summary, the findings from this study highlight eight dominant themes that present as challenges to employment for people with personality disorders. The subthemes within the dominant themes seem to be multifaceted. Together our thematic findings reflect the problematic behaviours described in the biosocial model of BPD (Linehan, 1993). The subthemes will help generate items for a new preparedness for employment scale for people with personality disorders (PES-PD).

**Strengths and Limitations**

The strengths of the study were that the information gathered from the focus groups captured a wide range of perspectives from relevant people involved in personality disorders and employment: occupational professionals, HCP’s, supporters as well as people with personality disorders. A limitation is that the study involved people who were interested in taking part in the study,
were socially able to attend group settings and were fluent in spoken English. Therefore, the study results may not be generalisable to people who have social difficulties or where English is not their first language. As with other research, selection bias means the views of those who did not wish to participate in the study are not identified and may be different.

**Conclusion and Future Directions**

The challenges to employment highlighted in this study will be used to develop the content for a new preparedness for employment scale for people with personality disorders. Instead of an employment scale that is explicitly designed to measure one aspect of preparedness for employment, which is apparent in the current literature (Song et al., 2018), a tool that can identify all elements of preparedness may help to tackle the unique challenges faced in work for people with personality disorders.

### 3.3 Study ii) e-Delphi – Devising the items

#### 3.3.1 Aim

The e-Delphi study aimed to identify what items and domains experts perceived as important and relevant for a PES-PD, with the anticipation of creating items for a new scale (see Appendix 7).

#### 3.3.2 Method

**Ethical Approval**

The study received ethical approval from West Midlands - South Birmingham National Health Service (NHS) Research Ethics Committee (REC) (ref 15/WM/0466).

**Participants**

The study recruited experts from the British and Irish Group for the Study of Personality Disorders (BIGSPD) and a third-party organisation who provide employment support people for people with mental health difficulties. A PhD supervisor, a specialist in the area of mental health and employment, also identified personality disorder and employment specialists. In total, the study identified 61 experts who were invited to take part in the study. Table 14
presents the experts involved in each round. There were 26 potential respondents who took part in round 1, yielding an overall response rate of 43%. Sixty-five per cent of these 26 participants completed round 2 and 54% of 26 participants completed round 3.

Table 14. Expert Panel per Round

<table>
<thead>
<tr>
<th>Expert Panel</th>
<th>Round 1 (n=26)</th>
<th>Round 2 (n=17)</th>
<th>Round 3 (n=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service User Expert</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Academic/Service User Expert</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Healthcare Professional/Clinical Academic</td>
<td>7</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Healthcare Professional</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Academic</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Employment Advisor</td>
<td>4</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Employment Advisor</td>
<td>5</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>1</td>
<td>-</td>
</tr>
</tbody>
</table>

The Items

The study used 60 items that derived from the scales reviewed in the systematic review and the themes from the focus group study. The domains were: Cognitive factors (n items = 17), Behavioural factors (n items = 15), Interpersonal factors (n items =12), Emotional factors (n items = 6), Environmental factors (n = items 7) and Vitality (n = items 3) (see Appendix 30).

Procedure

Experts established a consensus on items that were relevant for a preparedness for employment scale using a three round e-Delphi (Hsu & Sandford, 2007a). The study used emails (see Appendix 31) and questionnaire software system Survey Monkey (https://www.surveymonkey.com) to conduct the e-Delphi. In round one, experts were asked to rate the relevance of 60 items and asked if any items were missing for a preparedness for employment scale for people with personality disorders. Figure 8. presents a screenshot of round 1. In rounds two and three, the experts received feedback summarising the views of others in the previous round (except round 1) and asked whether they wish to modify their responses in consideration of this feedback. Figure 9. presents a screenshot of round 2. Feedback included median responses and
interquartile range, new items, items that reached consensus, and summarised comments.

Figure 8. A screenshot of Round 1 from Survey Monkey
I would like to thank you again for taking part in Round 1.

Round 1 Feedback
1) New items
   We summarised feedback from Round 1 and have decided to add the following as new items under question 3 in Round 2:
   - Negative future predictions
   - Fear of abandonment
   - Difficulties in self management (i.e. transportation to and from work, dealing with change in the workplace)
   - Difficulties in problem solving
   - Fear of being rejected
   - Conflict with employer
   - Difficulties in relating to others at work
   - Self awareness

2) Personality Disorders as a ‘one entity’
   Overall, there was a series of Personality Disorders (PD) being described as ‘one entity’ or the items being heavily skewed towards Borderline Personality Disorder (BPD). The items on this Delphi had been developed from a combination of information drawn from the literature and focus groups with people with PD, supervisors of those with PD, employers, and staff/employment support workers who have experience with supporting those with PD. The PD participants were a mixture of F Personality Disorders (including all excepting, including people with BPD).

Furthermore, given the opinion in mind, we would be interested to know where, in terms of employment, you think these types of individuals with personality disorders would face challenges for all personality disorders. We have created a separate comments box for this in Round 2.

Round 2
1) Round 1 Item Scores, Group Median Score, and Interquartile Range
   In Round 2, on the left-hand column under Question 3, we have presented you:
   - Your item score from Round 1
   - The group median score
   - The group interquartile range (IQR)

   Please review these scores based on information provided in the first round, revise any judgements you may have, and rate the items again. Consensus will be judged to have been reached when 70% of the group have responded within the same support band (1-3, 4-6, 7-9).

2. I am a ...(please choose all that apply)
   - General User Group
   - Healthcare Professional
   - Academic
   - Policy maker
   - Clinical Academic
   - Employment Adviser
   - Other (please specify)...

3. To what extent do you agree each item is a relevant barrier to employment for people with personality disorders? Please review your response from Round 1, the group median response and IQR, and select an answer accordingly, revise any judgements you may have, and rate the items again.

Figure 9. A screenshot of Round 2 from Survey Monkey; includes summarised comments, mean responses, and interquartile ranges.
Consensus

A 9-point scale was used to rate the items for relevance (1-3 disagree; 4-6 neutral; and 7-9 agree). Under each item, a comments box was provided for the rater to explain their rating. The study informed the panel that consensus would be judged to have been reached once >75% of the group has responded within the same 3-point range. The researchers discussed comments if two or more panel experts reported the same topic.

3.3.3 Results

Consensus

In round 1, none of the items reached an agreement. In Round 2, eight items reached consensus, and in round 3, 11 items reached consensus (see Table 15).

New Items

The panel suggested eight new items after round 1: “Negative future predictions”; “Fear of abandonment”; “Fear of losing benefits”; “Difficulties in self-management (i.e. transportation to and from work, dealing with change in the workplace)”; “Difficulties in problem-solving”; “Conflicts with employer”; “Difficulties in relating to others at work”; “Self-awareness”. None of these items reached consensus by the final round. No new items were suggested in rounds 2 or 3.
Table 15. *Items that Reached Consensus.*

<table>
<thead>
<tr>
<th>Item</th>
<th>Median rating range and Consensus %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cognitive Factors (5 out of 17 items reached consensus)</strong></td>
<td></td>
</tr>
<tr>
<td>Fear of being judged by others in the workplace†</td>
<td>(7-9) 78.6%</td>
</tr>
<tr>
<td>Fear of criticisms from others*</td>
<td>(7-9) 82.0%</td>
</tr>
<tr>
<td>The fear of what others might think when you disclose your mental illness/difficulties at work*</td>
<td>(7-9) 76.5%</td>
</tr>
<tr>
<td>Lack of self-belief*</td>
<td>(7-9) 76.0%</td>
</tr>
<tr>
<td>Fear of being on sick leave*</td>
<td>(4-6) 76.0%</td>
</tr>
<tr>
<td><strong>Emotional Regulation (2 out of 6 items reached consensus)</strong></td>
<td></td>
</tr>
<tr>
<td>Difficulties managing emotions*</td>
<td>(7-9) 88.2%</td>
</tr>
<tr>
<td>Overwhelmed by emotions*</td>
<td>(7-9) 76.5%</td>
</tr>
<tr>
<td><strong>Behavioural Factors (4 out of 14 items reached consensus)</strong></td>
<td></td>
</tr>
<tr>
<td>Difficulties in working independently†</td>
<td>(4-6) 92.9%</td>
</tr>
<tr>
<td>Inability to prepare for job interviews†</td>
<td>(4-6) 85.7%</td>
</tr>
<tr>
<td>Suicide attempt†</td>
<td>(4-6) 78.6%</td>
</tr>
<tr>
<td>Self-harm*</td>
<td>(4-6) 76.0%</td>
</tr>
<tr>
<td>Difficulties in learning new things†</td>
<td>(4-6) 79.0%</td>
</tr>
<tr>
<td><strong>Interpersonal Factors (5 out of 11 items reached consensus)</strong></td>
<td></td>
</tr>
<tr>
<td>Inability to check instructions with supervisor*</td>
<td>(4-6) 76.0%</td>
</tr>
<tr>
<td>Inability to get along with people†</td>
<td>(4-6) 78.6%</td>
</tr>
<tr>
<td>Difficulties resolving conflict with colleagues*</td>
<td>(7-9) 82.4%</td>
</tr>
<tr>
<td>Difficulties saying no to requests from supervisors to work overtime†</td>
<td>(4-6) 78.6%</td>
</tr>
<tr>
<td>Difficulties in declining a request to exchange workdays/duties†</td>
<td>(4-6) 85.7%</td>
</tr>
<tr>
<td><strong>Environmental Factors (2 out of 7 items reached consensus)</strong></td>
<td></td>
</tr>
<tr>
<td>Employers’ prejudices toward people with mental illness†</td>
<td>7-9) 78.6.7%</td>
</tr>
<tr>
<td>Employers’ prejudices about hiring people with mental illness†</td>
<td>(7-9) 78.6%</td>
</tr>
</tbody>
</table>

*Note.* *Reached consensus at the end of Round 2. †Reached consensus at the end of round 3.
Comments

Two panel experts felt that certain items that reflected behaviours such as suicide, self-harm, angry outbursts, and perfectionism represented lack of preparedness in employment for subtypes such as BPD and anxious personality disorders, but not for personality disorders in general. Therefore, experts scored these items in the neutral range (4-6). Comments from participants also indicated that there was a need to focus on conflict and relationships with others as a whole across all types of personality disorders (n=4). Experts (n=3) also made general comments on the management style of managers, and how the managers’ expectation of the performance of the individual was associated with prejudice towards people with mental illnesses. There were also comments that despite an increase in awareness of mental health in the workplace, stigma was still a challenge.

3.3.4 Discussion

The e-Delphi established a consensus on 19 items. Some items (n = 9) were agreed to be relevant and some items were agreed to be ‘neutral’; neither relevant nor irrelevant (n = 10). The majority of items did not reach consensus. The findings highlight some implications on item generation and may guide the selection of items for a PES-PD.

Over half of the agreed 19 items were thought to be neither relevant nor irrelevant. This finding may be because the expert panel deemed those items as too specific for a scale designed for all forms of personality disorder, as opposed to a scale designed for sub-types such as BPD. For example, items “self-harm” and “suicide attempts” which are paradigms strongly linked with BPD but not other types (APA, 2013). Some experts suggested that fewer, but broader items were ideal for the questionnaire. However, only a small number of experts reported this.

The panel agreed that less than half of the 19 items were relevant items for a PES-PD. These items reflected cognitive (e.g. “Fear of being judged by others in the workplace”), emotional regulation (e.g. “Difficulties managing emotion”), and interpersonal factors (e.g. “Difficulties resolving conflict with colleagues”). This finding may not be surprising as people with BPD, NPD,
PPD, and OCPD are found to show high levels of neuroticism and disagreeableness (Saulsman & Page, 2004). High levels of neuroticism and low levels of agreeableness are linked to negative urgency; acting impulsively in response to emotional distress and interpersonal conflict (Settles et al., 2012). Interpersonal and social impairments were also found to be associated with one general factor that underpin all personality disorders (Polek et al., 2018). Interpersonal difficulties are a key feature of people with personality disorders (APA, 2013; Hopwood, Wright, Ansell, & Pincus, 2013) and interpersonal conflict events are often experienced, especially in people with BPD and antisocial personality disorders (Stepp, Hallquist, Morse, & Pilkonis, 2011).

The expert panel agreed that two environmental items related to stigma, were relevant for a PES-PD (“employers’ prejudices toward people with mental illness” and “employers’ prejudices about hiring people with mental illness”). The study concluded that these items captured external factors that were beyond the control of the individual. Therefore, they may not be appropriate items in a PES-PD.

Based on the findings, the study may generate items based on the consensus that cognitive, interpersonal, and emotional items are deemed relevant for a preparedness for employment scale for people with personality disorders. Regarding whether to keep fewer and more general behavioural items and drop specific personality disorder related items, this study decided to keep the item pool large. Large item pools are typical in the initial stages of scale development. Furthermore, initial item pools are recommended to be at least twice as large as the proposed final scale (Kline, 2013) and at least five times as large than the final version (Schinka, Velicer, & Weiner, 2013). Typically, the number of items are reduced in the latter psychometric stages of scale development (Morgado et al., 2018).

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9 For more information regarding personality traits please refer to Chapter 1 Section 1.3.1 Models of Personality Disorder
10 Please refer to Chapter 1 Section 1.3.1 Models of Personality Disorder
Strengths and Limitations

A strength of the study was the non-direct and anonymous methodology (compared to the focus group study), allowing objective opinions without being inhibited by dominant contributors (Powell, 2003).

A limitation of the study was the low response rate compared to other e-Delphi studies (Cole, Donohoe, & Stellefson, 2013; Sowter, Cortis, & Clarke, 2011). In general, online approaches tend to produce low and various response rates (Boulkedid, Abdoul, Loustau, Sibony, & Alberti, 2011). This study did attempt to mitigate this by sending follow up emails every two weeks. Another limitation is the lack of empirical validity (Jordan et al., 2019). A consensus based on expert opinion can be of value but is limited in its findings. In other words, it is informative that we have a consensus on some items, but the results do not necessarily tell us why or that there is empirical evidence for this finding.

Conclusion

In summary, the study showed a consensus on some items that reflect cognitive factors, emotional regulation, and interpersonal factors. More than half of the agreed items were agreed to be neither relevant nor irrelevant for a preparedness for employment scale for people with personality disorders; this may be due to the fact the items were deemed too specific to personality disorder subtypes as opposed to all personality disorders.

3.4 Overall Conclusion of both studies

In summary, we have generated an item pool based on a combination of results from three studies; the systematic review; the focus groups; and an e-Delphi. We have used multiple approaches given that expert opinion alone is argued to be the lowest form of validity (Jordan et al., 2019) and it is generally recommended that researchers use several methods to generate items at the initial stages of scale development (Streiner et al., 2015).

What will set this questionnaire apart from existing measures is it will aim to capture all components of the biosocial model of personality disorder and reflect preparedness for employment for people with personality disorders. Drawing on the findings from the focus groups, the systematic review, and the
e-Delphi, the questionnaire will include items capturing emotions (emotional responses)/biological vulnerability, cognitive factors (worry thoughts, beliefs), interpersonal factors (working with others), behavioural factors (avoidance behaviours, shouting, impulsivity), environmental factors/demands of the workplace (support from friends and family/work deadlines), and vitality. Although stigma (regarding disclosure), was a theme for challenges to employment, it was deemed a factor outside of one’s control, and thus, to an extent, may not be appropriate for a preparedness for employment scale. Instead, the authors focused on cognitions and emotional responses regarding disclosure as potential items. The item pool will remain large and contain specific items as opposed to fewer broader items. The next steps in the development of the PES-PD will concern item selection (content and face validity). The next Chapter presents a pilot study of a new PES-PD.
Chapter 4   Selecting the Items (Content and Face Validity): A Pilot Study of the PES-PD

4.1 Introduction

This Chapter discusses content validity, face validity, item selection and presents a pilot study of the PES-PD. Regardless of whether one is designing a new measure or adapting an existing one, application of both content and face validity are required to assess for comprehensiveness, relevance and readability (Streiner et al., 2015). Empirical tests of validity and reliability alone are insufficient to fully establish the validity of measures. Content and face validity are both imperative in the development of scales (Patrick et al., 2011).

Face validity is the extent to which the measure appears to reflect what it is supposed to be testing (Holden, 2010). It can be used to select items for a new scale. It differs from content validity as it assesses whether the scale “looks like” a measure of the construct of interest, not whether the scale contains items from the desired construct. Content validity, on the other hand, is the extent items in an instrument are relevant to and representative of the targeted construct for a particular measurement purpose (Haynes, Richard, & Kubany, 1995). For example, in this study, content validity may focus on the extent that cognitive items that reflect ‘self-belief’ are pertinent elements of preparedness for employment for people with personality disorders. Although they are conceptually distinct, it is worth raising that in scale development face validity is evaluated as part of content validity (Mokkink et al., 2018). Furthermore, content and face validity tends to be conducted before performing quantitative methods such as construct validity (the degree to which a test measures what it claims to be measuring) (Mason & Bramble, 1989; Mokkink et al., 2018; Mokkink et al., 2010).

The judgement of content and face validity is usually subjective, includes the target population or those who work with them can also provide an expert opinion (Boateng, Neilands, Frongillo, Melgar- Quiñonez, & Young, 2018). Thus, in the present work, people with personality disorders and clinicians who
support those with personality disorders should ideally be selected to judge the PES-PD for its face validity. A 5-point Likert scale ranging from extremely relevant to extremely irrelevant can be used to gauge the suitability (Nevo, 1985). Previous personality disorder scales have used this technique in scale development (e.g. ZAN-BPD; Zanarini, 2003).

There is also increasing recognition of the need to include the target populations’ views on potential items (Connell et al., 2018). Traditionally, healthcare professionals and researchers often judged content and face validity on scales that were designed for the target population as opposed to the target population themselves forming this judgement (Patrick et al., 2011). Thus, in this study, people with personality disorders, as well as other experts, will judge items in the PES-PD, before performing construct validity and tests of reliability. This chapter presents a pilot study of the PES-PD.

4.2 Aim

This pilot study aimed to evaluate the content (including face validity) of the PES-PD. The objectives were to assess the extent the items in the PES-PD were relevant to preparedness for employment for people with personality disorders, select items, and assess for comprehensiveness and length.

4.3 Method

4.3.1 Ethical Approval

The study received ethical approval from West Midlands - South Birmingham National Health Service (NHS) Research Ethics Committee (REC) (ref 15/WM/0466) (see Appendix 7).

4.3.2 Participants

The study recruited 129 participants (participants with personality disorder [PD] n=78, participants without personality disorders [Non-PD] n=20, and Healthcare Professionals [HCP] n= 31) to complete a 57-item pilot PES-PD. An RA, the PhD student, recruited participants at Personality Disorder services and Increasing Access to Psychological Services (IAPT) at two NHS Trusts. The study was explained to clinicians and who were asked to distribute
the questionnaire pack to clients who were interested in taking part. The same process was repeated at third party organisations. In IAPT services in one NHS Trust, every patient has their mental health medical information stored in an electronic record in the Patient Case Management Information System (PCMIS). When the records were created, the patient was asked if they give their consent to be contacted in the future for any research opportunities for which they may be suitable. Patients were informed that when they are contacted for research, they can decide whether they want to be involved or not. This system was used to invite patients (who had given their consent to be contacted) to participate in the study and complete the questionnaire pack. The RA also recruited HCP participants to complete the questionnaire packs at the same locations and services as the other two subsamples. Table 16 presents the participants’ demographics.
Table 16. *Participants Demographics*

<table>
<thead>
<tr>
<th>Age*</th>
<th>PD (n = 78) %</th>
<th>Non-PD (n = 20) %</th>
<th>HCPs (n=31) %</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-25</td>
<td>21.8</td>
<td>25.0</td>
<td>9.4</td>
</tr>
<tr>
<td>26-30</td>
<td>20.5</td>
<td>10.0</td>
<td>18.8</td>
</tr>
<tr>
<td>31-40</td>
<td>19.3</td>
<td>25.0</td>
<td>37.6</td>
</tr>
<tr>
<td>41-50</td>
<td>17.9</td>
<td>10.0</td>
<td>12.5</td>
</tr>
<tr>
<td>51-55</td>
<td>9.0</td>
<td>15.0</td>
<td>6.2</td>
</tr>
<tr>
<td>56-65</td>
<td>6.4</td>
<td>5.0</td>
<td>6.2</td>
</tr>
<tr>
<td>66+</td>
<td>-</td>
<td>10.0</td>
<td>-</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sex</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>66.7</td>
<td>65.0</td>
<td>71.9</td>
</tr>
<tr>
<td>Male</td>
<td>26.9</td>
<td>30.0</td>
<td>25.0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>75.6</td>
<td>75.0</td>
<td>71.0</td>
</tr>
<tr>
<td>Mixed/multiple ethnic groups</td>
<td>2.6</td>
<td>5.0</td>
<td>6.5</td>
</tr>
<tr>
<td>Asian/Asian British</td>
<td>12.8</td>
<td>20.0</td>
<td>12.9</td>
</tr>
<tr>
<td>Black/African/Caribbean/Black British</td>
<td>5.1</td>
<td>-</td>
<td>3.2</td>
</tr>
<tr>
<td>Other</td>
<td>-</td>
<td>-</td>
<td>3.2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment Status*</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>44.9</td>
<td>60.0</td>
<td>NA</td>
</tr>
</tbody>
</table>

*Note. *Participants with PD, missing data n=1;
4.3.3 Measures

The Preparedness for Employment Scale for people with Personality Disorders (PES-PD: Appendix 32): The 57-item pilot PES-PD was based on the results of the systematic review, focus group study, and e-Delphi study (Chapter 2 and 3). The scale contained a section A) Challenges to Employment and section B) Supportive Factors. Section A) included the following preliminary domains: Cognitive Factors (n=11); Behavioural Factors (n = 6); Interpersonal difficulties (n=14); Emotional/Biological Vulnerabilities (n=7); and Vitality (n=6). Section B) contained the environment and supportive factor domain (n=12).

Section A) contained 45 item statements that included two questions; a) ‘To what extent do you agree with this statement?’ with an 11-point response Likert scale where ‘0’ represented ‘Completely disagree’ and ‘10’ represented ‘Completely agree’; and b) ‘To what extent does this get in the way of employment?’ with an 11-point response Likert scale where ‘0’ represented ‘Definitely does not get in the way of employment’ and ‘10’ represented ‘Definitely does get in the way of employment’ respectively. Section B) contained 12 items. The same a) and b) questions and response scales in section A) were used in section B).

The study based the format of the PES-PD on the design of the Barriers to Employment and Coping Efficacy Scale Scale (BECES), a measure reviewed in the systematic review (Chapter 2; Corbière, Mercier, & Lesage, 2004). The authors of the BECES developed the scale with a focus on barriers to employment and responder’s perception of coping with these barriers. The methodological quality was deemed excellent overall for content validity (including face validity). As the current study focused on preparedness for challenges in employment, it was decided to design the PES-PD on a similar format.

11 Cognitive Factors: Items 1, 3, 4, 9, 10, 12, 15, 21, 27, 33, 45; Behavioural Factors: Items 5, 6, 13, 19, 23, 37; Interpersonal Factors: Items 2, 14, 16, 18, 20, 24, 25, 26, 30, 31, 35, 39, 43, 44; Emotional Factors: Items 7, 11, 17, 22, 29, 32, 38, 41; Vitality: Items 8, 28, 29, 34, 36, 42.
The study used polarising words such as ‘always’ and ‘never’ and both positively and negatively worded items to reduce acquiescent response bias; the tendency for respondents to agree with statements regardless of their content (Lavrakas, 2013). The study included similar items but wrote both negatively and positively worded items to test which item responders will endorse more. It is important, however, to strike a balance between both positive and negative wording, as it might cause response errors due to the possibility responders may not notice that the order has changed (Adams & Cox, 2008). Hence, piloting the questionnaire.

Inclusion of individual item statements were judged based on a 5-point response Likert Scale where 1= ‘Definitely exclude’ and 5= ‘Definitely include’. Item statement comprehension was checked using a Yes/No response and participants were encouraged to give additional information if they selected ‘No’. Figure 10. shows an item statement example.

Feedback questions were included to check if people understood the instructions, the purpose of the questionnaire, the length of the questionnaire, whether there were any missing items, and item readability.

Figure 10. PES-PD item example and feedback questions.

The Standardised Assessment of Personality – Abbreviated Scale (SAPAS: Moran et al., 2003); Appendix 33): The SAPAS is a validated and reliable 8 item questionnaire measuring personality disorder traits. A score of three has been found to correctly identify the presence of DSM-5 PD (APA, 2013) in 90% of cases. Participants who scored ≥3 on the SAPAS were classified as people with personality disorder traits (probable PD; ‘PD’), and
those who scored \( \leq 2 \) were classified as people without personality disorder traits (‘Non-PD’). The pilot study also included a demographics form (see Appendix 39).

4.3.4 Procedures

Participants completed the questionnaires themselves and returned the packs by post in a self-addressed envelope provided. Each pack contained an information sheet, a consent form, a demographics form, the measures and a payment address form (client pack only) (see Appendix 32-41). The PhD student entered information from the questionnaires into a password protected excel spreadsheet in preparation for analysis. The study sent £5 gift vouchers to participants for each completed pack. HCPs were not provided compensation.

4.3.5 Analysis

It was agreed by the researchers that if items had 2 or more codes and judgement for inclusion was < 50% across respondents scoring 4 and 5; the study team would discuss whether these items need to be revised or discarded.

The study used thematic analysis (Braun & Clarke, 2006), with an inductive approach, to analyse content and face validity. An RA (PhD student) coded all feedback information and based coding on frequency (e.g. a code that occurred five times = F5) and reappearing patterns. The chief investigator (PhD supervisor) cross-checked the codes, and then the RA (PhD student) used these codes to cross-check across all the feedback information a second time. The study used NVivo 11 (QSR International Pty Ltd, www.qsrinternational.com, 2015), a software on MS windows ideal for qualitative research and IBM SPSS Statistics for Windows, Version 22.0.

4.4 Results

Seventy-eight per cent of participants (n=109) reported the instructions were clear and easy to follow (n= 13 did not complete this section). Of the participants who did not find the instruction clear, the thematic reasons were the
(a), and (b) format was confusing (F5), the example did not make sense (F2), and some words were too complicated (F2). The thematic analysis also revealed that the participants understood the purpose of the questionnaire (F45). Two items had < 50% of responders endorsing the item for inclusion (3. I am always unsure of what my employment related values are and 44. I always know how much my colleagues and/or supervisor want to share personal information with me) and forty-two items had two or more codes. Table 17 presents the descriptive statistics for each item.13

Other themes were that the participants felt the PES-PD required no additional items (F27). However, a minority of participants felt otherwise and that the following items that could be included in the PES-PD: reflect work pressures (F2); various stages of employment (F3); and family problems (F3). The themes for why some items did not make sense to participants were: the item wording was unclear (F68); the item was not applicable to the participant (F29); the items were irrelevant to the participant (F13); the words ‘Always’ and ‘Never’ in the item statement were confusing (F18); reverse wording confusion (F24); the response option did not make sense (F3) and repetitive item statements (F10).14

The average time to complete the pilot PES-PD was 30.35 (SD = 25.32) minutes. The majority of participants found the PES-PD to be too long/long (61.0%), but some found it fine in length (31.0%).15

In summary, the 57 items in the PES-PD were found to be relevant items for a preparedness for employment scale for people with personality disorders. The results found that the length was too long; the questionnaire contained repetitive items and used polarising language (e.g. ‘always’ and ‘never’), which created confusion in comprehension.

12 F= frequency. Please see Section 4.3 Method for full description.
13 See Appendix 42.
14 See Appendix 43.
15 See Appendix 44.
Table 17. *Descriptive statistics of PES-PD 57 items*

<table>
<thead>
<tr>
<th></th>
<th>Median Agreement Score</th>
<th>4 and 5 Agreement (%)</th>
<th>Codes &gt; 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 1</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Item 2</td>
<td>4</td>
<td>59.6</td>
<td>Y</td>
</tr>
<tr>
<td>Item 3</td>
<td>3</td>
<td>42.8*</td>
<td></td>
</tr>
<tr>
<td>Item 4</td>
<td>5</td>
<td>84.1</td>
<td>Y</td>
</tr>
<tr>
<td>Item 5</td>
<td>5</td>
<td>68.3</td>
<td>Y</td>
</tr>
<tr>
<td>Item 6</td>
<td>4</td>
<td>69</td>
<td>N</td>
</tr>
<tr>
<td>Item 7</td>
<td>5</td>
<td>66.7</td>
<td>Y</td>
</tr>
<tr>
<td>Item 8</td>
<td>5</td>
<td>86.5</td>
<td>Y</td>
</tr>
<tr>
<td>Item 9</td>
<td>5</td>
<td>80.1</td>
<td>N</td>
</tr>
<tr>
<td>Item 10</td>
<td>5</td>
<td>65.1</td>
<td>N</td>
</tr>
<tr>
<td>Item 11</td>
<td>5</td>
<td>81</td>
<td>N</td>
</tr>
<tr>
<td>Item 12</td>
<td>5</td>
<td>69</td>
<td>N</td>
</tr>
<tr>
<td>Item 13</td>
<td>5</td>
<td>76.2</td>
<td>N</td>
</tr>
<tr>
<td>Item 14</td>
<td>5</td>
<td>79.4</td>
<td>Y</td>
</tr>
<tr>
<td>Item 15</td>
<td>5</td>
<td>72.2</td>
<td>Y</td>
</tr>
<tr>
<td>Item 16</td>
<td>5</td>
<td>73.8</td>
<td>Y</td>
</tr>
<tr>
<td>Item 17</td>
<td>5</td>
<td>76.1</td>
<td>Y</td>
</tr>
<tr>
<td>Item 18</td>
<td>4</td>
<td>51.6</td>
<td>Y</td>
</tr>
<tr>
<td>Item 19</td>
<td>5</td>
<td>77.8</td>
<td>Y</td>
</tr>
<tr>
<td>Item 20</td>
<td>4</td>
<td>65.1</td>
<td>Y</td>
</tr>
<tr>
<td>Item 21</td>
<td>5</td>
<td>69.1</td>
<td>Y</td>
</tr>
<tr>
<td>Item 22</td>
<td>5</td>
<td>70.6</td>
<td>Y</td>
</tr>
<tr>
<td>Item 23</td>
<td>4</td>
<td>58.7</td>
<td>Y</td>
</tr>
<tr>
<td>Item 24</td>
<td>4</td>
<td>71.5</td>
<td>Y</td>
</tr>
<tr>
<td>Item 25</td>
<td>4</td>
<td>63.5</td>
<td>Y</td>
</tr>
<tr>
<td>Item 26</td>
<td>4</td>
<td>57.2</td>
<td>Y</td>
</tr>
<tr>
<td>Item 27</td>
<td>4</td>
<td>59.5</td>
<td>Y</td>
</tr>
<tr>
<td>Item 28</td>
<td>5</td>
<td>76.9</td>
<td>Y</td>
</tr>
<tr>
<td>Item 29</td>
<td>5</td>
<td>80.2</td>
<td>Y</td>
</tr>
<tr>
<td>Item 30</td>
<td>5</td>
<td>73.8</td>
<td>Y</td>
</tr>
<tr>
<td>Item 31</td>
<td>5</td>
<td>74.5</td>
<td>Y</td>
</tr>
<tr>
<td>Item 32</td>
<td>5</td>
<td>75.4</td>
<td>Y</td>
</tr>
<tr>
<td>Item 33</td>
<td>5</td>
<td>72.2</td>
<td>Y</td>
</tr>
<tr>
<td>Item 34</td>
<td>5</td>
<td>63.5</td>
<td>Y</td>
</tr>
<tr>
<td>Item 35</td>
<td>5</td>
<td>67.5</td>
<td>Y</td>
</tr>
<tr>
<td>Item 36</td>
<td>5</td>
<td>65</td>
<td>Y</td>
</tr>
<tr>
<td>Item 37</td>
<td>4</td>
<td>67.5</td>
<td>Y</td>
</tr>
<tr>
<td>Item 38</td>
<td>5</td>
<td>70.6</td>
<td>Y</td>
</tr>
<tr>
<td>Item 39</td>
<td>5</td>
<td>63.5</td>
<td>Y</td>
</tr>
<tr>
<td>Item 40</td>
<td>4</td>
<td>62.7</td>
<td>Y</td>
</tr>
<tr>
<td>Item 41</td>
<td>5</td>
<td>73.8</td>
<td>N</td>
</tr>
<tr>
<td>Item 42</td>
<td>5</td>
<td>69.9</td>
<td>Y</td>
</tr>
<tr>
<td>Item 43</td>
<td>5</td>
<td>68.2</td>
<td>N</td>
</tr>
<tr>
<td>Item 44</td>
<td>3</td>
<td>35.7*</td>
<td>Y</td>
</tr>
<tr>
<td>Item 45</td>
<td>5</td>
<td>72.2</td>
<td>N</td>
</tr>
<tr>
<td>Item 1b</td>
<td>5</td>
<td>69</td>
<td>N</td>
</tr>
<tr>
<td>Item 2b</td>
<td>4</td>
<td>53.1</td>
<td>N</td>
</tr>
<tr>
<td>Item 3b</td>
<td>5</td>
<td>65.9</td>
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<tr>
<td>Item 4b</td>
<td>4</td>
<td>58.7</td>
<td>Y</td>
</tr>
<tr>
<td>Item 5b</td>
<td>4</td>
<td>55.6</td>
<td>Y</td>
</tr>
<tr>
<td>Item 6b</td>
<td>4</td>
<td>60.3</td>
<td>Y</td>
</tr>
<tr>
<td>Item 7b</td>
<td>5</td>
<td>66.6</td>
<td>Y</td>
</tr>
<tr>
<td>Item 8b</td>
<td>5</td>
<td>61.1</td>
<td>Y</td>
</tr>
<tr>
<td>Item 9b</td>
<td>5</td>
<td>63.5</td>
<td>Y</td>
</tr>
<tr>
<td>Item 10b</td>
<td>5</td>
<td>70.7</td>
<td>Y</td>
</tr>
<tr>
<td>Item 11b</td>
<td>5</td>
<td>61.9</td>
<td>Y</td>
</tr>
<tr>
<td>Item 12b</td>
<td>4</td>
<td>68.3</td>
<td>Y</td>
</tr>
</tbody>
</table>

*Note. *Items 3 and 44 had < 50% of responders endorsing the item for inclusion.*
Participants found that some items were not applicable, some reversed wording also caused confusion, and some items were phrased in a manner that was unclear to the reader. Thus, the final changes to the pilot PES-PD based on the results were: 1) removal of the words ‘always’ and ‘never’ in statements and incorporated into the response option; 2) removal of a) and b) format; 3) introduction of an ‘N/A’ option; 4) removal of repetitive items; 5) All items coded as ‘unclear’ were re-written more concisely; and 6) All items coded with ‘reverse wording confusion’ were re-written.

The pilot PES-PD was reduced to 35 items which reflected these domains: Cognitive factors (n item = 6); Behavioural factors (n item = 5); Emotions/biological vulnerabilities (n item = 6); Interpersonal factors (n item = 8); Vitality (n item = 4); and Supportive factors (n item= 6) (see Appendix 45). Table 18. presents the items that were reworded/changed.
### Table 18. Items that were selected and reworded

<table>
<thead>
<tr>
<th>Pilot PES-PD Item</th>
<th>Changed item</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cognitive</strong></td>
<td></td>
</tr>
<tr>
<td>3. I am always unsure of what my employment related values are.</td>
<td>10. I would not stay in a job if it went against my values</td>
</tr>
<tr>
<td>4. I always worry that if I disclose my mental health status diagnosis, I will be rejected by my employer and/or colleagues</td>
<td>11. I worry that if I disclose (tell people) my mental health difficulties or personality disorder diagnosis, I will be fired.</td>
</tr>
<tr>
<td>9. I always worry I will be judged by my colleagues and/or employer</td>
<td>5. I worry I will be negatively judged by my work colleagues and/or manager.</td>
</tr>
<tr>
<td>21. I believe I will always be successful getting work</td>
<td>1. I believe I will be able to get a job</td>
</tr>
<tr>
<td>27. I believe I will always be successful keeping work</td>
<td>15. I believe I will be able to keep a job.</td>
</tr>
<tr>
<td>33. When I think about work my critical thoughts never get in the way</td>
<td>29. When I think about work my self-critical thoughts (doubts/judgements) get in the way</td>
</tr>
<tr>
<td><strong>Behavioural</strong></td>
<td></td>
</tr>
<tr>
<td>23. I always work longer than I am expected/my contracted hours.</td>
<td>2. I work longer than I am expected (more than my contracted hours).</td>
</tr>
<tr>
<td>6. I never act impulsively at work</td>
<td>3. I act impulsively at work.</td>
</tr>
<tr>
<td>8. I always find it hard to get motivated in the morning to go to work/go to an interview</td>
<td>4. I find it hard to get motivated in the morning to go to work/go to an interview.</td>
</tr>
<tr>
<td>19. I have never quit a job without thinking about the consequences</td>
<td>9. I would quit my job without thinking about the consequences.</td>
</tr>
<tr>
<td>37. I always say/do things at work without thinking about the consequences.</td>
<td>23. I say/do things at work without thinking about the consequences.</td>
</tr>
</tbody>
</table>

*(table continues)*
<table>
<thead>
<tr>
<th>Pilot PES-PD Item</th>
<th>Changed item</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Emotional Regulation</strong></td>
<td></td>
</tr>
<tr>
<td>1. When I am very emotional, I always find it difficult to get on with work/the interview/task</td>
<td>6. When I am emotional, I find it difficult to get on with doing my work.</td>
</tr>
<tr>
<td>7. I am always quick to show anger.</td>
<td>8. I am quick to show emotions at work.</td>
</tr>
<tr>
<td>22 I am always able to talk about how I’m feeling with other people at work</td>
<td>13. I am able to talk about how I am feeling with other people at work.</td>
</tr>
<tr>
<td>5. Feeling low in mood never stops me from going to work/going to an interview</td>
<td>16. Feeling low in mood stops me from going to work.</td>
</tr>
<tr>
<td>38. I am always able to manage strong emotions while I am at work/an interview</td>
<td>24. I am able to manage strong emotions while I am at work</td>
</tr>
<tr>
<td>1. I always find it difficult to calm down when I am angry at work</td>
<td>26. I find it difficult to calm down when I am emotional at work.</td>
</tr>
<tr>
<td><strong>Interpersonal</strong></td>
<td></td>
</tr>
<tr>
<td>30. I always know my limits and I am able to say ‘no’ in the workplace</td>
<td>17. I know my personal limits and I am able to say ‘no’ in the workplace.</td>
</tr>
<tr>
<td>26. I am never able to imagine what the other person might be thinking or feeling (i.e. colleague, supervisor)</td>
<td>14. I am able to imagine what another person might be thinking or feeling at work.</td>
</tr>
<tr>
<td>16. I never know when to share personal information with my colleagues and/or supervisor about myself</td>
<td>7. I know when to share personal information about myself with my manager/supervisor</td>
</tr>
<tr>
<td>2. I always understand how to read other people’s reactions when I share things</td>
<td>28. I understand how people respond to me (their thoughts and feelings about me) when I share my own thoughts and feelings at work</td>
</tr>
<tr>
<td>24. I always find it easy to socialise with people at work</td>
<td>12. I find it easy to socialise with people at work.</td>
</tr>
<tr>
<td>14. I always find it easy to interact with my work colleagues</td>
<td>19. I find it easy to interact with my work colleagues.</td>
</tr>
<tr>
<td>5. When I have had conflicts with colleagues and/or supervisors, I have never been able to discuss it.</td>
<td>1. I am able to discuss things with colleagues and/or managers, when I have conflicts with them.</td>
</tr>
</tbody>
</table>
4.5 Discussion

This study found that, overall, the pilot version of the PES-PD had good content and face validity. This finding, therefore, suggests that the pilot PES-PD appears to “look like” a preparedness for employment scale (face validity). Furthermore, as there was a strong endorsement for the inclusion of items (good content validity), it suggests that the items are likely to be relevant and representative of the underlying construct; preparedness for employment for people with personality disorders. Although good face and content validity was found, some changes were required in the length of the overall questionnaire, the wording of some items, reformatting of the response options (i.e. removing the ‘always’ and ‘never’)) and removing repetitive and non-applicable items. Overall, participants understood the purpose of the questionnaire. Consequently, 35 items were selected.

The content and face validity of the PES-PD, as judged by the target population, corresponds with the current personality disorder and employment literature. For example, items reflected cognitive, interpersonal, emotional, and behavioural factors, all factors associated with employment dysfunction in people with personality disorders (Sansone & Sansone, 2010; Zanarini et al., 2010). Often these pervasive patterns create challenges to obtaining employment for people with personality disorders, thus impacting their preparedness for work (Skodol, 2018). Similarly, it was found that the interaction between one’s thoughts, emotions, their consequent reactions and their environment, may contribute to difficulties at work (Song, Fonagy, Stansfeld, & Feigenbaum, 2019). Behaviours such as impulsivity (Sio et al., 2011) and social dysfunction (which is related to interpersonal functioning) (Newton-Howes et al., 2008) are found to be associated with personality disorders (Gratz & Roemer, 2008). Furthermore, the degree of neuroticism and disagreeableness (Michon et al., 2008), which is associated with people with personality disorders, is linked to employment dysfunction.

There were also supportive and vitality items that were deemed relevant to the construct of preparedness for employment for people with personality disorders. Supportive and vitality factors are associated with personality
disorders and employment. For example, the findings from the focus group study suggested that having a supportive manager may have a positive impact on preparedness in employment and that depletions in energy can manifest in problematic behaviours and poor employment decisions (Song et al., 2019b). Similarly, a supportive, compassionate manager, competent in understanding and working with mental health, may help dissipate barriers to retaining work for the individual with a mental illness (CIPD, 2016). Furthermore, new employment interventions have also incorporated skills around managing physical health to help manage energy levels and motivation (Feigenbaum, 2019), suggesting that vitality may be an important factor in preparedness for work. A scale containing these items may, therefore, be relevant.

Crawford et al. (2011) recommended that outcome measures used in mental health services to include a mixture of both positive and negative items, as opposed to solely focusing on negative associations with mental ill-health. In this pilot study, we included a mixture of both negative and positively worded items and also included polarising words such as ‘always’ and ‘never’ to prevent acquiesce bias\(^\text{16}\) (e.g. Item 16. I never know when to share personal information with my colleagues and/or supervisor about myself). The results suggested that some of the items were considered too extreme in their negative or positive nature, due to these words, which ultimately confused responders. For this reason, the authors decided to remove and reword these items.

Some of the participants noticed that questions were repetitive, due to the study testing for endorsement of positive and negatively worded items (e.g. Item 38. I am always able to manage strong emotions while I am at work/an interview and Item 11. When I am very emotional, I always find it difficult to get on with work/the interview/task). Therefore, the study kept the item that had the largest endorsement or item that did not create confusion for the responder (e.g. item 11).

---

\(^{16}\) Acquiesce bias refers to the tendency for respondents to agree with statements regardless of their content (Lavrakas, 2013)
The findings also suggested the response format, a) ‘To what extent do you agree with this statement?’ and b) ‘To what extent does this get in the way of employment?’ was confusing. This may be due to the polarising words ‘always’ and ‘never’ creating confusion when responding to part b). For example, if responders reported that they did agree with item 5: ‘I have never walked out in the middle of the day from a job without thinking about the consequences’ consequently, it would not be considered as something that would get in the way of employment. Therefore, this response format was removed.

This study satisfies the scale development precondition to gauge whether a new measurement appears to be measuring what it is supposed to measure in the target population, before evaluating its psychometric properties (Mokkink et al., 2010; 2018). It is important to complete stages of validity and reliability in scale development, as psychometric measures are becoming increasingly needed in mental health care (Marshall et al., 2000).

4.5.1 Limitations and Future Studies

A possible limitation to our study was the length of the pilot PES-PD itself; the 57-item questionnaire may have deterred people from participating. Furthermore, the length of questionnaires has been known to impact responder rates (Yammarino, Skinner, & Childers, 1991), where longer questionnaires reduce response rates. Another limitation of the study was that good face, and content validity does not necessarily equal good overall scale validity. Future studies may conduct further tests of validity and reliability.

4.5.2 Conclusion

In summary, the study evaluated the PES-PD for its content and face validity. It found that the items were relevant to preparedness for employment for people with personality disorders and after reviewing it for its comprehensibility and length, 35 items were selected. Future studies may involve testing the psychometric validity of the 35-item PES-PD. The PES-PD aims to gauge preparedness for employment and importantly when to enter
employment as to prevent premature job loss or unnecessary psychological distress.
Chapter 5  Reliability and Validity Testing: A Psychometric Evaluation of the Preparedness for Employment Scale for people with Personality Disorders (PES-PD)

5.1 Introduction

This Chapter will build on the previous chapters by conducting quantitative tests of reliability and validity to assess the psychometric properties of the PES-PD. It will start with a discussion on internal consistency, construct validity and psychometric test theories, and their relevance in scale development. This chapter then presents the psychometric evaluation, its results, and discussion.

5.1.1 Internal Consistency and Construct Validity

Internal consistency assesses the degree to which items on a scale co-vary, relative to their sum score (DeVellis, 2016) and is part of reliability testing. Construct validity indicates whether a scale is measuring what it purports to measure. Structural validity and hypotheses testing are tests of construct validity that are often implemented in scale development (Mokkink et al., 2018). Structural validity is the degree to which the scale adequately emulates the dimensionality of the targeted construct (Gravetter & Forzano, 2012). Hypotheses testing is an ongoing iterative process (Strauss & Smith, 2009) and typically involves the level to which the scores of a measure are consistent with a hypothesis. For instance, the scores of the developed scale may be hypothesised to have large positive correlations with the scores on other instruments which measure the same or similar construct or hypothesised to be differences between relevant groups (known-group validity) (Streiner et al., 2015). Hypothesis testing is considered a test of validity because if a study confirms a hypothesis, the results will be informative about the nature of the construct; in other words, the study will inform theory and thus, provide some evidence of construct validity (Wampold, Davis, & Good, 2003).
5.1.2 Psychometric Test Theories

The literature on instrument development emphasises the use of test theories to evaluate the validity and reliability of a scale (e.g. Mokkink et al., 2006; Mokkink et al., 2010; Streiner et al., 2015; Cappelleri et al., 2014). Test theories are the mathematics that underpins psychometric scales; they can provide evidence that scales are valid and reliable to measure ‘unobservable’ and ‘observable’ variables.

Classical Test Theory

Classical Test Theory (CTT: Novick, 1966) is the most common form of test theory used in instrument development. It is often referred to as ‘the true score model’ as it assumes that every person has a true score in which the person’s test score (observed score) consists of a true score and an error score (Crocker & Algina, 1986). In CTT, the error score is assumed to be normally distributed, uncorrelated with the true score and has a mean of zero (McDonald, 2013). If this theory is used to underpin scale development, then it is assumed that the scale’s reliability increases as the number of items increases, and reliability also increases as the correlations amongst items increase. CTT also includes several statistics to measure the reliability, validity, difficulty, and discriminatory validity of a scale. Factor analysis (including exploratory and confirmatory factor analysis) is a type of CTT measurement model (Furr, 2017) and often used in the development of scales (Worthington & Whittaker, 2006).

The CTT approach is successful in testing instruments for their psychometric properties as researchers are often familiar with its basic concepts; it is thought to be intuitive for researchers to comprehend (DeVellis, 2006). Another advantage of the CTT approach is it does not rely on individual items to have an optimal correlation to the underlying construct (Streiner et al., 2015). In other words, items that relate moderately to the underlying construct can be used if there are several of them. In scale development it may be difficult to create a singular item that can truly capture the construct, therefore, if the correlation among items is weak, adding items to the overall scale may resolve the problem, and thus achieve reliability.
Despite being the most common test theory used for evaluating measures, the CTT is not without limitations. CTT is argued to lack scientific rigour (Streiner et al., 2015). It does not inspect items at an individual level; thus, the precision of the scale using the CTT approach is, therefore, questionable (Erguven, 2013). The CTT approach also assumes that all items have equal variance, which is inherently problematic. People will likely answer items differently from one another (Streiner et al., 2015). With CTT, it is difficult to predict exactly what response people will give for each item as each item will differ in its ability to capture the measured attribute.

Another disadvantage is that the statistics that are the foundations of CTT are sample dependent (Erguven, 2013). That is to say; item properties are based on correlations computed on the sample, meaning different samples with different variances will lead to a variance in data. Thus, if a different sample is used to test the scale, such as a different diagnosis or non-clinical group, new norms would have to be produced, or new tests of psychometric validity conducted (Streiner et al., 2015). Clinicians should hold this limitation in mind when considering using validated measures in a clinical population that was not the target population used to evaluate the scale psychometrically.

Item Response Theory

Researchers created Item Response Theory (IRT) in an attempt to overcome the limitations in CTT (Embretson & Reise, 2000). IRT has three basic assumptions. The first is unidimensionality of a scale, meaning there is one underlying latent trait that the scale measures, e.g. preparedness for employment. The second refers to local independence of items; the probability of answering any item positively, is uncorrelated to the probability of answering any other item positively and that response to an item is an independent decision. The third assumption is the response to an item can be modelled by a mathematical item response function (IRF). In IRT, the model is defined at the item level, meaning essentially there is a unique model for each item in the scale. Thus, IRT has multiple score models as opposed to a single total score model (Yang & Kao, 2014).
Field studies of comparisons between CTT and IRT to understand the value of each of these different paradigms are rare. It has been demonstrated, however, that results were found to be similar across both mathematical approaches, but IRT provided more detail about how to improve the scale (Petrillo, Cano, McLeod, & Coon, 2015). Petrillo et al. (2015) found that despite this finding, each model had its strengths. CTT was able to identify redundancies and skewed responses. IRT was also able to show redundant items but also identified poor fit (discrepancies between observed scores and expected scores across all people) at the item level and information about the overall precision of measurement. For example, IRT was able to highlight inappropriate scoring structures, suggesting potential areas of improvement such as item misfit (i.e. removing items that do not fit the model being tested). However, as IRT inspects the model at an item level, a limitation of this mathematical approach is that it requires several items to allow a sufficient range to assess for levels of item difficulty and person attributes. Scales with too few items or single-item measures are not suitable for IRT (Cappelleri et al., 2014).

After considering the positives and negatives of two different mathematical test theories to evaluate the psychometric properties of the PES-PD, this thesis will use a CTT approach first to define a model and provide descriptive assessments (Cappelleri et al., 2014).

### 5.2 Aims

The study aimed to i) conduct structural validity to identify a factor structure in the initial 35-item PES-PD scale; ii) evaluate the internal consistency of the identified factor structure; and iii) to conduct known-groups validity by examining the ‘revised’ version against stated hypotheses. The study hypothesised that the personality disorder Group status (PD subsample versus Non-PD subsample) would have a significant interaction between Employment Status on participants’ scores of the ‘revised version’ PES-PD. Based on the literature reviewed in chapter 1, it was also anticipated that the PD subsample would score significantly lower in the ‘revised version’ PES-PD (less prepared) than the non-PD subsample in both the unemployed and employed groups.
5.3 Method

5.3.1 Ethical Approval

The study received ethical approval from Yorkshire & the Humber - Leeds East Research Ethics Committee (REC) (ref 18/YH/0183) (see Appendix 46 Ethical Approval Letter Psychometric Evaluation (Chapter 5)).

5.3.2 Participants

The study recruited 1163 participants (people with personality disorder traits (PD) n= 650; and people without personality disorder traits (Non-PD), n=513) from the general population and NHS mental health services. Those who completed the questionnaires were from a range of countries including the UK (44.3%), North America (30.8%), Europe (13.2%) and other (11.7%). Most PD participants were White (80.1%), female (64.9%), single/unmarried (61.9%). Most Non-PD participants were White (72.9%), female (65.1%), single/unmarried (49.9%) and completed the questionnaires in the UK (53.2%), North America (19.7%), Europe (11.3%) and other (13.9%). Table 18. presents other sample demographic characteristics.
Table 19. Demographic Characteristics

<table>
<thead>
<tr>
<th></th>
<th>PD*</th>
<th>Non-PD**</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n = 650)</td>
<td>(n = 513)</td>
</tr>
<tr>
<td>SAPAS Mean (SD)</td>
<td>5.48 (1.21)</td>
<td>1.90 (1.02)</td>
</tr>
<tr>
<td>Age Mean (SD)</td>
<td>29.11 (9.5)</td>
<td>32.85 (11.4)</td>
</tr>
<tr>
<td>Employment status (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed&lt;sup&gt;a&lt;/sup&gt;</td>
<td>342 (53.7)</td>
<td>122 (24.4)</td>
</tr>
<tr>
<td>Unemployed&lt;sup&gt;b&lt;/sup&gt;</td>
<td>181 (27.8)</td>
<td>335 (67.1)</td>
</tr>
<tr>
<td>Accessing Services (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community employment services</td>
<td>33 (5.2)</td>
<td>15 (3.0)</td>
</tr>
<tr>
<td>Inpatient employment services</td>
<td>5 (0.8)</td>
<td>3 (0.6)</td>
</tr>
<tr>
<td>Mental health services (no employment services)</td>
<td>322 (50.5)</td>
<td>105 (21.0)</td>
</tr>
<tr>
<td>No employment or mental health services</td>
<td>286 (44.9)</td>
<td>384 (77.0)</td>
</tr>
<tr>
<td>Educational Level (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Higher education (Undergraduate or postgraduate degree)</td>
<td>333 (52.3)</td>
<td>409 (82.0)</td>
</tr>
<tr>
<td>School leavers</td>
<td>304 (47.7)</td>
<td>98 (19.6)</td>
</tr>
</tbody>
</table>

<sup>Note</sup>. *n=613, missing n = 13; **n=513; missing n = 14; <sup>a</sup> Employed = Paid employment, paid and unpaid internship, voluntary work, supported employment, job training/apprentice, self-employed; <sup>b</sup> Unemployed = signed off sick, unable to work, looking for work, unemployed.
5.3.3 Measures

The Preparedness for Employment Scale for people with Personality Disorders (PES-PD) – long form: The study used the 35-item self-report questionnaire generated from the pilot study. This version included six preliminary domains: Cognitive (n item = 6); Behavioural Consequences (n item = 8); Emotional Regulation (n item = 6); Interpersonal Difficulties (n item = 5); Vitality (n item = 4); and Support (n item = 6) (see Appendix 47).

The Standardised Assessment of Personality – Abbreviated Scale (SAPAS) (Moran et al., 2003): The SAPAS is a validated and reliable 8 item scale measuring personality disorder traits. Each item has a dichotomous response option “True” or “False.” A cut-off score of four was used to detect the presence of personality disorder diagnosis, as a score of 4 has been shown to demonstrate sensitivity and specificity of detecting DSM-5 personality disorder in the community (Fok et al., 2015). Therefore, participants who scored ≥ 4 on the SAPAS were classified as people with personality disorder traits (probable personality disorder) and put into the subsample “PD”, and those who scored ≤ 3 were classified as people without personality disorder traits and put into the subsample “Non-PD” (see Appendix 33).

Demographics Form. To characterise the sample, participants were asked to complete a demographics form. The demographic form collected information on variables relevant to employment: age, sex, ethnicity, current employment status, whether they are accessing mental health or employment support services, and education (see Appendix 48).

5.3.4 Procedures

The responses from the SAPAS, the 35-item PES-PD, and the demographics form, were collected through the Patient Outcome Database (POD). POD is a computerised system that hosts the measures in an e-digital form and securely stores and organises scores anonymously and in real-time. POD was designed to include question validation, ensuring that the users answered all questions before continuing to the next, thus allowing to prevent
missing data. Figure 11. POD screenshot of the PES-PD shows a screenshot of the PES-PD on POD.

Figure 11. POD screenshot of the PES-PD.

A website (https://www.preparednessforemploymentscale.com) containing a link to POD was created to promote the study. The website also contained information about the study (see Appendix 49) and explained that by completing the questionnaire indicated implied consent. Social media (Twitter, Facebook, and Reddit) was used to advertise and promote the study.

Research Assistants (RAs), including the PhD student, tweeted and posted on Reddit and Facebook weekly (see Appendix 50). Social networks are an efficient and effective means of recruiting participants into a study (Ryan, 2013). Recent research by Heywood et al. (2015) compared three recruitment streams (clinics, patient register, and internet) and found the most successful way to motivate interest in participating was via the internet. Paper versions of the measures were also available for those who were unable or unwilling to use the computerised system (see Appendix 47-49, 51).

The RAs also distributed study flyers (with a link to the study), paper packs to clinicians (to give to clients) and put up posters at adult mental health
services. The RAs also handed out flyers, paper packs and put study posters up in public places such as libraries, YMCAs, colleges, and Department for Work and Pensions (DWP) Job Centres (see Appendix 52). £1 was donated to a charity of out of three choices in exchange for participation. It took participants approximately 15 minutes to complete the three measures.

5.3.5 Planned Statistical Analyses

The study used STATA (StataCorp, 2017) to perform structural validity and internal consistency tests. For known-group validity, the study used SPSS (Armonk, 2013).

Structural Validity. An exploratory factor analysis (EFA) was first performed, followed by a confirmatory factor analysis (CFA) (Mokkink et al., 2018). An EFA explored and identified the latent dimensions represented in variables, creating a model that fitted the data, and a CFA confirmed the model derived from the EFA (Henson & Roberts, 2006). Cross-validation is often recommended when reporting factor analysis (Schinka et al., 2013); thus, a random split-half sample was used to perform an EFA and CFA. The researchers set a criterion for factor loadings at .4 (Stevens, 2012). At the EFA stage, items were dropped if they cross-loaded on more than one factor or had high communality (Hair, 1998). The study conducted an EFA and CFA on the PD subsample and again on the Non-PD subsample to explore the similarities and differences between the factor structures.

At the CFA stage, to determine the model fit, the researchers used several goodness-of-fit indicators to assess the model (Hu & Bentler, 1995). Kline (2016) suggests that the minimum indices that researchers should report are the Comparative Fit Index (CFI), standard root mean square residual (SRMR), root mean square error of approximation (RMSEA) and Model Chi-Square ($\chi^2$).\textsuperscript{17} Table 19. presents the common fit indexes and the recommended index cut-off levels used for determining model fit in this study. A

\textsuperscript{17} For full description and references to Goodness of Fit indices please refer to Appendix 53.
good fit was considered when the majority of indices were met (Hooper, Coughlan, & Mullend, 2008).

Table 20. The Goodness of fit statistics used for Assessment of Model fit.

<table>
<thead>
<tr>
<th>Types of Goodness of Fit Statistics</th>
<th>Cut-off</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model Chi-square ($\chi^2$)</td>
<td>p-value &gt; 0.05</td>
</tr>
<tr>
<td>Comparative fit index (CFI)</td>
<td>CFI ≥ .90</td>
</tr>
<tr>
<td>Root mean squared error of approximation (RMSEA)</td>
<td>RMSEA &lt; 0.08</td>
</tr>
<tr>
<td>(Standardized) Root Mean Square Residual</td>
<td>SRMR &lt; 0.08</td>
</tr>
</tbody>
</table>

Source: Kline (2016) and (Hooper et al., 2008)

The study re-specified the model by deleting the problematic item if the model did not fit the data well when performing the CFA (i.e. the item with modification index (MI) > 20) (StataCorp., 2017). Subsequently, an EFA was repeated to assess this re-specified model for goodness-of-fit on the first split-half data. This item reduction process was repeated to assess the re-specified model if the re-specified model still did not fit the second split-half data well (Worthington & Whittaker, 2006).

**Testing the PD PES-PD model in the Non-PD subsample.** Once a PES-PD factor structure was confirmed in the PD subsample, the model was fitted to the Non-PD subsample to verify whether a model works in a Non-PD population. There were no reported missing values.

**Internal Consistency.** The study conducted internal consistency to examine unidimensionality of the PES-PD scale and subscales, using Cronbach’s alpha (Cronbach, 1951). An alpha of .65- .80 is considered adequate for scale development (Blunch, 2012; Green, Lissitz, & Mulaik, 1977; Vaske, 2008). There were no reported missing values.

**Known-groups Validity (Hypothesis testing for Construct Validity).** The study hypothesised that the PD Group status (PD subsample versus Non-PD subsample) would show a statistically significant interaction between Employment Status on participants’ scores of the PES-PD. It was anticipated
that the PD subsample would score significantly lower in the PES-PD than the non-PD subsample in both people who are unemployed and employed. After the structure of the PES-PD was confirmed, a two-way ANOVA was conducted to determine whether there was an interaction effect between PD and Non-PD and Employment Status on the scores of the PES-PD. Two-Way ANOVAs are ideal as they can determine whether there is an interaction effect between two independent variables (i.e. Employment Status and PD group status) on a continuous dependent variable (i.e. scores of the PES-PD) (Iversen, Norpoth, & Norpoth, 1987). Effect sizes were deemed small (.01), medium (.06), or large (.14) (Miles & Shevlin, 2001).

A two-way ANOVA requires three initial assumptions to be true: (a) there is a continuous dependent variable; (b) there are two independent variables that are both categorical with two or more groups in each independent variable; (c) there are independent observations. The study met these assumptions. The scores on the PES-PD was the continuous dependent variable, Employment Status (Employed versus Unemployed), and PD Group Status (Non-PD and PD subsamples) were the independent variables. Only independent observations were collected.

The study tested three more required assumptions; (d) there are no significant outliers in any cell of the design; (e) dependent variable (residuals) are normally distributed; and (f) the variance of your dependent variable (residuals) should be equal in each cell of the design (Rutherford, 2013). The study used boxplots to inspect outliers, QQ-plots and Kolmogorov-Smirnov test (Kolmogorov, 1933), visual and empirical tests to assess normality, and Levene’s Test (Levene, 1960) to assess the homogeneity of variance.

5.4 Results

5.4.1 Construct Validity: Structural Validity

PD Subsample

Preliminary analysis. Initially, the correlation matrix of the PES-PD was inspected for multicollinearity. This inspection identified the presence of several correlations above the recommended .30 cut off at the preliminary stage (Field,
2013; Tabachnick & Fidell, 2007), demonstrating that some underlying factors were present in the PD subsample\(^\text{18}\). Item 20 and 5b were removed because majority of participants found these items were not applicable (e.g. they had checked the “N/A” option).

**Exploratory Factor Analysis (EFA).** A Principal Components Analysis (PCA) was conducted on the 35 items with an orthogonal rotation. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMSA = .862) (Kaiser, 1970) and Bartlett’s test of sphericity (Bartlett, 1950) were found to be significant \((p = .00)\), indicating a factor analysis was suitable (Tabachnick et al., 2007). An initial analysis was run to obtain eigenvalues for each factor in the data. Four factors had eigenvalues over Kaiser’s criterion of 1 and in combination explained 59.2% of the variance.\(^\text{19}\) The scree plot showed inflexions that could justify retaining either three or four factors (see Figure 12). The study retained three factors because of the large sample size and the convergence of the scree plot and Kaiser’s criterion. The study removed items 1-5, 7-11, 15, 17, 18, 22, 23, 28, 29, 1b-4b, and 6b because they cross-loaded or loaded < .4 on the three factors (Hair, 1998). Most items were reduced from the preliminary PES-PD domains cognitive, behavioural, and support. Table 21 presents the removed items post EFA in the PD subsample.

![PD Scree Plot](image)

**Figure 12. PD Scree Plot**

\(^{18}\) See Appendix 54 for correlation matrix.

\(^{19}\) See Appendix 55.
Table 21. *Items removed from the EFA in PD subsample*

<table>
<thead>
<tr>
<th>Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I believe I will be able to get a job manager/supervisor.</td>
</tr>
<tr>
<td>2. I work longer than I am expected (more than my contracted hours).</td>
</tr>
<tr>
<td>3. I act impulsively at work.</td>
</tr>
<tr>
<td>4. I find it hard to get motivated in the morning to go to work/go to an interview.</td>
</tr>
<tr>
<td>5. I worry I will be negatively judged by my work colleagues and/or manager.</td>
</tr>
<tr>
<td>7. I know when to share personal information about myself with my supervisor.</td>
</tr>
<tr>
<td>8. I am quick to show emotions at work.</td>
</tr>
<tr>
<td>9. I would quit my job without thinking about the consequences.</td>
</tr>
<tr>
<td>10. I would not stay in a job if it went against my values.</td>
</tr>
<tr>
<td>11. I worry that if I disclose (tell people) my mental health difficulties or personality disorder diagnosis, I will be fired.</td>
</tr>
<tr>
<td>15. I believe I will be able to keep a job.</td>
</tr>
<tr>
<td>17. I know my personal limits, and I am able to say 'no' in the workplace.</td>
</tr>
<tr>
<td>18. I am able to ask for what I want in the workplace (e.g. ask for time off).</td>
</tr>
<tr>
<td>22. My physical health gets in the way of my ability to work.</td>
</tr>
<tr>
<td>23. I say/do things at work without thinking about the consequences.</td>
</tr>
<tr>
<td>28. I understand how people respond to me (their thoughts and feelings about me) when I share my own thoughts and feelings at work.</td>
</tr>
<tr>
<td>29. When I think about work, my self-critical thoughts (doubts/judgements) get in the way.</td>
</tr>
<tr>
<td>1b. I need help to problem solve the practical steps to seeking, getting, and keeping a job (e.g. financial support, transportation, the process in how to get a job).</td>
</tr>
<tr>
<td>2b. I am self-sufficient at work (or similar situation); I do not need to rely on my manager for advice or instructions.</td>
</tr>
<tr>
<td>3b. I need ongoing support from NHS mental health services with regard to employment.</td>
</tr>
<tr>
<td>4b. I need the emotional support of friends and family for me to be able to work.</td>
</tr>
<tr>
<td>6b. I am able to ask for adjustments to be made to my working environment for my mental health needs.</td>
</tr>
</tbody>
</table>
After excluding these items, the EFA was recomputed to ensure that the remaining items all had factor loadings of .40 or higher. Table 22 presents the final factor loadings, % of the total variance, and eigenvalues. The factors were labelled as Interpersonal, Emotional Regulation, and Vitality.

Table 22. EFA PD Factor Loadings

<table>
<thead>
<tr>
<th>Variable</th>
<th>Interpersonal</th>
<th>Emotional Regulation</th>
<th>Vitality</th>
</tr>
</thead>
<tbody>
<tr>
<td>19. I find it easy to interact with my work colleagues.</td>
<td>0.88</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. I find it easy to socialise with people at work.</td>
<td>0.88</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. I am able to talk about how I am feeling with other people at work.</td>
<td>0.78</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. I am able to discuss things with colleagues and/or managers when I have conflicts with them.</td>
<td>0.73</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. I am able to imagine what another person might be thinking or feeling at work.</td>
<td>0.55</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. When I am emotional, I find it difficult to get on with doing my work.</td>
<td></td>
<td>0.82</td>
<td></td>
</tr>
<tr>
<td>26. I find it difficult to calm down when I am emotional at work.</td>
<td></td>
<td>0.81</td>
<td></td>
</tr>
<tr>
<td>24. I am able to manage strong emotions while I am at work.</td>
<td></td>
<td>0.67</td>
<td></td>
</tr>
<tr>
<td>5. I worry I will be negatively judged by my work colleagues and/or manager.</td>
<td></td>
<td>0.53</td>
<td></td>
</tr>
<tr>
<td>25. If I am sleepy, I am able to go to work.</td>
<td></td>
<td></td>
<td>0.86</td>
</tr>
<tr>
<td>27. If I feel low in energy, I go to work.</td>
<td></td>
<td></td>
<td>0.84</td>
</tr>
<tr>
<td>16. Feeling low in mood stops me from going to work.</td>
<td></td>
<td></td>
<td>0.74</td>
</tr>
</tbody>
</table>

| Eigenvalue | 3.43 | 2.53 | 1.48 |
| % of explained variance | 28.58 | 21.11 | 12.36 |

Note. Items 1-5, 7-11, 15, 17, 18, 22, 23, 28, 29, 1b-4b, 6b were omitted from the EFA because of low variance (< 2% of cases) and factor loadings < 0.4.
Confirmatory Factor Analysis (CFA). The CFA model (Model 1) with 12 items (derived from EFA structure in Table 4) showed an adequate fit, meeting two of the goodness of fit indices (CFI and SRMR) (Hooper et al., 2008). However, an inspection of the modification indexes (MI) indicated that a better fit might be obtained by removing one item that had a problematic indicator (MI > 20) (StataCorp., 2017)20:

5. I worry I will be negatively judged by my work colleagues and/or manager.

The re-specified model (Model 2), with Item 5 removed, met three goodness of fit indices; RMSEA, CFI, and SRMR. Table 23 presents the goodness of fit indices for Model 1 and Model 2. The 3-factor loadings were significant (standardised λ between .38 and .93, p < .01) and the errors were standardised (δ between .2 and .86, p < .01; see Figure 13. PD CFA Model 2 of the PES-PD).

Table 23. Summary of Goodness of fit for Preparedness for Employment for PD subsample

<table>
<thead>
<tr>
<th>Model</th>
<th>Items</th>
<th>Chi-sq</th>
<th>CFI</th>
<th>RMSEA</th>
<th>SRMR</th>
</tr>
</thead>
<tbody>
<tr>
<td>PD CFA Model 1</td>
<td>12</td>
<td>.000</td>
<td>.919*</td>
<td>.086</td>
<td>.073*</td>
</tr>
<tr>
<td>PD CFA Model 2</td>
<td>11</td>
<td>.000</td>
<td>.943*</td>
<td>.077*</td>
<td>.055*</td>
</tr>
</tbody>
</table>

Note. * the model meets the recommendation of goodness-of-fit as specified by Hooper et al. (2008) and Kline (2005).

Internal consistency. Cronbach’s alpha for the full scale was .75, which met the recommended acceptability (Blunch, 2012). Interpersonal, Emotional Regulation, and Vitality all showed good internal consistency (α = .83, α = .74, and α = .77) respectively.

20 See Appendix 56.
Figure 13. PD CFA Model 2 of the PES-PD (n = 325, 11 items, IP = Interpersonal, ER = Emotional Regulation & V = Vitality)
5.4.2 Construct Validity: Structural Validity of the PES-PD in Non-PD Subsample

Non-PD Subsample

Preliminary analysis. Inspection of the data found that the Non-PD subsample correlation matrix showed multicollinearity based on a .30 cut off, indicating that some underlying factors were present. Item 20 and 5b were removed because most participants found these items were not applicable (e.g. they had checked the “N/A” option).

Exploratory Factor Analysis (EFA). A PCA was conducted on the 35 items with an oblique rotation. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMSA = .822) (Kaiser, 1970) and Bartlett’s test of sphericity (Bartlett, 1950) were significant (p = .00), indicating a factor analysis was suitable (Tabachnick et al., 2007). Seven factors had eigenvalues over Kaiser’s criterion of 1 and explained 59.3% of the variance. The scree plot showed inflexions that justified retaining four factors (see Figure 14).

![Non-PD Scree Plot](image)

Figure 14. Non-PD Scree Plot

---

21 See Appendix 57.
22 See Appendix 58.
The study removed items 4, 7, 9, 15, 16, 23, 25, 27 and 28 because they cross-loaded on more than one factor, loaded < .4 on factors or had the highest commonality (Hair, 1998). Most items removed were from the preliminary behavioural domain of the PES-PD-long form. Table 24 presents the items removed at the EFA stage in the Non-PD subsamples. Table 25 presents the final Non-PD EFA factor loadings, eigenvalues, and % of the total variance. The factors were labelled Interpersonal 1, Interpersonal 2, Employment Support, and Emotional Regulation.

Table 24. Items removed from the EFA in Non-PD subsample

<table>
<thead>
<tr>
<th>Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. I find it hard to get motivated in the morning to go to work/go to an interview.</td>
</tr>
<tr>
<td>7. I know when to share personal information about myself with my supervisor.</td>
</tr>
<tr>
<td>9. I would quit my job without thinking about the consequences.</td>
</tr>
<tr>
<td>15. I believe I will be able to keep a job.</td>
</tr>
<tr>
<td>16. Feeling low in mood stops me from going to work.</td>
</tr>
<tr>
<td>23. I say/do things at work without thinking about the consequences.</td>
</tr>
<tr>
<td>25. If I am sleepy, I am able to go to work.</td>
</tr>
<tr>
<td>27. If I feel low in energy I go to work.</td>
</tr>
<tr>
<td>28. I understand how people respond to me (their thoughts and feelings about me) when I share my own thoughts and feelings at work.</td>
</tr>
</tbody>
</table>
### Table 25. EFA Non-PD Factor Loadings

<table>
<thead>
<tr>
<th>Variable</th>
<th>IP1</th>
<th>IP2</th>
<th>ES</th>
<th>ER</th>
</tr>
</thead>
<tbody>
<tr>
<td>18. I am able to ask for what I want in the workplace (e.g. ask for time off).</td>
<td></td>
<td>0.75</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. I am able to discuss things with colleagues and/or managers when I have conflicts with them.</td>
<td></td>
<td>0.70</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. I know my personal limits, and I am able to say 'no' in the workplace.</td>
<td></td>
<td></td>
<td>0.66</td>
<td></td>
</tr>
<tr>
<td>29. When I think about work, my self-critical thoughts (doubts/judgements) get in the way.</td>
<td></td>
<td></td>
<td>0.63</td>
<td></td>
</tr>
<tr>
<td>5. I worry I will be negatively judged by my work colleagues and/or manager.</td>
<td></td>
<td></td>
<td></td>
<td>0.59</td>
</tr>
<tr>
<td>1b. I need help to problem solve the practical steps to seeking, getting, and keeping a job (e.g. financial support, transportation, and the process in how to get a job).</td>
<td></td>
<td></td>
<td></td>
<td>0.79</td>
</tr>
<tr>
<td>3b. I need ongoing support from NHS mental health services with regard to employment.</td>
<td></td>
<td></td>
<td></td>
<td>0.78</td>
</tr>
<tr>
<td>22. My physical health gets in the way of my ability to work.</td>
<td></td>
<td></td>
<td></td>
<td>0.60</td>
</tr>
<tr>
<td>4b. I need the emotional support of friends and family for me to be able to work.</td>
<td></td>
<td></td>
<td></td>
<td>0.57</td>
</tr>
<tr>
<td>11. I worry that if I disclose (tell people) my mental health difficulties or personality disorder diagnosis, I will be fired.</td>
<td></td>
<td></td>
<td></td>
<td>0.53</td>
</tr>
<tr>
<td>1. I believe I will be able to get a job.</td>
<td></td>
<td></td>
<td></td>
<td>0.46</td>
</tr>
<tr>
<td>12. I find it easy to socialise with people at work.</td>
<td></td>
<td></td>
<td></td>
<td>0.77</td>
</tr>
<tr>
<td>14. I am able to imagine what another person might be thinking or feeling at work.</td>
<td></td>
<td></td>
<td></td>
<td>0.65</td>
</tr>
<tr>
<td>19. I find it easy to interact with my work colleagues.</td>
<td></td>
<td></td>
<td></td>
<td>0.65</td>
</tr>
<tr>
<td>13. I am able to talk about how I am feeling with other people at work.</td>
<td></td>
<td></td>
<td></td>
<td>0.59</td>
</tr>
<tr>
<td>8. I am quick to show emotions at work.</td>
<td></td>
<td></td>
<td></td>
<td>0.74</td>
</tr>
<tr>
<td>3. I act impulsively at work.</td>
<td></td>
<td></td>
<td></td>
<td>0.67</td>
</tr>
<tr>
<td>26. I find it difficult to calm down when I am emotional at work.</td>
<td></td>
<td></td>
<td></td>
<td>0.64</td>
</tr>
<tr>
<td>24. I am able to manage strong emotions while I am at work.</td>
<td></td>
<td></td>
<td></td>
<td>0.63</td>
</tr>
<tr>
<td>6. When I am emotional, I find it difficult to get on with doing my work.</td>
<td></td>
<td></td>
<td></td>
<td>0.56</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Eigenvalue</th>
<th>5.17</th>
<th>2.52</th>
<th>1.72</th>
<th>0.24</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of explained variance</td>
<td>25.89</td>
<td>12.62</td>
<td>8.62</td>
<td>0.23</td>
</tr>
</tbody>
</table>

**Note.** Items 4, 7, 9, 15, 16, 23, 25, 27 and 28 were omitted from the EFA because of low variance (< 2% of cases) and factor loadings < 0.4 or had the highest commonality. IP1 = Interpersonal 1, IP2 = Interpersonal 2, ES = Employment Support, and ER = Emotional Regulation.
Confirmatory Factor Analysis (CFA). The CFA Model 1 (20 items) met only one goodness of fit statistic (SRMR), indicating a poor fit (Hooper et al., 2008). The study removed the following items based on the largest modification indices (StataCorp., 2017):

29. When I think about work, my self-critical thoughts (doubts / judgements) get in the way.

5. I worry I will be negatively judged by my work colleagues and/or manager.

The re-specified model (Model 2) without Item 29 and Item 5 met two out of four goodness of fit indices (RMSEA and SRMR), also indicating a poor fit (Hooper et al., 2008). However, large modification indices suggested that the following items were problematic (StataCorp., 2017):

8. I am quick to show emotions at work.

3. I act impulsively at work.

The final re-specified model (Model 3) without Item 8 and Item 3 met the majority of goodness of fit indices (RMSEA, CFI, & SRMR) (Hooper et al., 2008). Table 26 presents the goodness of fit indices for all models. The four-factor loadings were significant (standardised \( \lambda \) between .43 and .88, \( p < .01 \)) and the errors were standardised (\( \delta \) between .3 and .82, \( p < .01 \); see Figure 15. Non-PD CFA Model 3 of the PES-PD).

Table 26. Summary of Goodness of fit for Preparedness for Employment for Non-PD subsample

<table>
<thead>
<tr>
<th>Model</th>
<th>Items</th>
<th>Chi-sq</th>
<th>CFI</th>
<th>RMSEA</th>
<th>SRMR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-PD CFA Model 1</td>
<td>20</td>
<td>0.000</td>
<td>0.854</td>
<td>0.082</td>
<td>0.069*</td>
</tr>
<tr>
<td>Non-PD CFA Model 2</td>
<td>18</td>
<td>0.000</td>
<td>0.887</td>
<td>0.075*</td>
<td>0.067*</td>
</tr>
<tr>
<td>Non-PD CFA Model 3</td>
<td>16</td>
<td>0.000</td>
<td>0.070*</td>
<td>0.921*</td>
<td>0.058*</td>
</tr>
</tbody>
</table>

Note. * the model meets the recommendation of goodness-of-fit as specified by Hooper et al. (2008) and Kline (2005).

---

23 See Appendix 56.
Figure 15. Non-PD CFA Model 3 of the PES-PD (n=256, 16 items, IP1 = Interpersonal 1, IP2 = Interpersonal 2, ES = Employment Support, and ER = Emotional Regulation)
Internal consistency. Cronbach’s alpha for the full scale was .83, which met the recommended acceptability (> .7) (Blunch, 2012). Interpersonal 1, Interpersonal 2, Employment Support, and Emotional Regulation all showed good internal consistency (α = .77, α = .74, α = .72, and α = .72) respectively.

5.4.1 Similarities and differences between the PD and Non-PD CFA Models.

The PD CFA model structure had three factors, of which two were found in the Non-PD CFA model (Interpersonal and Emotional Regulation). One factor was not present in the Non-PD CFA model structure (Vitality). On the other hand, the Non-PD CFA model structure had two Interpersonal Factors, an Emotional Regulation factor and an Employment Support factor. Table 27 presents the factor structures and the associated items. Table 29 and Table 30 presents the mean scores of the PES-PD factors for PD and Non-PD.
**Table 27. Items in the Non-PD and PD CFA Models**

<table>
<thead>
<tr>
<th>PD</th>
<th>Non-PD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Interpersonal (IP)</strong></td>
<td></td>
</tr>
<tr>
<td>12 I find it easy to socialise with people at work.</td>
<td>17 I know my personal limits, and I am able to say ‘no’ in the workplace.</td>
</tr>
<tr>
<td>13 I am able to talk about how I am feeling with other people at work.</td>
<td>18 I am able to ask for what I want in the workplace (e.g. ask for time off).</td>
</tr>
<tr>
<td>14 I am able to imagine what another person might be thinking or feeling at work.</td>
<td>21 I am able to discuss things with colleagues and/or managers when I have conflicts with them.</td>
</tr>
<tr>
<td>19 I find it easy to interact with my work colleagues.</td>
<td></td>
</tr>
<tr>
<td>21 I am able to discuss things with colleagues and/or managers, when I have conflicts with them.</td>
<td></td>
</tr>
<tr>
<td><strong>Emotional Regulation (ER)</strong></td>
<td></td>
</tr>
<tr>
<td>6 When I am emotional, I find it difficult to get on with doing my work</td>
<td>6 When I am emotional, I find it difficult to get on with doing my work</td>
</tr>
<tr>
<td>24 I am able to manage strong emotions while I am at work.</td>
<td>24 I am able to manage strong emotions while I am at work.</td>
</tr>
<tr>
<td>26 I find it difficult to calm down when I am emotional at work.</td>
<td>26 I find it difficult to calm down when I am emotional at work.</td>
</tr>
<tr>
<td><strong>Vitality (V)</strong></td>
<td></td>
</tr>
<tr>
<td>25 If I am sleepy, I am able to go to work.</td>
<td>1 I believe I will be able to get a job.</td>
</tr>
<tr>
<td>27 If I feel low in energy, I go to work.</td>
<td>1b I need help to problem solve the practical steps to seeking, getting, and keeping a job (e.g. financial support, transportation, and the process in how to get a job).</td>
</tr>
<tr>
<td>16 Feeling low in mood stops me from going to work.</td>
<td>3b I need ongoing support from NHS mental health services with regard to employment and financial services.</td>
</tr>
<tr>
<td></td>
<td>4b I need the emotional support of friends and family for me to be able to work.</td>
</tr>
<tr>
<td></td>
<td>11 I worry that if I disclose (tell people) my mental health difficulties or personality disorder diagnosis, I will be fired.</td>
</tr>
<tr>
<td></td>
<td>22 My physical health gets in the way of my ability to work.</td>
</tr>
</tbody>
</table>

*Note.* Items in **BOLD** are items that differ from both structures.
<table>
<thead>
<tr>
<th>Table 28. PD CFA PES-PD Model Means and Standard Deviations</th>
</tr>
</thead>
<tbody>
<tr>
<td>PD PES-PD Scores  (n=650)</td>
</tr>
<tr>
<td>M</td>
</tr>
<tr>
<td>----------------</td>
</tr>
<tr>
<td>Interpersonal</td>
</tr>
<tr>
<td>Emotional</td>
</tr>
<tr>
<td>Regulation</td>
</tr>
<tr>
<td>Total Score</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 29. Non-PD PES-PD Model Means and Standard Deviations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-PD PES-PD Scores  (n=513)</td>
</tr>
<tr>
<td>M</td>
</tr>
<tr>
<td>----------------</td>
</tr>
<tr>
<td>Interpersonal  1</td>
</tr>
<tr>
<td>Interpersonal  2</td>
</tr>
<tr>
<td>Emotional</td>
</tr>
<tr>
<td>Regulation</td>
</tr>
<tr>
<td>Total Score</td>
</tr>
</tbody>
</table>

5.4.3 Testing the PD PES-PD model in the Non-PD subsample.

To test whether the 3-factor PES-PD model can be confirmed in a Non-PD population, the study fitted the CFA PD Model 2 (as presented in Figure 16) to the Non-PD subsample. The 3-factor PD model with 11 items met three of the four goodness of fit indices; CFI = .915; RMSEA = .078; SRMR = .064 (Hooper et al., 2008) in the Non-PD subsample. The Chi-sq was not met (p = 0.00); however, as there was a large sample size, this was expected (Anderson & Gerbing, 1984). The 3-factor loadings Interpersonal, Emotional Regulation, and Vitality were significant (standardised λ between .4 and .84, p < .01) and the errors were standardised (δ between .29 and .84, p < .01; see Figure 16. for the PD PES-PD Model in a Non-PD subsample). The final 11-item PES-PD can be found in Appendix 59.

---

24 Please refer to Appendix 53 for explanation of Chi-Sq.
Figure 16. PD PES-PD Model in a Non-PD subsample (n=513; IP = Interpersonal; ER = Emotional Regulation; V = Vitality)
5.4.2 Known-groups Validity

Three tests of assumptions were performed before conducting a two-way ANOVA. Outliers were assessed by inspection of a boxplot; normality was assessed using the Kolmogorov-Smirnov normality test (Kolmogorov, 1933) and Q-Q-plots, and homogeneity of variances was assessed by Levene's test (Levene, 1960). There were six outliers; however, after inspection of outliers, it was decided to include the outliers in the analysis regardless, as they had little impact on the overall results of the two-way ANOVAs\textsuperscript{25,26}. The Kolmogorov-Smirnov test showed non-normality ($p < .05$); however, the Q-Q-plots all showed normality\textsuperscript{27}. As empirical normality tests are considered supplementary to the visual assessments of normality (Elliott & Woodward, 2011), and violations of the normality assumption in studies with large sample sizes (i.e. $> 30$ or $40$) are unlikely to cause major implications (Pallant, 2005) we assumed normality. The assumption of homogeneity of variance was violated, as assessed by Levene's test (Levene, 1960) for quality of variances, ($p < .05$).\textsuperscript{28} However, as this study had a large sample size, and the ratio of the largest group variance to the smallest group variance was less than 3 ($\sigma^2 = 2.28$), a two-way ANOVA is still recommended, with a bootstrap of 1000 CI 95\% (Jaccard, 1998; Xu, Yang, Chen, & Yu, 2015).

Table 30 presents the PES-PD score means and SDs between Employment Status and PD Status Groups. There was a statistically significant interaction between subsamples and employment status for PES-PD score, $F (1, 976) = 97.144$, $p = .000$, partial $\eta^2 = .091$.\textsuperscript{29} Therefore, an analysis of simple main effects for PD group status was performed with statistical significance after applying a Bonferroni adjustment and being accepted at the $p < .25$ level. There was a statistically significant difference in mean PES-PD scores between PD and Non-PD who were employed $F(1, 976) = 67.393$, $p < .0005$, partial $\eta^2 = $

---

\textsuperscript{25} For outliers, please see boxplots in Appendix 60.
\textsuperscript{26} Two-way ANOVAs were run with the outliers removed and the results were essentially the same - see Appendix 61.
\textsuperscript{27} See Appendix 62 for Tests of Normality
\textsuperscript{28} See Appendix 63.
\textsuperscript{29} See Appendix 63.
.065, and between PD and Non-PD who were unemployed $F(1, 976) = 593.123$, $p < .0005$, partial $\eta^2 = .378$.

Figure 17 and Figure 18 presents effects of PD Group status and participant employment status on PES-PD scores.

Table 30. *Mean and SDs for Overall PES-PD scores*

<table>
<thead>
<tr>
<th>PD group status</th>
<th>Employment Status</th>
<th>M</th>
<th>SD</th>
<th>n</th>
<th>M</th>
<th>SD</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-PD</td>
<td>Unemployed</td>
<td>76.61</td>
<td>12.88</td>
<td>122</td>
<td>70.84</td>
<td>15.44</td>
<td>335</td>
</tr>
<tr>
<td>PD</td>
<td>Unemployed</td>
<td>43.55</td>
<td>16.95</td>
<td>181</td>
<td>58.10</td>
<td>14.85</td>
<td>342</td>
</tr>
<tr>
<td>Non-PD</td>
<td>Employed</td>
<td>70.84</td>
<td>15.44</td>
<td>335</td>
<td>76.61</td>
<td>12.88</td>
<td>122</td>
</tr>
<tr>
<td>PD</td>
<td>Employed</td>
<td>58.10</td>
<td>14.85</td>
<td>342</td>
<td>43.55</td>
<td>16.95</td>
<td>181</td>
</tr>
</tbody>
</table>

*Note. M and SD represent mean and standard deviation, respectively.*

All pairwise comparisons were run for each simple main effect with reported 95% confidence intervals and p-values Bonferroni-adjusted within each simple main effect. Results are presented in Table 31.

Table 31. *Bonferroni Comparison for PD Group Status in PES-PD Scores*

<table>
<thead>
<tr>
<th>Comparisons</th>
<th>Mean Score Difference</th>
<th>Std. Error</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>PD vs. Non-PD (Employed)</td>
<td>-12.37*</td>
<td>1.551</td>
<td>-15.84 to -9.60</td>
</tr>
<tr>
<td>PD vs Non-PD (Unemployed)</td>
<td>-33.05*</td>
<td>1.357</td>
<td>-35.74 to -30.23</td>
</tr>
</tbody>
</table>

*p < 0.01

---

30 See Appendix 63.
Figure 17. Simple Main Effects of PD Group status and Employment Status on PES-PD scores.

Figure 18. Simple Main Effects of Employment status and PD Status group on PES-PD scores.
5.5 Discussion

The study established an 11-item, 3-factor scale that demonstrated good internal consistency and structural validity. The findings also confirmed known-groups validity, providing some support for construct validity. The factor structure suggests a presence of three separate (but associated) dimensions of preparedness for employment, including employment difficulties in the areas of (a) interpersonal (b) emotional regulation, and (c) vitality in the PD sample.

The first factor of the PES-PD, interpersonal, consists of five positively worded items that capture interpersonal ability. Personality disorder is described to be associated with substantial distress or significant impairment in all areas of self and interpersonal functioning, including occupation (ICD-11; WHO, 2019). In line with this diagnostic description, the items are likely to be appropriate for the PES-PD in capturing these interpersonal difficulties.

For example, item 19 “I find it easy to interact with my work colleagues” captures the extent someone can co-operate with a colleague, in other words, how they can liaise and work with them. This item is pertinent as people with personality disorders are found to experience interpersonal conflicts with friends, family, and colleagues (Dunne & Rogers, 2013; Miller et al., 2007; Skodol, 2018; Zanarini et al., 2010). Item 12 “I find it easy to socialise with people at work” seems appropriate, as 40% of people with avoidant personality disorder (AVPD) are found to have comorbidity with social anxiety disorder (Cox, Pagura, Stein, & Sareen, 2009), and tend to find it difficult to socialise or avoid social situations altogether (Weinbrecht, Schulze, Boettcher, & Renneberg, 2016). Item 13 “I am able to talk about how I am feeling with other people at work” and item 21 “I am able to discuss things with colleagues and/or managers when I have conflicts with them” captures appropriate interpersonal behaviours. Often, people with personality disorder experience Maladaptive behaviours (e.g. impulsivity, dissociation, aggressive behaviour, substance abuse), as a consequence of emotional dysregulation (Crowell, Beauchaine, & Linehan, 2009; Ronningstam, 2009), which often leads to interpersonal conflict. These items seem to measure the extent of their effectiveness in discussing their emotions interpersonally. Item 14 “I am able to imagine what another
person might be thinking or feeling at work" relates to additional social and interpersonal skills. People with personality disorders frequently have difficulties in cognitive flexibility (Deberry, 2012; Hamed & Alireza, 2017; Paast, Khosravi, Memari, Shayestehfar, & Arbabi, 2016), thinking dialectically (Lynch & Cheavens, 2008) and mentalisation (Busch, 2008), consequently leading to behaviours that contribute to interpersonal conflict in the workplace (e.g. aggression, shouting, crying). These items are likely to gauge preparedness for employment, given that employment situations require a level of interpersonal understanding to facilitate effective relationships at work.

The second dimension of the PES-PD, emotional regulation, contains three items; item 6 “When I am emotional, I find it difficult to get on with doing my work”; item 26 “I find it difficult to calm down when I am emotional at work”; and item 24 “I am able to manage strong emotions while I am at work.” Item 26 captures the “slow return to emotional baseline” often described as a characteristic of people with BPD (Linehan, 1993). Item 24 further assesses emotional regulation by gauging the extent an individual is able to manage their strong emotions, and item 6 measures emotional impact on workload. People with personality disorders report difficulties in regulating their emotions (Cloninger & Svrakic, 2008; Dadomo, Panzeri, Caponcello, Carmelita, & Grecucci, 2018; Kuo & Linehan, 2009), consequently leading to difficulties in the workplace (Skodol, 2018). Managing emotions is important to preparedness for employment, as it is not uncommon to experience frustration or annoyance with colleagues or work. Therefore, mismanagement may lead to conflicts and dealing with work matters ineffectively. These items that loaded on this factor are likely to reflect this and may be useful in capturing preparedness in emotional regulation regarding employment.

Both the interpersonal and emotional factor structures in the PES-PD, incorporate concepts in the literature regarding personality disorders and employment. High levels of neuroticism and low levels of agreeableness\(^{31}\) in

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\(^{31}\) Personality traits and personality disorders are discussed in Chapter 1 Section 1.3.1 Models of Personality Disorder and 1.4 Personality Disorder and Employment
people with personality disorders are linked to negative urgency - acting impulsively in response to emotional distress and interpersonal conflict (Settles et al., 2012). Thus, if interpersonal conflicts arise in the workplace, those with higher levels of neuroticism may be more likely to behave in a problematic way. Furthermore, the degree of neuroticism and disagreeableness are thought to contribute to employment dysfunction (Michon et al., 2008). Evidence has shown that people with personality disorders tend to demonstrate high levels of neuroticism and disagreeableness, especially people with BPD, NPD, Paranoid Personality Disorder (PPD), and OCPD (Saulsman & Page, 2004). Thus, the items on both these factors may be able to identify these variables and consequently inform clinicians of areas for employment support.

The third dimension of the PES-PD, Vitality, underpins a concept of energy, mood, and preparedness for employment in people with personality disorders. The three items are item 25 “If I am sleepy, I am able to go to work”, item 27 “If I feel low in energy I go to work”, and item 16 “Feeling low in mood stops me from going to work”. Vitality refers to physical and mental energy (Ryan & Deci, 2008), where exerting self-control is thought to be associated with depletions of vitality. Self-regulation and control is often seen as a ‘muscle’ which requires energy and is exhausted by exertion (Baumeister, Muraven, & Tice, 2000). Thus, as all actions of self-regulation and volition draw on limited resources; using them leads to a depletion of self. Similarly, the management and suppression of thoughts, feelings, or urges may also lead to depletion of energy (Muraven, Rosman, & Gagné, 2007). In people with BPD, emotions are a source of energy and those feelings of diminished vitality are associated with feeling emotionally drained (Stanghellini & Rosfort, 2013). People with personality disorders also tend to have problems with sleep, such as poor quality and sleep disturbance (Dixon-Gordon, Conkey, & Whalen, 2018). Poor sleep is understood to contribute to aggravated levels of daytime dysfunction, such as reduced self-care and reduced work quality (Selby, 2013).

The three Vitality items also depict a strong mood element. It has been demonstrated that there is common co-existence between personality disorders and mood disorders (Friborg et al., 2014; Perugi, Fornaro, & Akiskal, 2011),
suggesting mood may be a relevant clinical feature to measure in people with personality disorders in employment. In a meta-analytic review of 122 studies, high comorbidity of personality disorders was found in all mood disorders, with the highest risk of comorbidity in dysthymic disorders (Friborg et al., 2014). More specifically, Cluster C personality disorders were the most common comorbid personality disorder with MDD (Corruble, Ginestet, & Guelfi, 1996; Frigborg et al.). Cluster B and C were comparable with BD. Similarly, Avoidant, BPD, and dependent personality disorders were most associated with mood disorders, particularly depressive disorders (Skodol et al., 1999). Comorbidity between personality disorders and mood disorders has considerable impact on psychosocial functioning. For instance, co-existence of personality disorders and mood disorders has been demonstrated to negatively influence prognosis and affect adherence to treatment (Pompili et al., 2009), and thus implies a higher level of psychopathology (Sanderson, Wetzler, Beck, & Betz, 1992). In prospective studies, the presence of personality disorders and mood disorders has negative impact on psychosocial and occupational functioning across the lifespan, compared to having a mood disorder alone (Cummings, Hayes, Newman, & Beck, 2011; Skodol et al., 2005). Therefore, taken together, the inclusion of the three Vitality items may be beneficial in capturing relevant mood features in relation to employment for people with personality disorders.

The extent to which the current three factor PES-PD and its related 11-items is a scale that solely reflects core BPD symptoms as opposed to a scale that captures work-related aspects is worth discussing. There are nine core BPD symptoms (APA, 2013). Three core BPD symptoms are reflected in the 11-item PES-PD; interpersonal difficulties (items 12-14, 19, 21), affective instability due to a marked reactivity of mood (items 6, 16, 24-27) and difficulty controlling anger and experiencing intense anger (items 24 and 26). The three PES-PD factor structures do not appear to capture any of the remainder core symptoms such as frantic efforts to avoid real or imagine abandonment, identity disturbances, impulsivity, recurrent self-harm or suicidal behaviour, chronic feelings of emptiness, and transient, stress-related paranoid ideation or severe dissociative symptoms. However, tests of discriminant validity with BPD symptom scales may be able to provide empirical evidence to support this.
It is worth noting that although this thesis drew on the biosocial model of BPD (Linehan, 1993), the PES-PD was designed for all personality disorders, and not just BPD. Items were further created from both deductive and inductive approaches; including literature on all personality disorders and employment, as well as qualitative studies exploring perspectives on preparedness employment. While the focus was not on BPD symptoms, the cross-over of the factors with core descriptors of BPD symptoms deserves further exploration in future studies.

The 11 items selected in the three factors of the PES-PD appear to focus on intrapersonal elements. It may therefore be argued that the scale adopts a slightly narrow approach towards employment preparedness and mental health. Situational and contextual features, such as educational attainment and life stressors have been demonstrated to impact preparedness for employment outside of the individual (Mueser et al., 2005; Everson-Rose et al., 2011; Thoits, 2010). Further work could extend the current 3-factor structure to include broader elements of employment. This may help with contextualising the individual in the workplace or their environment. For instance, questions such as, “Are you currently involved in any employment support?”, “Are you currently receiving any employment benefits/financial support?” or “How long have you been unemployed for?” may be included.

The results demonstrated some similarities and differences in factor structures for preparedness for employment between PD and Non-PD subsamples. Where the factor structures for PD and Non-PD shared similarities were in the dimensions of Emotional Regulation and Interpersonal. The items on both these factors seemingly capture common situations in the workplace; that anyone who is feeling emotional might find it difficult to continue with work or might find it difficult discussing things with colleagues or managers when there are conflicts. The findings suggest that these parameters are important within people without personality disorders, as well as in people with personality disorders. It is also in line with literature on personality disorder models that suggest that personality disorder is the extreme end of normal personality functioning (Bagby et al., 2008).
Where the factor structures differed was the Non-PD factor structure had two Interpersonal factors, an Employment Support factor, and did not have a Vitality factor. The findings suggest that people without personality disorders may have different underlying dimensions in the conceptualisation of preparedness for employment than people with personality disorders. As the factor Vitality loaded in the PD factor structure, but not in the Non-PD factor structure, this suggests that Vitality is not a common variance in Non-PD populations. It is important to note however, that this does not suggest that Vitality is not relevant to people without personality disorder, it may be the case that it is not the most important element in preparedness for employment for people without personality disorders. Furthermore, the employment support factor that is apparent only in the Non-PD structure, suggests that most people in this subsample scored relatively high on the PES-PD (more preparedness), whereas the responses from the PD group had very little communality.

As the PES-PD was designed for people with personality disorders and given that the factor structure of preparedness for employment differed in the two subsamples, the authors explored the three-factor PD PES-PD structure in the Non-PD subsample. The study found that the PD PES-PD structure had a good enough model fit in the Non-PD subsample, suggesting that the three-factor PD PES-PD model may produce a meaningful score for a normal population as well as in a clinical population.

The known-groups validity confirmed the hypothesis that people in the PD subsample who were employed had a significantly lower total score on the PES-PD than people in the Non-PD group who were employed. Furthermore, people in the PD subsample who were unemployed were also found to have a significantly lower total score on the PES-PD than people in the Non-PD group who were unemployed. The findings suggest that people with personality disorders may be less prepared for employment than people without personality disorders. This finding has implications for the PES-PD, as a confirmation of a hypothesis provides some evidence of construct validity.
5.5.1 Clinical Implications

As a reliable and valid scale, the PES-PD, may provide useful information on when to return to employment. Identifying the appropriate time to return to work may allow people with personality disorders to prepare adequately so that they are better equipped to deal with the psychological stressors of employment. Returning to work too soon, before addressing interpersonal, emotional regulation and vitality difficulties may lead to a lack of preparedness to overcome psychological challenges in the workplace. Consequently, this may lead to leaving a job prematurely or major setbacks at work (Nielsen et al., 2018).

5.5.2 Strengths, Limitations and Future Research

A strength of the study that may be considered is the use of the COSMIN (Mokkink et al., 2018) for guidance in the development of scales. Their guidelines are based on the Cochrane review guidelines for the development of scales (Higgins & Green, 2011). The COSMIN allowed a systematic approach in developing the PES-PD (Terwee et al., 2012). Furthermore, the taxonomy, terminology, and measurement properties defined by the COSMIN were agreed upon and reached a consensus from an international Delphi (Mokkink et al., 2010), thus enabling clarity in guiding the study to develop the PES-PD. According to the COSMIN checklist the quality rating for the methodology used for internal consistency, structural validity and known-groups validity were all rated as 'very good'.

Another strength of the study was the large sample size. Scale development is sensitive to sample sizes as large sample sizes allow the desired level of measurement precision or standard error (SE) (Thissen & Wainer, 1982). Sample sizes of 100-400 permit SEs around a correlation between 0.10-0.05. Various recommendations say to have 5-10 observations per item and a minimum of 300 (Mokkink et al., 2018).

32 Please see Appendix 64. for Table of COSMIN quality ratings for PES-PDs evaluation of internal consistency, structural validity and known-groups validity.
A limitation of the study concerns representativeness. It is unknown if the PES-PD is unique to mental health disorders or unique to personality disorders. Participants were classified as “PD” and “Non-PD” using the SAPAS (Moran et al., 2003), however, other mental health disorders and symptomology was not captured. The extent to which the PES-PD measures mental health disorders, as opposed to personality disorders is unclear. Future studies may need to test the PES-PD in mental health populations to evaluate whether the PES-PD is testing mental health disorders and not personality disorders. Measures such as the Brief Symptom Inventory (BSI: Derogatis, 1983) may be used to capture psychological symptomology and is often used to screen for psychiatric disorders (Rath & Fox, 2018).

There may be another limitation regarding representativeness of the target population, personality disorders. The Structured Clinical Interview for DSM-IV Axis II Personality Disorders (SCID-II; (First, Gibbon, Spitzer, & Williams, 1997) is often implemented in studies to discriminate and diagnose personality disorders. However, given the large sample size required and the requirement of qualified clinicians for administration, it was not feasible to collect this information using the SCID due to restricted resources. Instead, the SAPAS, a short personality traits tool, and not a diagnostic tool was used. The use of this screening tool may question the true representativeness of the sample. Furthermore, the SAPAS was originally developed using a clinical sample and is therefore argued to be most useful when applied to clinical populations. The SAPAS has also demonstrated a slightly lower specificity than sensitivity (.53 and .69 respectively), suggesting that there may be a risk of false positive responses. Despite these limitations, a cut-off 4 has on the SAPAS has shown to be sensitive and specific in detecting DSM-5 personality disorder in the community (Fok et al., 2015). It is also important to note that the study focus was less on diagnosis per se, and more on behavioural and emotional traits. Models of personality disorders are moving away from categorical diagnostic models towards models of dimensional traits (Caspi et al., 2014; Hopwood et al., 2009; Polek et al., 2018; Tyrer et al., 2015). The use of the SAPAS is in line with this approach. Nonetheless, the limitations of the SAPAS should be acknowledged and that the representativeness of this sample
may be questionable. Ultimately, the study cannot confirm for certain that people had a diagnosis of personality disorders.

Potential selection bias may be another limitation. Convenience sampling (a type of non-probability sampling) was used, namely people who took part in completing the questionnaires were volunteers. In non-probability sampling, the selection bias tends to be greater, since it is likely that people who choose to take part in the measure are not always representative of the general target population (Fricker, 2012). Furthermore, most people were recruited online, suggesting that the sample may only represent people who have internet access and are competent in using it. Frequently, personality disorders are associated with low socioeconomic status, meaning individuals with personality disorders tend to have lower education, lower-income, and lower occupational status (Chen et al., 2006; Sansone et al., 2012; Skodol, 2018). Thus, access to computers and the internet may be limited due to lack of finances. People with personality disorders often lead chaotic lifestyles and are more likely to self-harm, be hospitalised, lose belongings, have interpersonal problems and experience housing problems (Heikkinen et al., 1997; Meszaros & Fischer-Danzinger, 2000). This suggests that completing an online survey, let alone having the capacity to be interested in taking part in research, may not be a priority. Therefore, future research should involve using probability-based methods in questionnaire studies. Here, participants can choose to complete the questionnaire, which may subsequently help minimise the number of people who decide to opt-out, and consequently reduce selection bias (Fricker, 2012). Methods other than online to recruit participants to complete the questionnaires may also be an option. These include distributing paper copies at employment support programmes, Department for Work and Pension Job Centres, and third-party organisations who provide employment support.

Generalisability may also be another limitation. The study recruited participants who were willing and interested in taking part in the study, but few people who participated in employment support such as JobCentre Plus in the UK or employment interventions. These people may potentially be the people who benefit the most from this scale and may be more representative of the
target population. The PES-PD may therefore benefit from future studies evaluating psychometric properties but from samples drawn from employment interventions and vocational rehabilitation programmes where people with personality disorders are also likely to present.

Due to some of the restrictive assumptions for IRT, this thesis used the CTT method to evaluate the psychometric properties of the PES-PD. However, there may be potential limitations of the data using the CTT method. CTT assumes linearity which means that each item is treated with equal discriminatory value (Rusch, Lowry, Mair, & Treiblmaier, 2017). In other words, CTT focuses on ‘test-level’ of the scale as opposed to ‘item-level’ (Hillis, 1987). This suggests that although the PES-PD has demonstrated good internal consistency and construct validity overall, little is known about the precision of the scale in terms of item difficulty and item discrimination (De Champlain, 2010). IRT is an ideal method to inspect a scale at the item-level. However, IRT assumes unidimensionality, whereby a 1-factor solution is the preferable outcome of the factor analysis (Reckase, 1979; Reeve & Fayers, 2005). Although the concept of ‘preparedness for employment’ is treated as a singular entity in this thesis, the results of this study demonstrate that ‘preparedness for employment’ consists of three factors and suggests otherwise. If any of the assumptions are not met then the use of IRT is meaningless (Toland, 2014). IRT is becoming more popular in scale development and is perceived as the more sophisticated mathematical model that underpins psychometrics (Cappelleri et al., 2014), however, the application of the model should not be used without careful consideration and addressing the assumptions (Nguyen, Han, Kim, & Chan, 2014). Moreover, scales containing a small number of items such as the 11-item PES-PD, may not be suitable for IRT (Cappelleri et al., 2014), although there are no concrete rules as to the minimum number of items.

Other future studies may investigate the extent to which the PES-PD measures core symptoms of BPD and whether more general employment-related questions may enhance the scale. Such studies may involve discriminant validity tests with BPD symptom scales such as the Zanarini Rating Scale for Borderline Personality Disorder (ZAN-BPD) or qualitative studies
evaluating the content validity of including broader contextual work-related items.

5.5.3 Conclusions

In summary, the PES-PD was found to have 3-factors that demonstrated good internal consistency and construct validity. The PES-PD is the first employment scale for personality disorder that may be used to assess preparedness for employment by targeting employment challenges such as interpersonal, emotional and vitality factors. The PES-PD may be used as an outcome measure for employment interventions, in the planning of employment support, as well as identify timing in return to work; however, further evaluation of its psychometric properties is required to establish its clinical relevance.
Chapter 6  General Discussion

6.1 Summary

This thesis aimed to develop and evaluate a new preparedness for employment scale for people with personality disorders. The results of the systematic review (Chapter 2) found that there were limited psychometrically and conceptually sound scales for employment and mental health, and none specifically for people with a personality disorder, thus confirming the need to develop a new scale. The scales in the literature search were reviewed for their relevance to the Biosocial model of personality disorder (Linehan, 1993) and initial items were generated. Next, focus groups and an e-Delphi study (Chapter 3) were conducted to devise additional items and further refine the underlying conceptual model, preparedness for employment, which underpins the scale. Fifty-seven items were generated from these two studies. A pilot study (Chapter 4) assessed the content and face validity of a new scale and selected 35-items for the version of the preparedness for employment scale for people with personality disorders (PES-PD) to be psychometrically evaluated. The psychometric evaluation study (Chapter 5) led to further item reduction and arrived at an 11-item questionnaire, underpinned by 3 factors labelled Interpersonal, Emotional Regulation and Vitality. The scale demonstrated good internal consistency and some evidence of construct validity.

This chapter will build on the previous chapters by discussing the results concerning the thesis’ aims, the strengths and limitations of the different methods used to derive the scale, the implications of the results for clinical practice, and avenues for future research.

6.2 Scoping the Literature

The key finding from the systematic review (Chapter 2) was that there were limited scales that captured all components of preparedness for employment as outlined by the Biosocial model of personality disorders. This has implications because according to the personality disorder literature, interpersonal and self-dysfunction are key characteristics of personality
disorders that are associated with employment dysfunction (Johnson et al., 2005; Skodol, Morey, Bender, & Oldham, 2015). Very few scales incorporated both of these components. Furthermore, high levels of neuroticism, the tendency to experience negative emotions, such as anger, anxiety, or depression, is common in people with personality disorders (Saulsman & Page, 2004) and is also associated with occupational dysfunction (Hopwood et al., 2009; Ro & Clark, 2013). Therefore, this study suggested a new scale was required that incorporated all elements of the biosocial model to address the unique issues of employment for people with personality disorders.

A possible reason for this finding was because most of the reviewed scales focused on measuring functional and performance-based aspects of employment, as opposed to psychological aspects of mentally preparing for work. For example, patients with Schizophrenia were the target population for several of the scales. People with this condition often experience cognitive symptoms that impact attention, concentration, and judgement in work based tasks (Reed et al., 2019). Thus, the focus would be more towards addressing the workplace needs and reasonable adjustments for the person.

Although there were some measures of self-efficacy and readiness for change which could be useful for the personality disorder population, these concepts only measured parts of the biosocial model, and were not considered core features of personality disorder. Given that there has been a movement in the UK over the last few years, where an open culture is encouraged to talk about mental health in the work place (The Prince’s Responsible Business Network, 2018), the findings informed the critical decision to create a psychological scale that not only focused more on mental and emotional aspects of preparedness for employment, but also all elements of the biosocial model to make it more relevant to people with personality disorders.

However, these research studies developed a scale which captured only some parts of the Biosocial model; interpersonal, emotional regulation and vitality. It may be the case that despite the Biosocial theory encompassing a range of aspects that relate to BPD, they may not all be significant with regards to the interaction between the range of personality disorders and preparedness.
for employment. This is discussed in more detail in Section 7.5 Reliability and Validity.

The systematic review also identified that the reviewed scales were either clinician-reported or patient-reported, however, it was not explicitly clear in any of reviewed scales why a decision was made to create a scale using either of those methods. In the scales that were clinician-reported, the clinicians were observing patients on functional and cognitive abilities based on work tasks or were using a scale with patients who were part of a vocational rehabilitation programme. This thesis, therefore, considered a self-report measure based on the understanding that people who use this scale may not necessarily be working with a clinician or be part of a vocational rehabilitation programme where clinicians would be able to answer questions regarding work performance and ability. A self-report measure may allow the flexibility for any individual with a personality disorder diagnosis, who may not be in a position to receive direct employment support, to benefit.

The systematic review also informed critical decisions in the development of a new scale in other ways. By critiquing the quality of methods used in the reviewed studies, it enabled an increased understanding of psychometric test theories and feasibility in terms of time, practicalities, and resources required for scale development. Although the COSMIN (Mokkink et al., 2010) provided concise guidance in navigating the complexities in scale development, it was the process of reading and critiquing each study that was more informative in terms of anticipating the practicalities and limitations of scale development. For instance, it was noticeable that the majority of the studies performed reliability tests and construct validity, and very few performed longitudinal domains of sensitivity to change and responsiveness, possibly due to the time constraints and resources required in achieving these other aspects (Streiner & Kottner, 2014). When planning this thesis, it was important to consider the feasibility of scale development, and realistically what could be achieved within the time constraints and resources that were available.
6.3 Devising and Selecting the Items– Content Validity

The main outputs from these studies (Chapter 2-4) were the emphasis on triangulation to achieve content validity, the process of conceptualising the underlying concept of PES-PD, and questionnaires design. Triangulation refers to the use of more than one method to collect data on the same topic (Guion, Diehl, & Mcdonald, 2002). This method involves different types of samples (data triangulation), as well as different methods of data collection (methodological triangulation). For example, incorporating perspectives from the target population, healthcare professionals, families, and occupational health professionals from the focus group study (data triangulation), as well as combining methods to build on the concept of preparedness for employment for content validity, using a systematic review, focus groups, e-Delphi and a pilot study (methodological triangulation).

The triangulation approach was useful in contributing to the content validity of the PES-PD because it is common for researchers to create a scale based on their knowledge of the literature, as opposed to what is considered relevant by the target population (Feeny & Ronis, 2002; National Institute for Mental Health in England, 2008). Each researcher has their own set of biases however, these bias may not necessarily be problematic as researchers are also likely to include pertinent aspects, such as, in the present work, “interpersonal factors”. Nonetheless, using a triangulation approach by involving service users in research, as well as occupational health professionals, friends and families, and their views on measures, may confirm and also provide aspects that researchers may have missed. For example, in this study, “vitality”. Furthermore, including service users may include aspects that are deemed relevant to the recovery of the target population (Crawford et al., 2011). As employment is considered a key part of recovery from personality disorders, (Katsakou et al., 2012), involving people with the condition is critical.

Another advantage of triangulation was that it increased the confidence in the research, revealed unique findings, and provided a better understanding of preparedness for employment (Thurmond, 2001). For example, aspects of vitality and stigma arose from the focus groups and e-Delphi that were not
previously highlighted. Issues around interpersonal functioning were also cross validated across the studies. The use of triangulation, however, came with limitations. It required a large amount of planning, time and resources as well as potential researcher biases (Joslin & Müller, 2016). These limitations were nevertheless overcome by being explicit about the methods used for each study (Johnson, Long, & White, 2001), reducing biases by involving more than one researcher to cross-check analysis (such as in the focus group study) and describing the way in which triangulation adds to the overall thesis (Thurmond, 2001).

In comparison to studies that developed employment scales for other mental health populations, very few reported detailed methods of how they conducted content validity. Furthermore, few described the theory underlying the conceptualisation of the construct (Song et al., 2009a). This may be due to a focus on reporting the psychometric results of the scale rather than the underlying theory. In contrast, this thesis conducted four studies that contributed to the content validity of the PES-PD and reported them in detail. The underlying construct; the Linehan Biosocial model (Linehan, 1993), was also described.

Defining the underlying construct is critical, as there can be very different conceptualisations of the same construct. For example, this thesis considered the Biosocial model (Linehan, 1993) as the underlying concept for ‘preparedness’ for employment. Whereas previous research has described ‘preparedness’ for employment as a combination of ‘volition’ (personal causation, lack of self-belief), ‘habituation’ (process of planning), and ‘environment’ (friends, family, and co-workers) (Prior et al., 2013). Thus, if scales were developed from these different perspectives but under the umbrella term of ‘preparedness’ without a full description, there may be little association between the two scales, despite sharing the same ‘construct’ name. In previous studies comparing scales that measured social support from different perspectives, there was little association among these scales (Barrera, 1986; Uchino, 2009). This was because ‘social support’ was viewed as three different aspects; i) subjective opinion that there are others who will help when support is required; ii) the amount of support received; and iii) the size of one’s support
network (Barrera, 1986). Consequently, this thesis took the view that it was not adequate for a construct to be simply described on its own, instead it must be described alongside its underlying theory (Streiner & Kottner, 2014). This may allow clarity and understanding of what the scale actually purports to measure.

The pilot study (Chapter 4) assessed the relevance of items and comprehensibility of the PES-PD. The key findings from this study were that it confirmed good content validity and also highlighted key issues regarding questionnaire design, such as acquiescence bias, wording, and length. Although the study mitigated for acquiescence bias, the tendency for the participant to answer positively on each item (Lavrakas, 2008; Messick, 1967), this thesis found that the methods used confused the participants.

The confusion may be due to challenges in one of the four cognitive stages a respondent passes through in answering a question; comprehension, recall, judgement, and response (Tourangeau, Rips, & Rasinski, 2000). Personality disorders are associated with poor language development in childhood (Clegg, Hollis, Mawhood, & Rutter, 2005; Langdon & Coltheart, 2004) and generally have been found to have lower education attainment (Chen et al., 2006). Reduced educational attainment may have implications for language comprehension at adulthood. To overcome comprehension difficulties, it is recommended to first test the question to highlight what terms are misunderstood (hence the pilot study), and then substitute for a clearer word or phrase or provide a succinct definition (Tourangeau et al., 2000). People with personality disorders are also found to have poor memory (Hasler, Hopwood, Jacob, Brändle, & Schulte-Vels, 2014) and often have difficulties in making judgements (Bazanis et al., 2002), both of which may influence their ability to complete questionnaires. There is a reliance on the attention and motivation of the respondent in answering questions (Sudman, Bradburn, & Schwarz, 1995) where judgments are usually based on the information that comes to mind most easily. As memory may be a potential problem for our target population, it is recommended to use an appropriate reference period (Schwarz & Oyserman, 2001). This was addressed in our study by providing an appropriate reference
period of answering questions that reflect “in most instances” and “in this moment in time”, as opposed to answering questions that were in the past.

Questionnaire design issues, such as length, were also considered as a result of the pilot study. Shorter scales are generally considered to be more practical compared to lengthier questionnaires (Iglesias & Torgerson, 2000; Roszkowski & Bean, 1990) and more likely to reduce client burden (e.g. the short version of the Short-Form Health Survey [SF-36], SF-12 (Ware & Sherbourne, 1992). Furthermore, an inverse association was found between the questionnaire length and response rate (Edwards et al., 2009; Sahlqvist et al., 2011). Conversely, short measures are thought to be less valid and reliable and lengthier questionnaires better in providing clinical relevance (Keszei, Novak, & Streiner, 2010). The general rule of thumb is to aim for 10-15 minutes to complete an online questionnaire (Mavletova, 2013). For paper questionnaires, there are no apparent rules for time completion, as it vastly depends on the topic and the population (Boynton & Greenhalgh, 2004).

In terms of the PES-PD and our target population, the pilot study aimed to create a questionnaire that was appropriate enough to capture relevant content without being too lengthy. Feedback from the pilot highlighted that the PES-PD was long, informing the decision to reduce the number of items before psychometric evaluation. The study also stated approximately how long the questionnaire might take in the information page/sheet, as a statement of the length of a questionnaire in the invitation to participate letter may increase response rate (Koitsalu, Eklund, Adolfsson, Grönberg, & Brandberg, 2018). Thus, the pilot study was critical in the decision of shortening the PES-PD from 57-items to 35-items, which contributed to the content validity of the scale overall.

6.4 Reliability and Validity Testing

The 35-item measure developed from the triangulation processes and piloting was then evaluated for its reliability and validity in the psychometric study (Chapter 5). The psychometric study contributed to the discussion around the underlying construct of the PES-PD – preparedness for employment for
people with personality disorders. Our concept of preparedness for employment was based on the combination of the biosocial model of BPD (Linehan, 1993), personality disorder employment literature, and the perspectives of clinicians, supporters and the target population. However, the final version of the PES-PD presented three main factors; Interpersonal, Emotional Regulation and Vitality as distinct factors that related to this concept. Surprisingly, other factors such as cognitive, behavioural, self-instability and environment factors highlighted in the biosocial model of BPD, were not present in the factor analysis.

The findings suggest that the 3-factor model may represent a construct that is specifically relevant to work preparedness for people with personality disorders. In other words, it is possible that interpersonal, emotional regulation and vitality are the areas that are explicitly relevant for preparedness for employment for people with personality disorders. Likewise, it implies other areas suggested through the biosocial model or by personality employment literature were less discriminant. It is, however, difficult to know whether these three factors adequately capture preparedness for employment until further predictive validity testing, such as convergent validity, have been conducted.33

Another implication of the findings from this study was that this data-driven method eliminated several items that were created and deemed relevant by the target population and the personality disorder employment literature. Often data-driven approaches to item reduction result in information loss and restricted variability (McCracken, 2002). Thus, at least one cross-validation test is required to confirm the results of a factor analysis, if item reduction is based mainly on data-driven methods (Osborne, Costello, & Kellow, 2008; Streiner et al., 2015). In the psychometric study, this was anticipated, and cross-validation was conducted using a split-half procedure using an EFA, followed by a CFA34.

However, there may still be other reasons as to why items were reduced, that relate to the underlying theory (McCracken, 2002). The issue of whether the underlying theory is adequate is often queried if the data does not behave

33 Please refer to Section 7.5 for future studies.
34 See Chapter 5. XX Method
as researchers may expect the data to behave, in accordance to the theory (Clark & Watson, 1995). Thus, inspecting the underlying theory of preparedness for employment for people with personality disorders may help to understand why several items were not represented in the PES-PD factor structure.

This study based the preparedness for employment theory on the Linehan biosocial theory of BPD (Linehan, 1993) and the personality disorder and employment literature. The biosocial model and its rationale for its use in this thesis are discussed more extensively in Chapter 1; however, this thesis acknowledged that this model and its application to other personality disorders may be limited. The PES-PD is designed for all personality disorders, and not for a specifically for BPD. It is possible that the elements of the biosocial model were not concepts that are relevant to the general totality of personality disorders, for example, behavioural and cognitive instability. On the other hand, personality disorder and employment literature focus largely on BPD (Skodol, 2018). In addition, as people with BPD tend to present more to services than other personality disorders (NICE, 2009), they may be more likely to have access or be signposted to using the PES-PD. Therefore, the underlying construct of the biosocial theory may be considered an adequate model in the development of PES-PD.

Another reason several items may have been eliminated may be due to the nature of different personality disorders. In the e-Delphi study (Chapter 3), some experts on the panel suggested to include fewer items that were broader in nature, as opposed to items that were specific to certain personality disorders. For example, items relating to impulsivity which is a known to be a distinct behavioural characteristic of BPD (Carpenter & Trull, 2013). This finding, however, was approached with caution as the sample size for the e-Delphi was small and because of the limited empirical nature of a consensus study. Thus, it was decided that specific personality disorder items remained in the pilot version of the PES-PD, so that all the items may be subjected to empirical forms of validity and reliability testing.

Nonetheless, it highlights a point that behavioural characteristics are often different between each of the personality disorders (Livesley & Larstone,
2001). For example, people with BPD tend to act out impulsively on their emotions, by showing behaviours such as aggression, angry outbursts, and crying (Sharma & Singh, 2012). Whereas people with OCPD tend to have an absence of behaviours and often shut down due to experiential avoidance (Wheaton & Pinto, 2017). Similarly, cognitions may also differ between people with different personality disorders. For instance, people with narcissistic personality disorders may have strong meta-perceptions which impacts their self-concept/identity (Carlson, Vazire, & Oltmanns, 2011), which may result in strong beliefs in their ability to get a job and keep one. Whereas someone with BPD, a disorder often associated with low self-esteem, may think otherwise (Hedrick & Berlin, 2012). This may have implications in responses towards cognitive items such as “I believe I will get a job”, a question that was ultimately removed in the final 11-item PED-PD scale. Furthermore, people with personality disorders often experience cognitive distortions such as all or nothing thinking (Baer, Peters, Eisenlohr-Moul, Geiger, & Sauer, 2012; Tackett, Silberschmidt, Krueger, & Sponheim, 2008), consequently, influencing how they may respond to certain items. In the focus group study (Chapter 3), a clinician commented on how a client would have “all or nothing” thoughts such as “I can do this, I'm the best” to “I'm the worst, I can't get this job”.

If the samples collected in these studies contained a larger number of certain personality disorders, the responses might have skewed the data and influenced the outcome of the factor analysis. A limitation of the study, however, is that specific personality disorders were not measured. Thus, the frequency and comorbidity of each specific personality disorder are unknown.

6.5 Strengths, Limitations and Future Directions

6.5.1 Strengths

This research has several strengths, particularly from a methodological viewpoint; the use of a robust guidance tool (COSMIN; Mokkink et al. 2018) to help navigate the complexities of scale development, a range of qualitative and quantitative methods (i.e. mixed methods), and service user and family involvement.
Service users and families were involved in providing information, consultation, and participation in the focus group study, e-Delphi, and pilot study (Chapters 3 and 4), in line with NHS England recommendations for service user involvement in mental health (NHS, 2015). Both the National Health Service (NHS) and the National Institute for Health Research (NIHR) advocate the involvement of service users and the public in the development of services and research (Wallcraft, Schrank, & Amering, 2009). Furthermore, service user involvement is recognised as an important factor in the development of measures (Staniszewska et al., 2011; Trujols et al., 2013; Turner et al., 2007), as they can provide richer data as well as cross-validation (Thurmond, 2001; Keeney, 2010).

6.5.2 Limitations

There are several limitations in this research which suggest that further research is needed and need to be held in mind when considering the findings. Due to feasibility and restriction on resources and time in developing the PES-PD, evaluating other psychometric properties such as reliability tests (test-retest), other construct validity tests and measurement error were restricted. It is naive to say the PES-PD is a completely valid and reliable scale based on a few studies (Streiner & Kottner, 2014), therefore, further psychometric tests are warranted.

Another limitation is that the PES-PD is yet to be determined in terms of its clinical relevance; whether it would be useful in intervention planning or as an outcome measure, or both. Empirical evidence, such as reliability and validity that support the psychometric properties of scales are not sufficient for scales that are intended to be used in clinical practice (Streiner & Kottner, 2014). The PES-PD is likely to demonstrate good clinical relevance based on its preliminary psychometric properties; however, longitudinal tests such as change sensitivity and responsiveness testing is what is required to establish the clinical relevance of the PES-PD.
6.5.3 Future Studies

The limitations mentioned have provided directions for future studies. Such studies may involve further tests of reliability and construct validity of the 11-item PES-PD. For example, considering the PES-PD contains interpersonal, emotional regulation and vitality factors, testing for convergent validity using comparison measures such as the Inventory of Interpersonal Problems (IIP: Pilkonis, Kim, Proietti, & Barkham, 1996) or the Difficulties in Emotion Regulation Scale (DERS: Gratz & Roemer, 2008), or Short Form-36 for vitality (SF-36: Mchorney, Ware, & Raczek, 1993) may be appropriate to determine whether the PES-PD is an adequate predictive scale for preparedness for employment. Other studies may involve implementing the 11-item PES-PD twice, while participants are stable in the interim period (i.e. have not partaken in employment support) to assess for test-retest and measurement error. Taken together, the results of these studies may provide further evidence for construct validity and reliability of the PES-PD.

In terms of testing the clinical relevance of the 11-item PES-PD, future studies may involve participants to have undergone “change” by participating in an employment intervention and using the PES-PD at pre and post timepoints to capture change scores. Therefore, Randomised Controlled Trials (RCTs) are recommended methods to estimate the impact of a scale clinically, as they can provide opportunities to evaluate the scale on patients that are subjected to change (Lijmer & Bossuyt, 2009).

The PES-PD was developed as part of a National Institute of Health Research funded programme called Enabling and Motivating People (with a Personality Disorder) in Occupation, Education and Responsibility (EMPOWER; RP-PG-1212-20011). EMPOWER aims to help people with difficulties consistent with a personality disorder to obtain and retain employment and increase wellbeing by evaluating the effectiveness of a 17-week group-based psychological intervention; Dialectical Behavioural Therapy Skills for Employment (DBT-SE) with a feasibility study, followed by a full Randomised Control Trial (RCT). Future studies will involve evaluating the clinical relevance of the PES-PD alongside the EMPOWER RCT, to determine
whether the scale is helpful for intervention planning or as an intervention outcome measure.

Other future studies may also involve the development of an informant-reported measure. Given that friends and family, healthcare professionals, and employment support workers may all be involved in supporting the person with a personality disorder into employment; their perspectives may provide valid insight into their preparedness for employment. For example, clinicians have reported on general work behaviours (Work Behaviour Checklist [WBC]; Tsang & Pearson, 2000), occupational functioning (Occupational Functioning Scale, OFS: Hannula et al., 2006); and work readiness (Work Readiness Questionnaire; WoRQ; Potkins et al., 2016). Informant reporting, whether it would be a spouse, friend, parent or clinician may increase validity by effectively reducing response bias in self-reporting, although informants will also have their own biases (Klonsky, Oltmanns, & Turkheimer, 2002).

General comparison studies between self-report and informant-report methods in personality disorders are limited. Most studies concern the self-report of personality disorder diagnosis and symptoms (Huprich, Bornstein, & Schmitt, 2011; Hyler et al., 1989) and suggest that self-reporting alone is insufficient and that there are discrepancies between the two reporting styles. More studies are warranted, particularly in areas of the impact on the type of informant, type of sample, and the impact of different measures (Klonsky et al., 2002). The key element to acknowledge when using both types of measures is that even if there were discrepancies in agreement between measures, it might not necessarily suggest that the scales are invalid, the differences could instead provide a more in-depth and greater understanding of the person. Therefore, future research may include developing an informant version of the PES-PD or testing the 11-item PES-PD using informants or possibly comparing accordance between the two measures. Informants may include friends and family, employers or any healthcare professional that may be involved in employment support with the individual.

Additional future studies related to the elimination of items deemed relevant by the target population. Researchers that involve the target population
and their perspective on the topic of interest and discover any changes in the target content, then another set of qualitative studies to assess the changes may be required (Patrick et al., 2011). A measure that depicts items that are deemed relevant conceptually for the population, especially if by the target population, is ideal in clinical practice (Rose et al., 2011). Therefore, future studies may involve more qualitative studies that include the target population and clinicians who work with personality disorders or in employment settings to further assess the content validity of the 11-item PES-PD compared to the 35-item version. Such a study may produce a different scale that would need to be subjected to tests of psychometric validity and reliability.

A final suggestion for all future studies is to address issues of general representativeness regarding personality disorders. Such studies may benefit from gathering information on specific personality disorders, or a confirmed diagnosis of a personality disorder, either from self-report or more formalised measures of personality disorder diagnosis.

6.6 Clinical Implications

The PES-PD was developed to identify the appropriate timing for engaging in employment or returning to work. Timing is important as the relationship between employment, and mental health is complex and bidirectional. Thus, identifying the right time to engage in employment may mitigate premature job loss and any unnecessary psychological distress (Nielsen et al., 2018). For instance, if a person with personality disorder returns to work too early, and is psychologically unprepared, this may lead to difficulties in coping and managing, which ultimately leads to being signed off sick, or losing a job. Perpetual ‘failures’ may drive people towards low self-esteem, demotivation in returning to work, especially if self-esteem is contingent on events for self-worth (Kernis, 2005).

The PES-PD may also be used to identify areas of employment preparedness to inform relevant employment support and interventions. Scales

35 See Chapter 1 Section 1.2 Mental Health and Employment
are often used to devise treatment plans during psychological assessments (Beutler et al., 2000) provide information on the planning, implementation, and evaluation of treatment, as well as help to determine treatment duration and intensity (Groth-Marnat, 2009; Kubiszyn et al., 2000). In the UK, mental health services such as increasing access to psychological therapies (IAPT) have access to employment specialists, as part of the NHS Long Term Plan (NHS England, 2019). The PES-PD may be utilised by these employment specialists as people with personality disorder and personality disorder traits often present in these services (Hepgul et al., 2016). Furthermore, due to the nature and culture of IAPT services, short and reliable measures tend to be favoured (Williams, 2015). Thus, the 11-item PES-PD is likely to be an appropriate measure for these mental health services.

The PES-PD currently measures three factors; interpersonal, emotional regulation, and vitality and may be utilised as an intervention outcome measure. Previous authors of studies evaluating personality disorder and employment interventions argued that the key challenges to employment for people with personality disorders were interpersonal skills and emotional regulation (Comtois et al., 2010; Koons et al., 2006). More recently, in a DBT-adapted employment intervention for personality disorders, the manualised intervention contains skills that target these areas (Feigenbaum, 2019). Furthermore, as clients learn new ways to manage their interpersonal and emotional dysregulation, feelings of autonomy and motivation may increase (Ryan, Lynch, Vansteenkiste, & Deci, 2011). Motivation is described as “the study of both energy and direction of behaviours” (Ryan & Deci, 2017, p. 256) suggesting an increase in motivation may lead to an improvement in vitality. The PES-PD may therefore appear to be an appropriate intervention outcome measure, however, the extent of its clinical relevance has yet to be evaluated. In addition, as motivation and vitality may be similar, but not quite the same construct, it might be worth testing divergent and convergent validity on the PES-PD against measures of motivation to ensure the PES-PD is capturing what it intends to measure, as part of construct validity.
6.7 Conclusion

In summary, this thesis found a three-factor 11 item questionnaire measuring preparedness for employment to people with personality disorders, with promising psychometric properties. The findings from the thesis suggest that the scale is likely to provide clinicians and individuals useful information required in the planning of employment, to help identify appropriate timing in returning to work, as well as a possible useful outcome for interventions.
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Appendix 1 DSM-5 Criteria for Personality Disorders
(Chapter 1)

General Criteria for a Personality Disorder

The essential features of a personality disorder are impairments in personality (self and interpersonal) functioning and the presence of pathological personality traits. To diagnose a personality disorder, the following criteria must be met:

A. Significant impairments in self (identity or self-direction) and interpersonal (empathy or intimacy) functioning.

B. One or more pathological personality trait domains or trait facets.

C. The impairments in personality functioning and the individual’s personality trait expression are relatively stable across time and consistent across situations.

D. The impairments in personality functioning and the individual’s personality trait expression are not better understood as normative for the individual’s developmental stage or sociocultural environment.

E. The impairments in personality functioning and the individual’s personality trait expression are not solely due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or a general medical condition (e.g., severe head trauma).

Antisocial Personality Disorder

The essential features of a personality disorder are impairments in personality (self and interpersonal) functioning and the presence of pathological personality traits. To diagnose antisocial personality disorder, the following criteria must be met:

A. Significant impairments in personality functioning manifest by:

1. Impairments in self functioning (a or b):
   a. Identity: Egocentrism; self-esteem derived from personal gain, power, or pleasure.
   b. Self-direction: Goal setting based on personal gratification; absence of prosocial internal standards associated with failure to conform to lawful or culturally normative ethical behaviour.

   AND

2. Impairments in interpersonal functioning (a or b):
   a. Empathy: Lack of concern for feelings, needs, or suffering of others; lack of remorse after hurting or mistreating another.
   b. Intimacy: Incapacity for mutually intimate relationships, as exploitation is a primary means of relating to others, including by deceit and coercion; use of dominance or intimidation to control others.

B. Pathological personality traits in the following domains:

1. Antagonism, characterized by:
a. **Manipulativeness:** Frequent use of subterfuge to influence or control others; use of seduction, charm, glibness, or ingratiating to achieve one’s ends.

b. **Deceitfulness:** Dishonesty and fraudulence; misrepresentation of self; embellishment or fabrication when relating events.

c. **Callousness:** Lack of concern for feelings or problems of others; lack of guilt or remorse about the negative or harmful effects of one’s actions on others; aggression; sadism.

d. **Hostility:** Persistent or frequent angry feelings; anger or irritability in response to minor slights and insults; mean, nasty, or vengeful behaviour.

2. **Disinhibition,** characterized by:

a. **Irresponsibility:** Disregard for – and failure to honour – financial and other obligations or commitments; lack of respect for – and lack of follow through on – agreements and promises.

b. **Impulsivity:** Acting on the spur of the moment in response to immediate stimuli; acting on a momentary basis without a plan or consideration of outcomes; difficulty establishing and following plans.

c. **Risk taking:** Engagement in dangerous, risky, and potentially self-damaging activities, unnecessarily and without regard for consequences; boredom proneness and thoughtless initiation of activities to

C. The impairments in personality functioning and the individual’s personality trait expression are relatively stable across time and consistent across situations.

D. The impairments in personality functioning and the individual’s personality trait expression are not better understood as normative for the individual’s developmental stage or sociocultural environment.

E. The impairments in personality functioning and the individual’s personality trait expression are not solely due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or a general medical condition (e.g., severe head trauma).

F. The individual is at least age 18 years.

**Avoidant Personality Disorder**

The essential features of a personality disorder are impairments in personality (self and interpersonal) functioning and the presence of pathological personality traits. To diagnose avoidant personality disorder, the following criteria must be met:

A. Significant impairments in **personality functioning** manifest by:

1. Impairments in **self functioning** (a or b):

   a. **Identity:** Low self-esteem associated with self-appraisal socially inept, personally unappealing, or inferior; excessive feelings of shame or inadequacy.

   b. **Self-direction:** Unrealistic standards for behaviour associated with reluctance to pursue goals, take personal risks, or engage in new activities involving interpersonal contact. AND
2. Impairments in **interpersonal functioning** (a or b):

   a. **Empathy**: Preoccupation with, and sensitivity to, criticism or rejection, associated with distorted inference of others’ perspectives as negative.
   b. **Intimacy**: Reluctance to get involved with people unless being certain of being liked; diminished mutuality within intimate relationships because of fear of being shamed or ridiculed.

B. Pathological **personality traits** in the following domains:

1. **Detachment**, characterized by:

   a. **Withdrawal**: Reticence in social situations; avoidance of social contacts and activity; lack of initiation of social contact.
   b. **Intimacy avoidance**: Avoidance of close or romantic relationships, interpersonal attachments, and intimate sexual relationships.
   c. **Anhedonia**: Lack of enjoyment from, engagement in, or energy for life’s experiences; deficits in the capacity to feel pleasure or take interest in things.

2. **Negative Affectivity**, characterized by:

   a. **Anxiousness**: Intense feelings of nervousness, tenseness, or panic, often in reaction to social situations; worry about the negative effects of past unpleasant experiences and future negative possibilities; feeling fearful, apprehensive, or threatened by uncertainty; fears of embarrassment.

C. The impairments in personality functioning and the individual’s personality trait expression are relatively stable across time and consistent across situations.

D. The impairments in personality functioning and the individual’s personality trait expression are not better understood as normative for the individual’s developmental stage or socio-cultural environment.

E. The impairments in personality functioning and the individual’s personality trait expression are not solely due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or a general medical condition (e.g., severe head trauma)

**Borderline Personality Disorder**

The essential features of a personality disorder are impairments in personality (self and interpersonal) functioning and the presence of pathological personality traits. To diagnose borderline personality disorder, the following criteria must be met:

A. Significant impairments in personality functioning manifest by:

1. Impairments in **self functioning** (a or b):

   a. **Identity**: Markedly impoverished, poorly developed, or unstable self-image, often associated with excessive self-criticism; chronic feelings of emptiness; dissociative states under stress.
   b. **Self-direction**: Instability in goals, aspirations, values, or career plans.

AND
2. Impairments in **interpersonal functioning** (a or b):

   a. **Empathy**: Compromised ability to recognize the feelings and needs of others associated with interpersonal hypersensitivity (i.e., prone to feel slighted or insulted); perceptions of others selectively biased toward negative attributes or vulnerabilities.

   b. **Intimacy**: Intense, unstable, and conflicted close relationships, marked by mistrust, neediness, and anxious preoccupation with real or imagined abandonment; close relationships often viewed in extremes of idealization and devaluation and alternating between over involvement and withdrawal.

B. Pathological **personality traits** in the following domains:

1. **Negative Affectivity**, characterized by:

   a. **Emotional liability**: Unstable emotional experiences and frequent mood changes; emotions that are easily aroused, intense, and/or out of proportion to events and circumstances.

   b. **Anxiousness**: Intense feelings of nervousness, tenseness, or panic, often in reaction to interpersonal stresses; worry about the negative effects of past unpleasant experiences and future negative possibilities; feeling fearful, apprehensive, or threatened by uncertainty; fears of falling apart or losing control.

   c. **Separation insecurity**: Fears of rejection by – and/or separation from – significant others, associated with fears of excessive dependency and complete loss of autonomy.

   d. **Depressivity**: Frequent feelings of being down, miserable, and/or hopeless; difficulty recovering from such moods; pessimism about the future; pervasive shame; feeling of inferior self-worth; thoughts of suicide and suicidal behaviour.

2. **Disinhibition**, characterized by:

   a. **Impulsivity**: Acting on the spur of the moment in response to immediate stimuli; acting on a momentary basis without a plan or consideration of outcomes; difficulty establishing or following plans; a sense of urgency and self-harming behaviour under emotional distress.

   b. **Risk taking**: Engagement in dangerous, risky, and potentially self-damaging activities, unnecessarily and without regard to consequences; lack of concern for one’s limitations and denial of the reality of personal danger.

3. **Antagonism**, characterized by:

   a. **Hostility**: Persistent or frequent angry feelings; anger or irritability in response to minor slights and insults.

C. The impairments in personality functioning and the individual’s personality trait expression are relatively stable across time and consistent across situations.

D. The impairments in personality functioning and the individual’s personality trait expression are not better understood as normative for the individual’s developmental stage or socio-cultural environment.
E. The impairments in personality functioning and the individual’s personality trait expression are not solely due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or a general medical condition (e.g., severe head trauma).

Narcissistic Personality Disorder

The essential features of a personality disorder are impairments in personality (self and interpersonal) functioning and the presence of pathological personality traits. To diagnose narcissistic personality disorder, the following criteria must be met:

A. Significant impairments in personality functioning manifest by:

1. Impairments in self functioning (a or b):
   a. **Identity**: Excessive reference to others for self-definition and self-esteem regulation; exaggerated self-appraisal may be inflated or deflated or vacillate between extremes; emotional regulation mirrors fluctuations in self-esteem.
   b. **Self-direction**: Goal setting is based on gaining approval from others; personal standards are unreasonably high in order to see oneself as exceptional, or too low based on a sense of entitlement; often unaware of own motivations.

AND

2. Impairments in interpersonal functioning (a or b):
   a. **Empathy**: Impaired ability to recognize or identify with the feelings and needs of others; excessively attuned to reactions of others, but only if perceived as relevant to self; over- or underestimate of own effect on others.
   b. **Intimacy**: Relationships largely superficial and exist to serve self-esteem regulation; mutuality constrained by little genuine interest in others’ experiences and predominance of a need for personal gain

B. Pathological personality traits in the following domain:

1. **Antagonism**, characterized by:
   a. **Grandiosity**: Feelings of entitlement, either overt or covert; self-centeredness; firmly holding to the belief that one is better than others; condescending toward others.
   b. **Attention seeking**: Excessive attempts to attract and be the focus of the attention of others; admiration seeking.

C. The impairments in personality functioning and the individual’s personality trait expression are relatively stable across time and consistent across situations.

D. The impairments in personality functioning and the individual’s personality trait expression are not better understood as normative for the individual’s developmental stage or socio-cultural environment.

E. The impairments in personality functioning and the individual’s personality trait expression are not solely due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or a general medical condition (e.g., severe head trauma).
Obsessive-Compulsive Personality Disorder

The essential features of a personality disorder are impairments in personality (self and interpersonal) functioning and the presence of pathological personality traits. To diagnose obsessive-compulsive personality disorder, the following criteria must be met:

A. Significant impairments in personality functioning manifest by:

1. Impairments in self functioning (a or b):
   a. Identity: Sense of self derived predominantly from work or productivity; constricted experience and expression of strong emotions.
   b. Self-direction: Difficulty completing tasks and realizing goals associated with rigid and unreasonably high and inflexible internal standards of behaviour; overly conscientious and moralistic attitudes.

AND

2. Impairments in Interpersonal functioning (a or b):
   a. Empathy: Difficulty understanding and appreciating the ideas, feelings, or behaviours of others.
   b. Intimacy: Relationships seen as secondary to work and productivity; rigidity and stubbornness negatively affect relationships with others.

B. Pathological personality traits in the following domains:

1. Compulsivity, characterized by:
   a. Rigid perfectionism: Rigid insistence on everything being flawless, perfect, without errors or faults, including one's own and others' performance; sacrificing of timeliness to ensure correctness in every detail; believing that there is only one right way to do things; difficulty changing ideas and/or viewpoint; preoccupation with details, organization, and order.

2. Negative Affectivity, characterized by:
   a. Perseveration: Persistence at tasks long after the behaviour has ceased to be functional or effective; continuance of the same behaviour despite repeated failures.

C. The impairments in personality functioning and the individual's personality trait expression are relatively stable across time and consistent across situations.

D. The impairments in personality functioning and the individual's personality trait expression are not better understood as normative for the individual's developmental stage or socio-cultural environment.

E. The impairments in personality functioning and the individual's personality trait expression are not solely due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or a general medical condition (e.g., severe head trauma).
Schizotypal Personality Disorder

The essential features of a personality disorder are impairments in personality (self and interpersonal) functioning and the presence of pathological personality traits. To diagnose schizotypal personality disorder, the following criteria must be met:

A. Significant impairments in personality functioning manifest by:

1. Impairments in self functioning:
   a. **Identity**: Confused boundaries between self and others; distorted self-concept; emotional expression often not congruent with context or internal experience.
   b. **Self-direction**: Unrealistic or incoherent goals; no clear set of internal standards.

2. Impairments in interpersonal functioning:
   a. **Empathy**: Pronounced difficulty understanding impact of own behaviours on others; frequent misinterpretations of others’ motivations and behaviours.
   b. **Intimacy**: Marked impairments in developing close relationships, associated with mistrust and anxiety.

B. Pathological personality traits in the following domains:

1. **Psychoticism**, characterised by:
   a. **Eccentricity**: Odd, unusual, or bizarre behaviour or appearance; saying unusual or inappropriate things.
   b. **Cognitive and perceptual dysregulation**: Odd or unusual thought processes; vague, circumstantial, metaphorical, over-elaborate, or stereotyped thought or speech; odd sensations in various sensory modalities.
   c. **Unusual beliefs and experiences**: Thought content and views of reality that are viewed by others as bizarre or idiosyncratic; unusual experiences of reality.

2. **Detachment**, characterized by:
   a. **Restricted affectivity**: Little reaction to emotionally arousing situations; constricted emotional experience and expression; indifference or coldness.
   b. **Withdrawal**: Preference for being alone to being with others; reticence in social situations; avoidance of social contacts and activity; lack of initiation of social contact.

3. **Negative Affectivity**, characterized by:
   a. **Suspiciousness**: Expectations of – and heightened sensitivity to – signs of interpersonal ill-intent or harm; doubts about loyalty and fidelity of others; feelings of persecution.

C. The impairments in personality functioning and the individual’s personality trait expression are relatively stable across time and consistent across situations.

D. The impairments in personality functioning and the individual’s personality trait expression are not better understood as normative for the individual’s developmental stage or socio-cultural environment.

E. The impairments in personality functioning and the individual’s personality trait expression are not solely due to the direct physiological effects of a substance.
(e.g., a drug of abuse, medication) or a general medical condition (e.g., severe head trauma).

**Personality Disorder Trait Specified**

The essential features of a personality disorder are impairments in personality (self and interpersonal) functioning and the presence of pathological personality traits. To diagnose a personality disorder, the following criteria must be met:

A. Significant impairments (i.e., mild impairment or greater) in self (identity or self-direction) and interpersonal (empathy or intimacy) functioning.

B. One or more pathological personality trait domains OR specific trait facets within domains, considering ALL of the following domains.

1. Negative Affectivity
2. Detachment
3. Antagonism
4. Disinhibition vs. Compulsivity
5. Psychoticism

NOTE: Trait domain or one or more trait facets MUST be rated as “mildly descriptive or greater. If trait domain is rated as “mildly descriptive” then one or more of the associated trait facets MUST be rated as “moderately descriptive” or greater.

C. The impairments in personality functioning and the individual’s personality trait expression are relatively stable across time and consistent across situations.

D. The impairments in personality functioning and the individual’s personality trait expression are not better understood as normative for the individual’s developmental stage or socio-cultural environment.

E. The impairments in personality functioning and the individual’s personality trait expression are not solely due to the direct physiological effects of a substance (e.g., a drug of abuse, medication) or a general medical condition (e.g., severe head trauma).
Appendix 2 MEDLINE Search Strategy (Chapter 2)

MEDLINE Search Strategy [1946 to March 2016]
Key:
exp = expand
mp = title, abstract, heading word, table of contents, key concepts, original title, tests & measures
$ = truncation
ppv = pay per view databases

exp Mental Health/ OR mental health.mp. OR "Quality of Life"/ OR (quality of life or wellbeing or well-being).mp.
AND
exp Employment/ or exp Return to Work/ OR exp Career Mobility/ or exp Career Choice/ OR
(employ$ or unemploy$ or reemploy$ or labor or labour or job$ or occupation or vocation$ or work or career$).mp.
AND
exp Vocational Guidance/ or exp Rehabilitation, Vocational/ OR exp Vocational Education/ OR
(readiness or preparedness or vocational).mp.
AND
exp Questionnaires/ OR exp Work Capacity Evaluation/ OR (questionnaire$ or scale or scales or evaluation or measur$).mp.
AND
(validity or validation or reliability or sensitivity or specificity or predictive value or ppv or reproducibility).mp.
Appendix 3 PsycINFO Search Strategy (Chapter 2)

PsycINFO (including PsychEXTRA) Search Strategy [1808 to March 2016]

Key:
exp = expand
mp = title, abstract, heading word, table of contents, key concepts, original title, tests & measures
$ = truncation
ppv = pay per view databases

exp mental health OR mental health.mp
AND
exp Employment Status/ or Employability/ or exp Employment History/ or reemployment/ or supported employment/ OR occupational mobility/ or occupational choice/ OR (employ$ or unemploy$ or reemploy$ or labor or labour or job$ or occupation or vocation$ or work or career$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
AND
(readiness or preparedness or vocational).mp. OR occupational guidance/ or exp vocational rehabilitation/ or exp vocational education/
AND
exp questionnaires/ OR vocational evaluation/ OR (questionnaire$ or scale or scales or evaluation or measur$).mp.
AND
(validity or validation or reliability or sensitivity or specificity or predictive value or ppv or reproducibility).mp.
Appendix 4 HAPI Search Strategy (Chapter 2)

Health and Psychosocial Instruments (HAPI) Search Strategy [1949 to March 2016]

Key:
exp = expand
mp = title, abstract, heading word, table of contents, key concepts, original title, tests & measures
$ = truncation
ppv = pay per view databases

mental health.af. OR mental health.mp.
AND
(employment or Return to Work).mp. OR (Employment Status or Employability or Employment History or reemployment or supported employment).mp.
AND
(occupational mobility or occupational choice or Career Mobility or Career Choice).mp.
AND
(employ$ or unemploy$ or reemploy$ or labor or labour or job$ or occupation or vocation$ or work or career$).mp.
AND
(Readiness or preparedness or vocational).mp. OR (occupational guidance or vocational rehabilitation or vocational education).mp. OR (Vocational Guidance or Rehabilitation, Vocational).mp.
AND
Questionnaires.mp. OR Work Capacity Evaluation.mp. OR vocational evaluation.mp. [mp=title, acronym, descriptors, measure descriptors, sample descriptors, abstract, source] OR
(questionnaire$ or scale or scales or evaluation or measur$).mp.
AND
(validity or validation or reliability or sensitivity or specificity or predictive value or ppv or reproducibility).mp.
Appendix 5 Cochrane Search Strategy (Chapter 2)

Cochrane Database of Systematic Reviews (CDSR) [Inception to March 2016]

Key:
exp = expand
mp = title, abstract, heading word, table of contents, key concepts, original title, tests &
measures
$ = truncation
ppv = pay per view databases

"Personality Disorder" OR personality disorder or hysteria or avoidance or avoidant or
dependent or narcissistic or schizotypal or schizoid or borderline or obsessive compulsive or
antisocial or anti-social or inadequate or paranoid or impuls* or histrionic
AND
Employment or "Return to Work" OR "Career Mobility" or "Career Choice" OR employ* or
unemploy* or labor or labour or job* or occupation or vocation* or work or career
AND "Vocational Guidance" or "Rehabilitation, Vocational" or "Vocational Education" OR
readiness or preparedness or vocational
AND questionnaires OR Work Capacity Evaluation OR questionnaire* or scale or scales or
evaluation or measur*
AND
validity or validation or reliability or sensitivity or specificity or "predictive value" or
reproducibility.
## Appendix 6 COSMIN Agreement (Chapter 2)

<table>
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<th>Box A. Internal consistency</th>
<th>VSSAS</th>
<th>WBC</th>
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<td>rater 1</td>
<td>rater 2</td>
</tr>
<tr>
<td>1</td>
<td>Does the scale consist of effect indicators, i.e. is it based on a reflective model?</td>
<td>E</td>
</tr>
<tr>
<td>2</td>
<td>Was the percentage of missing items given?</td>
<td>G</td>
</tr>
<tr>
<td>3</td>
<td>Was there a description of how missing items were handled?</td>
<td>F</td>
</tr>
<tr>
<td>4</td>
<td>Was the sample size included in the internal consistency analysis adequate?</td>
<td>G</td>
</tr>
<tr>
<td>5</td>
<td>Was the unidimensionality of the scale checked? i.e. was factor analysis or IRT model applied?</td>
<td>P</td>
</tr>
<tr>
<td>6</td>
<td>Was the sample size included in the unidimensionality analysis adequate?</td>
<td>G</td>
</tr>
<tr>
<td>7</td>
<td>Was an internal consistency statistic calculated for each (unidimensional) (sub)scale separately?</td>
<td>E</td>
</tr>
<tr>
<td>8</td>
<td>Were there any important flaws in the design or methods of the study?</td>
<td>E</td>
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<tr>
<td>9</td>
<td>for Classical Test Theory (CTT), continuous scores: Was Cronbach’s alpha calculated?</td>
<td>E</td>
</tr>
<tr>
<td>10</td>
<td>10 for CTT, dichotomous scores: Was Cronbach’s alpha or KR-20 calculated?</td>
<td>NA</td>
</tr>
<tr>
<td>11</td>
<td>for IRT: Was a goodness of fit statistic at a global level calculated? E.g. χ², reliability coefficient of estimated latent trait value (index of (subject or item) separation)</td>
<td>NA</td>
</tr>
<tr>
<td>TOTAL</td>
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<td>Poor</td>
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E = Excellent; G = Good; F = Fair; P = Poor.

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<tr>
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<th></th>
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<th>WBI</th>
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<td>rater 2</td>
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<td>E</td>
<td>G</td>
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<td>E</td>
<td>F</td>
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<td>Karidi et al. (2005)</td>
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<td>E E Y</td>
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<td>G G Y</td>
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<td>F F Y</td>
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<td>E E Y</td>
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<td>E E Y</td>
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<td>G G Y</td>
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<td>E E Y</td>
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<td>E E Y</td>
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<td>9. for Classical Test Theory (CTT), continuous scores: Was Cronbach’s alpha calculated?</td>
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<td>E E Y</td>
<td></td>
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<td></td>
<td></td>
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<td>NA NA Y</td>
<td>NA NA Y</td>
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<td>NA NA Y</td>
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<td>Fair</td>
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<td><strong>Box A. Internal consistency</strong></td>
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<td>rater 1</td>
<td>rater 2</td>
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<tr>
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<td>Y</td>
<td>E</td>
<td>E</td>
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<td>E</td>
<td>Y</td>
<td>G</td>
<td>G</td>
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<td>P</td>
<td>N</td>
<td>G</td>
<td>G</td>
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<td>Y</td>
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<td>G</td>
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<td>Was the unidimensionality of the scale checked? i.e. was factor analysis or IRT model applied?</td>
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<td>Y</td>
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<td>E</td>
<td>E</td>
<td>Y</td>
<td>G</td>
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<td>8</td>
<td>Were there any important flaws in the design or methods of the study?</td>
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<td>N</td>
<td>E</td>
<td>P</td>
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<tr>
<td>9</td>
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<td>E</td>
<td>E</td>
<td>Y</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>10</td>
<td>for CTT, dichotomous scores: Was Cronbach’s alpha or KR-20 calculated?</td>
<td>NA</td>
<td>NA</td>
<td>Y</td>
<td>NA</td>
<td>NA</td>
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<td>11</td>
<td>for IRT: Was a goodness of fit statistic at a global level calculated? E.g. $\chi^2$, reliability coefficient of estimated latent trait value (index of (subject or item) separation)</td>
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<td>Poor</td>
<td>Y</td>
<td>Poor</td>
<td>Poor</td>
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<td>E</td>
<td>Y</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>2</td>
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<td>G</td>
<td>G</td>
<td>Y</td>
<td>G</td>
<td>G</td>
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<td>3</td>
<td>Was there a description of how missing items were handled?</td>
<td>F</td>
<td>F</td>
<td>Y</td>
<td>F</td>
<td>G</td>
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<td>G</td>
<td>N</td>
<td>G</td>
<td>E</td>
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<td>5</td>
<td>Was the unidimensionality of the scale checked? i.e. was factor analysis or IRT model applied?</td>
<td>E</td>
<td>F</td>
<td>N</td>
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<td>Was an internal consistency statistic calculated for each (unidimensional) (sub)scale separately?</td>
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<td>11</td>
<td>for IRT: Was a goodness of fit statistic at a global level calculated? E.g. $\chi^2$, reliability coefficient of estimated latent trait value (index of (subject or item) separation)</td>
<td>NA</td>
<td>NA</td>
<td>Y</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>Lowest score of items 1-11</strong></td>
<td>Poor</td>
<td>Fair</td>
<td>N</td>
<td>Fair</td>
<td>Good</td>
</tr>
<tr>
<td>Box A. Internal consistency</td>
<td>rater 1</td>
<td>rater 2</td>
<td>Consensus</td>
<td>rater 1</td>
<td>rater 2</td>
<td>Consensus</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>---------</td>
<td>---------</td>
<td>-----------</td>
<td>---------</td>
<td>---------</td>
<td>-----------</td>
</tr>
<tr>
<td>1. Does the scale consist of effect indicators, i.e. is it based on a reflective model?</td>
<td>E</td>
<td>G</td>
<td>N</td>
<td>E</td>
<td>E</td>
<td>Y</td>
</tr>
<tr>
<td>2. Was the percentage of missing items given?</td>
<td>G</td>
<td>G</td>
<td>Y</td>
<td>E</td>
<td>E</td>
<td>Y</td>
</tr>
<tr>
<td>3. Was there a description of how missing items were handled?</td>
<td>F</td>
<td>F</td>
<td>Y</td>
<td>F</td>
<td>F</td>
<td>Y</td>
</tr>
<tr>
<td>4. Was the sample size included in the internal consistency analysis adequate?</td>
<td>E</td>
<td>E</td>
<td>Y</td>
<td>E</td>
<td>E</td>
<td>N</td>
</tr>
<tr>
<td>5. Was the unidimensionality of the scale checked? i.e. was factor analysis or IRT model applied?</td>
<td>E</td>
<td>E</td>
<td>Y</td>
<td>E</td>
<td>E</td>
<td>N</td>
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<td>6. Was the sample size included in the unidimensionality analysis adequate?</td>
<td>G</td>
<td>G</td>
<td>N</td>
<td>P</td>
<td>P</td>
<td>N</td>
</tr>
<tr>
<td>7. Was an internal consistency statistic calculated for each (unidimensional) (sub)scale separately?</td>
<td>E</td>
<td>E</td>
<td>Y</td>
<td>E</td>
<td>E</td>
<td>Y</td>
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<td>8. Were there any important flaws in the design or methods of the study?</td>
<td>E</td>
<td>E</td>
<td>Y</td>
<td>E</td>
<td>E</td>
<td>Y</td>
</tr>
<tr>
<td>9. for Classical Test Theory (CTT), continuous scores: Was Cronbach’s alpha calculated?</td>
<td>E</td>
<td>E</td>
<td>Y</td>
<td>E</td>
<td>E</td>
<td>Y</td>
</tr>
<tr>
<td>10. for CTT, dichotomous scores: Was Cronbach’s alpha or KR-20 calculated?</td>
<td>NA</td>
<td>NA</td>
<td>Y</td>
<td>NA</td>
<td>NA</td>
<td>Y</td>
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<tr>
<td>11. for IRT: Was a goodness of fit statistic at a global level calculated? E.g. $\chi^2$, reliability coefficient of estimated latent trait value (index of (subject or item) separation)</td>
<td>NA</td>
<td>NA</td>
<td>Y</td>
<td>NA</td>
<td>NA</td>
<td>Y</td>
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<td>TOTAL Lowest score of items 1-11</td>
<td>Fair</td>
<td>Fair</td>
<td>Y</td>
<td>Poor</td>
<td>Poor</td>
<td>Y</td>
</tr>
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<td>Box A. Internal consistency</td>
<td>rater 1</td>
<td>rater 2</td>
<td>Consensus</td>
<td>rater 1</td>
<td>rater 2</td>
<td>Consensus</td>
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<tr>
<td>1</td>
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<td>E</td>
<td>E</td>
<td>Y</td>
<td>F</td>
<td>E</td>
</tr>
<tr>
<td>2</td>
<td>Was the percentage of missing items given?</td>
<td>G</td>
<td>G</td>
<td>Y</td>
<td>G</td>
<td>G</td>
</tr>
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<td>Was there a description of how missing items were handled?</td>
<td>F</td>
<td>F</td>
<td>Y</td>
<td>F</td>
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<td>E</td>
<td>Y</td>
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<td>E</td>
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<tr>
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<td>E</td>
<td>E</td>
<td>Y</td>
<td>E</td>
<td>E</td>
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<tr>
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<td>E</td>
<td>Y</td>
<td>G</td>
<td>G</td>
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<tr>
<td>7</td>
<td>Was an internal consistency statistic calculated for each (unidimensional) (sub)scale separately?</td>
<td>E</td>
<td>E</td>
<td>Y</td>
<td>E</td>
<td>E</td>
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<tr>
<td>8</td>
<td>Were there any important flaws in the design or methods of the study?</td>
<td>E</td>
<td>E</td>
<td>Y</td>
<td>E</td>
<td>E</td>
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<td>9</td>
<td>for Classical Test Theory (CTT), continuous scores: Was Cronbach's alpha calculated?</td>
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<td>Y</td>
<td>E</td>
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<td>10</td>
<td>for CTT, dichotomous scores: Was Cronbach's alpha or KR-20 calculated?</td>
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<td>Y</td>
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<td>NA</td>
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<td>for IRT: Was a goodness of fit statistic at a global level calculated? E.g. ( \chi^2 ), reliability coefficient of estimated latent trait value (index of (subject or item) separation)</td>
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<td>NA</td>
<td>Y</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>TOTAL</td>
<td>Lowest score of items 1-11</td>
<td>Fair</td>
<td>Fair</td>
<td>Y</td>
<td>Fair</td>
<td>Fair</td>
</tr>
<tr>
<td>Item</td>
<td>Question</td>
<td>rater 1</td>
<td>rater 2</td>
<td>Consensus</td>
<td></td>
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<td>N</td>
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<td>Was the percentage of missing items given?</td>
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<td>G</td>
<td>Y</td>
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<td>Was there a description of how missing items were handled?</td>
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<td>F</td>
<td>Y</td>
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<td>P</td>
<td>P</td>
<td>Y</td>
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<td>E</td>
<td>Y</td>
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<td>G</td>
<td>Y</td>
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<td>E</td>
<td>Y</td>
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<tr>
<td>9</td>
<td>for Classical Test Theory (CTT), continuous scores: Was Cronbach’s alpha calculated?</td>
<td>NA</td>
<td>NA</td>
<td>Y</td>
<td></td>
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</tr>
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<td>10</td>
<td>10 for CTT, dichotomous scores: Was Cronbach’s alpha or KR-20 calculated?</td>
<td>NA</td>
<td>NA</td>
<td>Y</td>
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<td>11</td>
<td>for IRT: Was a goodness of fit statistic at a global level calculated? E.g. $\chi^2$, reliability coefficient of estimated latent trait value (index of (subject or item) separation)</td>
<td>E</td>
<td>E</td>
<td>Y</td>
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**TOTAL** Lowest score of items 1-11: Poor Poor Y
<table>
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<tr>
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<th>WBC</th>
<th>VSSAS</th>
<th>WBI</th>
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<td>rater 1</td>
<td>rater 2</td>
<td>Consensus</td>
</tr>
<tr>
<td>1</td>
<td>Was the percentage of missing items given?</td>
<td>G</td>
<td>G</td>
</tr>
<tr>
<td>2</td>
<td>Was there a description of how missing items were handled?</td>
<td>G</td>
<td>G</td>
</tr>
<tr>
<td>3</td>
<td>Was the sample size included in the analysis adequate?</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>4</td>
<td>Were at least two measurements available?</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>5</td>
<td>Were the administrations independent?</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>6</td>
<td>Was the time interval stated?</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>7</td>
<td>Were patients stable in the interim period on the construct to be measured?</td>
<td>G</td>
<td>F</td>
</tr>
<tr>
<td>8</td>
<td>Was the time interval appropriate?</td>
<td>P</td>
<td>P</td>
</tr>
<tr>
<td>9</td>
<td>Were the test conditions similar for both measurements? e.g. type of administration, environment, instructions</td>
<td>E</td>
<td>G</td>
</tr>
<tr>
<td>10</td>
<td>Were there any important flaws in the design or methods of the study?</td>
<td>P</td>
<td>P</td>
</tr>
<tr>
<td>11</td>
<td>for continuous scores: Was an intraclass correlation coefficient (ICC) calculated?</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>12</td>
<td>for dichotomous/nominal/ordinal scores: Was kappa calculated?</td>
<td>NA</td>
<td>NA</td>
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<tr>
<td>13</td>
<td>for ordinal scores: Was a weighted kappa calculated?</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>14</td>
<td>for ordinal scores: Was the weighting scheme described? e.g. linear, quadratic</td>
<td>NA</td>
<td>NA</td>
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<td>TOTAL</td>
<td>Lowest score of items 1-14</td>
<td>Poor</td>
<td>Poor</td>
</tr>
<tr>
<td>Item</td>
<td>Question</td>
<td>WORQ</td>
<td>OFS</td>
</tr>
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<td>------</td>
<td>--------------------------------------------------------------------------</td>
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<td>-----</td>
</tr>
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<td>1</td>
<td>Was the percentage of missing items given?</td>
<td>E</td>
<td>G</td>
</tr>
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<td>Was there a description of how missing items were handled?</td>
<td>F</td>
<td>F</td>
</tr>
<tr>
<td>3</td>
<td>Was the sample size included in the analysis adequate?</td>
<td>G</td>
<td>G</td>
</tr>
<tr>
<td>4</td>
<td>Were at least two measurements available?</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
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<td>Were the administrations independent?</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>6</td>
<td>Was the time interval stated?</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>7</td>
<td>Were patients stable in the interim period on the construct to be measured?</td>
<td>F</td>
<td>F</td>
</tr>
<tr>
<td>8</td>
<td>Was the time interval appropriate?</td>
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<td>E</td>
</tr>
<tr>
<td>9</td>
<td>Were the test conditions similar for both measurements? e.g. type of administration, environment, instructions</td>
<td>G</td>
<td>G</td>
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<td>10</td>
<td>Were there any important flaws in the design or methods of the study?</td>
<td>F</td>
<td>F</td>
</tr>
<tr>
<td>11</td>
<td>for continuous scores: Was an intraclass correlation coefficient (ICC) calculated?</td>
<td>F</td>
<td>F</td>
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<td>12</td>
<td>for dichotomous/nominal/ordinal scores: Was kappa calculated?</td>
<td>E</td>
<td>N</td>
</tr>
<tr>
<td>13</td>
<td>for ordinal scores: Was a weighted kappa calculated?</td>
<td>F</td>
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<tr>
<td>14</td>
<td>for ordinal scores: Was the weighting scheme described? e.g. linear, quadratic</td>
<td>G</td>
<td>NA</td>
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<td><strong>TOTAL</strong> Lowest score of items 1-14</td>
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<td>Fair</td>
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<td>WSES</td>
<td>APQ6</td>
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<tr>
<td></td>
<td><strong>E = Excellent; G = Good; F = Fair; P = Poor.</strong></td>
<td><strong>Waghorn et al. (2000b)</strong></td>
<td><strong>Stewart et al. (2010)</strong></td>
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<td><strong>Box E. Reliability</strong></td>
<td><strong>Potkins et al. (2016)</strong></td>
<td></td>
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<td><strong>Was the percentage of missing items given?</strong></td>
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<td>rater 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>rater 2</td>
<td>rater 2</td>
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<tr>
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<td></td>
<td><strong>Consen-sus</strong></td>
<td><strong>Consen-sus</strong></td>
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<td><strong>Was there a description of how missing items were handled?</strong></td>
<td>F</td>
<td>F</td>
</tr>
<tr>
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<td>G</td>
<td>G</td>
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</tr>
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<td><strong>Was the sample size included in the analysis adequate?</strong></td>
<td>E</td>
<td>E</td>
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<td><strong>Were at least two measurements available?</strong></td>
<td>E</td>
<td>E</td>
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<td>E</td>
<td>E</td>
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<td>Y</td>
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<td><strong>Were the administrations independent?</strong></td>
<td>F</td>
<td>G</td>
</tr>
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<td></td>
<td>G</td>
<td>E</td>
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<td>E</td>
<td>N</td>
</tr>
<tr>
<td>6</td>
<td><strong>Was the time interval stated?</strong></td>
<td>E</td>
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<td>E</td>
<td>E</td>
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<td></td>
<td></td>
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<td>Y</td>
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<td><strong>Were patients stable in the interim period on the construct to be</strong></td>
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<td>E</td>
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<td>9</td>
<td><strong>Were the test conditions similar for both measurements? e.g.</strong></td>
<td>F</td>
<td>G</td>
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<td><strong>type of administration, environment, instructions</strong></td>
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<td>F</td>
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<td>F</td>
<td>E</td>
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<td><strong>Were there any important flaws in the design or methods of the</strong></td>
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<td>E</td>
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<td>Y</td>
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<td><strong>for continuous scores: Was an intraclass correlation coefficient</strong></td>
<td>F</td>
<td>F</td>
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<td><strong>(ICC) calculated?</strong></td>
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<td>E</td>
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<td>E</td>
<td>E</td>
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<tr>
<td></td>
<td></td>
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<td>Y</td>
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<tr>
<td>12</td>
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<td>NA</td>
<td>NA</td>
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<td></td>
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<td>E</td>
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<td>E</td>
<td>Y</td>
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</tr>
<tr>
<td></td>
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<td></td>
<td></td>
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</tr>
<tr>
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<tr>
<td></td>
<td>WBC</td>
<td>VSSAS</td>
<td>WBI</td>
</tr>
<tr>
<td>---</td>
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<td>-----</td>
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<tr>
<td><strong>Box D. Content Validity</strong></td>
<td>rater 1</td>
<td>rater 2</td>
<td>Consensus</td>
</tr>
<tr>
<td>1</td>
<td>Was there an assessment of whether all items refer to relevant aspects of the construct to be measured?</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>2</td>
<td>Was there an assessment of whether all items are relevant for the study population? (e.g. age, gender, disease characteristics, country, setting)</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>3</td>
<td>Was there an assessment of whether all items are relevant for the purpose of the measurement instrument? (discriminative, evaluative, and/or predictive)</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>4</td>
<td>Was there an assessment of whether all items together comprehensively reflect the construct to be measured?</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>5</td>
<td>Were there any important flaws in the design or methods of the study?</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>Lowest score of items 1-5</td>
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<td>Excellent</td>
</tr>
<tr>
<td>Box D. Content Validity</td>
<td>WORQ</td>
<td>OFS</td>
<td>TSSES-PMI</td>
</tr>
<tr>
<td>------------------------</td>
<td>------</td>
<td>-----</td>
<td>-----------</td>
</tr>
<tr>
<td><strong>rater 1</strong></td>
<td><strong>rater 2</strong></td>
<td><strong>Consensus</strong></td>
<td><strong>rater 1</strong></td>
</tr>
<tr>
<td>1</td>
<td>Was there an assessment of whether all items refer to relevant aspects of the construct to be measured?</td>
<td>E</td>
<td>E</td>
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<tr>
<td>2</td>
<td>Was there an assessment of whether all items are relevant for the study population? (e.g. age, gender, disease characteristics, country, setting)</td>
<td>E</td>
<td>E</td>
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<tr>
<td>3</td>
<td>Was there an assessment of whether all items are relevant for the purpose of the measurement instrument? (discriminative, evaluative, and/or predictive)</td>
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<tr>
<td>4</td>
<td>Was there an assessment of whether all items together comprehensively reflect the construct to be measured?</td>
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<td>E</td>
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<tr>
<td>5</td>
<td>Were there any important flaws in the design or methods of the study?</td>
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<td>E</td>
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<tr>
<td></td>
<td>E = Excellent; G = Good; F = Fair; P = Poor.</td>
<td>WSES</td>
<td>BECES</td>
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<tr>
<td></td>
<td>Waghorn et al. (2000b)</td>
<td>Corbière et al. (2004)</td>
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<td>rater 2</td>
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<td>E</td>
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<td>4</td>
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<td>E</td>
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<tr>
<td>5</td>
<td>Were there any important flaws in the design or methods of the study?</td>
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<td>APQ6</td>
<td>Stewart et al. (2010)</td>
<td>WoRQ</td>
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<td>rater 1</td>
<td>rater 2</td>
<td>Consensus</td>
</tr>
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<td>1</td>
<td>E</td>
<td>E</td>
<td>Y</td>
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<td>4</td>
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<tr>
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<td>Excellent</td>
<td>Y</td>
</tr>
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<td>Lowest score of items 1-5</td>
<td></td>
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<td>Box E. Structural Validity</td>
<td>WBC</td>
<td>WBI</td>
<td>WBI</td>
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</tr>
<tr>
<td>1</td>
<td>Does the scale consist of effective indicators, i.e. is it based on a reflective model?</td>
<td>rater 1</td>
<td>rater 2</td>
</tr>
<tr>
<td>2</td>
<td>Was the percentage of missing items given?</td>
<td>G</td>
<td>G</td>
</tr>
<tr>
<td>3</td>
<td>Was there a description of how missing items were handled?</td>
<td>G</td>
<td>G</td>
</tr>
<tr>
<td>4</td>
<td>Was the sample size included in the internal consistency analysis adequate?</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>5</td>
<td>Was the unidimensionality of the scale checked? i.e. was factor analysis or IRT model applied?</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>6</td>
<td>Was the sample size included in the unidimensionality analysis adequate?</td>
<td>E</td>
<td>E</td>
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<tr>
<td>7</td>
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<td>NA</td>
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<td>OAPS</td>
<td>URICA-VC</td>
</tr>
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<td>--------</td>
<td>------</td>
<td>----------</td>
</tr>
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<td>rater 1</td>
<td>rater 2</td>
<td>Consensus</td>
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<tr>
<td>1</td>
<td>E</td>
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<td>N</td>
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<td>G</td>
<td>G</td>
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<td>E</td>
<td>E</td>
<td>Y</td>
</tr>
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<td>NA</td>
<td>Y</td>
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<td>Lowest score of items 1-7</td>
<td>Fair</td>
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<td>Box E. Structural Validity</td>
<td>TSSES-PMI</td>
<td>WRSES</td>
<td>WSES</td>
</tr>
<tr>
<td>----------------------------</td>
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</tr>
<tr>
<td>E = Excellent; G = Good; F = Fair; P = Poor.</td>
<td>Chou et al. (2007)</td>
<td>Waghorn et al. (2000a)</td>
<td>Waghorn et al. (2000b)</td>
</tr>
<tr>
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<td>E</td>
<td>E</td>
<td>Y</td>
</tr>
<tr>
<td>Consensus</td>
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<td>E</td>
<td>Y</td>
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<tr>
<td>Y</td>
<td>E</td>
<td>G</td>
<td>N</td>
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<td>G</td>
<td>Y</td>
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<td>E</td>
<td>E</td>
<td>Y</td>
</tr>
<tr>
<td>Y</td>
<td>E</td>
<td>G</td>
<td>N</td>
</tr>
<tr>
<td>3. Was there a description of how missing items were handled?</td>
<td>F</td>
<td>F</td>
<td>Y</td>
</tr>
<tr>
<td>Consensus</td>
<td>G</td>
<td>F</td>
<td>N</td>
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<tr>
<td>F</td>
<td>F</td>
<td>Y</td>
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<tr>
<td>4. Was the sample size included in the internal consistency analysis adequate?</td>
<td>P</td>
<td>P</td>
<td>Y</td>
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<tr>
<td>Consensus</td>
<td>P</td>
<td>P</td>
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</tr>
<tr>
<td>Y</td>
<td>P</td>
<td>P</td>
<td>Y</td>
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<tr>
<td>5. Was the unidimensionality of the scale checked? i.e. was factor analysis or IRT model applied?</td>
<td>E</td>
<td>E</td>
<td>Y</td>
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<tr>
<td>Consensus</td>
<td>E</td>
<td>E</td>
<td>Y</td>
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<tr>
<td>E</td>
<td>E</td>
<td>Y</td>
<td></td>
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<td>6. Was the sample size included in the unidimensionality analysis adequate?</td>
<td>E</td>
<td>E</td>
<td>Y</td>
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<tr>
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<td>E</td>
<td>Y</td>
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<td>E</td>
<td>E</td>
<td>Y</td>
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<td>NA</td>
<td>Y</td>
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<tr>
<td>Consensus</td>
<td>NA</td>
<td>NA</td>
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<tr>
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<td>Poor</td>
<td>Poor</td>
<td>Y</td>
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<td>WVQ</td>
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<td><strong>Box E. Structural Validity</strong></td>
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<td>rater 2</td>
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<tr>
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<td>Was the percentage of missing items given?</td>
<td>G</td>
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<td>G</td>
<td>G</td>
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<tr>
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<td>Was the unidimensionality of the scale checked? i.e. was factor analysis or IRT model applied?</td>
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<td>Was the sample size included in the unidimensionality analysis adequate?</td>
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<td>NA</td>
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<tr>
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<td>Box F. Hypotheses Validity</td>
<td>VSSAS</td>
<td>TSSES-PMI</td>
<td>BECES</td>
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<tr>
<td>E = Excellent; G = Good; F = Fair; P = Poor.</td>
<td>rater 1</td>
<td>rater 2</td>
<td>Consensus</td>
</tr>
<tr>
<td>1</td>
<td>Was the percentage of missing items given?</td>
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<td>G</td>
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<td>Was there a description of how missing items were handled?</td>
<td>F</td>
<td>G</td>
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<tr>
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<td>Was the sample size included in the internal consistency analysis adequate?</td>
<td>G</td>
<td>G</td>
</tr>
<tr>
<td>4</td>
<td>Were hypotheses regarding correlations or mean differences formulated a priori (i.e. before data collection)?</td>
<td>F</td>
<td>G</td>
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<tr>
<td>5</td>
<td>Was the expected direction of correlations or mean differences included in the hypotheses?</td>
<td>G</td>
<td>E</td>
</tr>
<tr>
<td>6</td>
<td>Was the expected absolute or relative magnitude of correlations or mean differences included in the hypotheses?</td>
<td>G</td>
<td>G</td>
</tr>
<tr>
<td>7</td>
<td>for convergent validity: Was an adequate description provided of the comparator instrument(s)?</td>
<td>NA</td>
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<tr>
<td>8</td>
<td>for convergent validity: Were the measurement properties of the comparator instrument(s) adequately described?</td>
<td>NA</td>
<td>E</td>
</tr>
<tr>
<td>9</td>
<td>Were there any important flaws in the design or methods of the study?</td>
<td>E</td>
<td>F</td>
</tr>
<tr>
<td>10</td>
<td>Were design and statistical methods adequate for the hypotheses to be tested?</td>
<td>G</td>
<td>E</td>
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<tr>
<td><strong>TOTAL</strong></td>
<td><strong>Lowest score of items 1-10</strong></td>
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<tr>
<td>Box F. Hypotheses Validity</td>
<td>URICA-VC</td>
<td>WVQ</td>
<td>WoRQ</td>
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<td>G G Y</td>
<td>G G Y</td>
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<tr>
<td>Was there a description of how missing items were handled?</td>
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<td>F NA N</td>
<td>F F Y</td>
</tr>
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<td>Was the sample size included in the internal consistency analysis adequate?</td>
<td>E E Y</td>
<td>E E Y</td>
<td>E G N</td>
</tr>
<tr>
<td>Were hypotheses regarding correlations or mean differences formulated a priori (i.e. before data collection)?</td>
<td>F F Y</td>
<td>F E N</td>
<td>F F Y</td>
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<td>Was the expected direction of correlations or mean differences included in the hypotheses?</td>
<td>G G Y</td>
<td>G F N</td>
<td>G G Y</td>
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<tr>
<td>Was the expected absolute or relative magnitude of correlations or mean differences included in the hypotheses?</td>
<td>G G Y</td>
<td>G F N</td>
<td>G G Y</td>
</tr>
<tr>
<td>for convergent validity: Was an adequate description provided of the comparator instrument(s)?</td>
<td>NA F Y</td>
<td>G G Y</td>
<td>P P Y</td>
</tr>
<tr>
<td>for convergent validity: Were the measurement properties of the comparator instrument(s) adequately described?</td>
<td>NA F Y</td>
<td>G G Y</td>
<td>F F Y</td>
</tr>
<tr>
<td>Were there any important flaws in the design or methods of the study?</td>
<td>E E Y</td>
<td>E E N</td>
<td>E E Y</td>
</tr>
<tr>
<td>Were design and statistical methods adequate for the hypotheses to be tested?</td>
<td>G E N</td>
<td>F E N</td>
<td>F F Y</td>
</tr>
<tr>
<td><strong>TOTAL Lowest score of items 1-10</strong></td>
<td>Fair Fair Y</td>
<td>Fair Fair Y</td>
<td>Poor Poor Y</td>
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</table>
E = Excellent; G = Good; F = Fair; P = Poor.

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<th>Box G. Cross-Cultural Validity</th>
<th>WBI</th>
<th>WORQ</th>
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<tbody>
<tr>
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<td>Was the percentage of missing items given?</td>
<td>E</td>
</tr>
<tr>
<td>2</td>
<td>Was there a description of how missing items were handled?</td>
<td>E</td>
</tr>
<tr>
<td>3</td>
<td>Was the sample size included in the analysis adequate?</td>
<td>P</td>
</tr>
<tr>
<td>4</td>
<td>Were both the original language in which the HR-PRO instrument was developed, and the language in which the HR-PRO instrument was translated described?</td>
<td>E</td>
</tr>
<tr>
<td>5</td>
<td>Was the expertise of the people involved in the translation process adequately described? e.g. expertise in the disease(s) involved, expertise in the construct to be measured, expertise in both languages</td>
<td>G</td>
</tr>
<tr>
<td>6</td>
<td>Did the translators work independently from each other?</td>
<td>F</td>
</tr>
<tr>
<td>7</td>
<td>Were items translated forward and backward?</td>
<td>G</td>
</tr>
<tr>
<td>8</td>
<td>Was there an adequate description of how differences between the original and translated versions were resolved?</td>
<td>G</td>
</tr>
<tr>
<td>9</td>
<td>Was the translation reviewed by a committee (e.g. original developers)?</td>
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</tr>
<tr>
<td>10</td>
<td>Was the HR-PRO instrument pre-tested (e.g. cognitive interviews) to check interpretation, cultural relevance of the translation, and ease of comprehension?</td>
<td>P</td>
</tr>
<tr>
<td>11</td>
<td>Was the sample used in the pre-test adequately described?</td>
<td>NA</td>
</tr>
<tr>
<td>12</td>
<td>Were the samples similar for all characteristics except language and/or cultural background?</td>
<td>NA</td>
</tr>
<tr>
<td>13</td>
<td>Were there any important flaws in the design or methods of the study?</td>
<td>E</td>
</tr>
<tr>
<td>14</td>
<td>for CTT: Was confirmatory factor analysis performed?</td>
<td>E</td>
</tr>
<tr>
<td>15</td>
<td>for IRT: Was differential item function (DIF) between language groups assessed?</td>
<td>NA</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td></td>
<td>Poor</td>
</tr>
<tr>
<td>Item</td>
<td>rater 1</td>
<td>rater 2</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>---------</td>
<td>---------</td>
</tr>
<tr>
<td>1 Was the percentage of missing items given?</td>
<td>G</td>
<td>G</td>
</tr>
<tr>
<td>2 Was there a description of how missing items were handled?</td>
<td>G</td>
<td>G</td>
</tr>
<tr>
<td>3 Was the sample size included in the analysis adequate?</td>
<td>P</td>
<td>P</td>
</tr>
<tr>
<td>4 Were both the original language in which the HR-PRO instrument was developed, and the language in which the HR-PRO instrument was translated described?</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>5 Was the expertise of the people involved in the translation process adequately described? e.g. expertise in the disease(s) involved, expertise in the construct to be measured, expertise in both languages</td>
<td>G</td>
<td>G</td>
</tr>
<tr>
<td>6 Did the translators work independently from each other?</td>
<td>G</td>
<td>G</td>
</tr>
<tr>
<td>7 Were items translated forward and backward?</td>
<td>E</td>
<td>F</td>
</tr>
<tr>
<td>8 Was there an adequate description of how differences between the original and translated versions were resolved?</td>
<td>E</td>
<td>G</td>
</tr>
<tr>
<td>9 Was the translation reviewed by a committee (e.g. original developers)?</td>
<td>G</td>
<td>E</td>
</tr>
<tr>
<td>10 Was the HR-PRO instrument pre-tested (e.g. cognitive interviews) to check interpretation, cultural relevance of the translation, and ease of comprehension?</td>
<td>P</td>
<td>P</td>
</tr>
<tr>
<td>11 Was the sample used in the pre-test adequately described?</td>
<td>G</td>
<td>NA</td>
</tr>
<tr>
<td>12 Were the samples similar for all characteristics except language and/or cultural background? =</td>
<td>P</td>
<td>NA</td>
</tr>
<tr>
<td>13 Were there any important flaws in the design or methods of the study?</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>14 for CTT: Was confirmatory factor analysis performed?</td>
<td>P</td>
<td>NA</td>
</tr>
<tr>
<td>15 for IRT: Was differential item function (DIF) between language groups assessed?</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td><strong>TOTAL Lowest score of items 1-15</strong></td>
<td>Poor</td>
<td>Poor</td>
</tr>
<tr>
<td>Box H. Criterion Validity</td>
<td>OFS</td>
<td>WRSES</td>
</tr>
<tr>
<td>---------------------------</td>
<td>-----</td>
<td>-------</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>1 Was the percentage of missing items given?</td>
<td>G</td>
<td>G</td>
</tr>
<tr>
<td>2 Was there a description of how missing items were handled?</td>
<td>F</td>
<td>F</td>
</tr>
<tr>
<td>3 Was the sample size included in the internal consistency analysis adequate?</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>4 Can the criterion used or employed be considered as a reasonable ‘gold standard’?</td>
<td>P</td>
<td>G</td>
</tr>
<tr>
<td>5 Were there any important flaws in the design or methods of the study?</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>6 for continuous scores: Were correlations, or the area under the receiver operating curve calculated?</td>
<td>E</td>
<td>E</td>
</tr>
<tr>
<td>7 for dichotomous scores: Were sensitivity and specificity determined?</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>TOTAL Lowest score of items 1-7</td>
<td>Poor</td>
<td>Fair</td>
</tr>
<tr>
<td></td>
<td>WBI</td>
<td>WBI</td>
</tr>
<tr>
<td>---</td>
<td>-----</td>
<td>-----</td>
</tr>
<tr>
<td><strong>Box H. Criterion Validity</strong></td>
<td>rater 1</td>
<td>rater 2</td>
</tr>
<tr>
<td>1</td>
<td>Was the percentage of missing items given?</td>
<td>G</td>
</tr>
<tr>
<td>2</td>
<td>Was there a description of how missing items were handled?</td>
<td>F</td>
</tr>
<tr>
<td>3</td>
<td>Was the sample size included in the internal consistency analysis adequate?</td>
<td>P</td>
</tr>
<tr>
<td>4</td>
<td>Can the criterion used or employed be considered as a reasonable 'gold standard'?</td>
<td>E</td>
</tr>
<tr>
<td>5</td>
<td>Were there any important flaws in the design or methods of the study?</td>
<td>E</td>
</tr>
<tr>
<td>6</td>
<td>for continuous scores: Were correlations, or the area under the receiver operating curve calculated?</td>
<td>E</td>
</tr>
<tr>
<td>7</td>
<td>for dichotomous scores: Were sensitivity and specificity determined?</td>
<td>NA</td>
</tr>
<tr>
<td><strong>TOTAL Lowest score of items 1-7</strong></td>
<td>Poor</td>
<td>Poor</td>
</tr>
<tr>
<td></td>
<td>OAPS</td>
<td>CAS</td>
</tr>
<tr>
<td>---</td>
<td>------</td>
<td>-----</td>
</tr>
<tr>
<td><strong>E = Excellent; G = Good; F = Fair; P = Poor.</strong></td>
<td>Karidi et al. (2005)</td>
<td>Rogers et al. (2001)</td>
</tr>
<tr>
<td><strong>Box H. Criterion Validity</strong></td>
<td>rater 1</td>
<td>rater 2</td>
</tr>
<tr>
<td>1</td>
<td>Was the percentage of missing items given?</td>
<td>G</td>
</tr>
<tr>
<td>2</td>
<td>Was there a description of how missing items were handled?</td>
<td>F</td>
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<td>3</td>
<td>Was the sample size included in the internal consistency analysis adequate?</td>
<td>G</td>
</tr>
<tr>
<td>4</td>
<td>Can the criterion used or employed be considered as a reasonable ‘gold standard’?</td>
<td>P</td>
</tr>
<tr>
<td>5</td>
<td>Were there any important flaws in the design or methods of the study?</td>
<td>E</td>
</tr>
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<td>6</td>
<td>for continuous scores: Were correlations, or the area under the receiver operating curve calculated?</td>
<td>E</td>
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<td>7</td>
<td>for dichotomous scores: Were sensitivity and specificity determined?</td>
<td>NA</td>
</tr>
<tr>
<td><strong>TOTAL Lowes score of items 1-7</strong></td>
<td>Poor</td>
<td>Poor</td>
</tr>
<tr>
<td>Item</td>
<td>Question</td>
<td>rater 1</td>
</tr>
<tr>
<td>------</td>
<td>--------------------------------------------------------------------------</td>
<td>---------</td>
</tr>
<tr>
<td>1</td>
<td>Was the percentage of missing items given?</td>
<td>E</td>
</tr>
<tr>
<td>2</td>
<td>Was there a description of how missing items were handled?</td>
<td>F</td>
</tr>
<tr>
<td>3</td>
<td>Was the sample size included in the analysis adequate?</td>
<td>E</td>
</tr>
<tr>
<td>4</td>
<td>Was a longitudinal design with at least two measurement used?</td>
<td>E</td>
</tr>
<tr>
<td>5</td>
<td>Was the time interval stated?</td>
<td>E</td>
</tr>
<tr>
<td>6</td>
<td>If anything occurred in the interim period (e.g. intervention, other relevant events), was it adequately described?</td>
<td>G</td>
</tr>
<tr>
<td>7</td>
<td>Was a proportion of the patients changed (i.e. improvement or deterioration)?</td>
<td>E</td>
</tr>
<tr>
<td>8</td>
<td>Were hypotheses about changes in scores formulated a priori (i.e. before data collection)?</td>
<td>F</td>
</tr>
<tr>
<td>9</td>
<td>Was the expected direction of correlations or mean differences of the change scores of HR-PRO instruments included in these hypotheses?</td>
<td>G</td>
</tr>
<tr>
<td>10</td>
<td>Were the expected absolute or relative magnitude of correlations or mean differences of the change scores of HR-PRO instruments included in these hypotheses?</td>
<td>G</td>
</tr>
<tr>
<td>11</td>
<td>Was an adequate description provided of the comparator instrument(s)?</td>
<td>G</td>
</tr>
<tr>
<td>12</td>
<td>Were the measurement properties of the comparator instrument(s) adequately described?</td>
<td>P</td>
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<tr>
<td>13</td>
<td>Were there any important flaws in the design or methods of the study?</td>
<td>E</td>
</tr>
<tr>
<td>14</td>
<td>Were design and statistical methods adequate for the hypotheses to be tested?</td>
<td>P</td>
</tr>
<tr>
<td>15</td>
<td>Can the criterion for change be considered as a reasonable gold standard?</td>
<td>NA</td>
</tr>
<tr>
<td>16</td>
<td>Were there any important flaws in the design or methods of the study?</td>
<td>NA</td>
</tr>
<tr>
<td>17</td>
<td>for continuous scores: Were correlations between change scores, or the area under the Receiver Operator Curve (ROC) curve calculated?</td>
<td>NA</td>
</tr>
<tr>
<td>18</td>
<td>for dichotomous scales: Were sensitivity and specificity (changed versus not changed) determined?</td>
<td>NA</td>
</tr>
</tbody>
</table>

**TOTAL** Lowest score of items 1-18

Poor Poor Y
<table>
<thead>
<tr>
<th>Item</th>
<th>Question</th>
<th>Rater 1</th>
<th>Rater 2</th>
<th>Consensus</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Was the percentage of missing items given?</td>
<td>G</td>
<td>G</td>
<td>Y</td>
</tr>
<tr>
<td>2</td>
<td>Was there a description of how missing items were handled?</td>
<td>F</td>
<td>F</td>
<td>Y</td>
</tr>
<tr>
<td>3</td>
<td>Was the sample size included in the analysis adequate?</td>
<td>E</td>
<td>E</td>
<td>Y</td>
</tr>
<tr>
<td>4</td>
<td>Was a longitudinal design with at least two measurement used?</td>
<td>E</td>
<td>E</td>
<td>Y</td>
</tr>
<tr>
<td>5</td>
<td>Was the time interval stated?</td>
<td>E</td>
<td>E</td>
<td>Y</td>
</tr>
<tr>
<td>6</td>
<td>If anything occurred in the interim period (e.g. intervention, other relevant events), was it adequately described?</td>
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<td>F</td>
<td>Y</td>
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<td>Y</td>
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<td>P</td>
<td>Y</td>
</tr>
<tr>
<td>13</td>
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<td>E</td>
<td>Y</td>
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<tr>
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<td>E</td>
<td>Y</td>
</tr>
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<td>NA</td>
<td>NA</td>
<td>Y</td>
</tr>
<tr>
<td>16</td>
<td>Were there any important flaws in the design or methods of the study?</td>
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<td>NA</td>
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</tr>
<tr>
<td>17</td>
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<tr>
<td>18</td>
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<td>NA</td>
<td>NA</td>
<td>Y</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>Lowest score of items 1-18</td>
<td>Poor</td>
<td>Poor</td>
<td>Y</td>
</tr>
<tr>
<td></td>
<td>Box I. Responsiveness</td>
<td>rater 1</td>
<td>rater 2</td>
<td>Consensus</td>
</tr>
<tr>
<td>---</td>
<td>---------------------------------------------------------------------------------------</td>
<td>---------</td>
<td>---------</td>
<td>-----------</td>
</tr>
<tr>
<td>1</td>
<td>Was the percentage of missing items given?</td>
<td>G</td>
<td>G</td>
<td>Y</td>
</tr>
<tr>
<td>2</td>
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<td>F</td>
<td>G</td>
<td>N</td>
</tr>
<tr>
<td>3</td>
<td>Was the sample size included in the analysis adequate?</td>
<td>G</td>
<td>E</td>
<td>N</td>
</tr>
<tr>
<td>4</td>
<td>Was a longitudinal design with at least two measurement used?</td>
<td>E</td>
<td>E</td>
<td>Y</td>
</tr>
<tr>
<td>5</td>
<td>Was the time interval stated?</td>
<td>E</td>
<td>E</td>
<td>Y</td>
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<td>If anything occurred in the interim period (e.g. intervention, other relevant events), was it adequately described?</td>
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<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>7</td>
<td>Was a proportion of the patients changed (i.e. improvement or deterioration)?</td>
<td>E</td>
<td>E</td>
<td>Y</td>
</tr>
<tr>
<td>8</td>
<td>Were hypotheses about changes in scores formulated a priori (i.e. before data collection)?</td>
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<td>E</td>
<td>N</td>
</tr>
<tr>
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<td>Y</td>
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<td>G</td>
<td>Y</td>
</tr>
<tr>
<td>11</td>
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<td>P</td>
<td>P</td>
<td>Y</td>
</tr>
<tr>
<td>12</td>
<td>Were the measurement properties of the comparator instrument(s) adequately described?</td>
<td>P</td>
<td>P</td>
<td>Y</td>
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<tr>
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<td>Were there any important flaws in the design or methods of the study?</td>
<td>E</td>
<td>E</td>
<td>Y</td>
</tr>
<tr>
<td>14</td>
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<td>E</td>
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<tr>
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<td>NA</td>
<td>Y</td>
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<tr>
<td>16</td>
<td>Were there any important flaws in the design or methods of the study?</td>
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<td>17</td>
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<td>NA</td>
<td>N</td>
</tr>
<tr>
<td>18</td>
<td>for dichotomous scales: Were sensitivity and specificity (changed versus not changed) determined?</td>
<td>NA</td>
<td>NA</td>
<td>Y</td>
</tr>
</tbody>
</table>

**TOTAL** Lowest score of items 1-18

|   | Poor | Poor | Y         |

E = Excellent; G = Good; F = Fair; P = Poor.
Appendix 7 Items that incorporate Biosocial Model
(Chapter 2)

<table>
<thead>
<tr>
<th>Author and Scale</th>
<th>Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tsang &amp; Pearson (2000) VSSAS</td>
<td><strong>Behavioural Instability (n = 3)</strong></td>
</tr>
<tr>
<td></td>
<td>- Make an appointment over phone for a job interview</td>
</tr>
<tr>
<td></td>
<td>- Participate appropriately in a job interview</td>
</tr>
<tr>
<td></td>
<td>- Dress appropriately to attend a job interview</td>
</tr>
<tr>
<td></td>
<td><strong>Interpersonal Instability (n = 7)</strong></td>
</tr>
<tr>
<td></td>
<td>- Request urgent leave from supervisor</td>
</tr>
<tr>
<td></td>
<td>- Resolve a conflict with a supervisor</td>
</tr>
<tr>
<td></td>
<td>- Resolve a conflict with a colleague</td>
</tr>
<tr>
<td></td>
<td>- Avoid involvement in destructive gossip</td>
</tr>
<tr>
<td></td>
<td>- Co-operate with colleagues to perform a group task</td>
</tr>
<tr>
<td></td>
<td>- Refuse request from supervisor to work overtime when you have family responsibility or previous commitment</td>
</tr>
<tr>
<td></td>
<td>- Help to instruct or demonstrate a task to a new colleague</td>
</tr>
<tr>
<td>Tsang &amp; Chiu (2000) WBC</td>
<td><strong>Behavioural Instability (n = 8)</strong></td>
</tr>
<tr>
<td></td>
<td>- Hygiene and dress</td>
</tr>
<tr>
<td></td>
<td>- Irritating habits</td>
</tr>
<tr>
<td></td>
<td>- Odd behaviours</td>
</tr>
<tr>
<td></td>
<td>- Communication skills</td>
</tr>
<tr>
<td></td>
<td>- Attendance</td>
</tr>
<tr>
<td></td>
<td>- Punctuality</td>
</tr>
<tr>
<td></td>
<td>- Reactions to change in work assignment</td>
</tr>
<tr>
<td></td>
<td>- Reaction to unpleasant or monotonous tasks</td>
</tr>
<tr>
<td></td>
<td><strong>Interpersonal Instability (n = 6)</strong></td>
</tr>
<tr>
<td></td>
<td>- Amount of supervision after initial instruction period</td>
</tr>
<tr>
<td></td>
<td>- Accepts supervisory authority</td>
</tr>
<tr>
<td></td>
<td>- Tension at close supervision</td>
</tr>
<tr>
<td></td>
<td>- Requests for supervisor’s assistance</td>
</tr>
<tr>
<td></td>
<td>- Reaction to criticism and pressure</td>
</tr>
<tr>
<td></td>
<td>- Social skills with co-workers</td>
</tr>
<tr>
<td>Potkins et al. (2016) WoRQ</td>
<td><strong>Behavioural Instability (n = 7)</strong></td>
</tr>
<tr>
<td></td>
<td>- The patient generally adheres to a treatment plan, including medication.</td>
</tr>
<tr>
<td></td>
<td>- The patient is able to carry out activities of daily living.</td>
</tr>
<tr>
<td></td>
<td>- The patient is able to consistently keep appointments and schedules with only minimal assistance.</td>
</tr>
<tr>
<td></td>
<td>- The patient would have adequate impulse control when interacting with authority figures, peers or coworkers, and potential customers.</td>
</tr>
<tr>
<td></td>
<td>- The patient's behavior would not make others uncomfortable in a work situation.</td>
</tr>
<tr>
<td></td>
<td>- The patient's appearance would not make others uncomfortable in a work situation.</td>
</tr>
<tr>
<td></td>
<td>- The patient's current symptoms would not interfere with the ability to hold a job. Based on your clinical judgment, is this patient ready for work?</td>
</tr>
<tr>
<td><strong>Bryson et al. (1997) WBI</strong></td>
<td><strong>Behavioural Instability (n=12)</strong></td>
</tr>
<tr>
<td>---------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td></td>
<td>C1. Comes to work on time.</td>
</tr>
<tr>
<td></td>
<td>C2. Begins work tasks promptly.</td>
</tr>
<tr>
<td></td>
<td>C3. Follows rules and standards on the job.</td>
</tr>
<tr>
<td></td>
<td>C4. Takes breaks only when scheduled.</td>
</tr>
<tr>
<td></td>
<td>C5. Individual tasks are down within given time frame.</td>
</tr>
<tr>
<td></td>
<td>C6. Maintains pace once work is started.</td>
</tr>
<tr>
<td></td>
<td>C7. Takes initiative when work is available.</td>
</tr>
<tr>
<td></td>
<td>E3. Refrains from inappropriate joking and profanity.</td>
</tr>
<tr>
<td></td>
<td>E4. Personal hygiene is satisfactory.</td>
</tr>
<tr>
<td></td>
<td>E5. Comes to work appropriately dressed.</td>
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<td></td>
<td>E6. Refrains from saying irrelevant things.</td>
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**Interpersonal Instability (n =14)**

<p>| | |</p>
<table>
<thead>
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<tr>
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</tr>
<tr>
<td>A2</td>
<td>Seems comfortable when approached by others.</td>
</tr>
<tr>
<td>A3</td>
<td>Joins social groups when available.</td>
</tr>
<tr>
<td>A4</td>
<td>Appears interested in others.</td>
</tr>
<tr>
<td>A5</td>
<td>Expresses positive feelings appropriately.</td>
</tr>
<tr>
<td>A6</td>
<td>Maintains positive relationships with co-workers.</td>
</tr>
<tr>
<td>A7</td>
<td>Expresses negative feelings appropriately.</td>
</tr>
<tr>
<td>B1</td>
<td>Works comfortably in the presence of others</td>
</tr>
<tr>
<td>B2</td>
<td>Accepts constructive criticism without becoming upset.</td>
</tr>
<tr>
<td>B3</td>
<td>Listens attentively to directions.</td>
</tr>
<tr>
<td>B4</td>
<td>Follows directions without resistance.</td>
</tr>
<tr>
<td>B5</td>
<td>Listens without interrupting when given instructions.</td>
</tr>
<tr>
<td>B6</td>
<td>Cooperates with co-workers on the job.</td>
</tr>
<tr>
<td>B7</td>
<td>Asks questions when confused.</td>
</tr>
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**Bull et al. (2015) WBI**

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<th><strong>Behavioural Instability (n = 9)</strong></th>
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<td></td>
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<td></td>
<td>E5. Comes to work appropriately dressed.</td>
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<td>E6. Refrains from saying irrelevant things.</td>
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**Interpersonal Instability (n = 13)**

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<tbody>
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<td>B5</td>
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<td>B6</td>
<td>Cooperates with co-workers on the job.</td>
</tr>
<tr>
<td>B7</td>
<td>Asks questions when confused.</td>
</tr>
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<td>Category</td>
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<td>Hannula et al. (2006)</td>
<td>Behavioural Instability (n=1)</td>
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<td>OFS</td>
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<td>Finger et al. (2014)</td>
<td>Behavioural Instability (n = 2)</td>
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<tr>
<td>WORQ</td>
<td>18. “...starting and completing a single task such as making your bed or cleaning up your desk or workplace?”</td>
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<tr>
<td></td>
<td>19. “...carrying out your daily routine or day to day activities?”</td>
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<tr>
<td>Interpersonal Instability (n= 1)</td>
<td>31. “…relationships with people?”</td>
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<tr>
<td></td>
<td>22. “…starting and maintaining a conversation?”</td>
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<tr>
<td>Self-Instability (n= 1)</td>
<td>36. “In the situation of vocational rehabilitation, to what extent does your client have problems with......Appropriate expression of temperament and personality?” (clinician reported)</td>
</tr>
<tr>
<td>Cognitive Instability (n=3)</td>
<td>7 “…analyzing and finding solutions to problems in day to day life?”</td>
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<tr>
<td></td>
<td>6. “…thinking clearly?”</td>
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<tr>
<td></td>
<td>7 “…analyzing and finding solutions to problems in day to day life?”</td>
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<tr>
<td>Biological/Emotional Vulnerability (Affective Instability) (n =2)</td>
<td>4 … your usual daily activities because you felt sad or depressed?</td>
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<tr>
<td></td>
<td>5. “…your usual daily activities because you felt worried or anxious?”</td>
</tr>
<tr>
<td>Environment (n= 2)</td>
<td>15. “In your current situation, do you get the support you need from your family? Yes/No, If yes, please specify what kind of support you get:'</td>
</tr>
<tr>
<td></td>
<td>16. “If still employed, do you get the support you need from your supervisor or boss? Yes/No, If yes, please specify what kind of support you get:’</td>
</tr>
<tr>
<td>Corbière et al. (2004)</td>
<td>Behavioural Instability (n = 2)</td>
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<td>BECES</td>
<td>Low success rate at previous work experience (e.g., job loss)</td>
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<td>Low productivity in workplace</td>
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<td>Interpersonal Instability (n= 3)</td>
<td>Difficulties interacting with others</td>
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<td>Difficulties working with others</td>
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<td>Asserting oneself with co-workers</td>
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<td></td>
<td>Cognitive Instability (n=1)</td>
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<td></td>
<td>Lack of self-confidence</td>
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<td>Emotional Vulnerability (Affective Instability) (n =1)</td>
<td>Anxiety or fears</td>
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<td>Environment (n= 13)</td>
<td>Job market instability</td>
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<td></td>
<td>Lack of job opportunities in your field</td>
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<td></td>
<td>High unemployment rate</td>
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<td></td>
<td>Competition in workplace</td>
</tr>
<tr>
<td>Study</td>
<td>Behavioural Instability (n = 1)</td>
</tr>
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<td>---------------</td>
<td>------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Waghorn 2005b</td>
<td>17. Too inactive</td>
</tr>
<tr>
<td>WSES</td>
<td>Cognitive Instability (n= 10)</td>
</tr>
<tr>
<td></td>
<td>1. Too many thoughts</td>
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<tr>
<td></td>
<td>13. Worried about money</td>
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<tr>
<td></td>
<td>19. Feeling hopeless</td>
</tr>
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<td></td>
<td>20. Low confidence</td>
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<td></td>
<td>22. Bothered by unusual thoughts</td>
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<td></td>
<td>23. Bothered by unusual beliefs</td>
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<td></td>
<td>24. Bothered by unusual experiences</td>
</tr>
<tr>
<td></td>
<td>25. Feeling suspicious</td>
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<tr>
<td></td>
<td>33. Worried about my appearance</td>
</tr>
<tr>
<td></td>
<td>36. No one understands me</td>
</tr>
<tr>
<td></td>
<td>Interpersonal Instability (n= 5)</td>
</tr>
<tr>
<td></td>
<td>9. Difficulty understanding people</td>
</tr>
<tr>
<td></td>
<td>30. Problems with family or friends</td>
</tr>
<tr>
<td></td>
<td>31. Uncomfortable with others</td>
</tr>
<tr>
<td></td>
<td>34. Difficulty talking to others</td>
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<tr>
<td></td>
<td>35. Trouble recognising people</td>
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<tr>
<td></td>
<td>Biological/Emotional Vulnerability (Affective Instability) (n= 4)</td>
</tr>
<tr>
<td></td>
<td>12. Too irritable</td>
</tr>
<tr>
<td></td>
<td>28. Afraid of losing self-control</td>
</tr>
<tr>
<td></td>
<td>33. Worried about my appearance</td>
</tr>
<tr>
<td></td>
<td>15. Feeling worried, nervous or afraid</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Study</th>
<th>Environment (n= 17)</th>
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</thead>
<tbody>
<tr>
<td>Corner et al. 1997 WEIS</td>
<td>TIME DEMANDS: Time allotted for available expected amount of work.</td>
</tr>
<tr>
<td></td>
<td>TASK DEMANDS: The physical, cognitive, and/or emotional demands of opportunities of work tasks.</td>
</tr>
<tr>
<td>Stewart et al. (2010) APQ6</td>
<td>Behavioural Instability (n = 5)</td>
</tr>
<tr>
<td>---------------------------</td>
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<tr>
<td></td>
<td>Q1. Participation in employment in past week</td>
</tr>
<tr>
<td></td>
<td>Q2. Looking for work</td>
</tr>
<tr>
<td></td>
<td>Q3. Participation in unpaid work in past week</td>
</tr>
<tr>
<td></td>
<td>Q4. Participation in study or training in past week</td>
</tr>
<tr>
<td></td>
<td>Q5. Participation in general community activities in past week</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Zaniboni et al. (2010) WVQ</th>
<th>Behavioural instability (n= 4)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Poursuivre votre action malgré des obstacles de toutes sortes; Carry on in spite of all sorts of obstacles</td>
</tr>
<tr>
<td></td>
<td>Participer à des activités bien organisées; Participate in well-organized activities</td>
</tr>
<tr>
<td></td>
<td>Vous attaquer à des problèmes qui semblent sans solution; Grapple with problems that seem unsolvable</td>
</tr>
</tbody>
</table>
Entreprendre une action au risque d’être blâmé(e);
*Undertake to act even though you risk being blamed*

**Interpersonal Instability**
- Etre accepté(e) facilement par les gens avec qui vous travaille; *Be readily accepted by the people you work with*

**Self Instability (n=30)**
(all items)

**Environment (n=4)**
- Avoir affaire à un patron compréhensif; *Have an understanding boss*
- Etre dans un milieu bien organisé et bien équipé; *Be in a well-organized and well-equipped setting*
- Evoluer dans un milieu physique plaisant; *Be in pleasant surroundings*
- Etre placé(e) dans des situations menaçantes; *Be placed in threatening situations*
Appendix 8 Ethical Approval Letter (Chapter 3 and 4)

Reissue 02.02.2016

Health Research Authority

26 January 2016

Dear [Name]


REC reference: 15/WM/0466

IRAS project ID: 192384

Thank you for your letter responding to the Committee’s request for further information on the above research and submitting revised documentation. The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.
Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).


Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact: [Contact Details]. If the HRA does not, however, expect exceptions to be made.

Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management
Reissue 02.02.2016

permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Copies of advertisement materials for research participants [Focus Group Flyer for Clients]</td>
<td>Version 10</td>
<td>05 January 2016</td>
</tr>
<tr>
<td>Copies of advertisement materials for research participants [Focus Group Flyer for Friends and Family]</td>
<td>Version 10</td>
<td>05 January 2016</td>
</tr>
<tr>
<td>Copies of advertisement materials for research participants [Focus Group Flyer for Employers]</td>
<td>Version 10</td>
<td>05 January 2016</td>
</tr>
<tr>
<td>Copies of advertisement materials for research participants [Pilot Questionnaire Flyer]</td>
<td>Version 11</td>
<td>26 January 2016</td>
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<tr>
<td>Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Letter of sponsor]</td>
<td>Version 3</td>
<td>12 August 2015</td>
</tr>
<tr>
<td>Interview schedules or topic guides for participants [Focus group questions]</td>
<td>Version 3</td>
<td>12 August 2015</td>
</tr>
<tr>
<td>Letter from funder [Letter from Funder]</td>
<td>Version 3</td>
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</tr>
<tr>
<td>Non-validated questionnaire [Pilot questionnaire feedback form]</td>
<td>Version 10</td>
<td>05 January 2016</td>
</tr>
<tr>
<td>Non-validated questionnaire [Demographics Form]</td>
<td>Version 10</td>
<td>05 January 2016</td>
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<tr>
<td>Non-validated questionnaire [Member Checking Contact Sheet for Focus Group]</td>
<td>Version 10</td>
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<tr>
<td>Non-validated questionnaire [Travel reimbursement form for Friends and Family Focus Group]</td>
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<tr>
<td>Non-validated questionnaire [Payment address form for Pilot Questionnaire]</td>
<td>Version 10</td>
<td>05 January 2016</td>
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<td>Other [Self-Help Handouts for Focus Group]</td>
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<td>Other [Self-Help Handouts for Pilot Questionnaire]</td>
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<tr>
<td>Other [Response to PO covering letter]</td>
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<td>Participant consent form [Participant Consent Form Focus Group]</td>
<td>Version 10</td>
<td>05 January 2016</td>
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<tr>
<td>Participant information sheet (PIS) [Participant Information Sheet for Staff about Client Focus Group]</td>
<td>Version 10</td>
<td>05 January 2016</td>
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<tr>
<td>Participant information sheet (PIS) [Participant Information Sheet for Focus Group (Clients)]</td>
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<td>05 January 2016</td>
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<tr>
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Reissue 02.02.2016

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<td>REC Application Form [REC_Form_25112015]</td>
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<td>Research protocol or project proposal [Ethics Protocol]</td>
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<td>12 November 2015</td>
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<tr>
<td>Summary CV for Chief Investigator (CI) [Summary CV for CI]</td>
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<td>10 August 2015</td>
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Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

15/WIM/0466 Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project.

Yours sincerely
Reissue 02.02.2016

Chair

Email

Enclosures: “After ethical review – guidance for researchers” [SL-AR2]

Copy to:
Preparedness for Employment Scale for people with Personality Disorders (PES-PD): Focus Group or Semi-Structured Interview

We would like to invite you to take part in a focus group (group discussion) or a semi-structured interview. This sheet will give you some information about why we are running the focus group/interview, what you would be asked to do if you decide to take part, and how the focus group/interview will be conducted. You are very welcome to ask any further questions about the study, or if you find that any of the information provided is unclear.

1) The purpose of the focus group
A focus group is a group of people who come together to discuss ideas and opinions on a chosen topic. Listening to other people’s experiences or views can sometimes prompt new ideas that emerge from the discussion. Therefore, running a group discussion about employment can help us understand the obstacles and supports for people with a personality disorder in obtaining and retaining employment. The new ideas will be used to help us develop a questionnaire which we hope will: (1) help individuals to make decisions about when to enter employment, (2) help clinicians/employment staff identify what supports the individual will need to gain employment, (3) allow us to measure the outcome of interventions designed to help people gain and retain employment and (4) help us to give advice to employers about what support may be needed.

2) Why have I been invited?
You have been invited to take part in the study because you are an individual with a diagnosis of a personality disorder and are seeking employment, are employed or are unemployed. We feel that you would be able to help us think about issues and supports that you may face, when seeking, obtaining and retaining employment.

3) Do I have to take part in the focus group or semi-structured interview?
No, you do not have to take part. It is up to you to decide whether you wish to take part or not. Deciding not to take part in the study will not affect the care you receive from services either now or in the future.
If you do consent to take part, you are still free to stop participating in the group discussion at any time, without having to give a reason. If you wish to participate but do not want to join a group discussion, there is an alternative option to complete a semi-structured interview.

4) What will happen if you do choose to take part in the focus group/semi-structured interview?
If you wish to take part in the study, please notify EMPOWER by emailing: EMPOWER@nelft.nhs.uk or phone: 0300 555 1213 with your name and contact details.
A member of EMPOWER will ring or email you (depending on your preference for being contacted) to confirm your participation and to offer the opportunity to ask questions.
The day before the focus group/semi-structured interview takes place, we will call to remind you of the time and place. You will meet Leng Song and another member of EMPOWER staff at the
focus group/semi-structured interview. At the start of the focus group/semi-structured interview, you will be given the same information sheet to re-read and will be asked to sign a consent form.

The focus group/semi-structured interview will be audio recorded in order to transcribe the information for research purposes. Those who do not consent to be audio-recorded will be unable to participate. You will also be asked to complete a form which asks some questions about your age, gender, education, and employment experience. You do not need to write your name on these forms as the information you provide us will be anonymous.

During the group discussion or semi-structured interview we will guide you in thinking and discussing ideas regarding the challenges of obtaining and retaining employment. The discussion will take up to about 1.5 hours. At the end of the session you will be asked whether you would like to be involved in a corrective and clarity process. This involves reading an anonymised summary of information from the group discussion. The anonymous information will be summarised into themes (e.g. attitudes of my family to my seeking work). You will be asked to add additional information, correct any misinformation and confirm the interpretation of the theme is correct. This is an optional task; you are in no way obliged to complete this. If you agree to take part in this process you will receive the written summary either by email or post.

Your email address or postal address will be stored in a password protected document on secure NHS computers and deleted once the information has been sent to you. At the end of the focus group or interview you will receive a £15 high street voucher to show our gratitude for your time and travel. After the research is completed you will be invited to an optional presentation about the main findings in the future.

5) Will my information be kept confidential?
Yes, all information provided by you will be kept confidential. All of the discussion information you provide will be anonymised, so that you cannot be identified. Any quotes that you provide which are used in the published research will also be anonymised. If you choose to participate in the corrective process we will ensure your personal details will be kept separately from the transcriptions and stored in a password protected document on a secure NHS computer at North East London NHS Foundation Trust (NELFT).

In accordance with current NELFT Records Management Policy, research findings will need to be stored by NELFT as sponsor for 20 years after the research has finished. The NELFT Records Office provides a service to NEFLT staff and maintains archived records in a safe and secure off site location. All activities are conducted in accordance with the Data Protection Act 1998 and NELFT Data Protection Policy. Access to the data is strongly regulated and only members of the research team will have the right to use.

6) What are the possible benefits of taking part?
The information gathered during this group discussion will better inform our understanding of the experiences of individuals with PD and employment. This information will allow us to develop a useful scale and develop services in the future. We hope that you will find it helpful or interesting to talk about your experiences of seeking, obtaining and retaining employment.

7) What are the possible disadvantages to taking part?
People who have recently experienced difficulties in obtaining a job, losing a job or are having current difficulties at work may experience some distress when participating in the group discussion.

A second member of the EMPOWER study team will be present during the group discussion if you do become distressed, and will be able to support you. In addition, we will provide information on how to stay safe if distressed and who to contact; this includes a self-help handout of guided mindfulness, visualisation techniques, distraction and self-soothe techniques, and other support numbers before the focus group. If the distress is ongoing we would encourage you to contact your therapist (if you have one) or GP.

8) Expenses and payments
As stated above, at the end of the focus group or interview, you will receive a £15 high street voucher to express our gratitude for your time and travel.

9) What will happen to the results of the focus group or semi-structured interview?
The focus group is part of a larger study which aims to help people with PD gain employment. The information from the focus groups will help us to design a scale to help us measure readiness for employment in PD clients. This scale will be used in the larger study, which will be completed in autumn 2019. Additionally, the anonymised results of the focus group/semi-structured interview will be presented in a doctoral thesis, will be published in a scientific journal, and presented at national or international conferences.
Lastly, once the scale is fully developed it will be distributed across NHS Trusts across the UK. If you wish to be invited to a feedback meeting, where the results of the study will be presented, please tick the statement on the member checking form. We will send you a letter of invite with the details.

10) Who has reviewed the study?
The study has been reviewed by the National Institute for Health Research (NIHR) who have funded the study. The study has been granted ethical approval by the South Birmingham Research Ethics Committee.

Contact Details:
If you wish to discuss any of the information further, then please contact Leng Song on: 0300 555 1213. Please be aware that the EMPOWER research team have a duty of care to all participants. Therefore if we are concerned about your safety or the safety of other participants, the researchers will first speak you, and then inform their supervisors who will inform relevant healthcare professionals.
If you feel that this information sheet has not addressed your concerns adequately, or if you have any concerns about the study’s conduct, then please contact:

Dr. Janet Feigenbaum, Strategic and Clinical Lead for Personality Disorder Services, North East London NHS Foundation Trust and Senior Lecturer, Research Department of Clinical, Educational and Health Psychology, University College London.
Email: janet.feigenbaum@nhs.net
Work Office: 0300 555 1213.

Thank you very much for taking the time to read this information sheet. Please ask if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you would wish to take part.
We would like to invite you to take part in a focus group (group discussion) or a semi-structured interview. This sheet will give you some information about why we are running the focus group/ interview, what you would be asked to do if you decide to take part, and how the focus group or interview will be conducted. You are very welcome to ask any further questions about the study, or if you find that any of the information provided is unclear.

1) The purpose of the study
A focus group is a group of people who come together to discuss ideas and opinions on a chosen topic. Listening to other people’s experiences or views can sometimes prompt new ideas that emerge from the discussion. Therefore running a group discussion about employment can help us understand the obstacles and supports for people with a personality disorder in obtaining and retaining employment. The value of doing this as a group discussion is, new ideas may emerge, which are prompted by hearing other people’s experiences or views. The new ideas will be used to help us develop a questionnaire which we hope will: (1) help individuals make decisions about when to enter employment, (2) help clinicians/employment staff identify what supports the individual will need to gain employment, (3) allow us to measure the outcome of interventions designed to help people gain and retain employment and (4) help us to give advice to employers about what support may be needed.

2) Why have I been invited?
You have been invited to take part in the study because you are a family member or friend of an individual with a diagnosis of a PD. We feel that you would be able to help us think about issues and supports that people with personality disorders face when seeking, obtaining and retaining employment.

3) Do I have to take part in the focus group or semi-structured interview?
No, you do not have to take part in the focus group/semi-structured interview. It is up to you to decide whether you wish to take part or not. Deciding not to take part in the study will not affect the care you receive from services, or the care received by the person who recommended you, either now or in the future. If you do consent to take part, you are still free to stop participating in the group discussion at any time, without having to give a reason. If you wish to participate but do not want to join a group discussion, there is an alternative option to complete a semi-structured interview.

4) What will happen if you do choose to take part in the focus group/semi-structured interview?
If you wish to take part in the study, please notify EMPOWER by emailing: EMPOWER@nelft.nhs.uk or phone 0300 555 1213 with your name and contact details. A member of EMPOWER will ring or email you (depending on your preference for being contacted) to confirm your participation and to offer the opportunity to ask questions. The day before the focus group or semi-structured interview takes place, we will call to remind. You will meet Leng Song and another member of EMPOWER staff at the focus group/semi-structured interview. At the start of the focus group/semi-structured interview, you will be given the same information sheet to re-read and will be asked to sign an informed consent sheet. The focus group/semi-structured interview will be audio recorded in order to transcribe the information for research purposes. Those who do not consent to be audio-recorded will be unable to participate. You will also be asked to complete a demographics form which will ask questions about your age, gender, education, and employment history. You do not need to write your name on these forms as the information you provide us will be anonymous. During the group discussion or semi-structured interview we will guide you in thinking and discussing ideas regarding the challenges of obtaining and retaining employment. The discussion will take up to about 1-1.5 hours. At the end of the session you will be asked whether you would like to be involved in a corrective and clarity process. This involves reading an anonymised summary of information from the group discussion. The anonymous information will be summarised into themes (e.g. attitudes of my family to my seeking work). You will be asked to add additional information, correct any misinformation and confirm the interpretation of the theme is correct. This is an optional task; you are in no way obliged to complete this. If you agree to take part in this process you will receive the written summary either by email or post. Your email address or postal address will be stored in a password protected document on secure NHS computers and deleted once the information has been sent to you. After the research is completed you will be invited to an optional presentation about the main findings in the future (in approximately two years).

5) Will my information be kept confidential?
Yes, all information provided by you will be kept confidential. All of the discussion information you provide will be anonymised, so that you cannot be identified. Any quotes that you provide which are used in the published research will also be anonymised. If you choose to participate in the corrective process we will ensure that your personal details will be kept separately from the transcriptions and stored in a password protected document on a secure NHS computer at North East London NHS Foundation Trust (NELFT). All travel reimbursement address forms (see 8) Travel Expenses) will be stored in the same manner as the corrective process personal details.

In accordance with current NELFT Records Management Policy, research findings will need to be stored by NELFT as sponsor for 20 years after the research has finished. The NELFT Records Office provides a service to NELFT staff and maintains archived records in a safe and secure off site location. All activities are conducted in accordance with the Data Protection Act 1998 and NELFT Data Protection Policy. Access to the data is strongly regulated and only members of the research team will have the right to use.

6) What are the possible benefits of taking part?
We hope that you will find it helpful or interesting to discuss your ideas of your loved ones’ experiences of seeking, obtaining and retaining employment. The information gathered during this group discussion will better inform our understanding of the experiences of individuals with PD and employment, which will allow us to develop a useful scale and services in the future.

7) What are the possible disadvantages to taking part?
Those who have had recent experiences of supporting a loved one with a PD who may be finding it difficult to obtain a job, have recently lost a job or are having current difficulties at work may experience some distress when participating in group discussions. A second member of the EMPOWER research team will be present during the group discussions if you do become distressed and will be able to support you. We will provide information on how to stay safe if distressed and whom to contact, this includes a self-help handout of guided mindfulness, visualisation, distraction, and self-soothe techniques, and other support numbers before the focus group. If the distress is ongoing we would encourage you to contact your GP.

8) Travel Expenses
We understand that your time is important and are therefore offering a travel expense reimbursement. After the focus group/semi-structured interview, you will be asked for the address in which you would like your travel expense reimbursement sent to. We would also need a receipt of your travels as we will not be able to reimburse you otherwise. If you do not have the travel receipt with you, we can still reimburse your travel expenses by giving you a self-addressed envelope, with the travel reimbursement address form. You can then send your travel receipts and address form back to EMPOWER.

9) What will happen to the results of the research study?
The focus group is one part of a larger study which aims to help people with PD gain employment. The information from the focus groups will help us to design a scale to help us measure readiness for employment in PD clients. This scale will be used in the larger study, which will be completed in autumn 2019. Additionally, the anonymised results of the focus group/semi-structured interview will be presented in a doctoral thesis, will be published in a scientific journal, and presented at national or international conferences. Lastly, once the scale is fully developed, it will be distributed across NHS Trusts across the UK.

If you wish to be invited to a feedback meeting, where the results of the study will be presented, please tick the statement on the member checking form. We will send you a letter of invite with the details at a later date (in approximately two years).

10) Who has reviewed the study?
The study has been reviewed by the National Institute for Health Research (NIHR) who have funded the study. The study has been granted ethical approval by South Birmingham Research Ethics Committee.

Contact Details:
If you wish to discuss any of the information further then please contact [Contact Information]. Please be aware that the EMPOWER research team have a duty of care to all participants. Therefore if we are concerned about your safety or the safety of other participants, the researchers will first speak you, and then inform their supervisors who will inform relevant healthcare professionals.

If you feel that I have not addressed your concerns adequately or if you have any concerns about my conduct, then please contact:

[Contact Information]

Thank you very much for taking the time to read this information sheet. Please ask if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you would wish to take part.
Appendix 11 HCP Information Sheet (Chapter 3)

Preparedness for Employment Scale for people with Personality Disorders (PES-PD): Focus Group and/or Semi-Structured Interviews

What is EMPOWER?
The EMPOWER study is a National Institute for Health Research (NIHR) funded project focused on helping to motivate and enable people with Personality Disorder (PD) gain employment. While there are tools available to help Healthcare professionals assess readiness for work in terms of physical ailment, no such tools are available for people with PD. One of the aims of our project is to develop a means to assess readiness for work in this client group by creating a new questionnaire.

Why do we need to conduct a focus group?
The creation of the new questionnaire relies on the valuable input from different groups of people. We are speaking with healthcare professionals, third sector mental health staff, job centre staff, employers, the friends and family of PD clients and the PD clients themselves. Hearing from everyone will help us to build a clear picture of what the barriers and enablers are to employment activity for people with PD. Focus groups allow us to capture very rich information that would not be possible through the distribution of a questionnaire. We would like to run a focus group with your PD clients only (the groups will not be mixed) to help us better understand what obstacles and supports they encounter when seeking, obtaining and retaining employment.

We believe your clients’ views and experiences from the focus group will:
- Help us to develop an intervention to support people with PD gain and retain a job.
- Help us to develop a questionnaire that we hope will identify challenges and supports for people with PD gain and retain employment.
- Help us to develop a positive booklet for employers to use to better support people with PD in the workplace.

Who can take part?
We would like to hear from clients with a PD who are at different stages of employment; seeking employment, in the process of obtaining employment, or currently in employment. The important thing is we speak with people who are interested in talking about employment.

How ill taking part benefit my client?
We hope your client will find it helpful and interesting to discuss their experiences of seeking, obtaining and retaining employment. We also understand your clients’ time is important and would like to offer them a £15 high street store voucher to compensate them for their time and travel expenses.

What will my client need to do?
If your client wishes to take part in the study, they should be encouraged to contact the Research Worker, [name], who is based at Goodmayes Hospital in North East London NHS Foundation Trust (NELFT). [name] will then arrange for your client to attend a focus group at
Goodmayes Hospital or a convenient location in Hertfordshire. If they have not received an information sheet they will be sent one through the post. The focus group or semi-structured interview (should your client express strong preference), will be conducted by Leng Song and an additional member of the EMPOWER research team. At the start of the session (focus group/semi-structured interview) your client will be given the information sheet to re-read and asked to complete the informed consent sheet.

During the session Leng Song will guide the group/individual in thinking and discussing ideas regarding seeking, obtaining and retaining employment. The discussion will last for 1-1.5 hours. At the end of the session clients will be asked whether they would like to be involved in a corrective and clarity process regarding the information collected from the session. The corrective process involves inviting the client to read transcript summaries of the session. The information will be summarised into themes and your client will be asked to add additional information, correct any misinformation and confirm the interpretation of the theme is correct. This is an optional task; clients are in no way obliged to complete this. If your client agrees to take part in this process they will receive the transcript summaries either by email or post.

**What are the disadvantages for my clients?**

We do not expect there will be a specific disadvantage to your client taking part, however we anticipate talking about employment may be upsetting for some people. It may be that those clients who have had difficulty obtaining a job, have lost a job or are having difficulties at work presently may experience some distress when participating in the session.

All sessions will be facilitated by Ms Leng Song and be co-facilitated by a second member of the EMPOWER research team. Each member of the EMPOWER research team has experience of working with clients with PD and are trained in how to support clients should they become distressed. Your client is able to leave the session at any time and does not need to give a reason for their withdrawal. At the beginning of the session we will give self-help support sheets with information on how to stay safe if distressed and a supports number sheet containing contact details of organisations equipped to provide telephone support. If the client experiences ongoing or prolonged distress they will be encouraged to contact you or their GP.

**Does my client have to take part?**

No, taking part in the study is voluntary. Similarly, if your client enters into the study and subsequently withdraws then there will be no penalty. All clients are able to leave the session at any time and do not need to give a reason for their withdrawal. The EMPOWER team will remind clients that deciding to withdraw from the study will not affect the care they receive from services presently or in the future.

**What do I need to do?**

We are conscious you are very busy and would like to remind you that we are incredibly grateful for any help you may be able to offer. Leng Song will provide you with flyers and information sheets for you to pass onto clients you think may be interested in taking part. Interested clients are welcome to contact the EMPOWER team directly using the information in the flyers and information sheets. Where your client gives permission, you are very welcome to provide their contact details to the EMPOWER team who will contact your client directly. Alternatively, you are welcome to RSVP on behalf of your client.

**Data Protection**

The discussion will be audio recorded, anonymised, transcribed, stored electronically, and password protected at Goodmayes Hospital in NELFT.

**Contact Details**

If you wish to contact Ms Leng Song to discuss any aspect of this study in more detail then please email EMPOWER@nelft.nhs.uk or telephone 0300 555 1213.

Thank you very much for taking the time to read this information sheet. If you feel that I have not addressed your concerns adequately or if you have any concerns about my conduct, then please contact:

Dr. Janet Feigenbaum, Strategic and Clinical Lead for Personality Disorder Services, North East London NHS Foundation Trust and Senior Lecturer, Research Department of Clinical, Educational and Health Psychology, University College London.

Email: janet.feigenbaum@nhs.net, Work Office: 0300 555 1213.
Appendix 12 Occupational Professionals Information Sheet (Chapter 3)

Preparedness for Employment Scale for people with Personality Disorders (PES-PD): Focus Group and Semi-Structured Interviews

We would like to invite you to take part in a focus group or a semi-structured interview. This sheet will give you some more information about why the focus group or interview is being carried out, what you would be asked to do if you decide to take part, and how the focus group or interview will be conducted. You are very welcome to ask me any further questions about the study, or if you find anything on this sheet unclear.

What is EMPOWER?
The EMPOWER study is a National Institute for Health Research (NIHR) funded project focused on helping to motivate and enable people with a Personality Disorder (PD) gain employment. We aim to develop a positive booklet for employers to use to support people with PD in the workplace. While there are tools available to help healthcare professionals assess readiness for work in terms of physical ailment, no such tools are available for people with PD. We aim to develop a means to assess readiness for work in this client group by creating a new questionnaire. We also will be developing a booklet for employers to understand the difficulties experienced by people with PD in the workplace, and suggestions for reasonable adjustments and management support.

1) The purpose of the study
The creation of the new questionnaire relies on the valuable input from different groups of people. We are speaking with employers, healthcare professionals, third sector mental health staff, job centre staff, the friends and family of PD clients and the PD clients themselves. Hearing from everyone will help us to build a clear picture of what the barriers and enablers are to employment activity for people with PD. Focus groups allow us to capture very rich information that would not be possible through the distribution of a questionnaire. We would like to run a focus group with employers to help us better understand what obstacles and supports people with PD may encounter when seeking, obtaining and retaining employment.

2) Why have I been invited?
You have been invited to take part in the study because you employ staff who may or may not have a personality disorder. It has been shown, approximately 5 in 100 people have a PD; therefore it is likely that you employ or will employ someone with a PD. PDs are characterised by strong emotional responses, difficult interpersonal styles, and often impulsivity. Some people with PD also engage in risky behaviour at times to manage their emotions. We feel that you would be able to help us think about the issues for employers regarding staff with a PD. We are also interested in your views on what would constitute ‘reasonable adjustments’ in the workplace for someone with a PD.
3) Do I have to take part in the study?
No, we are hoping that you or one of your managers or occupational health staff, are willing to give us the time to take part in the focus group. If you do consent to taking part in the focus group you are still free to stop participating in the group discussions at any time, without having to give a reason. If you wish to participate but do not want to join a group discussion there is an “opt-in” option of semi-structured interview. Again, you are free to withdraw at any time, without giving a reason.

4) If you do choose to take part in the study, what will happen to you?
If you wish to take part in the study, please notify EMPOWER by emailing: EMPOWER@nelft.nhs.uk with your name and contact details. A member of EMPOWER will ring or email you (depending on your preference for being contacted) to confirm your participation and to offer the opportunity to ask questions.
The day before the focus group or semi-structured interview takes place, we will call you again to remind you. You will meet and another member of EMPOWER staff at the focus group or semi-structured interview. At the start of the focus group, you will be given the same information sheet to re-read and will be asked to complete the informed consent sheet. The informed consent form will state you agree to be audio-taped and to take part in the group discussion or semi-structured interview. Those who do not consent to be audio-recorded will be unable to participate. You will also be asked to complete a demographics form which is fully anonymous.
During the group discussion or semi-structured interview we will guide you in thinking and discussing ideas regarding the challenges of obtaining and retaining employment. The discussion will take up to about 1-1.5 hours. The group discussion will be audio recorded, anonymised, transcribed, stored electronically, and password protected.
At the end of the session you will be asked whether you would like to be involved in a corrective and clarity. This involves reading an anonymised summary of information from the group discussion. The anonymous information will be summarised into themes e.g. attitudes of my family to my seeking work. You will be asked to add additional information, correct any misinformation and confirm the interpretation of the theme is correct. This is an optional task; you are in no way obliged to complete this. If you agree to take part in this process you will receive the written summary either by email or post. Your email address or postal address will be stored in a password protected document on a secure NHS computer at North East London NHS Foundation Trust (NELFT).

5) Will my information be kept confidential?
Yes, all information provided by you will be kept confidential. All of the discussion information you provide will be anonymous, so that you cannot be identified. Any quotes that you provide which are used in the published research will also be anonymised. If you choose to participate in the corrective process we will ensure your personal details will be kept separately from the transcriptions and stored in a password protected document on a secure NHS computer at North East London NHS Foundation Trust (NELFT).
In accordance with current NELFT Records Management Policy, research findings will need to be stored by NELFT as sponsor for 20 years after the research has finished. The NELFT Records Office provides a service to NELFT staff and maintains archived records in a safe and secure off site location. All activities are conducted in accordance with the Data Protection Act 1998 and NELFT Data Protection Policy. Access to the data is strongly regulated and only members of the research team will have the right to use.

6) What are the possible benefits of taking part?
You may find it useful to know that the information from this focus group will help us to give advice to employers about what support may be needed by the individual at work.
It will better inform our understanding of the experiences of individuals with PD and employment, which will also allow us to develop a useful scale and services in the future.
We hope that you will find it helpful or interesting to talk about employing and working with people with a PD, and may help you to consider adaptations in your own workplace which may be helpful to the person with PD and to your managers.
7) What are the possible disadvantages to taking part?
We do not expect there will be a specific disadvantage to employers taking part. However, it may be possible employers who have had recent experiences of working with people with PD (or someone with high emotions and interpersonal difficulties) may experience some distress. We will provide a self-help and support numbers sheet at the beginning of the focus group.

8) What will happen to the results of the research study?
The focus group is one part of a larger study which is looking to help people with PD gain employment. The information from the focus groups will help us to design a scale to help us measure readiness for employment in PD clients. This scale will be used in the larger study, which will be completed in autumn 2019. Additionally, the anonymised results of the focus group discussion will be presented in a doctoral thesis, will be published in a scientific journal, and presented at national or international conferences. Any comments you make will be anonymised when the information is written up; that means that at the point of publication no personal data is used.

We will also be giving the scale to NHS Trusts across the UK once the scale is fully developed. If you wish to be invited to a feedback meeting, where the results of the study will be presented, please tick the statement on the member checking form. We will send you a letter of invite with the details at a later date (in about two years).

9) Who has reviewed the study?
The study has been reviewed by the NIHR who have funded the study. The study has been granted ethical approval by the South Birmingham Research Ethics Committee. Contact details:

If you wish to contact me to discuss any of the information further, then please ring on: [redacted]. Please be aware that the EMPOWER research team all have a duty of care to all participants. Therefore if we are concerned in your safety or the safety of other participants, the researchers will first speak to their supervisors who may need to act upon this information where necessary.

If you feel that I have not addressed your concerns adequately or if you have any concerns about my conduct, then please contact:

[redacted]

Thank you very much for taking the time to read this information sheet. Please ask if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you would wish to take part.
Appendix 13 Informed Consent Form (Focus Groups)
(Chapter 3)

Centre Number:
Study Number:
Patient Identification Number for this study:
Name of Researcher: 
Chief Investigator: Dr. Janet Feigenbaum
Title of Project: Preparedness for Employment Scale for people with Personality Disorders (PES-PD): Focus Group or Semi-Structured Interview

Please read the following statements carefully and write your initials next to each one indicating that you have read and understood them. When you have read, and initialed the statements, please sign your name and signature to consent to taking part in the focus group or semi-structured interview.

Please initial box

- I confirm that I have read and understood the information sheet 05/01/2016 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

- I understand that my participation is voluntary and that I am free to leave the focus group or semi-structured interview at any time.

- I understand that any information gathered during the focus group or interview will be audio-taped and transcribed, but no names or identifying information will be used.

- I understand that any use of quotes from the focus group or semi-structured interview will not include any information that could personally identify me.

- I understand that the researchers have a duty of care to all participants. Therefore if there is any concern about my safety or the safety of others, the researchers will speak to me first to ensure immediate safety, and then inform their supervisors. Their supervisors will then inform any relevant healthcare professionals.

- I understand that relevant sections of my data collected (information from the focus group/interview) may be looked at by individuals from EMPOWER, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

By signing below I agree to the above and to take part in the focus group or semi-structured interview.

Name of Participant Date Signature

Name of Person Date Signature
taking consent

When completed: 1 for participant; 1 for researcher site file
Appendix 14 Focus Group Demographics Form

(Chapter 3)

Participant number:

SECTION 1: PERSONAL INFORMATION

Age: 18-25 ☐  26-30 ☐  31-35 ☐  36-40 ☐  41-45 ☐
46-50 ☐  51-55 ☐  56-60 ☐  61-65 ☐  65+ ☐

Gender: Male ☐  Female ☐  Transgender ☐

I am a: ☐ Clinician ☐ Client with a PD ☐ Employer ☐ DWP employee
☐ Employment support staff ☐ Other Service User
☐ Friend or family of individual with PD ☐ Third Party Organisation Staff
☐ Other: ______________________________

What is your marital status?
☐ Divorced or separated ☐ Single ☐ Cohabiting
☐ Married/civil partnership ☐ Widowed

Do you have any dependents? Yes ☐ No ☐
If yes, in the space below list their relationship to you, age and gender.

Relationship to you: _____  Age:  _____  Gender:  _____

____________________________________  ____________________________________

____________________________________  ____________________________________

____________________________________  ____________________________________

____________________________________  ____________________________________

Please state your father’s occupation: _______________________________________

Please state your mother’s occupation: _______________________________________

How would you describe your national identity?
☐ English ☐ Welsh ☐ Scottish ☐ Northern Irish ☐ British
☐ Other: ____________________________________________

What is your ethnicity?
☐ Asian, Asian British, Asian English, Asian Scottish or Asian Welsh
☐ Black, Black British, Black English, Black Scottish or Black Welsh
☐ Mixed
☐ White
☐ Chinese
☐ Middle Eastern
☐ Other ethnic background

What is your main language?
☐ English ☐ Other: ____________________________________________

How well can you speak, read and write in English?
☐ Very well ☐ Well ☐ Not well ☐ Not at all

Are you eligible for employment in the UK? Yes ☐ No ☐

Do you consider yourself to have a disability? Yes ☐ No ☐
If yes, please state disability: ____________________________________________

SECTION 2: Health

Please indicate current diagnoses of mental health problems?
☐ Anxiety ☐ Depression ☐ Dissociative Disorder ☐ Post-Traumatic Stress Disorder
☐ Eating Disorder  ☐ Psychosis  ☐ Schizophrenia  ☐ Personality Disorder
If other, please state: __________________________________________________________
Are you currently accessing psychological therapies?
Yes ☐ No ☐
If yes, please indicate type of therapy:
☐ Cognitive Behavioural Therapy  ☐ Dialectical Behavioural Therapy
☐ Psychoanalytical Therapy  ☐ Compassionate Focused Therapy
☐ Art Therapy  ☐ Family therapy
☐ Drama Therapy  ☐ Mindfulness
If other, please state: __________________________________________________________

SECTION 3: QUALIFICATIONS
Current Level of Educational Attainment
☐ GSCE’s  ☐ A Levels  ☐ NVQs  ☐ College  ☐ University
☐ Postgraduate  ☐ City and Guilds (or equivalent)  ☐ other: ______________________
Relevant Training Courses Attended

<table>
<thead>
<tr>
<th>Course Title</th>
<th>Training Provider</th>
<th>Duration</th>
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SECTION 4: EMPLOYMENT HISTORY
Please indicate your current employment status:
☐ Employed  ☐ Unemployed
If unemployment, state for how long: _____ month’s _____ years
If unemployed, are you available for employment?  Yes ☐ No ☐
Please indicate which business sector you wish to work in?
☐ Medical  ☐ Health and Social Care  ☐ Education  ☐ Engineering  ☐ Hospitality
☐ Admin/Clerical  ☐ Retail  ☐ IT  ☐ Banking  ☐ Law
☐ Other: ______________________
Please state your career aspiration as briefly as you can in the space below:
__________________________________________________________
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Please state current or most recent employment details:

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Job Title:
Appendix 15 Focus Group PD Client questions (Chapter 3)

These questions are designed to guide and prompt group discussion. They are a guideline and will be used to elicit and encourage answers when appropriate.

Welcome to the group discussion on personality disorders and employment. The idea of a focus group is that by sharing your ideas and experiences and hearing other people’s ideas and experiences we will develop a better understanding of the issues. There is no right or wrong way of answering the questions as we are interested in your thoughts about employment and your experiences in the workplace.

Today we are going to guide you through topics on potential barriers for people with a personality disorder in the different stages of entering employment from thinking about whether to get a job, applying for and getting a job, and remaining in employment. The ideas we gather today and in the other focus groups we are holding will guide us in the development of a scale (questionnaire) we are developing called the Preparedness for Employment Scale for individuals with a personality disorder. We hope that this questionnaire will help individuals to identify the challenges they face in getting and keeping a job, will help us to evaluate whether interventions are helping people in their path to employment, and will provide a tool for clinicians and other staff to identify what areas need to be worked on to help someone to feel ready and able to get a job. We will also be using the information to create a booklet for employers about how best to support someone with a personality disorder once they are in the workplace.

Are there any questions before we start?

Thinking of Getting a job
For those of you not employed at the moment I would like you to consider the process of thinking about employment. For those who are employed at the moment I would like you to consider your process of thinking about employment before you got your job.

a) Let’s first think about the period of time before one begins applying for a job for the first time or after a long time unemployed. What thoughts might be going through your mind? What hopes? What worries? What fears? What memories?

When you began thinking about the steps to getting a job (i.e. CV writing, visiting job centres, seeking employment support, browsing online looking for job vacancies). What types of thoughts/worries came up for you?

How do think your thoughts stop or help you to begin looking for a job?

Have you had any thoughts around physical health and their impact on your ability to think about employment? What we mean by “physical health” are things such as pain, forms of physical disability, drugs and alcohol etc.

2) a) When you are (or were) thinking about getting a job but not yet started, what emotions were you experiencing?

b) Have any of these emotions stopped you thinking about getting a job?

a) When you are (or were) thinking about getting a job but not yet started, are there things you are (or were) doing that might be getting in the way of starting to look for a job? (Some examples might be taking drugs or drinking alcohol a lot, sleeping a lot, etc).

Putting all of what we have been talking about above regarding the process of thinking about looking for a job, what would you say are (or were) the main barriers or problems which were stopping you from moving to looking for a job? Is there anything else that was going on which stopped you that we haven’t discussed?

Gaining employment
Now I would like us to consider the process of gaining employment. This could be a number of things such as task oriented activities such as CV writing, visiting job centres and career fairs, seeking employment support, training) as well as certain thoughts and emotions. I would also like us to consider what “context” you were in. For example, did you gain a job in a large organisation, or a small employment setting, an office job, a physically intensive job.

a) For those of you who are unemployed what tasks have you considered, if any that you have started or completed in order to try and gain employment? i.e. CV writing, actively going into places with job vacancies and asking, speaking to people in job centres.
b) For those of you who are employed, what task did you complete or carry out in order to gain the employment you have at this moment in time?

c) Were there/are there any tasks you found/find difficult in completing? What was getting in the way?

In your experience did any beliefs get in the way of gaining employment? i.e. fear of rejection, self-criticisms, worries. Could you give any examples?

In your experience, what emotional responses did you have when gaining employment? For example, did you experience anxiety or excitement? What context were you in?

Retaining employment
What we mean by “retaining” a job is gaining a job and being able to keep or hold down a job without walking out, being dismissed or fired.

a) For those of you who are employed or have been employed, in your experience have you had any difficulties in keeping a job? If so, what were they? What did you think of these difficulties?

b) Has anyone had to work to deadlines but found them difficult? What did you do in that situation?

c) Has anyone had to work with colleagues whom they didn’t necessarily like or get on with? If so, what sort of thoughts came up for you? And how did you respond?

Did anyone experience any worries, concerns and frustrations?

a) When or if you experienced any difficulties, in your experience what were your emotional responses? What context were you in?

Have you ever experienced high emotions at work? If so, in what context?

Did any of these emotional responses lead to take ‘sick leave’ or disagreements with other colleagues or supervisors?

Clarifying questions
Can you tell me a little more about this?

Can you give me some examples?

Would you say you felt ____________?

Have you had any other experiences other than what you’ve mentioned?
Appendix 16 Focus Group Health Care professional questions (Chapter 3)

These questions are designed to guide and prompt group discussion. They are a guideline and will be used to elicit and encourage answers when appropriate. Welcome to the group discussion on personality disorders and employment. The idea of a focus group is that by sharing your ideas and experiences and hearing other people’s ideas and experiences we will develop a better understanding of the issues. There is no right or wrong way of answering the questions as we are interested in your thoughts about employment and your experiences in the workplace.

Today we are going to guide you through topics on potential barriers for people with a personality disorder in the different stages of entering employment from thinking about whether to get a job, applying for and getting a job, and remaining in employment. The ideas we gather today and in the other focus groups we are holding will guide us in the development of a scale (questionnaire) we are developing called the Preparedness for Employment Scale for individuals with a personality disorder. We hope that this questionnaire will help individuals to identify the challenges they face in getting and keeping a job, will help us to evaluate whether interventions are helping people in their path to employment, and will provide a tool for clinicians and other staff to identify what areas need to be worked on to help someone to feel ready and able to get a job. We will also be using the information to create a booklet for employers about how best to support someone with a personality disorder once they are in the workplace.

Are there any questions before we start?
What is a personality disorder?
It can be defined as someone with an enduring pattern of difficulties in managing emotions, behaviour as well as interpersonal relationships.
For instance, someone with a personality disorder may:
Feel overwhelmed with intense emotions leading to strong emotional responses such as angry outbursts
Have difficult interpersonal relationships possibly due to difficulties in receiving criticism or fears of rejection
Behave impulsively such as quitting a job without thought of consequence

Thinking of getting a job: Scenario 1
I would like you to consider a client or person with a personality disorder or personality disorder traits who has been unemployed for a substantial amount of time; we’re not talking about someone who has been unemployed for 3 months but people who have been struggling to get back into employment after a significant period of time, so more than (12 months). Do you think there are barriers to this person considering and thinking about employment?

a) I would like us to consider the thought process of this person before they apply for a job. What thoughts might be going through their mind? Do they have any worries? Any fears? Any memories?
b) When this person began thinking about the steps they needed to take to get a job (i.e. CV writing, visiting job centres, seeking employment support, browsing online looking for job vacancies). Did any thoughts/worries come up? What kind of thoughts of worries/thoughts were they?
c) Do you think their thoughts helped them begin to look for a job? Do you think their stop or help them to begin looking for a job? How?

Prompts:
As clinicians and employment support staff you may be familiar with some of the emotional difficulties people with a PD may experience in their day-to-day life. Just to clarify what we mean by “emotions” or “emotional responses” are those who may have angry outbursts, high feelings of anxiety, anticipatory fear in starting a job, excitement, frustration etc…. We would like to explore these emotions in relation to individuals with a PD thinking about whether they should get a job.
a) When individuals with a PD are (or were) thinking about getting a job but not yet started, what emotions were they experiencing?
Do you think any of these emotions stopped them thinking about getting a job?

Prompts:
Are there things they are (or were) doing that might be getting in the way of starting to look for a job? (Some examples might be taking drugs or drinking alcohol a lot, sleeping a lot, etc).
Overall, what would you say are (or were) the main barriers or problems that are stopping individuals with a PD from moving to looking for a job? Is there anything else that was going on which stopped them that we haven't discussed?

Gaining employment: Scenario 2
Let's consider that this person with PD or strong PD traits has now gained a new job and is returning to work. They may or may not have done a number of task-oriented activities (for example CV writing, visiting job centres and career fairs, seeking employment support, training).
Do you think there are any barriers that may stop them from gaining a job or returning to work in the first place?

Prompts:
a) In your experience what thoughts or beliefs did your clients have when in the process of gaining employment? i.e. fear of rejection, self-criticisms, worries.
b) In your experience did any beliefs get in the way of your client returning to employment? i.e. fear of rejection, self-criticisms, worries. Could you give any examples?
c) Do you think these thoughts stopped them from gaining a job or returning to work?

Do you think any of these emotions stopped them gaining a job or returning to work?

a) What tasks do you think this client may have considered in order to gain employment or return to work? Can you share any experiences of your own clients?
b) In your experience did any of your clients find this task particularly difficult or easy?
c) What do you think was getting in the way?

Retaining employment: Scenario 3
Now this person has started this job and has been in employment for about 6 months, there are some things they are feeling great about, there also might be something they are not feeling quite so great about and this might be putting a strain on their ability to keep this job.
In your experience what things may this client be finding ‘difficult’ to keep this job?
Are there any barriers at all? May there are no challenges at all? Do you have any examples of your own?

1) a) What beliefs do you think this client may have in relation to their ‘difficulties’ in the workplace?
b) Do you think they would experience any worries, concerns and frustrations?
c) Do you have any examples of your own experience with clients?
d) Do you think these thoughts are getting in the way of your clients retaining employment?

2) a) What emotions do you think this person with PD may experience when trying to keep their job? Fear? Anger? Frustration?
b) In your experience, when or if your clients experienced any difficulties in remaining at work, in your experience what were their emotional responses? What context were they in?
c) Do you think any of these emotions stopped them keeping a job?

a) Do you think there are things this client may be doing that might get in the way of them keeping their job? For example, taking drugs or drinking alcohol a lot, sleeping a lot, etc?
b) In your experience have any of your clients called ‘sick’ leave before or often have angry outbursts with other colleagues or supervisors?
c) Do you think these behaviours have stopped them from remaining at work?

Other prompts:
Putting all of what we have been talking about above regarding the process of retaining employment, what would you say are (or were) the main barriers or problems that are (or were) stopping individuals with a PD from keeping a job? Is there anything else that was going on which stopped them that we haven't discussed?

Do you think the physical health of individuals with a PD impacted on their ability to think about employment?
I would also like us to consider what “context” your clients were in. For example, did they gain a job in a large organisation, or a small employment setting, an office job, a physically intensive job?
Clarifying questions
Can you tell me a little more about this?
Can you give me some examples?
Would you say you felt ___________?
Have you had any other experiences other than what you’ve mentioned?
Appendix 17 Focus Group Supporters questions

(Chapter 3)

These questions are designed to guide and prompt group discussion. They are a guideline and will be used to elicit and encourage answers when appropriate.

Welcome to the group discussion on personality disorders and employment. The idea of a focus group is that by sharing your ideas and experiences and hearing other people's ideas and experiences we will develop a better understanding of the issues. There is no right or wrong way of answering the questions as we are interested in your thoughts about employment and your experiences in the workplace.

Today we are going to guide you through topics on potential barriers for people with a personality disorder in the different stages of entering employment from thinking about whether to get a job, applying for and getting a job, and remaining in employment. The ideas we gather today and in the other focus groups we are holding will guide us in the development of a scale (questionnaire) we are developing called the Preparedness for Employment Scale for individuals with a personality disorder. We hope that this questionnaire will help individuals to identify the challenges they face in getting and keeping a job, will help us to evaluate whether interventions are helping people in their path to employment, and will provide a tool for clinicians and other staff to identify what areas need to be worked on to help someone to feel ready and able to get a job. We will also be using the information to create a booklet for employers about how best to support someone with a personality disorder once they are in the workplace.

Are there any questions before we start?

Thinking about employment:

If the person you support is not working at the moment, I'd like you to consider the process of their thinking about employment, or if they are currently in work, the process of thinking about employment before they got the job:

Can you tell me the main challenges they face(d) when they are/were thinking about employment?

Or

In your experience, what sort of difficulties did they find when they are/were thinking about working or getting a job?

Prompts

How do you think their thoughts/emotions/behaviour stop or help them to begin looking for a job?

What sorts of things were going through their mind?

What were they feeling?

Under what sort of situation do this/these challenges arise?

Have you noticed any particular situations over the past year?

Was there anything they did that helped them overcome this challenge/help them cope?

Have you had any thoughts around physical health and their impact on their ability to think about employment? What we mean by "physical health" are things such as pain, forms of physical disability, drugs and alcohol etc.

Gaining employment

Gaining employment could be several things such as task-oriented activities such as CV writing, visiting job centres and career fairs, seeking employment support, training as well as certain thoughts and emotions.

I'd like you to consider the process of gaining employment. Can you tell me the challenges you may face during this stage of employment?

Or

If you are employed, did you find anything particularly difficult while getting this job?

Prompts

Why do you think that particular challenge was difficult?

What sort of thoughts did they have around that situation?

In this situation, how do/did they feel?

Was there anything that helped them at this stage in getting a job? What do you think may help them overcome this particular challenge?
Have you noticed any particular situations for your loved one over the past year?
How do you think their thoughts/emotions/behaviour stop(ped) or help(ed) them to begin looking for a job?

Retaining employment:
In your experience, what difficulties if any, might your loved one/person you support to find in the workplace?
Or
On your opinion, what difficulties if any, are there in the workplace for the person you support?
Or
What do you think the main challenges in the workplace are for your loved one?

Prompts
What sorts of thoughts are/were going through their mind?
In your opinion, do any of these thoughts stop them from staying at work?
In your opinion, how do these situations leave them feeling?
In your experience, do any of these feelings/emotions get in the way of them continuing work?
What did they do in this/this situation?
How do you think their thoughts/emotions/behaviour stop(ped) or help(ed) them to keep/lose a job?

Clarifying questions
Can you tell me a little more about this?
Can you give me some examples?
Would you say you felt ___________?
Have you had any other experiences other than what you’ve mentioned
Appendix 18 Focus Group Occupational professional
questions (Chapter 3)

These questions are designed to guide and prompt group discussion. They are a guideline and
will be used to elicit and encourage answers when appropriate.
Welcome to the group discussion on personality disorders and employment. The idea of a
focus group is that by sharing your ideas and experiences and hearing other people’s ideas and
experiences we will develop a better understanding of the issues. There is no right or wrong
way of answering the questions as we are interested in your thoughts about employment and
your experiences in the workplace.
Today we are going to guide you through topics on potential barriers for people with a
personality disorder in the different stages of entering employment from thinking about whether
to get a job, applying for and getting a job, and remaining in employment. The ideas we gather
today and in the other focus groups we are holding will guide us in the development of a scale
(questionnaire) we are developing called the Preparedness for Employment Scale for
individuals with a personality disorder. We hope that this questionnaire will help individuals to
identify the challenges they face in getting and keeping a job, will help us to evaluate whether
interventions are helping people in their path to employment, and will provide a tool for clinicians
and other staff to identify what areas need to be worked on to help someone to feel ready and
able to get a job. We will also be using the information to create a booklet for employers about
how best to support someone with a personality disorder once they are in the workplace.
Are there any questions before we start?
Definition of a PD [Give Employer Information Sheet “What is Personality Disorder”]
Side note 1: We are mindful that employees may not disclose they have a diagnosis of
personality disorder, but we are also interested in individuals who may not necessarily have a
‘diagnosis’ per se, but people who perhaps share similar characteristics. (High emotional states
or a tendency to act or behave impulsively or perhaps have difficulties with interpersonal skills in
the workplace.)
Side note 2: I would like to emphasise it is normal for people to feel anxious or frustrated in the
workplace for numerous and common reasons; conflict with a colleague/boss, deadlines,
appraisals. What I am interested in are people who are not only feeling anxious but may go to
the extreme and behave or act in a way that can make it difficult for them to function at work.
Side note 3: Throughout these questions, I would like you to consider someone you work with or
manage who may have some of these characteristics.
Getting a job
This refers to the application, interview, and reference checks.
1) Following on from the description of a personality disorder, have any of you in your role
been involved in the interview stage? Or appointed anyone?
2) In your role, do you have any experience of working with people who report their
interview experience?
a) What did they find challenging? What helped them?
b) Thoughts/behaviours/emotions of these individuals?
3) If disclosure comes up or not, ask about enablers and barriers to disclosing
OR
4) In your experience, have you been involved at this stage with individuals who share
these characteristics? Or who have disclosed?
New Starter (Gaining employment)
Does your role involved with new starters in terms of mental health and wellbeing?
What are the challenges these people may face starting a new role? What have you found
helps them? Thoughts/emotions/behaviours
What supports do you provide in your role?
Can you provide examples of adjustments or work modifications you have made to support
people with PD?
How often have you modified these supports?
Retaining employment
Once they have got a job, they want to keep it. However, they might find it difficult to keep a job. Give an example: Not being able to say no, overwhelmed, miss deadlines, anxious and then started missing meetings etc.

1) In your experience, what difficulties have these people found in the workplace?
2) In your experience, what things have helped to keep these individuals in the workplace?
3) How have they overcome these challenges?
4) How often do you modify these supports/Any examples of modifications?
5) Do you have anything specific for Personality Disorder?

Leave of absence:
Client group are more prone to take leave.
1) In your experience, has this occurred? What happened?
2) What were the challenges for the individual and what supports were in place?

Return to work:
After a leave of absence, often this client group want to return to work. Often they are very willing but find certain aspects of return to work very difficult.

1) In your experience, have any of the people you support at work experienced this?
2) What have they found difficult, and what is useful in enabling them to return to work?

What types of support or modification is in place for them?
What sort of things are they voicing/thinking in this given situation?
In this situation, how do/did you think they might have/may feel?
What do you think may help them overcome this particular challenge?
Do you think their thoughts/emotions/behaviour stop(ed) or help(ed) them in their role?
Has there been any adjustment at work for this individual? Have any changes been made in the workplace for this individual?
Can you tell me a bit more about this situation?
What was challenging for them?
Have they been trying to return to work?
What has worked in the past?
What hasn't worked?

Clarifying questions
Can you tell me a little more about this?
Can you give me some examples?
Would you say you felt ____________?
Have you had any other experiences other than what you’ve mentioned?
Appendix 19 Focus Group Client Transcription 1

(Chapter 3)

PhD STUDENT: Awesome, ok, do you guys have any questions from the information sheet today?
PhD STUDENT: We're going to talk about various stages of employment, so looking at "thinking about employment", so whether you're employed now or unemployed, at that point in time when you're thinking about it, to when you've "got the job" to "staying at work" and "remaining at work" and managing, erm anything that comes up in the workplace when you are there. Does that make sense? So, I want to ask you guys- erm- if I were to say to you, how would you describe someone with a personality disorder what would you guys say?
01012: Depends on what personality disorder you're talking about.
PHD STUDENT: I don't know it's up to you, what comes to mind?
01012: That's a pretty hard question for us…
(Laughs)
PHD STUDENT: Again, like I said there is absolutely no right or wrong answer. How about- is it easier if I say how one may act or behave, or things that they may do?
01009: Avoid doing things?
01012: High emotional response, like emotional responses?
PHD STUDENT: Yeah, so quite high emotions. Does that sound about right?
01008: We could get triggered really easily isn't it? You know, 'cos erm, it's difficult as well, 'cos you know, well for me anyway, in group we were learning ways of being able to get around or you know, deal with ourselves, but previous to that, it was very much, yeah just getting triggered at work then going through an episode potentially.
01008 & 01012: And interpersonal difficulties as well.
PHD STUDENT: Ok, yeah, so things that happen in your life are the sort of thing that can trigger off and [ () ].
01008: ()
PHD STUDENT: The reason I ask you guys, is because, these are kind of common things that you guys might feel, like you know, might happen with you guys (), you know getting high emotions. But I suppose we are here to talk about work aren't we and employment, and how that impacts us in the workplace, like you very much mentioned already [says a participant's name]. I just want you guys to think about in general, erm, when you’re thinking about employment, what do you guys think are the main things that get in the way?
01010: A thought of an interview.
PHD STUDENT: The thought of interviews?
01010: Yeah, like the pressures of the interview.
PHD STUDENT: Uh-huh, what kind of things comes to mind when you think of an interview, like what kind of thoughts?
01010: I won't know what to say or anything.
PHD STUDENT: Won't know what to say?
01010: Yeah.
PHD STUDENT: And then…so then you’re thinking about like, what you want to say? What about how you might be feeling?
01010: Really stressed.
PHD STUDENT: Quite stressed out, quite anxious? You’re nodding your head.
01008: Yeah, no definitely, just ’cos they do all those different types of interviews now, it's like, “give me a time when you did this?” and sometimes it's really difficult to actually think about a time that you have actually done ↑that. Erm, and..
PHD STUDENT: So is it being sprung on the moment after the question, sort of thing?
01008: Yeah, yeah exactly, and then you sort of go a bit anxious and nervous and don't say the right words, and erm….don't portray yourself to be the person that you are. ‘Cos previously like, when I was like, 20, it was more like an open, frank conversation, and now it’s a lot more structured, erm, and so you can’t actually you know, sort of (1) get out your point. I find it difficult
to get out your point, erm, when it's so structured that way. “Give me an example when you did this.” You know, “Tell me when you did that.”

PHD STUDENT: Yeah, what do you think might be helpful? I suppose, in a situation like that?

01012: Preparation and also I use, ‘cos I’ve got a number of things, ‘cos for me, I was going to say the main problem is even thinking about what I’m going to do. ‘Cos it’s very difficult when you’re not really, when you have difficulty with, erm, your identity... It’s hard to make decisions about what you want to do with your life and... easy to kind throw yourself into this or that or the other and then... think you want to do it and then find out you don’t. But in terms of like interview, I would say two things. First thing would be preparation, like there are websites where you can get like, types of interview questions and stuff like that. I quite rigidly just like plan and then I just use those to answer any [questions]

PHD STUDENT: [So you kind of do some self-help, so you go online]

01012: [Yeah] and the second is I’ve got quite a bit of training in acting so I just act... I just like act, I don’t go in as me (laughs)... I go in as like a character of a person who (laughs) is like able to deal with this job and stuff [I would go in]

PHD STUDENT: [So I suppose it’s a way to try and get through that interview isn’t it?]

01012: Yeah, but then it kind of just stresses me out because once you’ve done that in the interview you start thinking I’m going to have to start keeping that pretense the whole time.

PHD STUDENT: So when you’re thinking about employment, you’re thinking about interviews, [erm]

01009: [yeah it’s like], if I set myself up as this person will I be able to sustain it.

01012: I don’t get that far ahead

01008: Neither do I (laughter)

01012: I just end up leaving the job after a few months (laughs).

PHD STUDENT: So you guys don’t think that far ahead when you’re thinking about employment? You’re just thinking about the [interview?]

01012: [I am like,] “I’m just going to get the interview, gonna get a job I’m..

PHD STUDENT: So you [tend to-?]

01010: I stress about things that, like, yeah, not even on the page yet if that makes sense.

PHD STUDENT: Yeah, yeah I think it makes sense. We’ve got some nods across the room.

01012: I worried about being judged as well... like when I come out the interview like, I could go in and I’m usually ok for the day. I just do everything in the moment, erm and I know I’m prepared, and I don’t really think about it. And then I’m in there and it is what it is and then I leave and then I get really distressed because I feel... I go back over the whole thing in my head and try to dissect it and I feel like....

PHD STUDENT: So I just want to go back to the point that you said [says participants name] about... erm... so thinking about employment the thoughts of “well I don’t know what I want to do? Like, what- what is there out there?” I mean, erm if I open it up to you guys does that- is that similar?

01010: Yeah, ‘cos I’m a trained teacher which is really specific and now I’ve left teaching I don’t know what else to do.

01008: [Yeah]

01012: [I'm in a similar position] with research basically.

PHD STUDENT: So when you're at home and you’re thinking about these things do you, what do you do? Do you sit with these thoughts? Or do you talk to other people?

01012: Blind panic! (laughter)

PHD STUDENT: Ok..

01010: I just keep it to myself.

PHD STUDENT: Ok, and then what happens next? Did you guys like, I suppose I’m thinking about things like avoiding thinking about it, or do you go out and do things or?

01012: I’ve never really been in the position where I have not had to work. So what I do is I jump for job to job=

PHD STUDENT: Ok.

01012: =and just go for like, I’ll stay there for as long as I can be, either as long as I can tolerate it or until like, I get bored, usually- like most jobs I’ve left because I’ve like fallen out with the people. I just hate it and then I leave. Like-

PHD STUDENT: Let’s definitely come back to what it’s like working at work-
01012: but basically I sort of just job hop, so I have job hopped. I've done everything from
like...supermarkets to waitressing to...working with children, you know nurseries, special needs,
research...like...erm. I've done project management, erm now I'm doing consultancy work but
I've just been signed off from that ()

PHD STUDENT: So would it make sense to be like, you're thinking about employment you're like,
"this is not what I wanted", what else can I do and go to another one?

01012: Yeah I just yeah, I just get myself into this like mindset, where I'm like, I'll see a job
advert and...I'm like "Oh yeah, I can definitely do that!" And I'll get all excited and I'll like to put
on this character of like, and like I think like-I would throw myself — this is where I'm at at the
moment. I've been thinking a lot about this 'cos this is what I am focusing on in individual
therapy at the moment. But what I do is I- basically like, it's almost I continue the acting from the
interview and then I can't- as soon as I can't sustain anymore, then for some things I can longer
than others 'cos they fit me better but erm, but yeah, I just put on a role and do that. And just
decide () So it looks kinda bright and shiny, or convenient or whatever. And I don't really care I
just go. And then if I get the job, I'm like "oh wow, this really is happening". Erm..

PHD STUDENT: Ok...were you going to say something [says participants name]?

01011: hmm....

01008: The other thing as well is like erm, my brothers and sisters are actually really quite well
educated, my mum's a teacher, my brother's a civil engineer erm, my sister's a psychologist and
the other one's a legal secretary, so they're really erm, did really well at school and everyone
got good grades, went to university and what have you. Whereas myself I wasn't able to so erm,
so- I'm- there's probably two things that I'm looking for when I go for a job is that I'm always
wanting it to actually, make my parents proud of what I am actually doing..Erm.

PHD STUDENT: So is that something you're thinking about then, when you are thinking about
employment? "Hey, I want to make my parents proud?"

01008: Yeah, yeah, that they would ring up somebody who..yeah..and then the other thing as
well with jobs, I've always looked at erm- what's the salary they are giving you. And regardless
of whether or not I'm going like the job for a long period of time or not, I will always look at the
salary.

PHD STUDENT: Ok so money is quite an important factor then yeah?

01008: Well money is the only factor you could say.

PHD STUDENT: Oh ok, yeah ().

01012: You just want to make loads of money ()

01008: Oh yeah, exactly.

01012: That's why you're out of a job.

01008: Just to pay the bills and everything.

PHD STUDENT: So you do think about- you do consider actually like, if it's a well paid job
before you go for it?

01008: Yeah, absolutely.

PHD STUDENT: Is that similar across the board or?

01012: Yeah, cos I don't really feel like I will ever enjoy anything I'll ever do so I might as well go
for the first thing I can get.

PHD STUDENT: What do you think [says participants name]?

01009: I don't know. When I got my job I was only like 16. Erm, I just wanted to get a job and I
had to just be independent and then I kinda just..got ill and I couldn't sustain it anymore, so.
Money was never- I didn't need to work. I just wanted to like, be independent but I didn't realise
how it would impact me.

PHD STUDENT: Yeah, yeah, yeah it's interesting 'cos- I suppose you go for work for different
reasons, like financial, independence, any other reasons?

01010: I did it because I loved the job.

PHD STUDENT: Hmm...for the job itself?

01010: Yeah..

PHD STUDENT: Yeah, yeah, do you- that might play a role when you're thinking about
employment next?

01010: Yeah I think it's important for me to do something that I enjoy, if I can.

01012: I agree with that, I think I just like tricked myself with what I think I'm going to enjoy.
Because I have not really got...I'm not really connected with my own like values and sense of
self so I don't erm, know what- I don't know what I would like doing. So I couldn't say like, I love
working with this or that or the other.
PHD STUDENT: I just want to focus in on this whole “I don’t know what to do” I’m just trying to better understand how what you guys might be feeling. I know you mentioned that you felt quite panicked, but I wonder if there are any other emotions underlying in those thoughts?

01012: After a while like I think ( ). You just get, you start to feel hopeless. You start to feel like, there is nothing that will never not make you feel miserable after a couple of years. And then what I’ve started doing is then looking for like, better working environment, like a job that pays a decent salary and a working environment that I don’t feel is like abusive at all- that’s kind of like- you know flexible- that understands that I have like particular needs. That’s what I go for erm=…

PHD STUDENT: =Which will help you deal with some of the hopelessness you might be feeling?#

01012: Not really no. It just makes it easier to not leave, erm.

PHD STUDENT: Yeah ok, that makes sense.

01012: But you do, you just feel more and more and more hopeless because it just feels like I’m not in the position where I could ever not work and I never will be and it just- you just start to think what’s the point because I spent like, I spent more like percentage wise with my time doing this thing and it makes me unhappy.

PHD STUDENT: yeah mean having said that there’s kind of feelings of hopelessness, what do you think you guys- how do you think we could help; healthcare providers can help in that stage?

01012: I think helping us to understand like the work that we’re doing here at or the work I’m doing with my individual therapist, erm, I haven’t really started it yet but I feel quite positive that we’re going to do a lot of work on figuring out like who I am and what I want and finding that disconnect between my- cos I do the things somebody else ( ). I didn’t say anything, I have expectations where I should do this. This is what everyone has always expected me to be all my life, as oppose to ever having thought about what there being even being a me. Like I don’t feel like there is a me and we’ve just got to the point in therapy where my therapist has said “Yeah there is a you, we need to connect your brain back with the you, and then you’ll be able to feel…” I dunno I get the impression that other people can feel like they want to do…

PHD STUDENT: I don’t know, what do you guys think? Like do you feel like you know what you want to do?

01010: Some people feel, I don’t know, it’s almost like people are tricked into thinking about what they want to do but really they are just meeting expectations

01012: Yeah

PHD STUDENT: Ok so actually, sorry go on.

01009: I don’t know I suppose it could probably help if we could.. be… brainstorm your like persons values and own personal goals and then match that with a job.

01012: I definitely agree.

PHD STUDENT: That’s interesting.

01012: and also live work stuff because that comes into it too. I think it’s important for you to have family and how would that fit around the work that []

PHD STUDENT:

[So thing’s outside of work?]

01012: yeah, not just, but yeah- values- it’s the values and all that work (2) that we’ll be doing will start helping us to understand, or will make us happy. Cos right now I have no idea what will make me happy.

PHD STUDENT: Ok thank you. Just to wrap up this section, what would you guys say would be the main challenges for people with personality disorder in general, when it comes to employment, whether it be their thought or perhaps their interpersonal skills, the emotions?

01010: I think the stress of just having to go to lots of interviews.

01012: And the stress of working.

PHD STUDENT: The stress and the anxiety that comes [from- 01009: [We were] just thinking about employment could be just like, why am I expected to work? Feelings of frustration, like why do I have to fit into society’s work? So it’s just like, eugh, anything…. (laughter)

PHD STUDENT: I haven’t heard from you yet, any thoughts?

01011: No…

PHD STUDENT: No thoughts? Ok fine. Ok cool, so let’s imagine you are able to get through that interview process and you’ve got that job, you haven’t quite started but you’ve got it, erm what sort of stuff I suppose, at that moment in time- I’m not sure if you guys are employed or unemployed but if you are employed then imagine when you started and if you are unemployed
then try and imagine what it would be like or what that individual with a personality disorder would be like if they got and started a job, what sort of things might be running through your mind? Things that you might struggle with? Or positive things about that experience?
01010: I suppose just panic.
01008: Panic yeah.
PHD STUDENT: Is that an emotion or would it be more like fear?
01009: It's like you've set yourself up to fail because I've become this person from the interview and I'm like "oh shit, now I have to actually be that person" and it's like oh, what does that mean for me? It's just like more pressure.
PHD STUDENT: And what do you think you might end up doing? Do you think you're able to perform and be that actress?
01009: Like for me personally, I was fine for like a year. But then it just- it got me down so much it was just like "why am I being this person that I don't even know who I am really am". Now that everyone is expecting me to be this person I can sustain it anymore. It's just draining.
PHD STUDENT: If you don't mind me asking, did you end up leaving the job, staying in the job?
01009: I almost did, this December and that, erm, I almost did but I suppose my support of my family and the manager there. They were really helpful, I just stuck it out so I'm still there but=
PHD STUDENT: Oh that's really good to hear!
01009: =yeah so
PHD STUDENT: What kind of stuff did the line manager do to help you feel supported in the workplace?
010009: She suggested I sign off sick for that Christmas period so I could spend it at home. Cos where I work for retail it's just so much stress. With like all these happy people around and you're just like I don't wanna be here around you. I don't wanna pretend to be this person, I just don't have any energy for it. And she said just sign off sick and erm, she was really supportive. And she checked up on me and erm, like make sure I was well enough to come back to work and she just said like, just be who you are, and just tell me honestly if you don't feel ready to come back or you don't have to be this person anymore. Just be yourself.
PHD STUDENT: Yeah, that sounds really helpful.
01009: [So it was helpful]
PHD STUDENT: Really, really, really helpful all those words. I just want to backtrack a little bit, you know we talked about the interview process, what about other things that we do to get work, so some people might go to the job centre, some people might look online, like the applications, or write CV's, what about things like that? Do you find that difficult or easy? Or particularly challenging?
01009:
01012: Too easy. But I overwhelm myself with it. I sign up for like a billion different things and then I get so many emails that I can't even look at them (laughs)
PHD STUDENT: So you get lots in.
01012: Yeah it's really easy to sign up to all the different things but then it's completely overwhelming once they start coming through
PHD STUDENT: Any other experiences?
01012: and also applying to just too many things. Just applying for everything.
01008: Yeah, yeah and just (). (laughter)
01009: you could even be though, just erm, doing like applying for one job and then setting your hopes on that completely and then you're like...yeah.
01012: I think I am so scared of that problem.
01009: Or if you don't get it, and then you're like what's the point? Like I didn't get that one, then why am I going to apply for anything else?
01010: So it could be like one extreme to another, so apply for one or you apply for loads.
PHD STUDENT: So basically it's those thoughts that pop up isn't it? "Oh hangon, what's the point?" Do you think that's something that can challenge you to continue moving forward?
01009: yeah like whenever I have those feelings like I just tell my mum, and she's like, “well no, you can't just have that view point really”. She's trying to make it logical, so that' helpful but I mean I suppose it would be helpful for other people to have that support.
PHD STUDENT: Have another person to support you?
(agreement from group)
01009: Just take it slow, don't put too much pressure on yourself. Yeah, and just focus down on what you really want.
01012: I have the extreme flip side of that, I apply to like 20 jobs and I’m like, “I’m not going to get any of these” because then I don’t get my hopes up. I’m so avoidant at that, that I just- and then if I get an interview I kind of go, and then if I get the job I’m completely surprised. To answer the question you asked before which is what happens when you get the job. I don’t believe that I’ve really got it for the first like, like I get ideal-complete idealisation from it. I’m just like ()…especially if I was parting in like 3 months or something I’m like-

PHD STUDENT: do you think that impacts on how you might behave when you get there? So if you’re thinking “Oh my god, I can’t believe I’ve got this job”

01012: Yes! Yeah, yeah, yeah.

PHD STUDENT: In what way?

01012: I think I put myself down a lot especially when I start a job or I do- I flip, I look at myself down a lot. Erm, if I feel like I’m surprised that I got that job or I do the thing where I have to be this role that I think I must be in in the interview. So it depends on what thoughts I’ve had- like at the interview I thought, “Oh they probably just gave me the job because I’m like the only person who applied” or something like that, then I put myself down a lot so people don’t have expectations on me. Whereas if I think, “Oh I did really well to get that job” I’m like, oh my god I’ve got to be perfect. But either way I get into being “I’ve got to be perfect”. To answer the question you asked before which is what happens when you get the job. I don’t believe that I’ve really got it for the first like, like I get ideal-complete idealisation from it. I’m just like ()…especially if I was parting in like 3 months or something I’m like-

PHD STUDENT: do you think that impacts on how you might behave when you get there? So if you’re thinking “Oh my god, I can’t believe I’ve got this job”

01010: Maybe someone helping you write it?

PHD STUDENT: Do you mean someone as in a family member? Or do you think someone external? Erm, someone who’s specifically from employment or something.

01010: Could be either.

PHD STUDENT: Ok…what about physical health? Is that anything that could have got in the way of getting a job?

01009: For me, I didn’t want to say I wasn’t feeling very well. I would rather just not mention it even though it was detrimental to everything around it if that makes sense. It’s like I don’t want to expose the fact that, (1) that sometimes I’m not well because then that would impact more on not getting a job. Like its more ()

PHD STUDENT: When you say not well, do you mean that the mental health or do you mean physical health?

01009: Eitherway because like, mental health can affect your physical being=

PHD STUDENT: Yeah, that’s true.

01009: = So if it’s just, you’re not taking care of yourself properly you’re not gonna want to go to work and be like, a mess. If that makes sense?

PHD STUDENT: Yeah, yeah , it does. Is that something that has happened before or are you just talking in general when you think about it?

01009: Erm, I don’t know it’s just things that I thought I would end up as but I didn’t- I never, luckily I didn’t get to that point because then it was when I was able to like, to talk to them about it. In the end I’m in my mind I was like, I’m going to end up like just- looking like a pile of poo. Trying to be this person still, if that makes sense.

PHD STUDENT: Yeah [says participants name] do you have any thoughts on physical health?

01008: Erm, just basically, in my one on one I was having to () against my core beliefs and I can see how they have impacted me at work as well. In terms of getting work it’s like, erm, you know, running out and going through every single organisation that I can possible do and just going direct to them. And then, in a job, always you know just, I always () like to the degree and working on the weekends, and Friday nights and Saturday. And it all was very much, very much consuming my whole life basically. So, and I’ve always doubted myself, I’ve always…I was in sales, so it always about targets and about hitting targets and stuff like that. And I always began () targets. I wouldn’t get the numbers and what have you and then I had to be something that I wasn’t.

PHD STUDENT: We moved on quite naturally to erm, like being at work and keeping our jobs. So I’d like to ask you guys again, what were the main difficulties that arose and also the positives in the job; what was it in the workplace that helped you as well when you were there?

01012: Well I’m not very good at staying in jobs so…

PHD STUDENT: What is it about the job that makes it difficult for you to stay?
01012: People...erm...I'm (3) so it's been for different reasons throughout my life but I've left a lot of jobs on bad terms because I didn't feel like I was being treated with respect or...whatever and I just can't tolerate it at all.

PHD STUDENT: Can't tolerate the people or is more about the dynamic?

01012: It's the dynamic, and I can't tolerate it and I can't, I can't tolerate. I've never been able to come up with a reasonable solution, I've always just like (1) ended up getting so angry that I've just stormed out and quit.

35m 53s
PHD STUDENT: Let me break it down there a bit more. 'Cos you say a reasonable solution to...? To what?

01012: It's usually managers, it's usually like () managers and I had one job like, this one, like [says other participants name] just said which was when managers expectations were just like (1) ridiculous, like they actually expected like people to work from like 7 in the morning to 7 at night on like weekends, I'd like get emails from her on a Saturday asking for things to be done by Monday and just like they...no respect for the work/life balance. And I couldn't like, negotiate that I just flipped out one day and was like, "I'm not doing this anymore" and left.

PHD STUDENT: So I can imagine it was a lot of pressure.

01012: Yeah, and that was- the stress of that was too much.

PHD STUDENT: What kind of things were you thinking? Were you annoyed? Angry?

01012: Erm...Really angry.

PHD STUDENT: Worried? 'Cos I can [imagine..]

01012: [worried] a lot of it impacted on my self-esteem a lot because I felt like everyone else, I felt like, they were telling me it was me that like, I wasn't looking up to what I should be able to. So I felt like I was having- I had to do this extra- all this extra stuff. And also because they were quite belittling and like- of my work and they would, erm they would ask me to do things that were quite difficult for me that weren't really in my skills set like. Like I just didn’t have the knowledge to do and then they would like rip them apart and be quite critical. And I found it very difficult to...not just take- I take criticism and I just assume that the person who's telling me the criticism is right. And so I would just be like, "oh I've done everything completely wrong". So I find that hard. And then eventually, someone would point out, usually if I have a colleague or something who’s also struggling with the same thing, who I've become friends with and I’ll trust them or something. And then they will start talking about it and I’ll realise the same thing is happening to them and then I just flip. I just lose my temper because I suddenly realised that I can be taken advantage of.

PHD STUDENT: []

01012: [No no, I usually spend a little while ranting to my friends, family, colleagues, anyone who will listen.]

PHD STUDENT: I think that's quite natural though, isn't it? If you're quite stressed at [work.]

01012: [Then I try and start, erm, I usually try like I don't usually, I've never tried to like resolve it in a good way, I don't think. I always just try and like, become difficult. Become difficult basically at work with whoever causing me problems I just start causing problems back.

PHD STUDENT: What, like by not doing work or?

01012: Just being, just being difficult, being argumentative being- refusing to do things like, and then eventually I will just, I mean like, there was like- in my previous job I had erm..a manager who kept- she was a micro manager. And I'm like extremely liked to be left alone erm, and she was micro managing my management of somebody else. And in the end I just walked into her office and said to her, if you want to manage her manage her yourself and walked back out again. And like refused-

PHD STUDENT: And did that leave things with you and her?

01012: Erm...badly. Then she would send quite nasty emails and stuff like that and I would...I had a couple of really good colleagues who had become friends that were really supportive. They would like- I shared an office with this guy [says name] and I'd get an email, and I'll be like "Oh my god!". And he'll just be like, "Calm down, don't reply, just leave it". Like, so that would help. But in the end that job I just quit. I quit on the spot; well I gave notice but then I called in sick the entire notice period.

PHD STUDENT: So I wonder, do any of you guys experience something similar when you get a lot of pressure at work?

01010: Yeah
Erm I suppose for me it was all self-critical I would always put it back on myself. Because erm, I've got a manager from when I started when I was 16, but basically I've narrowed it down to that she wasn't the one to hire me so she would always cause me problems and I just thought it was because of me. Erm, and it was just that she was asking me to do stuff that like, I'm just a sales assistant I shouldn't be doing all this important paperwork. And then she'd say well you've done a mistake here, and you've done this for a customer and blah blah blah. And it's like, ooh, she told me to do it, and I've done what she's asked me to do and it's like, I put in back on myself and I'm like, why did I do it bad?

PHD STUDENT: So how did it impact you at work?

Erm…I suppose for the first year I was just like, I've only been here a short while like it's fine, she'll get used to me and it'll get better.

PHD STUDENT: Those are quite positive thoughts of yourself, you're like “yeah, well you know”. It was a lot like my mum and dad didn't want me to go out and quit ‘cos we're like, we're about- ‘cos they're very like strict- not strict but they like commitment and they don't want to see you just walk away from something. So I was like, ok fine. So I put myself through it and then as I got- as like my mental health got worse it was just harder and harder because it seemed like it was effecting me more. So it got to the point like before a new manager came I was just, I just hated walking into that place and knowing that she would pick on me. Because I spoke to my colleague and they were like, no I've never done that, she's never asked me to do that. Erm, no she's really nice to me. And I was like, why does she hate me? Is it something I've done? So it was always just, like but it was making my judgements of myself worse. Erm...

PHD STUDENT: What kind of emotions were you experiencing when you were going through things with that manager?

Erm: I suppose frustration but not towards her but myself.

PHD STUDENT: Ok.

Erm: And I was also, I dunno, it was sadness, just sadness about just knowing at the end of the week I would have to go there again. I would have to try and be this person still even though I hate being there.

PHD STUDENT: This is the previous job yeah?

Erm: Well no, I'm still in the same job its just the manager is still there. But there is a new manager there who's like, quite like my…what's the word? I dunno she's just erm...

PHD STUDENT: Someone who understands you?

Erm: Yeah but her sisters got BPD. Erm, she also, the manager doesn't get on with her either so it's like, we both have the same thing in common, like we're just erm…we can stick together and she'll stick up for me 'cos she's quite high up so she'll-

PHD STUDENT: Does she know erm, does she know that you're seeing a mental health service?

Erm: Yeah, she was erm, really pleased ‘cos at like Christmas she was really worried about me but she was pleased- I only recently just started at and stuff so I wasn't really, like on my feet with it if that makes sense. But, erm, yeah she's just been helpful and she gets picked on by the manager but she's told me now to stand up for myself. And she told me what I should do what I shouldn't do, and that I should stand up for myself.

PHD STUDENT: So how did go about disclosing if you don't mind me asking?

Erm: Erm, so basically I was erm, doing unhelpful behaviours and erm…she noticed…

PHD STUDENT: Like?

Erm: Are we allowed to like? Yeah, cos I don't want to like upset anyone?

PHD STUDENT: It's completely up to you what you would like to say.

Erm: Ok, so I self-harmed pretty badly. It was pretty much like every day. And then, I came to work and my arm was pretty messed up so I made up this lie about my dog scratched me and I was like oh it really hurts and I can't really move my arms so don't ask me to carry clothes in or whatever. So then, erm…I was reaching up to put something on the shelf and I suppose she saw my arm. I was a bit like, dodging it, trying to ramp it up. Erm, so…we were cashing up together and she said, "look if erm, if you don't mind me asking like, erm, are you like, self-harming? Because my sister’s in hospital because she has- she said I'm really worried, is it because you're here you do it? So then I kind of like spilled my guts out to her. Erm, she was really lovely and she was really supportive because her sister has the exact same thing.

PHD STUDENT: So she had an understanding.

Erm: Yeah.

Erm: And she was like, to be honest she shouldn't be treated you that way by the manager, and she was like you just need to stand up for yourself more. Even though I know it's hard but
she was like, I'll be there to stick up for you as well and tell you what's what. So (3) though the manager is still there its better because my other manager is there to support me so she can kind of put the other one in her place. Does that make sense?

PHD STUDENT: Yeah, yeah, it does, what about others? Any similar experiences or? What about you [says participants name]?

01010: Erm, I [suppose]

PHD STUDENT: [You were teaching before] weren't you?

01010: Yes, but very stressful job. And things have to be done by a certain date as it's- 'cos it's their exams and stuff. And I wouldn't say no to anything so they'll give you extra stuff to do. And I'll just keep doing it til it got too much and then I'll be off sick for like 3-4 months.

01008: That's amazing.

PHD STUDENT: So it sounds like you actually have a…it's a manager who is very understanding.

01012: The thing is I was like working in a department, a research department which is a health care research department between psychiatry and general practice, so my two managers are psychiatrists and GP.

PHD STUDENT: So it's a natural [ overlapping speech]

01012: [Overlapping speech] As soon as I said my diagnosis he was like, ok so you're not going to know what you need, it's going to be unpredictable, we'll review it as and when, whatever you need, just let me know.

PHD STUDENT: So having said [that…(i)]

01012: [I still ended] up getting signed off cos I still- I still couldn't

PHD STUDENT: Having said that, I've noticed there's kind of a mix between some managers understanding and some really not and it making a huge difference so what would you guys say would be helpful I suppose for people with personality disorders in employment to help support them?

01012: It's training for managers because and like..

01010: yeah

01009: I suppose distress tolerance and interpersonal effectiveness that kind of thing.

PHD STUDENT: So getting training in those sorts of skills?

01009 & 01012: Yeah.

01012: Skills for us and skills for them isn't it?

01009: I mean, it's all well and good if we know the skills but they're not gonna- sometimes they don't wanna accept it or they don't want to reciprocate and try and help out. But it's not a give and take type thing sometimes.

PHD STUDENT: Sure, sure. [Says participants name] I want to hear a bit from you because I haven't really heard from you yet today.

01011: Ok, erm, the thing they said for the training for the managers is, I think it's really important because they don't want to understand, I think they don't understand. If I, if I disclose
the problem, like I have personality disorder or something like this, they don’t understand this term. So they will take it other ways and I don’t want this. I need to hide actually, that I have this problem.

PHD STUDENT: So you don’t tell them? Are you working at the moment?
01011: Yeah, so and like yesterday, I have this mid appointment for today and they were texting me, my area manager was texting me to go to work today, and I said I can’t because I have an appointment at hospital. And still they were forcing me to go, they were saying so many things like, “you have to come or something like this” and I was so stressed, anxiety, so many feelings that I don’t know how I can make them understand. Like they don’t want to understand actually.

PHD STUDENT: So what did you end up doing?
01011: I said I can’t, because it’s very important for me.

PHD STUDENT: Well, well done! (Laughter). That’s really effective.
01012: I think it depends on the people because I know the mental health act inside out so I know what my rights are. Erm, but I don’t always feel comfortable asserting them. Like in my old job I was forced out because I was having mental health problems and they basically somehow made me quit. Which...

PHD STUDENT: The thing is you’re absolutely right in saying that you have rights.
01012: But, I think some kind of like, if they were people who in, I don’t know even in the health care service or in employment who will like, employment support kind of workers who could imp-like you have your erm…union rep or whatever, so if you have someone who could come with you and say to them, look, she’s got this, it means that her rights are to go to appointments to be treated. Her- any absence related to this, treated as a disability. Absence is not (). You’re not allowed to ask her to cancel appointments because they are related to long term mental health conditions as oppose to erm…as oppose to just being long sickness.

PHD STUDENT: I just wonder, sorry hold on [says participants name] is that something that you have had before? This sort of information that Katie has mentioned? Do you know there are options out there?
01010: Yeah, I know there is information out there.
01012: But it’s hard to assert them isn’t it. Like I couldn’t- having a person who could help you do it.
01009: Or even just like an information pack that you can give your employers saying…fair enough if you don’t understand but here is someone that you can talk to if you don’t understand what I’m going through because then that will really help me if you knew about it and ways that you can help me.

PHD STUDENT: You just reminded me and I forgot to mention earlier in the introduction that this is one of our aims of this research. The three main aims are we want to develop an assessment tool, a questionnaire. So people like myself, you know what’s going on for you right now, whatever difficulties we can try and gauge and can try and see what would be helpful for you guys. We also want to develop a positive manual for employers, like you mentioned [says participants names] specifically for employers to use so they can perhaps introduce some reasonable adjustment, and then we also want to develop an intervention which is based on DBT but specifically for employment. So those are our main aims, so it’s good to hear you say that. Was there anything else you wanted to add?
01009: [nothing]

PHD STUDENT: Ok thank you.
01012: Occupational health services as well could do with some training on personality disorders because I had a really bad experience with the occupational health service at my work when I was first diagnosed where I was waiting to get into the car and I didn’t know whether or not I was going to be- whether my referral was going to be accepted or not. So I was just in this like unknown period and I got phoned by a worker at occupational health who said they had a counselling service who would be able to- and I got- initially I got a phone call from them saying they would be able to offer me like 24 hour phone support, weekly appointments blah blah blah, I was like, this is amazing! And then I got a call week later saying actually, we’ve just like reviewed your notes and we can’t offer you anything erm because you’ve got this diagnosis and because you’re going into mental health services. And, but the way they phrased it made it sound like it was basically like you’re a lost cause and there’s no point even trying to help you. It made me suicidal. Like it was really, really, really bad and they obviously- PHD STUDENT: How do you think they could have better said it?
01012: Well I’ve learnt since that they are not like legally allowed to treat. So counselling services are not legally allowed to treat people with personality disorder because there was a
spate of suicides because they didn’t know how to treat them, erm…so if had just said that to me, if she’d just said, we aren’t qualified to work with somebody with your diagnosis. As oppose to making it sound like it was your fault. Instead of saying you’ll get attached to the counsellor…

PHD STUDENT: So actually it goes back to better training isn’t it? I just want to come back to [says other participants name] ‘cos you talked about being quite overwhelmed as a teacher, do you think having said talking about potentially addressing occupational health, or line managers to be better trained, do you think that is something that could work for you in that situation?

01010: When I went to occupational health about 3 or 4 times after I’ve been signed off sick and then I’ll go back and no one would talk about it. And they wouldn’t help me they wouldn’t do– it was as if, don’t talk to her about anything and it’ll go away.

PHD STUDENT: Gosh, that sounds terribly, that sounds awful.

01010: Yeah.

PHD STUDENT: So actually it goes back to better training isn’t it? I just want to come back to [says other participants name] ‘cos you talked about being quite overwhelmed as a teacher, do you think that is something that could work for you in that situation?

01010: Yeah, yeah, and then what did you do then afterwards?

PHD STUDENT: Ok..ok.

01012: Yeah my experience of occupational health is they tend to- ‘cos I have another appointment in about two- three weeks time. So I know- because I’ve had one before I know what’s going to happen and I walk in there and they say “what do you need us to do to support you”. And I say, “I’ve got no idea and here to ask you, what you- like aren’t you supposed to be the ones trained in mental health?”. So again, it’s like if they- they need to be trained in like what, because we don’t know what support to ask so I’m going to have to work with my individual therapist to try and work out what it is that I might need and also, they need to understand that like getting back into work isn’t actually a priority at the moment, although I can function, it’s blocking my progress in therapy and all those things. And my manager understands that but occupational health seems to have no clue, so yeah, just information for them like, personality disorders and mental health being different.

PHD STUDENT: I have some additional questions as well, about motivation and satisfaction when it comes to work. If you guys just thinking about being in the workplace, and you’ve been given a large work load and you’re thinking “oh gosh, you know, I’m just going to say yes, yeah I’ll do it” or “Ok so I’ve got to do all this work, I’ll do it all” but you’re also feeling slightly more panicked, a little bit more anxious, which may lead you to not being able to finish the work and then () because you’ve realised how much work you’ve needed to do and said yes to. So I would like to know if anything other than, I suppose label if you want to call it that, things like poor sleep, or physical health, would that impact your motivation to go to work?

01012: Definitely sleep yeah.

PHD STUDENT: Anyone else?

01009: I’ve noticed since like, they’ve upped my medication and said that I could take a herbal nyghtol over the past two weeks my mum has said just how different I am cos I’m sleeping properly. So she said you’re like a different person because you can get a proper night’s sleep and like you wake up and feel better because you’re not exhausted all the time.

PHD STUDENT: Does that help with your motivation?

01009: Yeah, definitely, I’ve started doing stuff again, I’ve gone out and I’m doing stuff with group and I feel more engaged with people.

PHD STUDENT: I can imagine how it helps when it comes to work as well.

01009: Yeah, like for work, it’s not as, it’s still difficult to go to work but I know it’s not going to be as hard and my manager is there so it’s more like I can reason with 57 m 50s myself easier, like it’s more of a positive argument than a negative. If that makes sense?

PHD STUDENT: I wonder if you guys can imagine a time where you might feel quite demotivated at work. What have you done with that? Have you gone to work anyway? Or went to work but didn’t do the work at work?

01012: I just don’t do the work. Well it depends on my circumstances. So my current job, I work from home but I don’t do anything. Erm, sometimes, and this is why I end up getting myself signed off because I’ve also got very high standards for myself. So I’m not happy with myself. Like I beat myself uploads for doing that. But I also can’t not do it and I just sleep all day or like.

PHD STUDENT: So how do you think your thoughts and emotions might impact on motivation?
01012: I just feel like so overwhelmed that I can’t start anything, because it just feels like too much. Erm, or like, I have- certain- so one main thing that I do, and most things I can do I get this like, feeling like there are all these things clustering around in the background like emails and things that I’ve let slip and it just feels like things are sliding out the edges of my…

PHD STUDENT: It’s like a sort of feeling?

01012: yeah, like a kind of, like chaos, kind of like I’m not very certain, not very good at labelling emotions.

PHD STUDENT: That’s ok, what do you guys think? It sounds like anxiety? Maybe a bit of fear?

01008: Kind of like a panic.

01012: Yeah…and also…

PHD STUDENT: And worry thoughts?

01008: Definitely.

01009: But mainly just the frustration that you can’t. It’s like I always feel frustrated that I can’t just do it.

01012: and also if it’s boring, coz I do consultancy work and sometimes in consulting it’s really interesting but it can be boring. So if it’s interesting or if I really like the person that I’m advising then I’m motivated. But if it’s a really boring project or I don’t like the person then I’m not very motivated at all.

PHD STUDENT: Unfortunately it’s really tough because at work you’re going to have to do things that you really don’t want to do.

01012: But those are the times where I almost can’t push myself over the edge.

PHD STUDENT: does anyone else experience something similar to that? So when you have to do something at work that you don’t want to do.

01008: No, well I’ve always felt this way in sales, or close to it and have a skill that allows me to rebound out of situations which is great, so if I get rejected by someone like that then I can get out of the situation, which is good. The problem with that is I’m not in touch with my thoughts and my feelings. So, if I’m having a bad day at work then I’ll just go home, get fresh and then go back in and tackle it again the next day. So…

PHD STUDENT: but then what happens in the long term I suppose?

01008: Er…well, that. It’ll just get to the point where I just can’t take it anymore.

PHD STUDENT: It doesn’t help you in the long term yeah.

01008: It’s interesting ‘cos I never actually saw there was anything was building up some way. It just actually got to this level.

PHD STUDENT: What was building up, these feelings of all the work?

01008: Just in general, like everything. Everything was building up to a point. I wasn’t even aware of it, just got rebounded out. I just wasn’t in touch with it, so it just whatever. I just got up and did it again, got up and did it again but after a while you hit a wall. And erm, it didn’t matter what was coming, I felt like I was against the wall but then one day, you know.

PHD STUDENT: I know we’re talking about things in general, but I wonder [says participants name] what do you think could have helped you in that situation?

01008: Interpersonal effectiveness, and the stuff we’re doing at IMPART has made a load of help.

PHD STUDENT: yeah, and those things can be applied to work?

01008: Oh yeah, absolutely. God yeah.

PHD STUDENT: Can you tell me anything specific?

01008: Erm, just like we’re doing a lot of work on interpersonal effectiveness and being able to ask for what we want for and so forth. Erm, and just like one specific thing was that, erm (1)…

PHD STUDENT: that’s ok.

01012: But you’re getting really good, like, ‘cos we’re in the same group and some examples that [says other participants name] gives you can see how much you’re learning from the group. Like how do I ask and how to say no as well. And I agree, it helps a lot.

PHD STUDENT: Has anyone had any similar experiences of wanting to ask for something at work? Or wanting to say no at work but finding yourself not being able to quite do that?

01009: Yeah like saying no to doing any other extra shifts.

PHD STUDENT: Ok.

01009: ‘Cos I’m only supposed to do like 4 hours which is nothing really. So 4 hours is like, I can just logically say it’s only 4 hours then you can go home. But it’s like I’d go there, and I’ll be asked to do people’s shifts during the week and then, or shifts the next day like on the Sunday. And I’ll be like, yeah, ok, sure and then they’ll ask again and again because they’ll no I’ll say yes. And it’s like, how can I say no because I don’t want to make them to feel like I don’t like
them or that I’m being horrible but I can’t manage it. So it’s like, well I’ve got to the point where I’ve spoken to my manager and I said just don’t ring me up during the week please, don’t offer me extra shifts. I can just do my 4 hours that’s all I can manage but please don’t put me down on the list to be asked by people because I sometimes I can say, well yeah I feel ok I can do your shift but you cover mine next week, so then it’s like I’ve not put myself out for no reason. They’re doing me a favour as well.

01008: That is really good.

PHD STUDENT: So my last question is around satisfaction, so I want you guys to think about in general, what sort of things would satisfy someone at work?

(laughter)

01010: Being valued?

PHD STUDENT: Being valued? Ok, can you expand on that?

01010: Just sort of acknowledging what you’re doing is good, rather than just picking up on stuff that you’re not doing.

PHD STUDENT: Yeah I can see that criticism versus being validated. Were you going to say something?

01012: I was going to say the same thing because that’s what kept me in my current job, they’ve made me think although I’m currently considering that I might do a career change, I will go back to this job because of the fact that they value me and respect me and will say to me, you know “we trust you to do your job well, even though you’re unwell, we trust you to tell us when you’re not going to do it”. Or there’s these kinds of things that like- it’s similar to what you were saying about the new manager who values you, is like – it’s a lot to have somebody who likes, values, but that’s not something you really can impose on. I suppose to can teach managers skills and validation but like- yeah maybe even if they weren’t naturally like that they could talk about people’s efforts more. Erm, like [says other participants name] would say instead of picking up on what she wasn’t able to keep up with also validating all the extra stuff she was doing and just validating that it was a lot of stuff she’d been asked to do as well. And that other people struggling and stuff like that.

01009: Especially because like find it hard ourselves, I don’t know about everyone but I find it hard to validate myself, so it’s even harder when someone invalidates you coz you then start [doing it wrong]

01008: [yeah..()] It just makes the situation worse because you’re already critical of yourself, and then if there is someone else it just makes you feel worse.

PHD STUDENT: What about from other work colleagues?

01012: that helps a lot too.

01008: I think it’s important to get along with work colleagues. Yeah, we’re there to do a job but we’re also work colleagues. One thing we used to do in [states country where they’re from] that they don’t it here as much erm is go out for drink, or something like that, it was real, you know during the week we worked hard and we’ll set our targets and do what we’ll manage to do but come Friday, it was like a big family sort of thing.

PHD STUDENT: That sounds quite nice actually. I wonder, you guys talked a bit about reasons for working, some mentioned good salary job, some look for things they really enjoy, and I just wonder if that has a part in satisfaction at work?

01008: Yeah, absolutely, yeah definitely, you know, if I could I would love to do a job that I just loved to do. It wouldn’t even feel like a job, it would feel like, you know.

PHD STUDENT: It wouldn’t be like work because you’re enjoying it. Any other thoughts? What else could satisfy you at work? Or how would you picture a satisfying job I suppose?

01009: Erm, I suppose just maybe you be able to walk away from it, like having a job where you didn’t have to go home and stress about it or think too much. You’ll be able to separate your life from work and yea.

PHD STUDENT: Ok right, cool, well we’re coming towards the end is there anything you guys feel like we haven’t talked about already when it comes to particular challenges or barriers when it comes to personality disorder in the work place? As well as supports to help you guys that we haven’t covered already?

(laughter)

PHD STUDENT: Ok…so now, what do you guys- so everything we discussed today, we’ve discussed loads of things from line managers understanding PD, anxiety, values, what do you guys things are the main struggles for someone with personality disorder in the workplace?

01012: I think maybe, like you said, your 4 hours a week and things I think an understanding and validation and that for us, that actually ‘cos I think that one of the biggest triggers for lots of
us is stress, erm and we probably are more vulnerable to them than some other people are and so maybe an understanding for us as well. Like training for us and the fact that we need to recognise earlier when we’re putting ourselves under stress and also we maybe need to not work full time jobs. Or like consider- take into consideration perhaps that we can’t do everything perfectly the way we want to do it, like helping us to say no to that. To be like actually, no, because of my personality disorder I can only work 20 hours a week, because or I need more holiday time or even like, cos like what I’ve done, what I’ve done at the moment is I’ve actually taken a period of planned sick leave so I gave them a month’s notice and then went off sick. And because my job is miraculously understanding they let me do that. That sort of thing I think can be built in to people being able to say, I can feel myself- ‘cos when you’re going down, you’re going down, you’re not gonna like, you need that break. And it ends up forcing you to leave jobs a lot of the time.

PHD STUDENT: So you’re saying actually, one of the main challenges really is stress, and one may be more vulnerable to it being triggered and that having something in place, or knowing, or a structure where you can- be able to sign off sick.

01012: Or even an occupational health help.
01009: Like a kind of risk assessment type thing.
01012: Or like if occupational health can help you structure your holiday time sort of thing. Maybe they can say to you, like you know, like it would be helpful for you probably have like a three day weekend every month so that – can help you plan, ‘cos I just can’t plan at all. And then I’ll just be like burnt out. Then I’ll have to use sick time as opposite to if I planned my holiday time like more appropriately I’ll probably be a bit better.

PHD STUDENT: So having someone there for you to help you plan. What about any thoughts on this side? So we’ve got, again I’m asking you know, the main overall challenges; we’ve got stressors, feeling stressed in general, and things that can help support that. Anything else other than stress?

01010: it’s like having the confidence to do it, to go and try. Like a new job or to try for interviews. Just like the confidence.

PHD STUDENT: So finding that confidence?

01008: Self-belief, I think as well like to be able to believe that you can actually do it and do the job. You have faith in yourself I think as well, you know, just being able to know that you are, like for me, you know “I’m not good enough, I’m a failure” but to know that I’m actually, I am good enough, and I am quite capable. Not every job is for me but you know, but being able to do that instead of grabbing the first job that comes to me. You know, I am looking for a salary but ()

PHD STUDENT: Yeah, yeah ok. Any thoughts [says participants name].
01009: Erm, I dunno just suppose getting over that first hurdle of erm...not setting yourself up to fail as in, not becoming this person that you won't be able to sustain.

PHD STUDENT: So being realistic?

01009: Yeah so being realistic and maybe just erm...you know, just making sure that you’re doing what’s right for you and looking for jobs that are right for you.

01008: Rejection as well. Not taking rejection personally, erm.

PHD STUDENT: Easier said than done. What would be challenging about it? Is it the thoughts that come up? Or how it leaves you feeling?

01008: Just your feelings, ‘cos like you’re going for a job and then you get rejected and I would say, I realised I did my skills so it’s alright, and then you get that 10, 15, 20 times in a row then it’s actually can really hit on you and some days your I guess for me my- one of my core beliefs.

01012: Asking for feedback can help with that, because I’ve had a few of those where I felt really bad after a job rejection and then I asked for feedback and the feedback was actually just really- was like- general- there was some really nice stuff in it and there wasn’t anything like critical, there wasn’t anything like you didn’t answer this very well, or you didn’t do that very well, it was more like “we thought this was great about you!” “We thought that was great about you” but we had another applicant

01008:=who was, who was

01012: =who’s got 10 years more experience than you.

01008: So I guess knowing those sorts of skills, and knowing that you can ask for that information..

PHD STUDENT: that’s very much assertive skills isn’t it? I was just thinking.

01008: Yeah, yeah or just knowing that you can actually have that information coming back to you.
01012: You can't always but.
01008: No, but yeah, just knowing that you can ask, yeah exactly.
(laughter) 01012: It's just sort of happened to me 'cos like, I dunno in academia it's more like, they all say, we'll give you feedback if you want and stuff like that and I also have applied for internal jobs before and not got them so then I've known the people who are hiring and it's easier then to get feedback because you know them.
PHD STUDENT: Ok, and any last thoughts [says participants name]?
01011: No
PHD STUDENT: ok, alright, so erm, that's it for today, I hope that was ok.
Appendix 20 Focus Group Client Transcription 2
(Chapter 3)

PhD Student: Yea, thank you for coming today! So, um, why are we here? So EMPOWER, uh, we are here to develop a questionnaire, an assessment tool, that’s my thesis. Um, we’re trying to help— use this tool to help identify particular challenges or difficulties that people with PD or Personality Disorders may face in the workplace. We can use it so we can better inform them what service they can use next and what areas we can help them in and better support them in. Um, we also want to develop an intervention as I think some of you guys are well informed about, to help people get back into work. And we also want to make a positive manual for employers to use in the future and that’s to better understand what some of the difficulties are you might be going through and how um, what we call you know, 'make adjustments in the workplace.' So um (1) yea, obviously we’re not going to develop any of those based on something that we’ve just made up. It’s actually really important to find out what it is otherwise it’s going to be completely (. ) useless. ((laughs)) Does that make sense? Cool, so, has anyone taken part in a focus group before? Or perhaps run one before? Got some nods. What do you usually expect, if you don’t mind sharing?

01001: Um (1) usually it’s just where there’s no right or wrong answer. And you can say whatever you think. If it doesn’t apply to you, it’s ok say that. Usually people take it in turns to speak, the sort of normal thing you do anyway in a group.

PhD Student: Yea, yea exactly. You’re definitely right, there’s no right or wrong way of answering anything, I genuinely want to know what’s going on for your guys. U::m but yea, it’s the coming together and sharing and hearing other people’s ideas. So we can get a better understanding of employment which is the topic at hand. Yea, cool, so do we have any questions before we start? (2) Ok, so it’s half two now, we’ve got the room til four. I’m going to try and aim to finish before four ‘o clock, so hopefully like quarter-to or something like that. Um ok, so, we’re gonna—I’m gonna ask questions um broadly around different stages, it’s what we kind of coin them. So the first one would be thinking about employment, so all the elements around that. The second stage would be, you know obtaining— getting, getting work and the processes around that. And then the third part of employment is you’ve got work and um it’s about keeping your job and staying there. So I’d like us to think about the first stage, so thinking about employment, Whether you’re in work no::w, you know regardless of where you are on the pathway for employment, but that stage of thinking about employment. What would you guys say (1) in general would be the main difficulties that you might come across when it comes to thinking about employment? (2) ‘Yea.’

01006: Um interacting with people, it scares me.

PhD Student: So do you mind expanding a bit m↑ore? So what is it about interacting with people? Is it talking to the::m? O::r=

01006: =It’s everything. Because I’ve got social anxiety, so um obviously that’s a huge dilemma because if you want to work, most of the time you have to work with people. So=

PhD Student: =So when you’re thinking about work, you’re thinking ‘o, god I have to work with people.’

01006: Mm

PhD Student: And so would you say it’s the thoughts that kind of pop up the most?

01006: Um, yea, ‘I can’t do it,’ that’s what I think. I can’t do it because I have to go to an interview and that’s like the most scary thing for me you know.

PhD Student: Yea, sure. And what’s helped in the past?

01006: Um, nothing.

01005: Didn’t you have someone come with you last time or something? Like didn’t you have=

01006: =Like now?

01005: =Like didn’t you have an interview to go []

01006: [:I’ve never had an interview ”before”]

01005: =Oh, cause I thought with your um boyfriend, you= 01006: =We just turned up.

01005: Oh, right

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I'm working with my boyfriend now, so=

PhD Student: =So you're working at the moment?

01006: Yea, yea, yea. Just like, part time. Um, but it's a lot easier with him, but that's not really a realistic (.) um option, you know. It's just like a short-- short time thing. But in real life, you can't have someone working with you like that you know.

PhD Student: May I ask, did you get the job through him or? Ok.

11:57

01006: Yea, I didn't do anything to get it.

PhD Student: 'I see.' Has anyone else had a similar experience-- similar experience to (states name) in the sense um, you know having to interact with other people: e, having these thoughts that come up? (1) Got a nod over there, do you want to expand?

01003: The thought of an interview terrifies me. Um, my last job was working with my mum. She had her own business so I didn't have to interview for that=

PhD Student: =Ok

01003: And I had that job for three years and it went well until it didn't ((laughs)). Um, but yea, I still haven't had an interview. But, um I did get one for an NHS job about a year ago and I just couldn't go. The anxiety was just too much, I couldn't leave the house, I kept getting changed, nothing looked right, nothing was appropriate=

PhD Student: '=Oh no.'

01003: And I called and cancelled and lied. Um, but yea it's just uh, I guess the fear of judgement, what um people might think if they see you um reacting the way you do (.) I suppose.

01005: Yea, I think it's the fact that nowadays they make such a huge deal about like (1) like you see all these interview techniques on YouTube and all that stuff; and they're purposely coming out with questions to trick you and things like that. So for me, the biggest challenge with interviews was like 'what if I answer something incorrectly?' And you don't know how much humour you can use. Like, sort of like=

01003: =Gauging.

01005: Yea, it's just the sort of fact that I feel like the interview is almost like an obstacle course, like they're purposely trying to throw things in your- under your path, to like to catch you out. And it's like, well no that's not getting the real- to know the real me because if you wanted to get to know the real me, you wouldn't be putting me in situations like that because that's not getting to know the real me, that's getting to know the anxious me; the me that's kind of freaking ↑out about things because I don't know what to ['expect'].

PhD Student: [So, (states participants name)] what would you find helpful in that situation then? If you-- if I were to ask you for an alternative, 'what would you suggest? ''

01005: (1) I think that rather than-- for me personally, what I found is that um and I think that will very much differ from person to person, but for me personally, I prefer to do like, days when you have to like (.) like trial shifts rather than like interviews interviews. And like just spending a day trying out what it would be like to work there rather than-- so (1) like with one of my jobs, I had to go into the office for a day and just do the day to day stuff that I would be doing. And

14:40

they just got to see how I was handling it. And that was a lot easier for me than sitting in a room with someone and they were trying to gauge in half an hour what I'm like.

PhD Student: So actually what you're asking for is perhaps a more realistic process=

01005: =Yea.

PhD Student: in terms of looking at someone's competencies.

01005: Yea.

PhD Student: Yea, ok that makes sense. I just want to come back to you (states participants name), what would you say um would be-- would've been helpful for you about a year ago (.hhh) you know with the thoughts that were coming up and the anxiety that you were experiencing, what do you think would've been helpful?

01003: Um (2) I don't know. I agree with what you said, definitely. Uh, trial day or something. Um because when you're in front of like an interviewer, obviously I've never done it, but I imagine it's more like sitting in front of a judge. Cause they are literally judging you ((laughs)).

01003: Judging if you're good for the job, judging if you're a good person or whatever. Um so yea so maybe a trial day cause then they're actually judging you on your skill to work rather than what you look like or what you talk like or (2) that makes sense?

PhD Student: Yea, “yea”
PhD Student: Ok. If that was just one person, maybe but even as soon as I think there's more than one person all staring at me (laughs).

PhD Student: I'm from a world-- say you said to me, (states participant's name) tomorrow these 10 chairs around this thing need to be replaced, I would get them replaced tomorrow. But (1) before I've priced the chairs up, checked that they're recyclable, checked that they're (1) correct, checked the health and safety boards, checked the finance minister has paid for the chairs, checked that the shipping from Japan has been sanctioned, I've lost it; I'm not interested anymore. It's gone, it's too much. You told me to get you 10 chairs; I've got you 10 chairs. That should be enough. The rest of it is just gumph! It's just health and safety (1) crap.

PhD Student: =Ok.

PhD Student: So do you think it's actually-- and I suppose I'm opening it up to you guys as well. So actually-- 'cause it sounds like it's a system thing as well, so it depends on the actual job. Right so some jobs may be more bit suitable to what you're looking for but the one's that aren't, that's almost like a barrier [so all these things come up],

PhD Student: =It's 'cause of the prejudice=

PhD Student: Or you've got mental illness plus unemployed for [such and such.]

PhD Student:  

PhD Student: =Course it is, all the time.

PhD Student: 'We::il, I don't even want to to apply for this job (. . .) because they're just going to do this. 'They're just gonna spend 5 minutes to judge' on your credentials and then ([)])

PhD Student: [And that adds to your anxiety] [and you::r] frustration.

PhD Student: [adds to the anxiety]. Go on (states participant's name)
01004: Can I just ask, um when, when an employer is looking at— is gonna (.) employ someone, um do they— do you have to let them know that you’ve got=
01005: >>No.<
01006: a mental illness or can they check that somehow?
PhD Student: Um, they can’t check it unless you declare it. Um and it’s up to you as an individual if you want to disclose it or not; as far as I’m aware. Um but we can talk more later if you want— if you have any more questions. Um, ok, thank you. (States participants name) did you have anything to say? ‘Cause I’m aware— from your— from your experience.
01004: Um, well I haven’t worked since I was 16 so um it’s gonna be a big like culture shock to me.
PhD Student: So it’s the time?
01004: Yea, it’s the time frame and the fact that I’ve been bringing up children. That’s what I’m anxious about and everything’s about technology. You know, everything’s on the computer and that makes me anxious. You know about being re-educated and that. I have to re-educate myself on certain things (.) that’s what I’m anxious about, yea just being with other people, y’tea.
PhD Student: That makes sense
01004: Yea.
PhD Student: Yea, ok. Was there anything else that you guys want to add?
01005: I think when I was thinking about um getting a job, um on previous occasions, one of the big ones for me was also like um (1) the (1) not just the judgements but also (1) the fact that sometimes I know and this kind of links back to the work trial again. I don’t mean to kind of drift off into that, but I knew that I was capable of doing a certain job. But I wouldn’t (1) because I don’t have the um— on paper it doesn’t have all the sort of evidence supporting it. Um, I just feel like they’re just going to (1) dismiss me. Like, I feel like a lot of the time I don’t stand a chance because I don’t have the correct— like they have the sort of— ok so you [would’ve gone]
PhD Student: [So you said you feel like they’re going to dismiss you=]
01005: =Y’tea
21:27
PhD Student: If I were to ask if you could put a label on that emotion, what would that be?
Would that be a fear that you’re not going to be accepted? Would it be anger? Like ‘I’m really pissed off, you’re not even giving me a chance?’ O:,:)?
01005: It’s um (1) it sort of saddening and it’s sort of disappointment, before the act. Because I (.) sort of feel like they’re going to look at the CV and they’re going to say ‘ok, she needs to go to this— she needs to have gone to university, she needs to have done the things— the correct pathway to get there. But obviously a lot of the time there’s different paths to the same goal. And I feel like (1) if you haven’t gone down the right path, that it’s gonna get dismissed. It makes me really um (2) – it’s not really say but it’s sort of um=
PhD Student: =What do you do I suppose? Do you not even reply— apply for that job? O:,:) do you apply for it ‘anyway’?
01005: I usually don’t apply because I look at it and I go ‘I could do this::s!’ I have done this in the past but they’re not going to take me so then I don’t bother.
PhD Student: (.hhh) Ok.
01002: So you’ve already got a preconception fear that you haven’t ticked all their boxes so think it’s an irrelevant act of doing it in the first place.
PhD Student: So what’s the point, I’m not gonna (.) bother.
01005: Because they usually have like things that you need to check. But even if you’ve done it in the past and you haven’t checked those boxes as you said, then it’s not=
01002: =But the thing with people our age, not your girls’ age. (4)The Branson’s of the world and you know these you know captains of industry who started off in the market stall, those days have gone. It’s impossible to do that now. It is, it just is! You have to have— you have to abide by the pigeon holes that people put you in i.e. (1) GCSEs. I mean they’re telling me now that kids have got to go to school ‘til they’re 19. They have to get a minimum of 5 A-C’s, they have to! Otherwise they have to get further educated again. So already (1) you’re pigeon holed. So already we’re way (). You know, so if I’ve gotta sta::rt at 16, I’ve got 25 years of experience (1) gone. That cannot be carried over. So, what chance have I got? I want to be in the workplace for another 20 odd years, until I retire hopefully. But if you’re telling me I’ve gotta go start with a 16 year old [again, what] chance have I got?
PhD Student: [Yea, yea, yea]. ‘I think that makes a lot of sense.’
01004: Yea, you feel like hopeless=
PhD Student: (States participants name), you were going to say something?

PhD Student: (States participants name), you were going to say something?

PhD Student: (States participants name), you were going to say something?

PhD Student: (States participants name), you were going to say something?
throughout the cold months, absolutely fine, wear a long sleeve if I can under a uniform or whatever or whatever I'm wearing. But um, as soon as it gets really hot, I don't even see my family, never mind go to a job. 'You know what I mean, so=

PhD Student: =So does that influence um the sort of jobs you go for?

01003: Ye: a: I wouldn't go for a job that requires wearing a uniform! Only something that requires wearing my own clothes where I can wear a long-sleeved top whenever I need.

01002: As an employer really, when they come to you in the summer months and their office is full up of you know, people wearing their blouses, they'll say ' (says participants name), what's the matter?'

01003: =Yea, 'why are you wearing long-sleeves all the time’?

27:26

01002: And and straight away, your issue is (1) in the public domain. And that's it, you go back into ( ) position, you: r ruminations kick in and you just leave. And you don't wanna be there. You know anxiety's a "bi: tch," I hate it!

01005: I was- I was actually very lucky because in my job, I sometimes when I cut, I cut on the top of my a: rms. So I work in retail so as soon as you go on the tills, it's out there for the world to see. But my employer was really good because she— 'cause I'd spoken to her about this and she said 'well ok, we can get you some long-sleeved shi: rts if you want?' A::nd she also lets me like— 'cause I've got quite a lot of bracelets. And usually you're not allowed to have as many bracelets, I've usually got more, but she's quite happy for me to have a lot of bracelets because she knows it covers it up. So (1), you know she does do these little things that (,) on the surface don't really seem hu:ge but it does like help you so much because when somebody comes up to your till and they're looking at your arms and you can see what they're thinking— it feels like you can see what they're thinking "cause you can't". Feels like they're judging you instantly, it just lowers your confidence like (states participants name) was saying, your confidence is just just shot. So um, actually that was one of the things that I found very very helpful with my employer.

01002: That's lucky, but (. ) on the [0]

PhD Student: [Has anyone – has anyone else experienced—]

sorry (states participants name) to cut you off. Um experienced um I suppose support like that in the workplace? So moving along from— we're moving away from thinking about employment, we're talking about being at work. Um, yea has anyone experienced any support or lack of (h hh) uh in the workplace? (1)

01004: I mean I had a lot of support when I was 16 'cause my manager paid for my rent, if my shoe broke he'd pay for everything. And I was working in Old Street, so he was really good to me. So he helped me like basically get up the ladder. And he didn't want the money back with my rent and things like that. So (1) that was really good, he supported me a lot my manager did=

PhD Student: =Yea

01004: He was great, yea.

PhD Student: =Yea, yea. So that's so— ↑ ok, has anyone else had similar? Similar experiences?

01005: I've got some more to share if you want to hear 'em?

PhD Student: >>Yep.<

01005: Um ((clears throat)) I actually um– my manager– usually my issue is that as soon as I tell my um employer that that is the issue I have- because usually how it starts is that one day I get overwhelmed and I don't turn up for work. And I call in sick or whatever. Then they wanna know what's going on. If I tell them I have this mental health issue, from then on, they don't fire me because I have anxiety or whatever, but they create— it feels like they're creating the environment to— rather than support me and say 'Ok, well that's fine! You know, 'you needed 30:03 that time off, forget that; let's move on you know and continue.’ They make it like 'well you know, you can only miss so many da::ys and you just have to tr::y.' And it's that sort of un-understanding environment. So I start thinking 'great, they're thinking I just can't be f*cked! So then the next day I skip again because I don't want to face that. So um, but my employer at the moment um, I've manage to— so usually in the end the environment gets suck that I quit! They make– not obviously they don't make me but it feels like they're making me quit. Because they don't want to deal with it. Um (1)

PhD Student: Do you think it's because of they don't want to or because they don't know how?

01005: ↑ I'm not sure, I think some of the time it's 'cause they don't want to, some of the time it's because they don't know how to. I think it kinda also goes hand in hand because I think if they knew how to deal with it (,) it wouldn't be such an issue. But I think from then, as soon as they
They hear it, they’re probably thinking something along the lines of ‘I don’t know how to deal with it, it is too much hassle, I’ve got a business to run; I can’t be fucked!’

**PhD Student:** Um (states participants name) it sounded like you wanted to say something.

**01002:** Yea, (2) it’s that thing where (1) when you’re in the workplace (1) and your boss, your colleagues, you suddenly become ‘special (states own name).’

**PhD Student:** What do you mean by ‘special (states participants name)?’

**01002:** You do, you’re just aware and your anxiety takes over, you think ‘oh are they talking about me?’ I missed yesterday, so what, deal with it guys; I’ll catch up my work. Or– and that just breeds in your head like wildfire! And then you have to explain yourself, well yes, I got shot in the head in Iraq; I’ve told that story 20 thousand times! I’m fed up! You don’t need to know that anymore! Do you know what I mean?

**PhD Student:** Yea 'cause you two mentioned that you um– you’ve talked about your mental health difficulties, isn’t it? So you’ve disclosed it in the workplace. I don’t know if anyone’s experienced not doing that at all or=

**01006:** =I wouldn’t know how to.

**PhD Student:** So you’re on the other end?

**01006:** Yea.

**PhD Student:** Expand a bit more please.

**01002:** I’ve had to because I’ve tried to get jobs and they told me (1) with their public liability insurance, I couldn’t get insured for the job I wanted to go for.

**PhD Student:** ‘I see.’ [So it depends on the job].

**01002:** [So I was discriminated] before I even got to an interview; which is– it’s a shamble! (1) ‘Cause when they don’t know how to deal with someone, whose you know, mental illness or PT- whatever it was, (1) they just don’t know how to deal with ya.

**PhD Student:** You sound really annoyed, (states participants name).

**Unknown:** (((laughs)))

**01002:** Of course I am.

**Several participants:** (((laughs))

**01004:** I just think they should teach um mental health in school=

**01002:** =Yea.

**01004:** That’s what I personally think. It should be– because I struggled from when I was a child and it was ignored, ignored, ignored, ignored that I was just a trouble maker. And you know, it didn’t get me the support I needed.

**01002:** 'You did set fire to houses, come on.'

**01004:** Yea, I did set them on fire (((laughs))). Do you know what I mean; I was just a trouble maker so I think mental health should be something like in schools.

**PhD Student:** How do you think that will help? Or how do you think that will influence (1) work. ‘Cause obviously I think that’s helpful in general, isn’t it?

**01004:** Yea, I think will influence ‘cause then people won’t be ignorant towards it. That’s the problem, ignorance is bliss! People are so ignorant against mental health, it’s like ‘oh my gosh, she’s mad!’ You know ‘she’s– you don’t go near her.’ You have that stigma. That’s the thing that goes into employment. ‘Cause when you have your GCSEs you’re just left (1) you know to carry on your life and that. But when you have mental health it doesn’t get dealt with in the workplace either.

**PhD Student:** I can see that, yea=

**01004:** =Yea.

**PhD Student:** That’s a [good point].

**01005:** [I kind of-] I kind of wonder whether it might be helpful for the employer to actually sit down with the person they’re hiring, ‘if they get the job, whatever’ and actually discuss how they want to– whether they want to disclose it to others. How they want to go about it and things like

33:56 that because I think a lot of the things– like what you were just describing, I think that could’ve been avoided if um the people knew how– ‘cause for them it’s all exciting and new and they’ve
never met— I've never met anyone whose gone through something that you've gone through; so I think part of that— it's not so much that they intend to make you feel that way it's just that they don't know.

01002: Oh yea, yea, yea. It's an absence of education.

01005: [So actually I think] it would be helpful if the employer sat down and said 'ok, what are your concerns about other people knowing or not knowing, how would you want to— so that there's like a plan so that if you did miss a day and you didn't want people to know=

PhD Student: =Yea, []

01005: They could just say 'oh he— you and the employer could collaborate on the story to say 'oh, he was at the doctors.' You know, just something, not necessarily lie to the other colleagues but keep the discretion (1) if you don't want to disclose and then (1) opposite you know for me personally I think it would be better to actually explain to the people what's happened once so then that's done over with. And it can, you know= 

PhD Student: =Yea, []

01005: [So I think] actually sitting down making a plan; that's probably the main point.

PhD Student: Ok, um I just wondered um, talking about employment and working, um has anyone ever experienced um any conflict at work with anyone senior to them? I suppose senior to them or just colleagues in general?

01005: ALL THE BLOODY TIME, MY MANAGER AND ME, WE LOVE EACH OTHER.

PhD Student: Is this the same manager that supported with []

01005: [OH, YEA] SHE'S VERY GOOD, she's very good but she drives me up the wall.

PhD Student: Do you want to expand a bit more?

01005: Uh, it's not really something to do with mental health, she's just very ambitious and it's um the more you give her, the more she asks for. And as a result, it's— when she then— when you eventually then can't=

PhD Student: =How's it make things difficult in the workplace?

01005: Yea, 'cause eventually when you can't give her anymore, she'll then say something like 'I'm disappointed' or whatever. And then I got home thinking— I suppose it does have something to do with mental health, because then I go home thinking, 'well I'm fucking useless, you know, anyone else can do it, I can't do it.' Like I'm not saying you can't set someone straight, if someone's taking the mick and not doing their job, they need to be told, but I think it also— sometimes they have unrealistic expectations and a normal person— "I say normal in quotations," but a normal person could handle being told something is not done right and they're disappointed and whatever. Um I think it needs to be— they actually need to think about what they're saying because for me I will go home and really dwell on it whereas a normal person will just go off and say, 'whatever, she was having a [shitty day].'

PhD Student: [So it can impact]. So it can impact your work.

01002: See this is where I'm gonna conflict with you, you're all going to [get your heckles out].

01005: [Nto, n10, n10].

01002: I'm from the military, ok. There's a problem at work, you go around the back. Someone calls you something or someone ain't done their job ((makes slapping sound)), that's it, done! Dealt with! You have a beer afterwards.

Several participants: (laughs)

01002: It is! And he never does that again, or she does that again; that's it! But in your world, that'll be a disciplinary. There'd be um a board, there'd be yellows, cards, red cards; you can do this, you can say that. There'd be levels of what's appropriate behaviour, what's not appropriate behaviour, and all that (1) is health and safety gone mad again; it is! Where— if you've got a problem with someone, manager or subordinate, tell them.

PhD Student: Hmm, you make it sound so simple, (states participants name).

01002: But it is!

Several participants: (laughs)

01002: Unfortunately because I had a bury on, everyone else had a bury on, that was it!

01005: See, this is the thing, this is like=

01002: =In your world, I can't do that.

01005: Yea, it's not [so much=]

01002: [=I'm not allowed to].
01005: just world, it’s also um, I think also like different experiences because like for me I take everything super emotionally. And it’s just something that– I suppose partly my personality disorder and partly also because I’m by nature quite an emotional person anyway. So I take everything to heart so much. SO, I can deal with people coming up to me, just taking me to one side and say ‘look, what you doin’? Get your shit together.’

PhD Student: But it does sound like some conflicts at work.

37:58
01005: But some of the things– like dealing with it as sort of (1) roughly as you just described, that would be quite bad from– like from my perspective.

PhD Student: I’d like to hear a bit more from you two if you don’t mind? What do you guys think? Have you had any experiences um of conflict or anything like that in the workplace? I don’t actually know your experience of– whether you’re working or not at the moment? What happened?

01003: I don’t know if my conflict’s relevant ‘cause it’s with my mum.

Several participants: ((laughs))

PhD Student: That’s alright. Do you have anything to um add, (states participants name)?

01001: (2) Um, about conflict?

PhD Student: Yeah, just if you’ve experienced anything like that in the workplace.

01001: (5) Um (1) I suppose I’ve um (2) in my previous job, um I didn’t disclose that I had a mental health condition. But in the job before that, I did disclose. I’ve kind of had a couple of different, you know="Experiences”.

01001: experiences. And then I’ve also kind of been the other- you know, the other side of it which is, you know having to employ people. Um um, who, you know um– so being aware of the kind of things that you need to consider as uh, someone employing somebody. But also having to kind of think to myself ‘well actually, I can relate to you, and you probably don’t know that I can relate to you.’ Um, you know and but uh, it’s where you are isn’t it? It’s where you happen to be.

PhD Student: So having that understanding, um (1) do you think that’s influenced uh how you’ve managed and worked with people in the workplace?

01001: Um, I think it’s tricky ‘cause you have different goals depending on whether you are managing or whether you are um working and you are working to somebody but you don’t have anybody yourself that you’re managing. So for instance um (1) I can be completely empathetic but I may not choose to disclose to someone I’m managing my own personal issues but I might fully understand where they’re coming from.

PhD Student: ‘Yea.’

01001: But if they don’t disclose, which is something that I wouldn’t have realised if I hadn’t been on this side– if they don’t disclose then I can’t help them early enough. Whereas if I– and again it’s everyone’s different. I’ve been managed by some people where it wouldn’t have mattered if I had come in with it on my birth certificate; they wouldn’t have been able to make any adjustments. But, in- (1) you know I can think of managing someone who was um– who I suspected but I didn’t want to ask without, (1) you know what I wanted them to say. And I could see the person was deteriorating so I asked them, you know if everything was ok. And they kept saying ‘they were fine, they were fine.’ Um and there’s only so many times you can ask, you don’t want to cross that line. And then when they um had to go off on sick leave, it kind of um– it escalated but having been on that side of the fence as well, um I kind of know that you know that once you’ve- (1) once you’ve stopped going into work, it can be really hard even ringing into your manager and having to have that conversation if you’ve not told [them].

PhD Student: [What’s hard] about it? Like what would be running through your mind if you were the person calling– calling in?

01001: Well usually, if you skip through to about day whatever it is, three or something where you have to have sort of been to see a doctor or whatever, you have to sort of say to them you know ‘I’m– the reason I’m off or the other question which is particularly– but I think this is across mental health difficulties, I don’t think this is particularly PD. Um, but you have to sort of estimate how long you think you might be off for which is really difficult to do=

PhD Student: ‘=Right.’

01001: Um, I mean you know, obviously your own GP might find it difficult to do. And I think you have to be able to sort of– you know it’s difficult to sort of– on one hand you have the sort of
what you have to do and the fact that you know, you’re not doing it while you’re off. Um and on the other hand you’re trying to be realistic, but you may not wish to say ‘actually, I really don’t have an idea how long it’s going to take and I’m not being awkward; I just genuinely don’t know, it’s as long as it is.’ You know, and then some managers will be ‘ok, well you knowing me in a couple—three days’ time’ but other managers are like you know, ‘I want you to ring me up every day’ and that can make you feel even worse.

PhD Student: Worse as in like—(1) super anxious?

01001: I think if you [know] you have to keep ringing in and saying to someone, you know it’s

PhD Student: [or annoyed]

01001: not measurable in the sense of like, you know (1) ‘I’m going to feel better on the third day’ and you know ()=

PhD Student: =By two hours.

01001: Exactly! I think it’s tricky to manage it. Also I think, you know there’s pros and cons of telling someone you have it or not telling. You know the last place the last workplace I worked in, it would definitely, you know—there’s the lip service to it but then there’s then the actual you know— the actual experience itself.

PhD Student: So thinking about—thinking about whether to disclose and then or whether not to is something that that you is something that you consider quite a lot?

01001: I think it’s mainly because in my experience, um if you—(2) if you haven’t disclosed and 43:48

then you do need some support, it can be tricky to you know— you sort of left yourself without a leg to stand on. But at the same time, you—I mean, part of my role was working with children and um you know I’m fully aware that if I said to sort of— you know, my employers might understand but if I was in the school environment, you know, it’s possible that you know a teacher or parent might not fully get that. And so there’s lots of things that you know that you’ve got to consider.

PhD Student: Yea, has anyone else—thank you, has anyone else had the similar experience of knowing whether to disclose or not? You mentioned that you hadn’t. (states participants name).

01006: You know, I just wouldn’t know how to do that. Um and I would feel like judged. And I would feel like, they don’t have a clue’ about really what’s going through—what’s going—what’s going on with me you know. And they would just misunderstand or not get it, think I’m ‘crazy’; so I wouldn’t even consider telling someone. I wouldn’t even consider that.

PhD Student: So, in your experience you haven’t—so you haven’t and you haven’t considered, and um what—how’s that impacted how you work?

01006: Um, the first two jobs I had were both working in a fish and chip shop. And it was so stressful for me, like dealing with the customers and the hot environment. And I’m basically dripping with sweat, my face is so red and it’s like those symptoms I cannot cope with. And I don’t know how to function anymore, you know. And what ends up happening is I just don’t turn up again. I just walk out and never come back. And I can’t call them; I can’t do that, definitely don’t know how to function anymore, you know. And what ends up happening is I just don’t turn on with me you know. And that can make you feel even worse.

PhD Student: =So you’re saying actually the type of jobs that you go for is something to be worth considering— to consider um=

01006: =Yea, and the jobs that I’ve had, there’s not really been an opportunity for me to—like it wouldn’t have made any difference if I did tell someone, just wouldn’t have made any difference 46:35

at all. Um, ‘yea.’

01005: I think um, what I was going to say originally ‘before um (states participants name)’ um is that um very often what I find is that, when you disclose um what has uh—what you do have or ‘don’t have,’ a lot of the time people kind of have this sensationalised um like opinion of what
it is. And they don't actually know what it is. Um, I know that, like because there's a lot of these like tumbler girls now and they're all depressed and they're all you know (1). A lot of the time-- I don't want to-- I hate to say it because I would hate to (1) dismiss someone who genuinely feels that way, but I think a lot of the time now there's this sort of 'it's cool to have mental health issues.' And um so people see the people who are constantly blogging about it, posting it on Facebook, you their pictures of them cutting themselves and all that sort of weirdness, and they don't actually know what it entails because there's a lot of the time faking it. And so when you say to someone in a job place, you know, say for example 'I'm depressed,' they won't understand what that really is they'll just say 'yee, well you need to get over that!'

01006: Not taking it seriously

01005: Yea, like they're dismissing it because all they have is like the image of these people who are not necessarily struggling as much as they'd like the world to believe. PhD Student: So when you're met with that, I suppose barrier in the workplace, where you feel like being dismissive, what sort of things might be going through your mind? So let's say, you've told them that you know you get=

01005: 'They don't believe me.' That's the only thing that's going through my mind is they don't believe me and they're going to fire me so I might as well quit.

PhD Student: Got some nods

01006: I agree. It's like when I tell someone I've got social anxiety, and it's like they don't really understand how severely it really affects me. You just think 'oh, she's shy.' No, no, no, no, no, no! Definitely not! And it just-(1) to be honest, like what I have, I feel like I could never work. I can't function. I can't get a job. Social anxiety and working do not go together.

01005: I think that's quite ironic because knowing you, I don't think you're shy at all.

01006: I'm sitting here and my heart's

01005: =You have anxiety but I don't think you're shy! And I think that's one of the key things with what you just said is that people don't know the difference between certain words like shy and anxious. And that is a big deal. Like, they think sad and depressed; they equate that to the same thing as well.

01006: It's not the same.

01005: But there's a lot of these key words where they're not quite understanding them.

PhD Student: Sure, 'that makes a lot of sense'. I'm just thinking about um, you guys mentioned the

49:31 interview process before. Um and I know that in the employment pathway there's lots of different things that you can do I suppose to kind of get you towards working. So that would be obviously attending an interview. Um someone mentioned, I think, someone mentioned CVs I think? Um (1) so I just wondered if um there are any particular activities-- I don't know if you want to call them that, or things that you guys would do to get a job that you might find difficult or don't like to do or think-- think it's not helpful. Or things that you do think are helpful. (3)

01002: How'd you mean?

PhD Student: So like, so let's say you're getting a job=

01002: =Yea.

PhD Student: And you're in that uh state I suppose of employment, um they'll be things that you might do-- that one might do. Someone might go to the Job Centre, someone might look online, some people like might make a CV. Um some=

01002: =Yea but they're the basics, you got to do it anyway.

PhD Student: But I just wonder in your experiences, what have you guys done and do you find them difficult? And if you do, what is it about it that you find difficult?

01005: My easiest way of getting-- like the way I found to be my most productive way of getting a job, 'and I have gone through a lot,'((laughs)) is um actually to-- and this is not necessarily to people keep a job but the easiest way I found to get a job was to actually be able to grab some CVs, go with a friend, you know, make it a nice day just like chat, you know like have an ice-cream or something, stop by some places and have like not an interview but just informally say-- you know speak to the manager, to have a nice chat for 5 minutes, you know; tell them a little bit about yourself, leave them with the CV and then you can continue. And you can kind of then find that you can put it behind you and you're not spending loads of time thinking back on it and like what did I do wrong and things like that. And you're not also-- because it's so spur of the moment, you don't have the time to work yourself up over/↑it. So, because I'm walking down the street, I see a sign, I say 'I'll be right back' to my friend, walk in, do it, come out, because there's not that sort of foreplanning, I don't have time to sort of ruminate on it= 391
PhD Student: =I think that’s true.
PhD Student: To like (1) you know what I mean.
PhD Student: Yea, what you gonna say, (states participant’s name).
PhD Student: Um, yea when I (1) ’cause two out of three jobs, I got it because someone gave it to me. Um, I didn’t do anything to try and get it you know. And then the— the second time I got a job was, I was going home from group and I saw this sign outside and I literally didn’t give myself any time to ruminate like you said or think about it you know; um like what I’m gonna say. I just went in and=

PhD Student: =What would happen if you guys had the time to think?

PhD Student: I wouldn’t do it.
PhD Student: ((laughs))

PhD Student: I know but let’s just break that down. So what is it? What kind of things were going through your mind? What would come up? What would pop up?

PhD Student: "You were gonna say something (states participants name)." 

PhD Student: You just get really anxious and panicky. Yea, that’s what happens.

PhD Student: And you don’t know what to say.

PhD Student: Yea.

PhD Student: When you do stuff instinctively, off the cuff, you’re natural. You’re mental illness (1) is in the bag. When you’ve got 5 minutes to stop and think ‘ok, I’m gonna go and ask John, ask him if have they got any CVs or— that’s it! It’s out the bag! ((makes explosion sound))

Several participants: ((laughs))

PhD Student: It’s out the bag and then you’re just walking in a cloud going blah blah blah carbamazepine, olanzapine and you’re talking and it’s another language. And it’s too late (1) it’s too late but the laws and statistic prove that one job you might get, off the cuff in your coffee morning moment, will be a fluke. That’s not gonna happen again, you know it’s not! And when you go to the job centre advice person and they say ‘well done, that’s a great strategy,’ I’ll say ‘fantastic! It’s a great strategy I got out of bed today, that was a fluke!’

Several participants: ((laughs))

PhD Student: You know what I mean, it’s not real; it’s not realistic!

PhD Student: I think also today— a lot of places that are with retail and this is sort of the lower jobs like retail and things, a lot of the time they’re starting to turn to applying online because it’s easier for them to go through. But that gives me that time to think about it, I think that they should be more open to people just coming in, speaking to the manager quickly and then giving their CV and then leaving.

PhD Student: Were you gonna say something, (states participant’s name).

PhD Student: That’s unrealistic. Everything’s online. You wanna go for a job, everything’s online and

PhD Student: =Well this is what I’m saying, though because=

PhD Student: Go on.

PhD Student: I think they should see you in person; that’s what I think, yea.

PhD Student: Tell me why though like=

PhD Student: ‘Cause like face to face you’re more natural and you know, it’s just ‘you go with the flow. Yea.

PhD Student: That’s so interesting, I find that so fascinating ‘cause I’m completely the opposite.

PhD Student: Yea, go on.

PhD Student: Because um, I would rather do it online so I don’t have to have the interaction and the whole kind of— um you know the kind of estate agent kind of selling myself which I’m really not that comfortable with. Whereas I’d rather be able to— I appreciate like if you take away the kind of like um IT aspect of it, I’d rather do it in my own time be that 10 o’clock at night or you know, whatever and do that. Like for instance, although I don’t particularly—you know, it’s not right there up there in my top 10 things to do, going to interviews, I mean you know, I don’t like them, they make me nervous=

PhD Student: =’I don’t think anyone likes [them], I think [that’s normal]." 

PhD Student: =’I don’t think anyone likes [them], I think [that’s normal]." 

PhD Student: [Exactly!] (1) [I think that’s] normal, exactly! But I think, you know, and I don’t like this either, I don’t like doing the uh, um you know when you practice interviews. But I know that— if I do enough of them, I actually get better at asking the question that I can freeze
on if I don’t prepare for it. You know the one about ‘why do you want this job? Why do you think we should give you this job?’ And you know you don’t want to say the first thing that comes into your head ((laughs))

01005: ‘CAUSE I NEED MONEY!
01001: Yea
Several participants: ((laughs))

PhD Student: Carry on.

01002: Is that the sort of thing that you’ve grown into? When you were 16, 17 straight out of school, did you have the confidence just to walk into Mark One, you won’t understand what that is, it’s an old shop, CNA and get a job?
01004: ((laughs))

01002: Do you know what I mean? We could do that, our peer group, we could do that. Everyone– we had school advisors as a 15 year old. I had jobs as a 15 year old before I even took my exams. Give me a job!
01001: So, you think I’m younger than you, do you?

56:07

01002: No, no. I’m guessing you’re my peer group, my age. I’m not gonna discriminate age, whatever. But you’re mentality that you’re just saying there, sounds like you’re conforming to the pigeon holes that the job centre wanted to put you in.

01001: No, what I’m doing is I’m explaining that that’s my– my comfort zone=
01002: =Yea, yea, yea=

01002: =Is doing something online. Um whereas when I was 16, I would’ve gone into– what I did do is walked into tower records and said like ‘give me a job, I love music.’ Yea, whereas now– I had incredible amounts of confidence when I was younger. Um and going through you know life, um you know, you take a battering.

PhD Student: What do you think would be helpful? You just talked about confidence, what do you think would be helpful in order to get back into being able to– do perhaps the way you did things when you were 16. What do you think would be helpful?

01001: Well I think for me certainly, I think um I did– I was um– I did what I was supposed to do. So um, if you like um– I suppose that’s kind of a little bit like the pigeon holing thing in the sense that you know I um– I went to university, that’s what my parents wanted me to do so I did it. You know, they wanted me to get a good job, that’s what I did. I think now, I would probably, instead of going right back into the stressful situation of the sort of job that I’ve been trained for, I think now, I would probably look at it very differently. And so, some of the things I’ve been thinking about is like you know obviously it’s like pay you. Financially that is an issue, but I’d think about volunteering and you know sort of saying to someone um you know ‘can I come in here and just– like you were saying try this job out um just to see what it is. I’m not expecting you to pay me but I just want to see what this is like or can I come in and chat to you so I know what sort of things you expect from people so I can think about you know the area– I’d do it very differently now. Rather than– but if I wanted to carry on in the world that I came from, there aren’t those– you know, you have to follow the pathway; you have to play the game. Or you know, you don’t– it’s not gonna adapt to you, it’s the other way around. But it’s just trying to find you know, help as you’re going along. I wouldn’t um, I wouldn’t– I suppose I don’t know if it’s sort of a result of being able to take this time off and do these sorts of courses and think about things and reflect on things and just think you know, maybe I’m looking in the wrong place or maybe I’m doing something that isn’t actually suited to me.

PhD Student: That is a possibility to, yea. Um, (states participant’s name) were you gonna say something about um you know you’d rather apply online?

01003: Yea, I was also gonna say um it would be nice for people to offer that ‘if you can’t make it in for a day that you can arrange to work from home.’ ‘Cause when I– the only reason why I actually didn’t continue working was because my anxiety got terrible. And I was only working in a room with my mum and my mum’s best friend who I’d known my whole life so I really shouldn’t have been anxious at all. But um, you know I could go home and work for the day. So I could still earn myself money, I could still have the feeling that I’ve done something for the day, that I haven’t completely failed. Do you know what I mean, like it made a really big difference=

59:44

01005: =But, I think=
01003: =It made such a big difference; it was hard to keep self-motivated still. Because, you know when you gotta motivate yourself working from home it is anyway, you gotta– deadlines are a lot tighter. You’re not as quick moving, you can go and have lunch when you want. But if I
could’ve continued doing that from home, that would’ve been great ‘cause then if you miss three
days’ work, you can still get the work done. You don’t need to be um sacked; you don’t need to
quit because you’re not um fulfilling the needs. Do you know what I mean? Um, obviously
certain systems you can only work with from work and I understand that completely. But if things
can be done from home, which most of my stuff all could be done from home, using Gmail,
using all of Microsoft’s programmes, um creating PowerPoints; all of that sort of stuff can be
done from home. And if someone has a job which it can be done from home, why not make
that=
PhD Student: =So it sounds like quite similar [experiences] here across the board.
01003: [an opportunity].
PhD Student: I have a question, so if– so that sounds really fortunate you had that option,
working with your mum and your family friend. Um let’s say you had another job (1) and that
wasn’t and option, but it could be, what would be helpful for you to get– what would you need to
do in order to (1) uh get your needs met?
01006: Interpersonal effectiveness. Um (2) =
01005: =To talk to them.
PhD Student: Yea.
01006: To speak to someone about it, you know?
PhD Student: Yea, yea, yea. But who would that person be? Like who would you speak to?
01006: Um, your boss.
PhD Student: Your boss.
01006: Your boss of course.
PhD Student: You make it sound so easy.
01005: This is [the thing I was going to say].
01006: [Yea, it’s not easy]
PhD Student: [Why’s it not easy?] Tell me what it is. What’s not easy
about it?
01006: Um, maybe asking for too much, maybe they’re gonna get pissy with you? Um or just
say ‘no’ straight up. It’s all those things you know?
01:01:22
01005: I was gonna say that with that system– for me personally, don’t know how other people
would view this but I think it would need to be as you said, interpersonal skills. You need to be
able to discuss it quite in depth with the manager and you need to see what you both feel
because I know that if I had that as an option=
PhD Student: =Yea.
01005: =anxiety would get the better of me and eventually, I would always want to do it from
work, so there needs to be that sort of like middle ground where– ‘ok you can have this today
and you can have tomorrow if you’re still not feeling well but after that you need to come in.’
PhD Student: Ok.
01005: You know, just something so that you’ve got the time to prepare and to kind of– (2) you
need that day so you need that day so it can’t be helped, but not to give you an excuse not to
come in. Because that’s how you spiral down, I think.
01003: Like a three strike rule or something.
01005: Yea.
01003: Like you can have a maximum of you know, whatever, three days whatever.
01005: I don’t think it should be so much as like a rule rule, but it should be something that you
can discuss with the person and set yourself limits with them rather than say ‘ok,well this is the
rule!’ ‘Cause I think that’s gonna make you even more anxious because you’re gonna ‘oh I’m
running out of days or whatever.’ But to kind of actually have that time so kind of set it with the
manager.
PhD Student: So more of a two way=
01005: =So it’s personal.
PhD Student: Yea, so two-way individualised (1) plan, yea. I w anno ask you guys some
questions about motivation. You know, I think it’s not unusual to have days where you’re feeling
pretty tired or let’s say you’ve been up really late the night before ‘cause you’ve been super
anxious about what work is gonna be like or what this interview is gonna be like. How do you
think that will influence, in your experience, your level of motivation? Whether you’re– you are–
so let’s say– sorry, I’ll ask the question again. Let’s say you’re at the stage of thinking about
employment and you’re trying to get it and you’re going to an interview, (1) so you do all the
necessary things to try and get a job and like– yea, one night you’re up really late because of anxiety and you get up the next day, how would that influence you?

PhD Student: Well obviously when you’re looking forward to something, you have positive images of what– how it is in your mind. So if you’re imagining going and having fun on holiday, you’re imagining going and having fun on holiday. And when you’re imagining all the bad stuff, that would obviously instantly crush your motivation levels from being really driven to it to dreading doing it.

PhD Student: What do you think would help in that situation? If you notice that you’re thinking, you know imagining terrible things and you realise it’s impacting your motivation to even get to the interview to get the job, what would be helpful?

PhD Student: Having a feel for what’s going to happen.

PhD Student: In the military we call it the ‘6 P’s.’ Prior Planning Prevents Piss Poor Performance.

PhD Student: Say that again slowly.

PhD Student: Prior Planning Prevents Piss Poor Performance.

PhD Student: Plan ahead! Everything! You plan that tube journey to the interview. You plan your wardrobe. You get up a week before, you do your 10 trips on the subway, you get off at Barking; ‘ok I’ve got through that one, next week I’ll get off at [Mile End].’

PhD Student: [Break it down].

PhD Student: You gotta play dumb to it. It’s a pain in the ass and you take your carbamazepine and you go, ‘I done that one, yay!’ And you do it again the following day. And you wear the same shoes and you get as far as you can the next day. You get to the business store; you do your education on them. You do your education on yourself, you check everything, you dot every i, cross every eye.

PhD Student: But here’s the thing though=

PhD Student: =Ok.

PhD Student: Um, and I will plan it. I will plan the journey and all that stuff, and I almost have this feeling– and it’s wrong, I know it’s wrong, when I get there and I don’t get the job, I get this feeling ‘but I’ve tried so hard! What the fuck? Why?’ And I think that’s something– I’m not entirely sure that that’s something that can be handled because at the end of the day they need to be able to say no to somebody.

PhD Student: That’s disappointment thought isn’t it?

PhD Student: It is something that will (1) um (1) like that um has an effect on my motivation. Like even as I’m working at the moment, I know that if I– I’ve got my own little section in the store that I look after. I will do everything in my power to make it perfect, and then I think I’ve done a great job, and the next day I come in and they might be moaning about something completely different and I’ll be like, ‘but look! Look at my section, damn it, look at it!”

PhD Student: Has anyone else had a similar experience? So you like, you know, you feel like you put the leg-work in and then you get met with no acknowledgement.

PhD Student: Yea.

PhD Student: Oh, I think that’s part of the course in any sort of– I don’t think you need a mental health anything. That’s just the world isn’t it? If you can’t– you almost have to– that example is really frustrating. And I totally get that, but you know=

PhD Student: =It’s radical acceptance, I’ve gotta work on it.
I've got a child, you know, there's no amount of tidying up-- you know I wanna just say 'can you just like not use this room at all.' 'Cause it's like, I've tidied up and you do it day after day after day after day; 'cause you just gotta do it. It's uh=

PhD Student: =The thing is (states participants name) you're absolutely right, it is absolutely normal to experience these things in the workplace and outside but the reason we're here today is because I want to find out for you guys what it is-- why's it-- it resonates stronger than perhaps someone outside of mental health services.

PhD Student: = It's because already we've had=

PhD Student: = And if that's the case, what would you find helpful?

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three quarters are. And you believe that as a stigma for yourself and that becomes a self-worth problem, and you ruminate, straight away. And you go ok, ‘wow, this week from April the first, I get my £7.25 an hour, whoopy do=

01005: =INSTEAD OF £7, YEA ((laughs)).
01002: Thanks for that! I used to manage 15 people and I used to shoot people in Iraq. Where’s the relevance? You just can’t=
PhD Student: =It doesn’t fit.
01002: It doesn’t fit. We don’t fit.
01004: It’s like we’re unemployable. Basically, that’s how I feel.
01005: I was gonna say in relation to that, do it like the 5p bag charge. Only certain companies have to do it, the larger ones; do the same! If you have over a certain number of employees, your managers have to attend a course like your health and safety course that will explain to them about mental health.
PhD Student: So make it mandatory?
01005: Y’ea!
01001: But you know, I’ve worked with people that have gone on these courses and they just go on it and you know what they do? They put it on their CV. The real difference is the kind of, you know, when you– I sat down with someone and she didn’t know that I had um mental health um issues. And um we sat down and we had to go through you know the back to work thing. And we had to go through what adjustments and you feel like you’re stupid asking because the last thing that they know– they’re just glad to be back in the door. You know, you’re asking what adjustments they would like and they’re like ‘well what have you got’ and type of thing. But one thing that really really worked well was because there was a high turnover where I worked, so one thing she came up with which I thought was really good– I thought I must nick this idea, was that she um did um like a sort of her own um like a very sort of short um document thing. Um not like a CV or anything like that but just a very short thing that said about like what the kind of you know– what the issues were for her, what the symptoms were that she might experience, what she wanted done if there was an emergency. And she just said that she had 1:13:07 worked with– I can’t remember if it was MIND or someone like that and it was really handy. I was able to look at it, read it– I then didn’t ask her questions that could’ve really upset her. But at the same time, then when I left her and someone else came in to look after her, she didn’t have to go through it again ‘cause it was just like ‘here it is.’ And I just thought, you know I wish I had had that. You know, it would’ve been so nice to have something where you don’t have to keep saying it over and over again.
PhD Student: It’s kinda like what you were saying before, wasn’t it?
01002: Yea. It’s that thing of disclaiming again.
01001: ‘Cause the more you say it, the more it can kind of effect your own confidence.
01002: Yea, it does.
PhD Student: (1) that language impacts the way you feel as well.
01002: But, on the flip of that, it’s great that that persons done that, but and she was a colleague and asset but (2) how many times did 50 other people in the workplace have to read her disclosure? And then 50 other people– and then one of them is thinking, oh look, there’s ‘special (states a name)’ over there. I’ve not gotta treat her differently because of that disclaimer and it shouldn’t be about that, it shouldn’t be. Even though she’s getting her personality sorted out, fantastic for her, kudos for her but=
01001: =She did have the choice. She did have the choice ‘cause it was her responsibility to carry it because we didn’t have like an HR that you could even see; you never saw anybody. So she carried it and it was up to her to use it, but it meant that on days or weeks that she was feeling like she didn’t want to speak or didn’t want to have much contact; if she happened to be um moved or whatever there, was something she could use when she didn’t want to sort of really talk when you have those weeks when you’re not feeling particularly social, there was something there. Um but if she didn’t want to use it, she didn’t have to. And we were bound by you know, the fact that we weren’t allowed to disclose anything either without someone’s consent. So I just thought it was something useful, it’s something I might think about when I got back into the um workplace.
PhD Student: Um, I wanna ask you guys about satisfaction. If you were um– if you had a job, um were employed, how would you– what would you find that would satisfy you in that workplace? Yea, what kind of things would you find satisfying in that workplace?
01005: I find it very satisfying when I get certain amount of— because as we discussed before, because we tend to go for the low-paying jobs and sort of crappy jobs, it is nice when I’m— when I do something— and I don’t mean just you know, pat on the back for the sake of being patted on the back, but if I do something and it does go above the line, that people actually notice and appreciate it. I like feeling like— I like it when my manager makes me feel like I have value to the company.

PhD Student: "Yea."

1:16:00

01005: Um obviously everybody does but it make such a difference for me, it’s not even just—(3) for me I always think I’m so replaceable, like if I died in a ditch tomorrow, they’re gonna find another person to replace me like that. But (1) when they actually acknowledge, when my manager acknowledges ‘you’ve done a good job, it’s um much better than I could’ve thought of’ or something like that, it kind of gives me that power up and then for the next week or two I’m just like ‘WHOO, great, let’s go!’

01003: 'Validation'.

01005: 'Yea! And it makes me feel like I wanna work harder for the company because um I kind of don’t feel like—I start feeling a bit more ownership of it as well. Like, it feels like I’m not just working for another person to have money in their pocket, I’m working for something— like I feel more part of the team and like our store has to be the best; I’m working for something.

PhD Student: I’ve got you two nodding, is that something that you can relate to?

01001: I think it’s a powerful motivator, isn’t it?

01002: Self-respect isn’t it, the best thing there is.

PhD Student: Helps your self-respect.

01002: ’Course it does. Even if you get 6 pound an hour, if you’ve given the best hour for 6 pound and you know you’ve given your best, and no one’s slagging you off and actually praising you, for your hours work for 6 pound=

01005: =YEA, APPRECIATING YOU WORKED FOR AN HOUR FOR 6 quid!

01002: If it’s the best hour they’ve ever seen for 6 pound, then fantastic!

PhD Student: That’s great! ((laughs))

01002: Because it raises you up! Even if you earn 35 pounds an hour taking your hands out of her heart for open heart surgery, it doesn’t matter what job you’re in. Doesn’t matter if you’re making these crochet weird sun-tan penguins, doesn’t matter what you’re in! But,(1) it’s self-respect. And that’s all it is, it’s acknowledgement of that self-respect. () ridiculed. You can be the cleanest cleaner or you can be the best Richard Branson there is, but as long as you know when you look in the mirror; your heads held high, that’s it!

01005: But that’s the flip side to that is that there’s obviously if you’re going to convey this to um managers or whatever, the one thing that is concerning me is that I don’t want them to feel like they need to praise me in a patronising way. I don’t want them to praise me because they think that’s the way to deal with me.

01002: Just go into (states therapist name) office, every four minutes ‘well done (states own name).’

Several participants: (((laughs)))

1:18:32

PhD Student: So um, I’m just aware of the time, um so my last question really is, is there anything I haven’t asked that you know that you guys want to talk about in terms of particular challenges or barriers in the workplace? Go on.

01002: I used to kill people for a living, hanging outside of a helicopter, how do I transfer that skill into an employable job?

Several participants: (((laughs)))

PhD Student: I don’t know the answer to that.

01002: Ok, next.

PhD Student: But in terms of things that we haven’t discussed already, like the barriers=

01004: =Like I think, sorry, like physical health.

PhD Student: Ok.

01004: Yea, physical health when you have physical problems and you can’t do certain things on a certain day.

PhD Student: Has that stopped you from like getting out there and looking for work?

01004: Yes.

01006: I have one.
PhD Student: Um, Yea. Sorry, before you go on, anyone else had experience— ‘cause I did ask a question about physical health and we talked about () but was there anything more? Do you want to expand a bit more on that and like your ↑ own experience (states participants name)?
01004: Um, it’s just about pains, like you know all the pains you get when you have to get up and move around. You know, stretch, and things like that=
PhD Student: How’ve you managed it, “so far”?  
01004: Um, painkillers. Yea it’s just like you know, if you’ve got a problem and you need a 5minute out, or you need to rest, something or, you know— ‘I don’t think I’m being very good about this.’
PhD Student: That’s alright, you were about to mention motivation, so does that impact your motivation?
01004: ‘Yea, ‘cause I feel like ‘oh god, I’m just an old woman.’ I got like so many physical problems.
01005: I feel like I’ve just not been born to live. ‘Cause it’s like my mind’s fucked up, my body’s fucked up, what’s the point?
01004: Yea, yea basically. Like will I even be employable?
1:20:06
01006: I feel like— ‘cause you’re talking about physical illnesses, and I feel like my mental illness, my anxiety literally has caused me physical problems. And it’s like telling someone I’ve got a mental disorder, ‘well you can still do this though, you can still work, you can still do that, it’s just in your head, right?’ But it affects me physically. And that’s the main problem I have, I don’t want other people to know that I have those problems and it hold me back a lot.
PhD Student: When you say holds you back, do you mean it stops you from going into work?
01006: It makes me terrified that they’re going to see it.
01004: It’s like a stigma, a stigma you have with you.
01006: And I just have no energy. I literally have no energy. It’s like such a struggle to get up, how can I get up every day to work and then come home and I’m literally my whole body is in pain because of it.
01005: What I was also going to say is, with the physical pains and stuff— also one thing I feel like needs to be highlighted is mental health, for me is different to like being ↑ ill. And it really frustrates me because like— this happened to me on a few occasions and it has been a reason for me being basically out of a job. I’d be sick, right, regular standard cold or whatever. And then I’d come back and because of the way they’d react about me being off or whatever, I’d then spiral and then I’d have a bad day mentally=
PhD Student: =Yea.
01005: and they just see it like I’m always sick. I think a lot of the time they don’t distinguish that mental health is a whole different thing and it’s not— you know, just ‘cause you have mental health doesn’t mean that you can’t then get cold. It’s like=
01001: =You don’t get a separate quota do you? Physical health quota and mental health quota. 
01005: yea, you get a certain amount of sick days and you can’t have— you know that’s the average time the person’s gonna be sick; that doesn’t change just because you have mental health, like they don’t subtract or add up, they’re like two separate things.
PhD Student: “Yea, “ that’s something I’ve been coming across in the focus groups. Ok, um alright, thank you guys.
Appendix 21 Focus Group Client Transcript 3 (Chapter 3)

PHD STUDENT I'm going to guide you through some questions. I'm going to guide you, it's kind of in an employment pathway, so in the sense that, the first part of the employment would be about thinking about employment. The middle part would be about perhaps getting a job and all of the activities that lead up to it, the process I suppose. And then the third part of employment we want to look at, you know you're in employment and you're working and about remaining at work and keeping that job. Um but there is, I want you guys to remember that there is absolutely no right or wrong answer. We genuinely want to know what it is that is going on for you guys. So before we begin have you got any questions?

Co-f: Also, I will be just making notes just in case these recordings do fail us, just to let you guys know.

PHD STUDENT And I've got some questions here so I might be referring to them. So it's not that I'm not listening, it's just because I've forgotten what I wanted to say next. So haha. Um, okay, I just want you guys to consider, because I'm not sure whether some of you guys are working right now or not working at all, or perhaps maybe some of you are signed off sick I'm not sure, um but just think about a time when you are thinking about employment. Um you know, what sort of difficulties perhaps might you face when it comes to even thinking about employment?

03005: I suppose concerns about, um like what if they find out. Like sometimes obviously you've got to disclose your medical history to employers.

PHD STUDENT Yeah, what kind of things would be going through your mind? What kind of thoughts?

03005: Quite like they're going to judge you based on your mental health, and if they're going to employ you because of it [hmm]. And whether you're going to be you know judged because of that, or even employed because of it; they might actually discard you because of disclosing that information.

PHD STUDENT Yeah, sure. Has anyone else experienced anything similar?

03003: I've got concerns about um do I have to disclose because I wouldn't disclose to be honest, not mental issues. I don't think that people attitudes to mental health issues are particularly sympathetic, empathetic or whatever you want to call it.

PHD STUDENT So you wouldn't necessarily be thinking about it, because you just know you wouldn't.

03002: I just wouldn't. But I don't know what the law regarding that is. Would I be somehow breaking the law by not disclosing it and not being ().

PHD STUDENT Is that something that is worrying?

03002: I think it's a big worry, whether we have to disclose it or not. And I know that in the job that I do, I would never do that.

PHD STUDENT Yeah. I wonder whether anyone has experienced when they have disclosed or not?

03005: I have had to disclose it in my current job that I am in.

PHD STUDENT So, you have?

03005: Yup.

PHD STUDENT So you've been signed off sick, it's that right?

03005: Yeah, I'm currently signed off. Before, when I first entered the job I had to disclose my mental health status. But um, I wasn't, I was still given the job, I wasn't um persecuted in anyway for disclosing it [okay]. It was just something that had to be shared.

PHD STUDENT And when it was shared if you don't mind me asking um, what was it like for you afterwards?

03005: I was really worried because I got like a email back from my boss saying that their occupational health wanted to speak to me regarding my application where I had filled in this form for them disclosing it. And so I was a bit worried as to what they were going to say =

PHD STUDENT = Was this in the beginning, when you first started?

03005: Yeah.

PHD STUDENT Okay.
03005: Right, right at the beginning of the employment. So I was really worried about what they were going to say and if they were going to then say actually you can’t have the job because of it. So I had to go through the process where I had to speak to a doctor [okay], and to go into more detail as to what was happening and why I was =

PHD STUDENT= You seem very calm when you’re telling us. Was it, would you say the experience was, I mean what was it like for you? Was it=  
03005: = I mean at the time it was really nerve racking. I was really like panicky. Because I thought, well you know, is this going to be a problem, am I going to get the job or not because of this one particular piece of information. But actually once I had spoken to the doctor that they had referred me to, um it was actually okay, they put my mind at ease, they said don’t worry it’s just something we have to through and just to make sure that we are meeting your needs.

PHD STUDENT= That sounds great. So you had some positive experiences of people supporting you when you disclosed. Okay =

03006: = Can I ask, was that, I don’t know what company it is but was it a large or respectable company?  
PHD STUDENT= It is a large company, yeah.

03006: = Yeah I think I’d expect that from a large company, but I don’t think you would get that from smaller company.

PHD STUDENT= Do you have any experiences of that?

03006: = No I don’t, but I think it is a fear that if you do disclose, particularly to smaller companies, they won’t employ you at all; because you’ve got a reputable company.  
03005: = Yeah definitely. I think that as well. Before I joined this particular company, um before that I worked in a smaller business and it was a family run business. And I hadn’t been diagnosed then, but I was obviously suffering quite bad, and I did have to have time off and things, and they weren’t very helpful in helping me through that. And I did come across a lot of barriers and hence why I ended up leaving that job.

PHD STUDENT= When you say barrier is would you mind explaining a bit more?  
03005: = More so that they were not very um good with like doctor’s appointments and things, and if I needed time off or if I was struggling to come to work because I wasn’t coping well. I was just, they made me feel like I was a burden and that I should you know feel ashamed of having this problem. And at that time as well, I wasn’t officially diagnosed, and so I was really struggling. So that made things a lot worse. And you know they made me feel that I had to keep going in even though I was unwell and felt that I couldn’t. And I didn’t feel like I had any support and so=

PHD STUDENT= I was just thinking about coming back to thinking about employment. Do you think perhaps what a barrier might be is employers having a lack of understanding of what is going on.

03005: = Yeah, I think so.

PHD STUDENT= Got some nods.

03003: = And making judgements as well.

PHD STUDENT= Okay.

03003: = Because they are. They’re just human. And um you know it’s about your ability to do a certain job.

PHD STUDENT= So let me ask, we all like you said are human and we all judge, so what would be so bad about them judging about what’s going on with you guys.

03003: = Because we’re all already judging ourselves and to have someone else judging us on top of that =

03004: = Reading someone’s face on it as well is just um, yeah, it’s like a fat of lava really, sitting init. We’re judging ourselves mentally, majorly, or maybe it’s just me, all the time when you’re going through something like that. When we are disclosing or talking to someone and they are not understanding it, it’s making you feel worse. And I find it quite patronising actually, the way sometimes you are spoken to. Because a lot of my cases you have to explain in quite a young manner, you don’t need to patronise me like a seventeen year old or thirteen year old child.

PHD STUDENT= You said 03004 that sometimes they can make you feel worse I just wondered, if I were to ask you what emotion you would be able to call that, what would you say? What I mean by emotion is you know you’ve got the primary ones like anger, sadness and happiness, what would you say would you be feeling when someone is talking to you in that way?

03004: = When I was working in a small business and they didn’t know anything about it. It was a lot of sadness. Sadness and it was, um [exhale outwards] it was judgment across myself all the way. It was never them, I never judged them. It was how incompetent and how incapable I was,
and the more they geared towards me the more sad I felt. The more ashamed I felt on myself and I couldn’t get out of that pit and the only way to do it was actually just to leave.

PHD STUDENT: So let me and I’ll open this up to you guys as well, having said that, what do you think would have been more helpful in that situation? What do you think would have been better to help you feel like you were better supported?

03004: Well recognising what I am doing is good, to be quite honest that I was good and competent, it was just that I wasn’t always able to serve customers. So I would rather be behind the background of some of the things, because my face wasn’t portraying “Oh have this and it’s lovely”, it was like “Get away from me”. But in the back, I was quite able to do it and get on, and they were not understanding that, some days aren’t as good and I’m trying to help out for your customers, but I’m not having this. But not always can you control. I feel my face is a () person really [laughter in speech] to be quite honest.

PHD STUDENT: Well feeling in a certain way and you can often see it on your face, yeah: it’s difficult. Has anyone had anything quite similar, in terms of feeling that sadness and frustration?

03001: I don’t like the way they kind of, it’s like they pre-judge your abilities before they even know you. Do you know what I mean? They just see your mental health and they already think ‘oh they can’t do that and they can’t do that’. And they already prejudice what you can and cannot do in their own mind-set rather than actually sit down and talk to you and be like, so what do you feel you know you can do within this job role, and what tasks are more challenging for you and what tasks do you think you’ll need more help with. You know like out front, face-to-face communication with clients you know =

PHD STUDENT = Yeah. So it sounds like it’s going back to employers having a better understanding would be helpful.

03001: Yeah, I’m not just saying just more understanding, but I’m saying they need to actually communicate with you more at a one-to-one level because everyone’s different. And everyone’s got that individuality and we’re not, even if we’ve got, if everyone’s that’s diagnosed with a personality disorder, doesn’t mean that we’re all the same. Do you see what I mean? We’re all different within that broad spectrum, we have different needs and we all have different abilities of what we can and can’t face, and of what we can and can’t do [sure], and they need to stop like putting us under that big umbrella.

03003: And realising that some days we can do some more, but other days we actually can’t. Because we don’t know what days going to be good and bad for us you know. We’d hope to wake up feeling good and great, but it’s not necessarily.

03005: It’s flexibility really. I think a lot of employers need to be more flexible.

PHD STUDENT: More flexible. And is that in terms of flexible in terms of meeting your emotional needs, or more tangible things like working hours or?

03002: I think both really?

PHD STUDENT: I guess it really depends on the person?

03005: Yeah again it depends on the person, on what they need, on what their diagnosis is, on what is best for them. Again it needs to be like on a one-to-one basis and its needs to be met to like their individual needs.

PHD STUDENT: Yeah I think that makes sense.

03004: Yeah because they recognise a pregnant person can’t do a certain amount after a certain amount of time, so it’s a recognition that you can do this up to this time, but you can’t go around lifting crates and that after that certain amount of time.

PHD STUDENT: Okay so tell me what the difference is because obviously, well you can see a woman that’s pregnant.

03004: That’s it. On our faces nine times out of ten when we’re walking, not all of us show it, but you can see a difference from a happy day if you know her, if you get to know us in a workplace. You can see what a good day, you can see a frustrating day and you can see a right bad day if you get to know the faces. And on those bad days when we’ve promised we can do so much; we’re beating ourselves up more than any employer can and just by the employer saying certain things makes us beat ourselves up even more. Because we are trying for them, we want to do it, we don’t want to let people down and it’s ourselves that we are letting down more than anything else because it’s ourselves that we are mentally we’re beating up.

03005: I think it’s also that mental illness is a hidden illness really. It’s something that you can’t see, but you have people with physical disabilities you know in the workplace that they get treated fairly, they get you know sat down, what do you need help with this? What’s challenging? What do you need help with? Do we need to widen doors for you? Do you want a comfier chair, do you want this and that? But for people with mental health problems, we don’t
get that. It's just the case, just because you can't see it, doesn't mean it doesn't affect your health.

PHD STUDENT Yeah, I mean, has anyone else gone through a similar experience? Feeling like it's a hidden illness? Got some nods. 03007 you’re deep in thought [hehe]. Um okay. I was just thinking um I wanted to ask you a question about physical health, because I know that a lot of the clients that we work with over at North East London, it's a combination of both. You know they might have um you know issues with their hips or their back as well as their mental health difficulties. Got some nods. Is that something that's common in your experience?

03002: I have an inflammatory bowel disease. So that really affects me and I've always had mental health difficulties and then that came along as well, so it's sort of both made my mental health aspect even worse having this and it's really restrictive as well. And that's also a kind of invisible disease as well. So they're both invisible and it's hard to do anything really without, because they can't see it, they can't, it's all inside, it's rotten=

PHD STUDENT =03002 can you tell me a bit more about um how that might stop you from thinking about employment, and getting back into it? Or if it does?

03002: Yeah well because it's kind of difficult with my stomach because err none of the medications have worked for me so it's constantly bad unless I get a colostomy bag.

PHD STUDENT So is it painful?

03002: I won't be cured.

PHD STUDENT Okay right.

03002: Yeah it can't be cured.

PHD STUDENT Right, right. So having that physical aspect and then working as well.

03002: Yeah, I don't know. Sometimes the mental health side can be worse than the physical health side as well. Um I think I would need to inform them that I have mental health issues because that maybe flare up as well, more so than the stomach. They are both always there. Um what was the question? [laughing in speech].

PHD STUDENT No. I'm just trying to understand you know, when you've got that on your mind you know, you're trying to sort out your=

03002: =Yeah that creates anxiety all the time.

PHD STUDENT And I'm just thinking, would you even think about employment, like oh my god I need to get this sorted?

03002: No, definitely not now, whereas before I wanted to. I finally got to a good place where I wanted to, um because I was so anxious that I couldn't even attend anywhere and I couldn't even talk, and then I got over that. And then this all came=

PHD STUDENT =Yeah. Sorry I didn't mean not wanting to, because I think it's very different to wanting to work then actually being able to, because there's too much going on or whatever is going on in your life in that moment in time. Um I had a nod over there. 03001 haha, do you want to add something?

03001: I have back problems and it runs in my family. I was working last year in a care home and I actually got sacked because I ended up in hospital with my back problem. I was numb from head to toe basically. I couldn't walk. I ended up in hospital and they sacked me for it, which affected my mental health so obviously I don't want to go into work because of my past experiences, it does scare me. So when people talk about employment, I don't want to do it. I would rather stay at home and let my partner go out to work because at least he would have a better employment life then I would.

PHD STUDENT So you said you felt scared, do you mean um, so in your experience you would feel scared that they won't understand you, or scared that you might get sacked again or=

03001: =Scared that I might get sacked again and that I would end up in hospital again, because I was overworked.

PHD STUDENT Ah okay.

03001: So, I hate hospitals.

PHD STUDENT You're not the only one hehe.

03001: I was actually at work; I was only in work for an hour and the ambulance got called and I was in hospital for about a week [ah I'm so sorry to hear that] because they overworked me. So they didn't really pay much attention to any of it [yeah], my mental health, my physical, my emotions, nothing.

PHD STUDENT I definitely want to come back to you when we are talking about when we want to stay at work and what is it that basically we face in terms of difficulties. Um so this stage about thinking about employment, is there anything, what would you guys think overall in
general um would be the main difficulties that you might face, or the barriers when it comes to 
thinking about employment?

03005: It is about whether, generally the fear of like, of a) am I going to have to disclose what I've got. If I disclose what I've got, what's going to happen? Am I going to get treated differently?

PHD STUDENT Lots of worries.

03005: Yeah. I think that is the fear with going out to the employment world, and then also if you've got a physical condition as well on top of that and you wouldn't be able to cope in employment.

PHD STUDENT Yeah. Lots of uncertainties isn’t it?

03005: Or them not really recognising any of them and you just get a job and you crumble and burn, and there’s no support. And the more you crumble and burn and come out of a job like 03001, you feel punished. You literally do feel punished.

03001: And you feel like you’re back at square one, which is why I won’t go back into work.

03005: Because you’ve done what you’ve been asked. Sorry we’re all talking on top of each other.

PHD STUDENT It’s okay.

03005: You’ve done what you’ve been asked and you’re been doing more than what you’ve been asked; and when you’ve actually crumbled and burned, and they’ve gone okay see you later, the next person pays.

PHD STUDENT And like you said, you feel like you’re being punished.

03005: Yeah.

03006: So what we need is some reassurance that all of that, none of that will happen and=

PHD STUDENT When you say reassurance, do you mean coming from the employer or coming from someone supporting you.

03006: Um well ideally it will be from the employer, because someone’s supporting them would be great as well. The encouragement has to be really coming from the employer because they are the ones who are going to be giving you the job. And you need to have the confidence that none of this will happen.

PHD STUDENT Sure. I think that makes sense.

03004: If you get the support and understanding on the days that you can’t cope. It only lasts sometimes a day, an hour or it can last a couple of days. It’s not necessarily a whole month that you’re going to be like that. But if you get support in that time, you think ‘oh yeah, do you know, I can do that. I’ve got someone there who can, they can understand me’. It’s not, and then you start picking yourself up when you think someone else believes in you. I think the way it is, you don’t believe in yourself, so you feel that the employer don’t believe in you, which gives you less belief in yourself where the employer is like oh you’re having a bad one in their head or, help you through it. But it feels like a little bit of belief to give you your little string to hang onto to climb up again. That’s me anyway.

03002: I haven’t really ever had a job, but I play football at the highest level you can play in really as a woman, and um I’ve always played in the Watford team since I was sixteen and when this illness came along with my stomach, um I missed the whole season last year. And I trained when I could, I literally tried so hard, and people were just not turning up and they got to play; and the manager refused to sign me because I was unreliable and all this. And um, like I ended up, my mental health got really bad and I jumped in front of a train; and so I was out for how along and they completely forgot about me, whereas the people who had injuries, knee injuries or something, they are now back in the team and they’ve completely forgotten about me. And now I don’t play football anymore. I went, they told me to trial and I was ‘are you joking me [laughter in speech]’. I had to re-trial and then they sent me an email the next day saying sorry we are not asking you back this time. And then I think, that’s sort of the same=

PHD STUDENT = 03002, if I were to ask you what would you suggest as an alternative to go about, to you know, your situation, how would you go about it if in the future it was to happen again, what would you say would help?

03002: I just think it was really disloyal of them considering I played for them for so long. I’ve always been punctual, I’ve always been like in training, I’ve always done everything. Um and I think that next time don’t be so rude and discard me completely from the whole team where I can. I don’t know, I think it’s really unfair.

03004: Sounds like you got no support.

03002: Yeah they just completely, they’ve just said forget about her and let’s continue with the season. Um and now it’s just got to a point where they’ve completely forgotten, and I’m not even in the team anymore.
PHD STUDENT: That’s so frustrating. I mean if you haven’t been in work, we can be talking about training or education, or something that you know that is similar to you all working anyway. Um okay=

03004: Doing that at that age, sorry I don’t know how old you are, but doing that at such a young age, it’s similar to what my daughter had already with dancing. She’s been a dancer since she was six, um she’s got anorexia, she ended up in a home, um but the school that we went back to had no understanding that she couldn’t do it every day, because of the weight loss that she had gained. It was a great thing for her, but it was a torture for me. Um and another school that I got her into, understood that I was coming and going, and they didn’t disregard her and they put her in competitions and they, because she was able to think of and he knew her dances, they took chances on her in teams and they actually done it so the school I had been with since she was six treated her like yeah, like she was scum, like she was not worth it. And now at the age of sixteen, she’s come out of dancing [yeah] um because she was in a street crew, um but she feels that, she’s with this other street crew because she relapsed that they’ve abandoned her. So where this one abandoned her and this one didn’t, and she’s gone from that to that, she now feels abandoned again. Because she’s been doing it since such a young age, even though its dancing or football, it’s still, you’re trying to keep them in something long-term, which with football it’s a long-term think like a job, so if you continuously continue to do the same thing, it creates in you that you can do long-term other stuff.

PHD STUDENT: I think that’s quite interesting actually that you used the word ‘abandoned’ and I wondered if you guys feel that that is a similar experience for you? You work somewhere and you’ve been working there for a while and then something comes up, and then they just don’t support you so therefore you kind of - Yeah, lots of nods. You feel abandoned because you’ve been training a lot, and then nothing. Okay.

03003: Can I add, I’ve had a similar experience as 03002. In my job I went off sick [okay] and I um (.) I was ignored and disregarded. They kept to the timetable for um sickness and sick pay and everything, and then as soon as I hit the six months trigger they started to go down the route of capability. And that’s in the public sector. Um but obviously people, and it was actually driven by peoples judgments of my ability to perform tasks. So not only was there no contact with me what so ever except for the mandatory ones. For example, the various, the occasional check-in (), um but there was no other contact, and then they started to go down the capability so I had no option but to hand in my resignation () really.

PHD STUDENT: That’s a real shame. I just wondered, it’s just got me thinking about the systems and what I mean, what do you would have been more helpful for you in that moment in time 03003.

03003: I think more um (.) more check-in, not necessarily=

PHD STUDENT=From the employer or the=

03003: My direct line manager was quite a young person, he wasn’t even thirty, quite new in that role, um and the line manager above that had no patience or um (.) desire to understand because obviously I wasn’t the first priority. The first priority was whatever was going on with () what not; so I wasn’t – An email check-in would have been nice, a text check-in, but there was nothing, nothing at all.

PHD STUDENT: Let me ask, how did that make you feel knowing that they weren’t checking in? (um) We’re you feeling frustrated, sadness again or-

03003: Um I felt um disregarded. A sadness yes because sadness, I was not – the work that I put in um (.) was not valued in any way so my contribution for the period prior to my mental health issues, my breakdown, so the job contributed to that, um it was not appreciated, it wasn’t taken into consideration; I was written off at the moment that they came out that I had an, yeah that I was not able to work for that period of time. Um there were – I was given options to reduce my hours, or to not do certain types of, so sort of you know no public speaking, and no sort of, for the time being, I would not lead on public speaking or I wouldn’t be attending courses or I wouldn’t – so I would do certain other things. But I think they assumed that because I had this breakdown that I wasn’t able to do the job and it was never expressed um “what’s the word that I want to say” it was implied so it was never explicitly stated.

PHD STUDENT: Yeah I was just about to ask you, was there an open discussion? Um okay we’ll come back to that [okay]. It’s absolutely relevant.

03006: Can I just ask, when you say ‘check-in’ what do you mean by that? If someone checks – I think I know what you mean by that () but to answer your question.

03003: From someone that you assumed you had a good working relationship with, a colleague from work that you worked closely with um, you could expect=
PHD STUDENT=Okay, not necessarily from management it’s just someone from the workplace who would just check-in with you in that way by text or an email.
03003: Yeah.
03006: But what I’m saying is basically would you want them to say ‘how are you doing? Are things okay?’ is that what you mean?
03003: Or ‘how are you doing? I’m thinking about you’ um basically ‘do you want me to do anything?’ Or ‘do you want me to say hi to everybody?’ anything like that. A communication other than an official one that I knew I was being documented.
PHD STUDENT03006 go on, what were you saying?
03006: So that’s it, so kind of like some encouragement, um and someone like you say, just to see how are you doing. You know, just like encouragement that makes you feel wanted, like you are wanted to come back to work, valued to come back to work, they want you to come back to work.
03003: And the only communication would have been with the occupational health doctor, which is someone who didn’t know me at all.
03005: My manager called me weekly.
PHD STUDENTAnd how did you find that?
03005: Yeah, it worked out. It was good, it was really good.
PHD STUDENTI mean you’re currently signed off sick, is that right?
03005: Yeah.
PHD STUDENTYeah you said yeah, okay.
03005: I’m currently signed off sick since the 6th of February. Um we, me and my line manager agreed on weekly contact. Um so she calls me, or if she misses me, I email her back and say sorry I missed you, call me when you’re next free or whatever and then she’ll call me back. Or we do it via email um=
PHD STUDENTSo tell me, when you are able to get in contact, what kind of things again are running through your mind? Are you thinking yeah this is great?
03005: Like we get on really well me and my line manager, and she’s really supportive so it’s great. And she’s never made an issue of me having to be signed off.
PHD STUDENTTell me how does it leave you feeling, in terms of your emotions?
03005: Yup. Really good, like I feel happy and I don’t feel worried at all that like I’m, like not being at work that my work mates are kind of talking about me or I’m kind of this evil person hehe.
PHD STUDENTHow does it like having a conversation with her, checking in every week, how does that influence your day-to-day, so do you like having your weeks of?
03005: It’s nice, it keeps me in the loop of what’s going on at work because she keeps me updated about what is going on. Um I feel better as well because um like you say I don’t feel like I’m being pushed out and it’s not so - if I was just receiving letters that are just official and via occupational health or via you know higher up, I would feel like I’ve just been forgotten about, whereas I don’t with her. And it’s not a formal chat either, it’s like a ‘hi okay well how are you feeling? Like how are things going? Um any updates? And then is there anything you want to talk about?’ and then I’ll say to her ‘yeah how’s work? How are my patients?’ and stuff like that and – So it’s nice, we keep that, and now we’ve cut it from weekly to like, I phone her like every couple of weeks just because we were like [talking quickly] ‘what should we talk about’ hehe or like ‘ what were we going to talk about’.
PHD STUDENTIt’s the idea that you check-in so you can get back into work?
03005: Yeah, yeah and so hopefully I’m going to go back on phased return eventually. But like I say, obviously my company is quite big that I work with, mm they work really closely with MIND. So um because we have, we’re also a university, we’re a teaching hospital, so we have to be really conscientious of the students and staff and their mental health. So we’re also taught as staff to watch out for other people’s mental health, and if we’re concerned about students or staff member’s mental health to flag it up. And because there’s a high suicide rate in um my profession, so um we obviously look after our whole team members.
PHD STUDENTSo do you think the nature of your employer helps you staying at work?
03005: Yeah definitely. And like I even like, my work colleagues, not just my line manager, I even receive texts from my work colleagues to say like ‘hey mate, how are things you know, we miss you’ um [can’t wait to have you back] yeah and ‘can’t wait to have you back’ and all of this so it’s nice. And it’s nice to know that I’m still being thought of and I haven’t been forgotten. Because, you know a few months ago, I was feeling quite down and was feeling like ah you know, I feel like I’m being forgotten. I’ll see them on Facebook and like the group on work
colleagues going out for drinks and things and obviously I’m like ‘I’m feeling left out’ ‘I can’t go’. And so I did feel like ah I’m feeling a bit seclusive, but when I got those texts from my work colleagues saying like ‘how are you mate? We are missing you,’ it was nice because then I thought ah they are still thinking about me.

PHD STUDENT: Um do you think having the support or what not, how does that influence your motivation to wanting to get back to work?

03005: Yeah a lot like I’m really pushing to get back to work. It’s more I want to go back to work; it’s their occupational health stopping me.

PHD STUDENT: In what way?

03005: They’re the ones saying they don’t want me back yet.

PHD STUDENT: I see.

03005: So they’re the ones saying that I’m unfit for work due to my mental health, not my physical health, because I was actually initially signed off for my physical health.

PHD STUDENT: Which was, can you remind us again?

03005: Which was fibromyalgia. So um I was signed off because of that and then I was – I am now on medication currently okay. I went to see the occupational health and they signed me off due to my mental health. And then they were like we don’t want you back for another two months. Whereas I’m like [exhales] “for fuck sake”; and I feel like I’m capable to go back but they’re like ‘we don’t want another psychological assessment, we want his we want that’. So that I suppose they need to work with because of where I work with a lot of medication of dangerous drugs and stuff, so they probably have to do that as safety keeping.

PHD STUDENT: “Okay, I’m just making some notes of that so I can come back to it”.

03005: That might be why they have to be really strict just because of the nature of my work so.

PHD STUDENT: Okay. Okay, so thank you. Um I want us to next consider um the period of time where you’re getting back into work. So that can be err I don’t know, it could mean different things for different people. So for some people it might be job seeking online, doing activities like that, or I wouldn’t call that activities but things that you do to find, get work. Right, so for some people it might be putting a CV together, or preparing for an interview. So if that’s not where you are right now that’s okay but I just want you to think about a time where you’ve got work and you’ve done the steps leading up to it. What kind of things did you face or could you face at that point in time, in terms of barriers and challenges?

03005: With the interviews process I suffer with really bad anxieties [okay]. I didn’t like the actual interview.

03005: Yeah I was like that as well. I had an interview at __________ and I couldn’t even look the lady in the eye, it was really awkward.

03005: I get really flustered like I don’t know how to like get my words out properly. And then because of my condition that I have, my fibromyalgia I get what’s called fibro fog, and it’s like kind of a memory loss thing and you cannot sometimes communicate properly what’s up here, you can’t get it out. And so it’s worse in stressful conditions, so in an interview process I’m like err.

PHD STUDENT: Hehe and that also the anxiety as well isn’t it, that can sometimes stop you from saying anything or freeze isn’t it [yeah]. You were about to say 03002, so you had an interview for __________ was it that you couldn’t look them in the eye either?

03002: No. And I just felt stupid when you have to say like ‘why do you want to work here?’ hehe. I didn’t want to come out with some really formal line, it would just be awkward.

PHD STUDENT: Sure. Does anyone else find the interview process um exciting? Hehe or is it a similar experience of feeling quite anxious?

03004: See I think that’s normal for anyone even without PD [yeah] to have anxiety in an interview, because you are meeting someone for the first time anyway, you’ve got your own judgments, and you’re constantly even before you get in there thinking that person’s judging you and you’ve never even met them.

PHD STUDENT: So what kind of things do you think you might be thinking because you’ve got your own judgments anyway.

03004: Incompetence. Am I going to be able to do this? Am I going to be able to answer the questions right? Am I going to say something stupid? Am I going to fall through the , which is my classic, as soon as the door opens I will hit the floor or my bag will open up or something. Um basically am I going to look like a completely stupid person naïve for the job and probably in my head I can do this backwards for you guys but to actually to portray it to someone. Yeah for me it looks like, I feel thick, stupid, blank, can’t think of anything, sweaty, um I want to run.
PHD STUDENT I can understand. I know what it’s like =
03004: = It’s really normal, isn’t it?
PHD STUDENT I know. I think so. I don’t know anyone who would go through an interview and not be a little bit nervous and kind of sweaty a little bit hehe. Um is there anything else in your experiences guys, in terms of getting work? I mean I don’t know if you guys have gone down to the job centres before? Or have you looked for things online?
03004: I don’t like job centres. I don’t like the way they treat you in there.
PHD STUDENT Can you tell us a little bit more about that?
03004: Um you are treated like what I would class as a (), like a freakin’ (). You walk in and when they find out you haven’t worked for a while, in my case back in the day I was in a job, out of job, in a job, out of a job, going round in circles. It was like lots of little ones on my CV which shows no consistency, no full-time job to say – they’re not so willing to help you because they thing ‘oh you’re going to be out of a job in no time whatsoever anyway’. Um the one that I went down to in [states name of area], obviously this was when I was really young, um and I cannot walk into my job centre anymore. I just can’t walk in because I feel inadequate, incompetent, stupid, thick, um even to the point that the man moaned at me saying the phone that I had on me was a really good phone for someone who is on benefits. And I looked at him and said do you want me to get my mum and dad’s paperwork to show that they bought it for me because they are frightened that I might go off and do something stupid. Um you just, I don’t know, you are just portrayed as this person that doesn’t want to work, is just going in for the jollies, and them not seeing mentally inside, I mean the fat of larva in my head screaming my whole body out begging for your help to help me to try and get me to somewhere that’s going to understand.
PHD STUDENT So you don’t use that service?
03004: No I went in with my daughter to the job centre because I though it’s the only way to do it. Um she walked out with the same feeling and she’s sixteen years old. She’s walked out with the same feeling that ‘no one’s bothering, no one’s caring’ and they don’t even know what’s wrong with my daughter. As far as they are concerned she’s fine.
PHD STUDENT What do you think would have been helpful in that situation for you and your daughter um to have an outcome I suppose?
03004: Well for someone to understand that I’ve gone in with my daughter to show her that this is the step ‘You’re sixteen and now you are coming up to eighteen and you are going to need a job. This is the steps, this is what you do, this is how you do it. If you can’t find it here, you go here, if not you can come back and we will support you’. Um no it’s basically ‘no, we don’t deal with this in [states name of area] anymore, you just go online and do it through there. And by the way she’s sixteen, she won’t get a job’. My daughter walked out crying. My other daughter had to literally hold my hand because I just wanted to go in and take the guy’s head off and out it on the table and say ‘Are you serious mate?! How are you going to do that to my kid’. Obviously I’m not going to do that [haha] but I’m just saying, they were the thoughts in my head and my daughters know that. They held my hand and were like you’re not going anywhere, but I just wanted someone because my daughter see’s that I haven’t worked, I’m her carer. I haven’t worked for a while and I don’t want her being at this age to think this is freakin’ life. It’s not life, sitting in your house, not being able to open your blinds and open your doors. It’s not a way of life. Um I wanted someone to show her but I don’t even feel the schools now-a-days are showing kids how to go out and get a job and she’s sixteen years old. I’m at home sitting there doing her CV with her. I’ve got my CV out and she was like ‘that’s not how it’s done mum’ and I was like () hehe. The schools are, there was no proper support then to literally now, um for parents. I don’t know if any other parents have had it the same when it comes to their kids. I see it with my kid now and it don’t, I see it with her at sixteen and then I think well how the hell am I going to get a job at 38, no you’re alright mate.
PHD STUDENT So you don’t use anything from the job centre but you did say that you and your daughter have worked together on your CVs together. Did you find that helpful?
03004: Um I’ve not, not my CV, I’ve worked on her CV. I can’t look at my CV because like I say, I have like a run of jobs and it’s all in the same year, so it doesn’t show me. But I sat down and I showed her this is what you don’t want on your CV. It’s because it shows no commitment. They want, on the first job I ever had, I was putting myself through college, it was the best time I ever had. I done two years cleaning, I stuck at that job. Um even became supervisor after that. But when I went into doing what I had done in college, I was made to feel in [redacted], inadequate. Because I had days that weren’t good but I was doing my job, but because I wasn’t communicating properly, um I got pulled out from that form.
PHD STUDENT: May I ask um, err how comes you switched jobs, you said you had quite a few in one year.

03004: Err mental breakdowns. Um I was, through college I’d done cleaning and put with it all the way through my college, it put petrol in my car and everything, and it was one of the best jobs that I had for two and a half years. But when I had done my college course, which was bakery, I wanted to go into bakery [okay], which is early hours in the morning, two in the morning till five because I was doing the bread side of things. Um and then from there it all went wrong in that job. Me and my manager majorly freakin’ clashed. I’m not going to lie, to the point that he pulled me out in the middle of the floor, to the point that I pulled him out in the middle of the floor, in front of all the customers and they all stood there and looked at him and I told him where to shove his job. Because you don’t do that, you drag me across that floor, you make me feel (), you make () up in front of everyone. From there and in, I went to another job which was a little business, bakery, and she made me feel inadequate, she made me feel stupid, I actually caught her lying to customers I had got on with, built reputations up with. These customers then had to support me down the job centre because of where my mind went. And then from that it was just another job, and I thought yeah I’ll go in and yeah I can do that, I told the whole world that I could do that for you, a couple of weeks down the line I had a mental breakdown and I couldn’t do none of it. And then I punished myself that I’ve said I can do that for you, but now I can’t do that for you. Whereas someone once said to me, well step back a minute, you can re-do it, its fine. And I was just made to feel each time that my best bet is just not employment, not to be around people. But I was made to be felt, I’m not adequate to be around people and that’s why I’ve never=

PHD STUDENT: I just wonder has anyone else had similar experiences to 03004 in terms of you know having a clash with someone perhaps, was it your manager?

03004: It was my manager.

PHD STUDENT: So obviously senior to you in the workplace? Go on 03001.

03001: The care home that I was at, my manager didn’t actually care that I ended up in hospital. Um she didn’t care that I was waiting to hear back about my mental health. She knew I was, but because I was in a care home, I had to disclose it. And I was so good at my job and they knew how good I was at my job. But there were days where I didn’t have the energy to actually just look after someone [yeah]. I didn’t have the energy to walk up the stairs so I would go in the lift, but apparently that is not allowed. All because I don’t have the energy to walk up the stairs, she’d have a go at me and send me home early that day. So me and her did not get along. The only person that I got along with in that job was one of the tenants. And that was because I was her main carer, no one else looked after her because she always requested me. She was actually the only person I ever managed to talk to, who actually understood, but she’s a tenant I’m not supposed to disclose this stuff to her [laughing in speech]. So it was very hard for me to actually even control anything at that job.

PHD STUDENT: But it’s about having someone like you guys have mentioned before, support, or some sort of encouragement= 

03001: She was=

PHD STUDENT: Exactly.

03001: I did end up finding it really really hard. And now I’m on ESA and I even find that hard, going to the job centre.

PHD STUDENT: Yeah, tell me more about that.

03001: Just to give them a sick note. Cheers, that’s it.

PHD STUDENT: What’s hard about it? Tell me.

03001: I have to go into the job centre every month to give in a sick note. I shouldn’t have to.

PHD STUDENT: They know I have a personality disorder, they know I have anxiety, depression, my hip and my back, they know I can’t work at the moment. There’s been a letter sent from here saying ’03001 cannot work’.

03002: And you still had to keep going back?

03001: And I still have to go every month with a sick note.

03002: That’s so silly, they should just do it=

03001: =They will not talk to me, they just say I have to give it to them. They’ve not talked to me for over a year now and I’ve been on employment support allowance. For over a year no one has actually told me why I have to give in sick notes. Every month I have to drag myself out of my house and I hate leaving my house, I hate opening curtains, opening windows, I don’t even answer my front door or my phone. My partner does all of it. So it’s very hard for me to get out of my house. Um so having to bring my sick note to the job centre because () it’s very hard
for me. But they don’t even care. So I struggle a lot [yeah], which is why I don’t even want to go into work [ah it’s so difficult]. Because if I get this at the job centre, how am I going to do it at work?

PHD STUDENT Yeah that’s a good point haha.

03001: The job centre is supposed to help you kind of look into getting back into employment, you know even when you’re on supported allowance. They don’t even do that with me, so how am I supposed to want to go into work [yeah]. So I don’t. I seclude myself from everyone.

03006: That’s the thing, the job centre don’t care really, the staff don’t care, and your employer really when it comes down to – unless you are lucky to get a good employer they don’t really care. They just want their business to run, they want them the money, they just want their cared amount, their income.

[Participant 03004 leaves the focus group]

PHD STUDENT So guys just to come back. 03006 you were in the middle of saying something? Can we just come back to the discussion.

03006: To be honest, to expect help from the job centre or the employer, so really your help in the best way is going to come from well the health service as like treemand. Um and that would be just ongoing support and encouragement when you’re working you know. And it’s got to be flexible, because you don’t want to have to wait for months to see someone, you need to see someone quite quickly.

PHD STUDENT Yup, so you want someone imminent. Um.

03006: So you can talk through these problems as they arise at work, so like you have the problem at the bakery or whatever.

PHD STUDENT Yeah they can run in parallel.

03006: Then before it becomes an issue with your manager and you start having arguments with your manager on the shop floor, you talk with a counsellor or mentor. I like to use the word mentor, and they then talk through your problem about how you can deal with this person and conflict with – and all of that stuff. You know, and I think that would go through the whole process, looking for the job, you preparing for the interview, doing applications, just the whole thing. Just encouragement really to do that. Things are going to be alright, it’s going to be alright, you’re going to be alright, all your fears, yeah all your fears might be unfounded.

03007: I’ve been to one of my friends () to go to the job centre and um I was too frightened to go through because of everything that people have said here, and his just finding it all really unhelpful. You get told off if you haven’t – you have to go on their website to try and look for jobs, if you haven’t actually been through their website and it’s really convoluted and it’s got – you have to keep logging on through every single job or something, and it’s just a really appalling website to find jobs. But if you don’t do it through them, then they don’t see that you’ve done it and then they’re just going to tell you off like little children. And they don’t give you real support.

03001: See I’ve had that. I’ve been under the mental health for two years now. I was on JSA originally, which is job seekers allowance. I had to go to the job centre, have a meeting with one of the people there, their advisor; they tell me what website I have to go on. I go on the website when I’m at home, and when I’m at home I think I can’t do this. You’re going into the job centre asking for help and they say we don’t have the computers for you to do it here, do it on your own at home. I can’t do it, they do not understand =

PHD STUDENT Which is why I’ve come back to= 03001: Which is why we’ve come back for help. If you don’t do it, they stop your money, you have no money to pay rent, pay bills or anything else [yeah]. So that is one of my massive worries, is when my ESA does stop=  03001: It will stop eventually, unless if I’m signed off completely forever and I am basically disabled.

PHD STUDENT So these are worries=  03001: = Unless you’re diagnosed as disabled and you get ESA forever, that’s very hard to do. You physically have to go to London, have a testing and everything else and it is very very hard. I might get it because I’ve done this assessment, but I didn’t go on my own. My partner came with me, my mum came with me, my worker with me, my social worker came with me, I couldn’t do it on my own. If I didn’t have any of them people there, I wouldn’t have even got it. They
make it very hard for you to even just live. Just for some money, because you can’t work. And again they do not understand; it is ridiculously really hard.

03005: And because again it’s a hidden illness. If you’ve got a hidden illness like we have that you can’t see, it’s even harder to get=

03001: You have to explain it yourself, no one else is allowed to explain it. You have to explain it. When you can’t physically put words to your mouth to explain it to someone, but what you’re doing is crying and panicking, they’re going to go ‘No. You’re perfectly fine. You can talk’. Then, it’s really hard.

PHD STUDENT I’m just thinking, what I’m hearing from you guys is a real lack of support coming from a lot of the services that are out there.

03001: They just don’t care and they don’t understand.

PHD STUDENT What would be helpful? To have someone who is based at the Job Centre that can do that? That sort of stuff.

03005: Yeah I think a lot of time as well you feel that they just, especially when you’re at our age, your young; they just think you’re young, you look healthy and young, you are just palming us off do you get what I mean, you’re just being lazy and don’t want to work. As appose to actually we do want to work but it’s that we’re finding it hard to work because we have a condition, we have a problem.

03001: That’s how I’ve managed to get to the point that ‘I don’t want to work. Because of all of this I’ve got to the point that I don’t even want to return to work because of everything that’s happened. I don’t even want to try. I’d rather just stay at home and not work at all because it’s too hard.

03005: I think this is a society thing as well. Other people have a go at me with the way that I’ve parked my car and like I’ve got out of it, and I’ve had people have a go at me and say ‘there’s nothing wrong with you d-d-d ‘how dare you park here’ ‘how dare you part like that r-r-r’. Just because of the way that I look.

PHD STUDENT You’re just talking about people judging in general?

03005: Yeah, I’m just think you have no idea. Just because I look young and healthy does not mean I am, unfortunately.

03001: My dad is disabled and has a walking stick. He doesn’t use the walking stick all the time and he has a disabled blue badge. He parks in the disabled bay, he gets out and he doesn’t have his stick, † “You can’t park there. You’re not disabled”. My dad is disabled, he can collapse at any point. Yet people have a go at him for this, or when they have a go at him and I’m with him, because he gets my back up, I end up in the middle of the street arguing with them.

03005: I think that’s the thing, people at the job centre, they look at you and then they look at you, they look at you and they just see a young, healthy because you look healthy from the outside=

PHD STUDENT = So it goes back to those judgements again?

03005: And they think that you know, you just are a lazy person =

[overlapping speech]

PHD STUDENT How would that impact you? Would you go away feeling pissed off, frustrated?

03002: I think I waited for the whole year for that money. I applied for PIT and I had to wait for about seven months for even the form to come through the post. I went to the interview, next day, ‘nope, sorry you can’t have it’, if it was that quick, why couldn’t you just no to me initially. And then it took for me jumping in front of a train to get money hehe [yeah]. It just doesn’t make any sense=

[Overlapping speech]

03005: () You don’t want to be here. Because there is so much stuff that you have to go through, that you can’t deal with and you just don’t want to be here. The worst thing is your mental health, it exacerbates it even more because you just feel like you have nowhere to turn and no one to turn to and you’re not getting the help that you need from the services that you should be getting help from. Then you just think what’s the point, just what is the point.

03001: I’m lucky that I have family support because if I didn’t have my family I wouldn’t even be here. And it is very clear that with everyone that I’ve talked to that, that is the case, which is why I’m lucky that I have a family to turn to.

03005: Unfortunately my brother didn’t get the help that he needed in his employment and he hung himself last year.

PHD STUDENT So sorry, that sounds terrible.

03005: its an example of not receiving support he needed when suffering from mental health.
PHD STUDENT: [exhales] You’ve given me lots of food for thoughts. Thank you so much for sharing these experiences, I mean yeah, it’s super important. We’ve already touched upon this and it’s all been quite fluid there. Um I just wanted to ask if you guys had anything else that you wanted to add in terms of challenges when it comes to staying in work? So we’ve talked about the different pathways to employment. We had 03004 talking about being in and out of different jobs for various reasons because of her mental health. We’ve talked about support in the workplace, all the lack of really. Um was there anything else in terms of things that you might have come across? That you’ve found difficult even? We haven’t heard from you 03007 that much.

03007: °I can’t think°

PHD STUDENT: That’s alright.

03001: You see staying at work for me, when I had the care home job, I enjoyed it but I struggled to get there, because I was always so tired, I had no energy, no motivation and it’s still part of my mental health.

PHD STUDENT: Tell me a bit about motivation.

03001: Um, I loved going into work when I worked at the care home, because I love looking after the elderly people. The problem I had was I had to physically get myself there, and I had no money for the bus so I had to walk there. And where I am so tired because I don’t sleep well because I’ve got insomnia, I don’t eat properly because I’m always so sick, so my motivation and my energy is very low and depressed. It all mixes together and it makes it very hard for me to actually get to work, and staying in at work is even harder. Um I’d get to work; I’d be there for an hour and a half. I’d be perfectly fine when I first arrive. I’ll be there for an hour and a half, I’ll go to have a break and I’ll get told that I can’t have my break because I’ve only been at work for an hour and a half. I cannot have a break is what I’m being told. Well I need one. It’s taken me an hour and half to get into work, I’ve done an hour and a half’s work and I’m now exhausted. I might only be twenty-three, but I’m not as healthy as most people think I am. I am not –and my employer didn’t understand that so it was very hard for me to physically want to stay at work and be jolly. So I’d always leave early, because I couldn’t stay at work, which is also how I even ended up having to lose my job, because I couldn’t stay for the full eight hours shift. Um (...) even when I did part-time work, I still struggled to even do four hours a day in a three day week. That was even hard. I could possibly do an hour or two hours, but I can’t do a proper shift.

PHD STUDENT: I just wonder was it something that was discussed with your manager? Like your situation.

03001: My manager knew, because I explained it all at the interview, when I had my first show around kind of thing, I explained all this to them. And they went well we’ll do this altogether; we’ll make it all flexible. It’s supposed to be flexible hours. No they ended up wanting me to do twelve hour shifts when I was actually only supposed to be doing eight. Because no one else wanted to do it, and because I was a caring person because its elderly people, I would push myself to do it, which made me worse because I felt guilty for not doing it.

PHD STUDENT: Yeah. Would it be different if you were able to say no?

03001: Even though I loved this job, you can’t just say no to someone, especially when you have a personality disorder. It’s very hard to say no to someone because you feel like you’re letting them down, or you’re letting yourself down. Um so physically saying no, it’s very hard, so I would always do whatever I was asked. I would never say no, I always just did it. Until my mum came into work and went, she just came () it got to that point where my mum physically had to come to my job and say that I had to take her home, she’s breaking. Because my mum couldn’t deal with seeing me how I was.

PHD STUDENT: What do you think could have helped you?

03007: It would have been helpful to say no hehe.

PHD STUDENT: But I just wonder hehe. It sounds so easy isn’t it.

03001: Having someone at work to help you understand what was happening and why you can’t say no.

03007: People not taking advantage of you.
0307: People giving you the flexibility they said they would give you.

PHD STUDENT Flexibilities for?

0307: They do take advantage because they know I don’t say no, and everyone else also says no, um and then you will be one, when everyone else says no they will just come to you. And if you say, oh well, maybe, you know if another person can’t – I had a nervous breakdown because all I asked for was for; I was working day and night jobs, and I asked for I think it was a Friday day time off work. I ended up having the following Monday and Saturday night and Sunday day time off from the two jobs. And all that I asked for, so I could have the Friday off because I didn’t get a break at all for, I just didn’t have a whole day off at all, and I had a one year old son. Um, and um, and um neither of the employers would let me, and I had a nervous breakdown. And this was after the doctor had said to me, oh you’ve got (), because I had finally managed to go to the doctors and say that I think I’ve got post-natal depression which the health visitor didn’t pick up on. Um and she was like oh it’s okay, it’ll go and then I haven’t spoken to them ()

PHD STUDENT That sounds like a number of things that came up there. So it’s like a let down from services as well, and it’s a pattern of the work place too. Um do you guys have anything similar? Perhaps the feeling of being let down from services? Or things that are out there?

Employers?

03005: I think one big challenge that I’ve faced, even in the company that I am in now. Even though they are great, working with Mind and things, is there an absence policy?

PHD STUDENT I’m not familiar.

03005: So they work on a scheme called the Bradford factor. I don’t know if anyone else has had a Bradford factor in their company. But um it’s all based on numbers and scoring a score. Um so it’s like, the number of times you’re off, times four, times the number of days in total. And then it generates a number [right]. Okay, and so in my employment you’re not allowed to exceed ninety in this Bradford factor okay. My number at the moment stands at 900 hehe.

PHD STUDENT Is that recorded every year?

03005: Over a year, yeah. And you’re not allowed to exceed ninety. I’m doing great hehe. Um but the way it works out is ridiculous. So my friend, my colleague, she broke her leg and was off for six months. Um but because it was just one incident, one broken leg; but for six months it was just one episode. So it was one times, however long six months is, equals, her Bradford factor should – so she stayed below ninety. But because in my year, I had a few different episodes off, so I had to have a time off here because I had a flu so I had two days off there, and then another month I had three days off here because I had um you know I was really fatigued. And at the time I hadn’t had my diagnosis given for my fibromyalgia, whereas looking back there was a pattern now that they can see that actually it was due to my condition. Because I had all these different, separate ones, it was like well you’ve had four episodes, so it’s four times the number of days, times the number of this, which got my score up to over ninety. So because of that, even though she’s had more time off then me because she had a whole six months off because of her broken leg, her score is lower than mine.

PHD STUDENT So actually the system of how they capture it isn’t actually, it doesn’t get everyone.

03005: No, and it doesn’t fit everyone on an individual base needs. So my year, last year was horrific. I obviously my brother died, um my Nan passed away shortly after that as well, um I divorced from my husband within two months after that. I had the most horrific year and I was like suffering from like this condition that I’ve now just been diagnosed with. Not knowing what it was, I was in that hospital also having to battle with my mental health as well. So I was having to have days off here and there and everywhere, yet I’ve been heavily penalised at work for it. And every time I came back for my ‘back to work’ interview from being off, they would say this is your score, you know naughty naughty it’s over ninety, um this is where you are on our systems. They have like a traffic light system, green, amber and red. You’re amber at the moment, but if you have one more day off, you’re going to go run into this red system. And so I was then constantly fearful of=

PHD STUDENT Absolutely.

03005: Because if I go into this red system, it’s then on my employment record.

PHD STUDENT And then how would that impact you when you’re constantly feeling like fearful, what would you do? Would you =

03005: = Well this is what happened. So I was then told that if I have one more day off. I then have to have an employment hearing which could then result in a disciplinary action, in me being retired. They can retire me early, I’m only twenty-seven haha and I was like oh my god.
Um and all sorts of things you know. And so then I was fearful and I was then trying not to have any time off. So I was then dozing myself off on vitamins, minerals, herbals =

PHD STUDENT So you were doing things to try and=

03005: Yeah, anything. I was going in whenever I was ill, like dying, whatever. Doing twelve hour shifts like dying. So in the end, I ended up having a breakdown, and literally – and they are, I was like fifteen minutes late for work and they pulled me in and they said um you’re late, um we’re going to have to put you on a behavioural report’ or something, just for me being late.

PHD STUDENT Does it add to your anxiety and stress?

03005: Does it add to my anxiety and stress? And I just break down. I say I can’t do this anymore. I’m signing myself off. And I just said I cannot do this anymore, it’s too much after everything that I’ve been through. I’m not well, I’ve been hospitalised two weeks ago =

PHD STUDENT And then all of the things that have happened to you in the last =

03005: = You’re done and that’s when I walked out and I got myself signed off and I’ve not been back to work since. But there is a fear, still have this fear that I am a little bit worried even though they have been great – like my manager like I said has been in contact with me, and I’ve had no issues while I’ve been off. I am a little bit worried though that when I do eventually go back to work that I’m going to have this employment hearing hanging over me because that is what I was told. If I have one more day off, and I’ve been off since February so it’s a lot of days now, um that I would fall into this bracket of having to have this employment hearing.

PHD STUDENT So let me ask you guys, and this is for you and the group as well, so you’ll have this hearing coming back to work, so what would you find helpful because you’re going to have to do it when you go back to work. What would you find helpful to prepare you and just get ready for that?

03005: I think for me, I think I’m going to, I would like some backing from like the mental health services for one, backing from the team that you know that you know say I am suffering from this condition, these are my problems, this is what, unfortunately this is what happens, this is what needs to happen.

PHD STUDENT So explaining things, backing you up, is that in the sense of supporting your anxieties, supporting the thoughts that come up, or is it more having someone from the mental health team actually come with you?

03005: Yeah. For me personally, I’d actually like a member of the team to come with me to the meeting. To be able to be there to support me, and if I am getting worried or stressed, or anxiety to support me then. But also maybe to voice, like their view of, because them being actual professionals=

PHD STUDENT =Like being an advocate, someone who speaks on your behalf to talk with you and for you depending on what you want that you feel is helpful. Okay, thank you. Um, just to sum things up, so is there. Let me rephrase my question. Overall what would you guys say would be the main barrier and challenges to employment with people with personality disorders? That we haven’t covered already, or if you want to emphasise before we wrap up.

03005: Understanding, flexibility, individual flexibility, that has to be individually based, and you need to work with that person.

PHD STUDENT And that work in a work situation. What about barriers per se themselves, or challenges that would arise?

03006: Just not having support. That’s it, just not having support throughout the process of looking, applying and working. We need someone there to help us with our issues, and if necessary then to come in with us and support us when we need it with our employer. Not like from the point of view, like a union a representative, this isn’t an employment issue, it is more of a health issue. Someone to support you, give that moral support, that’s really what we need I believe. And that encouragement to say ‘yes, you can do this job’, ‘you can deal with these situations in this way’, ‘yeah’.

PHD STUDENT Okay. Any last thoughts before I wrap up?

03003: So what do you do? I’ve always been – I work at quite a senior level or I did do because I’ve managed to stamp down on my emotions for twenty odd years [laughter in speech]. Um and it’s only through stress that I’ve been unable to um control whatever is that goes on in my head. Um, someone like me, there is less, seems to be less sympathy. For example, for my team I would bend over backwards, to keep them in work, and yet at my level there is absolutely no support and no understanding, and there is no flexibility at all. So what do I do? I can’t go, well I’m thinking I have to rethink my life completely now. I cannot go back and do the job that I used to do, because I have to explain ‘what if I leave in six months’, ‘what have I done in six months’?
And I don’t want to, I don’t wish to tell people, I have an anxiety disorder or I’ve been signed off with mental health issues or depression, or whatever. “So what do I do?”

PHD STUDENT I think it’s a good question. I don’t know if I mentioned, but I mean apart from speaking to you guys, I’m also talking to employers as well as people who work in job centres. Obviously it’s all anonymous.

03003: I would never go to a job centre.

PHD STUDENT I don’t know if it would help.

03003: It wouldn’t be helpful.

PHD STUDENT I can talk to you more so 03003 about this afterwards, um because it’s a really good point.

03003: Although I am tempted, I’d like to work in John Lewis hehe, or in Waitrose. I’d be sitting in (). I’m the official food taster [laughter in the room]. I mean, so I’m quite lost. You have a direction and you know where you want to be [TIME 01:20:27], you have some idea, but I’m completely lost.

03001: See I have no idea where I would want to go into work anyway.

03003: So maybe a career support questionnaire?

03001: I wouldn’t be able to do it. I want to go into college, but I can’t go into college without a job because I can’t afford it. I can’t live on my own and go to college if I don’t have a job. That is very very hard if you want to go into studying, you have to have a job to work along it, and that itself is very stressful which causes anxiety and depression, low moods. And it just puts me in the same path I was on when I was fifteen.

03003: What about career guidance with a, someone who has some understanding of mental health issues? So someone who can go with, through and say well ‘let’s talk about what you find difficult’ and ‘let’s talk about what have you thought that you could do when you look at each area’ and say alright I want to be, um a healthcare professional, ‘well this what you would, can do, this is what they expect from a person in that thingy. Um let’s look at and tick off what, can you do any of this stuff?’, or=

03001: = See I’m not allowed to go back to the career advisors I was. I did child=

03003: = So it would be lovely if someone could sit down and say well let’s have a look at what other options, so you could, they do that for sixteen year old and eighteen year old’s, what about people=

PHD STUDENT = Higher up, yeah. That’s talking about your career and a certain skill set. But you are also talking about having a professional who has a mental health understanding as well.

03003: Yes.

03003: And for someone with a physical disability, when you go in they would also say, ‘well you’re unable to climb stairs, um if this office does not have that sort of disabled access, would you consider working in this department for the same company?’; () example, I know=

PHD STUDENT =No, I think it’s a very valid example. I do, I do. Definitely come talk to me after because I’ve got some information which you might find, well it’s an open discussion, that you might find helpful. But thank you for sharing.

03003: I think maybe in the job centre that might be um a quite good service that they could provide. I think they would have more success.

03006: You said you’ve been talking to employers about this, what’s their general stance on this? Are they quite keen on employing people with problems or not, I mean?

PHD STUDENT It depends. It really depends. Let me talk to you, I can talk to you more so after the group.

03006: This is quite important, because I think if you get someone who on a face level is positive about people with problems, and sympathetic, well then you should in the best way you know how tell them to put their money where they mouth is and actually actively employ people, provide work experience or whatever. To people like us and see whether they will actually come up with a good with whatever they’re saying, or whether they are just paying a lip service to your research project and actually they don’t care. So that’s what I’d like to see, employers giving us either jobs or limited work experience, whatever. That’s what I’d like to see mainly. It would make the whole process easier so we could come into a job knowing we’ll be safe, we don’t have to go through a really hard application process and compete against better able people, and just give people like us a chance. I don’t know whether that’s realistic or not, but maybe you can challenge the people you are talking to =

PHD STUDENT Oh yes and no, I could talk to you guys about this for hours hehe. You two definitely need to stay behind if you can and we can have a chat. Because I can tell you a bit more about just what I’ve picked up over the research in the last year or so.
Appendix 22 Focus Group Client Transcript 4 (Chapter 3)

PhD STUDENT: So essentially, I mean we are here today to um, you know talk about and share and here other people’s thoughts and experiences. And then um I will guide you through some questions, but it will be very informal um, and the idea is that and I will take away the information that is shared today and we’ll write it all up. All your names will be removed so it will be completely confidential and anonymous, so no one will be able to tell that you know you’ve taken part. Um, and then actually I’m doing a thesis on developing an assessment tool. So again, you know, I will take that information back and write everything up, but again with no names involved. Um so yeah, ..take away and write up the findings and report and things like that. Um, because it’s a group discussion, there is absolutely no right or wrong way of answering any of the questions. We are genuinely here to just hear what is going on for you guys, because we’re not going to develop an intervention or an assessment tool based on whatever we think is right you know. It’s got to fit what are actually the current difficulties and what not, or supports that are out there. So, um, so that it in a nutshell. Um, we’re going to talk a bit about different stages of employment, so thinking about employment, getting employment and then let’s say you’ve got your job and you’re staying at work and maintaining um your job role. Um and then we’re going to talk through a bit about thoughts, emotions and behaviours as well. Um but again, it will be fairly informal so – I want it to be more of a discussion really, then me just asking you questions um all the time. So um so yes we are here today to talk about employment in personality disorder. I suppose my first question is, if you were to I suppose to speak to a friend or family, and tell them or describe to them what an individual with a personality disorder it is, what would you say? How would you describe it?

03008: Um, extreme emotions. So like, hey can become very quickly, like angry, very emotional, um extremely anxious, um within a matter of seconds. So it's very up, down. They could be really happy and then go really low. °So yeah°.

PHD STUDENT: Thank you. Has anyone got anything similar?

03009: Yeah. Quick shift of how you’re feeling, um you can feel like, in a second it can drop to suicidal, like really really quickly. Um feelings all over the place. Um anxiety and err, sometimes like with the anxiety you can hear like voices as well. You get hallucinations, um very very difficult to live with. Really hard. Depression [highs and lows], yeah, could get really angry like you said getting angry over the slightest thing. Um if someone looks at you in the wrong way, that it, you take it you know, it can really affect you um=

03008: It's like, you feel quite judged by everyone don't you?

03009: Yeah.

03008: Like being in public, and you know when you think people are talking about you.

03009: You feel like they can look into you as well. And I don’t like people looking at me, I have a real thing about that. And you don’t know what they think of you and it worries you all the time.

PHD STUDENT: So tons of worries and lots of anxieties it sounds like. I mean the reason why I ask is because yeah, I think you guys have hit the nail in the head you know speaking about your experiences. But I wonder, how those experiences impact employment in general? So that’s what we’re going to talk a bit more about today. So, bearing all of this stuff in mind, if we think about um the early stages so thinking about employment. Sorry, I’m not sure what your employment situations are at the moment, but whether you’re employment or not employed, and just at that stage of thinking about employment, so thinking about getting out there you know, or um perhaps looking for a job. Think about that. What things do you think are the main barriers that might stop you from doing that?

03008: Um, well, I want, for example I would like do something in marketing and advertising, um but I feel, but I’m constantly looking for simple jobs like admin work or like a receptionist because I can’t say, I can’t commit. So if they were to call me up and be like um you need to work today or.. but I don’t know how I’m going to be feeling. I have no idea. And with the sudden changes, it could be straight before work and I just can’t go in. And then they obviously you can’t understand that because [TIME 11:22] you know they’re paying you to work, so it’s really withholding me from what I actually want to do.

PHD STUDENT: So it stops you from going out and finding that particular job.

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PHD STUDENT: Has anyone had any similar experiences?

PHD STUDENT: = May I ask, what was scary, what was frightening for you?

PHD STUDENT: = Well they were the type of thoughts, what was running through your mind? Like things like 'I can’t', I wonder what else was going through=

PHD STUDENT: = Scared. Um like the mood changes, um the depression, I was terribly depressed. I had an eating disorder, I’ve got an eating disorder as well and I just felt like I couldn’t do it and then in 2003, um I saw a job advertised and it was like a test to myself to see if I could get the job. And that was an NHS receptionist job. And I felt so sick going for that interview, and there were six people and I didn’t really think I’d get it, but out of six people I got it. I didn’t want it hehe because I felt so scared and I can remember it was a summer’s day and I remember I got this job. And I said to my husband, “what am I going to do? I don’t want it. I only went as a test to myself. What am I going to do?”. I said I can’t ring them and say I don’t want it. And he kept saying, give it a go, give it a go, give it a try. And so I did give it a try and [well done] it was incredibly difficult. And it was for four afternoons, and it filled my eating disorder because I was so, all the time, quite stressed about it.

PHD STUDENT: Can I ask you, because um you know, overall…feeling scared to feeling anxious, um which is very understandable, but you went to the interview anyway, so I wonder what helped you? What helped you I mean in the time to get past that interview stage I suppose?

PHD STUDENT: = And you did it.

PHD STUDENT: = And you did it.

PHD STUDENT: = Okay, okay, I definitely want to come back to that, because that’s really interesting, to hear your journey and what’s come out of it so far. Um, I wonder 03010, can you associate with you know ..about feeling anxious, and um not doing jobs that they wanted you to do? Was there anything that you wanted to share?

PHD STUDENT: What was going through your mind?

PHD STUDENT: = It sounds really similar doesn’t it, with the judgment. How does that make you guys feel when you walk in there and you think the other persons going to judge me?

PHD STUDENT: = Oh god.

PHD STUDENT: = Oh god.
PHD STUDENT: What do you guys think in that situation, when you’re thinking about employment, might be helpful for you?

03009: I think employers don’t understand, and I don’t want to disclose that I have a borderline personality disorder. What I’ve told them is that I’ve got... which I have complex traumatic stress disorder. I think that that is a, comes across better to an employer then if, I just couldn’t disclose that I’ve got borderline personality disorder.

03010: I think the stigma around mental health that sort of makes you not want to disclose it, because people are so judgmental of it.

PHD STUDENT: In your experiences, have you guys, for those that haven’t disclosed, have you guys disclosed or has it come up?

03008: In my last job, I had to because I was at university and because I had borderline personality disorder, I had to drop out. Um but I just got this job, and obviously I had to pay for my house and stuff so I can live, so I wanted to stay on with the job and stuff, but it just got too hard for me, I just couldn’t do it anymore. And luckily it was a really small company, run by like a family, so I did, I was so nervous to tell them that I actually threw up before. Um I had to tell them because there were just so many thoughts racing through my head, like judgments and things like that, and then I managed to tell him, but I started crying, it was just awful. And then afterwards I was so anxious of what everyone else were going to think of me in the office, that I just never went back. I literally never went back. Because I was too scared if he told anyone, or if people would judge me, I don’t know.

PHD STUDENT: So the judgements were coming up again around the stigma isn’t it. Um were you able to disclose 3010 or was it something you stayed away from?

03010: My previous job, I had to disclose that I’d been in hospital previously, um after numerous suicide attempts. Um and I had to disclose that I had suffered with depression and anxiety, um but my medication was pretty much stable um by the time that I went back to work. Um and then I left that job about a year and a half ago, um and shortly after I left my job, I was diagnosed with borderline personality disorder. Um and I haven’t worked since, so I haven’t had to disclose anything.

PHD STUDENT: Um, yeah “food for thought”. So I’m hearing a lot of, a lot of fear actually around the label itself. Do you think, I don’t know, I’m asking you guys I suppose, what would be helpful in that situation? Do you think it’s better to disclose or you want to disclose but actually no.

03009: No.

PHD STUDENT: You don’t think that would be helpful?

03009: No. I think there’s so much stigma around just that label borderline personality disorder, more than any other mental health label I think that one – I think people think that you’re totally – but it doesn’t help with how it’s disclosed in films and things like that. They just – it’s just so negative. And [exhales]=

PHD STUDENT: Um, so you 03009 mentioned that you felt that it was a bit more approachable to say that you had post-traumatic stress disorder, so I guess my question is, how – or how can we – what would help to overcome the stigma for someone with BPD?

03009: Err I think people need educating about it. I think more than anything else, that is the one thing that is talked about the least. And people do not understand it. And I think there should be – on TV they have a programmes about bipolar, um schizophrenia, depression, anything, but never ever borderline personality disorder. So people don’t understand it. [TIME 22:06]

PHD STUDENT: So if I was to ask you specific to employers, what do you think would be helpful? And that’s opening up to everyone.

03010: I think it should be compulsory, if you’re going to be an employer, um to take courses of some sort that educates you in all the different spectrums of mental health. Um because it’s sort of just brushed over, and it’s difficult when you’re in an environment and no one sort of understands what you’re going through because they can’t see it, it’s as if it doesn’t exist to them, which then, if they’re just glazing over it, it makes you feel worse because you then feel judged again like they think you’re making it up, or it isn’t real, it’s all in your head. Um whereas [TIME 23:05] if they took a pause and they were sort of educated on all of the spectrums um then they would be able to, they would have some sort of insight into what we go through on a daily basis and then they would be more able to facilitate, and they would be more able to make a more calming environment as such. [TIME 23:56] So that () yup hehe.

PHD STUDENT: No:, I think that makes a lot of sense.
03008: Also I think they might need to educated, because say if like, um because I don’t normally tell employers, if I can’t come in for that day I’ll just be like ‘ah I’m ill’ or whatever. And then when it goes on for a few days, they can call, well I’ve previously had them call me up and be quite angry, like ‘where are you?’ Then I get myself into an absolute state, because then I think I’ve got to be okay because I’ve got to go to work. And then it’s just like an ongoing thing, and then=
PHD STUDENT: = So do you not go into work, or?
03008: No. Not at all. And then I sort of have to get my mum to call up, and that’s just embarrassing, like I’m twenty years old. Um but there’s nothing left for me to do, and I just feel like yeah I’m getting educated – just understanding that (.) because with – if you tell them, they sort of ask you questions about it, like ‘how are you feeling’ ‘what’s this’ ‘what’s that’ and I don’t want that. I don’t want people asking me that. I just want them to know, and not talk to me about it. Like, literally never talk to me about it, because I don’t know how to communicate with them about it.
PHD STUDENT: = Especially in the work place.
03008: Yeah.
PHD STUDENT: I think that makes a lot of sense. Okay. What about, let’s say you’re, you know, you’re getting a job so – some of the things I talked about before with other groups is things that people might do in order to get a job. So you like job applications online, or writing CVs, some people have gone to job centres. I wonder what your experiences are of those? And if there’s anything in particular that you find difficult, or what might get in the way, or what you might find challenging?
03009: Just looking at the forms hehe.
PHD STUDENT: What is it about the forms 03009?
03009: Um, I find it overwhelming () to fill in any forms. “Totally overwhelming”.
PHD STUDENT: Um, what kind of things are going through your mind?
03009: Err (), I think it’s really difficult because, when you’ve got borderline personality disorder, it’s like an express train going through your head all the time. And, it’s sort of quite difficult to =
PHD STUDENT: = So a lot, a lot of thought going though =
03009: = To motivate yourself to actually concentrate on a form.
PHD STUDENT: Yeah.
03009: It take a hell lot of=
PHD STUDENT: = I was going to say, well done for completing the demographics form; it was a bit of a nightmare hehe. Has anyone else experience anything similar (.) “with form filling (.) or CV writing”?
03008: Well like, obviously I was lucky that I was at university, so I had people there to help me fill out the forms and stuff. But, and I’ve had a lot of you know CV help, but my problem is that I’m very hard on myself. [TIME 26:58] So if I, say if I write the CV and my dad goes through it and changes some things, that can make me go really low, and quite like suicidal. Because I expect the best – because I work, because when I was at school I worked so hard. And I’m really dyslexic and dyspraxia, so I have to work harder than everyone else. And the minute that I failed or, if I got a 2.1 and not a first, that was just such a big thing for me. So when filling out these application forms, if I, if someone changed the wording, or um I got declined from a job or anything like that, that was quite hard for me.
PHD STUDENT: “Oh gosh”.
03008: Um because I just want to be normal.
PHD STUDENT: Do you feel quite sad about it [yeah] or do you=
03008: I feel really like, it’s difficult because although we talk about how hard it is to have a job, at the same time we probably all want a job. Like, I don’t know about the others but, I certainly want a job but I don’t know if I could keep a job or=
PHD STUDENT: = Well it sounds like quite a.. you know the job that you described, would you say that’s very similar to what 03008 just described?
03009: Yeah. Yeah, it’s very hard to, like I said; I can only do two afternoons. I feel quite angry that I can only do two afternoons because I’d like to do more, but I can’t. It’s just too much. I just can’t. And it holds you back so much.
PHD STUDENT: When you say, because you both basically said it’s too much, is it the job um, is it the job requirement itself or is it more about the overwhelming thoughts or emotions that come up?
03009: It's just um, yeah the emotions that you feel when you're there, and to actually get there as well. I feel very sick before I leave the house, and I have actually been sick, because I have to go and =
PHD STUDENT: Have you been sick?
03009: Yeah yeah, I've been physically sick. Um and when I get there, um I don't show it, but I'm quite stressed inside. But I'm very good at covering how stressed I am. But I still do that job very very well. Um, but, two afternoons is more than enough to feel that.
PHD STUDENT: So obviously it sounds like you know, before you even leave the house, you're at a certain threshold already.
03009: Yeah, because I find it extremely difficult to leave the house anyway. Um, I've never been out of the area alone in my life. So a lot of the time I will go out with my husband or someone's with me. Um so I've never ever been out of the sort of the [states name of area] area ever, on my own. So um, I get to work on my own, that's the one thing I do do, I drive back on my own [TIME 30:07], but yeah it's quite hard to actually leave the house and get there knowing you're going to experience stress. At the same time I do enjoy the interaction with other people when I'm there, as well as, but I do get the stress at the same time.
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haven’t – I’ve filled in the form but I haven’t done the little essay you have to do. And I had for four months. And it’s hard to =

PHD STUDENT: So is it the form filling again isn’t it like you mentioned? 
03009: Yeah. And I want to fill it in and send it off. I would like to do that. But um, because I think I could help people thought it.

PHD STUDENT: Yeah. Let’s definitely come back to that 03009. It’s interesting. Um what about you guys, have you faced any sort of challenges in the workplace when you’re working? 
03008: Um, I just think like, obviously my job involved being face-to-face with customers constantly, so there’s that, like people coming in all the time, there’s a lot of noises. Um this phone rings, but I’m doing this job and because I was like admin, I was expected to do all of that, but if I’m in the middle of doing something and then the phone rings and then they’re looking at me and I know I’ll be like feeling like I know I’ve got to be doing this, but I’m doing something else. And then it’s like a vicious circle like going on in my head. And then I just break down and end up doing nothing, and it’s just sort of like, as 03009 was saying like I just feel very left out. Um I just feel like I don’t fit in properly. Um if they make like, if I don’t catch up on jokes, like I’m quite gullible, and they sort of make me out to feel really dumb and stupid. And then I constantly just feel like I’m really stupid compared to all of them. And um =

PHD STUDENT: = What does that lead you to do in the workplace? 
03008: Cry, and then I get really embarrassed because I have to go and hide away. And it’s just so embarrassing when you like, I was in a small office and there’s not many places that I can hide. And I didn’t like that. I need my place to go away and hide, and I can’t talk to other people. I can’t tell them how I’m feeling, like I just can’t do it. So it was a daily battle with me. Um but yeah I just sort of, I just sort of feel like I’m not like everyone else like I constantly feel like I’m stupid like with the way they talk to me and things like that. So yeah I found that like really hard.

PHD STUDENT: Um did you, I’m interested did you cry, did you go away and cry or did you just= 
03008: = No I went away and cried. I would never let anyone see me cry. Like 03009, I’m very good at covering my emotions, like very good. Um but sometimes you know you just can’t. And it can also result in anger. Um I was told like I avoid my emotions, and by avoiding it I’m actually feeling really anxious or whatever. But it results in me being angry. So I can snap at people as well.

PHD STUDENT: Um has anyone else had experiences of being angry and frustrated at work? Yeah, go on 03010.
03010: Um obviously working in a nursery and we had forty three year olds=

PHD STUDENT: Forty three year olds?
Everyone: That’s quite a lot.
03010: Um, and it’s sort of, because with the whole adult child ratio, when they are over two and a half, it’s one adult to every eight children. And so we were always very stretched really thin, um and, obviously 03009 will understand having ten grandchildren hehe, that trying to keep an eye on eight children at once is not an easy task. Um= 
03009: = You need a lot of energy.
03010: Yeah. And especially if you’re having a rough day, um and you’re trying to keep an eye on eight children, one’s in the corner, one’s there, one’s climbing on the bloody something or the other. Um, and then while you’re dealing with something, something else happens. And then () my deputy manager came in, and asked me why I wasn’t watching the other child, and I said well I was dealing with something else, and he said well you should have been watching all of them. And I snapped, um completely. And I just screamed, and screamed, and told her that I didn’t have eyes in the back of my freakin’ head, um and if you want every child watched every second of the day then employ more staff. Don’t’ stretch us in and then blame us when something happens um and it is more when you have a low day and people are sort of at you constantly, and it does all just build up, and when you snap people look at you.. um and it is hard to sort of, you don’t want to let them see that they’re winding you up, so you try and hide it. But then that just builds up even more.

PHD STUDENT: So what happened afterwards? 
03010: Um, I left hehe, I just got my stuff and I walked out of the building.

PHD STUDENT: So you continued to feel angry when you got your stuff and left? 
03010: Um, I walked out to the car, um I kicked my wheel, not the best idea really um in hindsight. And then I built myself up and I was so angry, I was physically sort of shaking. Um and I took myself off to have a cigarette to try and calm myself down. Um, and I burst into tears,
and part of me was crying because I think I realised I screamed at my boss, which probably wasn’t the smartest plan. Part of me was crying because I then felt stupid for not watching every child, which then made me feel angry because it wasn’t actually my fault and then I="}

PHD STUDENT: = A whole load of emotions.
03010: Then I was crying because I felt stupid for crying, which then made me cry more.
PHD STUDENT: Um, did you return to that job?
03010: Um, I did. Um () and about three days later I was signed off.
PHD STUDENT: Is that your current situation at the moment?
03010: Yeah. Yeah, I’ve been signed off for about eighteen months.
PHD STUDENT: Okay. So, um, let’s talk more about, I suppose um something we call ‘reasonable adjustment at work’. And the idea is that you know, if you’re signed off sick for whatever reason, um the job usually gets involved, or the employer gets involved by making reasonable adjustment at work to make things manageable for the individual. So 03009 you mentioned you worked for two days a week now, and I don’t know what’s your set up now 03010?
03010: Um, I’m currently (.) just completely off work. Um I was on, I was still employed by my employer for about three months after I left, um and then they made me redundant. Um because there wasn’t, sort of, there wasn’t any, it wasn’t a definite that I would be going back. Um and even if I did go back, they didn’t know how long I’d be off. And obviously they were still paying my statutory sick pay, and then they were having to pay someone to cover my place, so they sort of cut their losses in a way, um and made me redundant. [TIME 43:07]
PHD STUDENT: I’ve got personal comments about that, but I’ll.. take it out of the interview. Um, what was I going to say, so we talked a lot about, because there’s a lot of emotions going on when you’re at the work place. Um, I wonder what would be helpful for you guys at this moment in time if you were to experience any difficulties.. go back and think about that? What would have been helpful to help you stay in that job, or maybe work for, or try...week. What do you think might be more helpful in those situations? [TIME 43:41] 03009: Um, it’s hard isn’t it?
03008: Yeah. I don’t know because I was working part-time, um maybe have like, if they give you um, I don’t know like a list of things you need to do for the week, and then you in your own time come in and do those jobs. Like for me that would have been easier. There wouldn’t have been so much pressure on me. Um because, if I have to get up for anything in the morning, I don’t sleep, I’m too anxious about anything in the morning the next day. So if it was sort of in my own time, I would, I might be able to get up and I might be able to sleep.
PHD STUDENT: What do the guys think about that? Doing things in your own time?
03010: Yeah, I tend to find that if like you said, you have a list, I work better from a list then if someone says to me ‘oh you need to do this’, ‘oh and don’t forget this’, ‘then there’s this’, ‘this has got to be done by this time’. I get all confused and I’m, I struggle to sort of, to prioritise, whereas if they, if they physically give me a written list and say that we have this, this and this to do, and I can physically see it there in front of me then I can do it, and as and when I need to, and sort of take it at my own pace rather than having someone in my ear constantly.
PHD STUDENT: It makes sense to me.
03008: It’s had though to find jobs that cater for that. Like, I’ve been trying to find jobs which I can like you know, um like transcription stuff like, from where you can just work from home and -- but I’m just having no luck finding that like suits me. But, personally like, till the moment that I start feeling more like myself, I just want to work from home, but="}

PHD STUDENT: You know when you said you’re having no luck, um what kind of methods have you used? How are you looking for that sort of work?
03008: Just literally online.
PHD STUDENT: Online, okay.
03008: I’ve looked on like … servers, then just you know on the normal job sites like gumtree and things like that. And yeah I’m having no luck at all really.
03009: I always think being a librarian would be the best job hehe, because it’s very quiet.
03008: I quite like libraries.
03009: That would be sort of chilled.
03008: Hehe, that would be really good actually.
PHD STUDENT: Why not go for it then?
03009: Hehe, there’s no jobs in the library.
03010: No one uses libraries anymore.
03008: No.
PHD STUDENT: That’s a good point. I wanted to ask you, when we think about employment overall, everything we discussed in the last hour or so, what do you think, if I were to ask you what would be the main barriers and challenges...

03010: A lack of education. Like, I think my, my main hold back is sort of the stigma that surrounds, especially as 03009 said, especially borderline personality disorder. It’s not very well known. Um, and, sort of (.) when I know myself, when I first was diagnosed. I didn’t know what it was, um, and it’s very confusing. Um and even, I found it more difficult because even people who knew, were supposed to know what they were talking about um didn’t seem to have any clue what they were actually doing. Um I think I saw three psychiatrists here, um and each one I asked them to tell me what this diagnosis was and what it meant for me. Um and they all struggled, and it kind of, if they don’t know what they’re talking about then what hope do I have to get an employer to know what they’re on about. An employer that understands what is going on. Um because I think if employers were more educated in it then I’d probably be more open with them. Um if they understood that it’s not just, it’s not just making it up, it’s not just all in my head, it is actually sort of, it is actually there. And although you can’t see it, it is a daily battle to do the littlest things. And if they understood that then maybe they’d, they would be more help in the workplace. Yeah.

03009: You’re spot on.

[laughter in the room]

PHD STUDENT: So if I were to ask you guys, so let’s say we in an ideal world, we introduced a bit more education and tackled the stigma around PD and mental health in general, do you think that would helpful to support you in the emotions you still experience in the workplace anyway?

03009: Yeah.

03008: Definitely.

03009: I think if employers were educated about it, we wouldn’t feel so stigmatised by, and being able to actually say that yeah we’ve got PD. It’s a horrible word, because whatever way you, you know ‘emotional unstable’ ‘personality disorder’, that [xxx] yeah it does. I mean can you imagine if you wrote that on your...

03010: I’ve actually had another job, and you’ve got to write that on your medical form. …. No.

03009: I mean what’s worse? The label of borderline or, you know they’re both the same thing. They’re both equally a horrible – just makes you sound awful. And I think that, I think employers should go on a course, all employers should go on a course and be educated about it so we don’t have to be frightened of disclosing it. And also you could get quite, I get quite paranoid as well, and you know when I’m at work I often think that people are talking about me, you know it’s horrible. So I think like, they should really understand about it. When I was diagnosed with it like you, I didn’t know what it was; and I got like a little booklet given to me, but you know what when I was told what was wrong, it was actually a relief because I felt, I wasn’t the only one that had got it. Because I didn’t know what was wrong with me. Why was I like this? And it was sort of a relief to know that other people had it as well and felt the same. And that I wasn’t alone. And so if we didn’t know about it, employers should know about it and I think there should be more TV coverage on it as well. So it’s sort of, so everyone understands it, because nobody understands it and you don’t realise how incredibly difficult it is to live every single day, to have those thoughts and the up and down, and the suicidal feelings, and you know you can self-harm, and it’s so hard to live with. Horrible. And if people realised and had to live with it for a day, they would feel more empathy with us, and they would be more thoughtful of how we feel and at work, just even if they gave us like five minutes time out when we felt overwhelmed and they understood that we needed it. That would really really help, because often that’s what I need and I can’t get it and then I get irritable when the phone rings. The stress I feel when the phone rings is awful, but my heart literally, you know that sinking feeling? Because I’m so overwhelmed and you have to answer it and I feel sick sometimes.

PHD STUDENT: Um let me quickly ask you because I know that you work for two days a week, you obviously do answer the phone within those two days, what things do you use to help you cope? Even when you answer the phone, and you do your job well? But, inside you’re feeling all those things, thinking all those thoughts, what helps you in that moment in time.

03009: Um, shaking? Err, sometimes I think it’s visible as well. Um just the feeling of being, feeling that I’m going to be sick sometimes.

PHD STUDENT: Sorry I mean what helps you, because I suppose [what helps] the reason you are feeling these things is because obviously you are able to do all that work in two days, so there’s something that you do that helps.
03009: .. helps, feeling that I don’t want people to see.

PHD STUDENT: Okay so I have to=

03009: = It takes great, err, strength to appear okay, and it also really tires you out. It massively
tires you out, and that’s the only way I can do the two shifts.

PHD STUDENT: That makes a lot of sense.

03009: After I’ve done those two shifts, I do two days running. When I walk out after those two
days, the relief is really intense, and then I think [sighs in] I don’t have to go back in for five
days. And you know, experience that. So yeah, it’s hard. But I would love to do more, but I
can’t. And you know, even at work, the manager I used to have, she said she recognised that I
couldn’t do it. And it was the community mental health nurse that said to me that you can’t do
four days, she said they’re right cut it down to two, they are right. But I felt like a failure by doing
that.

PHD STUDENT: They are judgements.

03009: Yeah.

PHD STUDENT: Do you guys want to add anything else to the main difficulties?

03008: Um, I think like, for example in work places you obviously get people who get pregnant,
you have people who have disabilities etc. and if work can really cater to those type of people,
and because of their, whatever is wrong with them, or being pregnant is a physical thing, ours in
our brain it’s mental, so they don’t get that we’re just like them. Like we are just like anybody,
but it’s happening in our head. Um I just feel like they haven’t really, they don’t really like um
cater for that and um understand that you know that so many people have so many different
types of issues, and you can’t judge anyone based on who they are, how they are. Um and I
know what it’s like, because everyone judges everyone, you know walking down the street
people judge each other. But I just feel like I get judged more than other people. And I just feel
like I’m never going to be good enough, like that’s sort of, like if you’re disabled you can kind of
show it so people know you are and you sort of have to deal with it, but when it’s in your head,
you don’t, you sort of hide away from it. And it’s sort of, you don’t want to tell people but you
know they need to know, but they wouldn’t understand. So it’s just sort of, it’s just sort of a battle
really, every day.

PHD STUDENT: Um, is there anything in the last hour that we haven’t touched on toda
that you guys feel like you would like to talk about? You know so when we think about
employment what comes up, and then if we haven’t discussed it we can.

03009: It is a disability isn’t it?

03008: Yeah.

03009: A massive disability.

PHD STUDENT: An invisible one.

03008: Yeah.

03009: Yeah, which like you say, makes it so hard.

03008: They just like, like my dad’s disabled =

PHD STUDENT: = As in physically disabled?

03008: Yes physically disabled, and I look after him every day, and things like that. And you
watch people stare at him, you know I went on holiday at Christmas and he couldn’t get on the
sunbed and he fell over, and a woman laughed at him. And it sort of just makes you think, I’ve
got just as many, I’m exactly the same as my dad. I’m exactly - I’m equally - I’m equal to him
you know, I just think in different ways and I get upset, and it just makes you want to bury more
what is wrong with you more and more. Just because I’m not physically disabled, people look at
those people and prejude them; I see it every day with my dad. And you just think if they knew
what was wrong with me they could do exactly the same to me. That’s literally what I think. And
I just sort of bury, bury it, and just don’t let anyone in. Half of my friends don’t even know.

03009: I know, my don’t either.

03009: They don’t even know that I’ve left university, or anything. I just tell them that I’m still
there.

PHD STUDENT: And I can imagine you guys have voiced um the lack of education, and
stigma, and if we were to promote that it could really help in your circumstances.

03009: Yeah. I think it would also help with – obviously like um, most of my friends at work,
they have relationships in work. You know they go out with all their work friends and I could
never do that. And it would be nice to sort of have a work and social life equal to that, that I
could sort of mingle and join in, and go out with all of them, but I’m just not at that level to do
that.

PHD STUDENT: That’s something that you would like?
Yeah, because I just feel like why is it that once you've left university or you've gone into work – just going into work, they're sort of your friends for life. But I don't have any friends from work.

Yeah, I feel socially isolated.

Yeah, really yeah

Totally.

It's sort of a vicious circle because you want to sort of make relationships at work, but you don't want to sort of – when they say 'oh yeah we're going out for drinks' and you're like I can't do that, I'm not going. So you make up an excuse and then the next day everyone comes in work and they're laughing about something that happened last night, and you feel more isolated. And then it makes you want to not go out with them even more because you've missed out on something that's happened, and it does just get worse and worse. And like Julie said, feeling left out from conversations because you weren't there.

Sorry guys, can you say more about why you can't, you know it's there but you can't – is it – yeah what is it?

I think when you're in a large group of people um going out, having drinks – I don't know going bowling, it's very loud, there's lots of people around, it's very in your face, and I can't deal with that. I can't deal with all these people chatting at me like, I need to talk to one person at a time. And then they will be having banter in a big group and I'm just missing all of it, I'm just standing there like a lemon. And I also feel getting to work, oh what time are they going, am I going to be late? Am I going to be early? I don't want to be the first one there but I don't want to be the last one there. What are they wearing? Am I going to look ok? Are they going to judge me for the way I look? Does my makeup look ok? That's my thought process for ever everything. I can't even just- like if I want to go to the shops I can't just be like, “Mum, I'm going to go down to the shops” ‘cos I'm too conscious of what I look like. It's awful. And I just constantly like, my boyfriend tells me, you know, “You look fine” “you look lovely”. And I look in the mirror and I feel physically sick, and I'm constantly looking at new tutorials for makeup to do anything to make me look better.

[laughter in the room]

I look in the mirror and it's like, awful. And also I can't stand like a lot of noise. It's too overwhelming.

Because of what's going on in your head all the time. You can't take any more in so there's a lot of noise and a lot of people, and music and its just- you can't deal with it.

I just want to say thank you so much for coming today because it just sounds like all this stuff has been really difficult for you guys so, it's brilliant you've come all this way to partake in this focus group. Another thing I want to ask you is, you're here today, what has helped you get here, help manage all these things that go on these thoughts, and these emotions that you're going through even to get. ‘Cos it would be similar to getting to work isn't it? So what helped you today?

When I read what it was about I thought it was important to come.

And knowing that other people are going through the same thing as me, I don't know anyone that I'm friends with that are going through what I am. It's just nice to know I'm not the only person.

Yeah I was due to come to the one on the 15th but I was discharged from hospital the same day and so I couldn't make it.

A lot going on then

Yeah. But I really wanted to come and sort of see what it was all about and sort of talk to other people that are going through the exact same thing. Because it's one thing talking to a therapist or talking to a psychiatrist and they're educated on what it is they don't understand it on the same level. They see it from sort of oh, they've read case studies or spoken to other people but they don't know the actual feeling of the overwhelming anxiety or depression or the suicidal thoughts. They don't understand any of it, they can only sympathise with it. And so I wanted to sort of come and talk to likeminded people that understand what's going on and see different sides of it as such.

So it sounds like really helped is because you had this value and wanted to come here and speak to other people. I suppose my question is, if you were to compare that and make it specific to work, it would be the same? So what would be helpful in that situation? Educating people?

If there are more educated and whatever they might start hiring people that have got what we have and it might become a more open conversation.
03010: Like it is now.
03009: So like we feel comforted like that we’re not the only people that are struggling at work. And then we can sort of work together to like, go on from there. Because you know even if I went in, if I’ve got a job and went and told someone I’ve got- I bet you any money that no one will have it or no one will say they have it. So then you’re just left to battle it on your own at work.
03010: I also find that the lack of education when I’ve been filling out forms or whatever and I write down that as I’ve got BPD people automatically assume that’s it’s bipolar disorder, because borderline personality isn’t like, known enough. And you sort of jump to conclusions and then they make their own mind up before actually knowing anything about it.
PHD STUDENT: So judgements?
03010: Yeah and I just think borderline personality disorder is sort of the lesser known of the mental illnesses and it does need to be talked about more. And people really need to sort of understand that if we’re having a bad day then it’s not being lazy or we just can’t be arsed it is a chemical imbalance in the brain and we can’t actually help it but there are certain things that people do to sort of help make our lives easier. Like not constantly get at us, and sort of if you think you do something wrong you could do it in a better way. Don’t be like “Oh well, why are you doing it like that? What’s wrong with you?” Sort of put it across as sort of “Oh I see how you’re doing it, I’d do it like this, I don’t know if you find it easier.” And sort of do it constructively rather than criticize. Yeah.
PHD STUDENT: I would react the same way. Any more lasting thoughts?
03009: I just really like want to highlight that when they show films and stuff, any sort of mental health illness people sort of think, are you psychotic? Like, is there something wrong with you? But like I’m watching desperate housewives at the moment and a guy’s got schizophrenia in it and he’s a killer and just all these bad things. And my boyfriend sort of “Do you feel those things?”
(laughter from everyone)
03009: But do you know what I mean? It’s just so people don’t have any clue and like, sometimes I’ve been asked whether I see people and like things like that. And I’m like “no!”.
Like, you don’t know what you’re talking about so you need to go research it. But even when I’ve researched it online it doesn’t even really tell you really what it’s all about.
03008: No there’s not much on it.
03009: No.
(Agreement)
PHD STUDENT: Listen thank you so much for coming today.
PHD STUDENT: So we’re here today to talk about personality disorder in employment. So um you know you guys are going to be bearing in mind your loved ones and I just wondered, you know how would you guys describe you know someone who has a personality disorder? In terms of how they might behave or the things they might experience themselves?

02007: Are you meaning within a job?

PHD STUDENT: Just in general.

02007: Just in general, yeah.

PHD STUDENT: Generally just agreeable to a lot of things [o::kay yeah], but maybe they don’t want to do that and they just approve.

02002: Occasionally irrational, aren’t they?

PHD STUDENT: Occasionally irrational, can be, yeah. So we’ve got agreeable, irrational, yup yup.

02001: Aggressive.

PHD STUDENT: Can be aggressive as well, yeah.

02012: “Not aggressive all the time”.

02001: “Well I’m just talking about aggression generally”.

PHD STUDENT: Yeah I’m not talking about all the time; I’m just talking about it in general about how that person is. Yeah, I mean these are all exact examples and you are right 02007 we are talking about employment today so, so you know kind of bearing in mind those aspects of being irrational I suppose or agreeable maybe in the workplace context. Because I want you guys to know like when we think about employment, I mean tell me what you think but if I were to start a new job I would find that quite anxiety provoking like I’d be quite nervous because I don’t who my team my team are going to be like or I might be really excited actually I don’t know but it’s actually quite I suppose usual to experience certain emotions that we have second thoughts before we go into work. But what we’re looking at is people and individuals with PD, I’m going to call it that just to make it shorter, um who experience them sort of things but to the extreme. So perhaps for someone who does agree, agrees to the point that they take on so much of the work, I don’t know what might happen, what will be the consequences if that makes sense?

02007: Yeah.

PHD STUDENT: So just get you guys to start thinking about things like that so. Um there is absolutely no right or wrong answer in this room tonight really like, I just want to know what you guys think it’s not about ticking boxes or anything like that okay. Um and feel free to help yourself to a glass of water or what not. So we are going to talk about certain stages in employment so um as part of the evidence we’ve been building on in different stages which is what we actually call it actually. So the first one being ‘thinking about employment’ so um if you bear in mind your loved one, you know whether they’re employed or unemployed. I’m assuming there was a time when they were thinking about employment so that kind of moment in time in employment, in pathway in employment. And then I want you guys to think about, and I’ll guide you guys through some questions um about a time when they got a job and they’ve started a new job and um some of the things that come with that and the challenges and positives as well. And then the third stage would be um they’ve got the job and they’ve been there for a while and it’s about keeping the job so they have to manage themselves and how they are in the workplace with their team or whoever it is that they work with. Um and then I’m going to ask some questions about external support as well. So whether it’s actually from you guys, some support that you guys provide or um support that healthcare providers also provide as well. So does that make sense. is that alright? And hopefully we will finish in time as well. So um I might be flicking through some prompting questions here, so I’m not being rude hehe, I just want to make sure I’m asking the right questions for you guys so. Um any questions before I begin?

02007: No.
PHD STUDENT: Okay cool. So I wonder how would you guys describe the help that healthcare providers may give in terms of employment to the person that you’re supporting? And again, negative, positive, there’s no right or wrong answer. Does anyone want to start?

02008: Well, from my point of view my loved one is a young person still in their teens, um and she was diagnosed quite quickly after, well not diagnosed but referred quite quickly by our GP who is very good. Mainly because um she was leaving school um and she’d found the last year when she was doing her A-levels particularly difficult, much more so than her GCSEs. And things started happening that she was unhappy about [okay], she expressed it to me and we said well the first step will be the doctor [okay] and then the school. But the school couldn’t support her [right] because she was in her final year. So it was sent down to our GP very quickly and then she referred her onto [blank][okay], although there was a bit of a nightmare to begin with I’d be honest with you. Um she was experiencing panic attacks. She’d actually=

PHD STUDENT: = can I just interrupt you. Sorry. Can I actually ask you did the GP take into consideration her age, education or any other further support other than [blank].

02008: Um he felt that because the school couldn’t support her because she had sort of fallen into cracks because of her last year at school, um that it would be better to start with a referral.

PHD STUDENT: Okay so start with addressing um the disorder I suppose per se.

02008: Yeah.

PHD STUDENT: Okay, okay.

02008: She had already been in touch with [blank] and had been given a telephone diagnosis, which I have to say wasn’t very happy about, um because I didn’t understand it myself [yeah]. Um we then had a situation where um mama bear got over her crown completely because she was left for forty-five minutes um at [blank]. Kept going to reception and saying I’m here I’m here and them saying someone will come and see you someone will come and see you, and they didn’t. So I had to go and charge up there, well I didn’t have to but I did [yup]. And um she was in bits and then we had to decide what we were going to do from then. Well we then tried again, what was she going to say no completely to begin with she should have said no completely=

PHD STUDENT: = Well it sounds like there’s a lot of support coming from your side really [I hope] so really the GP you know was the first point of call, the GP was there to help with the necessary supports and refer you on. And it also sounds like you took on a lot of things yourself. Which is not, which not a particularly bad thing [laughter]. Did anyone else experience something similar with the GP?

02003: Ditto. Nothing really from the GP.

02001: We started with the adults, 16-17 when she was going into CAMHS=

PHD STUDENT: = So we’re talking specifically about employment here=

02001: = yeah but right when, she is now eighteen and half and she’s started a part-time job and then suddenly quit, and she quit absolutely everything. And this was in her like year twelve, she was coming up to AS’s, coming up to AS’s. And um I was just recently trying to get her to go and sign on because she’s been just like a vegetable in her room 24/7 not wanting do anything. And I got as far as the, across the road from the job centre one day and she just went into panic mode and we sat there for nearly an hour talking about what happened, but I could not get her to go.

PHD STUDENT: So really you were trying to support her in getting her to sign on and take it from there [yeah]. So how did you guys hear about the signing on system, like how=

02001: Well that’s a natural thing isn’t it for kids that –

02008: Well my ones got a part-time job, and she’s had a part-time job for nearly two years with a very famous, well a very classy and um famous clothing shop, which she was very happy with. But the manager um how I put this politely, [go on, go ahead] is an idiot, and she didn’t even know what anemia was because my daughter was actually suffering from that initially. This sort of seemed to be the run up to everything. She wasn’t feeling well, she wasn’t well, um first of all it was anemia that was diagnosed, and then obviously her behaviour started to change=

PHD STUDENT: = Is she still, sorry, is she still working part-time now or =

02008: = She is, and in actual fact we’ve just had a real bit of luck because the manager was trying to get her out, I mean it was obvious and on one occasion um when she arrived for work, she basically said well your sickness level is too high and um the company won’t put up with it=

PHD STUDENT: = So I just wonder 02008, from the struggles she’s having at work, apart from you being able to support her, was there anyone else external helping? I don’t know like charities or anything to do with healthcare?

02008: She didn’t want that.
PHD STUDENT: She didn’t want it, okay yeah.
02008: She didn’t want that =
PHD STUDENT: = Were the options made available to you by the GP?
02008: No. Um but she was quite clear about who she wanted involved and who she didn’t want to be involved. Um so she was quite happy for us to discuss it within the family [okay okay], um but certainly the school was aware of it, um her GP was aware of it, but she then decided that she wasn’t going to go down any other road. She wanted to keep it=
PHD STUDENT: = Did anyone else experience anything else similar with their loved ones about them wanting to disclose only so much I suppose with certain providers?
02006: My ex-wife got my daughter her job. And we did go through um I can’t remember er, I don’t know what is um, Hilary I remember [yeah I know Hilary] so [yeah she’s the employment support staff within um NELFT] yeah she was brilliant. I don’t know how my daughter would have been, if it hadn’t been at her mum’s place [oh I see in the family home with, at your mum’s place, I mean her mum’s place sorry] yeah [yeah, okay]. Because that was obviously an issue was disclosing (.) what was wrong with her [oh I see in the family home with, at your mum’s place, I mean her mum’s place sorry] yeah [yeah, okay]. From a work point of view [yeah] because to be fair Hilary was, she was brilliant [good], um it didn’t work out in the end but um (.) and she only worked for, what did she work for, about three months [oh okay] and that was with a lot of leeway=
PHD STUDENT: = And do you know what it was about Hilary that really helped?
Because I know [____] is just one person, well a one person team basically.
02006: Well she did give her a lot of, I think it was just the fact that she was there when she went into the workplace and [yeah she was a lot of support for her] and that [.05] probably doesn’t work for everybody, but um=
PHD STUDENT: = usually it works for three or four months yeah?
02006: Yeah and that was like I say with a lot of help from the err them to have to go in in the end because she started experiencing () problems.
PHD STUDENT: Do you mind if I ask where she was working?
02006: Um TMT.
PHD STUDENT: TMT, okay.
02006: She was only doing a little data entry and stuff [okay] but um (.). And after that she basically she’s left now, I mean she’s on the NSA and PIP.
PHD STUDENT: Okay, and was she able to do that um on her call?
02006: No hehe. No. Na, we got that done in the end and that took a little bit of pressure, she wasn’t happy about doing it in the first place. But it is quite hard knowing what benefits to get them put through on=
PHD STUDENT: =How to navigate the benefit system as well.
02006: She gets full rate um living, it’s know how to, um it’s a bit of a mind field but you know she gets quite a bit of reasonable money now, um so that allows her to go to all her meetings [yes]. She’s just doing a get fit for life twelve weeks in the gym and all that. So it’s just allowing us to get things moving a little bit.
PHD STUDENT: Yeah so that’s quite beneficial in those way.
02006: Yeah. And it’s just knowing where to go. I mean she gets all free um concessionary bus pass and everything now. It’s err=
02007: How did you know about that? [yeah] There’s not enough information [] nothing no [do they have to say].
02006: There’s no information, no.
PHD STUDENT: Where did you get that information from? So we can move on. If you don’t then it’s okay we can just move on.
02006: I’ll find it all out for you because um =
PHD STUDENT: = what you guys can do is after the meeting you can exchange details yeah [yeah]. Did you want to say something 02005.
02005: Um yeah, I mean, when my daughter had to err quit her job, and she was a teacher, um and in the end it all became too much and she quit teaching. She’d been ill for about eighteen months. She’d had quite a few long stints off work because of her depression and stuff. Um and then when she, when it all got too much, she was second in department at one time and then there were plans for her to be head of department and that’s when it all started to come crashing down and she couldn’t cope with the pressure. Um and then when she went back to work she had the occupational health meeting that the school sent her on. Um and she had a bit of phased return back to work after she had been off for about three months. Um that okay but
they still expected the same amount of work in a shorter time [okay]. There was no ‘oh we will take this job off you’ or ‘that job off of you’ she was still expected to do it=

PHD STUDENT: = At work you mean?

02005: = At work yeah.

PHD STUDENT: Did she have any external support other than [ ]? Did she ever have [ ]?

02005: She wasn’t actually with [ ] at that time [ah okay]. She has bipolar as well as her PD, and so she was being treated for the bipolar from the EIP team. And she used to see them once a week she would go after work for a meeting with her support worker [yeah, okay]. But anyway, um she then decided that it was too much so she quit her job and she was going to, because she’s always been into physical fitness and stuff, she used to play a lot of sport, um she was going to be um, she was going to train to be a personal trainer [okay, yeah]. So she had a six weeks holiday and then started in September which she joined up for this course [yeah] she went there for first day and just found it just completely overwhelming with all these other people. She just couldn’t cope with it, and that is when you know we said you can’t carry on. And then I just phoned up and sort of claimed benefits because she was too ill to work. The doctor gave her a certificate and she hasn’t worked since.

PHD STUDENT: That just reminded me actually 02005, I didn’t reiterate the aims of our research actually and one of them is, we’re developing a treatment right adapted along DBT which is what we use in [ ] specifically for employment. So it’s aiming to help people get ready for work and to be able to cope and manage those anxieties um that’s one of the aims and that’s why we’re here today to find out the information that will be helpful for that treatment. Also we are looking to develop a questionnaire assessment to help gauge, so you can imagine like, someone like you’re loved one or your daughter coming to us and then I would use the questionnaire with her, we can kind of identify some of the challenges she might be finding difficult at this moment in time and then be able to know how best to move forward from there in terms of the support we can offer. And then the third one is actually developing a plausible manual for employers, to better understand what it’s like for someone with a personality disorder in the workplace. So it’s not a manual to be like you’ve got this, get out! It’s more about what can we do to help you adjust to the work place and make it better=

02005: Yeah the school were aware of her diagnosis [yeah, okay]. You know she didn’t try to hide it as such [yeah] um but the actual job itself was too much for her and she just completely lost her confidence. And she’s gradually built it up now. She is, touch wood, she’s doing quite well at the moment [yeah]. She’s been doing a lot of volunteering [that’s good] um she’s just finished an on-line recognised accreditation for level two mental health awareness. She’s just done that, she’s looking into doing another course. She just wants to keep busy. She does want to get back into employment, it’s just a question of what because she does thinks well I’ve only ever been a teacher, what else can I do? [Yeah, yeah] So, and she doesn’t want to go back to teaching because it’s too stressful=

PHD STUDENT: = I’m going to pause you there because some of the things you said I think are really, really interesting and really relevant to what we’re doing. Um so I’m going to come back to what she might think of, in terms of her thoughts or what other avenues she had. But thank you for sharing I think it’s really important that we can do that here as well. Umm=

02005: = But at the same time, I think when you’re saying about what help is available [yeah, yeah] I think [mentions her daughter’s name] was under the EIP team =

PHD STUDENT: = That’s the early intervention psychosis team.

02005: Um and there was lots of benefits that were available to her [okay] but=

PHD STUDENT: = For employment, or for other just general=

02005: Just generally. I mean she couldn’t drive at one time because the doctor had said that she was not fit to drive and she wasn’t even aware that she could apply for a free bus pass.

PHD STUDENT: = Oh right, so how did she find out about those sorts of stuff?

02005: She found out speaking to somebody else [okay] and then =

PHD STUDENT: = Was that a profession or =

02005: = No, just generally. And then you know, then she said oh I think I can get a, I’m entitled to a free bus pass, and she must have spent like pounds and pounds when she used to get onto the bus. Yet if she was going to work or trying to go to a group she’s you know, she’d have to spend to the money and [overlapping speech]these benefits that are available, they’re not promoted by the professionals. [Chatter]. They’re definitely not. You have to find out about them yourself.

02012: They are an absolute mind field.
And I means she used to say =
PHD STUDENT: I mean I do know=
She gets CSA and she gets PIP [yup yup]. But she’s also got her own flat [yup]. You know she’s got a mortgage.

I mean is she the ()=

She gets CSA and she gets PIP [yup yup]. But she’s also got her own flat [yup]. You know she’s got a mortgage.

So lots of different factors that are putting pressure on =

Yes.

Sorry did you say she’s working at the moment?

No, she’s not.

But she has worked before?

She was a teacher before. She hasn’t worked since July 2014.

Okay =

She does want to get back into employment.

Do you, sorry I hope you don’t mind me asking, but I’m just trying to I suppose get the context here, but um do you live with her at the moment?

No. She’s got her own flat [yes you said]. She spends um a lot of time at my house, but she also she sort of alternate, like she is going home tonight.

The reason I just asked is that when we’re thinking about our loved ones and their thinking about getting back into employment, in that kind of contemplation stage.

What sorts of things do you think gets in the way for them? Or they find difficult to even think about employment to even get started?

I mean I don’t know how well [states daughter’s name] can cope with going for an interview to be quite honest.

[lots of talking on top of each other]

We’ve always been in a fortunate position that my daughters always worked. She’s worked for this company for six years now, but I do remember=

And they’ve been very, very good. They’ve been extremely helpful. She’s done a day and a half last week, and nothing was said, you know.

I remember when I took her to the interview. I mean she was absolutely in pieces and I kept saying to her it doesn’t matter if you don’t get this job. You know just use it as a practice and she was just in pieces. But it’s just getting that confidence to do that and then she came out and she was absolutely beaming because she had got the job. And her company I must admit over the last six years have been absolutely brilliant. I suppose if you’re working in education, or civil service or you know good companies that do adhere to the law, as far as mental health goes, they treat it exactly the same as you’ve got a physical illness. And they do. And fortunately they’ve been really good with her. So she has her bad days, um she can work from home.

Can I just ask 02001, when you helped her with the interview at that moment in time, what kind of things do you think were running through her mind before the interview?

It was just the thought “I won’t get the job” or “I’ll be terrible” =

or “What if I don’t get the job”.

Yeah, “I’ll be terrible” “I’ll be crooking over my words”, “I won’t answer” – you know “What sort of questions are they going to ask me?”=

And what do you think helped? Because she did get the job in the end so do you think helped?

I think she beat about half a dozen people “going for the job”.

I suppose what do you think helped her in that situation? I know that sometimes=

I don’t know whether me saying to her it doesn’t matter if you get the job it’s not the end of the world. You know, so don’t worry about it.

So reassurance from you.

Yeah. I didn’t keep saying well if you don’t get this job it will be terrible you know, you’re not going to be able to do this that and the other. You know I just kept saying to her it doesn’t matter. We’ll get another interview and you can get something else you know. I just tried to make her think as though it wasn’t the worst thing if she doesn’t get the job you know.

She’s now doing exams isn’t she?

Yeah.
PHD STUDENT: Does anyone else have any similar experiences I suppose kind of offering out reassurance to their loved ones. =

Everyone: [Overlapping speech]. All the time.

02003: I think it's part of [the nature] yeah. You've got to make sure that all the time not to be angry and to be able to encourage.

[overlapping speech]

02005: Because they are so lacking in self-esteem and self-confidence=

PHD STUDENT: = self-esteem and self-confidence, yeah.

02005: You just to keep encouragement and positivity all the time.

02012: You can hear it sometimes; there's a shake in the voice and it's so sad to hear you know. I mean all of our kids deserve our attention and care you know [yeah] they are our kids. And when you hear that shake in their voice you know, it's upsetting.

02007: Can I ask, um my husband's got PD. He hasn't worked for about three years. But the job that he did have, he got so stressed out. He actually had a complete breakdown in a meeting at work. All I know is that is happened. He came home completely upset, and then he, because the job was causing him so much problems and I didn't know “he had PD at the time”, so I said to him well if it's that bad then leave and find something else. He left the job and then he went self-employed and that didn't work. But since then he hasn't worked. But when we have talked about him finding a job, he gets stuck at the point of well what can I do, I don't have any skills. Because he was in sales before, but his very intelligent [yeah]. But now it's like I don't have any skills, what=

02006: And the thought of retraining is too much for him?

02007: The thought of retraining is more like well I'm not good at studying.

PHD STUDENT: Yeah, I'm not good at studying at all.

02007: Or I don't do that, or I can't do that.

PHD STUDENT: Do you think these thoughts are stopping him from going in to do these things?

02007: Yeah. Because the thing is he's extremely intelligent, extremely knowledgeable and able to put things together. But his got these skills that he doesn't see as skills because they're not the norm.

PHD STUDENT: Do you think it's linked to what some of the others have echoed, you know self-esteem and confidence?

02007: Yes, because for me if I had a skill in being able to you know create something, create a travel itinerary to perfection. I could do that for so many hours if I can't get anything else that might be an opportunity.

02006: But if someone's negativity just clouds =

02007: No it's not negativity it's more like ahh I can't do that. There's always like a=

PHD STUDENT: =It sounds like a hopelessness feeling where you think I don't think I can do this. Does that sound–

02007: It's not hopelessness, it's more like confidence, it's like even knowing you can do this and how valuable it is to me who cannot do this. But in his world it's like, yeah but nobody. I think what goes on in his head is 'nobody's going to pay me for this'.

02003: I think that's where voluntary work has a big part to play, because I think it gets people's confidence back.

PHD STUDENT: Voluntary work?

02003: Voluntary work yeah.

02002: There's no way in, there's no pressure there is there. [Lots of overlapping speech]

02002: There's so much voluntary work out there that you can probably get voluntary work that is more near your skill base whatever you want to do. Whether it's gardening or clerical work or whatever.

02006: Yeah like what you say, sometimes it's something that is not even near your skills base.

02007: This is why I'm saying this. His got this skill base that he doesn't recognise, his got all these things that his done before and whenever he gets stuck he goes back there and pick that up again. And that makes him so unhappy. Do you know what I mean? =

PHD STUDENT: = There's lots of things that are going on in his mind when he is thinking about employment isn't it?

02007: Yes. It's like I've done this before, I know how to do this so I'll do this.

02008: Or all of it is how companies deal with it. I mean, my daughter's employers are useless. They didn't even understand what anaemia was, certainly didn't understand what PD was. As
far as she was concerned well she didn’t want any of it and yet now the store is in [states the name of an area] and is now closing and yet my daughter has been able to double her contract hours in [states a name of an area]. Because somebody other than that manager is dealing with her. And she’s getting her confidence back.

PHD STUDENT: So she has very nice employers.

02008: And also she has been having her one to one sessions =

PHD STUDENT: With?

02008: [Stated name]

PHD STUDENT: Yup.

02008: And I’ve seen a big, big change, for the better. Big change.

PHD STUDENT: I need to ask you, when you say big change, in what way? In how she behaves? Or her thoughts, maybe more positive thoughts?

02008: Well there’s two things. That’s been a major issue, the other thing was that when she had to go back to have a medication assessment at the GP, and they’ve increased the dosage of her citalopram and I’ve seen an improvement since then as well. So she’s not lying in bed till half eleven, she’s up, she’s doing things, she’s helping me =

PHD STUDENT: So she’s actually being more productive in her day to day, so=

02008: Yes she has a very productive daily routine. I was very worried because she’s starting university in September [yup], she’s very happy about that and that’s all she wants to do and also which I’m very pleased about, it’s going to be much more nearer to home then the place she was first looking at. Um but you know with all of that, it’s turning her around again to be what I used to know about my sixteen year old that suddenly between sixteen and eighteen fell apart.

PHD STUDENT: So we’ve talked a bit about like our loved ones coming out the journey of education, we’ve also talked a bit about our loved ones being at work and then not at work. Um but I suppose in terms of if they’re thinking about employment, I mean when we’ve talked about self-esteem and confidence as well, what would you guys say are the main challenges for that person just in general? Um at the moment in time when they think about employment, like how did they go about it.

02012: I wish we knew the answers to that yeah.

02001: Yeah.

02003: Because you don’t know what’s going on there half of the time.

PHD STUDENT: Do you think it’s the thoughts then that are saying=

02012: We thought our daughter was ill from the age of about 22/20. But she wasn’t. She told us it was from the age of 13.

02007: I think it’s a lot to do with confidence. My husband, his started with IMPART and there’s been a big shift in the whole thing. It’s like he tells me when I’m going off into my emotional=

PHD STUDENT: So his actually behaving differently [completely] being more assertive I suppose you could say? [Yes very much] from what you’ve said.

02007: And I tell you what the best surprise is, ten years we’ve been together and his never once said it, but he said it three times, that “I’m really good, I’m great”. It’s like his always like “you’re amazing” and I would say “well, so are you” and he would go ‘hmm’. But his actually used phrases like that three times and I think back and think wow. And I say that to him, that’s really good for me to hear that because I=

02002: They do appreciate what you do for them. He does=

02007: I’m sure he does, let me rephrase that [sorry], talking about his saying that his amazing about himself.

02002: Oh brilliant! Yeah, yeah, yeah.

02007: Because he would say that about me, but he has never said that about himself.

PHD STUDENT: Do you think that was helpful for him in general, like when it comes to work? Because we’re talking about him struggling, like oh I’m actually quite good at what I’m going to do?

02007: Yeah, a lot of the things that he was known for. We used to, you know the black and white, um I don’t know if you’ve read about it, but there’s a black and white attitude of doing things. So it’s like, either a yes or a no and that’s it. A lot of the times now, it’s like I don’t get a ‘no’. And I actually realised that this morning when I was getting ready and thinking ‘I don’t get no’s now’, I just get like ‘oh maybe’. And that’s such a big shift because before it was a struggle to get anything done. You know?
PHD STUDENT: Yeah. And, I’m just going to move on to a bit about physical health. You mentioned that your daughter has anaemia did you say?
02008: Yes, well she had anaemia yes.
PHD STUDENT: So I just wondered if physical health in general for you guys and your experience of how, if that’s impacted your loved one in terms of finding work and looking for work as well.
02008: My daughters been diagnosed with an eating disorder.
PHD STUDENT: Okay, and how did that impact her and her studies and further education?
02008: [breathes out] Not as such, but I think it had an impact on her when she in a sort of bad phase, before it was diagnosed. Um my son didn’t help. He’s older then she is, not very sympathetic until now.
PHD STUDENT: And did it kind of impact on her in terms of what she did, did she just stop doing things [yeah]?
02008: She had been a dancer since she was two and a half and a very good one. Um she stopped going to dancing at sixteen, not because she didn’t like it anymore, but because of the costumes. So she stopped.
PHD STUDENT: She stopped, I’m assuming because of being self-conscious?
02008: Large, yes.
PHD STUDENT: Okay, yeah. Any other experiences of physical health?
02006: We just had a lot of problems with medication.
PHD STUDENT: Okay.
02006: I think she put on nearly two stones or one of them. Well she’s stopped all of her medication at the moment because we had so much trouble with her hormones. Um=
PHD STUDENT: =Was that affecting her moods as well?
02006: The weight gain was a major issue [okay]. Um and the hormone issues, that’s got a bit out of control it has at the moment. So um yeah she’s had to stop all of her medication now.
PHD STUDENT: And has that impacted her [oh yes] feelings [yes], because not just in general but in terms of employment, because she’s studying right now is that right?
02006: No she’s not doing anything at the moment until we get things straightened out a little bit. And obviously, my daughters a bit compared to what she is now, she was quite a severe self-harmer. Um and she’s got a lot of issues about scars and stuff like that you know, so that makes it big.
PHD STUDENT: Do you mean about what to wear?
02006: Yeah.
PHD STUDENT: Yeah, that’s actually a really interesting point.
02007: My husband has the same thing about what to wear so his arms are not visible. He would not go out for months and then he eventually starting going out and then we went out one day and somebody said to him what are those scars? And asked him directly and I think it was just really lucky because we were at the dentist that day and he couldn’t speak, so I said ah it was just a really little accident that we had don’t worry about it.
PHD STUDENT: Do you think that’s something that might play on his mind?
02007: He’ll think about how to get shirts that will go around.
PHD STUDENT: It’s also in general as well isn’t it, like when he is thinking about work and what might other people think.
02007: Yeah, so like in general he wouldn’t go out, but now I’ve convinced him that you know it’s not too bad, we can put a jumper on or this stuff. So his kind of started going out and then about two weeks ago somebody actually asked him what is it? And so now his gone back to thinking how I can cover this up, and if somebodies coming around the jacket goes right up and he just doesn’t want to open the door.
02008: Well my daughter spend a lot of her hard earned money on buying herself some swimwear [TIME 48:44] that was a marketed as swimwear and sold as swimwear. And she was ten minutes in the pool at [states name of swimming facilities] and asked to get out by a lifeguard, being told that she wasn’t wearing appropriate clothing. And then she had to stand in a queue, when there were acquaintances of ours, and explain to the duty manager why she was wearing what she was.
PHD STUDENT: To the duty manager?
02008: Yeah.
PHD STUDENT: I mean all of these things can play a really big impact on that person.
02008: Nothing was wrong with it; that was the whole point.
PHD STUDENT: Ah:: I'm sorry that she had to –
02008: (. ) and absolutely hurt as you can imagine [yeah]. And I wrote a very stiff letter, um got a decent answer but nobody admits to anything anymore do they. And they basically said to her the life guard was wrong, and I know he was wrong, you could have told him that three weeks ago!
PHD STUDENT: These things are really quite unfortunate.
02008: She had actually gone back.
PHD STUDENT: Okay, good.
02008: She's gone back and she's swimming again which is great.
02002: A bit of confrontation went in there=
02008: I have to admit she dealt with it much better than I did. You know because sometimes I will call all the name from under the sun and she dealt with it very very well.
PHD STUDENT: Sorry I just wonder, was she concerned about that sort of stuff in an educational setting or if she goes back into work? Obviously wearing a swimming costume to work is not going to happen but –
02008: I mean she has to wear a uniform and she buys it from the store, she gets a discount to do that. Um yes she can still be a little bit [TIME 50:13] um self-conscious.
PHD STUDENT: And what you think she needs in order to get that support when she's at work already?
02008: At work? No it doesn't happen at work.
PHD STUDENT: Okay.
02008: No I realise. No as long as, I did have to sort of try to be tactful, you know when you feel like you're walking on egg shells and sort of say to her you know that I appreciate that you've got an eating disorder but you know if you can't get uniform to fit you, you are not going to be able to work there. Um you know we need to be able to deal with this somehow.
PHD STUDENT: Okay. Sorry I'm just conscious of the time, so I'm just going to move on to keeping a job. So let's say even if your loved one is perhaps not working at the moment, maybe if they were working in the past before or doing a part-time job or anything like that. Or if they are working at the moment then just think about um when they got the job for the first time, um what was it was like for them? Was there any struggles, was there anything positive.
02001: I think it was a positive experience.
02012: Yeah, a very positive experience.
02001: I mean she had been working before, but at this new job she's got she was absolutely um=
02012: She's working at from home isn't she before she went around [okay].
02001: Yeah and um (. ) yeah because the first employment she had she left at eighteen, she was there for three years, but the floor manager bullied her so she was forced to leave [oh gosh] and really=
02012: We didn't know she was ill at that point really?
02001: Yes
PHD STUDENT: Okay, so that was the first time really (. ). What was she thinking when she first started this job?
02001: What with the job she’s got now?
PHD STUDENT: Um no about the one she had before? You can talk to us about both actually.
02001: She was actually doing extremely well, she had gone got promoted and she was really flying. And then this floor manager came in and she really destroyed her confidence, and she used to literally come through the front door and she used to burst into tears. And it went on for weeks and weeks, so in the end =
PHD STUDENT: = So she was feeling really frustrated then?
02001: Yeah, she had gone to the deputy manager and told her and she said there’s nothing I can do about it basically, and in the end she left and=
02012: = And it was a national company.
02001: So with the company that she is with now, there was something that happened at work= [Overlap speech]
02007: Sorry was this at Barclays?
02001: Yeah. But this new company she was with=
PHD STUDENT: = Sorry, yeah keep going 02001.
02001: Um two years ago something happened at work and her line manager started to harass her and so the same thing was coming again and we sort of talked about and I said to her
you’ve either got to leave or you’ve got to fight him [yup]. So she said I’m going to fight him. So I said you’ve got to be strong enough because he’s going to back his corner telling everybody that it’s all your fault. During the process she did absolutely collapse with it all.

PHD STUDENT: What was she experiencing? Was she feeling frustrated?
02001: She went to Richmond.

PHD STUDENT: Okay, Richmond Fellowship.
02001: And they helped her with this and she won the grievance. It was found that he was bullying her and another member of staff. He got dismissed.
02012: Did he?
02001: He did. And um she won the case, but she absolutely couldn’t – And she had six weeks off work, um but they put that down as authorised leave [okay] which didn’t affect her sickness record.

PHD STUDENT: That’s fantastic.
02001: So she has really got the help.

PHD STUDENT: Do you think Richmond Fellowship helped her? ()
02001: Yes I think they did. Because they were sort of trying to give her confidence so she can fight it. But she was quite determined but she couldn’t cope with it.

PHD STUDENT: Yup.
02001: And she had the six weeks off and she sort of said I’m not going back until they make a decision ().

PHD STUDENT: This is the current job she is in?
02001: Yeah. They have really been on her side. But the only thing that worries me now is that if she ever gets another job, you have to disclose your medical condition and I think if you’ve got any mental health issues they put on that disclosure, I know it’s not meant to but I think it will affect a job that she will go to in the future.

02006: Because I’ve wondered about this, whether this is something you do need to disclose.

02005: It’s not supposed to make any difference but =
02012: = You have to disclose it.
02005: It’s a bit like age [overlap speech], it's not supposed to be discrimination but it is. [Lots of overlap speech]
02006: My daughter has applied for some part-time jobs recently and I’m like you need to let them know.
02002: Absolutely.

02006: Because of these issues.
02001: But if you work for a big company it’s not going to be such an issue because they have to adhere to the law. But if you are working for smaller companies [Lots of overlap talk]

02005: It’s not – you declare your medical condition past, and by law it’s not supposed to make any difference. You should be treated as an equal candidate to somebody else who hasn’t got the problem. But it’s a bit like age, there’s not supposed to be age discrimination when you apply for a job but there is and everybody knows that.

02002: It’s like anything, that the job market is so competitive.

02005: Exactly =
02002: = That a manager who interviews anybody, will not pick somebody who has a mental health record. They will not =

[Overlap speech]

02005: It’s the same thing with age.
02002: It is like age discrimination. I have interviewed so many people in my time. Age discrimination, mental health discrimination, sick discrimination, even down to ethnic discrimination some managers use and I’ve seen it.

02005: Oh yeah, and they say that person did not get this job because this candidate was better or whatever. [Overlap speech] And they may even interview because they are seen to be doing the right thing, but you won’t succeed.

PHD STUDENT: [Overlap speech] () certain employers. 02007, yeah?
02007: I completed a form like you say about declaring your mental health right. Now I have CBT therapy, I have done for about two years now or more. And I was anxious about declaring that, but when I looked at the form, the form never went back to the company or any other third organisation that actually insures the company, so it was for insurance purposes.
02002: So you made a default declaration to the insurance company, or you made the correct declaration?
02007: I made the correct declaration, but what I’m saying is the company never got to see that form.
02002: They will have been informed. The insurance company wouldn’t give them the risk, because the insurance company would charge the company for the service.
02007: But it did say that it was confidential information which can be shared =
02002: I know confidential and how confidential works.

[Overlap speech]
PHD STUDENT: Going back to what 02001 was saying in terms of – yep?
02008: With manager who was – because you know my daughter’s looking forward to a new manager, that isn’t an idiot and that can deal with things properly. Um and I wrote a letter for when we handled this issue with the manager.
02001: And I’m sorry to interrupt, but going back to companies. HR knows her position, but she has specifically told HR that she does not want her manager to know and they respected that request. So if she’s got any problems she goes straight to HR. So I’m not sure if most companies would do that to be honest?

PHD STUDENT: What do you think has helped her to do that? Because I can imagine when you are in the workplace and you don’t feel like you have any particular support, I mean there’s support coming from you, from her parents giving her ideas, or is it something that she’s come up with herself, where she can just think about these things?
02001: She doesn’t want her work colleagues to know her problem so she always=
02002: = but she knows it’s necessary for HR to know.
02001: Absolutely. So that’s why, I mean her last line manager was dismissed through harassment, but the new one she has told them that she doesn’t want anyone to know about her problems=
02006: = Does your daughter have clashes with people at work? Or has anyone, or does she have clashes?
02001: No, absolutely no.
02012: She did a little while back. People taking her the wrong way or –

[Overlapping speech]
02012: Absolutely nothing wrong with her lying mostly, most of the time you know. There’s no issue there that there’s something noticeable about her, that you know they are going to take up an issue about.
02001: She’s very protective of her problem.
02012: I think she’s ashamed of it.

[Overlap speech]
PHD STUDENT: Hold on guys, I think this is really interested, so she hasn’t had any conflicts now but before maybe a little bit. Would you mind talking us through a little bit about that? Was that something she kind of found quite common in the work place, where she might have conflicts or arguments?
02012: When you say did she enjoy them, I mean there’s somethings that she’s confident about yeah. It’s just like, when she’s down, you can hear it in her voice it’s not what she says, it’s the way she says it.
02006: See I’ve been with my daughter where she will stare at people [okay]. Um not consciously [my daughter does that as well]. I mean the amount of times the fights she’s been in () it’s ridiculous. Um=
PHD STUDENT: Was that in the work place or in general?
02006: That’s nearly happened in the work place. You know she thinks people are talking about her, she starts to get over obsessed with that. Um she says things a bit inappropriate sometimes and not in the way of context and=
PHD STUDENT: =So you said that it nearly happened in the work place, what stopped her? ()
02006: Her mum stepped in on it [okay]. Yeah that flared up quite badly. But I mean it happens in pubs, it’s not just in the work place.
PHD STUDENT: Yeah. You were going to say something about ()?
02005: Um my daughter tends to do that. She’s never had any problem at work with it, but that’s something she tends to do. She’ll see something and she’ll just keep looking. Not intentionally, it’s never like that. She’s actually the opposite, she takes a lot of things on and can’t say no, so she would get a lot of extra work put on her because she’s not able to stand up
and say hang on a minute I think I’ve taken on a bit too much here. And then she will take it all on and then suddenly she can’t cope and it’s all then just too much. She’s not able to say no, actually I’ve got enough on at the moment, can you get someone else to do that.

02003: Do you think if she stayed on just as a teacher and not taken on the =

02005: No. Well what happened is as I say, she gave up her responsibility position and went back to being a teacher, which the school were quite happy for that. Um but she just found there’s too much work.

02003: (too much responsibility. The (, the stress.

02005: And then at the time she was having trouble with the medication, it wasn’t right for her and she had=

PHD STUDENT: =What do you think would have helped actually? Would it have been the skills to be able to say ‘no’ or do you think it’s actually the employers who should have been like actually hang on a minute I need to give you less work?

02005: The employer wasn’t very supportive. I mean they made all the right noises, but in actual fact they didn’t really do anything to help her.

PHD STUDENT: Okay, so not much support there.

02005: I think I’m glad she went, because oh god you know she might - what if she kicks off in class or something you know? And one time she went a little bit manic in class because she’s got bipolar as well, um and one time she went a bit hyper in class and the kids were a bit like ‘what’s the matter with Miss’ you know. And one of the other teachers had to actually get her out of the classroom, so that was a bit of a problem.

02006: The bipolar affects her work role as well though? Like does she get a bit of mania and um =

02005: Yeah, she’s been quite steady for quite a bit, like for a year or so now, so it’s quite manageable at the moment. But obviously as soon as you get a little bit of pressure or a bit of stress as I say she does volunteering, she actually volunteers at the Richmond Fellowship, she does reception. She does reception because she’s got a thing about phones, because she doesn’t like talking on the phone. So that was a way of getting her to speak to people?

PHD STUDENT: How did she find that? Has she found that helpful?

02005: She really enjoys it. She only does one afternoon a week. But it gets her out, it’s gets her mixing with people [that’s fantastic] and it gets her, I mean sometimes she does a bit of data input for them or whatever you know, and she’ll answer the phone and stuff. It’s just getting back to mixing with people in the work environment.

PHD STUDENT: I can imagine yeah. I just want us to rewind to that actually. So to talk about getting a job, so that would be things like I don’t know I suppose you could imagine your loved ones doing things like writing CVs or like looking for work perhaps. I’m not sure what mediums they might use, or maybe go on the internet or through the newspapers you know, I don’t know if people do things that way. Or maybe they went down to the job centre like you mentioned and, um do you think there are things that would make it difficult for them to do those sorts of stuff, or has been difficult?

02001: I don’t think it would be difficult to get the interview, but mostly it’s done via the internet now. I think it’s actually the stress of going to the interview because as you said it’s so competitive now.

PHD STUDENT: The interview process is stressful now, which is quite normal I think in general isn’t it.

02001: I can imagine, and when you’re unwell.

PHD STUDENT: What kind of things do you think they will be experiencing? What kind of things will be going through their mind?

02001: I think it could just be nerves, and might make them stutter or not being able to put a sentence together or just freeze=

02012: Not really presenting themselves as they really are, you know, to how they normally are.
02001: I think probably interview techniques would be probably a good idea, saying what type of questions there are because some of the questions now are quite psychological and they will say things like what are your worst traits? And you just think oh you know haha [laughter in the room].
02005: Say somethings positive yeah. [laughter in the room]
02002: There's no correct answer. [laughter in the room]
02012: You just stop doing work. [laughter in the room]
02007: Before I started my own help and I joined IAPT way back in 2013, um I couldn't get a job. I was in that position where I was a carer, my mum was 100% bed ridden and it was just devastating because I had a job lined up, I had to let it go and then try and find another job and I just didn't have the confidence. But I went to one of their, I don't know what they call them, career or employment advisors or something and the one thing I remember is she started asking me questions as they would in an interview and I just went completely blank, I've got nothing to say, because I haven't done this for such a long time. I've been a carer and I felt completely worthless, that I couldn't answer those questions, and then she just worked with me. And I think in the second session that we had, I had all the answers, oh no I did that, I forgot I did that, I did that, I did that. So I think that kind of sort of reminded them=
PHD STUDENT: Having that someone to support you to remind them=
02007: =Of all the things that they've done and they think are not=
02001: =You might have three people in front of you and they're all asking you different types of questions and I think that's quite nerving as well.
02007: Yeah.
02001: Um sometimes you might have to fill in some sort of test or test of something, like you might have to perhaps do a Maths or English test.
02007: Have you heard of the five step process?
ALL: No.
02007: The five step process for the job that I got now and that was nerve racking for me but if he had to do it I don’t think he would be able to do it.
PHD STUDENT: Well we can talk a bit about Hiliary who's an employment service staff in um Barking. Did she do anything like helping your daughter write a CV I don't know, I'm not sure?
02006: I think she would've done if she had to write one. Um yeah there's a hell of a lot of, yeah she’s got a, there’s someone else who works with her, who talks to her more on a one-to-one.
PHD STUDENT: Yeah I think there’s a=
02006: =I can't think of her name now.
PHD STUDENT: There’s a support worker who usually works with Hiliary.
02006: Yeah the support is not there if you don’t ask for it.
PHD STUDENT: Yeah if you ask for it.
02006: I mean, because she does money management and everything. There’s a hell of a lot that she does do, you know.
PHD STUDENT: It's just about having that one person perhaps who can help you with employment=  
02007: =It didn’t take long, but at that stage of my life at that moment, I wasn’t in a very good place. There was like nothing I could do=  
PHD STUDENT: =Sorry, what happens with your anxieties would you say?  
02007: Anxiety, panic, because I was constantly panicking about mum, is she going to fall down again or are we going to be back in the hospital, because I have been in and out of a hospital for a year with her. And um just that one session where I went in with her thinking that I've got nothing to say=  
PHD STUDENT: = I've just got one question..  
02007: And then the next session I was able to just go bla bla bla. 
PHD STUDENT: And that can sort of be helpful for people with personality disorder.
02001: Sorry I remember going back into work after having children after a ten year break. On my first day, I was like, my stomach was crouching, I had stomach cramps, I was sweating. I just felt absolutely awful. Just thought all I want to do is get back into work. So if you've got a person who's got additional problems, I think that would drive them mental. It's an added thing that you've got cope with. That was a horrible day that I just, however I got to there I just don’t know and I just walked through the door and they said to me a few days later 'when you walked through that door you looked absolutely terrified' [laughter in the room] and I just thought=  

PHD STUDENT: So it sounds like it was combination of things such as having employment support, having an employer, or a line manager that can maybe perhaps be a little bit more understanding. Um it can be self-confidence as well and self-esteem, and then support from you guys as well.

02008: I think you can’t underestimate the way manager’s act to anyone. I mean I’ve just been a, as a result of it, I’m out of work after thirteen years with the same company. Um went off with stress, turned out to be more, but you know the way my employers dealt with me it was horrendous. Now it was bad enough for me because I wasn’t well, um but I did my usual you know, I stood up to them. But I was treated appallingly and now if that is somebody being treated like who has also got mental health problems, then even worse, because you know=

PHD STUDENT: So you’re saying you were able to stand up and speak to them, what would someone with PD=

02008: =Because everybody, without, exceptionally my office, I was treated appallingly.

PHD STUDENT: 02007 you were going to say something?

02007: When my husband was treated badly, and in all the time that we’ve been married and that he has worked, he has had the most awful things done to him and he falls back and his you know. He worked for a company for what for four years, they gave him a promotion to come and work over here, then they decided they didn’t want to pay him for all the time and give him enough money to get a flat, he accepted it. And then he went back there and they took his old job away from him and made him start from scratch, and he just took it.

PHD STUDENT: What would have been helpful for him? What do you think would have helped him even, in that situation?

02007: Um I think the two things in that situation was that having the confidence that you know the job was not the only thing he could do, and also being able to be assertive and actually standing up for himself and saying actually this is really unfair to me, you haven’t done it to anybody else, why me?

02008: Even with my daughter, it was her manager who was doing things to her, that she shouldn’t have been doing, in terms of what she set her basically on one occasion. And then she was making people do things they shouldn’t have been doing. It was only when a new assistant manager came in, who put a stop to it all, um that things and certainly for my daughter she went for an even kill. Because she wanted to leave and I said well, you know if you do then you’ve got that little bit of pocket money gone, you know. And also where she’s going to university in west London. [States retail shop] is who she works for; [states retail shop] is down the road. She wants to be able to a part-time job there. So it’s another thing tied up with this employment, but when she went into err sort of black phases I would call it when she didn’t want to get out of bed, she didn’t want to go into work, she couldn’t deal with the women because the women was so difficult and she was difficult. Um and she was the sort of person she couldn’t talk to you or speak to you properly not even me, even when in there as a customer, she would ignore me. And you know it was very very difficult. And as I say until this woman came in, until she got on with her 1:1 and the communication seemed you know better that she’s turned the corner and turned things for the better.

PHD STUDENT: So, thank you. I’m just going to wrap up, but before we do is there anything that we’ve discussed today that we haven’t discussed yet that you think is really important when it comes down to personality disorder and employment?

02007: Can I just say that I think that with PD, people that don’t actually read enough about it, have not experienced it, are not around it=

PHD STUDENT: = have a lack of understanding.

02007: There’s such a huge, because they actually think that the other person is just difficult or=

PHD STUDENT: = I mean are you talking about other people in the workplace or their employees=

02007: = Well okay, my sister. She knows what happened to my husband, I say these are the problems, she still doesn’t get it.

PHD STUDENT: So that’s in the family. Do you=

02003: = But that’s everywhere=

PHD STUDENT: = Everywhere =

02007: = That’s what I’m saying=

02001: = I wouldn’t have known about PD, until my daughter was diagnosed with it. So it’s like a big vicious circle really, that do we have to educate employers, do we have to get more therapy for our people or =
PHD STUDENT: = Well this is what we’re trying to find out ha ha ha.
02001: So isn’t it just a vicious circle.
02007: But I think if we’re educating employers because the things is, my sister who knows all that happened, still doesn’t understand it. And then you’ve got strangers outside that run companies, are told this person has got this and they think yeah okay and then they have them in and then they can’t understand the behaviour.
PHD STUDENT: I have to say definitely from the research that we are doing so far, that’s starting to be somethings that’s quite a trend you know, you know there’s a real lack of understanding. Yeah, that’s what I’m saying.
02007: Because the trouble with it is that it can be so easily put down to it’s just a quirky thing, if you don’t know them that well, but well that’s what they do you know, do you know what I mean? You know like for example the staring, if you’re staring into space, oh you know that’s what she does, she’s off on a day dream.
02008: And it’s interesting, my son who is not the most sympathetic of people, um he had to go for, he was referred for his skin, and the new medication he is on which is brand new, um does have an impact on any mental health issues. So one of the questions which he was asked was, are there any mental health issues in your family? And of course he had to say that his sister was diagnosed with borderline PD, and at that point they very kindly explained to him what that meant. So that did me a big favour because he has totally changed his attitude to his sister.
PHD STUDENT: = So actually it all comes down to the label and what it means to the other person [absolutely].
02008: And it’s interesting, my son who is not the most sympathetic of people, um he had to go for, he was referred for his skin, and the new medication he is on which is brand new, um does have an impact on any mental health issues. So one of the questions which he was asked was, are there any mental health issues in your family? And of course he had to say that his sister was diagnosed with borderline PD, and at that point they very kindly explained to him what that meant. So that did me a big favour because he has totally changed his attitude to his sister.
PHD STUDENT: = So education.
02008: Education, education, education.
PHD STUDENT: = Thank you, I’m going to finish it off there. Um so if you guys have any other further questions from today or if anything arises next week, send me an email or give me a call. Um in the pack that I gave you guys before, there’s a form which basically invites you guys to be part of the process further along. It’s basically a clarity process. So you know when I mentioned that [blank] and I and another colleague, we’re going to be going away and listening to these tapes and transcribing it, and then what we’re going to do is that we’re going to put them into summaries. So if you guys are interested in reading the summaries and making sure that it’s right, and we’re not just making stuff up, um please do write down on this form um here if you guys don’t have it in the packs already. And then what will happen is that I will give you guys a call, it will be a while because these things take time unfortunately. Um but I’ll give you a phone call to ask if this is something you still want to be a part of and then I’ll send it through the post or by email, and then you guys will have like two weeks to come back with any sort of amendments or anything like that. [END TIME 01:17:07]
Appendix 24 Focus Group Supporter Transcription 2
(Chapter 3)

PHD STUDENT: So why are we here? I was just saying to (states participants name) - to the other two about uh EMPOWER overall. I know you read the information sheet, but in a nutshell, we’re looking to develop an intervention in the long-term to help people get back into work. And also develop an assessment tool or questionnaire that will help identify what potential challenges are or supports are needed for that individual. And we can’t really do that without asking ‘people’ like yourself first. Otherwise, you know like anyone can make up a questionnaire and be like ‘this is what we’re doing,’ and it doesn’t actually show anything. So that’s why we’re here. So um, ya, um I don’t think there’s anything else? This is (states RA’s name) maybe you met before.

02009: That sounds like an unusual name; you don’t hear it very often.

M: Oh, it’s Indian, the name, but in Spanish apparently it means naughty. Um, so I’m a research assistant and I work on the EMPOWER project and we work together.

PHD STUDENT: “Yea, yea”. Cool.

02009: So did you say you used to work for [blank]?

PHD STUDENT: Yes.

02009: In what capacity was that?

PHD STUDENT: Assistant Psychologist.

02009: What’s that? Assistant psychologist? I didn’t think that was possible.

PHD STUDENT: Basically, exactly the same as a psychologist but lesser workload and I do a lot more admin work ((laughs)).

02009: Do you still do that?

PHD STUDENT: No, no, no, I changed roles. I’m a research worker like (states RA’s name) and a PhD student as well.

02009: So you’ve done that and you’ve moved on from that? You’re not going to go back to it afterwards, are you?

PHD STUDENT: I might do, I don’t know.

02009: Oh, so you’re just having a break, maybe? Is that it?

02010: Exploring.

PHD STUDENT: It’s just something different; it’s just something different from what I was doing before. Um, ok. So, we’ll be talking for about an hour about employment. I’m going to guide you guys through certain questions, just remember there’s absolutely no right or wrong answer; we’re just here to listen to your ideas and– have you guys been part of a group discussion before or focus group before? Like facilitated one or been in one?

02009: When they say semi-structured interview, does it– it all means the same thing?

PHD STUDENT: That’s a good question, so the information sheet shares it’s information for two different things. So, if you say for example couldn’t make it today or didn’t feel comfortable speaking in a group environment, then there’s an option that you can have a one-on-one with myself, yea.

02009: So this is the focus group and the structured interview ()

PHD STUDENT: So I’ve got the recorders on and um usually we just try and speak one at a time because as you guys know, (states RA’s name) and I are gonna be transcribing this afterwards and it’s incredibly difficult for us to do and it’s understandable because people get quite excited and they want to say you know as much as they can but um, if we can speak one at a time to be clearer for the recording and to hear each other, that’d be great! So, yea before we begin, do you guys have any questions? (2)

02009: No, I don’t think so.
PHD STUDENT: It's ok if you don't, that's fine. There'll be opportunities to ask more questions later. But if I were to ask you guys, um, so if I were to ask you a person or individual with personality disorder; how might you describe that one person? Again, there's no right or wrong answer. In terms of perhaps how they might be in the presence of other people or how they might feel? (7)

02009: I think (states name) in general who's very nervous around people and that's his main problem, he's very anxious around people and he often smokes and he goes off and has a cigarette and um very jumpy=

PHD STUDENT: =So he=

02009: =He's very scared, yea, around people. And um, he has done voluntary work; he not long ago worked with age concern. Um, I think it was in Ilford. He worked there for a while, 'cause he's very good with computers and he's had different jobs. And I think he's done a City and Guilds course to do the computers.

PHD STUDENT: So he's done a few things, but generally speaking, he's quite an anxious person, yea? (1)

02009: Yea.

PHD STUDENT: So he feels a lot of anxiety. Is that a similar experience with you guys, with the people that you care for?º

02010: In part, I guess. I mean my experience is-- 'cause (states name) is not the only person I know who has something similar to BPD. Um, but the one common trait between the two of them is that they have problems kind of regulating a reasonable response to something that they feel is either injustice or something of that nature. Um, I mean a good example is this morning (states name) gone off to a study in London where they're doing a brain scan and=

PHD STUDENT: =Ah, yea, yea! (states name) study, yea.

02010: So those kind of things. And um, she completely forgot about it and she got a knock on the door from my dad this morning saying 'uh there's a taxi outside waiting to pick you up.' So her instant response was just to shut down and kind of get very angry with god knows what instead of doing something productive. So that's-- and that's the major thing that I've seen with a lot of people with BPD is they don't-- they go straight to the emotional response rather than the logical or reasonable response.

PHD STUDENT: Yea, yea.

02011: Yea actually, I can totally concur with that, exactly. You know, emotion rather than reasonable and not being able to then think clearly.

PHD STUDENT: I think that makes a lot of sense, I mean-- well the reason I ask you is because I think, yea, what you guys have experienced is absolutely right and what I'd like us to think about is that but in the context of employment. So, the way that we try and look at it, and it's not, it's not linear um but it's different stages of employment, so you got from thinking about employment to contemplating it to in the process of getting a job so like interviews and things like that to people who are employed um and we just wanna find out those sort of experiences, how that might impact those different stages.

02009: What do you mean? What's linear? What's linear?

PHD STUDENT: It's like in a line like that, so like A plus B is C when actually they're all kind of intertwined as opposed to in a line.

02010: It's not straight.

02009: Sorry () follow you () ((laughs))

PHD STUDENT: That's ok.

02010: What it is, it's not like a straightforward progression from one to the next. There's often a lot of backtracking and mixing of things.

PHD STUDENT: Yea, in a nutshell. Um, where was I? Um, so yea, if you were to consider um-- I suppose the first stage would be contemplating and thinking about employment. So, regardless of your loved one and where they are at this moment in time, I just want you to think about them and then everything in general. What do you think the main barriers might be for that person with personality disorder when it comes to thinking about employment? (3)

02011: Anxiety. Low self-esteem. (4) Anxiety about being able to cope with pressure. But the biggest one is about how they'd be perceived by an employer. So when you're applying for a job, when you get the medical questionnaire and it says you know 'have you got any mental health problems='

02010: =Are th ey allowed to ask that?

02011: Yes.

02010: They are? Oh.
02011: Yea. Not um, not before you’re offered the job. So if you’re interviewed, you’re interviewed and they mustn’t ask any questions about your medical history, period. But after they’ve made you a conditional offer, they can then ask you to fill in a medical questionnaire.

02010: Fair enough.

02009: Oh, so that would happen after the interview.

02011: After you’ve been offered a conditional—so conditional offer of employment. They can then ask—

02009: =Sometimes I know like when I’ve applied myself, like application forms do sometimes ask you for your medical history, before you go to the interview.

02011: They shouldn’t. They shouldn’t because that’s against the Equality Act. They shouldn’t do that.

PHD STUDENT: If I can just come back, so you mentioned anxiety and then did you say self-esteem as well?

02011: Mmm

PHD STUDENT: Do any of you guys have similar experiences or?

02010: There is an element of that. For me I wouldn’t identify that as one of the biggest issues. Um, it can present very strongly, especially at like pre-interview stage=

PHD STUDENT: =How would it present? Would it be the things they say or the thoughts that come up “for them”?

02010: It’s um, I mean with (states name) she’s had a few chances— I mean she’s got a job now but before when she was unemployed, she had a few chances to go to interviews and stuff. She’d gone through the first stage of applying online then she was Invited to the interview and she could be really excited and happy about it the night before and then she’d wake up in the morning and go ‘I don’t want to go, like I don’t feel like I’m going to be good enough, like the other candidates are obviously gonna=

PHD STUDENT: =What do you think keeps her in bed? Is it the thoughts? Like as soon as she wakes up, the thoughts you know, ‘I don’t think I’m good enough for this?’ Or do you think it’s the actual anxiety? Sounds like anxiety that’s coming through.

02010: Um, I mean I can only go on my personal feelings because she’s not very open about when she’s in that situation, but um from what I see she gets very— she like compares herself to the most extreme possible situation and then comes to the conclusion that she can’t do it.

02011: You just made me think. My daughter applied for a job recently and said she was invited to interview, so she accepted the interview and then she was told that she was going to be given a presentation to do at the interview. Like you turn up and they say ‘you’ve got to do a presentation on this.’ At which point she just thought, ‘can’t do it, because if I’m asked to do a presentation on something that I don’t know what it’s about, I’ll just freak.’ So rather than go to the interview— you know I said ‘just go, it doesn’t matter you know,’ but she just couldn’t be in that position where she’d be asked to do something that she couldn’t do.

PHD STUDENT: I just wonder what do you think would’ve been helpful for her at that moment?

02011: Well if she had known what the presen— I mean I know I know that the whole part of asking to do a presenta— I mean you can ask someone to do a presentation and somebody else can do it for you, you know, help you with it, so I understand why an employer would say that. But um to actually know in advance the territory or the format of the presentation, to have something rather that say ‘oh, you’re gonna be asked to do a presentation on something’ and you won’t know until the day what it’s going to be. It just seems like really really daunting.

PHD STUDENT: Yea, that makes sense.

02009: I have to say though, what you said, I think most people would be terrified. I would if someone asked me to do a presentation, regardless of whether I had mental illness. So somewhat—I think some of that is quite expected really.

02011: Yea, ‘cause it could literally be on anything, couldn’t it?

02009: Yea, the thought of me doing a presentation terrifies me; I mean I’d be terrified. Especially if they didn’t tell you beforehand, just to say ‘oh do a presentation,’ that’s putting you on the spot. That’s terrible!

PHD STUDENT: So can I ask, did your daughter, did she go through with the interview?

02011: No. She just told them she wasn’t going.

PHD STUDENT: Ok, and how did she— how did she um like feel afterwards when she decided not to=

02011: =Really devastated. Yea, really, really devastated. She thought she’d let herself down, she thought she’d let a potential job down. You know, so it’s=
PHD STUDENT: Has it um perhaps influenced or impacted how she might look for another job? Or other jobs out there?

02011: No, she did subsequently go for another interview which she was successful at. So she was given a conditional offer, but then that was—that was much more laid back; it was more like a chat rather than a sort of formal=

PHD STUDENT: =Yea, yea, yea. So more of a like open discussion. Um, I just wonder if you guys have any thoughts about the interview process.

02010: What do you mean specifically about that?

PHD STUDENT: If you had any thoughts around it in terms of your loved ones experience? If they had any () [interviews].

02011: [I’ve got one] um, interviews, my daughter went for an interview and the people interviewing her um— it was in the local authority, they asked incomprehensible questions. You know, it was all like jargonistic, um not in plain English. You know, she’s a bright girl, she just didn’t understand what the questions were. And you know like this thing where you’ve got to ask like a convoluted question and put it in the most difficult language rather than just ask a straight forward question. (2) So she found it really difficult.

PHD STUDENT: Hmm, I just wondered um, what do you think would be helpful for people with personality disorders at this stage to get them thinking and get them over those difficulties?

02010: A reassurance of there is nothing bad that can come of this. Even if you completely mess up the interview, it’s not gonna put you in a worse position, the only thing that this interview can do is make your life better. And that’s— I mean that’s the only thing that I can actually say to (states name) when she gets into a position where she doesn’t want to do something.

PHD STUDENT: And when you say reassurance, so, that’s coming from yourself?

02010: Or from uh, an employer, or from society or whatever. Not have a stigma attached to if you fail in an interview, you’re automatically like going to fail every interview and you shouldn’t even try; which is quite easy for someone with paranoid tendencies to think.

PHD STUDENT: You say stigma, do you mind expanding a bit more on that?

02010: So, uh, especially around a social context, um, I don’t know about slightly older generations, but I’m in my early to mid-twenties. Um and a lot of my group, if someone fails an interview, and other people hear about it, people just take the piss because it’s something to joke about. And most people take it quite well whereas with (states name) and my other friend, they’re both very um— even though they’ll play along to the joke at the time, it will really affect them later on.

PHD STUDENT: How would it affect them? In terms of=

02010: =Just, it just destroys their confidence. (3) So I think people like— generic people who even marginally associate with someone with personality disorders need to know that what they say to that person is going to be a lot more effective than to someone else.

PHD STUDENT: It’s gonna last a bit longer, the impact.

02010: Yea.

PHD STUDENT: Yea.

02011: And then it doesn’t help them the next time does it? Because they— whereas other people might just go off an interview and say ‘that was really crap, I really mucked up but I learned from it. Let me write down the questions that I couldn’t answer, you know and be better prepared for next time.’ But it doesn’t sort of work like that does it. It’s just like ‘uh, I can’t do it.’

02010: Can’t do it, yea.

PHD STUDENT: Um I just wondered guys, in your experience um, do you any of your loved ones have physical health problems as well?

02011: No.

02009: (2) Sorry ()

PHD STUDENT: I just wondered, in your experience guys if any of your loved ones experienced uh physical health difficulties as well? As well as their mental health. So maybe you might have um, I don’t know um, I’m trying to think what’s common.

M: Diabetes?

PHD STUDENT: Yea, like diabetic problems or anything like that? If it’s not, that’s fine, I just wanted to ask.

02011: No.

02009: No.

02010: The only thing I can think of is uh quite chronic back pains, but I don’t think that’s related so much, that’s just more of an inherited
PHD STUDENT: =Oh, ok. So it doesn’t impact with the mental health as well?

02010: =Well it does, they do impact each other, um like when she’s got back pains she doesn’t want to get up and do things. But sitting there all day and doing nothing, she feels like a waste of space. So in that example there is an impact but there’s not like a direct correlation between them.

PHD STUDENT: =Sure.

02009: =I think with (states name), part of his um– with BPD, um because of that I think he finds things very difficult and gets stressed out more. I mean he had a heart attack, a mild heart attack when his benefits were stopped. Because he went into his assessment and was joking around with his assessor saying ‘I’m fine, I’m doing– ‘cause he puts on this mask, ‘I’m fine, I’m doing voluntary work. Yea I’m doing really good and everything.’ And I thought ‘oh (states name), what have you done?’ Took him off benefits. And I said I don’t know what you’re worried about and he said it’s really stressful. And I went ‘it’s fine, it’s fine’ ((laughs)). And he had a heart attack. And um yea, he finds it difficult to because of his age as well, he’s 50, 51= PHD STUDENT: =Yea.

02009: =It’s difficult for him to get employment because of the age as well as BPD.

PHD STUDENT: Yea.

02009: =But I think it would be good to have maybe, to get some of the professionals, clinical psychologists maybe here that could maybe um maybe do () I don’t know. Maybe think about (1) um supporting people and giving them advice about interviews and things like that and have someone=

PHD STUDENT: =So having physical [support in terms of employment]

02009: =People that they can talk to] that can help them when they have interviews and support them. Um=

PHD STUDENT: =You mentioned he had a heart= 02009: =And maybe, maybe, I don’t know.

PHD STUDENT: You mentioned he had a heart attack, so he has some physical health complications too then (1) as well as=

02009: =Would you say that was?

PHD STUDENT: Y↑ea, yea, I would say.

02009: =He takes a lot of medication and=

PHD STUDENT: =But I suppose my question is um, that element of taking medication, had a heart attack, has that impacted or perhaps made it difficult for him to look for work or think about work?

02009: =I think he’s lost a lot of confidence. Um (2) and probably, yea, definitely I mean it would do. He puts on a mask, ‘I’m fine,’ which he does all the time and he laughs a lot. When people say certain stuff, he’ll laugh along but inside it’s a totally different story, a bit what like (states name) said.

PHD STUDENT: Yea.

02009: =And he jokes a lot, ‘cause he puts on this front. Yea, he’s like um– yea, always telling jokes and trying to make everyone else happy; and he focuses on helping other people but he neglects himself.

PHD STUDENT: Um= 02009: =And he jokes a lot, ‘cause he puts on this front. Yea, he’s like um– yea, always telling jokes and trying to make everyone else happy; and he focuses on helping other people but he neglects himself.

PHD STUDENT: And does he do that– so he’s volunteering at the moment, is that ‘r↑ight’?

02009: =He was, but he stopped. Um because when his benefits stopped, basically everything went haywire. He just– everything just came crashing down. Everything halted in his life, it was catastrophic for him. Um he thought he was gonna be kicked out, made homeless; he thought he was gonna lose his council fl↑at. He thought he was gonna be made homeless and he was terrified.

PHD STUDENT: =So, I just wondered with benefits= 02009: =Absolutely terrified.

PHD STUDENT: =You talked about finance. Is there any sort of connection between finance and finding w↑ork and that being something that might get in the way with employment?

02009: =I know when I met him having relationship, he was very– he wanted to work. (2) Because sometimes with men, I’m not sure, they want to work to kind of– they feel like they’re a failure if they’re not working. You know, um so he wanted to work and he’s also worked when he was with his partner; he worked like seven days a week or something. And he’s always pushed himself, he feels like he has to be working and he has to push himself and (1) he (1)
yea, he feels like that's what he should be doing. I'm not really quite sure why. And I'll say 'look, you don't have to push yourself, you've worked your whole life. If you wanna have a break and do some voluntary work or just, you know, do that=

PHD STUDENT: =So it sounds like [()]

02009: [[()]]. And he's like, 'I've gotta work, I've gotta have a job.' Like, he's a failure if he doesn't have that.

PHD STUDENT: Um, I just wondered guys, what do you think about um-- you know if you're looking for a job, you might be applying for jobs online or you might be writing your CV or however people do it these days. Um, has your loved one experienced any sort of difficulties doing those sort of things?

02009: Oh, yes!

PHD STUDENT: Got some nos.

02009: (States name) had trouble with his CV and he's going around everywhere trying to find somewhere-- someone to help him. And he couldn't find anywhere! Like he tried Barnabas workshop=

PHD STUDENT: =You said he had some trouble with his CV, in what respects as in he wasn't sure what to write or um=

02009: =I'm not sure, 'cause he did go the Richmond Fellowship to get help and he said they weren't very helpful. Um and everywhere he went, they charged. 'Cause he needed help to (1) make the best CV he could, I suppose. I mean he's obviously had experience um putting a CV together, I think it was trying to get advice on how to make it the best it could be which is what you wanna do. If you've been out of work for a while-- you know he's done various jobs, you want someone to make it the best it can be. And he said a lot of places were charging 100, 200 pounds to look at your CV. And I think-- so he gave up with that. But there needs to be more support with people, I think with all mental illnesses um when doing interviews, doing everything like that; filling in forms. Even I have trouble myself when I have application forms and I think 'oh how am I gonna fill that in?' I don't know if it's the right thing to say or not, you know. And if you don't have the support from parents or friends, which I don't myself, um you need help from people.

PHD STUDENT: I was wondering um, the Job Centre is uh=

02009: =They're useless.

PHD STUDENT: It is the service that can provide some of the things that you described (states name), so what's your experience [of using it]?

02009: [(acquired)] but they do say 'oh, you can have help with your CV and stuff,' and you think (2) 'yeea, right' ((laughs)).

02010: I have never seen (states name) more depressed and down with life than the two months that she was going to the Job Centre every week.

PHD STUDENT: So tell me, what was going through her mind, like what=

02010: =It's generally speaking, the one in Romford at least, you walk in and you're hit with this depressive atmosphere=

02009: =((laughs))

02010: Um, everyone that goes in there seems very sort of hacked off with life. The staff aren't friendly or particularly helpful um and everything is such an arduous, long task. To get, you know, (1) to get a job that's worth doing, you can either go to the Job Centre and fill out a million forms and applications so that they will give you your benefits (1) or you can just try and go out alone, which (states name) found was the preferable method.

PHD STUDENT: 'Ok."

02010: But=

PHD STUDENT: =So she felt that they weren't helpful?

02010: Um yea, I mean the only incentive was to get the 60 pound a week or something. That-- that is it like, Job Centres they just don't work.

02011: No, they don't. And the people that work there, don't have the skills to help or the inclination to help.

PHD STUDENT: Tell me a bit more about that (states name).

02011: Well this is going back a long time but I know when my daughter when um-- (2) can't remember when it was now. Um but she went there, but it was it was a real incentive to get a job actually, 'cause she said 'I just do not want to come to this place.'

PHD STUDENT: ((laughs))

02011: It was 50 quid a week at the time, you know, it's not worth it. Um but you know, so she found a job for herself.
PHD STUDENT: Hmm, yea I haven’t heard that before but that makes a lot of sense. It’s a good incentive in that respect.

02010: That’s such a good way to look at it actually.

PHD STUDENT: Yea ((laughs)).

02010: Maybe that’s why they do it that way.

02009: No, but that's not what they should be doing. Because if you feel pressured to getting a job, that’s a wrong start in the first place. I mean Job Centres are appalling, I mean you go in there and they’re so depressing, everyone just wants to, you know=

PHD STUDENT: =You said it’s the wrong– it’s the wrong reason to start looking for a job if you’re pressured, because of that process. Is that something that (states name) can relate to?

02009: Um, (2) not necessarily (states name) but I think for me, I’ve been in work programmes and you just want to get a job to get out the programme because they make you apply for any job, even if it’s not relevant to you. You’ve got to apply for a certain amount of jobs. The people in the Job Centre don’t care, they’re often very rude.

If you’re not confident, they will absolutely annihilate you. Um, I used to bring my friend to the Job Centre with me and they used to give her dirty looks like ‘how can you have someone to support you?’ Because they don’t like it if you have someone supporting you because they might actually get challenged and uh you might actually– they might actually stick up for you. It’s just awful and um, the way they treat people, and yet they say to you not to be rude and all this stuff but– and have security guards there for I don’t know why. It’s very intimidating. And um, yea.

PHD STUDENT: What would be the alternative? If there wasn’t something that was run by the Department of Work and Pensions, if there wasn’t Job Centres, what would be the=

02010: =Not having a capitalist society.

PHD STUDENT: What was that, sorry?

02010: Not having a capitalist society.

Unknown: ((laughs))

02011: Well, there are– I mean, when I was working, I was=

02009: =Anything would be better!

PHD STUDENT: Are we talking in terms of personality disorders and those individuals?

02011: Yea. But when I was working, I was responsible for in– um Barking and Dagenham, a network of children’s centres and we used to run work clubs for the children centres, primarily aimed at the parents of sort of younger children. But they were about actually supporting somebody to write their CV. And people would come in and think they didn’t have any skills at all and it was about talking to them and finding out actually, they’re a brilliant cook, they can speak two languages or three languages. They can do this, they can do that; you know, they’ve got all sorts of skills. So it’s starting with people, finding out what their skills are and then starting to construct a CV. And then sort of trying to tease out what their aspirations are and then say ‘what’s your aspiration?’ Right, let’s try to get a little plan how you might reach your goal. So it might start– so for example, a woman who was really depressed, felt she couldn’t do anything, was useless and what have you, it turned out that she was a really good cook, um and was bilingual um and would actually want to work in the food industry; so it’s actually getting her on a you know, food hygiene course or something. Um and so that started her on her trajectory. What it’s about is actually having tailor made support for individual people, not this generic you know like Job Centre you know, you fill in you had X number of things for anything that you don’t want or you’re never gonna get, just so you can get your 50 quid or whatever. But it’s about providing individualised support, genuine support for individual people based on their individual needs and their individual aspirations. You know, it’s got to be tailor made. And it’s got to be given by people that are skillful and empathetic and caring, you know rather than Job Centre staff who don’t want to be there.

PHD STUDENT: Um yea, absolutely.


02010: It’s so easy to get it right. You know [if you (), it’s not that] difficult really.

PHD STUDENT: [So what sort of things]

02009: I know.

PHD STUDENT: Despite all this stuff going on, what sort of things do you think your loved one would be experiencing like emotionally wise? So yea, ok, you know Job Centre, you know it’s a
depressing place, like what would they be experiencing? I'm gonna find the work elsewhere? Do they feel frustration? (1) A bit of anger? Or just pure sadness?

02010: Frustration, definitely frustration. Whenever she would come back on Thursday evening after being at the Job Centre, it was just like throw the bag in the corner, slump down on the sofa, 'I hate life.' Yea, that's it.

02009: When you go to the Job Centre, you just want to go in and get out as quick as possible. That's what I did. That's what I wanted 'cause it's just not a nice place um for people that don't have a mental health problem and even 10 times worse if you do. Because they don't even factor [that into the equation].

PHD STUDENT: [Would you feel that] (states name) perhaps experienced a bit of frustration as well? Similar to (states name) experience with (states name)?

02009: Well at the moment he's not really in that realm of going to the Job Centre, he's not there.

PHD STUDENT: So he's not even going there?

02009: No, no, no, he's not. At the moment he's just having therapy and he doesn't want to do any voluntary work 'cause he feels like he's done– he's like 'I've done a lot of giving' and he feels like he hasn't gotten anything out of it. Because when he was working with Age Concern, he wanted to get a paid job, I think. Well he did and he was disappointed that nothing came out of it. So I suppose he feels like, 'why don't they want me, I'm not good enough.'

PHD STUDENT: Sure, yea.

02009: He takes– everything is seen as a big rejection. Everything is all about being rejected for him and it just sets him back.

PHD STUDENT: Gosh, that really impacts him then looking for [other work] because of the rejection

02009: [Oh yea! Yea].

02009: So at the moment, he– I mean his therapist has suggested voluntary work, straight away, as soon as he goes– has gone to see his therapist, 'oh have you thought about doing voluntary work?' He's like 'what is the rush with pushing people all the time?' They'll do it in their time when they're ready. You know, I mean, you gotta be ready.

PHD STUDENT: Has anyone else had similar experiences in terms of rejection? How that might've impacted them (1) going on to look for work or employment? (4)

02010: Yea, I think it can be quite demoralising after you've– especially um if it's a job that they've got quite excited about. The next job that they apply for, they'll lose the excitement and the enthusiasm because they don't want to be disappointed again, but by losing that, they're less likely to ever get the job, you know?

PHD STUDENT: Yea! Yea, 'sure.'

02011: It's all about sort of the need to develop confidence rather than destroy it, isn't it?

02010: Yea.

02011: So that was the experience with my daughter with the incomprehensible questions at the interview, it was just; you know it really destroyed her confidence.

PHD STUDENT: So, I mean like rejection does happen at some point in people's lives, so I wonder what is it about individuals with personality disorder that really impacts them and then furthermore, what could help them get over that if– yea, that's my question.

02011: One thing that– when you apply for a job, you can declare a disability, can't you? I'm just wondering whether when applying for jobs, if you declare the disability then you can actually ask what support you need at interview, can't you?

PHD STUDENT: I'm not sure actually, I don't know the ins and outs. I think it depends on the employer.

02011: You can, you can. Say for example, if you declare disability and they can say– so for example with the presentation, you can say I find presentations really difficult, you know I need a bit of support with that. But then [again you think=]

M: ['Social support'].

02011: Yea.

M: 'Social support for interviews, sometimes they ask you.'

PHD STUDENT: But not all employers, but sometimes they do.

02011: But if you consider that having a diagnosis of BPD is a disability, you can go under the protection of the Equality Act. (2) But it's a () isn't it? To right at the upfront let everybody know 'I've got BPD.' [()]
PHD STUDENT: [But is that something] that’s been common? You find that your loved ones are experiencing? Whether to disclose it or not?
02010: Yea, I mean, absolutely. And you know, you get to that question ‘do you have a disability?’ You know, do I tick the yes or no box?
02009: But isn’t a disability more physical, isn’t it?
02011: No.
02010: No, it’s an impairment in any way, shape or form.
PHD STUDENT: It’s your interpretation as the individual.
02009: But from my experience, mental health and physical disability are two separate things. ‘That’s what I thought.’
02011: No, mental health problems are a disability like depression can be a disability or BPD is definitely a disability.
PHD STUDENT: So going back to that question, um, yea have any of your loved ones experienced the same thing like being able to disclose or not?
02010: Oh yea, definitely.
PHD STUDENT: Yea?
02010: Because they don’t– uh with (states name), when she was applying for jobs and then got a conditional interview at one place and they asked, she was just like ‘if I write this down are they gonna think I’m some mental case, treat me different or?’
02011: =Or, I mean the other thing is, like um– ok as an employer, you see somebody tick ‘oh yes I’ve got a disability’ so yes I have to give them an interview, but that doesn’t mean to say that you give them the job, does it? You just have to give them the interview, you can find some other reason not to give them the job. I mean, you’re not gonna say ‘I didn’t give you the job because you’re bonkers’ but=
PHD STUDENT: =So has that stopped your loved ones from apply’ing?
02011: No, it stopped her from ticking the box. So, you know, by ticking the box she might have gotten the support with the interview process and presentation, but then you’re declaring that you’ve got something wrong with you and then the employer is thinking well, you know, ‘do I really want this person?’
02009: But people might think, seeing the form, they might think if it’s a disability, they might think it’s physical, possibly.(2)
PHD STUDENT: Yea, they could do, yea.
02009: To me, they’re supposed to be separate. I mean I know that’s how they deal with things from my experience. Maybe this is something new they’re doing but it should be separate. Physical is different from mental and if you put it together, that’s– people with mental illness can be left and seen as– if you look at someone with a mental illness, you’re not going to think they’ve got a disability, they look normal.
02011: It’s just because it’s invisible, it’s not visible.
02009: So, and a physical thing, they’re two different things. I don’t think they should be together.
02011: But it’s still disability.
02010: Well I was just thinking, sort of going back to your original question of what would help at that stage um is a sort of– especially from a therapy point of view, is the sort of mental training that ‘if you fail at an interview, it’s not the end of the world, it’s not going to have negative repercussions. And that needs to get drilled into them before they get the confidence. Because if they keep thinking to themselves ‘if I fail at an interview, I’m an automatic failure,’ then they’re not gonna get anywhere. And it’s– I mean that was the sort of point that I had to keep reiterating in a hundred different ways to get (states name) to go and actually apply for another job. And funnily enough the very next one she applied for, she got, so=
PHD STUDENT: '='That’s great.’
02009: I think what they could do here is actually maybe do some workshops for people who have maybe had their therapy. ‘Cause I know that (states name) did a work– not support group, I don’t know what it was called. It was um skills something, mindfulness skills? You’ve not heard of it?
PHD STUDENT: “Not sure, keep going.”
02009: Yea, you run it at [ ] That’s what (states name) did first anyway. It’s a group they do. I’m a bit worried that nobody’s heard of it.
PHD STUDENT: It’s probably [just the DBT groups].
02011: [0]
02009: [0]
PHD STUDENT: [It's probably] just the general group for DBT that they run at

They have individual=

02009: =Yea, I'm not sure what it is either, I don't know.

PHD STUDENT: What about um the stage of employment where, let's say– um, sorry, I'm not sure, so your daughter's working at the mom↑ent?

02011: No, she's got a conditional offer of employment so she's just waiting for her final checks to come through.

PHD STUDENT: Ok, and (states name), (states name) is=

02010: =She's employed.

PHD STUDENT: She's ↑employed at the moment. Is (states name) working at the moment?

02009: No. He's been seeing a therapist (1) for 8 months.

PHD STUDENT: Ok, I just wondered because I wanna ask you guys a bit about the stage of um– if one with PD is in employment, um some of the difficulties they face in keeping that job and staying in work, and managing their emotions. Um, in your experience– I know that she's not working at the moment, but, I suppose you can try and imagine=

02011: =No, she has worked in the past.

PHD STUDENT: Oh, she worked in the past? Ok, yea, what are your experiences of that aspect?

02011: It wasn't really an issue to be perfectly honest because with my daughter, all the problems are in relationships. You know like close personal relationships. That's where her difficulties really surface. Um but () that difficulties in that relationship that impact on her work, if you see what I mean?

PHD STUDENT: Y↑ea, yea, it does, do you mind expanding a bit more?

02011: Well just I mean if she's sort of having an explosive personal relationship, it obviously has a knock on effect at work.

PHD STUDENT: Oh right, sorry, I misunderstood. You meant personal outside of work?

02011: Yea, not () at work, yea.

PHD STUDENT: Yea, ok, that makes sense. What sort of thing would she do at work then? You said it would impact her, so would it impact her w↑ork?

02011: Well it's the way that she's feeling about things, you know, feeling sort of emotional and under pressure and stressed.

PHD STUDENT: But not necessarily to do with work, but it does all feed in?

02011: Yea.

PHD STUDENT: Um, yea, that makes sense. Did you want to say something (states name)?

02010: Um, I suppose, (states name) is at work at the moment, and she's got a fairly stable job in the way that she hasn't really had any disciplinaries or whatever for being late but she's got very close to it at times. Um and the hardest bit for her is going out the door in the morning. That's where she has to make the decision, like the very conscious decision 'I'm just gonna go for it even though I don't feel like life today. Um=

PHD STUDENT: =What, do you mind me asking, what kind of thoughts might be popping up?

02010: So the phrase that she always goes to is 'I'm just tired.' But when she says that, she doesn't mean tired 'cause I've just woken up. It's like I'm sick of trying so hard just to perpetuate my existence. You know, emotionally drained from trying to keep myself together when I just want to break down and cry. Um, I have to think about how people are responding to me and what I'm doing and what I'm saying all the time so that I don't offend someone. Those kind of things that you know I find fairly easy to do but I suppose with her condition, it's much harder for her to regulate those.

PHD STUDENT: "Absolutely."

02010: So that's her biggest issue when it comes to keeping a job.

PHD STUDENT: And she's still at work, so I wonder um– (2) there must be some ways that she's helping her manage and cope with the work place, do you know what it [might b↑e]?

02010: =Well the thing] is, she always says to me once she's off the train when she's actually at work, she can kind of switch off, go into autopilot and it's fine. You know– you know how you do something kind of absent mindedly, not really thinking about what you're doing= PHD STUDENT: =Sure.

02010: that's how she describes it. So, I don't think there's any um issues with her actually working, it's just the motivation to go into work.

PHD STUDENT: Motivation, yea.

02011: Does she enjoy what she does?
For the most part, yea. She works at Hobby Craft and she’s quite a creative person. So she likes the environment and being able to walk around think of ideas, ‘what can I do with this part,’ so she enjoys that aspect of it. Um, from a social aspect, not quite so much. She hates kids, absolutely despises kids. And when you have a group of kids come in and they start throwing stuff around, she will almost lose it.

PHD STUDENT: But something stops her from losing it, so what helps her?

PHD: (If she slaps a kid ((laughs))).

PHD STUDENT: She’s worried she might act on her frustrations.

PHD: Yea, yea. Um, yea. Or just, you know start going, I’ve been at work consistently for this long, I don’t feel I’m () and just not go in, things like that. And she has done that before and every time she’s called up and sort of faked it or whatever, but it’s starting to get to the point where she can’t do that anymore. But what stops her from acting on her emotions when she’s at work is this idea that if she loses this job, that’s it for her (1) which isn’t all that healthy in itself.

PHD STUDENT: When you say things go ‘too wrong,’ do you think you can expand a bit more on that?

PHD: So, if she lost the job for example, which is why=

PHD STUDENT: =How would she lose the job?

PHD: (1) If she slaps a kid ((laughs)).

PHD STUDENT: Does she um, it sounds like she talks to you a lot in terms of what goes on in her mind. Do you think having another person to speak to can support that person in the workplace? Or things that are going on? ‘Cause it just sounds like she shares a lot with you in terms of what’s going on in her mind, getting up in the morning, not wanting to go to work, it sounds like she actually talks to you.

PHD: Yea.

PHD STUDENT: So, do you think having another person, so a loved one, or a friend or just another person you can talk to about all this stuff, what’s going through your mind and how you’re feeling, can be helpful?

PHD: I think that depends on the individual. I don’t think that’s something that’s inherently specific to the traits of borderline personality disorder. For her, yes, but for other similar people, not so much. Like me, personally, I mean I don’t have borderline personality disorder but when something goes wrong for me, I don’t like expressing that or telling anyone because then it’s admitting to someone else that I’ve fucked up, for lack of a better word.

PHD STUDENT: “Yea, sure, that makes sense.” You just made me think about (states name) because you mentioned that he gets quite anxious and scared and then he avoids, doesn’t he?

PHD: “Yes.”

PHD STUDENT: So, I mean, just listening to what (states name) was saying about his partner, does (states name) experience something similar or does he tend to not speak about his um emotions when it comes to the work or volunteering?

PHD: He doesn’t that much, no. (4)

PHD STUDENT: Do you think that stops him from finding work?

PHD: (3) Yea, he doesn’t open up. Yea, he kinda opens up about some things but not others. I don’t know, maybe that’s a trait in men, they don’t really– they find it harder to talk about their emotions whereas we can just sit together, watch a movie, eat popcorn and just chat about everything. Men think, ‘well suck it up’!

PHD STUDENT: I don’t think it’s specifically emotions, I think it’s failure or weakness. Emotion is fine to discuss, but when you’re talking about making yourself vulnerable in more than just a passive way, (1) you=

PHD: =Sorry, I don’t understand most of what you said ((laughs)).

PHD STUDENT: That’s ok.

PHD: It’s not ‘cause of you, it’s just=

PHD STUDENT: =It’s a lot of information.

PHD: I just find it hard when people use big words. I do it myself, but yea ((laughs)).

PHD STUDENT: I’m just wondering, with your kind of situation with (states name), does he tell you if he’s feeling angry about something or upset about something, does he tell you that’s how he feels?
02009: No, no.
02010: He doesn’t?
02009: He keeps it inside.

PHD STUDENT: Like you say, he [tends to avoid, “not say anything”].
02009: [He keeps it inside, yea]

PHD STUDENT: So I just wonder how that might have an impact with him [in terms of the workplace].
02009: [Which doesn’t help], ‘cause I know I used to bottle things up myself, and it always comes back to bite you in the end. You keep it in, you keep it in and you think— you do it out of habit, even if I do it now, you keep it in and that’s how you get depressed and ill. So you need to express it, not repress it. Express ((laughs))).

PHD STUDENT: Do you think that’s possible in the workplace for people with PD?
02009: What’s that?

PHD STUDENT: So if you’re upset and frustrated about something, like something’s not going right=
02009: =Oh, no!

PHD STUDENT: Do you think it’s possible that, you know=  
02009: =It’s hard for anybody in the workplace, but it’s 10 times harder if you have a mental illness. I mean I had to— I’m not working at the moment, but when I did work, I was signed off with depression and stress and I wanted to leave the job but I couldn’t get another job because I was so big and down that couldn’t walk into an interview and be confident. So I had to leave the job. And people were so kind of like ‘oh, you shouldn’t leave the job, you should stay in it and look for another one.’ But they don’t know what they’re talking about ‘cause at the end of the day, if you’re unwell or you’re stressed, you have to leave the job, you know. And um, yea, so, (1) a lot of people, they say most people that call in sick, probably a lot of it is to do with stress; I wouldn’t be surprised.

PHD STUDENT: What if um leaving the job wasn’t an option and you’re loved one was feeling particularly stressed at work? But at that moment in time, it wasn’t an option to leave that job, what do you think would be helpful for them to deal with their stress?

02010: I think if uh, if an employer is aware of the person’s condition, um especially the— I mean with (states name), what her managers do when they notice her getting particularly stressed or frustrated or whatever, um because they know about her condition and they’re exceptionally cool managers, um but they let her just go outside for 10 minutes, go and have a cigarette or whatever she wants to do. And as long as she’s back after 10 minutes, you know— and having that (3) option to go and escape for 10 minutes=

PHD STUDENT: =That’s fantastic!
02010: is enough to completely make her feel like she can handle the rest of the day.

PHD STUDENT: And how did she go about setting it up to have that understanding with them?

02010: Um, she had a breakdown in the store. Um, and one of the managers sort of was there when it happened and they were like ‘what’s the deal,’ and she just sort of opened up and said everything that was going on. So, him being a very soft kind of person just said ‘look, next time you think that this is getting close to this, obviously don’t abuse this but if you genuinely feel like you can’t handle it just let me know and you can go out back for 10 minutes, whatever and come back when you’re ready.’ And that works very well but I don’t think that would be something that most employers would be happy to do. I just think she got quite lucky.

49:15

PHD STUDENT: That was very fortunate, what were you going to say, (states name)?
02011: Yea, no, I just agree but I just think you know that (states name) was lucky to have that manager that was very supportive but lots wouldn’t do.

02010: Yea.

02009: Is it still, I’m not sure how clear it is, I know there’s still a bit of confusion, when you apply for a job, whether you tell them you have a mental illness or you don’t and all that?

PHD STUDENT: I think it’s up to the individual. It’s up to the individual.

02009: But that’s a problem area I think (states name) would struggle with, do I tell them? I don’t personally know. Like if he were to ask me, I wouldn’t know. What are the procedures and things like that, I think that would help for people to actually know what you can say, what are
the repercussions um and you know, if you do tell them, and they're not as helpful as um with (states name)– I mean they sound great! That's like, you couldn't imagine managers being that– I mean I couldn't imagine that to be honest. Managers being like that, I mean they're like very very rare, very rare.

02010: It's funny 'cause my managers are exactly the same as hers.

02009: Really!

02010: Yea, mine are like so cool with me as well. So I think we both got very lucky. From my own personal circumstances, it seems that as long as you're genuine and sincere with the manager, they're usually more lenient.

PHD STUDENT: I can understand that, but let's say even if you are genuinely concerned, what would that individual with mental health difficulties beforehand be feeling? You know it's about approaching that subject. Would they be thinking 'yep, even though I'm being genuine, they will understand me' or would they be thinking, 'they're not gonna get me'?

02010: Well that's exactly it, isn't it? I think um– isn't this the whole part of the study to try and kind of set up a system where employers and sufferers can kind of work together to kind of find some kind of way to make it easier for both of them?

PHD STUDENT: So there are three elements, we're definitely developing and intervention to help people prepare and get ready. So that's what we're talking about. I've been asking you about your thoughts and their feelings. The second thing is the assessment tool and then the third thing is a positive manual. So it's a way to educate– it's a manual in a sense that we give to employers to better understand people and experience of– their experience of people with personality disorders. So it's not a manual to be used against them but how to better perhaps do reasonable adjustments at work. So like you mentioned the break for 10 minutes for your partner, I think that would be counted as like a reasonable adjustment, and it's a booklet for them to refer to to understand, so yea.

02010: Yea.

02009: I think sometimes when people are vulnerable, you can– in my, in the jobs I’ve had, all my managers have been total wankers, sorry. But um, yea, so, if I– I think, a lot of people, if you're vulnerable– I mean I suffer from anxiety and depression. If you're vulnerable, people take advantage of you. It's like they smell it and a lot of people– I had a manager, he was a right– he was a Jekel and Hyde. He'd be really happy one minute then really horrible the next. And I was always genuine when I worked on that job, but there were people that used to mess about and not turn up, and they would get away with it. But it was the genuine people that got treated like crap. So, and I think employers– there's a lot of horrible employers– I mean with his situation that is very very rare, extremely rare and I'm sure most people have not experienced that and for both of them to have that, I mean that's pretty good. But, ((laughs)) but yea it's like if you're vulnerable and you have a mental illness, people can take advantage. There's a horrible– there's a lot of sick people out there, nasty, vicious people and when they're managers, they're control freaks, you know power goes to their head and if you're vulnerable, um they take advantage of you; so that needs to be addressed. Because when you have a mental illness, you're not really () or what's the word ((laughs)).

PHD STUDENT: (States name), were going to say something? You look like you're deep in thought.

02011: No, no. I was just listening. But I think disclosing you're mental health status is a very personal thing and I think before you do it, you've got to feel like you can trust the person that you disclose it to and you can't know that until you're actually in work. Um, but I got a friend whose daughter's also got BPD and got a job, and didn't actually disclose it but then she had to keep going out and was on the phone to her mum all the time, and eventually they said 'why are you always on the phone,' and she then explained. And they sort of said 'fine, if ever you need to go talk to your mum, just talk to your mum, no big deal.' But it's a bit potluck isn't it?

PHD STUDENT: It sounds like it, yea.

02009: I think what this could do as well is eliminate the fear of employers and um yea get rid of the fear by actually making people more knowledgeable.

PHD STUDENT: So what do you mean, fear the employers=

02009: =Well fear of having an interview, fear of disclosing it and how will they react once they know; will they hold it against you?

PHD STUDENT: So helping them to manage one's fear when it comes to disclosing if they choose to?

02009: Well that's the issue, that's why people with mental health will not want to go for a job or anything like that, because they feel like they're going to be susceptible to bad treatment.
PHD STUDENT: So, um I just want to wrap it up, we're coming up to about an hour now. So, um if I were to pose you guys the question, of everything we discussed today, what would you say the main barriers were or challenges for your loved ones or people with personality disorders in the workplace?

PHD STUDENT: Stigma.

PHD STUDENT: Yea.

PHD STUDENT: Lack of understanding and stigma. Um, you have stuff like bipolar; it's quite fashionable now to have bipolar, isn't it? You know, lots of celebs have got it, you know so it's quite you know. But saying you have BPD is a lot different to saying you have bipolar. It's a massive stigma.

PHD STUDENT: Yea.

PHD STUDENT: And I suppose that comes from the fact that it was perceived to be untreatable for so long. (5)

PHD STUDENT: I'd say exactly the same.

PHD STUDENT: And the problem is with employers, and with um, lack of information out there. More needs to be done. And the stigma, that really needs to be addressed. I think more knowledge, more understanding, more out in the media. More, yea, more involvement in employers, more training for employers. Oh yea, a lot of training for employers. Um and basically, what this group is is a good start. You know you said about assessment tools, what was that?

PHD STUDENT: Oh, that's the questionnaire that we're going to be developing. I can go back to that in a moment. Did you want to add something?

PHD STUDENT: Yea! And the emotional response to the situation instead of looking at it as an opportunity to learn something or instead of saying 'ok this didn't go so well, let's move on' instead of going straight for the 'I'm a fuck up, I can't do this, my life is going to absolute rubbish.' That's the kind of main issue that I can identify. (4) So it's re-training someone to think instead of 'this went wrong, therefore I'm useless' to 'this went wrong, let's move on and do the next thing'.

PHD STUDENT: Yea, so working on their thoughts that come up, that could really challenge (4).

PHD STUDENT: Yea.

PHD STUDENT: Cool. Cool. Lots and lots and lots of opinions guys. Is there anything else that you guys would like to add before we wrap up? Anything we haven't covered that you feel quite important? (3)

PHD STUDENT: “Yea. That makes a lot of sense.”
02009: I think also the stress. I think people with BPD will have—find it more difficult to deal with stress, so they need more support in that. It may be, like in (states name) situation, a bit more lenient in that sense for those people who maybe need (2) time or whatever.

PHD STUDENT: So different needs. We've talked about stigma; we've talked about how to deal better with stress and one's inner kind of um critical appraisal and how that can be shifted.

02009: And advice! 'Cause there's no advice out there really, or anything, nothing.

PHD STUDENT: Ok, alright, well thanks. Thanks for that guys, I hope that you found that interesting.

END 1:00:09
Appendix 25 Focus Group Occupation Professionals

Transcription 1 (Chapter 3)

PHD STUDENT: So I'm going to pop these on now. AC can I just give you that to put?
CO-FAC: Yep, where would you like it?
PHD STUDENT: Just right down the middle away from me.
CO-FAC: There, oh hang on
PHD STUDENT: Yea that's perfect. Stays clear of my booming voice
CO-FAC: Is that right here?
PHD STUDENT: Just
CO-FAC: Yes it keeps working like it

[Opening pre-amble different on the two recordings, as recordings started at different points]

PHD STUDENT: Just write down the middle away from me. Can you hear my, yes that's perfect thank-you. My booming voice (laughs). Ok, so erm I thought before we begin we'll do a little ice-breaker. So I'd just like us to say our names and our role and then I'd like you'd to say two truths and a lie about yourself and then essentially what you need to do is just guess which one of the three statements is a lie. Does that make sense? So I'll go first and then we'll go to my right.

04002: Your right?
PHD STUDENT: (laughter) So 04003 my name's LS. I'm a Senior Research Assistant and a Phd student at EMPOWER and erm I'm basically run focus groups like this and help collect the research and the data and help analyse it. So two truths and a lie. (Pause, laughs). I have a brother and a sister. Erm I speak Mandarin and I have a pet cat at home. Which one is the lie? (Pause, laughs). Any takers?

04003: Brother and sister
PHD STUDENT: Brother and sister
04005: I'd say cat because she said pet cat and I'd think you would just say cat if you really had one!
PHD STUDENT: (laughs)
04004: That sounds good to me, I'd go for that too!
PHD STUDENT: Your right 04005, I don't have a cat (laughter). I think I gave it away, yea, that's very observant.

04004: Insightful!!
PHD STUDENT: Yea. Thanks. (Laughter) Go on 04002.
04002: So erm 04002 [job role and place] Er I have three pet children (laughter), I'm a grandad and I have a dog called Albert.
04001: I know, I’m saying nothing
04005: I think it's the first one. The number of children.
CO-FAC: Yeah
04002: Um hm
04005: Is it?
PHD STUDENT: Woah
04002: I have two children
04005: Two children
04004: Yea, oh well
CO-FAC: Good dog name
PHD STUDENT: Yea (laughs)
04002: Fantastic dog name (laughter)
04005: I love that!
CO-FAC: Ok, so I am, my name's AC, I am the programme manager for the EMPOWER piece of research, which means that I coordinate all of it so all of, we have lots of different work streams that run under the heading of the research erm so I oversee the coordination of each of them. Make sure everything runs to etcetera. Erm so yeah and the reason why I'm here today is because I was the person who initially made contact erm with [employer] and LS behalf
PHD STUDENT: Um hm
CO-FAC: Erm so
PHD STUDENT: Yeah
CO-FAC: So that's why I'm here. Erm so my, er my statements. So I'm an Arsenal seasonal
ticket holder, erm as a teenager I was county Archery champion (laughter) and I have an
orange cat that weighs a stone.
PHD STUDENT: I know the answer to this, though
04005: You've had too long to think about them (laughter)
CO-FAC: It doesn’t feel very prescriptive though
04003: Does she look like [name] though in the Arsenal team? (laughter)
04001: Erm I don't know all of those were pretty convincing weren’t they?
04005: Um they were
04003: What was the second one again AC?
CO-FAC: When I was a teenager I was county archery champion
04005: Yea, I’d say that
04003: I don’t think you’d allow your cat to get that heavy (laughter). That’s quite sophisticated,
county archery champion isn’t it. It’s quite specific, archery yea.
PHD STUDENT: Any takers?
04003: I’m not sure
04005: I’ll go for Arsenal season ticket holder bit
CO-FAC: I am an Arsenal season ticket holder
04005: Ah you are, ok, ooh
04003: And I’ll go for the cat
CO-FAC: And I do have an orange cat that weighs a stone (laughter)
04005: Oh really
CO-FAC: It's actually not because he's fat, he's just huge (laughter)
04003: I wouldn’t want that on my lap
04005: That’s like a Tiger
CO-FAC: I’m actually not very good at archery (laughter)
04003: Have you ever done archery?
PHD STUDENT: That's fabulous! Thank-you AC, 04003
04003: I’m 04003 and I’m the [role and company] and I’m the only [role] in [company] so in fact I
was an expedition [role] in the [place], I rode horses to quite a high level and I have (pause) two
dogs [said quickly]
04005: Ooh
04002: So I happen to know the first one is true
04005: I suspected that
CO-FAC: That's amazing
04005: Dogs
04001: She’s definitely got at least one dog
04005: Yea, I know, yea
04001: Maybe you’ve got one dog
04005: Yea at least one, yea she’s got a lab
04002: Well, you said, I can’t remember, I’m trying to rewind the conversation we had cos we
talked about dogs and puppies and everything
PHD STUDENT: What's the second one again sorry?
04001: I've forgotten now
04005: Expedition up the [place]
04003: and ride horses at high level
04002: No
CO-FAC: Yea
04001: Exhibiting at a high level, at high levels
PHD STUDENT: (laughs)
CO-FAC: I think it’s the number of dogs
04001: Yea
CO-FAC: I think the dogs one
04003: Yea I was a bit sneaky really because I was the expedition [role] but not in the [place]
All: Ahh (laughter)
04003: It was actually in [place]
CO-FAC: That’s very good
04005: That's splitting hairs
04001: Sneaky
04002: That is splitting hairs, yea
PHD STUDENT: That is splitting hairs (laughs)
04003: No
PHD STUDENT: That was testing you 04002 (laughter). Thank-you. 04005
04005: Right, I'm 04005 [role]. Two lies and a truth. I had a dog, a Scottish terrier called [name].
I was born in Wales and I have one brother
04002: Well I know you have at least one brother
04001: Yea
04002: Because we've spoken about him before
04001: It's very specific about the dog as well innit
04002: Yea, would you be able to make that up [indistinct] (laughter)
CO-FA: That's a great dog name
04003: Yea it's quite a lot when you have to shout for it innit
PHD STUDENT: Oh I'll say. So any guessing? Any takers?
CO-FA: Welsh born
04005: I'm not Welsh born
PHD STUDENT: There we go
04005: My [relative] is but I'm not
PHD STUDENT: I say
04005: Which is annoying
PHD STUDENT: Well done AC. Thank-you
04004: Erm, (pause). Sorry, trying to think of my [indistinct] already (laughter)
PHD STUDENT: Absolutely
04004: I'm getting ahead of myself, erm, I'm 04004 erm and I [role]. Erm I have erm three sisters. I have erm, I have, I have erm fish, tropical fish, they're very boring and I have erm I have erm oh I am licenced, a licenced chaperone for children for shows.
04003: Oh, that's true (laughter). You told me that back on Tuesday (laughs). You've got at least one sister
CO-FA: I think the fish, I don't think they're tropical, because you said they were tropical fish
04004: I did
04005: Yea, yea
04004: I have got those, so that's true actually (Oh). They are boring, that was my [relative's] instead of a dog (laughs). It was never the same
04005: I managed to kill all ours off (laughter)
04002: Harder to take for walks, aren't they?
04004: Thank God, yea
PHD STUDENT: So what was the
04004: So it's the number of sisters. I've got two sisters
PHD STUDENT: Oh, ok
04003: I knew you'd got one
PHD STUDENT: Thank-you. Last but least
04001: And I'm [name] I'm, I work as [role] erm and we attempt to try and manage mental health in the workplace and people at risk of harm to themselves or others in the workplace. Err, I was born in Cornwall. I have two dogs and I played Netball at Wembley
04001: Ooh that sounds good
04004: I think you did that (laughter). I'm not sure why you now live in [place] if you were born in Cornwall
PHD STUDENT: Oh
04004: Who would want to leave Cornwall! (Laughter)
04001: It's still [place] though, it's still nice isn't it
04004: Er
PHD STUDENT: Um. Any takers?
04005: Born in Cornwall
CO-FA: Yea, I'm going born in Cornwall as well
04001: Correct, very good
PHD STUDENT: Ah
04004: So where were you born?
04001: [Place] (laughter)
04003: That's nearby
It is, yeah
CO-FAC: You're good.
PHD STUDENT: That's brilliant. Thank-you so much guys. Erm, ok so today is er our focus group is going to take about an hour to an hour and a half depending on how much want to talk about really. Erm, I have some notes in front of me so if I'm looking down there's not, I'm not being rude and not listening to you, I am, I'm just making sure we're on track. AC's going to be taking some notes on her laptop so she's not checking emails or anything like that she is completely here (laughter) erm so first and foremost, has anyone ever taken part in a focus group before, perhaps facilitated one themselves?
04003: I took part in one down in [place] University where they were doing a study similar really actually to employing people with bipolar disorder
PHD STUDENT: Um
04003: And so I was part of the clinical, clinical team and then we had, they had a group of managers and then a group of people with bipolar
PHD STUDENT: Um hm
04003: And the three groups, the three groups obviously ran separately. But we went down, we did about three meetings I reckon like this
PHD STUDENT: Ok and what do they, what, what did you do, what did they make you, make you do
04003: So really talk about, our, so a lot of it was brainstorming problems that we saw for people with bipolar but also what we thought managers would see were a problem and what we thought individuals would see as a problem and then and then sort of cross referencing and that really
PHD STUDENT: Mm Mm Sounds really similar to what we're going to be doing today. But not with bipolar but with personality disorder. So it's essentially that. I'll be guiding you er through the group discussion with some questions. And it's just the coming together of sharing our opinions and experiences erm so that will better inform our topic at hand which is personality disorder and employment. So there's no right or wrong answer cos it's really actually more about what, you know, your experiences themselves. So erm I know you guys have read the information sheets but our aim in a nutshell we have three main aims for EMPOWER which is the name for the research project and the main aim is, one of them is, developing the employment er the employer positive manual so I think with anything with research you know we have ideas but we, you know, we can quite easily just make it up and, and there you go you have it but it's not really going to be relevant without speaking to people on the ground first. That's why we're running not only focus groups with employers but also people, individuals with personality disorder, their friends and family as well and erm yea, and erm, yes we've run this is actually the, the eighth one that we've run so far. So that's one aim. Second aim is we want to develop a intervention er to help people with what we call PD to go back into the workplace so whether it's they haven't been working for a while or whether they've been off work, as in maybe signed off sick and they're returning to work. Erm and so er hopefully we're going to be going live, I think we are live, yes
CO-FAC: We are live
PHD STUDENT: We are live as from yesterday and
CO-FAC: We are live
PHD STUDENT: Recruiting for the actual testing of this intervention. So it's exciting and if it's successful it will go on to erm a much larger study er but this information from the focus groups will help better inform the therapy itself. Erm, which will be great. And then
04001: Can I just get some water?
04005: Of course you can
04001: Oh thank-you
PHD STUDENT: And then the third aim is to develop an assessment tool to help us identify what the particular challenges or barriers may be for those individuals. Erm and actually that's part of my PHD. That's part of my thesis. So the idea is you know if we can identify what the difficulties are it will better inform ourselves, whoever uses the tool, the individual what help is out there. What supports are out there so we can recommend them to go and take it on and then help them along their employment pathway. So does anyone have any questions from the information sheets or anything? (Pause) Ok, great. So we're going to talk about erm some topics today erm, which we refer to different stages of employment. So I understand it's quite fluid it might not be as, as early as one after another but it's going to follow the trend of an
individual with PD getting a job, moving on, they've got a job, keeping the job, maybe perhaps leave of absence and then, them returning
CO-FAC: You can read that information on top
PHD STUDENT: to work.
04004: If you wouldn’t mind, thank-you
PHD STUDENT: Erm but don’t worry about it too much because I’ll just guide you through the questions anyway. So ok. So I have a question for you guys. Erm if you were to describe to a colleague of yours what er personality disorder is, what would you guys say? How would you picture that?
(Pause)
04004: It’s quite funny you should ask because when I was reading the briefing erm it didn’t, it read as being broader than, a broader definition than I was thinking it was
PHD STUDENT: Erm
04004: Actually in terms of your research so, so I was thinking of all the erm the bipolar’s and those sorts of categories. But actually when, when I was reading your briefing it seemed to me much more basic er
PHD STUDENT: Ok, was there any part of kind of stood out more, being quite basic or broader?
04004: Erm, I'm just having a quick look. (Pause). So it was your, your definition where you said erm that PD is characterised by high and strong emotional responses and difficult interpersonal styles. Erm, impulsivity, erm so that seemed quite a broad definition really and actually I was thinking actually that’s, that’s a lot more erm sort of different, people of different
PHD STUDENT: Yes
04001: Personalities
04005: Yea
04001: Personalities than I was actually thinking this was about, this,
PHD STUDENT: Yes
04001: These focus groups, so
PHD STUDENT: If’s, it’s true I mean, sorry do you want to say something 04003?
04003: You know, and I think, I think, my view is, you know, you’re looking at people with sort of, that people just see as difficult, volatile, and difficult to get on with
PHD STUDENT: Yes
04003: Difficult to manage or difficult managers, is that the sort of thing?
PHD STUDENT: Um hm, Um hm, Yea, yea
04005: Or people that colleagues deem are different. What does different mean?
04002: But I think they also display erm you might put it as personality that is, personal traits that perhaps we all display in different ways
PHD STUDENT: Um hm
04002: But are actually more magnified in that individual (sounds of agreement)
04005: Absolutely
PHD STUDENT: Exactly, yea, exactly yea, absolutely 04002 did you want to add something?
(Laughs).
04005: I was going to say yea, you know
PHD STUDENT: (Laughs) Yeah, I mean, essentially, everything you’ve said it, it hits the nail on the head. It’s, it’s broad in the sense that personality disorder there is there are ten of them so it’s across a spectrum and they all have particular traits. But actually what we’re looking at, um and I mean we probably see ourselves in a lot of these descriptions but what we’re looking at is that those traits but to the extreme.
04004: Yea
PHD STUDENT: To the point where it could be disruptive to your everyday living so not just with your friends and family but into the workplace. So erm I just wonder, so having said that high emotions and what and err, er feeling those intense emotions and behaving impulsively I wonder er if you guys can think how that might relate to the workplace?
04001: There’s almost like a code of contact, code of conduct in, in the workplace that we’re kind of adherent to. Erm, it’s almost unwritten to, in some degrees as well. Almost behaving oneself at work
PHD STUDENT: Um hm
04001: And, and er kind of to, to a degree controlling myself at work and regulating my emotions.
PHD STUDENT: Yes
04001: So not, you know, not having that explosive kind of anger or if someone upsets me kind of being able to manage that. Erm and then kind of deal with that effectively by talking to my line manager or colleague that’s the thing, whereas, if somebody’s struggles to do that
PHD STUDENT: Yea
04001: Then others, then it, it changes others’ perception, their attitude towards them as well and sometimes you may not know that person’s even got personality disorder
PHD STUDENT: Exactly. Exactly 04001. So if I take your examples. So that, let’s say that individual is erm has a very kind of perfectionist way of thinking. Erm, which isn’t necessarily a bad thing at all, in fact that can be very effective in the workplace, you know, you get, you want to get your work done. But let’s say that perfectionist or that person erm you know takes on a lot of work, so much so they feel overwhelmed. So they have those intense emotions and they experience anger and then what might happen is that, that might lead to a burn out. You know, or that anger, they could be, it could lead to conflict with other people in the workplace or their seniors and then what happens then an argument could lead to, I don’t know, it could lead to them being fired or they could walk out erm
04001: Impulsive behaviours
PHD STUDENT: Quite impulsive in that sense. Or there could be the other end of the spectrum of personality disorder where someone might be feeling very anxious. Erm from I don’t know er numerous reasons, it could be again, maybe there’s an appraisal coming up and again I think it’s quite, I think it’s really important to emphasise that feeling anxious for an appraisal is quite normal, erm but what we’re looking at is that anxiety to the extreme. What, what does it lead them to do? Does it lead them to miss the appraisal completely? Does it, does it lead them to go out drinking the night before and then turn up hungover I mean. So we’re looking, I want you guys to start thinking about erm, about, those scenarios and those individuals. Erm,
04001: Sorry, I think for me though, it’s the impact on the other people (general agreement)
04003: Exactly
04001: Around and I think that can get overlooked too often
PHD STUDENT: Um
04001: The focus is on the person
PHD STUDENT: Yea
04001: Who’s got the personality disorder. But the impact on others can be quite far reaching.
PHD STUDENT: That’s a very good point
04004: Yea, and sometimes because of the confidentiality aspect of somebody’s health
PHD STUDENT: Yea, yea
04001: Sometimes the line manager might know but they might not be able then to, to talk to others and that person might not want the line manager to talk to colleagues.
PHD STUDENT: Yea
04004: So it can be difficult then for those colleagues to know what’s happening with that person
PHD STUDENT: I’m just going to make a note because that’s really important- confidentiality
04004: Yea, so, so sometimes er confidentiality is great a thing but it can be also a barrier to, to kind of erm helping that person in the workplace cos colleagues can be very useful
PHD STUDENT: Um, yea
04001: With regards to interventions because the colleagues usually spend more time with the person than the line manager does
04003: And they’re likely to spot things earlier than our
04001: And they’re likely to spot things earlier, yea
PHD STUDENT: Ok. I’d definitely like to come back to issues around confidentiality 04001. So I’d like us to um think about these characters, these characteristics that we’ve just discussed and in terms of the first stage of that individual getting the jobs. That can be anything from, and like other people as well who are, who are getting jobs, you know, that could be from them applying to get the job online or you know in person and to er get, getting the interview. And being interviewed, being successful and that period, that stage between getting the job and starting work. And I wonder in your roles, in your experience if you’re involved at that stage of that individual, with these characteristics? It’s ok if not, I just want to find out
04004: I have been recently
PHD STUDENT: OK
04004: Because I’ve been doing apprentice recruitment
PHD STUDENT: Ok
04004: So erm, so we have done that erm and that’s an age group, tends to be an age group that erm are quite anxious when they come in for the interviews because it’s not just an interview, it’s an assessment centre so erm
PHD STUDENT: Ok, what’s the age group?
04004: So it would vary from probably about seventeen erm up to about thirty
PHD STUDENT: Ok
04004: So, so you’ve got the range of people who have done GCSE’s up to people who have done degrees and what have you and are still applying for an apprenticeship
PHD STUDENT: Um um. So you mention that they get, they, they experience a lot of anxiety around the assessment process
04004: Erm, yes er but I wouldn’t say that it must start before then because erm we’ve done a number erm a number of assessment centres in the last year and we’ve had a, a massive drop-out rate of people who say they’re coming and then they don’t actually turn up. So whether that’s, there’s an impact before they come about thinking of having to go through an assessment centre and they just decide actually you know what, it’s too much. Too much trouble to do that, you know
PHD STUDENT: What do you think might be helpful for, for those, I know that’s er an interpretation but
04004: Yea, erm well I think we do try to erm keep in contact, to encourage them to come it, it’s not actually onerous you know the apprentice assessment centre but erm so, you know, we sort of share that with them
PHD STUDENT: Um
04004: But we still do need them to come and, and, and go through with the assessment basically
04002: Do we call it an assessment centre to them?
04004: Erm, I don’t know actually, I’m, I’m not sure whether we do or not, it’s what’s written in the letters but they do know that they need to go through a number of exercises and interviews too
PHD STUDENT: Are you thinking about the name itself?
04002: I just wondered yea, if, if people then start to
04004: I mean they may call it a selection or whatever a selection exercise
04002: Yes
04003: But it’s obvious that it’s a testing period
04004: Yea, but you know you’ve got to go through a process of, of different tests
04001: I suppose it could be a barrier if somebody has,
PHD STUDENT: Um
04001: Has personality disorder in trying to get a job in the first place
PHD STUDENT: Um Um Um Um
04002: Because part, part of the selection centre will be not just how you perform as an individual but actually how you interact with others erm and I guess that may come, you, you may get some issues from
PHD STUDENT: So it, is it the fear of interacting with other people or do you think you could be whatever’s going through their mind, their thoughts that would stop them coming?
04003: (and numerous others) A lack of confidence, I would think
04005: Its interesting thought isn’t it. Because if they’re people who’ve come, they’ve gone from school, they’ve gone through further education, they’ve perhaps gone to University. The environment of selection, process whatever you call, they will have come across it in that life, so if they haven’t got used to it then or haven’t had the help then
04004: But maybe, maybe it’s because it’s erm, erm it’s, it’s a, you know, you’re with an employer aren’t you, so that’s the key difference, if you’re at a college it’s different to, to actually going into an organisation (general agreement)
04001: It’s different again
PHD STUDENT: Different in what way, if you don’t mind me asking?
04004: Erm, I don’t know whether it’s erm maybe it’s just that they’re not experienced in, in the world of work that, you know, or erm
04005: They’ll be joining the real world won’t they, it’s that key difference
04001: Yes
04004: And there is pressure to get the job as well
04002: And it might be their first one as well
04004: There’s the pressure because they want the job. They want a job and to get employment
PHD STUDENT: What do you think would be alternative though for these individuals who, who experience these difficulties?
04003: I think I’ve got erm mixed views, one of, sorry
04001: It’s preparation
04003: Yea, preparation
04001: Some preparation to er even to start er some volunteer days maybe erm to because even be, again back to that work ethic, that work, that code of conduct that we kind of all suddenly meet after University and you get away with some behaviours at university that you’d never get away with, you know, even you LS, you know, you’re kind of still researching and still in university and, and that kind of thing and then you’re in the workplace as well, you know and then there’s, there’s, I think if I, if I break it down, when I was at university and then I went to work, things I did in university and spoke and even way spoke to some of my lecturers would be very different to how I’d speak to my boss. I’d still have respect for the lecturers but it’d be very different to how I’d speak to my boss. I’d still have respect of the lecturers but it’s very different
PHD STUDENT: So it’s preparation, that’s the key
04001: Some preparation for, for meeting the workplace, or even if you’ve had a job and you’re returning to work. Erm so kind of what, what’s broken down for that individual, what areas that they’ve found difficult. Erm cos it’s going to be different for everybody but there, there can be something that could be put in place for erm for everyone possibly to start preparing for, for that. So it’s not such a shock. I think sometimes, and I think that’s what we, we see as well. The amount of people that start with us, and we’re not aware there’s a mental health issue erm, they even pass their probation and then sometimes these behaviours start to come out.
04005: Yea, exactly
04001: So it’s almost like they’ve sat on this time bomb all this time
PHD STUDENT: Yea
04001: And then six months or twelve months later and then we start getting performance reviews or they’re not er there, their attendance is quite erratic so things start to come in, or there’s work place pressures or there’s personal pressures
PHD STUDENT: OK
04001: Erm and then things start to seep out and we start to see maybe more magnified behaviours like you were talking about earlier
PHD STUDENT: So let’s fast forward then to the new starters. So these individuals, that we’ve described, erm they’ve now you know they’ve got the job and they’ve just started. So I wonder again in your roles erm whether you’re involved in new starters in terms of mental health and wellbeing?
Multiple respondents: No
04003: Not until they go sick you know
04002: Yea, if it becomes a problem
04004: Yea
PHD STUDENT: Ok, so it’s when it becomes a problem
04002: Then it appears on my radar potentially
PHD STUDENT: And when you say it becomes, when it becomes a problem what does, what does that look like in the workplace?
04002: So, so the example that could be erm their behaviour so as you were saying we have erm a code of conduct in terms of what’s appropriate and inappropriate behaviour, as any organisation would have
PHD STUDENT: Yea
04002: And sometimes I think some of the personality traits or the way they behave erm might manifest itself in, in a potential discipline issue perhaps or maybe even a performance issue or maybe from an attendance require from er an absence viewpoint. Erm and, and then, then that’s when it begins, when it becomes a potential problem erm if you’ve got a more astute line manager they might recognise some of the symptoms and seek some help or ask questions to see whether it’s a, a behave, whether, whether it’s just someone doing the wrong thing or whether that’s caused by a medical condition. In which case then that will take you down a slightly different route.
PHD STUDENT: Yea
04002: But if they don’t do that then you’re taken down the disciplinary route as an example then that’s when you get into more issues.
PHD STUDENT: Do you think that by having an assertive manager is something that would be helpful to these individuals?
I think
An astute manager, I think
Yea, I'm not sure it's
Somebody, somebody that recognises and we do try, we try and do resilience training for managers so that we can get them to spot early problems within their people. But it's that, it's getting that out, you know, that's the hardest thing I think
I just (sighs), to be honest, a lot of the emphasis in work is, is focused on maybe anxiety and depression

PHD STUDENT: Ok
And maybe not so much on personality disorder and, and it's (general agreement) prevalence in the workplace

PHD STUDENT: Why do you think that is?
Maybe a bit of, well, when we do our management health workshops for example erm we, more of the focus is on anxiety and depression erm suicide, people at risk. Er I think that's because it's more prevalent in the workplace

And there, there, well their sickness absence is written down as, as anxiety and depression (general agreement) and we don't know that there's ever actually a personality disorder. Because we know if their diagnosed with it but what we see is anxiety and depression. We see that as our leading cause of absence etcetera. So they're the things that we're trying to focus on but it’s, it's defining where somebody's actually maybe got something else that's, you know, coming out as an anxiety.

PhD STUDENT: And, and in your experience has anyone disclosed in the workplace that they have a personality disorder?

Multiple voices: (indicating yes)
Occasionally, yea, sometimes
Sometimes, yea
But quite a long way down the line I would definitely say that
We've never seen it at pre-employment state

PHD STUDENT: Ok
Never seen it there, it’s always further down the line, where, you know, people have been employed and they're then suddenly their struggling
And sometimes, I mean, if, for, for us in, in our team, erm we may be working with the line manager who’s got somebody at risk cos they're, they're not coping in the workplace. And the anxiety and depression might be, the depression might be masking something (general agreement: Yea, exactly). Also, like, so, we’re talking about keeping a job then erm for example I was working on a case the other day and there's a young lad who he's been employed, he’s had previous suicide attempts and he was on a call and he’s been behaving, his emotional regulation is, is, is challenged let’s say and he was on a call and the call didn’t go so well and he just stood up, shouted, took his headset off, couldn’t deal with it and the line manager was thinking why, you know, he, he was totally capable of dealing with this call and there are other behaviours. And I was looking at this, cos we were doing this, this was coming up, and I was thinking this potentially could be somebody in the workplace, I’m not, I couldn’t diagnose obviously

PHD STUDENT: Um

Erm, but is this someone potentially we have in the workplace that, you know, erm and if, if then we were concerned about such behaviours, what do we do about it if we’re then identifying somebody's who potentially might not just have anxiety and depression

PHD STUDENT: But show very similar characteristics
But show very similar characteristics and to, for, for employers and for us even to our, management mental health course to include things like personality disorder, you know, but even then, even if a line manager does spot some of these traits then what do they do? Refer back to a GP?

PHD STUDENT: Yea and then

You know, which is the obvious route but which is quite slow and convoluted (some agreement expressed)

PHD STUDENT: Erm I wonder er if you could I guess, what, what if could have been for that individual that had that outburst, what, what he might have found difficult or challenging at that moment in time in the workplace?

Yea
PHD STUDENT: Do you know maybe, you can guess what it is that he, you know, why, why he might have had that outburst?
04004: Er it was, for, I’m sorry I certainly don’t know everything about it but erm he’s, he’s had a period of absence recently erm he’s, there was some performance issues and then he could, he just seemed to struggle with the performance issues and being asked about them and trying to, you know, I suppose raise his game really. And he found that incredibly, incredibly distressing erm there are times when he, he, he’s on his headset, I think it was at the call centre and his emotions when he’s talking to customers was quite, quite different to the other colleagues, sort of thing
PHD STUDENT: Um
04004: Erm and so I suppose if he got, if he got a difficult, difficult customer
PHD STUDENT: Yea
04004: And he’s got his headset on and then somebody’s challenging him back or someone’s not happy with something erm he seems to be much more, highly sensitive than maybe the next person
PHD STUDENT: Yea
04004: You know, and, and kind of the, the [? blessing] for, for him to try and then to deal with that and then line manager to then deal with that
PHD STUDENT: To support him
04004: Then the business trying to deal with that as it’s a customer er then you’ve got all these things coming into play.
PHD STUDENT: (laughs)
04004: All these variables and er but with, you know, we’re trying to support him as much as possible
PHD STUDENT: So how did you deal with the, erm the line manager to help support this person?
04004: Erm, he was referred, he was referred to erm something called [name], which is a CBT orientated thing well he wasn’t referred, he was asked if he wanted to be referred. He was also referred back to his GP
PHD STUDENT: Um
04004: Erm
PHD STUDENT: This is sorry, this is the employee that the line manager was managing?
04004: Yes, yea erm he was referred to his GP which wasn’t really how it works. He was, he was at risk at that time so we, his, we got the [role] involved and er
PHD STUDENT: The AP?
04004: Sorry [programme name]
PHD STUDENT: Ok
04004: And then they contacted his GP with their concerns about him
PHD STUDENT: Oh, ok
04004: Cos he’s, he gave permission for that
PHD STUDENT: Ok
04004: Erm, yea I don’t
PHD STUDENT: I wonder if you wouldn’t mind explaining a bit more about, about the, the systems you have in place?
04005: Well yes, so we’ve got, we’ve got the occupational health service, so people can get referred to them to be seen, or spoken to by a clinician and that gives out a report back to 04004: I think it was that as well, we referred to occupational health as well
04005: Managers. Erm, we then have various support services around, around as well. So we have access to the [programme name] where people can have counselling, we have [programme name], this is then the managers 04001’s team that then can help to support the managers through problems with their people basically. And then we have [programme name] who offer a mental health support service. So they’ll offer cognitive behavioural therapy as well. So that’s more work focused than the [programme name] which tends to be a sort of, you know, anything whether it’s home or domestic or, and work but, you know, but the, the [programme name] is very much more a work focus, erm and then what else to we have?
04002: That’s probably about it
04001: [Programme name]
04005: Oh yea, [programme name]
04001: And then you can get the specialist people in
04004: Oh yes
04001: So then [programme name] are, we use them with access to work to help get, provide and advise on adjustments that we might need, but it’s often more practically but in, within the workplace to keep them at work
PHD STUDENT: That’s fantastic
04005: There’s a lot of support
04004: And we have health and wellbeing passports. So if, if somebody is diagnosed with a physical or mental health issue in the workplace
PHD STUDENT: Um
04004: Then the health and wellbeing passport they can, they can put down erm, they can work with that, the line manager can work with that individual to what are your triggers
PHD STUDENT: Yea
04004: What are your warning signals, how will we know if you becoming unwell, for, for example, erm how would others know you’re becoming unwell
PHD STUDENT: Yea
04004: Erm what’s your, what’s your strategy, who are your support networks, even your family, next of kin, emergency contact. Erm, who would we call in an emergency, what’s your GP, erm how do erm er yea
PHD STUDENT: And so is that is something, so I asked you guys when the new starter comes um when, at what point do, do you get involved and it was not until a problem arises, that you said 04002, so then, then all these things are
04004: Well all the information is there
04001: That’s the problem I think we find we have in [company] a bit. We’re such a big company and whatever we try to put out to tell people
PHD STUDENT: Ok
04001: About all the support services we’ve got and we’ve got a, a work fit programme that, that gives an awful lot of information on physical wellbeing and mental wellbeing. We’ve got massive mental health support. But I think people don’t, they don’t find the information a lot of the time, and it’s there
04003: But that’s where
04001: And, and that’s what we’re working on isn’t?
04003: Yea, that’s what we’re trying to make easier
04001: Because we have so much of it, in [company], we are unique I think in [company], I’ve never known another company have so much erm but I think it’s for accessing that so that the line managers know and the individual knows that, that they can then, there is support there for them, I mean
04002: I think they’ve also, in addition to that, we’ve got various training from [indistinct] through, that is specific around health and wellbeing, either management level or training and other, other things. We’ve also got a case management team, which 04005 is part of, which will provide support for line managers erm against our processes like our conduct and discipline performance, sick absence, erm and particularly around sick absence they will bring in then the other support that we’ve just talked about like the [role] [programme name] erm and I think also we’ve got so, s, s, so and a, a lot of that support is there for the individuals but also for, for the line manager as well.
PHD STUDENT: Um
04002: We’ve got fact sheets for people around some of the more common mental health issues as well so that there’s, there is, as I say, there’s a lot of information out there but it’s, if you’ve got an individual, you are a manager and you’ve got a busy workload you might be managing twenty odd people (agreement expressed) erm, or up to twenty people erm and then you’ve got an individual who’s behaving in a certain way. Perhaps might be, you’ve not experienced it before, you might then just instantly associate that to a discipline issue or performance issue and then what, what I’ve found is that it’s not until those people have been managed down that route that actually it’s some, at some point down that route then it becomes, sometimes it becomes known that actually it’s a medical issue that, that’s causing it not something else
PHD STUDENT: And that would therefore enable that, that employee to, to seek help and use resources that, that [company] can provide
04002: Yea and for the manager. I mean, one individual I knew erm he was very vocal about the conditions erm, you know what condition, the conditions he had and actually used to go around talk to different team meetings, erm we’ve also got networks as well in [company]. So
there is a disability network, there is a carers network and these are networks of people that perhaps are carers or have disabilities can join but also anyone else can join
PHD STUDENT: Yes
04002: Managers, and again that’s a really good source of support as well
PHD STUDENT: I wonder, so going back to, I think it’s fantastic, like I said that you have all of these resources but one issue is, is accessib, accessibility
04002: Yes
PHD STUDENT: So I wonder, besides from that if there are any other barriers for people coming forward and saying ‘hey I need help’ in the workplace?
04002: Stigma (general agreement)
04003: We’re working on it though aren’t we, you know it
PHD STUDENT: Tell me more about that, when you say we’re working on it
04003: Well, it’s, it’s just being much discussed when it’s mental health week, whatever
PHD STUDENT: Um
04003: And everything that comes out. We have a forums, we try and say this is something discussed and we all erm signed up to time to talk to try and just encourage people to spend five minutes talking. So it’s, it’s that, so we are working on it, as is the country isn’t it really (laughter) but, but it’s, it’s the stigma
04002: It’s a journey isn’t it?
04003: Yea
04004: It’s not an easy fix
04001: And it is on our home page as well isn’t it
04004: Yes
04001: So about,
04004: It is and
04001: Like you know, kind of reducing the stigma and people can make comments erm and even [online resource], for example, they, they have something, is it called Let’s talk or something (general agreement). So [online resource] in itself has, you know, it’s got the majority of employees as their line of business with [company] but they have then people that have experienced mental health issues and they have been sharing those with,
04005: Sharing those stories
04001: With, sharing those stories
04005: One of those things, we have, Tuesday 04004 was showing us this guy that had committed, tried to commit suicide and he’d, he’d gone through everything, he’d had all the support and was in a much better space and he said I want to share, she said would you share. And he actually did one of these videos where he just held up pieces of paper and erm, it was so, so moving and it, it was only, it only on [computer service], but it’s on the [online resource] page and she said within two days of that being on the [online resource] page it had had about five hundred people saying, you know, contacting him and saying gosh, you know, thanks for sharing that. It seems that thing was fantastic
04002: Well I think some, sometimes it’s, it’s the, I don’t symptoms might not be the right word but erm what, what we tend to focus on are the more common mental health issue like depression, anxiety and (general agreement), and even suicide up to a point if you like through some of the training that we do. But I guess with what we’re talking about today it’s also about behaviours (general agreement)
PHD STUDENT: Exactly, so, even though primarily our research is on personality disorders we are looking at those who just show very similar characteristics. It’s not necessarily about the diagnosis per se
04002: Yea, but I think sometimes what we, what we react to is the symptom erm whether it be a suicide attempt or whether it be anxiety or depression rather than actually the, the condition that perhaps the person has actually got
PHD STUDENT: Yea (and others express agreement)
04003: But if they don’t share that with us, that’s all we are left dealing with isn’t it
04002: Yea, exactly
04003: It’s the symptoms that’s the challenge
04005: So they could be, yea, and they probably don’t know that’s the reason. How many people know they’ve got a personality disorder? (Some indication of agreement)
04004: I think one of the things I, I end up dealing with and 04001 probably as well is, is where somebody’s personality is causing a problem within the placement
PHD STUDENT: Yea
04004: And the manager is then worried about how to deal with it. And the manager’s worried about the responsibilities that they’ve got and shouldn’t, they don’t want that person in the workplace

PHD STUDENT: Ok

04004: Because they’re worried about the, you know, what if they go and do something

PHD STUDENT: Ok

04004: And so they want us to say that he’s got, they’ve got to be sent off sick and you get this, this complete sort of, you know, two sides where you, you’re trying to support the managers but you’ve also got somebody that you’re not wanting to just say well off you go, you know

PHD STUDENT: Yea

04004: So, you know (general agreement)

PHD STUDENT: How do you usually erm handle that?

04004: I think it depends, it has to depend on the situation and we have had to take cases where we, we’ve had to get the GP involved and say actually perhaps this person shouldn’t be at work at the moment

04005: Yea, yea

04004: But it’s never, you know, it’s while it’s then their hopefully actually accessing treatment support

PHD STUDENT: Yea

04004: But otherwise it’s, it’s talking with the managers to try and see exactly what the concerns are. Sometimes it’s just that, they’re sort of worried about insurance and that sort of thing. You can say, you know, well there’s evidence that they shouldn’t have to feel it’s their responsibility and that all we can do is make sure we’re being as supportive and offer people that, that help

PHD STUDENT: Yea. I just want to go into that example erm just touch on another a stage, which is the leave of absence. So that individual, you got them into contact with a GP. Have you guy’s had experiences of, of individuals actually, yes who’ve referred them on and then they’ve had leave of absence (yes indicated). The reason I ask, is cos with this client group it is actually very common

04001: With the community kind of psychiatric nurses or whatever but erm

PHD STUDENT: Do you know what that those individuals, what kind of challenges they were experiencing before or they decided to go on leave?

04003: Err, I suppose from a personal point of view, you’re not, you don’t know, really necessarily always, you know, information or we don’t erm in terms of what they’re experiencing at work it, it just manifests in different behaviours really

PHD STUDENT: What do they do?

04003: Erm, most of the people I look after would be, or that I’ve looked after, would be customer facing or on the telephones with customers and they, you know, the erm calls with the customers would be disruptive

PHD STUDENT: Um

04003: And you know, they’re not, they’re not, not managing the customers (laughs), you know and it can get abusive or, or whatever

PHD STUDENT: Yea

04003: So you have to, we actually have to intervene and stop calls or pass the calls on and take

PHD STUDENT: Yea

04003: People off the, off the phones. Erm but actually there isn’t really hardly any alternative work that you can give to them that’s not

PHD STUDENT: Yea I was going to ask

04003: Customer interfacing

PHD STUDENT: Because it’s part of the job requirement

04003: Um

04004: You know and if you’ve got, of course if you’ve got somebody who’s, who’s in, in a phase or for want of a better word who’s being very impulsive

PHD STUDENT: Um

04004: And they’re risk behaviour is heightened and they’re [work task]

PHD STUDENT: Um

04004: [Work task]

PHD STUDENT: Yea
In [work equipment], you know with the, wearing safety equipment or it’s with, you know, somebody else as well. That can get quite dangerous for them and for others.

PHD STUDENT: Has that happened before? Are you speaking from an example or?

04004: Erm, no. I can’t think of an example but, but I think of examples where, where somebody, for, for example erm is, is quite perfectionistic.

PHD STUDENT: Um

04004: And may take erm I don’t know many hours to complete tasks when as an engineer maybe that goes into people’s homes and er so perfectionistic that, that, they, they maybe have seven jobs to do in a day and they can only complete two or three.

PHD STUDENT: Yea

04004: Because they cannot physically leave and if they, until they’ve checked everything twenty-five times.

PHD STUDENT: Um

04004: You know, erm or somebody who I don’t know might be recently, emotionally at, at that time not in a good place and then they’re in a [work equipment] erm and they refuse to put safety equipment on or they, you know, they’re on their phone in the [work equipment] at, you know (general agreement). When I say the [work equipment], I mean the, the.

04001: The [work equipment]

04003: The [work equipment] thing

PHD STUDENT: Oh, ok

CO-FAC: The thing that raises them up to get the

04003: The thing that raises them to

PHD STUDENT: Ok, I see

04004: Yea, yea, so, so, so you know it’s, it’s not that they’re sat in a call centre. Sometimes they could, they could be undertaking quite er you know things that require a lot of health and safety considerations as well.

PHD STUDENT: So I wonder, because obviously there’s the risk aspect but wonder with these difficulties that they face erm if there is room for any sort of modification in the workplace.

04002: Yea, so, so reasonable adjustments is something that we take quite seriously not just from a legal perspective cos obviously there is employment law around that but also it’s the right thing to do anyway. Erm, I guess the question is what’s reasonable (general agreement) erm and, and obviously part of the employment test is, because we’re such a big, large resourced company there is more onus on us than there might be on a small organisation. Erm, it depends on what the job is, will depend on what adjustments you can make.

PHD STUDENT: Ok

04002: Erm, er but what, what we can’t do is compromise on things like health and safety.

PHD STUDENT: Um

04002: So erm we wouldn’t be able to make an adjustment that would compromise the individual’s health and safety but we could make other adj, or we could look at other adjustments erm in the workplace for that individual.

PHD STUDENT: Ok, can you give me an example 04002?

04002: So er an individual that we had erm er we, the, there was all sorts of adjustments that we made for him. So erm we, we, we kind of, we, we got to a point where it was getting more difficult to get work for him with that team would actually do.

PHD STUDENT: Sure

04002: Erm for whole raft of reasons and in the end what we were doing was actually making up work, that, that had to be done but actually it wouldn’t, it wouldn’t normally be one person’s job. So that we actually gave this, one of the things that this individual couldn’t really do was interact with individuals particularly well. But actually, that, that would be fundamentally part of his job normally so actually what we did was we took away some of those elements of the job, gave them to someone else and so what was left erm he had. But what we found over time was that it was increasingly more difficult for us to actually sustain those adjustments.

PHD STUDENT: Ah, ok

04002: Because of, you know, sort of areas erm, efficiencies that was put, that were trying to be made and all the rest of it. And we.

PHD STUDENT: Do you mean like logistical things or?

04002: Well, it could be, it could be a range of things. So we, we were try, we were trying to relocate people into centres of excellencies erm but actually an, another condition that this individual had meant it was very difficult for him kind of travel so he was allowed to work at

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home most of the time but with some erm er working in, in offices for, for some time but not all of it. Erm, but it, it was just, we, we have a re-deployment unit in our team so where an individual’s job would kind of, where their role would disappear through maybe an efficiency

PHD STUDENT: Yea

04002: We wouldn’t make people redundant. What we would try to do is find them an, an alternative job. But they wouldn’t er, there, there are rules around what people you’d put into the re-deployment unit and one of them is around health. Erm and so actually the onus will be to try and keep the individual in their, in the job they’ve got

PHD STUDENT: Ok

04002: If they’ve got a health condition rather than move them into this kind of virtual centre and find them an alternative

PHD STUDENT: Almost like a last resort, that’s what you would do

04002: Yea. But of course, if you got to the point actually where you couldn’t sustain the adjustments being made you get to a point of well, what do we do with this individual

04003: Yea, erm

PHD STUDENT: And is there a rule up to er at what point you, the number of times you can make these adjustments for an individual?

04005: It's what's reasonable

04002: No, yea

04004: It’s purely what’s reasonable. So we have to show we’ve done everything that we can but we can’t actually manufacture a role that isn’t there. So we’ve got to try and find something, and you know, we’re a big company so we can a lot of the time, but we can’t, we can only go as far as what's reasonable

PHD STUDENT: Um

04004: You know, and what’s reasonable. You can’t define it precisely (laughs) erm

04003: It’s more difficult now isn’t it with the technological improvements there’s less roles for people who are perhaps, cos a lot of is around technology

PHD STUDENT: Ok

04003: And people’s inability to be able to work around that. But given the improvements, you know, a lot of the engineers are working off laptops now doing the work that used to be done manually. So it does make it more and more difficult

04001: They’ve had to adapt, haven’t they

04002: There is another angle to this

PHD STUDENT: Um

04002: Which, which was erm with, with, with a, a particular individual I’m thinking about actually was extremely time consuming for the line manager to manage that individual (general agreement). So actually another question that we, we had to ask was, how reasonable is it for that individual or for a line manager to actually use a disproportionate amount of their time to manage that individual when actually they had, you know, whatever their other day job was plus they might have other people that they would have to manage

PHD STUDENT: Um

04002: So that was almost quite a, quite an interesting, unique aspect in terms of what is reasonable. Erm, er because you know this individual particularly was, was actually taking more and more time

PHD STUDENT: No thank-you

04002: Err, with, with the line manager

PHD STUDENT: Yea and so it’s striking that balance between supporting and then getting the work functioning, the work done I suppose

04002: Yes (general agreement) I think so

04001: I think one important thing we do, we tend to have multi-discipline which, as you’ll know in, in hospitals.

PHD STUDENT: Um

04001: Multi-discipline calls, so you pull in the relevant people, [service], [service], legal, first, second line managers,

PHD STUDENT: Ok

04001: The HR business partners, case management, occupational health. We’ll pull in whoever we think can have an input to that and bring as 04002 was talking, the different angles to it so that you can get a rounded view of what can you do

PHD STUDENT: And is that done on like a case by case basis?

04002: Yes (general agreement)
04001: Yes it’s individuals case by case
PHD STUDENT: And as and when sort of thing
04001: As and when necessary
04004: Yea, the line manager, the line managers or occupational health or erm will, will usually alert erm or case management actually (some agreement indicated), we’re getting more case management in our team so if they’ve got somebody with leave of absence erm or regular bouts of, of absence they erm and there are mental health issues there. Erm and they’re, they’re struggling to know how to manage that then they might call those people in. Erm, i.e. the, the [service] team and our teams to try and kind of wade through the treacle together really with all of us. Erm I think some, sometimes if they’ve, I think we’ve got a very good system erm however, for, for any improvement sometimes I wonder, you know, sometimes we’re doing that without the inclusion of the individual
PHD STUDENT: Oh, ok
04004: As such. So we’re trying to support the line manager and the line manager then support the colleagues of that person but quite often that, that person isn’t involved in those conversations and er I was just going to on to say, you know, we, we’ve probably got, well it’s not just [company] really everybody’s probably got er many people that are diagnosed with a mental health issue and you get very little back from community mental health teams or crisis teams that are working
04001: Yea
04004: With these people. And if we could work more collaboratively. All of us including the individual that, then I think that, that would, that would bring a considerable improve, improvement. Because, you know, if, if, if like if we talk about health, health and wellbeing passport. Ok, who is your mental health worker if you have one, erm who would we contact, would you give us permission to contact them so that they, if the wheels start to fall off then we can make that early intervention and get that person support. Loop them in a bit quicker, as well as the mental health professionals and, and, and work together. I know sometimes even, people with mental health issues, they, they don’t want the mental health team involved either erm but even with, with very, very serious cases of, of, of depression or schizophrenia in the workplace we don’t get anything back from mental health teams. We’ve got, we’ve got a few people who are in psychiatric care and, and we’re, we’re trying to ascertain, ok, so if, so at some point if they come back, how do we help manage this person. And then they’re discharged, then they’re out in the community. They might see somebody once a month or once a week. Erm, we get no coms from them, er they won’t hear from us either erm and, and then that persons then at some point coming back to work. And we might try and prepare them for that. So we’ll go out and do home visits or meet them somewhere that’s, that they would want, prior to coming back to work. They might come in for coffee so it could be a gentle phased return to work, but it’s coming in for a couple of hours
PHD STUDENT: That’s exactly what I wanted to ask you next actually
04004: Yes
PHD STUDENT: So people who have gone off for absence of leave and then erm want to return to work, cos a lot, our client group a lot of the time, they have been signed off sick or absence of leave and they’re still employed and want to come back. They, they’re really, really willing and they really want to but they just find it incredibly difficult. So I wanted to know a little bit more about your experiences in terms of erm, you know, how, like you said the phased return, getting them back to work and a bit about some of the supports that you provide and your experiences in general
04004: Yea, so, so it could be, I mean we don’t get to know about everybody so I think line managers try to manage it sometimes and, and quite often on their own without any support. Erm if they don’t know about our service cos again [company]’s massive erm so they might not know to call us anyway erm so, so, but most would be advised if they do call to, to try and do something, what would help, what would not help. How can we best support you type questions. Erm, they might put the health and wellbeing passport in place
PHD STUDENT: Ah, ok
04004: As well erm anyway as particularly, particularly if they’ve been off for a mental health issue. If they move jobs that also comes back, that also should move with them, if they go to another job within [company]. So, the passport is transferable to another role and it’s, it they then should alert that next manager. Erm, sometimes they may come back with a fit note erm from the GP so they’re ready for work but erm they’re, they might be able to do these tasks erm
but they can't do all of them or they might do a phased return, say two to three hours a day initially. But we'll, what we'll do, we'll do that initial

PHD STUDENT: What do you think would be most difficult for the, for these individuals for them to face when they return to work?

04003: I think coming back into the workplace at first (general agreement) and facing people and we sometimes try and suggest that they come back in and perhaps call in and say hello to people

04001: Yea, to come in before they properly, to have a coffee

PHD STUDENT: Oh ok

04003: So just, just to get them to go back to the workplace to say hi

04005: A phased return, yea

04003: And they've shown their face and then it's not quite such a big thing when they go back in and that certainly something we encourage

04001: Getting back into the building that can be a barrier, getting them into

04003: Exactly, yes

04001: So if we have a, you know, come in for a coffee, it, you know, broken that

04003: You've broken that first barrier

PHD STUDENT: Is that a first stage that's specific to the phased return, so that's something that can

04003: No, it can be

04001: It can be pre

PHD STUDENT: It can be, oh right,

04005: It can be

04003: It's a suggestion that we'll make

04004: Yea, so we'd, we'd ask the line manager to ask the individual about you know it's, it's things like do people know what you've been for

PHD STUDENT: Um

04004: Would erm

PHD STUDENT: So things like disclosure again isn't it

04004: About disclosure again, yea. Would, would you like, what, what, if, if, if there, would be, is there anything you would like me to ask er er say to your colleagues? Is there something you would like to talk about with your colleagues? Erm, where would you like to do that if they say yes, that sort of thing. So we'd be advising them to kind of be thinking about that anxiety of returning to work and what colleagues might say, what they might be talking about, you know, so, putting themselves in that, that person's shoes really if they were coming back with an, and having had a mental health episode or a new erm diagnosis or something. Erm and talking with that person about what they think those challenges are to return to work anyway. So we'd be asking their line manager to be doing that

PHD STUDENT: Um

04004: I think that's ok but I think sometimes erm either before an individual goes off or when they return to work sometimes they can latch onto colleagues and almost pass on the pressure that they're feeling onto colleagues and colleagues then feel, they feel like a big weight on them of responsibility to, to look after er this person or watch out for them or whatever erm

PHD STUDENT: How would that impact the workplace?

04004: Or they feel uncomfortable

PHD STUDENT: Ok

04004: With what's been shared with them and the expectations of them from the person who's returning to work

04002: So, I think, I think what, what, what 04001 said was important in terms of having a strategy. So you pull the

04003: It is, yea

04002: The various parties together. You have rules erm and then even protocols so with, with the individual erm that I, I worked quite closely with erm that individual would fire off emails to the senior managers within, within the team (general agreement)

04005: We've had a few of those, yea (laughs)

04002: To the chairman, to the CEO to all those sort of things. Erm and we had to put rules in place saying, to make it very clear to that person, we don't do that. Erm, and this is the reason why you don't do that. If you have an issue you channel it, so, so you kind of put some, some rules and regulations in place both for them but also for us as well. And you have a strategy so, as you were saying 04004
04002: Sometimes they might overburden other people
04004: Um

04002: And so we'd be very clear, this is your channel, this is your single point of contact
PHD STUDENT: Ah, ok

04002: This is what, and, and these are the barriers that you don't contact them in the middle of the night.
04004: Yea

04002: Erm if you've got an issue in crisis you ring up the employee's assistance or your GP or whoever you might need to, so, so, it's very clear lines of what you do, what you don't do. And, and we talked about conduct and discipline erm we had to reinstate a or er with that individual what, make it very clear where the boundaries are
PHD STUDENT: Yea

04002: Erm and we, we made some allowances for them to a degree but we would still draw the line somewhere.
PHD STUDENT: Yea

04002: For us it might be here, for that person it might be there perhaps but to make it very clear that if you overstep that boundary the
PHD STUDENT: I see

04002: Then, then there maybe consequences
PHD STUDENT: So there's a flexibility with some of these erm strategies you've implemented?
04002: Yea
PHD STUDENT: Yea

04002: And part of that is, is adjustment, so an adjustment for that individual might be actually we draw the line slightly, that we take into consideration erm you know their, their personality traits or whatever it might be and so you, you might, or you draw it somewhere else but actually there is still a line at which you cross that, that's not appropriate
PHD STUDENT: Um, um, um

04003: I can think of at least three cases where I've had line managers being threatened by the individuals (general agreement), as well, whether it's by email, where, whether it's 'I know where you live' er you know, 'I know your family' we, we've had all those erm
PHD STUDENT: Tell me a bit more about that experience
04003: Experiences

PHD STUDENT: How, how did erm you go about supporting that line manager and then, then also supporting those individuals as well?

04001: I think erm, I think, I guess it's the degree of involvement that, that the line manager then has and also making sure that they don't share too much personal information with the people, with their people really but erm, but sometimes that's difficult because they come from small communities quite often you know we've, like you know, in X we've had a case like that where it's a small community, everybody knows each other so actually you can't avoid them knowing that situation. But, erm, it, it's as you say, it's about boundaries and just reinforcing the boundaries then that erm

04005: But if there's a real threat you, we involve security, we've got a security division
04001: Yes

04005: And they will give guidance as well
04001: We can manage, I'm just not quite sure if security always understand the finer points if you like

04005: I do agree, yea
04001: Of the mental health, managing the mental
PHD STUDENT: Has, has some difficulties arisen from, fro security before?
04001: Erm, not that I'm aware of but erm I think they need an awareness don't they of how to manage those situations cos security's like a, a broad brush
04002: I think it often depends on, on who you talk to doesn't it cos some, some people in security team normally the more senior managers are ex-police and so in their old job
04001: Yea
04002: They would have been used to dealing with scenarios like that
04001: Yea

04002: Others come from different backgrounds and just happen to work in security, almost like a call centre but in terms of security issues and therefore their kind of knowledge and understanding will, will be different
PHD STUDENT: Um um
04003: We had another case in, in a call centre in Y, fairly recent and this individual would erm, would corner the managers in rooms and shut the door and so the managers would feel threatened physically, threaten them. She wouldn’t actually, actually touch them but she’s, you know, big, a big lady and, and had them standing in a corner erm until she’d finished downloading whatever she wanted to say. But err, you know, we had to make sure it, that they, they didn’t find themselves in that situation, the managers that they tried to manage the situation so they weren’t caught in a room with this lady. She, she wasn’t doing things wrong that you could discipline her for, whatever, but her behaviour was erratic
04004: But that’s often the problem isn’t it
04003: Yea
04004: It’s, it’s those are the ones, the ones that people find hardest to manage cos it’s, it’s not enough that we can be saying well actually, you know, we don’t feel you should be in this position but it’s enough that it’s really disconcerting for the people managing and working with them
PHD STUDENT: So it, it also comes down to a bit of health and safety like you said before
04001: It does, yea
04003: So duty of care
PHD STUDENT: And duty of care
04004: So can I ask you a question then? So people, you’re saying what five percent of people have a
PHD STUDENT: Yea, one in twenty, yea
04004: And is that a diagnosis that they’ve then had from a doctor and how, what stage is that you know, cos you’d see this much more than we, than I see, is, is what's led them to get that diagnosis and how far down the line and how many of them have been in a job and ended up off sick and that’s led to their diagnosis? You know, cos, I don’t, I don’t, you know. It’s one of these things to know, it’s quite difficult to see, where, where the diagnosis comes in with
PHD STUDENT: I mean I’m not an expert in the percentages and the stats but I do
04004: No but
PHD STUDENT: Know it’s, just in the general population its one in five, er one in twenty
04004: Twenty
PHD STUDENT: So five percent with an actual diagnosis. Erm, but in terms of, erm, in the workplace I, I couldn’t say
04003: And where, where were they when they got diagnosed, yea, I don’t know
PHD STUDENT: Usually speaking they get diagnosed when they’ve been admitted and seen by a psychiatrist
04003: Oh ok
04001: So they become quite unwell
04003: To hospital?
PHD STUDENT: Second, it will be secondary care
04003: Right, yea
04004: Yea, cos I doubt many GP’s are going to particularly diagnose or even refer on
PHD STUDENT: No they don’t,
04004: Some here, they’ll, they’ll just see them as their heart sink patient (laughs)
PHD STUDENT: But the pathway will be like this. The pathway will be, they go to the GP, the GP will see if they can recognise some traits, not diagnose, but then refer them onto the specialists and then,
04004: So there are specialists, aren’t they, yea, yea
PHD STUDENT: And then they will diagnose them
04001: Give them medication and
PHD STUDENT: Yes
04001: Send them away
PHD STUDENT: So it can be misdiagnosed but it’s a lot more common
04003: It’s very common, yea, one in twenty is massive
04005: It’s massive isn’t it (general agreement)
PHD STUDENT: Yea. That’s why we’re here to talk about, not just to about the diagnosis per se but actually people who present with very similar characteristics. So erm, are, is there anything else that we haven’t discussed today that you’d like, that you think is really important in terms of personality disorder and employment?
04002: I think the bit that I sort of mentioned earlier on around the booklet and it being for managers and what about it being for the employees as well. So I, I think that's erm it, it's kind of individuals knowing what the expectations are perhaps for them within a work environment as well perhaps, with a condition like the ones that they might have

PHD STUDENT: I think that's a really key point 04002. yea

CO-FAC: Yea, we'll raise that with CI actually and it's definitely something that I'm sure that she'll actually would think that she'd be really on board with as well. It's the, cos it's part of the thing that we're doing is, is to work more harmoniously sort of with the individual themselves and then you know,

04002: Yea

CO-FAC: With their people as well so

04002: Cos, cos what

PHD STUDENT: And what's interesting is I've, I've been running so many of these focus groups so I'm starting to see a theme. Lots of things coming up and I'm shaking my head because that's, that is definitely one of the strongest, one of the strong themes that has come up so far

04002: Yea

04001: Ok

04003: Can I ask

PHD STUDENT: Yea

04003: Sorry go on 04002

04002: So, so if I could just, just on that point what, what I'd, I kind of experience and I don't know if this is common or not but actually the individual just had a very self-centred view of what take, take, take rather than actually recognising that they had a part to play in it as well. Er that might be a clumsy way of describing it but that's kind of how it came across

PHD STUDENT: Ok

04002: I don't know if that's common or typical or whether that's kind of unusual but that's, that's certainly how it came across (general agreement)

PHD STUDENT: Actually what, what I think, a lot of the time what it is, is that they don't actually know what it is that they want and what they need (general agreement) and then if you put that in couple with the fact that, there's, there's not just one diagnosis of personality disorder

04002: Yea

PHD STUDENT: So it's actually quite difficult question to ask them when they come back to work, so what do you need, what, what's, you know, they don't know

04002: Or, or you might ask them that and actually they will tell you but what they tell you is not reasonable within a work environment (general agreement)

CO-FAC: And part of that is because sometimes you can find in people who've got difficulties that are you know consistent with a personality disorder, they're not very good at something we'd call mind reading, so it's something that we would do kind of quite naturally, like mentalising. These are sort of more technical terms but all this means is really, the real ability to be able to put yourself into somebody else's shoes and to be able to kind of understand how, how somebody else might be thinking or, or viewing a situation. And this is something that a lot of the clients that come through our service, this is something that they get taught because it's not something that comes naturally to them and it's not because they erm, they don't necessarily care about other people and their feelings and, and the things that might happen, it's just that they, they

04004: Yea, they can't

CO-FAC: They don't have the ability always to be able to put themselves in the [indistinct] to say, 'Gosh actually I can see now what, what, what they're, what people are thinking now', oh and they haven't necessarily realised the, their, the impact that they might have. So it can come across as almost quite selfish

04002: Yea

CO-FAC: Taking behaviour (general agreement)

04004: Insular, yea

CO-FAC: But actually it's, it's almost sort of a erm, more like a, just a, just a clumsiness and a little bit of a misunderstanding of not actually really being able to understand how things might impact on others

04002: Yes, that makes sense, cos trying to reason with someone who can be quite manip, it's almost, it kind of reminds me, reminded me of having had teenage children (laughter) and then going through and having of, of obviously I was a teenager once. Erm, it was, it, it kind of, some of the sort of traits seem quite similar
PHD STUDENT: Yea, yea absolutely
04003: Sure, and I used to run dual diagnosis groups and I spent far too many years working in the addiction field and er we couldn’t have more than two in the group with personality disorder cos er unfortunately, I’m very sorry to say this, but the, it, it would suck up the energy and time in, in the room so if we had more than two referred. If we had them in the group already we had, if we had two people in the group of say twelve or fifteen we had to kind of have a waiting list for others that, that had you know co-existing mental illness as well and that was because of the, the, the the difficulty in relating to others and they thought it was ok to talk for an hour and a half about themselves and take up all the time and not let anybody else speak and then trying to educate, you know, and trying to work with that person to get them to share that, yea
PHD STUDENT: But that’s interesting, cos they, they that tend to have an inability to understand boundaries and
04003: Yea
PHD STUDENT: And limitations within themselves (general agreement) and with others so if you,
04001: Yes, so you mentioned the boundaries and then the empathy as well, kind of thing
PHD STUDENT: So if you were to kind of link that back into the workplace and 04002 you mentioned about you know putting a package together and setting boundaries for them that’s why they might find it very difficult because (laughing) it’s something that’s new to them, they’re not used to what these boundaries are
CO FAC: It’s something they haven’t been taught as children and as they’ve grown up that learning boundaries isn’t necessarily, especially if we’re talking about people who’ve definitely got a diagnosis of personality disorder. Actually learning boundaries as a young pers, you know, starts from when you’re a small child and it gets taught to you and this isn’t necessarily something that’s taught to somebody who actually does have, end up with, you know, with a personality disorder as an adult. It’s not something that
PHD STUDENT: Hence you say it reminds you of other teenagers because actually that’s, that’s when a normal individual would learn those barriers or boundaries
CO FAC: Yea, will test them
PHD STUDENT: And test them
04002: Um hm
PHD STUDENT: But you could argue that an individual with personality disorder perhaps didn’t have that opportunity or they’ve only learnt one way for most of their adult life (laughs)
CO FAC: Yea
PHD STUDENT: Erm and then here they are in the workplace with these rules and boundaries erm and that’s why they might experience really high anxieties er emotions, it’s not that, that they’re unable to, but it’s that inability to erm have that flexible way of thinking of, about what the other person might be experiencing
CO FAC: They do, they do, er, you know, you can find that some people in employment they do seem to have quite, it will seem quite an inflexible way of thinking they get quite rigid (general agreement) about things and it’s
04003: And erm, it, it’s, er, sorry I keep saying they, I don’t mean to sound disrespectful
CO FAC: It’s ok
04003: Erm, er, it’s, they, there seems to be quite a common erm also, as well, so say something simple, like somebody didn’t turn up for an appointment or somebody was off sick, their worker was off sick for example, there will be quite a severe reaction to that you know and if we then transfer that to the workplace and they’re relying on a boss who’s then on holiday and they’re not there you know anxiety starts to raise and you know so it’s ‘well that’s person’s not there, they’re not there for me’ and it’s and you know it’s
04001: Well that’s where the abuse, abusive emails come in and
04003: Yea, it is
04001: Yea, the texts in the middle of the night and
04003: There’s almost an over-reliance sometimes on that person and an easily offended kind of, erm I suppose attitude for want of a better word
PHD STUDENT: Yea
04003: And erm er and a highly sensitive, a highly sensitive to rejection
PHD STUDENT: Very
04004: You know, highly sensitive and that, and that could be you know, you could say, they could say ‘well you didn’t speak to me today in group, why didn’t you speak to me in group?’ you know and it’s or ‘you didn’t have eye contact with me’ or it could be something
PHD STUDENT: So what do you think would be helpful in that situation to help them manage it there and then?
04004: Well management there and then is I suppose some knowledge of that erm certainly some knowledge of, of personality disorder. It being for, for us to be working with the line manager and the, the individual, we must include them in this (general agreement) we can’t exclude, exclude them in this, so I mean I just wrote down er individuals that have a diagnosis, what do they say they need and we said we don’t know sometimes what they say they need. However, we have to try and find out what they need pre-work, during and, and how to maintain that, or sustain it in some way
PHD STUDENT: And what’s a very good approach is like what 04002 mentioned already, actually focus more on behaviour, so it’s not really the symptoms per se but it’s more about
04004: No
PHD STUDENT: How we might have an impact on what they do (general agreement). So if you can start from there then you can, you can work backwards on other difficulties they might face, whether it be their emotions or their thoughts
04003: What’s the average age of somebody who’s diagnosed?
PHD STUDENT: Oh gosh, I don’t know the average age, in our CO-FAC: Yea, in our service they can be, they can be more, slightly younger
PHD STUDENT: I just
CO-FAC: I would have thought
PHD STUDENT: I know the demographics in our service is
CO-FAC: Yea
PHD STUDENT: Predominately Caucasian, female and erm actually it’s in the twenties
CO-FAC: Yea, it’s between sort of, sort of er twenties to thirty-five I think is the most recent stats that were, were pulled out
PHD STUDENT: But it doesn’t mean that we don’t see people over the other age limits
CO-FAC: Oh yea, certainly we do have males that are older and outside of that bracket and you know that we it, yea, it does vary, but that’s, that’s the predominant group
04001: So being older does have an advantage (laughs)
04002: Is, is there not or well I’ll ask a question instead of a statement, what, what education is being done within schools etcetera then because I assume that erm you know we talked about setting boundaries earlier on, we talked about er having a sort of diagnosis and presumably once a diagnosis has been made then that’s helpful because then it can be managed and all the rest of it. Erm, and we talked about erm the difficulties sometimes of people getting a job with this condition erm and particularly if that’s the first time that, that perhaps it, they’re coming across something that, that might give them anxiety or
PHD STUDENT: Um
04002: Or a clash or whatever it might be in this way. So, what, what is happening within schools to try and raise the awareness of it?
PHD STUDENT: I mean this is based on my, on my knowledge, I could, I couldn’t say this specifically what’s happening but I know, I know that [mental health charity] in [place], so again this is very localised
04002: Yea
PHD STUDENT: And it’s only one [area] in [place]. They were doing a lot of psychoeducation in schools, erm in fact that’s what I’m doing (laughs), like a couple of years ago so I know that for a fact. Erm and that’s, that’s like workshops specifically for secondary schools going in, doing an hour and a half, educating them about er anxiety or not, I know there was a study done at South London, Maudsley, so Brixton area and Lambeth area
04002: Yea
PHD STUDENT: Er where they were developing actual interventions to go into schools. They did have like a nice little booklet specifically aimed at adolescents but it’s not therapy per se it’s psychoeducation and it’s educating them more but erm I wouldn’t know the stats about that and it’s not specific to personality disorder either, that’s just
04002: Yea
PHD STUDENT: A generic term for mental health [indistinct]
04005: And I would think that’s probably one of the problems, you’re, you’re diagnosing, writing personality disorder and then you’re, there’s not that wealth of information that you can find on anything, you know, anywhere else. So like we’ve got masses of information but we haven’t got any, any of, anything on personality disorder have we probably in [company] at all
04001: No we haven’t have
04005: So maybe that's a classic example, that you, they'll suddenly feel they're a bit isolated on this little track
PHD STUDENT: But
04005: That they don't really fit in with anxiety, or really fit in depression and yet there's nothing, so you know, so their suffering from it but we've got and I have no idea that it was, you know
PHD STUDENT: Yea
04005: That high a proportion. You know, we're a big company, if you say you've got five in a hundred that's nearly five
04002: It's about five thousand people potentially
04005: Thousand potentially got it
PHD STUDENT: And it's one of the most dis, most diagnosed, diagnoses as well (general agreement)
04002: But what's the impact of being labelled with
PHD STUDENT: Impact in what way?
04002: On, on the, the individual
PHD STUDENT: Is it the person?
04002: Yea
CO-FAC: Incredibly negative. You're being told that the thing that makes you, you is wrong
04002: Yea
04004: Yea, yes, oh yea
PHD STUDENT: So we usually when they come to our service, I mean they could be a variety of things, people might actually like that, having that label, you know it's
CO-FAC: Some do, some find it quite helpful
PHD STUDENT: But one thing we'd normally say is that it's personal, you know, personality disorder, it means it becomes just a label
04001: It's a very negative label, it is to have
PHD STUDENT: Yea, it is (general agreement). It's just the wording of personality disorder
04004: Cos it's personality disorder (emphasised), you know, you, your personality is your personality just because it doesn't fit
PHD STUDENT: Exactly
04004: With the trend
PHD STUDENT: So we usually say, you know, we can help you
04004: It's quite (laughs)
PHD STUDENT: It can become ordered again. You know it doesn't mean it's fixed for life (general agreement) it's something that can, you know, you can
04004: It's just out of order
04003: Yea
04004: But it's a very negative thing isn't it
PHD STUDENT: It is
CO-FAC: Yea, it's, yea, it's, it's something, (sighs) something that, that we, yea, yea
PHD STUDENT: So erm it's interesting this (laughter)
CO-FAC: Yea, it is
PHD STUDENT: No it's interesting hearing your thoughts because again, one psychological approach would be focusing more on what they experience and what they do in their behaviours, it's like, oh well do you feel anxiety, do you feel depression, that's a little bit more socially accepted. And they usually say oh yea, yea and then, and then that's how we can, get them to kind of seek the help that they need
04002: It's just that if you're, you're having a look at that booklet and I'm not saying that you'd use terms like that or what you would call it but erm if, if we're also trying to educate managers for example, erm and we're trying to challenge the stigma that's and, and get people to look at it in, in a more sympathetic, an empathic way
PHD STUDENT: Yea
04002: Then I'm just wondering about the label
CO-FAC: Um
04002: Then actually what, what does that do to actually set someone's, a manager's framework in terms of how they support that individual and what connotations will they have

PHD STUDENT: Absolutely and I think even if we skirt around it, surely that's that would be feeding into the whole stigmatism as well, so actually, do you own that
04005: Yea
PHD STUDENT: Own that label or you own that name and then
PHD STUDENT: There are other names for BPD like emotionally unstable, I don’t know if you’ve heard of that?

CO-FAC: Which isn’t (laughs)

PHD STUDENT: Which is

PHD STUDENT: Exactly, exactly

FF: It’s not a lot better (laughter)

CO-FAC: Yea, it’s not great, emotionally unstable, yea

PHD STUDENT: So, I, I’m just thinking back to somebody who used to work in our team

PHD STUDENT: And they had a son who was only I don’t know five or six, was extremely disruptive at school, used to spit at other youth, children, used to bite them. Was moved schools, was
excluded from school so frequently and moved schools because of it and she kept appealing about the, the decisions to move that child. Eventually, she went, I don’t know where she went, because I didn’t take a lot of notice of it, but eventually she got her child diagnosed with is it

PHD STUDENT: ADHD or

PHD STUDENT: It’s probably conduct disorder

PHD STUDENT: I don’t know which it was

CO-FAC: Antisocial disorder

PHD STUDENT: I don’t know. No, they was, they was still a small child I think it had got four letters but she was highly delighted

CO-FAC: Probably ADHD then

PHD STUDENT: That, that child had been diagnosed and she’d got a label

CO-FAC: It’s because that they then there’s some understanding

PHD STUDENT: So how is that child going to grow up

CO-FAC: Yea, it’s, that it can be helpful for a parent to have this because then it means that their child will get specialist support, specialist funding because there’s funding available. Er

PHD STUDENT: So it’s used for communication and er to treat people

CO-FAC: It’s, it actually, it actually can be a very effective thing for erm for the child in the end because then it means the child isn’t bounced from school to school to school being disrupted the whole time

PHD STUDENT: And they’ll be alright, yea

CO-FAC: It means that they can, they can then have access to specialist erm support tutors who can work with them either in the school

PHD STUDENT: Right

CO-FAC: That they’re in or they can be placed then in somewhere which is more appropriate for their needs. So it could be that there’s a school where the teachers are specifically trained for how to help the child manage the symptoms that they experience to then mean that they can then go ahead and learn

PHD STUDENT: And it will be same to go

PHD STUDENT: The same will go for other diagnoses as well

PHD STUDENT: Yea, they’re giving them strategies

PHD STUDENT: My son was at school like that, he’s dyslexic, he’s not labelled, he’s not, has headache, he’s never had any other medical labels put on him and he’s not statemented so we don’t get financial support but he needs, he was not going to cope with a normal school. But he’s in a school where fifty percent of the children are statemented and get that support. But the school is phenomenal at giving them, they get three or four hours a week one-to-one of social skills. So that’s what they’re getting

CO-FAC: Yea

PHD STUDENT: At, at that school
PHD STUDENT: But I can imagine maybe in the workplace here at [company] if someone were to disclose and say they had X, Y and Z then you’ll know. It’s a bit of a catch 22 isn’t it, so if they disclose or not, if they disclose then, they do get a lot of support
04004: Yea and I don’t, I mean (sighs) I think the link up as well between CAMHS and then the community mental health teams
04002: So, what’s CAMHS?
04004: Sorry, the child and adolescent mental health service, sometimes I mean you might not get somebody who’s diagnosed pre-eighteen
PHD STUDENT: Yea, yea
04004: Necessarily because they might be too young and the reason why I say that is because I have erm a step-daughter that er if I had a guess, I would guess that she had personality disorder erm we’ve been through CAMHS twice erm she’s now, she’s now nineteen erm she cannot hold down a job, she bounces from, well she, she doesn’t want a job anymore because it’s incredibly stressful for her
PHD STUDENT: Um
04004: She won’t now go back to the GP anyway erm she won’t see anybody about it. She’s sitting at home incredibly anxious erm highly sensitive, will barely go out erm and you know the system, I feel the system has let us down erm you know and this somebody who had lots of boundaries actually when she was younger
PHD STUDENT: Mm
04004: Erm and was incredibly violent growing up, erm incredibly sensitive on the other hand. I think she just didn’t know how to manage herself and we didn’t know how to manage her either so we kept asking for help. And er they just kept saying, you know, well you know she’s, she’s ok in school sometimes you know but on the other hand she wasn’t ok in school. She was then incredibly anxious erm then we found out she was self-harming as well and, and now she’s nineteen and it’s, it’s like well where she’s going to go now. She, you know, she is, she is starting to think I, I’ve, there’s something up
PHD STUDENT: Yea
04004: But she won’t
CO-FAC: Well I mean there can be can be more accessible services if she’s feeling depressed or going to her GP. You might want to access your local [charity] centre, to be honest because they actually do run supportive therapeutic erm programmes through there so if she’s feels aversive towards attending the GP and she’s starting to think that she might want some support, [charity] is somewhere that you can access
PHD STUDENT: Yes, she can also self-refer to something called IAPT
CO-FAC: Yea, that’s true, yea
04004: Oh yea, yea
PHD STUDENT: And erm they, even though they don’t, ok, so you’re saying she hasn’t been diagnosed but it sounds very similar erm to what we’ve been discussing today but erm they, they can either see her there or they’ll be able to refer her on to something that’s more suitable for her
CO-FAC: That’s true as well
04004: Right, yea
PHD STUDENT: Erm and she doesn’t have to go through the GP, that’s completely self-referral
04004: Um
CO-FAC: Cos that can be, and that can be quite common actually that erm clients will access our service not via a GP erm frequently
04004: Right, yea
CO-FAC: You know, it’s just maybe that they’ve, that they’ve come to the, a point where they can’t work with their GP any longer erm just you know from various interactions over the years and it maybe that they end up actually accessing the service through a completely different route altogether
04005: Yea, yea, yea
04004: Yea but just looking at her, if she has got a personality disorder, I totally get the difficulty for her and the workplace (general agreement) cos she’s not even really hit the workplace, she’s no jobs you know for the last two or three months sort of thing. She can’t cope with college either, you know, she can’t cope with the people at college, you know and she can’t read their faces so there may be a little bit of Asperger’s here I’m not sure, she can’t read their faces, she can’t read people’s emotions either and er and highly sensitive so, so you know
PHD STUDENT: So this is what erm our intervention that we’re trying to develop is help, help those prepare and get ready for work
04004: Yea exactly, get them into the work.
PHD STUDENT: So erm that, yea, that, that’s, that’s kind of the people who we’re targeting
04001: Yea
CO-FAC: Yea and also we’re going to be erm also recruiting and targeting people who have been away on leaves of absence from work
04003: Right, yea
CO-FAC: So actually helping them to return back to work and er like LS already said a few times. We tend to find actually that our client group is so desperate for work, they want to work, they want, they want to be independent, they don’t want to have to depend on erm
PHD STUDENT: Their friends and family and
CO-FAC: On their friends and family. They want, you know, they don’t, they, they do, they feel a sense of burden incredibly greatly and they do want to, they do want to help, but you know they want to do something for themselves. Erm but you know the crippling, they have crippling anxiety, self-confidence erm attitude towards themself which will mean that they just aren’t able to take the next step and this is, this is what we’re doing and, and this is why we’ll also take people who are on, you know, extended leaves of absence and you know we just get, we’re hoping to just try and help people learn the skills to be able to manage the different experiences that they have at work
PHD STUDENT: And we’re really hoping that it, we’re testing it, we’re testing it, for once
CO-FAC: Yea
PHD STUDENT: And the idea is that if it’s, if it’s, you know, positive outcomes then it will be a much larger scale will be given. Hopefully run it across the country but we just don’t know yet until, until er you know towards the end of the year
04003: Do you know what, I just, so part of me thinks anything you know we need to start somewhere and
04005: Better than nothing, yea
04003: Er I know there are things out there but we need to start somewhere and one in twenty is, is big, it’s, it’s huge and erm anything
04001: Are there certain types of
04003: Would be better than nothing (laughs). Cos there’s nothing really
04005: Certain types of, of occupational skill sets or whatever that are better suited towards people with
CO-FAC: It, it depends on the individual
PHD STUDENT: Precisely
CO-FAC: We wouldn’t be able to say to you
PHD STUDENT: No, no
CO-FAC: That they’d be a particular role
PHD STUDENT: But a lot, there are also a lot of people with personality disorder, disorders who are very high functioning (general agreement), you know, like they can be in, you know, high flying jobs
CO-FAC: Yea, but you probably won’t know, you know, (general agreement; no) erm yea
PHD STUDENT: So actually their skill set completely varies, yea
CO-FAC: Yea
04003: So how, what, what is the difference between what do they do if they’re, if they’re high functioning what do they do that is different to others that, that struggle, you know
PHD STUDENT: No, er, one is, so I can give you a case study example.
04003: Yea, um
PHD STUDENT: So there might be someone who works very high up in the government and they manage a team erm and they’re very good at what they do. Very highly perfectionistic erm and maybe a little bit obsessive compulsive. Fine, that’s absolutely fine. It gets the job done. It’s, it’s very, very effective. But then there might be something that, something happens in the workplace, it could be, I don’t know, they miss one deadline
CO-FAC: Something unexpected, you know they fall down
PHD STUDENT: Something completely unexpected, it’s out of their structure and it, it usually actually it’s linked finance, usually erm and then it all comes (laughter), it all comes out. It all comes tumbling down and so they struggle in the sense that these are new emotions that come up and then how that manifests in the workplace could be, I don’t know, they could suddenly have an outburst and then they might, I don’t know, shout at their boss and then get fired and
then that’s it. And then their journey through employment would be very different from someone who perhaps has borderline and a different age but it’s still similar (general agreement) in terms of their struggle with the difficulties that they face, so erm

CO-FAC: Erm another example which I can give which actually comes from er a friend of mine. Some person not involved in our service at all, works in a completely different area of [place] but who works erm is currently working with erm an incredibly high functioning er, er person who has a personality disorder who also happens to be a very, very effective [occupation]. Erm, very, very effective [occupation] erm but this person has erm quite narcissistic traits so actually does make a very effective [occupation] for many, many, many reasons (laughter) but isn’t well liked by their colleagues and isn’t necessarily very able to have relationships with others at work and they are currently working on maybe smoothing over some of those relationships at work because the other partners find, find it a bit challenging on occasion when they have the more junior er [occupation] team coming through who are then unable really to work with this particular individual

PHD STUDENT: Yea

CO-FAC: So this is something that they are working with at the moment and yea. So, you, you can have you know like LS was saying incredibly effective people but they’ll, you can usually, there’s usually an area where there is a little bit, that there is difficulty, so

04004: Yea, it’s funny isn’t it because you know just thinking about the groups [?battle] and what you saying there with that case erm it, it, people shy away from that, they do, I could see from it from the groups that we ran, they weren’t popular people, you know. And it’s almost like you know, so then people don’t with, they don’t know how to relate to them and they, and vice versa, it goes both ways. And, and so people don’t talk to them so then they think well obviously I’m just awful, I’m horrible

PHD STUDENT: Yea

04004: Raises the anxiety

PHD STUDENT: Yea

04004: Raises that, that crushes the self-esteem even more erm and, and then people back off. They back off from them, you know, and it’s, it’s this, this

PHD STUDENT: And that’s the consequences of their behaviours and they don’t

04004: Yea, and they’re so complex, it keeps going round and round and, and then the circle of rejection keeps going round which compounds it even more

PHD STUDENT: Yea, it does

04003: And then they avoid, end up avoiding like the workplace anyway

PHD STUDENT: Yea

04004: Er, I’m sure there are probably thousands that leave the job, a bit like [name] did with her most recent one. She had a lovely little job and then she had a panic like attack in the morning. She was scratching at her face ‘I can’t go, I can’t go’ erm and, and then she, she wouldn’t phone them, she wouldn’t, you know, that sort of thing erm

PHD STUDENT: Yea

04004: Disruptive and destroying for that person, you know

PHD STUDENT: It’s starting a cycle again, yea. Erm, I actually have, so we work in a mental health trust as well so I actually have these support sheets prepared for you guys. I didn’t think, I don’t think you might, you know, would use them or need them but just in case because I appreciate that these topics we’ve talked about are sensitive erm

04004: Thank-you

PHD STUDENT: So you might find them helpful, you might not erm

CO-FAC: You might find them helpful maybe for people that you work with

PHD STUDENT: Yea

CO-FAC: So people who cross your path professionally who are having difficulties as well sometimes. I don’t know, but, these are something that we give out really as, as standard

PHD STUDENT: Yes

CO-FAC: Because erm it’s good practice for us to do so

PHD STUDENT: Yes

04003: Would these be given to children as well? This, this, this sort of advice, not really because it’s still quite something that you could erm focus

PHD STUDENT: This is actually developed from our adult service (general agreement) erm so

04003: Yea, yea

CO-FAC: So it’s more intended for people who are aged over eighteen

PHD STUDENT: Yes
PHD STUDENT: Erm but there are plenty of resources online specific, specifically aimed for adolescents and younger, younger children. Erm, so closing note, any, any last, last thoughts? If not, that's fine, you have opportunities to speak later on as well. Erm, so I'd like to invite you guys to something we call like a clarity process after, after the research is done. So I'm going to go away and I'll have, the yea the lucky job of transcribing it all (laughter) and then what I'll do is I'll write it all into erm summaries so, you know, I'm not going to send you the full transcript cos you probably won't read it but I'll send you just the summaries of today's discussion and erm then it will be an opportunity for you to read it through, correct anything or maybe add any kind of er residual thoughts after today's discussion and so if you're interested all you need to do is just pop your name and contact details down. There's also a question erm a tick box here if you would be happy for me to contact you in er, well I couldn't say when, a years or twos time when we actually collate all the information and we are thinking of doing a meeting er, presenting a meeting with the results, if you're interested. So it's just a tick box to say if you're interested in us contacting you then I will in due time to invite you to a certain date in the future. Does that sound alright? (General agreement)

(Sound of paper being distributed)

CO-FAC: I probably don't need to fill one out!

PHD STUDENT: (Laughs) I know where you live!

CO-FAC: But it's, it's nice that you've included me in it, you know, I feel erm, I feel part of the focus group. I've had all the texts from [indistinct]

PHD STUDENT: Is everything ok?

CO-FAC: Everything is fine. I just told her to stay in touch with me because I knew that she'd been speaking to potential first recruit

PHD STUDENT: Ok

CO-FAC: So, but that, that's fine. So, she's been, she's been in touch

PHD STUDENT: Ok, good, great

CO-FAC: So I said, just, just keep on texting

PHD STUDENT: Thanks 04002

CO-FAC: Text away

PHD STUDENT: Marvellous

CO-FAC: This was erm really fantastic for us actually

PHD STUDENT: Yes

CO-FAC: Erm

PHD STUDENT: Really, really helpful guys

CO-FAC: Really incredibly helpful for us

04003: And have you doneseveral, how many have you, what, what with sort of employers how many, have you now done?

PHD STUDENT: So this is the first er for employers

CO-FAC: Our next will be with erm [organisation]

04003: Oh

PHD STUDENT: Yea and then hopefully we'll be speaking to the job centre as well. We've got some contacts there

CO-FAC: And we're going to, I think erm, I might see if I can erm

PHD STUDENT: Thanks 04005

CO-FAC: Involve a couple of other employers as well

PHD STUDENT: I think we should, I think we should

CO-FAC: Cos I think it would be good to have

PHD STUDENT: I'm absolutely very impressed erm the amount of resources that [company] has

CO-FAC: Yea, there enormous

PHD STUDENT: To provide for the amount of support for mental health and wellbeing I think that’s fantastic and we, you know before contacting you, I, I couldn't find enough information online about all of these fantastic things that you guys do. I mean I

CO-FAC: You know it’s not

04003: From outside you wouldn't know, you, you wouldn't would you

PHD STUDENT: But I think, I can imagine if people knew about it, it, it would attract people to work at [company] er there's that support

CO-FAC: I know that erm

PHD STUDENT: Even more so

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CO-FAC: That [name] and [name] were telling us about erm quite a few things when we initially spoke to them on the telephone
PHD STUDENT: But prior to that I didn't know
CO-FAC: Erm no, we, we weren't aware actually. Though we did get erm
PHD STUDENT: That's for you to keep 04002
CO-FAC: We did get a sense though when we attended a, we attended erm a health and wellbeing at work conference in [place]. I don't know if any of you attended?
04002: Ok, yea, I was there
PHD STUDENT: Oh, were you there, ok. We were there as well
CO-FAC: Yea, we'd, so I wasn't, that we, LS and I sort of divided our time, and, and both ran around going to various different lectures
04003: I normally go to it, I couldn't go this year
CO-FAC: Erm and that was really helpful actually. We spoke, we, we, we've managed to recruit actually a lady who, who spoke about her experience of having borderline personality disorder
PHD STUDENT: I don't know if you guys were there, yea, for her er, er patients' story
CO-FAC: She was, she was really quite impressive and er actually we, we've recruited her into the study erm about her experiences of, of actually being told erm that she, you know she could never come off probation somewhere, at one employer. She now works for [company] who are very supportive of her and is the head of the, of their sort of mental health arm, their disability network. Her and there's err, they're really very, very supportive of her by all accounts
PHD STUDENT: Yea
CO-FAC: And doing a lot for her. Erm but yea she's told. I think she was even told by a GP not to bother trying to work
PHD STUDENT: She was told by a psychiatrist at A&E that
04003: Oh no
PHD STUDENT: She could never work
CO-FAC: You'll never work
04004: That's just written off and that
PHD STUDENT: Yea. But actually it just made her even more determined (laughs)
[Indistinct- everyone talking at once]
CO-FAC: By somebody who should be supporting her
04003: It should be the opposite, shouldn't it
CO-FAC: Yea, by someone who actually should be supporting her
04003: Yea, that's it
CO-FAC: And encouraging her
04003: Yea exactly
CO-FAC: Yea, no, you'll, you'll never work
04003: Oh, ok
PHD STUDENT: It's very infuriating, yea
CO-FAC: It's an astonishing view erm we found actually so, yea. It's really quite something
PHD STUDENT: So er yea, really, really insightful today
CO-FAC: Yea, it is incredibly, incredibly helpful, it's, it's incredibly helpful for us and this is the reason why we're running the focus groups with different groups of people so
[New audio recording starts- slight gap in discussion]
CO-FAC: Can be kept separate from their physical health record erm you don't have permission to view it. That's also the other, the other thing so I mean in, in our trust it's actually just all been amalgamated together now, so actually everything is now in one place
04004: So you've got access to it
CO-FAC: We've got access to it but we're not, you know, we wouldn't be looking at it because it's not something that
PHD STUDENT: It's also issues about confidentiality as well
CO-FAC: Yea, it's confidentiality and it's, it's the remit of access to things, so
04004: But if individuals have access to it at all as you're saying in some circumstances the GP can
CO-FAC: No, and, and some, in some places, some places completely separate. Completely separate systems
04002: So that's part of the problem isn't it?
PHD STUDENT: Erm
CO-FAC: Yea, yea. Erm and it's also, it's also, yea, I mean there's lots of, it's, this is partly and associated with the data protection act and also things like that. In the fact though you shouldn't really be
04002: Is it really that or is that just [indistinct]?
CO-FAC: It is yea because
04003: Yea, it is
CO-FAC: We shouldn't be accessing parts of clients' records that aren't anything to do with
PHD STUDENT: Mental
CO-FAC: Work with mental health. With what we're working on. It's actually, we're actually not allowed to look at it, it's a breach of our position to look at it because
04001: What even for you?
CO-FAC: Yea, absolutely
PHD STUDENT: Yea, it is
CO-FAC: We're, you know, we're, we're not erm we're not medical doctors in the sense that we, we would have a right to look at physical health
PHD STUDENT: Because that is the data, it's the data is patient owned data, so they're the ones who have to give the consent
CO-FAC: Yea
PHD STUDENT: Erm to that. So we send all, as a clinician you send all the referrals and the letters and, through their own GP
CO-FAC: Everything goes through the GP
PHD STUDENT: Erm, um
04003: Yea, so they get everything
PHD STUDENT: Yea but going back to integrative care though I don't know if you're aware but they are implementing psychologists now at erm at erm job centres
04003: Job centres, yea I did hear that
CO-FAC: Yea that's the plan
04003: Well
PHD STUDENT: There are two pilot sites, yea
04005: Psychologists, what one at each job centre?
PHD STUDENT: That's the idea, yea, that's the idea
04005: Blimey
04003: It will cost a fortune that will
PHD STUDENT: Yea well (laughs)
CO-FAC: Yea, so one of the things that erm so our chief investigator is, is sort of wondering and hopeful for, is if, if our intervention is effective and erm we're hoping it is effective because the evidence base, the scientific base suggests that actually it, it, it is effective (general agreement). We know it is otherwise we wouldn't do it in clinical practice, it wouldn't be the recommended treatment for people with personality disorder if it weren't
04001: And what do they do, so, what. what, what's their role then if there are psychologists there
PHD STUDENT: If the psychologist's there
04001: 'Yea, if the psychologist's in the job centre. What will they do?
CO-FAC: It will be management, it will be management
PHD STUDENT: I'm, I'm going to find out a bit more
CO-FAC: Yea
PHD STUDENT: When I, when I do the focus group with, with the job centre er because they manage the team and there's a psychologist based there. So it will be interesting to find out exactly what it is that they do
CO-FAC: Yea, because we don't know, I mean we can make guesses, we can make guesses that it would be just on sort of self-management
PHD STUDENT: Yea
04003: So teaching
PHD STUDENT: And education about
CO-FAC: Basic self-management and, and how to access services and that kind of thing, you know, but
04004: Yea, cos I remember, erm, erm is it dialect, diætætical behavioðal therapy
CO-FAC: Yea, that's what we do
LS: That's the model that we use, yea
04004: See that was, so that was kind of the main, the main way that the people in our groups were referred to but the waiting lists because it, it was actually quite effective but it was so long, it's over a year long
PHD STUDENT: Yea
04004: Wasn't it
CO-FAC: Yea this is, yea this is the programme for people who are
04004: Yea, and, yea
CO-FAC: Really in crisis essentially it's when, it's when they would access our service
PHD STUDENT: Yea, a year long
04004: Yea, right
CO-FAC: So the programme that we've tailored is actually a sixteen week erm dialectical behaviour skills for employment. So it's, it's incredibly short but that should, that should be fine actually because it's basically [indistinct]
PHD STUDENT: Because erm the idea of the evidence behind that is that erm I suppose they're a little less risky in terms of self-harming
CO-FAC: Yea
PHD STUDENT: And suicide
04004: Oh ok
PHD STUDENT: Cos our, our argument is it's not as if they're not ready for work. We're not saying they can't, those sort of people can't work it's just if they're self-harming and cutting and they're too emotionally distressed and are they actually ready for work at that moment in time (general agreement). So we're aiming the intervention for those who are less risky for now. But we're just going to see, that's the whole point of the pilot test, to test it out [Indistinct sentence by another speaker about psychologists resulting in laughter]
04002: You might get some funny looks
PHD STUDENT: But traditionally DBT is a whole year long yea
CO-FAC: You won't get [indistinct] 04002
04002: [Indistinct] yea
PHD STUDENT: But our intervention is basically adapted from DBT
04004: Oh ok, yea that's good
PHD STUDENT: Yea
04004: Yea that's good, that's good cos
PHD STUDENT: Yea
04004: A year-long seems quite long and somebody, like dual diagnosis for example is, is er and to keep them in it
CO-FAC: Yea
PHD STUDENT: Yea, but in a way
04004: They stay, yea
PHD STUDENT: In a way it's actually, you know, have they ever known anything
04003: And they're not lose in that year
PHD STUDENT: Their lives are so chaotic,
04003: Yea
PHD STUDENT: To have something that's constant for a whole year could actually be really effective for them, they're just getting
04004: They seem to enjoy it to be fair (LS laughs)
PHD STUDENT: After the first few months, yea (laughs)
04004: Yea, yea, no, I remember them saying that
04003: You manage it for the first couple of months and then you think it stays and er
CO-FAC: Yea, and this is, so we have, so the, the clients then would have erm a one-to-one therapist, then they also attend skills group so actually we work with groups of people with personality disorder, twelve of them in one group. So I know you were saying, sort of two people with others is almost too much
04004: You've got twelve!
PHD STUDENT: It's great, it's great. No it's great there, they're a great bunch
CO-FAC: Yea it is great and erm actually they are, they are all pretty excellent individuals when you’re, you’re working with them actually they’re really erm yea, they, yea, they are good, they are great (LS laughs). Yea, yea, they have some, have some excellent viewpoints.

PHD STUDENT: Yes, it’s brilliant.

CO-FAC: Erm about different things and different ways of thinking of things that we haven’t always thought of PHD STUDENT: Yea, but the model we use is, is NICE, is NICE recommended.

CO-FAC: Yea.

PHD STUDENT: And it's the most effective erm in terms of its efficacy specifically for personality disorder, yea, BPD yea, so. Thank-you so much for coming today, it's been a pleasure.

Several voices: Yea, thank-you.

CO-FAC: Yea, thank-you everyone.

PHD STUDENT: And erm I will be in touch with the er summaries so

04001: Yea, it will be interesting, thank-you.

04003: It will be good.

CO-FAC: And erm.

04004: Good luck with them.

PHD STUDENT: Yea, thank-you.

CO-FAC: We'll have a, erm a think about if there’s any other erm groups within [company] who might be useful for us to speak to.

PHD STUDENT: Yes, exactly, we’ll speak to [name] about it.

CO-FAC: And we’ll have a conversation with [name].

04002: Um.

CO-FAC: Yea, really, really excellent to speak with you all today.

04004: Yea it was good.

CO-FAC: Thank-you so much for coming.

04002: No, thank-you.

04001: Thank-you.

CO-FAC: Oh that’s great.
Appendix 26 Focus Group Occupational Professionals

Transcription 2 (Chapter 3)

PHD STUDENT: Two just in case one breaks, erm, we've got another back up as well
F3: Ok
PHD STUDENT: So that's there. Ok, fantastic, erm so the aim of today is I shall discuss employment and er personality disorders but part of the research er we're doing, EMPOWER is to develop an assessment scale that's actually part of my PhD and that will help us identify any sort of particular barriers or challenges er to people in, with personality disorders in the workplace so being able to develop that hopefully will help identify what areas we can perhaps give them more support in erm and, and yea basically on the lines of recovery like that. Erm the other two aims are to erm develop a intervention to help people get ready to prepare themselves for employment erm and by exploring what the potential challenges and barriers are it can help inform us better how to, how to develop that intervention itself. And the third one which might be more of interest to you guys is, to develop a positive manual for employers so, it and the idea is to be used by employers to help better understand that individual who might be experiencing those difficulties and how best to support them in the workplace. So that's us in a nutshell. I want to quickly go through different topics, so different stages of employment so things like getting a job to, they've got a job, they're a new starter, keeping that job, perhaps taking some sick leave erm and then also returning to work after that absence of, of leave. Erm any questions so far? Ok, fab. So if you were to speak to a colleague or turn to a colleague and say to them, describe to them what a personality disorder is what would you guys say? Again there's no right or wrong answer
M1: If someone was having an emotional or behavioural difficulties that affects their erm ability to dealing for some social function
PHD STUDENT: Yea, yea absolutely [M1] yea
M1: Cos it’s a long-standing erm forms of their character that make it, make them at odds with sort of mainstream society, I guess
PHD STUDENT: Um
M1: Like hard for them to get on life
PHD STUDENT: Yea, kind of interrupts their kind of day to day living and that includes being in the workplace as well, yea, absolutely. Yea, I mean that's basically erm, yea a very good description in a nutshell and erm the reason I, I want us to discuss the definition beforehand is you know I'm very mindful that as, you know [company] as an employ, employer employees may not necessarily disclose that they have a diagnosis per se. And that's fine. I mean our research is interested in people with personality disorders but we're also interested in individuals who don't necessarily disclose but they might show very, very similar characteristics, yea. Erm or very similar traits, so like you say kind of emotional responses erm perhaps behaving quite impulsively and or maybe even you know they could be have traits of perfectionism, which isn't necessarily a bad thing at all, right, I mean actually it could be very, a very good trait to have at work. Erm but we're looking at someone who perhaps takes that trait to the extreme, so that they end up perhaps overworking themselves or erm yea taking on too much they can take and then end up having a breakdown or an outburst at work. So, that's sort of, that's the sort of individuals we're thinking of erm that when we're discussing here today. Erm another thing I would like to emphasise as well that is, it's actually er what, it's very normal for people to feel anxious and frustrated, er frustrated at work you know if there's something like an appraisal or a deadline coming up I think that's quite understandable to feel particularly anxious. So again we're looking at people who, you know are not only feel anxiety erm or frustration but they might go to the extreme and it might lead them to do things that they didn't necessarily do. You know they might not, they might not turn up at all or erm they might freeze and make it, find it very difficult to explain you know what it is that they're experiencing. So that's the sort of erm, yea, sort of erm ideas that we want to bear in mind today. Erm so yea when I guide you through the questions I'd just like you to consider someone that you perhaps work with in terms of supporting erm who may have some of these characteristics erm and we'll take it from there. Ok, any questions so far? Ok
M1: Someone we, that we work with?
PHD STUDENT: Someone that you support. Cos I believe I think your roles are
M1: Well, you mean the, the employees not someone from us (laughter)
PHD STUDENT: Fortunately I’ve had time, yea
F1: I wouldn’t like to identify people
PHD STUDENT: No that’s a good question
F2: There’s a variety of personality disorders, isn’t it
PHD STUDENT: Quick question though
M1: I’m narcissistic!
PHD STUDENT: You are all part of occupational health is that correct?
F3: Yes
PHD STUDENT: And your roles are slightly different, so I believe some of you are physicians, is that right?
F3: Um, most of us
PHD STUDENT: Ok
M1: But I think we all have the capacity to, we’ll be seeing people in the kind of er patient kind of (? Disorders) and
PHD STUDENT: Ok. So in that case, what I meant by that is someone that you support erm, yea, yea, I wasn’t sure so. Ok, fantastic. So I have a question in terms of erm the stage of that, that employee perhaps they’ve got the job of getting the job. I don’t know if you guys are involved at any point in the application stage or
M1: Yes
PHD STUDENT: The interview stage?
M1: Pre-placement medical
F1: No they need to use the
F3: Not in the interview stage
F2: So the interview stage
F1: Or application stage
PHD STUDENT: Ok
F1: And legally you’re not allowed to ask in-depth medical questions until they’ve been given the job offer. So we do get involved in the pre-placement stage
PHD STUDENT: And that’s once you’ve erm
F1: Once they’ve been given the job
PHD STUDENT: Ok, ok, I understand. Do you think you can perhaps, talk me through that, how that works in terms of that process. Do, so for example, do they disclose or that they haven’t erm any sort of difficulties to do with mental health and wellbeing or
F1: Yes, so depending on the type of role that they’re going for
PHD STUDENT: Um hm
F1: So we have non-safety critical, safety critical erm so if it’s non-safety critical normally it’s a questionnaire, a health questionnaire that they will do. If it’s a safety critical role then there will be a health questionnaire and then er a face-to-face assessment
PHD STUDENT: Ok, fantastic erm and so leading on from that answer, in your experience is there anything in particular that these people erm might face that they might find particularly challenging? Erm filling out this questionnaire or at that process or situation
M1: Well they have to declare it obviously and they might feel that, that would affect their job offer at that stage
PHD STUDENT: And do you find that any of them might experience difficulties declaring it in the first place or is that something that’s not
F3: I have never seen any questionnaires
F2: I’m sure
F3: On pre-employment that contained ‘I have personality disorder’. No-one has ever to my knowledge declared it
M1: But later on you get, it comes through

F3: Has anyone? Yea, only later on you see it but at the pre-employment have you ever seen it?
M1: No
F3: No, I have never seen it (pause) never
PHD STUDENT: So tell me a bit more about, so you say later on erm

F3: Later on when the problems start occurring at work

PHD STUDENT: And what
F3: And then they are referred back to us
PHD STUDENT: Oh ok
F3: Because the problem has occurred
PHD STUDENT: And erm
M1: So the issue might be, I think because people might not know they've got a personality disorder cos you miss
F3: Some of them don’t, some of them will know
M1: Not diagnosed, misdiagnosed and er or they don’t accept it as a diagnosis, is it a diagnosis, that sort of thing
F3: Also there’s also the hiding, people will, I’m sure, there is lots of people who apply for the jobs, go through the interviews and are offered the job come for pre-employment, they don’t declare it on the questionnaire
PHD STUDENT: Um
F3: They know they, they have been diagnosed with it and they don’t declare it
PHD STUDENT: Ok
F3: At the same time there are people who have had problems in work, at err, err, in life, at school, at previous jobs
PHD STUDENT: Um
F3: But never been formally diagnosed, that’s also true
PHD STUDENT: Um um um
F3: You know, but I’m sure there are people who know that they hold, have a diagnosis of personality disorder and never declare it in pre-employment for the fear that they will have a problem getting the job (general agreement)
F2: And stigma
PHD STUDENT: So there’s a huge fear around disclosing it, ok
F3: Do you think there is a fear of stigma?
M1: Um
F2: I think so
F1: Do you?
F2: There could be
M1: I think now because people are quite willing to diagnose anxiety or put down anxiety depression cos the stigmas gone hasn’t it? (mixed agreement expressed)
M2: If they’re not already employed then a lot
PHD STUDENT: Hold on a moment, sorry er M3 did you want to say something?
M3: Yes, I find that in the questionnaire the mental health section some people might say I’ll tell the doctor so they might not want to say exactly what it is, that’s, I’ve seen at least one or two
PHD STUDENT: Um mm
M3: Ok, so I’ll tell the doctor or it’s a mix of erm with depression or something erm and then they say oh I’ll tell the doctor so, it will just be
PHD STUDENT: Do you think you guys can tell me a little bit more about what happens next if someone does come to you and they do tell you they have certain mental health difficulties. Like you said they might not disclose, cos they might not even know they have a personality disorder or let alone disclose a diagnosis, but let’s say they do come and erm disclose characteristics that are very similar to personality disorders. What will happen next?
M2: Well I mean they, one or two cases that I’ve seen is that erm they would say you know obviously when they come in to see the doctor, we want to be able to evaluate that
PHD STUDENT: Um mm
M2: Er ask what exactly is it and sometimes they already erm, they already know the diagnosis or that, you know like er, erm my colleague had said that sometimes they, it’s a misdiagnosis or er or it was a long time ago
PHD STUDENT: Um hm
M2: It was a long time ago and that they’re all, they’re well now and there are no issues so we want to be able to evaluate that further
PHD STUDENT: Ok, ok has anyone like to add
M1: Yes our role would be to do a clinical assessment
PHD STUDENT: Ok
M1: And then give a report to the manager either based on what we’ve found out or we might want to get a report from a specialist and then what, all we’re doing is then advising the employer whether or not you know if they need any adjustments for that role or if they’re at all suitable for that role
PHD STUDENT: Ok. Does anything come to mind? Is there an example of any sort of adjustments that had to be made for that individual?
M1: Well the safety side here is the main thing so it’s, there’s [work equipment] and
PHD STUDENT: Right, right
M1: And they’ve got to make decisions that could affect their safety, other people’s safety so that’s
PHD STUDENT: That sounds like quite a lot, quite a large responsibility and quite a high
M1: Yes
PHD STUDENT: Pressured
M1: So that’s, that’s why
PHD STUDENT: Position
M1: Yea, individuals with this, these types of problems you know need more careful consideration as to what they can do
PHD STUDENT: So what would usually happen with erm, with their roles? Would their roles be slightly adjusted or?
M1: Yes, our role is to advise on the adjustments
PHD STUDENT: Ok
M1: And then HR will make the decision as to, to where they’re placed or if they can employed
PHD STUDENT: Ok
M1: And then we don’t generally know what happens
PHD STUDENT: Afterwards
M1: Yea, yea, unless we see them again when they’ve had problems later on
PHD STUDENT: Um mm. So is this, it sounds like the support that you provide is very much as, as and when required is that right?
M1: It’s advisory so we’re not, I mean these guys might treat, offer treatment but the, the doctors here are purely just to advise, not really for diagnosis
PHD STUDENT: Ok, yea
M1: They’re not really for, you know, treating
M2: Quite, quite often erm we make, in the case er it’s er known that they, they have had personality disorder we want to be able to find out whether er they’ve been stable and well in recent years so it might actually lead to erm, that we need to write to the GP or the specialist that saw that quite leads to erm a delay in from the time they we have their, they have their assessment until the time maybe they are declared fit for some sort of work or
PHD STUDENT: Um
M2: Yea, so it may lengthen, it takes once a year or so but it depends
PHD STUDENT: Yea
M2: So
PHD STUDENT: Erm and does that have any sort of erm impact on that individual?
M2: Well it’s difficult, I mean I can’t really, it’s very likely
PHD STUDENT: Um mm mm
M3: Very likely
F1: In the working environment
PHD STUDENT: Yea
F3: Really the main issue is, I know, I can see from the brief and from what you are saying and asking that the main focus you have is on the individual and how to assess them. Whether they are fit for work and how to support them through the work er life. The main issue that we have is as doctors in occupational health and at the, the main issue the employer has is the impact of person’s personality disorder on other workers. So it’s at the other side of the coin that we are actually dealing with. With F1 maybe and M2 will more be dealing with the person himself or herself
PHD STUDENT: Ok
F3: Offering the support, offering CBT or things like that. Well I mean that’s usually what you do isn’t it. Trying to get them to understand how what they say, do or behave impacts on the colleagues you know and to sort of modify their own behaviour. Er that’s what they do mostly.
We will deal with the other, the other side and that is how that affects the working environment and maybe try

PHD STUDENT: Ok

F3: To offer some kind of advice to the manager, or to the employer if you want to call it in how to handle that situation er to sort of mitigate that, that mismatch in between the person with personality disorder and his colleagues

PHD STUDENT: Um mm

F3: Um and the, to be honest with you, I have only seen one case in this organisation. I, I’ve been over twenty years here, one case that worked

PHD STUDENT: Um mm

F3: And that one worked because the person was later diagnosed he was in employment, he had a lot of problems, misunderstanding, they perceived him rude, he was er snapping at customers, you know all sorts of complaints

PHD STUDENT: Sure, yea

F3: Erm he eventually was er referred to occupational health and er I think [F1] was also involved and we, we eventually came to the diagnosis of personality disorder. He was, he had actually had a very good insight because he understood that throughout his schooling and early life he was always an odd ball

PHD STUDENT: Um

F3: And in a way, you know, having a, a label to put on made him feel better about himself. He knew now ok, you know, something is the, I’m different because of and that didn’t really put a stigma, that actually made him feel better about himself. So, I think you provided him with a lot of support and CBT

F1: Mm (? Sighs)

PHD STUDENT: May I ask of this individual

F3: Yea

PHD STUDENT: What’s erm, what the initial kind of erm difficulties for this individual in the workplace?

F3: I cannot quite remember it was some time ago. I can’t quite remember but I think there was, those, lots of erm misunderstanding in between him and other colleagues which has resulted in a lot of complaints and grievances

PHD STUDENT: From, from his colleagues?

F3: From the colleagues

PHD STUDENT: Um

F3: And also I think erm some of the customers had complained that he’s rude, unhelpful, overbearing or you know it, it wasn’t the route, good customer service. He was er a customer service, a customer service assistant working on a station. So he wasn’t, although he was keen, he was actually not doing a very good job. So eventually you know he returned to the workplace after

PHD STUDENT: Ok

F3: We had a diagnosis and err, a, a lucky circumstances was that he had a very supportive manager who was interested in psychology as a subject. So, he went and researched and erm found his niche and found how he’s going to support him, cos he was acting as the buffer in between him and the colleagues. In between him and the passengers. Every so often he would pull him in the office

PHD STUDENT: The manager

F3: The manager and say well this went wrong. Why did it go wrong? What can we do differently? So that went on for a number of years and I’ve forgotten

PHD STUDENT: Um

F3: About the man, I’ve forgotten his name now and then because he was now doing so well at the job he got a promoted

PHD STUDENT: That’s fantastic

F3: No!

PHD STUDENT: Oh, no, ok my goodness

F3: Cos he got promoted to the higher grade

PHD STUDENT: Right

F3: Now with promotion he got more responsibilities

PHD STUDENT: Right
F3: He was now in a position when he was effectively making safety difficult decision, he was running the stations, he was to a degree managing other staff. Now when you, I, when he was referred to us for promotion transfer I become very, very wary because I was thinking oh I don’t know how’s this going to pan out. We then sent him for top up of CBT and
PHD STUDENT: You say top up
F3: Top up
PHD STUDENT: So he had more
F3: Yea, he had more and then came back and had more (laughs). So we sent him for top up.
To refresh his
PHD STUDENT: Right
F3: Skills and knowledge. And the erm old manager contacted me and he said listen when he starts working in a new job and gets a new manager he is going to have a problem. So why don’t you liaise with the new manager and put me in touch and I will coach them. And that happened. For a while it was fine. Then we had a change of management, the whole thing fell apart and he left
PHD STUDENT: Um
F3: So, as you can see what we really deal with it, what we deal with is not supporting individuals so much like (general agreement) managing the environment that they work in
PHD STUDENT: That
F3: And how on earth are we going to find that kind of supportive environment for the person, for the people that are coming in. And they are coming in, in droves, there is loads of people with personality disorder of course. I mean with a small amount of symptoms they will somehow manage to, you know, go through life and go through work. The ones with florid symptoms will have more problems
PHD STUDENT: Um mm mm
F3: So yea that, that is the bit we are interested in. If you come up with something that we could use as a template to teach our managers to deliver in training courses to, you know, do something like that. That would be great because at the moment we are doing our best but we are really well walking in the dark.
PHD STUDENT: I’d like to know a little bit more about what, you say you’re trying your best and, there’s clearly some things in place because you obviously spoke to that manager at that time, gave him advice in terms to how to manage that individual. I’m just interested in, in, in knowing what was useful for, for them. Was there anything in particular?
F3: It was useful that manager was open to it and found time to do it. Because you will often find a manager who, regardless of how long, how much they would want to support a member of staff
PHD STUDENT: Yea
F3: They have other duties and other jobs they are not always available or in a situation to be er that kind of supportive person or, or they have personality disorder themselves (laughter) they can’t really provide that support. That is true!
PHD STUDENT: Yea
M1: The catalyst most of the time is sickness absence isn’t
F3: Yea
M1: That’s the thing, so if they’re there doing something they might be under the radar but when they start becoming absent, you know, unpredictably probably in a case of personality disorder
PHD STUDENT: And is, is that something that’s quite common? For sick leave?
M1: Well that’s how, that’s the probably the management issue, isn’t it, sort of and that’s how we might get to know about the problem erm or if they’ve had some safety problems erm er I think from, from what I can see, because obviously we all see different people that is, is when they’re absent, like if they have, been a, er went to hospital with an overdose that, that’s when we get to know about it
PHD STUDENT: Ah
M1: And that’s when the manager will contact us
PHD STUDENT: Does that happen? Is that, is that something that you’ve experienced?
M1: Yea, I think there’s quite a few isn’t there?
F1: Yea, yea it is. Erm the main issue erm for the people that I see is interpersonal difficulties so difficulties with colleague liking F3 was talking about, difficulties with colleagues, difficulties with customers and with erm difficulties with their managers. So interpersonal difficulties and of course because of the safety critical nature of the, some of the jobs, erm we do have to be careful
PHD STUDENT: Yea
F1: As well
PHD STUDENT: So erm, what, what do you think would be helpful for that individual in terms of trying to manage their interpersonal difficulties? What, erm has, is there things that you’ve tried and it’s worked or is there anything in place for that?
F1: I also had one case and er a lady with borderline personality disorder and again it was exactly the same as F3’s case where managerial support was really the key. Where the manager was having to provide really intense, regular support
PHD STUDENT: Um
F1: And I don’t know how feasible that is. I mean this manager was really keen, like your manager,
F3: Mm
F1: But erm I don’t think most managers have the time or the capacity to provide that kind of support and so people are just left to deal with their difficulties usually
PHD STUDENT: Um
M1: Cos this is one environment isn’t it, it’s a safety critical environment with you know full shifts, lots of employees, millions of customers so it’s, it’s a different challenge isn’t it to get the support for the people
F3: Um, mm
M1: Compared to somewhere else where it’s might be a small shop with three or four youths or something
PHD STUDENT: Yea, absolutely, yea
F1: There is
M2: We are explore, I was just going to say we are exploring peer support so I guess that something that possibly could be adapted in this context and that isn’t something we’ve looked at specifically in terms of personality disorder and it could be quite onerous I guess for people who’ve had very limited training so
F1: Um
M2: But it's, it’s a consideration I guess
PHD STUDENT: Absolutely
M2: And something we’re trailing at the moment for more general, things like anxiety problems
PHD STUDENT: Um mm mm
M2: And there’s, there’s a trauma specific approach we use which is alongside the [been for about 12 years]
PHD STUDENT: Oh that’s really interesting. Can you explain a bit more in terms of the peer support? Would it be one-on-one or would it be group?
M2: Yea, it’s one-on-one and it’s, with the trauma it’s in relation to a traumatic event and they’re given basic understandings of how to er deal with shock essentially and enable the appropriate early support and then we’re looking at err, we’re trialing a version of er something somewhat similar again one-to-one support for more general mental health problems in corporate settings
PHD STUDENT: Yea, oh
M2: So, I, I guess that, that could in theory be adapted for this but
PHD STUDENT: Um mm early stages
M2: It would need quite a lot of thought
PHD STUDENT: Great, fantastic, thank-you M2
F1: Erm there is a tool, I don’t know if you aware but it’s erm I, I’ve seen it being used in other mental health conditions like bipolar. It’s called I think an advanced statement or erm a declaration or something along those lines. But it’s basically a contract between the manager and the employee in terms of their roles and responsibilities. Erm so it’s sort of like adjustments erm but it’s a contract between the manager and the employee in terms of what each of their responsibilities are so
PHD STUDENT: Um
F1: Erm it, it was something I was keen to use for my case with, with borderline erm I’ve seen it used, erm being used in bipolar, but basically the, so for example, the manager will provide regular support, will provide feedback erm if there are any issues and the employee will then agree to erm not breach sort of certain codes of conduct and things like that
PHD STUDENT: Um mm mm
F1: Erm something that I’m quite keen to use are these sort of things
PHD STUDENT: So you have used it like you said as, as of yet but you’ve thought about it
F1: No but I’ve seen it being used erm, other employers do use it erm
PHD STUDENT: And what usually happens if perhaps something is breached?
F1: That's a good point actually
M1: Well that's the issue
F1: Yea
M1: Cos you can use it in a treatment setting or whatever but like in a
F3: Exactly yes
M1: When you've got equality, the rules and things [indistinct]
F1: But
F3: My understanding of that contract is really that er sort of erm clarifies er what you should be
as a manager, what you should be looking for. Well especially that is, easy to explain in bipolar,
where you know you are looking
PHD STUDENT: Um
F3: At it, at a change of the moods, change of the behaviours and unusual behaviours, erratic
behaviours, being sluggish, being over the top, you know, something that is out of character.
Erm I suppose something similar can be adapted for this as well
F1: Yes
F3: However, having said that, that is quite a risk, you know, that people are not fitting in and
they're causing, that is causing a problem that is quite obvious. This is why we end up seeing
them because it has resulted in a problem at work
M1: But what are you going to do
F3: So, yea
M1: When they don't follow the contract. It's not like driving with alcohol where you're gonna,
where they've breached their drugs and alcohol
F3: No, you cannot dismiss them but you, you can actually
F1: But you can manage
F3: At, at that point you can say this is it (hits table), at as of now you are not working and you
are going to see occupational health or [indistinct], whatever, you know
F1: Depending on what the breach is (general agreement) erm you know you can, the manager
can say well we're going to performance manage, or I'm going to send you to occupational
health
F3: Yea, yea
F1: So, I mean all of these things do need to be agreed beforehand
F3: And it may
PHD STUDENT: Absolutely, yea
F1: And it's, it's a contract, you know, it's a mutually agreed contract
PHD STUDENT: Um mm mm. Not like a reprimand or anything like that
F1: No
PHD STUDENT: No, yea
F1: Not necessarily (laughs)
M2: Well I guess it has the virtue of reminding some, someone that it's a workplace environment
F1: Exactly yea
M2: Which I think some people, with some of these conditions can lose a sense of, there can be
a greater sense of their needs are very, very primary and kind of, they are quite engulfing
(general agreement) so, so that, that then could be quite useful boundary in principle
PHD STUDENT: Um yes
M1: Actually
PHD STUDENT: That's an important word (laughs). Erm I wonder if you guys can tell me a little
bit more about erm so we talked a bit about people who do take leave erm I wonder about
people who have taken leave and perhaps are returning to work. I don't know if those are the
sort of people that come through, through to you? In terms of things that they, you know, they
might experience some challenging erm difficulties. I wonder if you guys could expand on that?
F3: If these, if the people, if we are talking about people with personality disorder
PHD STUDENT: Um mm
F3: And if they are going off work for the related issue, they could go off because they have
pneumonia, but if they are going off work for the related issue it would be probably due to
stress, anxiety or depression. They will call it one of the three. So, when they are returning to
work I suppose you don't treat them any different than any other person who has been returning
suffering from depression, anxiety or stress. Erm the, the problem with them is that you have the
er prediction of this being induced again and again and again
PHD STUDENT: Erm and so having said that are there things perhaps and, or supports in place here that can help them recognise when it’s, you know, when the problems might arise again, how they can manage it or anything like that?

F3: But as I said apart from CBT and understanding that’s better the, very, very little because really their perception of the world is somewhat different from mine. So although I may see that their behaviour is a bit odd, they don’t see it

M2: Um. But we, we do run as a complement also to the, er additional to the one-to-one therapy

F1: Ye

M2: Erm stress reduction groups and for those perhaps on the more mild end of the spectrum that kind of (general agreement) input from the group can be, you know it’s broadly a psycho-ed group, and that can be useful but I think it, it obviously depends, how, how far they are on the spectrum

PHD STUDENT: Yea absolutely. And these psycho-ed erm sessions, are they specific to employment or they’re kind of like a general

M2: They’re in general but I mean it’s obviously, in, in the employment context so it’s very rooted, so there will be discussion around difficult, you know, sort of thing around dealing with stressors basically in the different roles

F2: Workplace stressors

M2: And then obviously exploration in the group about how to manage that. (Intake of breath) how to enhance resilience and stuff

PHD STUDENT: Um mm

M2: So that, that could be useful but I mean I guess yea with someone in a particularly bad place it’s going to be a bit difficult

PHD STUDENT: Ok. Erm I just want to ask, I want to know a little more about the erm, I suppose the process of, of that individual receiving that support so it, they would go to occupational health, is that right, so they might disclose

M1: Mm

PHD STUDENT: They’ve got some sort of difficulties and then is it something that would be ongoing and openly discussed with their manager or er is

M2: There’s a lot of restrictions around confidentiality

F3: Confidentiality

M2: And obviously we’re not the place to, unless, unless they tell us there’s a diagnosis, we wouldn’t necessarily, you know it’s not appropriate for us to diagnose them

PHD STUDENT: Yea, yea, yea

M2: Around a, a personality disorder. So it would tend to be framed as the same around depression or anxiety

PHD STUDENT: Ok and so how do they usually get around perhaps attending these sessions if it’s something they don’t want to share with their manager?

F2: Which sessions are you talking about?

PHD STUDENT: Er CBT or attending

F2: What the, what would happen is the manager would refer them to us in the first place

PHD STUDENT: Ok, mm mm

F2: And usually it would be for something else erm maybe he’s not getting on well with everybody or everyone’s complaining or he’s usually they’ll be off by this time, they’ll be stressed. That’s the time when they come in and a lot of the time they’re not aware of the effect they’re having on others. So that’s the first work we’ve got to do. Where they’ll sit down, they’ll come in as the victim of the troubles so after we’ve, after we’ve done all that

PHD STUDENT: Yea

F2: It’s then we then say now has, what did actually happen. Because they’ve been able to offload and talk about how they’ve been wronged and by that time they feel more confident, more relaxed to be able to say what actually happened and then we can then say ‘how do you think the other person felt?’, as in terms of they should have known and then it’s a matter of trying to manoeuvre things and because we work in a, a short-term work so it really has to be done quite fast and

PHD STUDENT: Short-term being like six weeks?

F2: Short-term is six weeks, six weeks. Erm by, by the end of the six weeks they’re probably would start being ready to go back to work and usually depending on the circumstances, the client, it, they have, they have some inkling of, of where they are as a matter of, if you want to be happy in your job, what do you think you need to do. So that’s where, we then start from and probably then we work out how they’ll return to work
PHD STUDENT: Um
F2: Then if they've got a supportive manager you find that really it does help very much. If they don't get on well with the manager that's another problem in itself
F1: Mm
PHD STUDENT: What sorts of things might they be thinking or experiencing when they want to return to work? Are they quite excited or
M2: Er I think a significant element is, is fear to be honest (laughs)
PHD STUDENT: Yes
M2: I think that, that's a leverage we have that they don't want to get medically redeployed or, or
F2: Yea, they don't want to lose their job
M2: Lose their job. So that's an advantage, that's a leverage but I guess that means often you're not necessarily able, given the limitations of time, you're not really treating too much the underlying
F2: The underlying
PHD STUDENT: Mm
M2: Erm but you are kind of you know encouraging them to be aware of the context and to how it's useful for them to adjust their behaviour in relation to it
PHD STUDENT: Yea
M2: To be a bit more self-aware but I mean, obviously as you know the longer the most of the treatments for personality disorder therapeutically are, are long-term treatments
F2: It's long-term
M2: Yea a year or
F2: It's not short-term at all
M2: DBT and mentalisation based therapy and all this. They're not things you do in six weeks so yea
M1: And they're not widely available anyway in the NHS so that
F2: There's private, unless you go private
M1: Yea and so it's difficult in an occupational setting to do run better than, than what's out there anyway
PHD STUDENT: Um um absolutely. I mean we're looking to develop a sixteen week programme so it's, it's slightly longer but not as long as traditional erm DBT and mentalisation therapy as well. Erm so if I were to ask you erm, and we've had a lot of really interesting erm ideas and perpectives, perspectives here today but if I were to ask you overall, if we're looking at people with personality disorders in employment, what would you guys say would be the main barriers, barriers and challenges erm to them kind of finding work and well then let alone keeping work
M1: Well here the main thing is again the safety side. So I think it depends on which industry you're talking about. I think that's, that's what we always think about first before you know and then from the manager's point of view it's kind of about attendance really
PHD STUDENT: Um
F1: And the interpersonal difficulties (general agreement) and definitely that's the main barrier, yea
[? F2 speaking but too quiet to hear]
M2: I think it can be hard for people to get the sense of individual responsibility
PHD STUDENT: The individual themselves you mean yea?
M2: Often I guess people who have more PD seem to me to be people who are more, the problem is out there
PHD STUDENT: Um
M2: And that's a very difficult thing to shift in six weeks so it's, it's and obviously with a very change oriented workplace environment
PHD STUDENT: Um
M2: That, as there is here in and I guess in many, most big organisations now, that, that then makes it all harder, all the, easier in a way to see the problem as out there rather than their difficulties with adapting
M3: I think parts of the stigma as well with personality disorders, er comp, when you compare that with common er mental health problems like anxiety and depression so PD quite often er the stigma of being you know
PHD STUDENT: Yea
M3: How you say, like what that stig PD can be quite er a significant barrier so erm
PHD STUDENT: Er is that a similar case cos I remember earlier on I was saying, not necessarily for this particular person but I suppose, I mean what do you think, you could swing both ways or
M2: Well this is from a point of view of er entry, gaining entry to work for
PHD STUDENT: Ah
M3: So, pardon me, I've done quite a lot of recruitment medicales and so I seem to see things from that point of view er point in erm yea
PHD STUDENT: But that's very valuable cos like I said there's different stages when you think about employment isn't it, from, from getting work, applying to, to being in, in work and keeping the job itself so erm it's very much one relevant
F2: I think what would F1 was saying referring to in fact where er a member of staff struggled for years and is at the point where he's either going to lose his job or is in redeployment. I think now gets this diagnosis, there's a reason
PHD STUDENT: Uh
F2: So that's what we're talking and then he can get the appropriate supports. Cos then we leave the, so this is the reasons not that I'm a bad person
PHD STUDENT: Yea, yea
M1: But when you see the other side though when you start labelling all interpersonal difficulties as mental problems because (some agreement expressed by M2) there's other things that are coming up now like erm you know autistic spectrum disorders diagnosed as adults who've been working here for you know twenty, thirty years so it's
F1: Yea and because sometimes I don't think a medical diagnosis it doesn't help erm because especially with personality disorders it is going to be long-standing. It's difficult to access treatment so erm sometimes managers do want a quick fix or expect erm people to get better within a short period of time
PHD STUDENT: Um
F1: Erm and, and that's not the reality
PHD STUDENT: Um. Is there anything you wanted to add [M4]
M4: Not, not at the moment
PHD STUDENT: (Laughs) Ok. Erm
AC: Can I ask a question
PHD STUDENT: Yes
AC: So if the option was open to you, to refer erm so your clients into a programme like ours which is obviously specifically for employment, would that be something which is of interest to you?
M1: Sixteen week treatment programme?
AC: Yea
F2: Would it have cost implications or it's free
AC: No
PHD STUDENT: It's free
M2: I guess the issue would be release and I guess it'd be weighing up
F2: Release, yes
M2: For the manager whether it was cost effective
F2: Yea, to allow that
M2: To do that in order to keep the person
AC: Yea
M2: Cos they were valued I guess those who are valued it could be a good thing yea if there was evidence base for it, yea
AC: Yea so cos, dialectical behaviour therapy generally has an incredibly strong evidence base
F2: For PD
AC: Yea, which is one of the reasons why this particular version of therapy's been erm designed. So there've been two really successful pilot studies that have been run in the United States on a similar vein erm now the reason why we're obviously testing it as well in the UK is because here we have a very different employment and support benefits structure here. So we have to see if it also works here. But we have an idea that it potentially will be quite, erm quite useful. So yea, it was really just seeing if there were something like this because erm if the project is, is successful then it's something that would be we hope made nationally available through IAPT
M1: It sounds [indistinct]
F2: The NHS
AC: Yes
M1: It, it would probably depend on that person having a diagnosis then would it rather
F2: Yes
M1: Than us er instigating it, if you see what I, is that, is that what you mean
PHD STUDENT: Erm
M1: Or could we refer, refer someone who we thinks having difficulties?
PHD STUDENT: Yea, actually for this feasibility study erm its self-referral as well as
AC: Um mm
PHD STUDENT: You know, so it's not really about the diagnosis per se. In fact we don't do a
diagnosis we do a screening
AC: No
PHD STUDENT: So that's why
M1: Yea
PHD STUDENT: I emphasised that actually it's we're really looking
AC: It wouldn't be appropriate for use to do a
PHD STUDENT: At the characteristics
M1: Which is why, the way you are talking about personality disorders is there's obviously
people having difficulties who haven't got that diagnosis
PHD STUDENT: Um mm
M1: If, if, if there was help for people having these kind of work place interpersonal issues who
can't seem to get over
PHD STUDENT: Um mm
M1: It in the workplace then that's probably a better approach then trying to get someone with
that diagnosis cos
PHD STUDENT: And that's, that's ultimately what we've erm been aiming to do. So we're, from,
from a research point of view it's very difficult to recruit the people saying do you have PD, do
you want to join us, it's not (laughs)
M1: Well the psychiatrist will write something like oh yea it's bipolar whatever but then he'll write
in the paragraph below but I'm not sure it could be, I think it's probably personality disorder
M3: Or it's on the review or something
F2: Yea with that spectrum
M2: And thinking about it that a lot of those people would fit
F2: Yea with that spectrum
M2: Erm you know with the, with significant interpersonal problems and so I guess there will be
a cost benefit to the company if, if there was err, err, it would be err, there will be erm more
release time but I guess probably if erm a greater likelihood of change cos it's, it's longer
PHD STUDENT: Um mm
M1: So, so that type of thing is, it'd be useful for
PHD STUDENT: Um
M1: Because if other, if people had to have the diagnosis then
M2: This could link to, in fact we have a paid service, a service that's normally paid called the
behaviour change programme
PHD STUDENT: Oh, ok
M2: And thinking about it that a lot of those people would fit
F2: Yea with that spectrum
M2: Erm you know with the, with significant interpersonal problems and so I guess there will be
a cost benefit to the company if, if there was err, err, it would be err, there will be erm more
release time but I guess probably if erm a greater likelihood of change cos it's, it's longer
PHD STUDENT: Um mm
M2: So that, that bunch, a proportion of them, I guess there could be strong argument for
sending them
PHD STUDENT: Yea, and so we're currently testing the sixteen week yea
F2: How does that work then? We talked about it being linked to IAPT I hear a lot of time
they've got waiting lists. Wouldn't that be the same, wouldn't we have that problem?
PHD STUDENT: (Sighs) I mean I couldn't say
F2: Or would it be a special project where you can take in as many and
PHD STUDENT: It depends
AC: Well it depends how successful we are
PHD STUDENT: Yea and I know currently right now there are two pilot sites, job centres where
they have erm they have a IAPT therapist based in the job centre provid, giving in
psychological, psychological, talk therapies erm so the idea is that we want to introduce you
know kind of an IAPT service in, in job centres rolling out something like this so erm we wouldn't
know what the numbers are at this moment in time but
M1: I also think how are you going say what the prevalence of this type of problem is and er that
there's a need for it?
PHD STUDENT: For
M1: For personality disorders
PHD STUDENT: And employment?
M1: Yea
PHD STUDENT: Well actually
M1: How, how, where, where would you get the
PHD STUDENT: Currently this is my thesis, I’m, I’m doing all the research so I’ve been covering
lots of literature reviews, running focus groups as well erm
M1: But is there any accurate sort of er epidemiology
PHD STUDENT: Statistic link
F1: Link
PHD STUDENT: There is yea,
F1: Yea
PHD STUDENT: There’s some, yea
M1: Is it oh right (laughs)
PHD STUDENT: I can actually provide you more information if you’re interested
M1: But what’s that based on though, like where did you collect the data
PHD STUDENT: Erm so I got some information from the department of health, erm the
department of work and pensions, for work and pensions, their stats for people
M1: Like the office of national statistics office, that sort
PHD STUDENT: Yea exactly
M1: So that’s based on, of a, a cross section of questionnaires sent out to people or?
PHD STUDENT: Mm mm, that’s correct, yea, yea that’s right. Erm and then like I said I’m
currently conducting two systematic reviews exploring personality disorders and employment.
Erm as well as er employment work scales as well
M1: Cos it’s probably underdiagnosed but I don’t know how you the ever find the statistics
PHD STUDENT: Mm
M1: the accurate stats
PHD STUDENT: Especially if we’re not looking at diagnosis per se but we’re actually looking at
very strong traits and characteristics
M1: That sixteen week thing is that, how often do they go then? Or is it one day
PHD STUDENT: So
M1: A week
PHD STUDENT: Yea one day a week for three hours. So it’s slightly different from erm the
traditional DBT which will be two hours a week per group and then individual for one hour
M1: And then who would you write the report to, to us if we referred you or is that what you’re
planning to do?
PHD STUDENT: I mean
AC: So this was something that erm we’re potentially thinking of working, depending, well, it’s
really up to the employer erm but for the, the randomised controlled trial that we’re running there
is a possibility that we’ll actually be able to recruit people into the trial that, that actually are
currently kind of on your books so to speak
M1: So what would you want us to do in our role with that person and your department?
AC: It would be up to the individual whether they wanted to do it. Erm so this is something that
erm I’m going to be speaking more with [name] about. So whether it’s appropriate in the first
place and how erm how we go about getting erm getting the information to the potential ern
employees who might benefit from it erm and then the opting in on their, like for them rather
than them being sort of referred into, if you see what I mean, it’s erm, it’s more difficult when
we’re working with employers in this respect because we can’t have any sort of erm er hint of
coercion from the employer that the individual needs to attend otherwise there’ll be some kind of
er problem. Erm so yea it’s something that’s
M1: So if you were going to do it, when would you start this, is it
AC: The randomised controlled trial will be running next year err
M1: Oh it’s still a year away then
AC: Yea, it will be in, it will be next year. So we’re, we’re currently ern recruiting for just a
feasibility study at the moment and we don’t actually have ethical or employer permission ern to
recruit from employers at the moment. Erm but this is something that the chief investigator and I
have been discussing for the randomised controlled trial. How would we implement it with the
employers because it would be fair considering obviously we’re working with you guys in terms
of collecting focus group data if we’re then able to offer not only an employer manual, so which
will include guidance ern for working er with your clients who have personality disorder traits
er but also if we are able to see if we’re able to actually include some of the people as well maybe in the RCT then they can benefit from the therapy kind of thing. So, yea, so this is something that yea that we’ll be discussing with [name] to see whether it’s something which she would be happy with and that she can take higher erm to see if it is something that we can do. But it’s certainly something that’s on the cards erm in the future for planning so

PHD STUDENT: Mm
AC: It would make good sense to us erm so yea. And this would apply to people who aren’t just currently sort of coming through but people who are perhaps signed off long-term at the moment, who are hoping to get back to work and things like that erm so yea we, we’re recruiting quite a lot of people into the study at the moment who have been off work for two years and things like this so who are so desperate to go back but are so frightened of going back to work

PHD STUDENT: It’s going back to the fear again so yea it’s very understandable. Ok any more questions before we wrap up? Ok I think AC you’ve already explained the member checking process is that right

AC: Yea

PHD STUDENT: You don’t want to add the form
AC: So, yea, so if anybody, I’ll give you these LS to er pass

PHD STUDENT: Oh, thank-you. Ok so thank-you so much for coming today and erm you know expressing your ideas and erm thoughts. So the member checking is just an opportunity for you guys to keep being involved with our research. So I’m going to have, well actually not me, we’ve got another, someone else transcribing these audio recordings into summaries erm so if you want to, I can send you the summaries, you can have a read you can see what the general conclusion was of today and if you’d like to add anything more or change anything erm that, this will give you the opportunity. Erm we’re also, there’s a tick box here, which will be a feedback meeting of the results so er it could be some time. I couldn’t say exactly when it could be a couple of years from now but we would like to give you the opportunity to come and attend the meetings so we can present to you the results of, of the focus group of erm feasibility erm if that’s something that you’re interested in. If so, you just need to write your details down

M1: Well maybe it’s better just to have one point of contact do you think cos various people will leave and

F1: Oh well you can, can get back in touch, yea [indistinct as F1 and AC talking simultaneously] but I’m happy to sign the
AC: It’s, it’s not confidential and that’s the only thing

M1: Oh right
AC: So you don’t then have to be contacted to provide feedback anonymously that’s the only thing with it

PHD STUDENT: I mean what I’ll do is I’ll contact you first cos they’ll be some time to check if it’s still ok. If not then that’s, that’s fine. Ok, ok thank-you

[Sound of papers]
F2: Thank-you, bye
[Sound of papers]
M1: Do we have a dot in our emails? We don’t do we? There’s no dot, in our emails

PHD STUDENT: I thought you did, I just, because I borrowed [name] erm desktop so (laughs) and she does have a dot in her email. Thank-you very much, Thank-you very much for attending

F1: That’s a lot of personal information you’ve got there
PHD STUDENT: I think that’s safe to say (laughs) should I
F1: Yea you click confidential (laughs) things
PHD STUDENT: This will definitely be confidential and locked up away
F3: Ok
F1: Thank-you take care

[End recording 46.43].
Appendix 27 Focus Group Healthcare Professional

Transcription 1 (Chapter 3)

PHD STUDENT Record now, so we have it going, just one here and one there. And then of course for...not just for research purposes for recording..erm...if we can try and just speak one at a time (.) not only so we can pick it up for the recording but just so we can hear each other as well (.) and ideas that come up.

PHD STUDENT If you guys haven't been here before, the toilets are just outside (.) this room on the right (.) so is the fire exit, so just out there on the right. There isn't any tests for alarms today just so you know, so if it does go off (.) that means it's real. (#1) So you just need to follow me and I will take you outside to the safety place. Ok, so yeah, tea and coffee is over there and (.) and please help yourself to doughnuts and everything else that is in front of you. Water is on the table too. So...erm...before we begin,(.) I'd like us to do a little icebreaker, just to go round in a circle, so er...what we're going to do is two truths and a lie. So, what you need to do is to say 3 things about yourself, and one of them or 2 of them are truths about yourself and one of them is a lie. You have to guess which one is a lie(.) Does that make sense? (#1)

PHD STUDENT Ok well I'll go first. (.) Erm (#2) Ok so I have a tattoo...erm...I speak mandarin and I have a brother and a sister. (#6)
P8: Do you want us to guess now?
PHD STUDENT Yeah sure.(#2)
Everyone: :::

[Last one...just the last one...first one....which one?] ( )

PHD STUDENT The tattoo? Ok...what did you say?
P4: Brother and sister.
PHD STUDENT Ok,(.) any other?
P6: Yeah...you speak mandarin.
PHD STUDENT: oh you think that's a lie? (.) Oh right..(#1) (laughs). Erm so the lie is the first one, I don't have a tattoo.(.)
P1: I knew that (laughs)
Co-f: So erm..(#2) I'm a dancer, I'm (#2) a freelance makeup artist and I have (#1) brothers and sisters, many of them,(.)yes.
PHD STUDENT: which one? I don't know. (#8)
P8: You're not a makeup artist
Nope.(#4)
PH: many brothers and sisters? (#2)
I do have many brothers and sisters, I am a free lance makeup artist (.) I'm not a dancer. (Everyone laughs). [It's quite hard to guess] ( )
PHD STUDENT: Do you want to go next? (#1) So this is (Says persons name).
P1: (#1) Hi...(#2) I used to be an all terrain biking instructor (#1) I love green peppers (#3) and erm...I have lots of siblings (#7)
01107: What was the first one, sorry?
P1: Erm...I don't remember(.) (Laughter).
PHD STUDENT: It was the first one then...You got her {01107).
01107: Something with bikes, Something about bikes, P1: oh yeah. All terrain biking instructor (.)
PHD STUDENT: Or is that just a fool to get us? (#2) I don't know, last one, siblings.
Siblings ya.(#2)
01107: ( )
P8: yes...hmm.
P1: I hate green peppers (laughter)
PHD STUDENT: Alright I'll make a note to myself (laughter). Thank you.
P2: (#1) I'm {says name} from the Richmond Fellowship erm...I'm a part time radio presenter (#2) erm I'm from Dublin in Ireland and I've been in holiday in China (#4).
P4: You're not from Dublin (#4). P2: I am from Dublin (laughter). (#4) PHD STUDENT: Oh I don't know..
RM: Holiday in China?
P8: Yes, that's right. Yeah it's the lie. P4: He looks ( ) maybe he doesn't actually ( ) work. PHD STUDENT: Yeah maybe too hard (laughter) (#3)

P2: Correct.

Everyone: Ah!

P2: Although I have been on holiday to Japan (laughter),(#2)

PHD STUDENT: If you haven't been I would recommend going its amazing (laughs).

P3: Erm...(#2) Alright.

P1: I know it's so hard (laughs).

P3: Erm I'm an only child, I have an 18 month old daughter (#1) and I've worked in mental health for 18 years. (#1)

01107: you haven't got an 18 month. (#2)

P3: (#3)(laughter) You didn't see me when I was pregnant!

PHD STUDENT: That was good. Thank you.

P4: I have an 18 year old daughter.

PHD STUDENT: uh huh.

P4: Erm I'm training for my second marathon (#1) and I went on holiday to New York this year.

00:05:14-7# P8: The first one. 01107: The first one. 18 years old...

P4: The first one, she's nearly 19 (laughter)

P6: You didn't go to New York this year.

P4: I did...P1: Was it good? P4: it was brilliant. (laughter) [P4: I've never run a marathon, P1: You know that's my home. PHD STUDENT: You know I thought, I thought that perhaps, you would have done I know know...( )](#4).

P6: OK sorry...(laughter). PHD STUDENT: Ok this is {says name}, P6: ok...(#2)(Laughter). I (#2) am the only male of 5 siblings I erm... (#8) I am the only male of my...I er (#2) used to play in a band(#4) and I do (#2) a (#) I don't know what I want to say...(#3) I used to work with cars. 01107: (#2) No...you didn't work with cars (laughter).(#2) That's a lie right? P6: No..P8: Used to be in a band? The only male...is the lie (#3). P6: Yeah.

Yeah. P1: Oh I have heard you tell that.

PHD STUDENT: I thought it was a truth. P8: Oh...( )]

PHD STUDENT: Thank you. 01107: The first one is...erm...(#2) I used to run 100m, erm (#2) I erm (#2) was part of a dance group and the last one is I have over (#4) 7 brothers (#5) (laughter). Which ones the lie? P3: The 7 brothers.

PHD STUDENT: We're getting better at this aren't we? (laughter). Thank you.

P8: I'm (says name). (#3) I do yoga every week without fail, I have done a parachute jump (#1) and

Before we begin discussion today, I just wonder anyone particular take in part focus group before? whether as participant? Focus group? internet or facilitated yeh? L

No, do you want to share(#1)Mhm (bejahend) your experience in one of the group? What you guys do?L

Mm mm

9:28 not clear P1

Ok bring carers to get some information more ideas...general discussion as well yeh, yeh, exactly. L

9:33 not clear P1

I suppose this is what we hope to aim today. So.. coming together to hear your ideas and overhearing other people's ideas as well. From your information, hopefully will give us all relevant information about all personality disorders and unemployment. L

So.. great..ahm ok so why are we here?L

Ahm. just quickly I follow up here for you, but just quickly let you know 3 main things we want coming up of focus group today the information is to mainly develop a treatment manual for clinicians as well as for staff, for the staff like the employment staff, they can use, essentially to help clients prepare for employment yeh. So it could be through either teaching better skills such as managing intense emotions or mainly more practical skills or interpersonal practical skills like that. L

So in order to develop a treatment manual, we also want to go and develop a scale, a questionnaire ahm it is called preparedness for employment scale for individual's personality disorder, so using this scale hopefully we aim to identify the challenges or potential support for
people with PD to obtaining and retaining in employment. Ah. Also to evaluate the intervention of developing to see how we are helping them along in the path to employment. L
So a lot of thing is to develop a footprint for employers and this is ah. I am really excited about it. This is a positive manual we want to aim for really, it’s, it’s, it’s guide in a way how best to support someone with the PD in a workplace. Ahm, Really, trying to reduce the stigma and to improve the work environment for both parties.
PhD Student: Ahh..Can I just ask a question?
P2; Yeh of course.
The question as am covering for others who couldn’t be here today?
PhD STUDENT: Sure
P2: Just give a definition, right, then there’s also border- I often hear borderline personality disorder. So I wonder could you just clarify, you know give a bit more erm, information on PD er and also the mentioned term borderline so I’m just fully in tune. Maybe it’s the same for others as well? Oh, is that what you’re coming to?

PHD STUDENT: Exactly! So that’s a very good, relevant question! Absolutely yeah, I thought that might come up so you, pre-empted! (laughs). So, EMPOWER is looking at, when we say personality disorders we’re looking along a spectrum, so a cluster of different disorders. Borderline would happen to be one of the 10 when you describe someone with personality disorders. So, I won’t go into too much detail for each one as I think it will take too much time, but they all have certain different personality traits. So individuals may have met that diagnosis because those traits may have interrupted their daily life. So that’s why they have met that diagnosis per se, erm, but I actually wanted to ask you what you’re understanding is of PD or your experience of working with an individual with personality disorder.

P4: I work in Waltham Forest in the mental health access team so we would, we would- our team is divided into two we’ve got our intake service which is a triaging service, so all the referrals into mental health come by our team. And then we have what we call ‘brief intervention’ so if somebody needs ongoing support but not the support- if they don’t meet the needs- the criteria of CRT, the brief intervention service we’ll support them until hopefully mental health is stable and they go back to their GP. My role is around job retention so I’m supporting all of those clients who have job retention needs and liaising with employers. But we have, we do have a lot of clients with either the diagnosis of a PD or have traits of PD, ‘cos it hasn’t been formally diagnosed as yet. But I suppose, you know, you have there are certain sort of criteria that you- you pick up on. So certain symptoms you’ll pick up on and you look for indicators that person potentially has a PD. Erm, but my experience a lot really, there’s a lot of personality, to take away personality disorder, the person behind it in terms of how they’re coping you know, so you get people with a range as you say, a spectrum of difficulties or challenging presentations and erm…you really have to address that person as you find them there and then as opposed to saying, well you have this diagnosis so therefore we treat you this way, if that makes sense=

PHD STUDENT: =and when you say a ‘range of difficulties’ would you say it kind of falls into perhaps emotions=

P4: =Absolutely, it’s impulsivity, struggling, managing sort of, you know, the peaks and troughs of daily life. You know, like throws these curve balls at us on a daily basis and some people can cope better than others, and obviously its having that difficulty in coping with day to day issues. And that then linking in with sort of emotional instability erm, and struggling, and needing that support to sort of cope with that phase until that face has passed.

PHD STUDENT: Yes, essentially that. I mean the reason I brought it up today is to clarify what EMPOWER is all about and the definition we’re using is very much in line with what [says participants name] just described in that situation. So these individuals tend to have very intense emotions and forgive me if you already know this erm, but just for the sake of clarity for this discussion we often find they may have difficulties in things like interpersonal relationships. So whether it’s in the workplace or whether it’s within personal relationships either way, yes, they do tend to perhaps impulsively, and that in the workplace, I don’t know, that’s why we’re here today to discuss those areas of interest. Any questions so far? Ok, fb.
P4: If you’re interested in looking up the different diagnosis there Royal College of Psychiatrists do very good handouts that we often give clients. But its sort of easy layman’s terms I suppose, without it getting very clinical.
P2: That’s on the website yeah?
P4: It’s on the website.

PHD STUDENT: So, for the next hour or so erm I’m just going to guide you through various stages of employment. Specifically we’re looking at the stage where people with PD are thinking about getting a job, followed by erm, applying and gaining a job and then the third stage along the time line is remaining at work, and keeping your job. What I would like us to think about is what potential impacts that might have on people with PD and also try and consider some of the potential barriers that might come up for them. So, before we begin I would like to clarify there’s absolutely no right or wrong answers for this discussion today, I really am just purely interested in what you have to say. And we’re also really interested in both positive and negative comments. So a lot of time from my experience the negative comments are the ones that- you know- give us (1) information we didn’t necessary think of before. I think it’s also really important to note that in employment in general, let’s say, you are at work and your line manager has given you a deadline to work towards, I think personally it’s going to create some sort of anxiety right? It would for me! Erm, so what we’re looking at is not just that, but someone with a personality disorder will maybe not only experience anxiety but perhaps take it to the extreme where they may perhaps miss that deadline, or not go into work. We are focusing on those who experience those extremes and then take it a step further. Does that make sense?

PHD STUDENT: We’re at the stage of thinking about getting a job. I would like you to think of someone or an individual with a personality disorder or strong traits, who’s been unemployed for a substantial amount of time. So we’re not talking about 3 months here, but talking about at least 12 months or more and they really are struggling to get back into work. What do you guys think? Do you think there are any barriers to them considering and thinking about employment? I see some nods. [Says participants name]
P3: Erm, I’m just thinking about- I’m working with two- two quite young ladies at the moment who actually fall into quite a positive category in terms of getting back into work. They are within the young people’s age, they qualify for a lot of the stuff ’cos they’re under 24 erum but thinking about those two and people I’ve worked with over the years. When they first come to us they have quite a clear idea of where they want to go and how they want to get there, erum you will work with them to support them in that process. Erm, but you may find when you get to the stage where you’re looking to apply they’ll put their own barriers up and decide that’s no longer what they want to do because I suppose, it’s starting to become real.

PHD STUDENT: So before they come to you, what do you think might help them, even, ’cos they’ve already thought about employment beforehand so what do you think has helped them? To get to that point to come and see you?
P3: Erm, I think it- normally a lot of encouragement from whoever they’re working with at you know, erm, I think- I mean when you look at the referrals we get coming through they tend to come from certain professional staff, so I think obviously, one of the consultants at the moment for the last probably 4 or 5 years, he seems to have vocation quite at the top of his agenda. Whereas 10, 15 years ago the psychiatrists weren’t thinking about a holistic, they were thinking about treatment. Erm..so, I think “sighs” if they’ve got that relationship and they’re thinking you know, and I think a lot of young people are thinking that, because they’re thinking that’s what everyone else is doing, and that’s what I want to be doing. Erm.

PHD STUDENT: So a lot of external influences? Especially the support they’ve got at the moment in time.
P3: I mean a lot of the people I’ve worked with- most of the people we worked with have been unemployed for normally (pause) sometimes up to 10, 15 years. So you’re talking long term. Erm, but I think even even when we’re looking at where they are 20 m 18 s want to go and how they’re going to get there. Sometimes they’re so far away from the job market, it’s about breaking it down into really, really, small steps. Erm, and actually trying to support them every step of the way. Erm, I mean one of the ladies at the moment wants to first of all, she only wanted to volunteer, now she’s changed her mind and she wants to go to college but she actually wants us to go along with her and be part of that process. And I just think-

PHD STUDENT: Sorry, I just wonder, sorry to stop you there, but you mentioned that- so they have the mind set already that’s why they’ve come to see you erm then you say that, as you work with them they notice certain barriers come up? What kind of barriers come up? In your experience? Is it things like thoughts or…?
P3: Yeah...I think probably around confidence, around anxiety, I dunno, you know like sometimes the thought of something you know, is really good and you want to work towards it but then, I mean I do myself sometimes but then you'll put your own barriers up or if I do that erm, I m- some- with some clients its around the benefits. Erm, because they're worried about you know, especially because of the changes coming up erm, for other people I don't know, maybe its just about taking that initial step (pause), because you know its going into the unknown and once their own that journey are they going to be able to maintain, you know, to continue on that journey.
PHD STUDENT: SO lots of kind of worries it sounds like.
P3: Yeah.
PHD STUDENT: Has anyone else had any similar experiences to what [says participants name]'s mentioned?
P1: Pretty much everything.
P6: Because I’m thinking about, because years ago I have been referring lots of people to you [says participants name]. I think, I, I will- at a point when I am with a client, they're really eager, they're really up to go. I think by the time they get to [says participants name] and you start trying to get them into doing into what they want to do, that's when obstacles come up. I don’t think we see as much of the obstacles as you do. When we pre-empt them they think about what they are, but by the time they get to your stage it actually hits them because you’re just focusing on employment, getting them back into voluntary work, and I think that’s when the barrier hits them. So everybody in their circle as well that you’re dealing with, it’s kinda their going the same thing, I don’t know if you work the same way.
PHD STUDENT: So is it then is it about managing their expectations?
P6: I think - I think it’s about managing the transitional stage. I, I wish sometimes, I used to wish that we could be linked up a lot more between that transition stage from moving from myself [therapist] to someone else like [says participants name] [Richmond Fellowship] who will then take me to the next stage. I think sometimes it’s a breakdown of that link and we don’t have enough time to do. Either when I call I might speak to someone else.
PHD STUDENT: So it sounds like there’s a lot of operational things that could get in the way?
P6: I think it’s not just operational, I think it’s the way the NHS is structured. It’s structured where services are not- should be joined up, but because we’re in different bases, because we probably have different phone numbers and its difficult to get in touch with different people...
PHD STUDENT: Do you think it’s quite an important factor that might- be a barrier about thinking about employment?
P6: I think it is, I can only site the difference between working with [says participants name] and [says another healthcare professional outside of the focus group] we were here and on the same base. Erm
[One participant enters late]
PHD STUDENT: Just take a seat, we just did some introductions and we’ve been talking about – erm, there is some water here if you need one- we’ve just been talking about the stage of thinking about getting employment. Please feel free to jump in as well.
P5: I’m [says name] from [says organisation]. So sorry to be late.
PHD STUDENT: Hi, welcome, ok, please carry on.
P6: Yeah, I guess when [says another health care professionals name] and I were on the same base and therefore she could come into my room and speak to me if she’s just seen the client that I had referred to her, “[clients name] is going through these difficulties, can you help me with this?” Or I can go and see her, “Guess what, he has changed his mind, how can we work with him?” . That, that process and I can think of people that we have worked with who did end up in full time employment because we were able to work together.
PHD STUDENT: [says participants name] did you want to say something?
P8: Well it's when I was thinking, just about the people who experience personality disorder, erm, I suppose I work with a lot of people who are in retain, so keep their job, who have personality disorder, not so many finding work. But one of the things that comes to mind is that somebody might be very, very specific and now what they want to do. And the fascinating thing, I think its part of vocational analysis is about actually looking, assessing, and supporting health and somebody’s finding out whether that’s realistic or not. And sometimes that’s a bigger job for someone with a personality disorder because either they will, or can, we all can over estimate their skills and what they want to do – “I want to work in the Ritz” “I’m not looking anywhere else, I want to work in the Ritz”, “I’m good for that, I’m not good for anything- I’m not working in Tesco’s or in a café, I want to work in the Ritz”. That kind of specifics. And sometimes it’s the
PHD STUDENT: I just wonder whether-
P8: -so make vocational analysis part of the work is important.
PHD STUDENT: I just wonder whether they have these thoughts about specific things, exact
things they want to go for, do you experience a lot of- are these thoughts quite prominent for
them? “I definitely need to do this, I have to do this” and things like that?
P8: it depends on the individual really. You have some people who will come in and they will-
you know when you’re actually looking at their background, their skills, their knowledge, their
experience, ern what they do in their private life maybe they’re, there are things they are doing
part-time or that they want to look at has, ern, you know doing PE or going to the gym and
they’re really- they sometimes it can be realistic for example somebody goes to the gym and
wants to do that, and said “right, well actually I wanted to make that professional” then that’s
really, that’s possible, that profession. But it can be something completely off the wall. Ern, but it
varies, it’s so different according to the individual. But it’s that sense of emptiness and (1) and
feeding back one to another what was possible what isn’t possible, you know?
PHD STUDENT: I think…
P8: The self-understanding when sometimes the self-understanding is a little bit off.
PHD STUDENT: I think it’s really interesting that you mention that you’re experience is a lot
about retaining that job and I suppose, I have broken it down to three parts, from thinking about
employment, but just going back to emotions, are their any particular emotions that come to
mind that your clients individual experience, when they’re at that thinking process?
P8: Fear, I think it’s the main one.
PHD STUDENT: Yeah?
P4: Just to go back to what [says participants name] was saying I think in my experience, clients
with PD don’t have trouble finding the job, they get the jobs. And when I was doing employment
support as well as some job retention, now I’m just doing specific job retention I didn’t have
many clients referred with a PD who would need the support finding a job its more that clients
with psychotic condition or maybe depression or poor motivation etc. So my experience is
people with PD will have the motivation and have a lot of very good skills on paper, look
excellent but obviously, they get into the job and it’s then when the interpersonal difficulties get
in the way.
PHD STUDENT: So I wonder, what do you think helps them get that job then in the first place?
P4: Well as I said, they have the motivation and you look at any of the evidence you know, if
you’ve done the IPS training, evidence says its somebodies motivation is what’s going to get
them the job. Erm, rather than necessarily, well you obviously need experience and skills but if
you have experience and skills but you’re not
motivated, you’re not going to get a job so having that motivation coupled with some experience
in training. You know, a lot of my clients with diagnosis of PD are highly skilled, highly trained.
But obviously when it comes down to the day to day social interaction with colleagues at work,
you know being able to manage those you know difficulties that happen, or perceived as
difficulties to them.
PHD STUDENT: I definitely want to move on to that stage of when they are in work and
remaining, but just coming back to what [says participants name] mentioned about that feeling’s
of fear before even initially getting there, I mean how would that manifest itself in your client?
P1: Avoidance, I don’t know I’ve had a few clients where you just spend so much time trying to
get them in and they just don’t show up. But everytime they’re like “I really want to” and then
when you say “Ok, so this week you’re going to go do this”. “Ok” and then next week, it’s not
done and then…yeah.
PHD STUDENT: I’ve got some nods.
P1: Just a lot of avoidance, a lot of avoidance.
PHD STUDENT: Has anyone else had similar experience?
P5: Even sabotage, I know that’s a strong word but sometimes you kind of go through a big,
huge process, you know you’re there, almost and then suddenly it’s like no, no more, enough.
So it’s a lot of combinations of fear and everything else just at the last minute so…
P1: I think they’re afraid of judgement a lot too, like, there is so much stigma around them,
they’ve probably been told horrible things in the past and so they’re, what I’ve found especially
recently, just a lot of fear of what people are going to say, what they’re thinking, erm…
PHD STUDENT: You mentioned memories, or things in the past, is that something that comes up quite frequently?
P1: Definitely
PHD STUDENT: So not just about thoughts about what other people might think but what’s happened in the past?
P1: Yeah I definitely think that the past comes up, but I think a lot of it is just fears that aren’t locked at. You know? Like realistically? Like factually. So I feel like a lot of it, once you actually break it down, there’s not a whole lot there.
PHD STUDENT: Ok
01107: That’s why I think that’s what’s missing, what I think I’ve always noticed missing is that, we know all of this so we we’re aware of the fears, we remember the thoughts that they have about themselves and others and it’s something for me, sometimes that is always missing is to kind of bridge that gap, so I totally agree with you, they have not got a problem with (). They haven’t got a problem finding a job or even getting one.
P1: They’re usually quite personable.
01107: It’s just at that time when the fear pops up and the thought pops up, and it’s just not that person there to help you with that at the time to normalise it. To say, actually going into a job with a boss that’s – has huge stigma around personality disorder or mental health, It’s really tough. Just at that point or over hearing somebody in the canteen talking about people with personality disorder and- or mental health. And have to go into work the next day I think that’s the issue, how do we bridge that gap, so that retention? Retention is maintained.
P1: I think just a huge fear of failure as well.
PHD STUDENT: Fear of failure, ok.
P1: I think it’s probably one of the main things that we-
PHD STUDENT: Is there any other emotions you think could get in the way?
P8: That’s a really good point that fear of failure. Because the sense of the fear of failure can be there and yet that reluctance to actually look at that fear, but prefer to say “I’m not afraid”. “I’m not afraid”. And you underline, you know, and it’s- that’s really difficult and ever so hard for the individual. Ever so hard for the individual.
P6: I think another side to that though, is erm, shame. Because people struggle with that diagnosis.
P1: ‘Cos they don’t have identity yet, don’t they? A lot of them, especially the younger ones that we work with. They have no identity so they don’t even know who they are let alone what they want to do.
P6: Yeah.
PHD STUDENT: Ok, that’s really interesting, another thing I wanted to bring in in this section is- so we’re focusing on the individual with PD but there might be other elements and I- tell me what you think, but things like physical illness or learning difficulties, even a criminal record and issues around benefits. Do you find that, that is a potential barrier for even thinking about getting a job?
P1: Absolutely, yeah. Absolutely.
PHD STUDENT: We have a lot of nods, does anyone want to say anything? [Says participants name]
P2: Well just from my experience with the () tidying up of procedures and benefits, is that people may have good intentions to erm, get back out there into the workplace but if the perception is something might go wrong, and I could have (), then they would rather not try.
P1: Agreed.
P2: Erm, so that becomes an issue in itself. It was just that they might have good intentions erm, opportunities even my come up but it’s not just the fear that it might not walk out, but it’s also the fear that it could affect their benefits.
P1: Yeah!
PHD STUDENT: Ok.
P2: And then the struggle to, you know get the benefits back to stop the worrying.
said, you know, what should I put down and what I'm going to say something like that are you at the interview. So it's how to explain, it's just I think personality disorder, it's almost saying there's something wrong with me-as a person and so often times when clients have been applying and said, you know, what should I put down and what I want to put down about my mental health.
And then I would say, “Well you know, you also suffer from anxiety don’t you? Put that down instead if you don’t want to use personality disorder” so its sort of trying to fudge that diagnosis because, let’s face it, it isn’t the nicest of- you know there’s something quite different.

P2 & P8: [yes ()]

PHD STUDENT: There’s a lot of concerns and worries about what other people might think?
P4: Yeah, what does- aside from you know, if even if you don’t know what personality disorder means to a lay person its basically saying there’s something wrong, inherently wrong with you as a person, so it’s- I think that just enables personal disorder, it doesn’t sit comfortably with it…without even knowing what it means.

PHD STUDENT: Has anyone else had similar experiences?
P5: I think when it comes to filling out application forms it asks for health, that is you know a massive sinking point there because it’s pretty kind of black and white as “what is the health problem that you’ve got”, “Are you taking this, that and the other, what are you getting help with?” You know, and it’s again, whether to explain it kind of as anxiety but any kind of mental health problem these days involves a form that goes to occupational health so there’s this extra hoop to jump through really and that puts a lot of people off.
P1: Always being singled out.
P8: And there’s a real sense that erm, the reason that you probably disclose is if you want an adaptation to the work. The equality Act.
Everyone: Yeah, yes.
P8: If you don’t want any adaptations, you don’t want people to know, then you don’t say. And that’s a personal choice.

PHD STUDENT: So what you do you guys would think would help that individual then at that moment to continue on their pathway if there is fears about disclosing?
P4: Sometimes I would have a doctor that would contact me about a client and say this person is wanting to apply for a job but not sure how to- what to word on the application form and whether they should disclose or not. And I’ll just see somebody for a one off session and explain the pros and cons of disclosure about the equality act, what that might entitle them to etc, etc, and then leave it to that client to make that decision as to whether to disclose or not but if they are going to disclose, I’d give them advice on actually how to do it. Whether it’s in the application form or whether it’s in the interview or whether its when they’ve been offered the job, then making 42m 30 s that disclosure. So, I suppose its educating the client around what they can and can’t do, what the actions are and sometimes that can be really helpful. “Oh actually, I now understand” and it takes some of the anxiety away and then they know what to do. So..
P3: Yeah, and I think as well, it depends what question they’re actually asking right on the application form. Like on your form there, you said, do you consider yourself to have disability. So that’s going to [be=

P4: [a grey area]
P3: [yeah] yeah I mean, I’ve got a disability that’s covered under the equality act but I don’t consider that to be a disability because it’s not disabling me because I’ve got something in place to you know, so, it is. It’s based on what the individual perceives and what they- but other forms it clearly doesn’t give you yeah- yeah do you have? Do you have? So it’s a black or white yes or no answer. So it’s about having that conversation isn’t it?
P4: Exactly.
P8: Under the equality act one should not be asked= [(i)]
P1: [I was going to say that! That’s illegal! They shouldn’t be asking that]
P8: anything about your health situation because it would be against the equality act.
P1: Yeah it’s discrimination.
P2: Absolutely.
[Everyone talks]
P8: …and you don’t have to answer when actually if anyone says anything you can say, actually under the equality act that’s not right.

01107: and I think it’s that type of education that I would tell my clients, and say you know, and keeping it within the law, and saying, “you do not have, you have the right not to disclose, this is the information, [the pros and cons.]
P1: [Even at interview] they’re asked. You don’t have to answer those questions.
P6: But I think that, that, erm, there is that element of responsibility at that stage that- that, for compl- I’m gonna put this information down which I’m going to be responsible for (1), you know, and I think for it’s a transition for some people who we work with because responsibility up to that stage may not have been completely them or responsibility may not have had such an onus until you put- you know your information down on the application form.

PHD STUDENT: So let’s say this person realises actually this is more responsibility than I’m used to, what sort of things might be going through their mind at that moment in time.

What kind of emotions might they be experiencing?

P6: “Will I be in trouble?” “What’s going to happen?” You know.

P1: “What if I find out? And I don’t put it down”

P6: Right yeah.

P8: What if they find they-?

PHD STUDENT: So that fear then isn’t it? Of what could happen?

P8: yeah yeah

P1: Oh yes.

P1: They are very good and coming up with all the kind of worse case scenarios that could happen.

PHD STUDENT: and these worse case scenarios, these thoughts and emotions do you think that actually stops them? What does it lead them to do? Do they continue to?

P1: I think it’s avoidance, they tend to avoid. Often at times.

PHD STUDENT: Yeah.

P1: Or they go in it without a plan and so they are not able to regulate ‘cos they’re having all the negative thoughts which turns it into a disaster and then they really avoid.

P8: I think it needs to be reco- there’s kinda something about erm, people with personality disorder can be sometimes have- as you say, huge, huge, struggles and difficulties and feelings of unworthiness and not able, and people, you know would feel guilt and find out and there’s actually people with personality disorder who do incredibly well.

PHD STUDENT: and so those who do incredibly well, what helps, what do you think is helpful for them at this stage, so that they’re able to write that CV, what sort of thoughts might be helpful for them?

P8: Well those people won’t come to us…’cos they all will have incredible confidence and they will possible be able to say things which aren’t absolutely…

P1: They’re just a bit more resilient.

[Everyone agrees]

P4: They do come to us when then they break down at work.

PHD STUDENT: That’s when you experience when they want to remain at work.

01107: That’s when I would refer to say [says healthcare professionals name] to say, can you go to this guys workplace with him, to the staff meeting, and erm, she’ll be excellent in just making sure that they give him the time off, keep their job, go to try their emails and those kind of stuff.

P6: But I think the other thing is, is that support network, so whether it’s a professional support network or not, it’s that support network.

PHD STUDENT: Sorry that support network that helps them to?

P6: Go through

01107: Connectivity.

P1: To do the process. They don’t have- people don’t have families do they a lot of them.

P8: I think that’s the thing that’s the difference between someone with a personality disorder as you were saying, they’re alone.

P6: [Hmm.]

P1: [Very much so.]

P8: And somebody who is actually supported on all sides will actually change and support them recovering.

PHD STUDENT: I just want to clarify this support network, are there clients out there who perhaps do have a support network so on paper they do have a mum and dad but actually then still struggle?

P6: [Hmm…yeah]

01107: [Yeah]

P1: It’s the environment at times.

01107: I think for me the- the, from the time I hear and this is my judgements somebody coming into our service, [says service department] I always think (1) the invalidating environment that
they’re actually in, is maintaining some of their behaviours, or reinforcing some of their behaviours and that same environment, very rarely do I have clients where I got clients where their environment is validating. It’s either, they’ve left the abuse from a childhood and now they’re in a situation whereby whoever they’re living with is reinforcing the same behaviours that they’re there to change. So I try my best not to use the environment that they’re in. Because that’s why we have support workshops to educate the environment; to help the person to change.

PHD STUDENT: Ok, ‘cos I was going to say-
01107: It’s not that the new environment is not doing very well but all it’s doing is reinforcing the same behaviour.
PHD STUDENT: I was going to say, ‘cos if you bear in mind the environment we know that sometimes we can’t change the environment that we’re in but what, correct me if I’m wrong but what you’re saying is perhaps, putting in place a support network to create that environment where they can start-
01107: Or helping the environment that they’ve got, understand, like we you know like therapy would do. We would have support workshop for the supporters, we have DBT skills books for the- P1: and GP information, ‘cos GP’s can get in the way
01107:...educating the whole environment around this person. It’s hard work but…
P8: And so you’re sort of talking about actually working with the system- the system the person is in.
01107: yeah, so the structure that they’re in I think is the issue.
P1: ‘cos [says another participants name] and I were talking earlier and just to tab onto that. Like I’ve had- I can think of at least 5 clients off the top of my head since I’ve started with [says name of service], that the GP’s have told them not to go back to work.
PHD STUDENT: Right ok.
P1: and I work so hard to get them thinking about work, excited about work, and start to think about what their future would like, and what does that mean? And then they go to their GP and the GP’s like, “Oh er, you don’t need to worry, don’t worry about that”.
P8: There is also the sense of the two sides, or four sides of the house where maybe the GP’s seeing one side, we’re seeing another.
01107: Hmm…that’s a good point.
P8: because we don’t know how someone is presenting themselves to somebody else and I find that when one does go into work, with the experience and understanding of how somebody is at work and what you’re hearing, and then maybe what they’re saying to the GP can be very different. Because it can be that manipulative part, you know that somebody needs to manipulate the situation in order to get their needs met because they’re not used to actually asking to get their needs met. So that actually, kind of comes out in situations they’re in, you know that, and that’s really tough I think, I think that’s really tough for us, to have you know, they might be that the GP or the therapist is being really difficult or it might be, we don’t know do we, we only know- we don’t know which.
PHD STUDENT: So there are lots of different contexts that have come up at this stage. I just wonder because we mentioned the emotions of fear and shame whether that is something that is carried on to this stage of employment? So, like going to the GP, being told that sort of thing, what sort of things might they be experiencing?
P2: Can I just say that if erm, if they- when they start the job, if they haven’t actually said what their condition is and then they have some very intense emotions which could just spring up over some procedure. They’re quite capable of doing very well most of the time or they have an impulsive period, you know, that’s, that’s going to need to misinterpretation. Erm, it could affect other colleagues, and get a reputation so on and so forth. Erm, even if people don’t want to mention the word that includes ‘disorder’ it’s becoming more acceptable now to say “Well I have anxious periods from time to time” or even employers ask “how do you deal with stress?” it’s one of the questions they’re asking more and more now. People can put it across in erm, er more acceptable way, say and the next question will be, “Well, give us an example” and you could say, “Well I got very annoyed with this particular procedure, and I can even say, well I know it’s even a little bit silly but I felt very passionately about this and I kind of and I express myself very- whatever. Erm, so they would know that. But if you don’t say anything at all and then there’s an incident. It’s more difficult to recover.
01107: [says another participants name] I think should write the book.

52 m 30 s
PHD STUDENT: Yeah because that's like a gentle support, that environment for that individual. Yeah, any other thoughts about that?

P1: Role plays yeah.

PHD STUDENT: So we talked about various contexts, I just wonder do you think- what other tasks do you think this individual might consider in order to gain employment, or return to work?

P1: Role plays in session.

P5: Well practicing the questions for an interview.

PHD STUDENT: Ah, so the interview process? Ok.

P3: Which is maybe you know, you'll have the job description, you might get somebody to some- a mock interview or some sort of panel or group or you know really difficult questions. Then it'll be worse than you would anticipate it to be, so yeah.

PHD STUDENT: So you found that it's been helpful for them.

P8: One thing we do is explain the shortlisting process and how people are marked on competency. And also how people are marked in competency interviews. So they really understand why they are getting or not getting the job.

PHD STUDENT: In what way?

P8: If people you know, if you go through competencies or if you look at the competencies and you know what you're being judged on then its much easier to prepare.

PHD STUDENT: So I assume that because you are practicing interviews with them that they find this task particularly difficult? What is it about that tasks that they find difficult?

P4: I think that if you haven't sat in an interview for a number of years, it's daunting, I think interviews are daunting for anybody. So it's about upsampling somebody if they haven't sat an interview especially if you haven't sat an interview for years, the way as you mentioned about the competencies the interviews are very different now than they used to be. It's not just "tell us all about yourself" it's you know, "explain a time when you've done x, y and z".

PHD STUDENT: and do you think that would be particularly- so like you said it's quite anxiety provoking but-

P4: I don't think it's particularly daunting for anybody with PD I just think this what we do to prepare any of our clients when we're working with them. Just general preparation.

P8: The thing with people with personality disorder () is that, is that's person's presentation.

PHD STUDENT: Their presentation? Right. So, in how they behave?

P8: Over confidence, as well as under confident, it's the- and allowing somebody to understand how it feels 'cos empathy is a hard thing as well. To understand how it feels to meet the interviewer with their presentation. Which is the same for everybody you know, something we're really, really, nervous but there's actually some people who will answer the question, "Well I've done it! I've done! I did it!" "I seem to have done it perfectly!"

PHD STUDENT: What I'm interested in [says participant's name] is you talk about someone who's really over confident. I wonder what would their thought process be? Behind that?

P8: I work with people who truly believe- they look at the competencies and they say, "I've fulfilled all them! I explained that all perfectly! Oh, well why didn't they choose me?" and that understanding that somebody is better. And it's not, I'm brilliant, but it's "oooh, actually probably the pain that I've failed and that somebody was better than me"

P1: It's always like this.

P8:...but it won't come out as that. It'll come out as..."I should have got it"

PHD STUDENT: And what about someone who maybe is at the interview process but actually really anxious?

P1: It's always like this.

PHD STUDENT: that's a [coping strategy, and I guess that's why over confidence=]
P8: What someone doesn’t smile, I feel they maybe don’t like me…
01107: what is that for? Really?
P3: I think as well with the competency based interview questions, erm a lot of them are asking you about your experiences in certain situations especially for some of the younger people, if they’ve not had jobs before they find it difficult to relate it back to a situation other than. So it’s drawing out a situation with them beforehand that can relate, you know so they can answer the question but it relates to another part of their life, yeah.
PHD STUDENT: It goes back to what [says a participants name] was saying about that certain age, and not letting, having that experience to fall back on.
P6: Sorry the other thing I was thinking of though is going back to the interviewing process, for all of us, right it’s a human thing, irrespective of what’s on paper, it’s a human thing and I think that, that I know that for some of the people that I work with, it’s, I, you’ve got to be able to just small talk, because you know interviewers. You might be saying the right thing but just like you might judge, the interview is going to judge as well. So to kind of be aware and understand that, so therefore part of the training is, you’ve just got to know how to small talk.
P5: It’s the unwritten thing isn’t it, that kind of body language, that kind of body language, do you fit in there? Are [you…
P4: [Are you going to fit in with the team?]
P5: Exactly. Yeah, does he like you? This kind of thing, and all the kind of before you get to the ‘interview’ situation, are you going to be late? Haha. What should I dress? That kind of- what’s the organisation culture like? Trying to find all that out as far as researching.
P1: I was going to say research early. It’s really important.
P5: Yeah, all these kind of tools to dispel the anxiety when you get there. There more prepared you are. So you’re more prepared and things like that.
P8: It’s also the recognition of finding out if it’s the right job for you.
P5: Exactly!
P8: If you like it or not.
P8 and P5: (talk over each other)
P1: You’re interviewing them just as much as their interviewing you. That's what I always say to clients, maybe you won’t like the job, maybe you won’t want it.
P5: Yeah you might say no.
PHD STUDENT: So we touched on a lot of things about fear and maybe lack of experience…
P1: I think they come with a lot of ‘shoulds’ as well.
PHD STUDENT: So lots of sh- judgements, so lots of thoughts that come up as well?
P1: Like I should be better, especially when people who have lots of skills already. "I should be able to do this”.
PHD STUDENT: What do you guys think would be the main barriers then at this stage?
59m 51s
(pause)
PHD STUDENT: So this is applying and gaining a job?
P5: It’s the competition isn’t it? For me, that’s what it’s all about. The amount of people that are going for a job now and people know that and it’s kind of- you gotta be really, really hot. They’re gonna have a pool of people to choose from and anybody will be able to do the job. It’s about standing out isn’t it?
PHD STUDENT: So that pressure would be more so if someone had a personality disorder?
P5: Yeah.
P8: The fear of failure, over and over again.
P1: I think it’s the mental [aspect ()]
Everyone: [()]
PHD STUDENT: So the fear of being a failure or?
P8: No failure! They will be going for lots of jobs they won’t be getting until like, you know I work with somebody for two years, who’s amazing that struggle like hell with interviews and was actually getting worse because his confidence, every time he was rejected, he’s gonna feel rejected, you know very powerful emotion so that like comes to the surface. So the support for the failure is really, really, important to hold the confidence up, you know, ‘cos as I said that that thing, “why didn’t they choose me, why aren’t I good enough?” “Why wasn’t I the first one to past the post?” “Why was someone better than me?” “Why was I the one to be rejected?”
P1: So meaning making would probably be really helpful at that stage for when things don’t go well. So that they can see it as an opportunity to learn and grow rather than something that, you know, sets them back and is a reason to not try again.

P8: Getting feedback when the interview is so so important and then debriefing on the feedback.

P6: But I’m also thinking though about how you accentuate your strengths and competencies at this stage because you can get so caught up in personality disorder you forget about you know, what you do actually possess.

PHD STUDENT: So some of their strengths and focusing on that?

P6: Yeah.

PHD STUDENT: The positives as oppose to what they struggle with?

P6: But also as what’s said before, you know that to understand that, you know you may not have worked but you may still have competence.

PHD STUDENT: Ok.

P8: The other thing is by using the marking system for competencies, somebody can understand that they can miss out by one point and that I think is really, really important so that you really emphasize that you might have failed by oh, like a whisper. “ ‘Cos they said near or near abouts, what does that mean, what does that mean?” It means you might have just failed by one point. So what you do is you go over the thing, and that sounded like you nearly got a three, but two for that, two for that, maybe that was red, but you know it’s very near. To be able really understand that the system that they’re being judged by is not personal but it’s actually a () point system.

PHD STUDENT: So just moving onto the final stage then. This person has now started the job and they have been in employment for about 6 months or so, so this is about….

01107: Can I just say, sorry, something stuck in my mind. Can we just- I feel like I also need to remember the language that we use when we work with people with personality disorder because the language that you use are a lot more emotional kind of connectivity for them than it would be for somebody if I failed at an interview. So even though I used the word, erm, you’ve just failed. For them, it would mean “my goodness, everything’s going to come crashing down, my life is over, I can’t carry on anymore, everybody’s going to abandon- I mean the rolling effect so I guess that could be a barrier, just to be aware of-

PHD STUDENT: And it could also be a support I can imagine because if you’re aware of that language and you’re working with them, I can imagine you helping them along that pathway. Sorry I don’t mean to cut you off [says participants name] I am just aware of the time. So going onto the next stage, so now they’re at the job and they’ve been there for 6 months, and there have been some things that have been great about the job, but also some things they are finding difficult at work. And this might be putting a bit of strain on their ability to keep the job. I would like you to consider what sort of things might they be finding difficult and what sort of things might they find easy?

01107: People! (laughs)

P5: Relationships.

P1: Asking for help and saying no. Our clients really struggle asking for help and saying no and I think that sometimes they put themselves in a really difficult position at times that is not sustainable. Because they are not able to stand up for themselves and speak up, or know where the boundary is between…

PHD STUDENT: So you say they’re not able to stand up and speak for themselves=

P1: At times.

PHD STUDENT: =at times. What sort of things are getting in the way of them being able to?

P1: Erm, well I just think they have no assertiveness skills. I think they really lack the ability or were never taught how to communicate with authority in an effective way. So that they can get their needs met while still maintaining some professionalism. Because I think that’s really important to be able to say no, because, I don’t know some of my clients have been at work and they just keep saying yes, and then all of a sudden it really has a negative impact on their self-respect, their self-esteem, their ability to manage the job or they’re afraid to ask for help because they’re afraid it might make them look weak, and they’re afraid it might them look stupid.

PHD STUDENT: So again, I feel like fear is coming up again.

P1: Yeah.

P8: It’s fear of judgement.

P1: Yeah! Major fear of judgement.
P6: But also I think it’s also, for me, it’s also about erm, when these things are occurring what to do, when I’m in the situation in work.

PHD STUDENT: So again, the skills.

01107: Yeah, for example, do you know what actually need to go for a walk. You know, how do I go about doing that? I can’t go for a walk, things will just escalate you know, or I need to kind of use some kind of i.e. anxiety management strategy here, but I can’t because there are these deadlines.

P4: and I think as well because sometimes clients don’t have those coping strategies so the alternative is to just get up and walk and I’ve had a number of clients have done that. Just I can’t cope anymore, and I’m gone.

PHD STUDENT: Coping strategies such as like, removing themselves from the room?

01107: Distress tolerance

P4: Or just being able to actually to speak to a manager, like last week, but this- they haven’t so this thing has just kept on and it’s escalating, escalating, and I can’t cope any more so I literally pick up my bag and I walk out and I go home.

PHD STUDENT: So when they’re having this difficulty, I wonder, what kind of beliefs do you think is running through their mind?

P1: I don’t deserve to ask for help. I should know this. Lots of should, I don’t’ know.

P4: Or negative judgements about managers to them, that’s it’s all about, yeah, everybody’s against me, because they’re not being asked to do this. And the manager is asking but giving them a longer lunch break than me. Well that type of misinterpretation of..

P1: Unfairness.

PHD STUDENT: and do you think these thoughts stop them from being able to continue in their job?

P8: Well it’s, it’s, something about the pain, erm about not being able to do something and then not asking about- and then the fear of judgement. So there’s a sense of erm, “I can’t do this” “I can’t ask for help” “I really feel- I’m not going to my manager” so what happens in psychodynamically is it goes to so “they are not ok”. So the managers “not ok”. The procedures are “not ok”, the policies “aren’t ok”. So therefore I’ve ben treated badly, I’m leaving.

PHD STUDENT: But those thoughts of “they’re not ok” do you think that stops them from being able to continue?

P8: It’s the pain, it’s the pain of acceptance of I need help. Yeah, I can’t do this, I need help, I want to ask for help or I want to say no, but to avoid that, some of them just walk out really and then come and say “well managers were crap, their policies aren’t just crap”.

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PHD STUDENT: I’m interested because you say ‘pain’ and I wonder, what does that mean?

Does that mean physical pain or are they experiencing certain emotions?

P8:I mean the emotional pain. It’s the emotional pain of erm, it’s the emotional pain of the feeling of pain. I feel it. You know? I’ve done it. I’ve got to be perfect like mad, it’s crazy, if I don’t get- and I’m very bad at asking for help, and I push and push and try, and I have it. I can go, “blinking managers, rubbish, I’m not being supported properly, I haven’t actually asked…”. Yeah but it’s kind of that kind of thing going on where you haven’t asked for help you haven’t so, you know, I and other people, and possibly people with personality issues have that maybe a little bit more accentuated with huge emotional response and then the “I’ve got to walk away before I’m abandoned” all of that you know.

PHD STUDENT: I think you said that sometimes you yourself might be experiencing some of these thoughts, sometimes emotions.

P8: Yeah, we all do it.

PHD STUDENT: I actually think that’s a really important point to make, so when you start a job for example, I think it could anxiety provoking for anyone. You don’t know what your teams going to be like, so it’s important to know that, that does happen maybe with an individual who doesn’t have PD but I suppose we are thinking about someone with PD and ask, what is it for them?

P8: That’s exactly the point when we go in, we can go in and say “I’m not going to be any good at this job for the first three months because I’m training” but somebody else might go in and want to- the second day they’re there be able to do it all and feel really scared and worried that they can’t do it.

P6: I also think though that it’s, it’s when you have the recurring set backs. They’re gonna occur, you know, and you kind of like feed one on top of another, one on top of the other, one on top of the other. Erm, and (pause)
PHD STUDENT: How does it leave them feeling?
P6: Like s**t.
P8: Demoralised.
P6: Completely. It’s kind of like reinforces.
P1: And then you tack all the stuff that’s going on at home on top of that and then you’re looking at a nice pile of difficult life stuff going on.
P8: And it can- you know we’re talking about being at home and the situations, you know, staying in situations which aren’t right, staying in jobs which aren’t right, you know that can be actually reinforced within the job and the people that are there as well.
P6: Hmm…
P8: you could stay with a really rubbish boss who’s a bully and nasty, if that’s what you did with all your life.
P1: Yeah, it’s so true.
PHD STUDENT: So, would that impact them staying in that job then? Having a nasty job?
P8: They might stay there and get very miserable and- until you know, it reaches crisis and then they’ll come for help.
PHD STUDENT: Ok.
P6: The other thing as well that I’ve mentioned, for me with people who fit into this scope right, it’s, it’s the likelihood of bringing stuff into work, so, “Right, I’m on my way to work, erm, bus was late, that’s it my minds gone and so by the time I get to work I’m already up here” You know, “I haven’t, you know, I haven’t brought things down”.
PHD STUDENT: So do you think it’s about managing the emotion that comes from those events? Or managing the thoughts that come from events?
P6: Whatever it is, it’s to be able to write, well that’s for that, and this is here.
P1: To be able to separate work from personal life.
PHD STUDENT: And what do you think would be helpful in a situation like that for that client?
P8: It’s the thoughts talking to the themes.
P3: And people catastrophising.
PHD STUDENT: Yeah, ok.
P1: ‘cos if you’re only focused on work, or you’re only focused on your personal life then somethings going to give in one area or the other.
PHD STUDENT: Ok, so I’ve got- I’m just thinking of other emotions that I thought people with personality disorders might experience and I’m aware there might be lots of different types of contexts when they’re in work, but what about frustration?
P8: Oh, frustration and anger yeah.
P5: disappointment.
P1: I think some sadness as well.
PHD STUDENT: Sadness?
P1: Connected to “shoulds” and “why am I not this way”, “why do I struggle?” and…
PHD STUDENT: Sounds like a bit of hopelessness.
P1 & P8: Yeah.
P1: I think some sadness as well.
PHD STUDENT: Sadness?
P1: Connected to “shoulds” and “why am I not this way”, “why do I struggle?” and…
PHD STUDENT: Sounds like a bit of hopelessness.
P1 & P8: Yeah.
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P8: And fitting in with your colleagues.
P6: But also, which I’m going to do in my groups, is just managing being ok.
P1: Yeah.
P6: Simply managing being ok.
P8: Yeah, that it’s good enough, yeah.
PHD STUDENT: What do you mean by being ok?
P1: Just having a normal life! It can be really hard.
P6: Because being ok, being ok isn’t normal.
P1: they’re not used to that.
P6: Get used to it.
P1: It’s awkward. That’s why they start sabotaging.
P6: Right yeah.
PHD STUDENT: Like you say, there are used to perhaps having emotion- or being emotional for a long time and then change.
01107: And also our clients may say “[says their own name] I can feel it coming now, it’s been too good for too long, I know something is wrong. I know something is round the corner” and I’m
like “ok, let’s just wait and see”. “No, but I know I’ve got to prepare myself, I know something is around the corner”.
PHD STUDENT: So what do you think might be helpful is actually just getting them to acknowledge that, that it’s ok to be ok.
0107: Yeah what [says other participants name] said.
(laughter)
P8: there is something about the moment, I don’t know, in transactional analysis there is something called “drama triangle”, to rescue a relationship and the persecutor, and then go well from victim to rescuer, to persecutor and around, around, around again and actually maybe some training in understanding that triangle, that- and the difference between you know, recognising vulnerability, you know, being responsive and therefore being potent and moving things forward and being able to actualise that slight difference.
PHD STUDENT: I’m just going to pause you guys there as I’m aware of the time. I wonder, in terms of this stage in employment, has anything else got in the way of them keeping their jobs, so in terms of alcohol? Or drugs?
[All in agreement]: Yes, of course.
01107: Interpersonal difficulties.
P5: I’m just thinking of somebody I’ve been working with who is- manages- is a manager of a counselling service. She’s got quite a big job and she’s heavily, heavily relying on alcohol at the moment to get to sleep, to block out things, and just kind of can’t cope with it really.
PHD STUDENT: Has it lead to this person, has anything happened at work because of the alcohol consumption?
P5: It happened before, erm the alcohol is the crutch. It was a fall out with some people that she managed and erm, her boss was on her side and then suddenly wasn’t anymore and then the whole thing. It was all because of personality and her manager relationships.
PHD STUDENT: Lots of conflicts in the workplace?
P5: Yeah.
PHD STUDENT: Has anyone else had similar experience of alcohol and their client? Drugs?
P1: Yeah, I had a client lose her job because she was actually a waitress it was like a pub restaurant and she was drinking on the job and lost her job because of that.
P8: I also work with people who manage their drug and alcohol very well.
Can I just ask in this instances, for yours instance is it that because of the pressures of the job eading to or just that’s general kind of behaviour?
P1: I think with this particular client was the fact she had an alcohol addiction and she worked in a place that served alcohol, so it probably wasn’t a great idea (pause). So now she’s looking for waitressing jobs and places that don’t serve alcohol which I thought was a brilliant idea!
P6: At the moment I’m working with somebody and she’s moving away from it but how she manages is to take herself off to the toilet and burn herself=
Everyone: Hmm
P6: =and you know, she says her argument is its “I burn myself, cover up, go back, it works”. PHD STUDENT: does she see it as a problem?
P6: well we recognise that it is a problem. It’s only a short term relief thing.
P1: ‘cos if she didn’t realise it was a problem she wouldn’t be hiding it in the bathroom doing it.
P6: Yeah, exactly.
PHD STUDENT: So how, I suppose, how would you get her to see or try and change her ways?
P6: It’s about looking at the bigger picture. You know, fine, as she said, it’s short term, so how does that fit in your general life goals? It don’t really and so it’s about developing alternative ways to manage that kind of build up.
PHD STUDENT: Alternative ways such as?
P6: Erm, increase her awareness of noticing, being able to just stay with certain feelings and sensations, recognising when she’s certain- how she’s judging. That kind of thing.
P1: Just breathing.
P6: But as she says, “Fine [says their name], but that takes time…I can just burn myself with a few minutes on the back of my legs”.
PHD STUDENT: [says another participants name] did you want to say something?
01107: No, I was just thinking about a client but…
PHD STUDENT: So was there anything else that we haven’t discussed already today in terms of
what you think might be the main barriers or supports with people with personality disorder in employment? So again, we’re thinking about the different stages. Is there anything you feel like we haven’t quite covered?

01107: Educating. I would love [says another participants name] to continue with the book he’s writing.

(laughter)

01107: I think the main issues is not only the- our clients only but it’s about getting the managers to kind of understand what it is that (everyone starts talking).

PHD STUDENT: So managers and employers, ok.

P4: What I do with a client, I sit down and put together what is called a ‘healthy work plan’ and we identify- it’s a confidential document and we identify managers or people in work who should have access to it. It’s usually the line manager, their manager and someone from HR but there is various different sections in the document that first identifies reasonable adjustments in the work place that will help to support them, that person. And we just tailor it to that individual, so for example if I’m feeling stressed as [says one participants name] said, erm, I need to take a time out break and that might be going, sitting in the toilet with the cubicle door locked, nobody could go near me, I could plug in my mindfulness app for 5 minutes, listen to that and then go back, or it might be like I go out for a walk, whatever it may be. We look at reasonable adjustments like hours of work, duties, responsibilities; its anything that we think will be an adjustment. And then another section we look at workplace triggers for you, and how to kind of avoid them, so identify specific triggers for that person, and if they can’t avoid them what they should do if they can avoid them, what are the alternatives.

P1: it’s the plan, a plan, it’s an awesome idea!

P4: and then we look at, so we do reasonable adjustments, workplace triggers, warning signs, early warning signs in the workplace that they are becoming unwell. So those are specific to them and what you would like your manager to do if they notice any of those warning signs. And then definite signs that you’re unwell and again what you want your manager to do, and then if your manager is concerned about your health, is there anybody you’d like them to contact ‘cos I’ve often have managers call me even though the person has been discharged from mental health services you know, a year down the line saying you did this plan with your name down, we’re actually now worried about “Jo”. Erm, he’s been tearful at work, blah, blah, blah. Or one client who was manic, he was a bipolar client of mine, and so often times, or if somebody is not well at work and the manager says, you know you’ve got a supportive manager, go on home. That manager is then left with this anxiety, are they ok? Did they get home? Has anything happened? So if there is somebody they can contact to say we’ve sent “Jo” home today just to let you know and be aware, it could be helpful. And then we have also put in a review date, so we go meet with a manager, present the plan, agree it and then we say, right we’ll come back in a months’ time to make sure everything you’ve agreed that you will do is actually being put in place.

PHD STUDENT: and is this manager aware of the diagnosis per se? Or...

P4: Not necessarily the diagnosis. They would have to be- you have to- the client has to sign consent that they’re happy for me to liaise with the manager, obviously if they’re haven’t given consent then we can’t do that, but if they’ve disclosed their mental health condition, as a mental health condition, not necessarily PD erm, then we will let’s say go ahead and meet with that managers because often times you find managers who want, they know something’s not right, you know, it’s not rocket science when somebody has been off. And they would like to put in some support but they don’t know what to do, somebody runs out of the building, so, that can be really helpful.

PHD STUDENT: Ok, thank you. So just a few more minutes…any other thoughts that you would like to address?

P8: We do something very similar, erm, called- the first thing we look is, how are you when you’re well. So everything is comparison to that (), which is like a WRAP. Wellness, recovery, employment Action Plan but we can do it with the same kind of thing but do it with the individual, stand alone as well doing it in (). Because if they don’t want or the other person doesn’t want to, it’s what they can do and how they can communicate differently, how they can learn to say no. In certain circumstances they need to learn to say no so its kind of that sense of- you were saying [says other participants name] about the girl and the relationship- that people trying to understand themselves, and being able to help themselves and really get that okness.

P6: The other thing I was thinking was, sorry, the law. Law, yeah.
P8: Understanding information about the law.
P1: Oh yeah, absolutely. That can be so difficult for clients.
P8: Or empowering. The employer has to, I’m categorised under the equality act, therefore the employer has a responsibility to do this, the sponsor has a duty of care etc and all of that. That’s very, very good.

PHD STUDENT: Alright, thank you for your comments and ideas. So we are going to wrap up now I know we’re a little bit late. Infront of you there is something we call member checking. What it is, it’s a clarification process, so what will happen now is we will go away and will be transcribing what we have heard today and then we’ll be summarising them into topics and so you can be involved with erm, the information that’s come out. What will happen is, we will send you the summarised topics and it will give you the opportunity to add more information, or maybe correct anything that you think wasn’t discussed today and also give you the opportunity that if anything else arises after today’s conversation you can write to us and let us know. If you are interested please leave me your details, again this is all confidential which is why you have it on separate pieces of paper. Thank you! Thank you so much for coming everyone. If any of you have any more questions feel free to come find us afterwards.
Appendix 28 Focus Group 2 Health Care Professional

Transcription 2 (Chapter 3)

PHD STUDENT:: So thank you for er... attending today and I appreciate that you guys have very busy schedules being therapists so it’s very much acknowledged that you are here to participate. First of all do you guys have any questions from the information sheet I gave to you? If not, that’s fine you can ask us later as well. In terms of the voice recorders er, so like I said I’ve placed one there and one up here. If we can just try and keep to speaking one at a time, not just for the recording sake, but also so we can hear each other clearly as we go along. I am anticipating that it will be a lively debate. Housekeeping, so we’ve done some introductions, I’ve spoken about the voice recorders. Erm it’s a bit different because this is not our usual site (laughs) so I assume you guys all know where the toilets are in this building already. Um and I assume, I don’t think there is going to be set fire alarms today [no] so I don’t we will be expecting anything like that in the next hour and a half. So I thought we can begin with a quick ice breaker, so I know we know our names, but just again to reiterate our names, I would like us to do something called ‘two truths and a lie’. So just say two things about yourself that is the truth and one thing that is a lie and then we are going to guess what it could be (laughs). So I’ll go first, just to give you an idea. As you know my name is [name], erm I have a brother and a sister, I speak [language] and I have a tattoo

P2: Do you want us to guess it?

PHD STUDENT:: Yes

Ad: You don’t have a tattoo.

I: (laughter) yes you guys guessed that pretty right. Should we start with you?

P1: Okay my name is [name] erm when I was 15 I ran away to America by aeroplane, I erm (laughter) I am very much into cats and I have a tattoo

PHD STUDENT::I think you stole that from me (laughter)

P2: I don’t think you like cats

Ad: I think the first one is wrong

P1: Yes it’s the first one actually, I never ran away to America it was Africa (laughter)

AC: My name is [name], I am a season ticket holder for the [place] football club, erm I am a certified diving instructor and I once went out with an [place] footballer

?: Hm diving instructor?

AC: That is a lie.

PHD STUDENT::Really?

AC: Yes

I: Well guessed

AC: The other two went together. I can dive but I am not a qualified instructor

P2: I have two Guinea pigs, I play the clarinet and I used to live in [place]

Several P: Guinea pigs

AC: [place]

P: I used to live in [place]

AC: Well done P (laughter)

P3: I have a passion for playing tennis, and I have two cats and I love Vivaldi

Two P: Tennis…… (Laughter)

I: Thank you

P4: My name is [name]…. (Laughter) erm my husband used to have a single in the charts, I have a pet cockapoo and I speak fluent French

P: French

P5: I like playing hockey, I like watching the boxing and I’ve got two sisters

Several P: Hockey, sisters, boxing

P5: Boxing

P6: I enjoy painting, I have a cat called [name] and I am a singer Song writer

AC: Painter

P6: Yes that’s a lie, how did you get that? (Laughter)

P7: I’ve got 33 first cousins, I love swimming and I nearly have seen half of the world

Several P: Swimming
I'm scared of water (laughter)

Thank you. I hope it didn't feel too much like you were being put on the spot [laughter in the room]. Um so I just wonder before we begin, has anyone participated in a focus group or perhaps run one themselves? I see some nodding over there. Would you like to share your experience of running a focus group and what it's all about?

Erm I used to be a PhD Student: (I: Um) so I erm didn't actually do focus groups for my research but I took part in some other friends' ones so err, er what's it about, erm I guess it's about trying to get quite a good discussion going and trying to get people to have, what er voice different opinions and possibly to have some lively debate

Yea, absolutely. I mean really it's about coming together and sharing your ideas (P: Um), getting a discussion going and also hearing from other people as well to really kind of inform ourselves about the topic at hand, which is about PD and, PD and employment. So there is really no right or wrong answer, we're really just truly interested in what you guys have to say so yeah. Okay so erm, just to go quickly through why we are running these focus, focus groups. I did mention them in, in our presentation earlier but it will help us to develop a treatment manual, so to, adapted version of er DBT. Erm and so it can be various things through teaching various skills, erm managing intense emotions erm or improving interpersonal relationships. Erm we're hoping from the focus groups today, it will help us to develop erm an employment scale specifically for those with PD and again then hopefully this will help us identify erm particular challenges or, or, you know, supports for people to obtain and retain employment in PD and again to evaluate the interventions and see where they are erm what best, what else we can do to help them along with the employment pathway. And then the third thing is to develop a positive booklet for employers. Okay so I thought I'd just ask you guys er what your experiences, just briefly, of working with someone with a personality disorder just in general. That's not supposed to be on there (laughs). Anyone care to share?

Challenging (I: Um) Erm lots of ups and downs. So, yea, so you think you, you think you're going, you're doing really well and they're doing really well and then suddenly it all comes crashing down and you have to kind of (I:Um) pick things up and start again erm so

Yea the ground shifts (P: Yes) quite rapidly and very often (P: Yes) and you think you have a good rapport with somebody (I: Um) and you're their best, you know, as far as their concerned you're their best mate and you're their best source of support and then the next week they, you just say one wrong thing and you might not even realise and they might not even say anything and then you know (I: Um) five weeks later you suddenly realise that they've been seething because nothing's straight forward (P: Yes) and open and transparent (P: Yea). So then you, you end up kind of trying to tread carefully and not, and not, not, not tread, say the wrong thing and then you realise that also isn't very helpful and you need to confront these things (P: Um). So there's a lot of, kind of, ground shifting (P: Um um) and not, not always knowing where you are with people (P: Yea)

Is that quite similar for everyone, for everyone else as well?

Yea, I think they are, it is a little bit like walking over some egg shells, you know, you have to really watch where you, where you put your feet sometimes

And, and, and another is, it's the thing you don't notice that's the most, sometimes when they, it's erm you think you've got an idea and it's actually something which you've disregarded an idea, you might have disregarded in the past because that (I: Um). So sometimes it's quite difficult to work with these people

So lots of difficulties around, challenges (P1: Um) and emotions and erm other, other things as well. I thought that might be quite useful in terms of, I suppose defining what it's like to work with someone with PD. And just to define er what we, how we will capturise it in Empower. So very much like what, what, very much like what you have shared, you know. They might experience very intense emotions erm but you might not be aware till a few weeks later, er you know, in response to something within, within that session, erm they might have some difficult, you know, interpersonal relationships, erm again possibly due to difficulties in receiving criticism or advice, or, you know, or fears of rejection. Erm and they behave impulsively, so like you say, one week they might just behave in a different way that you least expect. Erm so in terms of personality and disorder and employment, you know it could be something like quitting the job without thought of consequence and things like that. So in the discussion today we're going to really be looking at various stages of employment. So erm before we go onto that err, we'll be looking at, well, I've, I've put it into three kind of stages but it could be you know depending on the discussions today, it could go to two of the three. But
we’re essentially looking at the contemplation stage. So thinking about employment, you know, getting ready. We also want to look at er getting, er get, steps to get employment and then getting employed. And then the third stage would be they are employed and they’re wanting to retain it and remain er at that job. So er I’d like you to try and just consider those different stages as well as, what kind of, these stages might have in terms of an impact on the individuals with a personality disorder; as well as, consider some potential barriers or what’s that, that’s helping them along the way. Erm I’d just like to say that, er I think for anyone starting a new job, for example, you know, going into a new team, new colleagues can be quite anxiety provoking. I think that’s actually quite, quite normal (P: Um). Erm, I don’t know what you guys think (P: Yes, absolutely) yeah, so, you know, you might, you might, one might feel quite anxious, naturally. So I’d like you guys just to consider what, I mean, what we’re looking at really is those feelings of anxiety to the extreme, so what would that lead that individual with PD to, to do or behave or act. Erm so yeah, and, and again, there’s absolutely no right or wrong answers for this focus group and we’re interested in both positive and negative experiences erm and your comments as well, okay. So any questions before we begin? Okay so this first scenario, this first stage here, I’d like you guys to consider an individual, maybe it’s someone that you’ve been working with or in general through your experiences as a clinician, erm someone with a personality disorder or significant traits and they’ve been unemployed for a substantial amount of time. So we’re not talking about a month here, we’re talking about at least three months or more and they really are perhaps struggling or finding it difficult. So do you think there are any barriers to them considering and thinking about employment? Would anyone like to, I see lots of nods

P: Failing the job, it could get them, it could, getting the job and then it not working out and then just adding it to the list of failures (I: Okay)

P72: It’s also getting the job in the first place isn’t it, I think er just to get an interview or to even find a job that they think they’d be able to do I think would be quite a challenge (I: Um). Erm there would be maybe self-doubt that they could do it so they wouldn’t even apply (P: Yeah) and maybe erm then, then not present themselves (P: Clears throat) particularly well in the interview or say something, something would go wrong in the interview that sort of thing

PHD STUDENT:: So there’s a lot of, kind of, elements there to the process of them

P: And if they’ve been out of work for a long time, they may well not get the job because of the competition (P: Um)

PHD STUDENT:: So it’s the type, there’s kind of a time, a timeline to that as well (P: Um). So the longer they’ve been out of work, it might be more difficult

P: I’ve also got clients who’d say er well I know that on a good day I could do this job (P and P: Yes) and I’d be really, really good at it but then I’ll have a bad day and I’m just going to mess completely (P: Yea). So though I know I could do it, I’d know that I also that I couldn’t be reliable (P: Yea) and, and do this job every day

I: When you say “good day” what does that mean to them?

P: Erm a day when they can get up in the morning and function and think and be, you know, and, and be rel, relatively calm and measured, and be able to be dependable. And I mean it’s often just about being able get up in the morning and get there (I: Okay), and on a bad day I’ll just put the duvet over my head and not, you know, (P: Um)

I: When they’re on their bad day, do you think there’s any particular thoughts that are going through their mind or beliefs, or anything like that?

P: “I can’t do this”, er “I don’t want to do it” “I just want to, I just want to bury my head under this duvet and go to sleep and not think about life and the world”

PHD STUDENT:: I was just thinking, [name] you mentioned failure, do you think there’s any sort of thoughts that might be linked to, to that?

PL: Er well unfortunately past history (P: Yea, yea) erm and erm erm I, there’s an, a mind reading thing where they (P: Um) they think people that don’t like them and that it’s not going to work out for them and it’s just, this is just what happens in their life (P: Um), negative (pause) on-going pattern really (I: Yea, pattern of life that they’re going through)

P: Also, beliefs about other people, so some, some of our clients believe that other people are er, you know, mean them harm, they’re going, are going to be horrible to them (P: Um) and erm so, you know, there’s an expectation that, that it will, you know, they, they just want, they don’t to have, they don’t feel that they could actually develop proper relationships with people at work

I: So about expectations and erm perhaps managing some of those (P: Um). Erm have you had any experience of er perhaps ways of managing those thoughts that have been helpful in your experience?
P: Erm yea well, sort of, erm challenging some of the beliefs using CBT or DBT approaches, erm stepping back mindfully erm
PHD STUDENT::Is there a particular approach in CBT or DBT that you, you think from your experience has helped? (P: Um) or aspects or component of one of those therapies?
P: Er I mean I suppose the behavioural exposure work is, you know, just actually getting out there, and, and, erm because if somebody goes from being completely isolated to plunging themselves into a full-time job then that's erm quite a shock, but if they, even kind of the exposure of being in the group itself (I: Um) they start to have more positive interactions with people (I: clears throat), erm doing voluntary work that kind of thing (I: Yea)
P: as an employment adviser, what I find helps is, Cos I can, I'm not a CBT or DBT trained (I: Um um) is to encourage the service user to, to draw on their, their bank of the, the tools that they, they've learnt from, from you and other practitioners (P: Yes). So er that's something I, I encourage the service users to do, you know. So "what technique would, would, would, erm [therapist name] say to use (P: Yes) in that situation" and they're usually able to, to draw on it and I'll say “okay, so how, you know, how are you going to put that in place in this situation?”; so for me it's, it's been invaluable learning a little bit about DBT (P: Um) so that I can help the client, you know, to put that in place when things go wrong at work
PHD STUDENT:Um um and have you had any experiences erm when they're at that contemplation stage and they first come to you, is that the sort of erm, I suppose, tool that you use with them to kind of get them to go back to look at their work in therapy?
P: Erm not a tool as such (I: Um um), but more, they might have discussed with the person that referred, referred them to me, what the, the vocational goal might be or they just might know they want to do something but are not sure what. So then it would be doing just a, a bog standard vocational profile, you know, to talk about their history and their qualifications and their hobbies and interests and what would they like to do. Erm and then err, but then the barriers are the fears and the hesitancy, which has already been discussed, you know (I: It has, yeah), the past jobs that have gone wrong, erm so it's (I: A lot of its worries, it sounds like) yeah and so a lot of my role is kind of just reassurance and rationalising, that's er really
P: I think the cope ahead skills are quite useful in, in the contemplation stage, erm and, and, erm the DEAR man skills and actually practicing in the session erm you know certain scenarios that they're afraid might happen
PHD STUDENT:So being able to practice those, opportunities to practice those assertiveness skills (P: Yeah) in the room
P: There's another barrier that gets in the way, which is about when people have been out of work for some time, they lose their sort of day-to-day structure (P: Um) and organisation and the thought of actually having to, you know, cos it can take all day just to do nothing very much when you’re at home all day, so the thought of actually having to be on the ball all the time is very, very daunting for people (P: Um, yeah)
I: Yeah so the thought of getting up and doing all that structure and things
P: And having to have that discipline because you know erm, I mean, I've got one client who actually, well actually part of it, in some, on one way, in one level she, actually I don’t know why she’d go to work, I, I actually prefer doing other things. So there’s also a wilfulness, which is slightly different but it's also related it's, I mean, I think it is related to that (I: Yeah) er lack of organisation, but it’s also well, actually, you know, you get used to being at home and it begins to feel safe, not just safe, but also, you know, nice, why would I want to put myself through this, you know, (I: that change to, yeah, um) all this trouble and effort, erm while I’m on benefits what do I need to (P: clears throat)
PHD STUDENT:I suppose in that situation what do think might, might be helpful for, for that, for that individual to kind of get the ball rolling I suppose
P: Well, with this particular person it's been very hard, but I mean, you know, you try to get them to think about structuring their days when they are not working, get themselves in to a regular sleep pattern, get them thinking about the incentives of going to work and earning your own money and what that feels like, the rewards, erm the feeling that you’re contributing and thinking about the pros and cons of working or staying at home (I: Um) erm and
PHD STUDENT:So lots of imagery as well as practical (P: It's sort of planning ahead), planning ahead yeah
P: Er and er organising but I think, I think sometimes it is also about just the, you know err, you can get a bit too comfortable at home so (I: Yeah) it’s about actually getting the motivation and thinking about what the rewards are of going to work (I: The motivation, yeah)
P: It’s looking at values and (I: Yeah) and thinking (I: Values, trying to identify that) and identifying, you know, goals for building a life worth living (I: Clears throat) isn’t it (P: Yeah) and whether that fits in with that which may not be the case, mightn’t it (P: No), for that particular client

PHD STUDENT: So I just thought, I just wondered there’s been a mention of, you know, fear and failure. So if I were to ask you, you know, what kind of emotions they might be experiencing at the stage of contemplating, would it be quite right to say, they’re feeling quite anxious?

P: Yeah, definitely (P: Um)

P1: One of the things I’ve noticed erm in the last year with a couple of clients I’m seeing at the moment, erm (coughs) she’ll come in and she’ll say “I’ve found a, I know what I’m going to do, I know what I want to do with my life” and she’ll go “right I need to, I want to be a DBT therapist” for example (slight snort form another participant), she does, she wants to be a DBT therapist so, I said “right ok” and she’s really motivated (I: Um), she’s really into it for a few weeks. So we sort of try and think about coping ahead, we look at ways of doing this and it takes a couple of little hiccups, so she misses, she can’t get the bus to college in the morning and (I: Yeah) it’s just, it’s this rigid and this, this catastrophe of something, a little thing I would consider to be quite small (I: Um), would take her, derail her completely (I: Um) and then next thing we’re talking well, “you know I earn a £220 a week with my benefits, why shouldn’t I just carry on with that” (P: Um, um, um, yeah). So there’s this kind of real nihilism about it, as soon as something very small happens, a little hiccup with something that happens with somebody where they’re working or where they’re at college (P: Yeah) and it’s just completely the opposite kind of erm sort of er attitude (I: And do you) and sort of thought pattern, you know, “oh can’t be bothered”

PHD STUDENT: And, oh, so thought pattern, yeah, I was going to ask you because like you said, so thinking about those little kind of triggers would

P1: Yeah it’s very sort of black and white (I: Yeah) I, I love, I, I wanted this so (I: Yeah) and it’s this sort of planning, this idea that this is the job I want to do (I: Um), she’s sort of jumping from A and Z without doing the alphabet (P: Um) (I: Yeah). Getting to that job sort of thing and it’s very much this kind of impulse (P: Um um) a lot of the time.

I: Yeah, so do you think in that, in that situation it’s the thoughts that come up that perhaps could be a barrier to her getting employment or getting work (P1: Well it) or is it more about the frustration of missing that bus (P: Um) or the feelings of anger

P: It’s, it’s, erm it’s aiming the arrow too low I think. I think, you know, they’re, they’re sort of, so aiming the arrow too high (I: Um) so they’re sort of aiming of (I: Their expectations too high) at something, yeah so the expectation is too high and, and, undoubtedly they will fail at that and it’s that sort of, bringing them back and trying to get them to say right well this is normal, we’ve got to work on this, we’ve got to go through the whole alphabet to, to get to this objective and (I: Um um um) that’s the difficulty I struggle with. It’s the actual motivating them to, to just play the long game rather than this kind of (I: Um) gratification of, without that (I: Instant gratification) yeah

PHD STUDENT: Trying to break down each step so it has small parts (P: Um). Yeah, has anyone had any similar experiences?

P: Yeah I’ve got a client who basically can’t make eye contact, she comes in and she’s like this all the time (I: Um) and erm she wants to be a paediatric nurse (I: Um) and, you know, she’s not actually, she doesn’t really, er she’s quite socially phobic, she doesn’t really go out much (I: Yeah) so the distance between where she is now and being a paediatric nurse (I: Yeah) is just vast (I: Um) erm so talking to her about how she’s, you know, well you know the first thing might be to learn how to look at people (slight chuckle) (I: Yeah) and it, it’s, so the expectations, as you say, is far too high in but that

PHD STUDENT: I just wonder with that eye contact, is that something, is that, is that driven from her fear or is it, is it a learned behaviour? I just wonder

P: So it’s, yeah, its I thought, well that’s what I thought, it be some sort of shame but I (I: Shame, okay) I mean it’s, it’s, I think it’s real anxiety, just real social anxiety about looking at people and making eye contact (I: Um), you know, she doesn’t, so for paediatric nursing well she’s all, she’s not too bad with children but, you know, as I say, well I guess if you’re a nurse you gonna have to talk to the parents. If I was a parent and I had a child in hospital I’d want be able to have a conversation with a nurse erm so even getting her to think about that and what, and she’d have to go college and all the rest of it first. (I: Um) So there’s a lot, there’s a long way to go and it’s such a long way and as [P1] says you know often it’s about needing instant
gratification and it’s just, it’s almost as if it’s too far (P1: Um) too far to be able to think about all the steps in between

PHD STUDENT: So I suppose erm as, as, as a clinician er where do you think your more, more, most likely to start? Because it sounds like so there’s a lot, like, a lot of the clients, there’s a lot of things going on (P: Um), you know, you mentioned the eye contact, you mentioned that actually there might be feelings shame and or fear. Er what would you say, I mean, I don’t want to, but all of you?

P: Confidence. I think it’s about confidence building in the first instance just to be able to interact with people even before, because she’s, this girl’s not in, she’s not ready to go to work. There’s a realism about (P: Yeah) er her concrete goals and er maybe step-by-step as well (P: Yeah, yeah, exactly) so breaking it down

P: But I think the problem is that this step-by-step is, it is so slow and people do have this kind of, they don’t really stop to think about every, if they stop and think about all the steps in between. It’s almost like, well they’re just too discouraged, because they (P1: Um) because they do, they sort of need this instant reward

P: But there’s also sort of financial erm (P: Yeah), you know, burden here. Erm I’ve worked quite hard with someone to erm, to get her into employment and she is working but she’s now planning on giving in her notice. Erm and it seems to be financially driven actually that she erm has to have some sort of operation on her foot which means that she’d have to have unpaid leave for I think a month or two months and she actually said look I can’t afford that (I: Um) so she would prefer to give in her notice and go back to benefits because she’s lived with, well you know, she’s done both so to speak (P: Yeah, yeah) erm and I was quite surprised, that it was last week when she said that to me because actually I’d written letters, you know for her and, you know, to, to get her the job because of the self-harm and, you know, it’s, it was a complicated individual and she was put on sick leave and, all this sort of thing. So I think it’s about sometimes erm whether people can sustain employment which I think is slightly different from what you’re talking about but I think it seems to be for this particular person (I: Um) she gets jobs but then can’t keep them for more than a couple of months really (I: Um)

P: Cos erm the, for with my [job role] hat on, erm I think it’s admirable that within therapy that you are, kind of work, helping clients to work towards employment goals. But I think it would maybe help the client and you, if they were, had an employment advisor to support them because then you can focus on your therapy (I: Um), erm the employment advisor can help to look at vocational goals and make sure they’re realistic but also if they were with, within the clinical team like myself, then the person can link in with, you know, the psychologists, the psychiatrists whatever. Erm just to, to help and also another thing that jumps out is importance of, of er benefits advice, which again you (P: Yes), you can’t be expected to do (P: Um). So I think it really does need, need to be a holistic team (P: Yeah) that supports, you know, any of those issues (I: A holistic team, okay) to help them to

P: Well this particular person did see, they did see [name] actually (P: Yeah)

P: I’ve got a, I refer everyone to you, though (laughter)

P: She really does (laughter)

P: I think it depends on what stage the client is at. Cos the one I was talking about isn’t anywhere near actually. The client, she’s just, she’s just thinking, you know, (P: Yes) a year down the line that’s what she’d like to, so

PHD STUDENT: And that’s interesting because we are talking about the contemplation stage at this point so what, what gets them, what stops them so, from even considering about getting as far as erm as employment support staff so

P: I think another point is erm a lack of support that our clients have because I’m, I’m thinking of quite a young girl that I’m working with whose got two children and she is desperate (stressed) to get a job because she just feels like, you know, her whole life is around the children, but she’s got very little support from family (I: Oh I see, yeah) so what would she do with the children when she’s at work? (I: Um) And also she’s had social services on her back and, and erm she’s really scared to do anything that would suggest that she’s not being a good mother

PHD STUDENT: Yeah, so it sounds like there are some other kind of external factors as well at play when it comes to considering about employment (P: Um). Erm, okay, was there anything else that er you feel like we haven’t covered, just, just in terms of this particular stage about contemplating?
P: Err, yeah I think, yeah, contemplate, in the, in the contemplation stage, as well as the confidence building (I: Um) erm something to do with maintaining relationships because often erm relationships in the work place erm are misunderstood (I: Um) or developed too quickly or, or, yea, just there’s, I’m going back to the mind reading that I mentioned earlier (I: Um) it that there’s, yeah this is, er in my experience the people that erm have left work with a diagnosis of personality, it’s been because of altercations with other staff members

PHD STUDENT: Yea okay, so conflicts in the workplace (P: Yeah). Okay that's interesting. Erm so I wonder, overall what would you say would be the main barriers, barriers or problems at this stage of employment? So thinking about work and moving forward to finding work?

P: Confidence
I: Confidence yeah, I think that’s come up
P: Unrealistic expectations
P: Yea, is it sort of in the sense of (I: Yeah, managing expectations) that they, they will gain more that they will, than they will lose (P: Yeah, yeah it’s exactly, it’s the motivation and the confidence thing) so anticipating change

PHD STUDENT: Anticipating change
P1: Realistic sense of failure (P: Um) as well
PHD STUDENT: Yea
P: It’s the stigmas

PHD STUDENT: And stigma in the workplace?
P: Yeah and the fear of, of, you know, do, do I disclose that I’ve got this diagnosis or not
P: The other element actually with this, cos one of my clients I’m thinking of is that actually it was what’s socially conventional in her circle, you know, she, she lived amongst all her mates and her family and everyone around her didn’t work, that was the, that was the culture (I: Yeah, yeah) in, where she lived (I: Um), and so it sort of reduced the, the incentive really, well what, why, you know, I don't need, why would I work when other people don’t. So it became normal, normative, not to work

PHD STUDENT: Yes it’s kind of a systematic, a systems problem there
P: I’ve had someone saying that I haven’t got time for work (I: Oh right) as well, you know, that they are so busy with all their other activities so it, it feels I mean I did have to sort of bite my tongue a little bit at that point but it’s, it’s this idea of, of really erm if they haven’t worked for a very long time (I: Um) it is, it’s a culture change, you know

PHD STUDENT: When you say activities do you, what, what do you mean by that?
P: Well she does erm various sort of socialising and she erm maintains her home and she has children and her mother and, you know er other social things going on
P: But then you have like other clients who constantly have medical appointments and, and erm psychiatric appointments and outpatient appointments and then so, you know, to go to work would be, well how are they going to fit them in (P: Um, um)
P: It’s something about changing their ident, their sense of their own identity as well because some people who are so kind of caught up in their identity as a, as a sick person

PHD STUDENT: Yeah, so something about identities as well
P: Well I even worked with somebody who’s never even, never worked in her life (I: Um) and she’s in her thirties and, and never really even thought about working, it’s just not (sighs)

PHD STUDENT: So it really is a cultural kind of change, a shift that’s needed in terms of erm, erm their social environment that they’re used to. Okay, thank you
P: Just, just one other thing that links to confidence is that er often people have become deskilled (P: Yeah, um) when they’ve been out of work for so long so that kind of links into the confidence as well, that if someone hasn’t used the computer for five years and, they’re not going to be able to function well but there’s

PHD STUDENT: So kind of tangible skills as well (P: Yeah) erm that’s required. Okay. So I’d like us to consider now a different, different stage, I suppose, of employment, erm so the process of gaining employment. So again, considering a person with PD or with significant traits and er they’ve now gained a new job, yeah, erm or they’re returning to work, erm they might or might have not done a number of task orientated activities, you know, so like writing a CV or visiting a job centre. Erm but do you think again there are any potential, er if there any barriers er to stopping them from gaining a job or returning to work?

P1: Experience
I: Experience?
P1: Yeah work experience. Many people look at how much work experience they’ve got and somebody with a severe personality disorder might not have had that work experience. I mean
I've got a lady who's forty-two and she hasn't really worked for twenty odd years and she's in the last sort of twelve months done quite a few erm catering and, and a chef course actually (I: Um), and she just can't get work and it, she's, she's struggling erm to actually to just get an interview at the moment and, and it's down to you know a forty-two year old woman whose background, er who wants to be a cook, they expect a little bit of experience

PHD STUDENT: That's quite interesting because it makes me think about what you mentioned before in the earlier stages of managing expectations. So she will, you know, her expectation of wanting to become (P1: Yeah) that and then the necessary process

P1: No, absolutely, you know this, this erm, this idea that she'd be working at erm [names pub owner] pub in [names area] straight away, you know, but actually what she's looking for now is agency work at hotels (I: Okay) er that kind of stuff and, and she's struggling with it and it's that, it's that sort of er knock back every time she, they say no. Er that's, she's sort of struggled with that, yeah

PHD STUDENT: Um. Has anyone had any similar experiences? To do with expectations or others?

P: (sighs) The client I saw yesterday who erm, she wants to be a special police officer and she, whatever, she kept, she kept offering her interviews and whatever and she kept putting it off and putting it off and in the end they said this is your last chance and it was because it was the very, very, last opportunity before they said no way, she, she decided to go for it. But she was very, very impulsive, very, very last minute. Didn't do any preparation (P: Yes), didn't get any sleep the night before, turned up, didn't know where she was going, didn't, completely chaotic (P: Yeah) then turned up and tells me that she did this fabulous interview because she's running on adrenaline and they thought she was wonderful. So erm I don't know what the outcome is and whether she's got the job (I: Okay) but there is something about that it's something, that, you know, almost what sounds like self-sabotage, sometimes I mean I have had, you know, clients who've been like that before

PHD STUDENT: So what kind of thoughts do you think was going through her mind then with that, in that situation because it sounded like there was a lot going on but then she's still

P: It's almost like it is this instant gratification thing, I mean if I can't get this straight away it's almost as if I can't quite be bothered and maybe if so, you know, if I don't get this it will be because, it won't be because I'm not good enough, it will be because I didn't prepare (I: Um) erm and because she knows that in spite of all this even if she does get it, she's actually not going to get it because she has all sorts of medical problems, that she hasn't yet disclosed. Once it gets to the next stage, she probably won't be able to do it (I: Um). Erm so, I don't know, I mean I think it was something about just not quite being able to tolerate going through the methodical, systematic process because it's really, really boring and you have to do everything on adrenaline, last minute because that's what gives you the drive and the buzz

PHD STUDENT: So she couldn't tolerate the process because it was boring?

P: Of, of pre-planning in advance and preparation, making sure she's got petrol in her car, you know, just (snorts)

PHD STUDENT: What do you think the underlying emotion would be for that? I'm just thinking boredom (P: In what ah) What is it?

P: It's an impatience and [P: Yeah], I don't know, it's, it's like it's (I: Is it shame?) a frustration of, no I don't, sort of, she's very, very, intolerant (I: Um um) of all sorts of things but it's a sort of intolerance of boredom and having to do sensible

P: It's impulsiveness

P: Yeah it's impulsivity (P: Um)

PHD STUDENT: Yeah, um

P: I think there's also a, a lot of our clients lack the ability to erm self-manage to err, you know, er problem-solve

PHD STUDENT: Particular tasks that might be relevant (P: Yeah) to getting that job (P: Yeah) yeah. Um. What do you think might, might help them I suppose?

P: Training in problem solving and, and erm er yeah, er self-management

PHD STUDENT: Erm self-management, um

P: And mindfulness, stopping and thinking through

P: Yeah, that can be very hard for some of our clients, yea

PHD STUDENT: What, before acting impulsively, yeah

P1: I think also erm a bit of knowledge about the working life because a lot of these people don't (coughs), haven't had that experience, so erm they might look at getting a job and but
there’s not all the, the thoughts around how I’m going to achieve that job, how I’m going to maintain that job, and it’s, and it’s kind of there’s that lack of knowledge as well really

PHD STUDENT: The lack of knowledge can lead to certain thoughts right (P1: Yeah) so then working on those thoughts that come up?

P1: Yeah (clears throat), just, just some of the smaller things, you know, erm you getting a reference for example (I: Yea), finding a, a, getting somebody to give you a decent reference. That might be a real struggle for somebody with a personality disorder, because in their past experiences, job wise, they might have walked out of jobs (P: Yeah) er and things like that

PHD STUDENT: Or like you said they lack experience

P1: Or the lack of experience yeah, yeah (I: So they may not even have someone they can ask) and yeah erm so there’s this kind of, there’s this golden gate of where they need to be but it’s, it’s just getting, getting to those, you know, the nitty gritty of how, how you actually achieve that (I: Um). And a lot of it is hard work isn’t it? And some people haven’t actually used to that, they’re not used to actually working directed study for themselves, getting what they need to do to get that job before they’ve got it, you know, that sort of state of mind

PHD STUDENT: Um, um [name] any other experiences from your point of view in supporting, yeah?

P: Well from my point of view it’d be practical so erm helping with erm getting their CV up-to-date and as it should look (I: Um) and helping to get volunteering or work experience or to retrain depending on what their career goal is

PHD STUDENT: And do they find it quite easy, fill, filling out a CV or

P: Erm it depends on the individual really (I: Um). One individual I can think of wouldn’t really let me make any changes to a CV. It was very long and kind of I, obviously, I was trying to advise him as the erm or the expert on that and yeah he wouldn’t let me take certain things out because it was, it was, he had very black and white thinking (I: Right) and it was “No, no, no, no. I want people to know that I worked there” and I was like, but it was twelve years ago people don’t need to know that, but he wouldn’t let me take it out (laughs). So erm so you know its

PHD STUDENT: So kind of like his thought process was really getting in the way there of, of changing

P: Yeah very and that was the, the theme throughout with that gentleman (I: Um)

P: It’s probably about being told what to do

P: No he, he wouldn’t take any advice (P: Yeah, absolutely) and actually when, oh God don’t start me (I: laughs) when, when I got him (laughter), got to get it out of my system (P: Yeah), no, but when erm I helped him get some work experience and that was the theme at work actually was that he was er stubborn. Wouldn’t, wouldn’t take instruction at work, wouldn’t er do as, as he was told and erm it was almost like erm, it was a game

P: But he construed it as people being mean to me

P: Yeah, yeah he did, yeah (laughs)

PHD STUDENT: So again there’s the thoughts that he’s thinking isn’t there

P: Yeah, people were mean to me, they ganged up against me and they were mean to me. That was his take on that

P: Yeah and that was it, so that’s

PHD STUDENT: His interpretation and his thoughts of what was happening, yeah

P: Yeah, and there was some odd behaviours from the employers granted, erm (I: Um) but that was (I: What were) the gentleman’s erm interpretation (I: Okay, okay, yeah). But I think we didn’t disclose, we, we, it was the first placement that, that, err, that this man had had. We didn’t disclose, they just knew he had a mental health condition and we didn’t disclose anything (I: Um um). I, I did say that if he finds behaviour, he finds it, relationships in work difficult but I didn’t expand on that. So with hindsight I think it would’ve been better to do full disclosure with the client’s permission and er I can’t wait to see the booklet that you’re going to write for employers (I: laughs)

P: That’s, that is actually really important because that’s another thing that discourages people because it’s like well, erm what am I going to say, you know, I’m going to this job and I’ve got mental health problems. Should I tell people, should I not tell people? If I don’t tell people and they’re going to expect me to be as good as everyone else (P: About disclosure yeah) and if I do tell people they’re going to be biased against me. So there is that real, er I think that’s a really important point actually about disclosure

PHD STUDENT: It’d be interesting to know whether, where disclosure plays er a part like, for example, you know, the contemplation stage whether to disclose then (P: Yeah, yeah) or
thinking about clients that are already in work, and having disclosed and do they dis, disclose then. I don’t know from your experiences what, what have you come across?
P: Yes, it’s a similar problem with Asperger’s clients, cos clients with Asperger’s the same issues kind of, it is the same
P: Well, I’ve got a client who works as a receptionist in a GP practice and erm they had a big reorganisation and people being moved around and she was absolutely terrified that because she thought there going to, this, this will be an excuse to get rid of me (I: So the fear, yeah) anyway she, she did disclose to her employer. And they couldn’t have been nicer to her and she got a lot of, you know, say in where she was going to be based and she wanted to be in a err, she, she didn’t want to be in a place where she’d be on her own, so she went to another place and it worked out really well (P: Um)
PHD STUDENT: That’s a really positive story
P: Yeah
PHD STUDENT: So actually that, what you’re saying is, it depends on the context doesn’t it (P: Yeah) of, of where you work and the environment (P: Yeah) and who you’re working with
P: People have quite strong opinions don’t they about whether they should disclose or not (P: Um, yeah) and erm we might think that it would be advantageous for them to do so but, but they actually are quite strong in their sort of judgment on that and you obviously have to respect that (P: Um yeah). Erm but, I mean, I find it difficult in terms of, sometimes, erm, you know, making appointments with people in terms of (I: Um) if they haven’t disclosed (P: Um) then, you know, coming to, to, you know, nine to five type clinics (I: Yeah) it’s, it’s really quite problematic (P: Yes) (I: Yeah, absolutely) erm so trying to do it in their lunch hour (I: Yeah) or, you know, what last thing or the first thing and it, it, you know, in some ways would it be easier if they had disclosed (I: Um) but then they face the stigma or you know kind of judgements of others or their perceived judgments of others
PHD STUDENT: Yeah so there’s been a talk, a lot of talk about erm a fear as well and I wonder what kind of emotions er clients with PD might, might undergo when they’re, you know, trying to gain employment in that stage. Would you say
P: Terrified I think a lot of the time (P: Um)
I: Terrified of?
P: Being judged
P: The judgement of others
P: And erm and also may be losing control of their own behaviour
PHD STUDENT: Okay, so the fear of losing control of their own behaviour
P: Yea, I mean the explosions and tantrums in the work place, yeah a fear of that
P: Maintaining a good working environment rather than
PHD STUDENT: So fear of people as well
P: I think, as well, going into a different environment, you know, you’re going to be removing a lot of the safety barriers that they’ve put up over time and they’re going to be feeling really quite vulnerable to all of these things (P: Yeah)
PHD STUDENT: Yeah so quite scared
P: Cos it’s so safe at home isn’t it? (P: Yeah) You can just avoid all the
P1: I, I had a gentleman a few years ago, it was before the erm, you guys were about actually, there was, there was a sort of course that the council used to put people on and erm this gentleman, he was very wilful about what he was specifically what he wanted to do and they got him a job at [names supermarket]. And erm the first job they put him on, they put him on erm a night shift, to, to, just stack, stack shelves. Er so he wouldn’t do that because it was night shifts. So then they put him in the garage and there was this erm there was an incident at Christmas where he was asked to carry some logs on his shoulder and somebody, a fellow employee made a comment about him looking like Santa Clause and he just completely erm said “I can’t do that job any more”. So it was this kind of wilfulness when something goes wrong. There was this kind of, and, and he was well set up with [names supermarket] and they (coughs), they really looked after him (I: Um) and they actually moved him about five different jobs within, within the space of five months, and unfortunately it didn’t work out there. Erm but there was this, from what I got, there was this real wilfulness (P: Well was it inter) and this interpersonal relationship with people (P: Was he on the autism spectrum?) (Clears throat) Well actually erm he, he wasn’t, he certainly had a personality disorder but he also had a, a diagnosis of schizophrenia, but he was in, he was doing really well. He hadn’t been erm unwell for a couple of years, you know, and erm it was the personality that, that was being the problem I think
PHD STUDENT: So this individual went before he started working at [names supermarket], er were you working with him before, leading up to there?

P1: Yea, I got him set up, I forgot the name of it, it used to be this kind of erm thing that err, [place] council did

P: [Name]?

P1: [Name], that's the one (P: Oh yea), yea, so

PHD STUDENT: It's not there, it's not here anymore?

P: No it is (P: It is, it's still going), yea it's still going (I: Oh, okay)

P1: Well they're, they're a bit more difficult to get the referrals to apparently. (P: Are they?) Anyway, erm, I, we used to use (P: I see), yea [name], er we used to use them guys and erm he would attend the, the course cos it was like a erm thing, I think it was like a four or five month course and erm it was about just reading newspapers. You know going through newspapers, looking at, job, job adverts and he just felt that erm it was below him and he, he wouldn't do it, he wouldn't do that sort of thing. And I was, I was saying to him this is the core, this is how we get you motivated, this is how we're going to get you to get up at nine o'clock or eight o'clock every morning to go to work (I: So it's a start, yeah) and it's, it's not at work, it's not a job, this isn't what I want to do sort of thing. So we kind of rushed him along and it was a bit of failure actually er he just wouldn’t settle, he couldn’t settle down

PHD STUDENT: Um, um and then in the end he left, he, because you said interpersonal difficulties wasn’t it?

P1: Er yeah, he just had problems with, with people and the more places that he was, it was the same department, the same shop, but lots of different departments and he felt like people were pushing him away. They were sort of saying “oh we don’t want him working in our team”. However, every single time he made a, a complaint that he couldn’t work in that job but he still sort of saw it as erm people were talking about him, people were erm moving him to somewhere else (P: clears throat) (I: Yeah) and, and he sort of develop this, erm, well I know he’s got, he wasn’t, it might have been paranoia but there was this very self-consciousness about this guy’s erm his, his job at [names supermarket] (I: Um) throughout the

P: But people probably were talking about him, if he was that difficult

P1: Yeah I think, yeah I think he was absolutely right. I think they were talking about him and, and sort of suggesting that he’s a really difficult guy to get on with, I think. So I think, yeah, it was justified a lot of what he was saying

PHD STUDENT: Um. So it sounds like it’s external factors as well as what was going on internally for, for that, for that person as well [P1: Um]. Yeah, I’m just thinking, I’m just thinking about (P: coughs) what you said about [Name service] is, is there a lot of services out there, is, is it still working, does it still, is this still existing even?

P: Yeah, as far as I know

P: Yeah, it does, yes

PHD STUDENT: Yeah, okay, (laughs). Erm, okay I just wondered actually in terms of erm clients’ behaviours at this stage, so they’re trying to gain employment so, you know, thinking about maybe perhaps task-orientated stuff like CV writing or what not, erm are there any particular behaviours that they might have that might to get in the way or behaviours that help?

P: Procrastination

PHD STUDENT: Procrastination, yeah

P1: One thing I’ve noticed on (I: Yeah) on people erm, well specifically the people I’ve been working with the last year, is that she’s put on a lot of erm stuff on her CV that weren’t exactly true (laughter) (I: Oh) erm and also that, some of the references were just friends and things like that (I: Oh right). And erm I sort of challenged that (I: Um) and this is why I mentioned it earlier, she’s sort of I’m struggling to get a reference so I use a friend, who I once used to cook for him. So basically he said, the guy was going to give her a reference and erm I couldn’t really challenge it, but, you know, I wanted it to work and I, err, and then I realised that er the CV wasn’t in, all together, I’m sure you get that all the time, do you?

P: Ah yeah (P1: It was sort of, yeah), often (P1: Yeah) yeah

P: It must be very hard if you haven’t worked very much. You haven’t really got much of a CV have you, you know

P1: And you sort of look at it and think yeah that’s a bit far-fetched but erm do you want sort of chat, no, no I’ll stick to that one. And you just think, you know, when somebody else reads that they’re going to see that and think that’s a bit far-fetched, you know, I: So if that was the situation, what, what would do you do to help them, if, if there’s a fact that they don’t actually have a lot of work experience but they do want to build a CV?
P: Erm well the key is to kind of get them doing something now such as some volunteering just so that their CV is up to date and then you can use that current placement as a reference. But also you can use professionals such as the GP or erm if they’ve known a, a social worker or whatever for two years or yourselves for, I think it’s one or two years, erm. But I guess they won’t want put down their, their clinical psychologist as a reference unless they’re going to disclose

P: And the GP might have a, you know, an, an experience of them as being, you know, in crisis or, you know, which is not going make it easy (P: No, no), what are they going to write

P: Yeah, so it’d just be, it could only be a character reference

P: With the best will in the world, you know, they’ve got to write what they know (P: Yeah, I know)

PHD STUDENT:Erm I just wonder from your, in your experience at this stage, if there’s any other things that hasn’t been mentioned already er that might impact er this stage. So, for example, things like physical illness erm might stop (P: Um, yeah) them from perhaps going to the job centre (P: Yes) or, or seeing the employment staff or alcohol use, or you know (P: Yeah, yeah all of that, yeah) (laughs) (P: Yeah) erm

P: Also erm, I mean I’ve got a client who is, has a history of violence, which was due to alcohol use. I mean he doesn’t drink anymore but he’s still a very angry man and he’s terrified of his anger. So he just keeps away from people (I: Um, um, um) and he used to have a really high powered job (I: Um) and but now, you know, he, he just can’t even contemplate going to work because he’s scared that someone will wind him up and then he could attack them

P: I’ve had one like that as well

PHD STUDENT:So for him, for him it sounds like it’s really fear, it’s really the fear that’s stopping him from

P: It’s the fear of the anger

PHD STUDENT:Fear of the anger yeah. Yeah, that makes it problematic from him

P: Yeah I’ve had the same (P: Yeah, um)

PHD STUDENT:So I suppose again, asking you guys at this stage, of, you know, taking steps and gaining employment, what would you say would be the most important or the most, kind of, I suppose, pertinent barrier to, to that person with PD getting employment, getting employed?

P1: Well, er (P: I was (laughs), you go ahead) get the, no (I: Go on P1). Well I was just going to say erm, you know, some of the DBT skills are really essential to it. I think it’s that kind of willingness, can do attitude and that’s the only thing people need to get a job. (I: Ok, so you think willing, willfulness?) Yeah, absolutely, it, it can get a job anywhere if they’ve got that can do, willing, willful, you know, being willing (I: Um) to, to do the job

P: But also emotion regulation skills, erm because this guy, I mean, he could actually end up attacking someone at work and that really wouldn’t be good, so, you know.

P1: Yeah so they can, that’s, that’s the sort of er the way to, can do attitude isn’t it (P: Yeah, yeah) being able to regulate the emotion (I: Um)

P: I do think it’s really hard in a competitive job market, you know, but and that comes back to this question about whether they should disclose. Because, you know, to actually, for anyone to get a job is a challenge (P: Yeah, yeah) I, I would find it really challenging (I: Yeah exactly, absolutely) to go for a job, any, any job. If I was to apply for any job I would be nervous and worried about (I: Um) how I’d perform and how I’m going to come across and what people would think of me. And if you had a personality disorder on top of that, I think there is that real, you know, it’s, realistically it’s going to be hard (P: Yeah it’s going to be more difficult)

P: So this is somewhere an employment advisor would advise the client to just to go along and you, just a summary cos it’s a huge area. The advice is don’t disclose until you’ve had an actual job offer in writing and then you can think about who you’re going to disclose to, whether it’s just occupational health, probably not advisable in, in, if a PD is the diagnosis (I: Yeah). Erm and who, you know, how are you going to disclose. That’s where I think it’s er useful for the er client to work with an employment specialist

PHD STUDENT:And is that because you’re not sure about how they might receive it on the other end or, or

P: Yeah I think it’s, they’d, they’d be useful for the client to have guidance about what to say, who, when to say it, who to tell (I: Um). It’s a really huge area because if they thought for a, er moment that it, it would stop the person doing the job then they could retract the offer, the job offer so

PHD STUDENT:So not until they’re given the offer. Erm before we move on I, [name] did you want to say something?
P: Erm I think I was going to say that it's the routine of doing some sort of voluntary work, you know, I think it's about actually practicing and, and getting sort of used to being able to manage (I: Okay) that kind of routine that

P: Yeah, just one thing about voluntary work. I've had clients who will do voluntary work but don't ever move beyond that because somehow if it's voluntary it isn't as much of a commitment and they won't be letting people down as much. And the idea that they could then move to something paid it's almost like they don't, they don't feel confident enough. They might feel confident enough to do a bit of voluntary work cos they can phone in sick and then it won't really matter

P: Yes I've had that as well actually (P: Yeah, yeah) that it's okay because it's voluntary, a voluntary job (P: Um)

PHD STUDENT: So different sort of attitudes to different works (P: Yeah). Okay, interesting. Erm I would like us just to move on, to, I suppose, the final stage erm of the employment pathway. So, so I'd like you just to consider this scenario, so they're now erm getting a job and, or they're getting a job and err, or they're in that job and they're trying to remain in it and retain it. So again consider this person with a PD or with significant traits and they're perhaps struggling to retain this or they find some things that are quite, you know, that they do enjoy about this job. There are also some things that they do find difficult as well. Erm from your experiences err, what would you consider, would there be any potential barriers to this stage of employment or potential things that has worked for them?

P: I think, I think one problem can be erm lack of assertiveness and inability to say no. So I had a client who got a job as a carer (I: Yeah) and she ended up working incredibly long hours and was, was being taken advantage of. And then just couldn't cope with the stress and just sort of, you know, completely fell apart really (I: Um) cos she wasn't able to maintain any boundaries (I: Yeah) and look after herself (I: Yeah)

P: Yeah, assertiveness is an important skill actually. There's another lady, who er I can think of, I'm working with, who er she doesn't, she, she doesn't know how to communicate very well in the workplace and so I think she upsets people and then obviously then they don't like her and that causes friction and then she takes out a grievance against them and then so it escalates. Err, yeah, she's kind of currently complaining to the race and equality commission or something and (I: Yeah) so, so it goes up to government, you know, she's going all the way with it. Erm so I think if she, I think it's her communication style at work

PHD STUDENT: So communication and assertiveness skills

P: Yeah

PHD STUDENT: Um. Any other similar experiences or when you think of, of the person you mentioned at [names supermarket]?

P1: Yeah, (I: At the end) (P: Yes, I've had one like that as well) (I: Um) I was just thinking also erm, it's a lot down to erm attendance isn't it. I mean er people, in, you know, just from my experience that they do tend to erm go off sick quite a lot which, which erm (I: Okay) which affects them. (I: Okay) You know, there'll be mornings where they just feel really hopeless and they don't want to, they just can't go to work and of course that sort of impacts on (I: Yeah, that's really) their position (I: Yeah) and, and their reputation with other people at work as well

PHD STUDENT: Um. I wonder what other, er that, you know, so that's calling in sick, I wonder if there's any other behaviours that perhaps that you might have experienced that they've, your clients have, have done erm in order to cope?

P: I can talk about the, the person I spoke about earlier

PHD STUDENT: Sure

P: Which I spoke to earlier but erm so this person, she erm wanted, got, got a job erm then they found out that she self-harmed and so they put her on full pay but sick, sick pay. Erm so she was off work for erm probably about two months or so, erm and she really wanted to get into the work and she didn't think that her difficulties would impact her doing the job (I: Okay). But she has in the past erm walked out of jobs because of, I mean it's to do with emotional regulation (I: Oh, okay) and she maintains that her problems are just at home, relating to her family (I: Right). But actually she then was able to tell me that she had walked out of jobs because of relationships at work. Erm but so there was certain amount of not actually sort of facing the difficulties that she had.

PHD STUDENT: So I just wonder, cos she's, you said it's about not being able to er regulate their emotions, so what, what kind of emotions was she experiencing?

P: Erm well she self-harms a lot, I mean it's, it's mainly to do with anger

PHD STUDENT: Anger at work
P: Erm well, with any relationships really. Erm I think she comes across as, as very erm passive and doesn’t, doesn’t voice her opinions and then, and then self-harms. Erm but then, so she’s now, as I say, now because of financial pressures (I: Yeah) in that she’s now going to be getting erm, she has to take unpaid leave for a, for a, a foot operation. She’s now actually now going to go back to benefits. So I, I mean I did wonder if there was any way that she could be helped to maintain that but I mean she’s actually, she has seen erm [name] but now actually hasn’t, she’s actually now opted out of seeing him again, erm

PHD STUDENT: Erm is there, was there a reasoning behind that?

P: Ah I think that there’s an element of willfulness that she kind of, it’s quite comfortable going back to how she previously was (on verge of chuckling) (I: Um) and benefits and being at home, so a certain amount of avoidance going on as well

PHD STUDENT: Avoidance yeah, so it sounds like a typical behaviour there (P: Um). Erm, um, any other similar experiences? (Pause). Do you have any other clients that have been maybe in a job before and been dismissed or walked out like you said?

P: Yeah I think often it’s to do with relationships

PHD STUDENT: Okay

P: So erm I’ve had a few clients who’ve had difficulties in relationships with bosses and, and erm (P: Authority), yeah

PHD STUDENT: Authority, okay

P1: And that, not being able to say no to things at work as well, I’ve had a few people like that

PHD STUDENT: So I just wonder when they’re at that workplace, erm I err, of course it depends on the context doesn’t it of whether they’ve been there for a while or whether they’re finding it particularly difficult at that point in time. I just kind of wonder what kind of things might be going through their mind. You know are they thinking gosh I’ve got this, I’m really good at this job, I’m not going to lose it or they’re thinking they’re going to fire me for x, y and z (P: Um, um). I don’t know, from your experience what sort of things come up for themes?

P: I’ve had both of them (P: Yeah)

P: I’ve had clients being amazingly confident about their position and their roles and how well they’re doing and then it all goes pear shaped and they don’t see it coming (I: Okay) and they don’t understand it and they don’t accept it when it’s happened (I: Um). Because it’s everybody else’s fault (P: Yes) and there was nothing they did wrong and it was all other people (P: Yes) and I’ve had people who are terrified all the time about losing their jobs and then they have appraisals and they’re, you know, often absolutely fine

PHD STUDENT: Okay (P: Yeah). So it’s, it sounds quite similar across the different stages in terms of erm people experiencing a lot of, of being, feeling quite scared actually, feelings of failure and erm feelings of and lots of worries as well. Do you think there are any other emotions at play or when it comes to trying to retain their job?

P: Anger

PHD STUDENT: So anger

P: Anger at the, you know, that “my boss is a complete bastard” and “how can you treat me this way”

PHD STUDENT: Yeah (P: Yeah) and how’s that manifested in terms of her actions? So you mentioned that, you know, some of them walked out

P: Yeah, just kind of losing it or having a big row (I: Yeah)

P: I had someone else who was really angry that she didn’t get a promotion. There was an external candidate and she felt that because she was an intern, an internal candidate (I: Uh huh) she should have had priority (I: Um) erm and she really felt this was unfair so she, she actually applied for some other jobs and ended up actually moving and er applying for another job but erm she actually struggled with working full-time and was looking to, for part-time hours, which probably would have suited her better

PHD STUDENT: So that’s quite interesting is what you mentioned I think, I think that’s quite, I think it’s important to remember that’s quite normal in the workplace isn’t it (P: Of course). If you were to work internally somewhere and then you go for a job and you didn’t get it, someone else did. I mean I know I would feel quite, well I’d feel quite upset (P: Yeah), I’d be quite angry. So I suppose in her situ or his situation erm what, what did they do in the end? Er what

P: She, she actually moved

PHD STUDENT: So she moved across (P: She moved to another) so (P: Yeah), okay so she obviously left.
P: Yeah, yeah, so in a way you could argue, I mean, it’s nothing to do with PD but it was just the way of, a strategy of getting out of a situation she felt was, was unfair (I: Yeah). So in some ways she dealt with that very well really if you think about it and it’s what, what any of us would do

PHD STUDENT: Yeah, yeah that’s an interesting point, um

P: Can I just check on the time. How long are you going to on because it’s
I: Er well I was going to go on for another ten minutes or so (P: Ok, that’s ok just err), but erm that very much depends on what else we’ve, we’ve got to cover so. Just a few more questions (P: Okay). Is that alright?

P: Yea that’s ok, I just need to go quite soon
I: Okay, sure. Erm so I suppose erm contemplating, considering this, this stage, this process that they’re, you know, they’ve got this job and they’re obtaining. What would you say would be the, the, er most important barrier or something that comes to mind that stops them from, from keeping that job? Whether it’d be their thoughts and emotions or some of the actions that you’ve mentioned?

P1: I, I think it’s very much the self-invalidation they, they provide for themselves really (I: Okay) a lot of the time, you know, there’s a, there’s all sorts of emotions going on there, you know, erm what, a particular person I know she erm had to have a lot of time off for physical health problems and they, they, she’s gone back to work now but she feels there’s a lot of guilt and shame about her having all this time off and erm she err, you know, she, it’s, it’s about her, so it’s about who she’s, she, she thinks she is at this particular place of work and, and what her function is and it’s very kind of derogatory, you know, she feels like she is the sort of er the weakest link within that employment, that, that team she works for (I: Um). Erm and it’s, it’s this self-invalidation this sort of getting that confidence (I: Yeah) getting, you know (I: The self-validation) yeah, self-invalid, yeah, self-validation

PHD STUDENT: Yeah, anything, yeah, any other similar experiences?

P: The thing about, you know, you can learn to invalidate yourself (P: Yes) but you still need the interpersonal skills and I think sometimes it’s the interpersonal skills (P: Um) the lack of interpersonal skills is (P1: Um), is, you know, pissing other people off and then they do end up losing jobs. So that’s also a barrier (P1: Yeah, yeah). So they need to learn how to be civil when they’re angry and, and how to deal all those things

I: Um, and you mentioned erm assertiveness skills as well (P: Um, yeah), incorporated into interpersonal effectiveness as well (P1: clears throat) as well, yeah

P: And then there’s the practical erm support that could come from an employment specialist as well, which I think would help as well as the, the emotional stuff

I: Yeah, so kind of erm, holistically put together, it could help enable someone to keep, keep a job where they’re at

P: Um (I: Um) and also part of the employment advisors role would be to liaise with the employer as well so erm hopefully help the person to, to retain the job

I: Yeah, um, absolutely. Okay, so my, my final question is, we’ve covered various elements of the employment pathway at different stages and I, obviously I, I mean what we’ve gathered today is not quite as straightforward as putting it into those three stages but I suppose if we were to consider all of them. What would you say would be the main barriers to someone with PD in terms of employment? And what would be the main things that you think would be helpful to support them?

P: So we sort of touched on this, but one of, not directly, but they, one of the barriers is about just being able to consis, be consistent (I: Consistent). So being able to (P: Sustain) just sustain (P: Yes) the routine mundane boring day-to-day demands of getting up in the morning, get there, being dependable and not having these kind of sudden switches in behaviour where you know one day you’ll be brilliant and the next day you’re completely not able to function and I think that’s a, one of the biggest barriers I think

I: So maintaining a routine (P: Yeah). Okay

P: So is that an, is that an internal thing then cos that’s, I’m assuming that’s, er, regulated by the individual themselves isn’t it (P: Yeah) or how (P: Yes), you know, this, this self-validation (P1: Um um) (P: Yeah, um) maybe

P: It’s also the motivation

P: And also the chaos in their lives

P: Yea, it’s about getting it under control, just getting their lives under control (P: Yea, yea) (P1: So)

P: Problem solving isn’t it really as to why they can’t manage that

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P: Isn’t it tolerating the mundane, that’s what I find quite often. Cos they can’t tolerate the mundane (P: Um)
P1: And, and just being able to, look, work on their vulnerabilities so it makes them, you know, you can, you can have somebody with a drug and alcohol problem, they can’t get up in the morning because they’re (P: Um) too hungover (P: Yeah) so there’s these vulnerabilities that emotional regulation (P: Um) and interpersonal effectiveness (I: So yeah) as well but er
P: Yeah it’s linked to that, so that being able to (P1: So yeah) take responsibility for being, you know, erm functional all the time, so that you can be (I: Yeah) dependable
I: So maintaining a routine (P: Yeah) whether it be more internal in terms of regulating their emotions by reducing their vulnerabilities
P1: Yeah and just identifying just a healthy lifestyle maybe (P: Yeah) something like that, that, a work healthy life, you know, in order to go to work you have to have a healthy life really (I: Um)
P: It’s something about walking the middle path isn’t it (I: laughs) because of, I’m just thinking some of, some of our clients are very erm perfectionist and you know it’s either, either they’re going to do it perfectly or they’re going to give up (P: Um) and erm, you know, there’s no in-between
I: Um, so that, yeah exercising the middle path and moving away from the black and white thinking (P: Yeah, yeah). Okay, alright, great, so is there anything else that you feel like we haven’t covered in the last hour or so? That hasn’t been voiced yet?
P: I think I, I, one specific thing (I: Yeah) I know that erm er when clients have had to get a police check done (I: Um), we’ve had a couple of experiences where the police checks have come back be, because the police have been called out when they’ve been suicidal, so they then have a, some kind of police record (P: Yeah) and that goes against them (I: Right) erm but it’s not to do with them being a risk to the public (I: Um um), not at all er but if it’s going to come up on their DBS check, they need that, someone like myself to give them advice on how to deal with that
I: Yeah, absolutely in the system that surrounds that individual
AC: So does something like that appear in a DBS check then?
P: It did, yeah
AC: Is that consistent?
P: I think that’s what happens, I haven’t come across that (AC: Yeah) I don’t think myself but erm yea that the, erm again if so, well er what I have come across if someone’s having an episode and they might erm cause harm to someone or prop or harm to property then yes that will be on the DBS so it’s again they need advice on how to disclose that to the employer, if, if it’s going to come up on their DBS check, they need that, someone like myself to give them advice on how to deal with that
P1: That’s terrible because it’s not breaking the law is it
AC: Yeah I know, yeah
P: But I guess it comes down to competition doesn’t it, if, if there’s other people (P: Um) then they’d prefer to employ the other person, you know, that’s, that’s there’s a line on this that there isn’t so many jobs out there, I guess that’s what I was getting at, that hasn’t been said today maybe but they’re, you know, this is a tough, tough er jobs market isn’t it
P: Exactly
P: I’ve had somebody who’d erm gone down to the train track it’s, saying that she was going to throw herself under a train and then someone had notified the police and the trains were stopped and she was charged with causing a public nuisance, lost her job (I: Ah gosh)
P: She lost her job?
P: That’s awful, gosh
P: Phwrf
P: And also it’s making the situation worse isn’t it
P: I mean it wasn’t the first she’d done such a thing, but yeah
I: Has that stopped her from getting another job
P: She’s not working at the moment
I: At the moment, okay, right, so there’s one element there
P: Gosh, I’m aghast
P1: But that is quite an important thing to put down to stop her from doing it in the future
P: Well yeah but she lost her career didn't she
P1: Yeah
P: Gosh

PHD STUDENT: I'm sorry I'm going to have to stop it there but thank you so much for participating erm before you guys go I just want to run through what happens next. So we have this thing called erm member checking. And basically it's a clarification process. So what we'll do now is we'll go, take these tapes away and we'll have the fun job of transcribing it all erm and then we'll summarise them into topics erm we'll give you an opportunity to view these topics and feedback on them. So it's, it's er a opportunity to perhaps give us more information that you've thought of after the focus group or just, you know, if, if we've misinformed it in one way from writing it up. It will give you the opportunity to correct it. Erm if you're interested er you could erm write your details down of how best to contact you and then we can get in contact that way. Also erm this er with your details would you be interested in us sending you the pilot questionnaire? So obviously from the, these focus groups, from not just today but from the other focus groups we're developing that questionnaire. So erm if that's okay that's fantastic erm so that part of the research unfortunately we won't be using erm er participants who've partaken in the focus, focus group for the pilot questionnaire so we need basically new people to, to fill out the questionnaire for us. So if we send it to you, er if you wouldn't mind forwarding it on to colleagues or potentially clients fantastic but for yourself unfortunately er you can't, you can't fill it in yourself (laughs)
P: There's no point being sent it then is there (laughs)
I: Well I mean you can have a look but I just, you know, if, if that's ok erm
AC: It's really if you'd be willing to give it out to people
I: Yeah, if you wanted to send it on
AC: So [Name] will send you the links, yeah, that would be great
P: Yeah, that's fine, that's alright, yeah (laughs)
I: If I pass it on to you
AC: Yeah, cos you know best how to get hold of your colleagues
P: Yeah that will be fine
I: Yeah sure
AC: That be lovely, yeah
I: That's great (P: There?) yeah. Erm yes. I think if you, yeah, that one. Okay thank you very much
P: Thank you very much
I: That wasn't too much hassle for you
P: No not at all
I: Great. Thank you so much
P: Thank you very much
I: Thank you
P: Okay
P: Is it okay to go?
I: Yes so thank you
AC: Yes you're free!
I: For participating
AC: You're released
I: I hope you found it interesting
AC: Thank you
I: And erm, yeah, we'll be in touch so (laughs)
P: Good luck
AC: Thanks a lot
P: Thank you
P: Sorry I'm a bit confused about
I: Oh, this is my one I think, yeah, I think, this is, yea
AC: It's kind of in an orange buff because I've got a big old orange cat
I: Is there any more sheet?
P1: Is that a dog?
AC: No I think it's that orange cat
P1: Cat
AC: He really is big and fat
P: Do you want to
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9a.1 Attitudes towards PD as a ‘hidden illness’
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9a.7 Attitudes towards smaller companies
9a.8 Attitudes towards importance of social environment at work
9a.9 Assumptions
9a.10 Lack of jobs in the job market
Appendix 30 Delphi Items (Chapter 3)

**Cognitive Factors**
Lack of self-belief
Feelings of hopelessness
Fear of failure (i.e. not getting a job, losing a job, not doing the job well)
Self-criticisms/Judgements on oneself
Fear of criticisms from others
Difficulties identifying personal barriers to employment
The fear of what others might think when you disclose your mental illness/difficulties at work
Fears of social interaction with colleagues
Fear of not completing a task properly
Fear of being judged by others in the workplace
Fear of being on sick leave
Fears of working overtime
Fear of pressures from work
Lack of self-identity
The fear of social stigma in the workplace
Fear of physical health affecting job performance
Fear of being on sick leave

**Behavioural Factors**
Difficulties interviewing for a job
Throwing up from anxiety
Difficulties in time management
Difficulties attending interviews
Difficulties in working independently
Difficulties in working to a consistent quality
Difficulties in learning new things
Suicide attempts
Difficulties in consistent attendance at work
Difficulties with taking initiative at work
Avoidance in seeking work
Perfectionism – i.e. working overtime to get a piece of work done – missing deadlines as spending too much time making work ‘perfect’
Inability to check instructions with supervisor
Inability to prepare for job interviews
Self-harm

**Interpersonal Factors**
Inability to maintain positive relationships at work
Inability to get along with people
Difficulties in initiating conversation with co-workers
Difficulties in asking for help (when looking for work, preparing for interviews, or at work)
Difficulties in declining a request to exchange workdays/duties
Difficulties in asking for ones needs at work
Difficulties asking for things that you need
Difficulties in saying ‘no’
Inability to work in a team
Difficulties in following instructions/rules
Difficulties saying no to requests from supervisors to work overtime (in relation to family commitments)
Difficulties resolving conflict with colleagues

**Emotional Factors**
Difficulties with managing emotions
Emotional outbursts
Overwhelmed by emotions
Feeling anxious about interviews
Angry Outbursts
Inability to tolerate emotions
Environment Factors
Lack of one-on-one individual support at work
Lack of an understanding manager
Lack of mental health service support
Employers’ prejudices about hiring people with mental illness
Loss of unemployment benefits when you get a job
Lack of family and friend support
Employers’ prejudices people with mental illness

Vitality
Low in energy
Difficulties in looking after one’s physical health problems
Tiredness
Appendix 31 Delphi Email Invite (Chapter 3)

Dear....

Subject Title: Personality Disorder and Employment - a Delphi study

Who we are and why you have been invited

The EMPOWER study is a National Institute for Health Research (NIHR) funded project focused on helping to motivate and enable people with Personality Disorder (PD) gain employment. While there are tools available to help healthcare professionals assess readiness for work in terms of physical ailment, no such tools are available for people with PD.

One of the aims of our project is to develop a means to assess readiness for work in this client group by creating a new Preparedness for Employment Scale (PES-PD). Collecting everyone’s response on each item will help us to build a clear picture of how relevant/prevalent the items on the questionnaire identifies what the barriers and enablers are to employment activity for people with PD.

You have been invited because your expertise can help develop the PES-PD into a useful clinical tool.

What it will entail

There will be three rounds of questionnaires.

Round 1: You will be sent a questionnaire of items, in which you will be asked to rate the relevance of each item along a 9-point Likert scale. Each item represents a barrier to employment for people with PD. Responders will have a week to respond from when the round was first sent. Round 1 will take approximately 10-15 minutes to complete.

Round 2: Within two weeks, you will receive a second questionnaire and asked to review the items summarised by investigators based on information provided in the first round. You will be given your previous responses and the means of other participants’ responses. You will also be asked to revise any judgments, and asked to rate the items again for relevance. You will also be asked to rank the items in order of importance. Round 2 will take approximately 10-15 minutes to complete.

Round 3: Within two weeks, you will receive a questionnaire that includes the remaining items and ratings, minority opinions, and items achieving consensus. You will have an opportunity to revise your judgments. Round 3 will take approximately 10 minutes to complete.

If you are interested in taking part, please click on this link below.
Appendix 32 PES-PD - 57 items (Chapter 4)

Preparedness for Employment Scale for People with Personality Disorders (PES-PD)  
(Pilot Scale)

Participant ID number:

This questionnaire was developed by asking the opinions of people who have had difficulties with emotional regulation and interpersonal difficulties with regards to employment. It looks at the sort of things that might get in the way of thinking, looking for, getting, and keeping employment. The questionnaire is divided into two parts: the first part looks at difficulties frequently encountered at work; and the second part asks about what support is needed to manage the difficulties.

At this stage we are interested both in what are the difficulties people are encountering and what people’s views of the questionnaire are, as we are in the process of fixing this questionnaire to be most helpful.

Section A has 45 and Section B has 12 statements. For each statement, please start by reading it carefully. You will then be asked to answer four questions about each statement. Two questions in the left column form part of the questionnaire, and the two questions in the right column are feedback questions. Please circle the number for each question on the left column to show how you have felt in most instances at this moment in time.

Please be assured that all information is confidential and anonymous. There are no right or wrong answers. For each statement the questions will be formatted like this:

1. Example statement

(a) To what extent do you agree with this statement? (please circle a number)

<table>
<thead>
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<td><strong>Completely disagree</strong></td>
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(b) To what extent does this get in the way of employment? (please circle a number)

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Does the statement make sense to you? (✔)

Yes ☐ No ☐ If you ticked no, in your own words why?

________________________

PES-PD V2
### Section A: Challenges to Employment

1. I find it very **easy** to disclose my mental health diagnosis in the workplace

<table>
<thead>
<tr>
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<thead>
<tr>
<th>(b) To what extent does this get in the way of employment? (please circle a number)</th>
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</tr>
</thead>
<tbody>
<tr>
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</table>

2. **I always understand how to read other people's reactions when I share things**

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</table>
3. I am always unsure of what my employment related values are

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</table>

4. I always worry that if I disclose my mental health status diagnosis, I will be rejected by my employer and/or colleagues

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Please turn over
5. I have **never** walked out in the middle of the day from a job without thinking about the consequences

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Does the statement make sense to you? (✔)

Yes ☐ No ☐ If you ticked no, in your own words why?

6. I **never** act impulsively at work

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Does the statement make sense to you? (✔)

Yes ☐ No ☐ If you ticked no, in your own words why?

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7. I **never** find it hard to talk about how I’m feeling with other people

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Does the statement make sense to you? (✓)

Yes [ ] No [x] If you ticked no, in your own words why?

________________________

8. I **always** find it hard to get motivated in the morning to go to work/go to an interview

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Does the statement make sense to you? (✓)

Yes [ ] No [x] If you ticked no, in your own words why?

________________________
9. **I always** worry I will be judged by my colleagues and/or employer

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| does not get | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | | | | | | | \|
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| employment | | | | | | | | | | | | | | | \|
| Neither gets in | | | | | | | | | | | | | | | \|
| or does not get | | | | | | | | | | | | | | | \|
| in the way of | | | | | | | | | | | | | | | \|
| employment | | | | | | | | | | | | | | | \|
| Completely | | | | | | | | | | | | | | | \|
| agree | | | | | | | | | | | | | | | \|

10. **I always** know what type of job I would like to have

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| Completely | | | | | | | | | | | | | | | \|
| agree | | | | | | | | | | | | | | | \|

Please turn over

PES-PD V2
Preparedness for Employment Scale for People with Personality Disorders (PES-PD)

(Pilot Scale)

11. When I am very emotional I **always** find it difficult to get on with work/the interview/task

<table>
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</table>

12. I **always** know why having a job is important to me

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Please turn over

PES-PD V2
13. After I have not worked for a while (i.e. after sick leave, holiday, gap in employment), I find it very difficult to get back into the routine of work

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</table>

Does the statement make sense to you? (√)

Yes ☐ No ☐ If you ticked no, in your own words why?

14. I always find it easy to interact with my work colleagues

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Does the statement make sense to you? (√)

Yes ☐ No ☐ If you ticked no, in your own words why?

Please turn over

PES-PD V2
15. I *always* worry that how I act in the workplace (due to my mental health diagnosis) will be judged by my colleagues/employers

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Does the statement make sense to you? (✓)
Yes ☐ No ☐ If you ticked no, in your own words why?

16. I *never* know when to share personal information with my colleagues and/or supervisor about myself

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PES-PD V2
### Preparedness for Employment Scale for People with Personality Disorders (PES-PD)

(Pilot Scale)

#### 17. I am always quick to show anger

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Yes [ ] No [ ] If you ticked no, in your own words why?  

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#### 18. I always find it easy to recognise what other people are willing to speak about

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Yes [ ] No [ ] If you ticked no, in your own words why?  

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Please turn over

PES-PD V2
19. I have **never** quit a job without thinking about the consequences

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20. I am **always** able to figure out what someone is feeling (happy, frustrated) by looking at their face

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Please turn over
21. I believe I will **always** be successful getting work

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22. I feel **always** calm at work even when things are difficult

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PES-PD V2
Preparedness for Employment Scale for People with Personality Disorders (PES-PD)
(Pilot Scale)

23. I **always** work longer than I am expected/my contracted hours

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Yes [ ] No [ ] If you ticked no, in your own words why?

24. I **always** find it easy to socialize with people at work

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Yes [ ] No [ ] If you ticked no, in your own words why?

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PES-PD V2
**Preparedness for Employment Scale for People with Personality Disorders (PES-PD)**

(Pilot Scale)

25. I am **always** able to talk about how I’m feeling with other people at work

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Completely disagree | Neither agree nor disagree | Completely agree

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<tr>
<td>3</td>
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</table>

26. I am **never** able to imagine what the other person might be thinking or feeling (i.e. colleague, supervisor)

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PES-PD V2
**Preparedness for Employment Scale for People with Personality Disorders (PES-PD)**

**(Pilot Scale)**

27. I believe I will **always** be successful keeping work

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28. Feeling low in mood **never** stops me from going to work/going to an interview

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**PES-PD V2**
29. I can **always** continue working when I’m experiencing strong emotions

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30. I **always** know my limits and I am able to say ‘no’ in the workplace

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Please turn over
Preparedness for Employment Scale for People with Personality Disorders (PES-PD)
(Pilot Scale)

31. I am never able to ask for what I want in the workplace (i.e. annual leave request)

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Does the statement make sense to you? (✓)
Yes ☐ No ☐ If you ticked no, in your own words why?

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32. When I feel very emotional I never go to work/interview

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</table>

Does the statement make sense to you? (✓)
Yes ☐ No ☐ If you ticked no, in your own words why?

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Please turn over

PES-PD V2
**Preparedness for Employment Scale for People with Personality Disorders (PES-PD)**

*(Pilot Scale)*

### 33. When I think about work my critical thoughts **never** get in the way

(a) To what extent do you agree with this statement? (please circle a number)

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<tr>
<td>Completely disagree</td>
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</table>

(b) To what extent does this get in the way of employment? (please circle a number)

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<td>Definitely include</td>
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</table>

Does the statement make sense to you? (✓)

Yes ☐ No ☐ If you ticked no, in your own words why?

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### 34. When I use alcohol and/or drugs it **never** stops me from doing my work/going to an interview (i.e. hungover, currently intoxicated)

(a) To what extent do you agree with this statement? (please circle a number)

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<tbody>
<tr>
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(b) To what extent does this get in the way of employment? (please circle a number)

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To what extent should this statement be included in this questionnaire? (please circle a number)

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</tbody>
</table>

Does the statement make sense to you? (✓)

Yes ☐ No ☐ If you ticked no, in your own words why?

---

Please turn over

PES-PD V2
Preparedness for Employment Scale for People with Personality Disorders (PES-PD)
(Pilot Scale)

35. When I have had conflicts with colleagues and/or supervisors, I have **never** been able to discuss it

<table>
<thead>
<tr>
<th>(a) To what extent do you agree with this statement? (please circle a number)</th>
<th>To what extent should this statement be included in this questionnaire? (please circle a number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completely disagree</td>
<td>Neither agree nor disagree</td>
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</tbody>
</table>

(b) To what extent does this get in the way of employment? (please circle a number)

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<th>Definitely does not get in the way of employment</th>
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<tr>
<td>Does the statement make sense to you? (✓) Yes ☐ No ☐ If you ticked no, in your own words why?</td>
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36. My physical health **always** gets in the way of my ability to work-going to an interview

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<tr>
<th>(a) To what extent do you agree with this statement? (please circle a number)</th>
<th>To what extent should this statement be included in this questionnaire? (please circle a number)</th>
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<tbody>
<tr>
<td>Completely disagree</td>
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</tbody>
</table>

(b) To what extent does this get in the way of employment? (please circle a number)

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Please turn over

PES-PD V2
37. I **always** say/do things at work without thinking about the consequences

(a) To what extent do you agree with this statement? (please circle a number)

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To what extent should this statement be included in this questionnaire? (please circle a number)

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Does the statement make sense to you? (✓)

Yes ☐ No ☐ If you ticked no, in your own words why?

__________________________

38. I **always** able to manage strong emotions while I am at work/an interview

(a) To what extent do you agree with this statement? (please circle a number)

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Does the statement make sense to you? (✓)

Yes ☐ No ☐ If you ticked no, in your own words why?

__________________________

Please turn over

PES-PD V2
Preparedness for Employment Scale for People with Personality Disorders (PES-PD)
(Pilot Scale)

39. When I have conflicts with colleagues and/or supervisors I **always** keep quiet

<table>
<thead>
<tr>
<th>(a) To what extent do you agree with this statement? (please circle a number)</th>
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<tbody>
<tr>
<td>0</td>
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<tr>
<td>Completely disagree</td>
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<tr>
<td>(b) To what extent does this get in the way of employment? (please circle a number)</td>
<td>Does the statement make sense to you? (✔)</td>
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<tr>
<td>Definitely does not get in the way of employment</td>
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<tr>
<td>Yes</td>
<td>No</td>
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</table>

40. Even when I am sleepy I **always** able to go to work/go to an interview

<table>
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<tr>
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Please turn over

PES-PD V2
**Preparedness for Employment Scale for People with Personality Disorders (PES-PD)**

**(Pilot Scale)**

41. **I always find it difficult to calm down when I am angry at work**

(a) To what extent do you agree with this statement? (please circle a number)

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</table>

Does the statement make sense to you? (√)

Yes ☐ No ☐ If you ticked no, in your own words why?

____________________________________

42. **When I feel low in energy I never go to work/an interview**

(a) To what extent do you agree with this statement? (please circle a number)

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</table>

Does the statement make sense to you? (√)

Yes ☐ No ☐ If you ticked no, in your own words why?

____________________________________

Please turn over

PES-PD V2.
### Preparedness for Employment Scale for People with Personality Disorders (PES-PD)
(Pilot Scale)

43. Even when I disagree I am always willing to follow instructions given to me by a line manager/supervisor

<table>
<thead>
<tr>
<th>(a) To what extent do you agree with this statement? (please circle a number)</th>
<th>To what extent should this statement be included in this questionnaire? (please circle a number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
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44. I always know how much my colleagues and/or supervisor want to share personal information with me

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Please turn over
**Preparedness for Employment Scale for People with Personality Disorders (PES-PD)**

*(Pilot Scale)*

45. When I think about work my worry thoughts (i.e. “what if…”) *always* get in the way

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### Preparedness for Employment Scale for People with Personality Disorders (PES-PD)

(Pilot Scale)

#### Section B: Support

1. I believe (my) employer(s) generally know(s) a lot about mental health difficulties

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Does the statement make sense to you? (✓)
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#### 2. I always need help with transport to work

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Does the statement make sense to you? (✓)
Yes ☐ No ☐ If you ticked no, in your own words why? ________________________________

PES-PD V2
# Preparedness for Employment Scale for People with Personality Disorders (PES-PD)

(Pilot Scale)

## 3. I really need advice on the process of how to get a job

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## 4. I always need financial support to get to interviews/work

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Please turn over

PES-PD V2
**Preparedness for Employment Scale for People with Personality Disorders (PES-PD)**

*(Pilot Scale)*

5. **I am always self-sufficient; I do not need to rely on my employer/supervisor**

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Does the statement make sense to you? (✓)

Yes ☐ No ☐ If you ticked no, in your own words why?

6. **I never need ongoing support from NHS mental health services with regard to employment**

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Please turn over
7. I **always** need the emotional support of friends and family for me to be able to work

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Does the statement make sense to you? (✓)

- Yes  
- No

If you ticked no, in your own words why?

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8. When I am absent from work due to my mental health difficulties I **never** need reassurance from my colleagues and/or employers

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Please turn over
## Preparedness for Employment Scale for People with Personality Disorders (PES-PD)

**Pilot Scale**

9. I am always able to ask for adjustments to be made to my working environment for my **physical health needs**

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</tbody>
</table>

10. I am never able to ask for adjustments to be made to my working environment for my **mental health needs**

<table>
<thead>
<tr>
<th>(a) To what extent do you agree with this statement? (please circle a number)</th>
<th>To what extent should this statement be included in this questionnaire? (please circle a number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Completely disagree</td>
<td>Neither agree nor disagree</td>
</tr>
<tr>
<td>Definitely exclude</td>
<td>Definitely include</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(b) To what extent does this get in the way of employment? (please circle a number)</th>
<th>Does the statement make sense to you? (✓)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Definitely does not get in the way of employment</td>
<td>Definitely gets in the way of employment</td>
</tr>
<tr>
<td>If you ticked no, in your own words why?</td>
<td></td>
</tr>
</tbody>
</table>

Please turn over

PES-PD V2
Preparedness for Employment Scale for People with Personality Disorders (PES-PD)
(Pilot Scale)

11. Employers never provide enough support for when I return to work

<table>
<thead>
<tr>
<th>(a) To what extent do you agree with this statement? (please circle a number)</th>
<th>To what extent should this statement be included in this questionnaire? (please circle a number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>Completely disagree</td>
<td>Definitely exclude</td>
</tr>
<tr>
<td>Neither agree nor disagree</td>
<td>Definitely include</td>
</tr>
<tr>
<td>Completely agree</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(b) To what extent does this get in the way of employment? (please circle a number)</th>
<th>Does the statement make sense to you? (✓)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Yes ☐ No ☐</td>
</tr>
<tr>
<td>Definitely does not get in the way of employment</td>
<td>If you ticked no, in your own words why?</td>
</tr>
<tr>
<td>Neither gets in or does not get in the way of employment</td>
<td></td>
</tr>
<tr>
<td>Definitely gets in the way of employment</td>
<td></td>
</tr>
</tbody>
</table>

12. It is easy for me to have adjustments made to my working environment for my mental health needs

<table>
<thead>
<tr>
<th>(a) To what extent do you agree with this statement? (please circle a number)</th>
<th>To what extent should this statement be included in this questionnaire? (please circle a number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>Completely disagree</td>
<td>Definitely exclude</td>
</tr>
<tr>
<td>Neither agree nor disagree</td>
<td>Definitely include</td>
</tr>
<tr>
<td>Completely agree</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(b) To what extent does this get in the way of employment? (please circle a number)</th>
<th>Does the statement make sense to you? (✓)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td>Yes ☐ No ☐</td>
</tr>
<tr>
<td>Definitely does not get in the way of employment</td>
<td>If you ticked no, in your own words why?</td>
</tr>
<tr>
<td>Neither gets in or does not get in the way of employment</td>
<td></td>
</tr>
<tr>
<td>Definitely gets in the way of employment</td>
<td></td>
</tr>
</tbody>
</table>

Please turn over

PES-PD V2
Appendix 33 SAPAS (Chapter 4 and 5)

REMOVED FOR COPYRIGHT REASONS
Appendix 34 Client Information Sheet (Chapter 4)

PLEASE KEEP ME
You are being asked to take part in a study to develop a questionnaire about the obstacles and supports for people with a personality disorder (PD) in obtaining and retaining employment. We hope that this questionnaire will help individuals to make decisions about when to enter employment, help clinicians/employment staff to identify what supports the individual will need to gain employment, and will allow us to measure the outcome of interventions designed to help people gain and retain employment. We also hope that the information we gather will help us to advice employers about what support may be needed by the individual at work.

This study will involve completing a draft of the newly developed Preparedness for Employment Scale for people with Personality Disorders (PES-PD), feedback form about the PES-PD, and a demographics form. You are welcome to contact the research team with any further questions about the research or if you find that any of the information provided is unclear. The questionnaire pack will take approximately 45 minutes to complete.

1) The purpose of the study
The purpose of this study is to develop and evaluate a scale which we hope will:

i) Help individuals with a PD to make decisions about when to enter employment

ii) Help clinicians/employment staff to identify what supports the individual will need to gain employment

iii) Allow us to measure the outcome of interventions designed to help people gain and retain employment

iv) Help us to give advice to employers about what support may be needed.
We would like to test the questionnaire and ask you questions around its length, readability, vocabulary, and clarity.

2) Why have you been invited?
You have been invited to take part in the study because you are a person with a PD who is seeking employment, is employed, or is unemployed. We feel that you would be able to help us think about issues regarding seeking, obtaining and retaining employment. We also hope that you would be able to think creatively about other people who could take part in this research.

3) Do I have to take part?
No, you do not have to take part in the study. It is up to you to decide whether you wish to take part or not. If you do consent to taking part in this study you are still free to stop completing the questionnaire pack at any time without having to give a reason. Deciding not to take part in the study will not affect the care you receive from services either now or in the future. If you are not currently receiving care this will also not affect you receiving care in the future.

4) What will happen if you do choose to take part in the study?
If you do wish to take part in the study, after reading this information sheet you will complete the full pack; a demographics form, the pilot questionnaire of the Preparedness for Employment Scale for people with Personality Disorders (PES-PD), the Standardised Assessment of Personality – Abbreviated Scale (SAPAS), and a payment address form. You can return the
completed paper packs (on yellow paper) in the prepaid envelope provided in the pack and return the payment address form in the separate prepaid envelope. By returning the completed paper packs, you have given consent to participate in the research.

5) Who will know you are taking part in the study?
All of the forms except the payment address form do not require you to enter any information which could lead to your identification. We will ensure that when we receive your payment address form, the research team will store them separately from the other completed forms in the questionnaire pack, in secure NHS computers at North East London NHS Foundation Trust (NELFT). Please do not write any personal information on the questionnaires (e.g. your name). Any quotes that you provide which are used in the published research will also be checked to ensure no one could be identified by what they have written.

In accordance with current NELFT Records Management Policy, research findings will need to be stored by NELFT as sponsor for 20 years after the research has finished. The NELFT Records Office provides a service to NELFT staff and maintains archived records in a safe and secure off site location. All activities are conducted in accordance with the Data Protection Act 1998 and NELFT Data Protection Policy. Access to the data is strongly regulated and only members of the research team will have the right to use.

6) What are the possible benefits of taking part in the study?
We hope that you will find it helpful or interesting to complete questions about your experiences of seeking, obtaining and retaining employment. You may also find it helpful to know the information gathered from this study will better inform our understanding of the experiences of individuals with PD and employment, which will allow us to develop a useful scale and services in the future.

7) What are the possible disadvantages or risks of taking part in the study?
People who have had recent experiences of finding it difficult to obtain a job, losing a job or are having current difficulties at work may experience some distress completing the questionnaire pack. We would advise you to consider if you are in a ‘calm state of mind’ before proceeding to the questionnaire. We will provide information on the front of the questionnaire pack on how to cope if you are feeling distressed; a self-help handout of mindfulness, distraction, visualisation and self-soothe techniques, and other support numbers. These are for you to keep. If the distress is ongoing we would encourage you to contact your therapist (if you have one) or your GP.

8) Payments
For each completed questionnaire pack participants will receive a £5 gift voucher. We will only be able to pay you if you complete the payment address form and return it, sealed with the completed questionnaires (PES-PD and demographics form) in the envelope provided. If you have not received your voucher within 1 month please contact EMPOWER research team on the number or email provided on the top of this sheet.

9) What will happen to the results of the research study?
The piloting of the PES-PD is one work-package of a larger study which is looking to help people with PD gain employment. The larger study will be completed in autumn 2019. The information from piloting the questionnaire will help us to develop the scale further and prepare it for a full psychometrics evaluation of the questionnaire. We hope the validated scale will help us to measure readiness for employment in PD clients. The anonymised results of piloting the PES-PD will be presented in a doctoral thesis, will be published in a scientific journal, and presented at national or international conferences. Once fully developed, the scale will be given to NHS Trusts across the UK.

If you wish to be invited to a feedback meeting where the results of the study will be presented, please refer to the statement on the payment address form in the questionnaire pack and tick appropriately. We will send you a letter of invite with the details at a later date.

10) Who has reviewed the study?
The study has been reviewed by the NIHR who have funded the study. The study has been granted ethical approval by South Birmingham Research Ethics Committee.

Contact Details:
If you wish to contact to discuss any of the information further, then please contact on: [Contact Information]. Please be aware that the EMPOWER research team have a duty of care to all participants. Therefore if we are concerned about your safety or the safety of other participants, the researchers will first speak you, and then inform their supervisors who will inform relevant healthcare professionals.
Preparedness for Employment Scale for people with Personality Disorders (PES-PD): Piloting of the PES-PD

Please keep this document for your records

You are being asked to take part in a study to develop a questionnaire about the obstacles and supports for people with a personality disorder (PD) in obtaining and retaining employment. We hope that this questionnaire will help individuals to make decisions about when to enter employment, help clinicians/employment staff to identify what supports the individual will need to gain employment, and will allow us to measure the outcome of interventions designed to help people gain and retain employment. We also hope that the information we gather will help us to advice employers about what support may be needed by the individual at work.

This study will involve completing a draft of the newly developed Preparedness for Employment Scale for people with Personality Disorders (PES-PD), feedback form about the PES-PD, and a demographics form. You are welcome to contact the research team with any further questions about the research or if you find that any of the information provided is unclear. We are looking to hear from lots of people, so even if you do not share similar difficulties to people with a PD your input is still really important. The questionnaire pack will take approximately 45 minutes to complete.

1) The purpose of the study
The purpose of this study is to develop and evaluate a scale which we hope will:

i) Help individuals with a PD to make decisions about when to enter employment
ii) Help clinicians/employment staff to identify what supports the individual will need to gain employment
iii) Allow us to measure the outcome of interventions designed to help people gain and retain employment
iv) Help us to give advice to employers about what support may be needed.

We would like to test the questionnaire and ask you questions around its length, readability, vocabulary, and clarity.

2) Why have you been invited?
You have been invited to take part in the study because you are a service user seeking employment, are employed, or are unemployed. We feel that you would be able to help us think
about issues regarding seeking, obtaining and retaining employment. We also hope that you would be able to think creatively about other people who could take part in this research.

3) Do I have to take part?
No, you do not have to take part in the study. It is up to you to decide whether you wish to take part or not. If you do consent to taking part in this study you are still free to stop completing the questionnaire pack at any time without having to give a reason. Deciding not to take part in the study will not affect the care you receive from services either now or in the future. If you are not currently receiving care this will also not affect you receiving care in the future.

4) What will happen if you do choose to take part in the study?
If you do wish to take part in the study, after reading this information sheet you will complete the full pack; a demographics form, the pilot questionnaire of the Preparedness for Employment Scale for people with Personality Disorders (PES-PD), the Standardised Assessment of Personality – Abbreviated Scale (SAPAS), and a payment address form. You can return the completed paper packs (on yellow paper) in the prepaid envelope provided in the pack, and return the payment address form in the separate prepaid envelope. By returning the completed paper packs, you have given consent to participate in the research.

5) Who will know you are taking part in the study?
All of the forms except the payment address form do not require you to enter any information which could lead to your identification. We will ensure that when we receive your payment address form, the research team will store them separately from the other completed forms in the questionnaire pack, in secure NHS computers at North East London NHS Foundation Trust (NELFT). Please do not write any personal information on the questionnaires (e.g. your name). Any quotes that you provide which are used in the published research will also be checked to ensure no one could be identified by what they have written.

In accordance with current NELFT Records Management Policy, research findings will need to be stored by NELFT as sponsor for 20 years after the research has finished. The NELFT Records Office provides a service to NELFT staff and maintains archived records in a safe and secure off site location. All activities are conducted in accordance with the Data Protection Act 1998 and NELFT Data Protection Policy. Access to the data is strongly regulated and only members of the research team will have the right to use.

6) What are the possible benefits of taking part in the study?
We hope that you will find it helpful or interesting to complete questions about your experiences of seeking, obtaining and retaining employment. You may also find it helpful to know the information gathered from this study will better inform our understanding of the experiences of individuals with PD and employment, which will allow us to develop a useful scale and services in the future.

7) What are the possible disadvantages or risks of taking part in the study?
People who have had recent experiences of finding it difficult to obtain a job, losing a job or are having current difficulties at work may experience some distress completing the questionnaire pack. We would advise you to consider if you are in a ‘calm state of mind’ before proceeding to the questionnaire. We will provide information on the front of the questionnaire pack on how to cope if you are feeling distressed; a self-help handout of mindfulness, distraction, visualisation and self-soothe techniques, and other support numbers. These are for you to keep. If the distress is ongoing we would encourage you to contact your therapist (if you have one) or your GP.

Payments
For each completed questionnaire pack participants will receive a £5 gift voucher. We will only be able to pay you if you complete the payment address form and return it, sealed with the completed questionnaires (PES-PD and demographics form) in the envelope provided. If you have not received your voucher within 1 month please contact EMPOWER research team on the number or email provided on the top of this sheet.

9) What will happen to the results of the research study?
The piloting of the PES-PD is one work-package of a larger study which is looking to help people with PD gain employment. The larger study will be completed in autumn 2019. The
information from piloting the questionnaire will help us to develop the scale further and prepare it for a full psychometrics evaluation of the questionnaire. We hope the validated scale will help us to measure readiness for employment in PD clients. The anonymised results of piloting the PES-PD will be presented in a doctoral thesis, will be published in a scientific journal, and presented at national or international conferences. Once fully developed, the scale will be given to NHS Trusts across the UK.

If you wish to be invited to a feedback meeting where the results of the study will be presented, please refer to the statement on the payment address form in the questionnaire pack and tick appropriately. We will send you a letter of invite with the details at a later date.

10) Who has reviewed the study?
The study has been reviewed by the NIHR who have funded the study. The study has been granted ethical approval by South Birmingham Research Ethics Committee.

Contact Details:
If you wish to contact to discuss any of the information further, then please contact [redacted] on: [redacted] Please be aware that the EMPOWER research team have a duty of care to all participants. Therefore if we are concerned about your safety or the safety of other participants, the researchers will first speak you, and then inform their supervisors who will inform relevant healthcare professionals.

If you feel that I have not addressed your concerns adequately or if you have any concerns about my conduct, then please contact:

[redacted]

Thank you very much for taking the time to read this information sheet.
Please ask if there is anything that is not clear or if you would like more information.
Please take time to decide whether or not you would wish to take part.
Appendix 36 Members of the Public Pilot Information Sheet (Chapter 4)

Preparedness for Employment Scale for people with Personality Disorders (PES-PD): Piloting of the PES-PD

Please keep this document for your records
You are being asked to take part in a study to develop a questionnaire about the obstacles and supports for people with a personality disorder (PD) in obtaining and retaining employment. We hope that this questionnaire will help individuals to make decisions about when to enter employment, help clinicians/employment staff to identify what supports the individual will need to gain employment, and will allow us to measure the outcome of interventions designed to help people gain and retain employment. We also hope that the information we gather will help us to advice employers about what support may be needed by the individual at work.
This study will involve completing a draft of the newly developed Preparedness for Employment Scale for people with Personality Disorders (PES-PD), feedback form about the PES-PD, and a demographics form. You are welcome to contact the research team with any further questions about the research or if you find that any of the information provided is unclear. We are looking for individuals both with and without characteristics similar to people with PD. The questionnaire pack will take approximately 45 minutes to complete.

1) The purpose of the study
The purpose of this study is to develop and evaluate a scale which we hope will:

i) Help individuals with a PD to make decisions about when to enter employment
ii) Help clinicians/employment staff to identify what supports the individual will need to gain employment
iii) Allow us to measure the outcome of interventions designed to help people gain and retain employment
iv) Help us to give advice to employers about what support may be needed.

We would like to test the questionnaire and ask you questions around its length, readability, vocabulary, and clarity.

2) Why have you been invited?
You have been invited to take part in the study because you a member of the public. We feel that you would be able to help us think about issues regarding seeking, obtaining and retaining employment. We also hope that you would be able to think creatively about other people who could take part in this research.

3) Do I have to take part?
No, you do not have to take part in the study. It is up to you to decide whether you wish to take part or not. If you do consent to taking part in this study you are still free to stop completing the questionnaire pack at any time without having to give a reason. Deciding not to take part in the study will not affect the care you receive from services either now or in the future. If you are not currently receiving care this will also not affect you receiving care in the future.

4) What will happen if you do choose to take part in the study?
If you do wish to take part in the study, after reading this information sheet you will complete the full pack; a demographics form, the pilot questionnaire of the Preparedness for Employment Scale for people with Personality Disorders (PES-PD), the Standardised Assessment of Personality – Abbreviated Scale (SAPAS), and a payment address form. You can return the completed paper packs (on yellow paper) in the prepaid envelope provided in the pack, and return the payment address form in the separate prepaid envelope provided. By returning the completed paper packs, you have given consent to participate in the research.

5) Who will know you are taking part in the study?
All of the forms except the payment address form do not require you to enter any information which could lead to your identification. We will ensure that when we receive your payment address form, the research team will store them separately from the other completed forms in the questionnaire pack, in secure NHS computers at North East London NHS Foundation Trust (NELFT). Please do not write any personal information on the questionnaires (e.g. your name). Any quotes that you provide which are used in the published research will also be checked to ensure no one could be identified by what they have written.

In accordance with current NELFT Records Management Policy, research findings will need to be stored by NELFT as sponsor for 20 years after the research has finished. The NELFT Records Office provides a service to NELFT staff and maintains archived records in a safe and secure off site location. All activities are conducted in accordance with the Data Protection Act 1998 and NELFT Data Protection Policy. Access to the data is strongly regulated and only members of the research team will have the right to use.

6) What are the possible benefits of taking part in the study?
We hope that you will find it helpful or interesting to complete questions about your experiences of seeking, obtaining and retaining employment. You may also find it helpful to know the information gathered from this study will better inform our understanding of the experiences of individuals with PD and employment, which will allow us to develop a useful scale and services in the future.

7) What are the possible disadvantages or risks of taking part in the study?
People who have had recent experiences of finding it difficult to obtain a job, losing a job or are having current difficulties at work may experience some distress completing the questionnaire pack. We would advise you to consider if you are in a ‘calm state of mind’ before proceeding to the questionnaire. We will provide information on the front of the questionnaire pack on how to cope if you are feeling distressed; a self-help handout of mindfulness, distraction, visualisation and self-soothe techniques, and other support numbers. These are for you to keep. If the distress is ongoing we would encourage you to contact your GP.

8) Payments
For each completed questionnaire pack participants will receive a £5 gift voucher. We will only be able to pay you if you complete the payment address form and return it, sealed with the completed questionnaires (PES-PD and demographics form) in the envelope provided. If you have not received your voucher within 1 month please contact EMPOWER research team on the number or email provided on the top of this sheet.

9) What will happen to the results of the research study?
The piloting of the PES-PD is one work-package of a larger study which is looking to help people with PD gain employment. The larger study will be completed in autumn 2019. The information from piloting the questionnaire will help us to develop the scale further and prepare it for a full psychometrics evaluation of the questionnaire. We hope the validated scale will help us to measure readiness for employment in PD clients. The anonymised results of piloting the PES-PD will be presented in a doctoral thesis, will be published in a scientific journal, and
presented at national or international conferences. Once fully developed, the scale will be given to NHS Trusts across the UK.
If you wish to be invited to a feedback meeting where the results of the study will be presented, please refer to the statement on the payment address form in the questionnaire pack and tick appropriately. We will send you a letter of invite with the details at a later date.

10) Who has reviewed the study?
The study has been reviewed by the NIHR who have funded the study. The study has been granted ethical approval by South Birmingham Research Ethics Committee.

Contact Details:
If you wish to contact to discuss any of the information further, then please contact [redacted] on: [redacted]. Please be aware that the EMPOWER research team have a duty of care to all participants. Therefore if we are concerned about your safety or the safety of other participants, the researchers will first speak you, and then inform their supervisors who will inform relevant healthcare professionals.

If you feel that I have not addressed your concerns adequately or if you have any concerns about my conduct, then please contact:

[redacted]
Email: [redacted]
Work Office: 0300 555 1213.

Thank you very much for taking the time to read this information sheet.

Please ask if there is anything that is not clear or if you would like more information.

Please take time to decide whether or not you would wish to take part.
Preparedness for Employment Scale for people with Personality Disorders (PES-PD): Piloting a Questionnaire
You are being asked to complete a set of questionnaires to help develop a new questionnaire (PES-PD) about the obstacles and supports for people with a personality disorder (PD) in obtaining and retaining employment. The questionnaire pack will take approximately 20 minutes to complete.

1) The purpose of the study
The purpose of this study is to develop and evaluate a scale which we hope will:
   i) Help individuals with a PD to make decisions about when to enter employment
   ii) Help clinicians/employment staff to identify what supports the individual will need to gain employment
   iii) Allow us to measure the outcome of interventions designed to help people gain and retain employment
   iv) Help us to give advice to employers about what support may be needed.
We would like to test the questionnaire and ask you questions around its length, readability, vocabulary, and clarity.

2) Why have you been invited?
You have been invited to take part in the study because you are a staff with experience of working with PD. We feel that you would be able to help us think about issues regarding seeking, obtaining and retaining employment. We also hope that you would be able to think creatively about other people who could take part in this research.

3) What will happen if you do choose to take part in the study?
You will first read this information sheet and then complete the questionnaire pack; a demographics form, and the pilot questionnaire of the Preparedness for Employment Scale for people with Personality Disorders (PES-PD). By returning the completed paper packs, you have given consent to participate in the research. You can return the completed paper packs in the prepaid envelopes provided and send it in your own time.

4) Who will know you are taking part in the study?
No one will know whether you have participated or not. All forms except the feedback meeting form, will not require any information which can tell us who you are. As we will have no means of identifying who completed the questionnaires, we are therefore unable to remove the data once it has been returned. Any quotes that you provide which are used in the published research will also be checked to ensure no one could be identified by what they have written.
In accordance with current NELFT Records Management Policy, research findings will need to be stored by NELFT as sponsor for 20 years after the research has finished. The NELFT Records Office provides a service to NEFLT staff and maintains archived records in a safe and secure off site location. All activities are conducted in accordance with the Data Protection Act 1998 and NELFT Data Protection Policy. Access to the data is strongly regulated and only members of the research team will have the right to use.

5) What are the possible benefits of taking part in the study?
We hope that you will find it helpful or interesting to complete questions about employment. You may also find it helpful to know the information gathered from this study will better inform our understanding of the experiences of individuals with PD and employment, which will allow us to develop a useful scale and services in the future.

6) What are the possible disadvantages or risks of taking part in the study?
We do not anticipate any disadvantages or risks of taking part in this study.

7) What will happen to the results of the research study?
The piloting of the PES-PD is one work-package of a larger study which is looking to help people with PD gain employment. The larger study will be completed in autumn 2019. The information from piloting the questionnaire will help us to develop the scale further and prepare it for a full psychometrics evaluation of the questionnaire. We hope the validated scale will help us to measure readiness for employment in PD clients. The anonymised results of piloting the PES-PD will be presented in a doctoral thesis, will be published in a scientific journal, and presented at national or international conferences. Once fully develop, the scale will be given to NHS Trusts across the UK.

If you wish to be invited to a feedback meeting where the results of the study will be presented, please refer to the feedback meeting form in the questionnaire pack and return the form separately from the questionnaires. We will send you a letter of invite with the details at a later date.

8) Who has reviewed the study?
The study has been reviewed by the NIHR who have funded the study. The study has been granted ethical approval by South Birmingham Research Ethics Committee.

Contact Details:
To ask any questions please contact Leng Song on: 0300 555 1213.
Chief Investigator: Dr. Janet Feigenbaum, Strategic and Clinical Lead for Personality Disorder Services, NELFT and Senior Lecturer, Research Department of Clinical, Educational and Health Psychology, University College London.
Email: janet.feigenbaum@nhs.net
Work Office: 0300 555 1213.

Thank you very much for taking the time to read this information sheet.
Please ask if there is anything that is not clear or if you would like more information.
Please take time to decide whether or not you would wish to take part.
Appendix 38 Pilot PES-PD Informed Consent Form
(Chapter 4)

Centre Number: 
Study Number: 
Patient Identification Number for this study: 
Name of Researcher: 
Chief Investigator: 

Title of Project: Preparedness for Employment Scale for people with Personality Disorders (PES-PD): Piloting a Questionnaire

Please read the following statements carefully and write your initials next to each one indicating that you have understood. When you have read and initialled the statements, you may begin completing the questionnaires.

Please initial box
I confirm that I have read and understood the information sheet dated XXX for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to stop completing the pilot questionnaire, feedback form and demographics form at any time without giving any reason.

I understand that any information gathered in this study will be anonymous, and no names or identifying information will be included.

I understand that once I have returned the sealed questionnaire pack as they are anonymous, there will be no way to remove the data from the research.

I certify I am 18+ years old. I understand that by returning the pilot questionnaire, feedback form and demographics form to EMPOWER, I am consenting to participate in this study.

I understand that relevant sections of my data collected during the study maybe looked at by individuals from EMPOWER, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my record.

Please keep this informed consent form for your information but return the completed pilot questionnaire, feedback form, demographics form and payment address form.
### PES-PD Demographics Form

**Participant ID Number:**

**Please return this form**

#### Section 1: Personal Information (please tick one box per question, unless otherwise stated)

<table>
<thead>
<tr>
<th>Age</th>
<th>What is your sex?</th>
<th>What is your main language?</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-25</td>
<td>Male</td>
<td>Please state:</td>
</tr>
<tr>
<td>26-30</td>
<td>Female</td>
<td></td>
</tr>
<tr>
<td>31-35</td>
<td>Transgender</td>
<td></td>
</tr>
<tr>
<td>36-40</td>
<td>Prefer not to answer</td>
<td></td>
</tr>
<tr>
<td>41-45</td>
<td>What is your legal marital status or same-sex civil partnership status? (please tick one)</td>
<td></td>
</tr>
<tr>
<td>46-50</td>
<td>Not married and not registered a same-sex civil partnership</td>
<td>Very well</td>
</tr>
<tr>
<td>51-55</td>
<td>Married/civil partnership</td>
<td>Well</td>
</tr>
<tr>
<td>56-65</td>
<td>Separated, but still legally married</td>
<td>Not well</td>
</tr>
<tr>
<td>66+</td>
<td>Divorced</td>
<td>Not at all</td>
</tr>
<tr>
<td></td>
<td>Single</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Widowed</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Prefer not to answer</td>
<td></td>
</tr>
</tbody>
</table>

Are you eligible for employment in the UK?

| Yes | No | Prefer not to answer |

What is your ethnic group?

#### A White
- English/Welsh/Scottish/Northern Irish/British Irish
- Any other White background: __________

#### B Mixed/multiple ethnic groups
- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed/multiple ethnic background, write in: __________

#### C Asian/Asian British
- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background, write in: __________

#### D Black/African/Caribbean/Black British
- African
- Caribbean
- Any other Black/African/Caribbean background, write in: __________

#### E Other ethnic group
- Arab
- Any other ethnic group, write in: __________
- Prefer not to answer

#### Section 2: Mental Health

Please indicate whether you have any current diagnoses of mental health disorders (tick all that apply)

- Anxiety
- Personality Disorder
- Depression
- Dissociative Disorder
- Post-Traumatic Stress Disorder
- Eating Disorder
- Psychosis
- Schizophrenia
- None
- Prefer not to answer

If other, please state: __________

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**PES-PD Version 13 03/07/2017**
PES-PD Demographics Form

Participant ID Number:

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Section 3: Qualifications

Which of these qualifications do you have? (Tick every box that applies if you have any of the qualifications listed, if your UK qualification is not listed, tick the box that contains its nearest equivalent. If you have qualifications gained outside the UK, tick the ‘Foreign qualifications’ box and the nearest UK equivalents (if known)).

<table>
<thead>
<tr>
<th>Qualification</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - 4 O levels /CSEs/GCSEs (any grades), Entry Level, Foundation Diploma, NVQ Level 1, Foundation GNVQ, Basic Skills</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5+ O levels (passes)/CSEs (grade 1) /GCSEs (grades A*- C), School Certificate, 1 A level/2 - 3 AS levels/VCEs, Higher Diploma</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NVQ Level 2, Intermediate GNVQ, City and Guilds Craft, BTEC First/General Diploma, RSA Diploma</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Apprenticeship</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2+ A levels/VCEs, 4+ AS levels, Higher School Certificate, Progression/Advanced Diploma</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NVQ Level 3, Advanced GNVQ, City and Guilds Advanced Craft, QNC, OND, BTEC National, RSA Advanced Diploma</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Degree (for example BA, BSc), Higher degree,(for example MA, PhD, PGCE)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NVQ Level 4 - 5, HNC, HND, RSA Higher Diploma, BTEC Higher Level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional qualifications (for example teaching, nursing, accountancy)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other vocational / work-related qualifications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Foreign qualifications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No qualifications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Section 4: Employment History

Please indicate your current employment status (tick all that apply, include any paid work, including casual or temporary work) | If you ticked unemployed, please state for how long:

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Yes</th>
<th>No</th>
<th>Prefer not to answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Student</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Volunteer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Signed off sick</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Freelancing paid work</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Maker</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If you ticked unemployed, please state for how long:

<table>
<thead>
<tr>
<th>Years</th>
<th>Months</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Were you actively looking for any kind of paid work during the last four weeks?

Yes ☐ No ☐ Prefer not to answer ☐
### PES-PD Demographics Form

**PLEASE RETURN THIS FORM**

Please state your **current or most recent** employment details (most recent first)

<table>
<thead>
<tr>
<th>What job do/did you do? (Please write in the space below. Please write N/A if not applicable)</th>
<th>At your workplace, what is (was) the main activity of your employer or business? (tick all that apply)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Medical</td>
</tr>
<tr>
<td></td>
<td>Banking</td>
</tr>
<tr>
<td></td>
<td>Education</td>
</tr>
<tr>
<td></td>
<td>Health and Social Care</td>
</tr>
<tr>
<td></td>
<td>Hospitality</td>
</tr>
<tr>
<td></td>
<td>Engineering</td>
</tr>
<tr>
<td></td>
<td>Admin/Clerical</td>
</tr>
<tr>
<td></td>
<td>Third sector / charitable organisation</td>
</tr>
<tr>
<td></td>
<td>IT</td>
</tr>
<tr>
<td></td>
<td>Retail</td>
</tr>
<tr>
<td></td>
<td>Prefer not to answer</td>
</tr>
<tr>
<td></td>
<td>Law</td>
</tr>
<tr>
<td></td>
<td>Other:</td>
</tr>
<tr>
<td></td>
<td>Prefer not to answer</td>
</tr>
</tbody>
</table>

**In your job, how many hours a week (including paid and unpaid overtime) do/did you usually work?**

- 15 or less 31 – 48
- 16 - 30 49 or more Prefer not to answer

Please list **other** employment history

<table>
<thead>
<tr>
<th>What did you do? (Please write in the space below. Please write N/A if not applicable)</th>
<th>At your workplace, what is (was) the main activity of your employer or business? (tick all that apply)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Medical</td>
</tr>
<tr>
<td></td>
<td>Banking</td>
</tr>
<tr>
<td></td>
<td>Education</td>
</tr>
<tr>
<td></td>
<td>Health and Social Care</td>
</tr>
<tr>
<td></td>
<td>Hospitality</td>
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<td>Engineering</td>
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<td></td>
<td>Admin/Clerical</td>
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<td>Third sector / charitable organisation</td>
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<td>IT</td>
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<td>Retail</td>
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<td>Prefer not to answer</td>
</tr>
<tr>
<td></td>
<td>Law</td>
</tr>
<tr>
<td></td>
<td>Other:</td>
</tr>
<tr>
<td></td>
<td>Prefer not to answer</td>
</tr>
</tbody>
</table>

**In your job, how many hours a week (including paid and unpaid overtime) do/did you usually work?**

- 15 or less 31 – 48
- 16 - 30 49 or more Prefer not to answer

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PES-PD Version 13 03/07/2017
# Appendix 40 Staff Pilot PES-PD Demographics Form

(Chapter 4)

## Staff Demographics Form

**Participant ID number:**

**PLEASE RETURN THIS FORM**

### Section 1: Personal Information

<table>
<thead>
<tr>
<th>Age</th>
<th>I am a (please tick all that apply)</th>
<th>How long have you worked in this position?</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-25</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26-30</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31-35</td>
<td></td>
<td></td>
</tr>
<tr>
<td>36-40</td>
<td></td>
<td></td>
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<tr>
<td>41-45</td>
<td></td>
<td></td>
</tr>
<tr>
<td>46-50</td>
<td></td>
<td></td>
</tr>
<tr>
<td>51-55</td>
<td></td>
<td></td>
</tr>
<tr>
<td>56-60</td>
<td></td>
<td></td>
</tr>
<tr>
<td>61-65</td>
<td>If other, please state:</td>
<td></td>
</tr>
<tr>
<td>66+</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### What is your sex?

- Male
- Female
- Transgender
- A-gender
- Bi-gender
- Intergender
- Prefer not to answer

### What is your ethnic group?

#### A White
- English/Welsh/Scottish/Northern Irish/British
- Irish
- Any other White background: ______________

#### B Mixed/multiple ethnic groups
- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed/multiple ethnic background, write in: ______________

#### C Asian/Asian British
- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background, write in: ______________

#### D Black/African/Caribbean/Black British
- African
- Caribbean
- Any other Black/African/Caribbean background, write in: ______________

#### E Other ethnic group
- Arab
- Any other ethnic group, write in: ______________
- Prefer not to answer

### Section 2: Employment History (Please state your previous jobs starting with the most recent)

<table>
<thead>
<tr>
<th>Job Title:</th>
<th>How long did you work in this position?</th>
<th>How many hours did you work per week:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>____ year(s) ____ month(s)</td>
<td>____</td>
</tr>
</tbody>
</table>

### Type of Employment (Tick all that apply)

- Medical
- Admin/Clerical
- Education
- IT
- Hospitality
- Retail
- Law
- Banking
- Health and Social Care
- Third sector/charitable organisation
- Engineering
- Prefer not to answer
- Other: ______________

---

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Demographics V2 03072017
Staff Demographics Form

<table>
<thead>
<tr>
<th>Job Title:</th>
<th>How long did you work in this position?</th>
<th>How many hours did you work per week:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>__ year(s) ___ month(s)</td>
<td></td>
</tr>
</tbody>
</table>

Type of Employment (Tick all that apply)

<table>
<thead>
<tr>
<th>Medical</th>
<th>Admin/Clerical</th>
<th>Health and Social Care</th>
<th>Engineering</th>
<th>Prefer not to answer</th>
<th>Other: ____________</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>IT</td>
<td>Retail</td>
<td>Banking</td>
<td>Fork lift</td>
<td></td>
</tr>
<tr>
<td>Hospitality</td>
<td>Retail</td>
<td>Health and Social Care</td>
<td>Engineering</td>
<td>Prefer not to answer</td>
<td>Restaurant</td>
</tr>
<tr>
<td>Law</td>
<td>Banking</td>
<td>Third sector/charitable organisation</td>
<td>Banking</td>
<td>Engineering</td>
<td>Other: ____________</td>
</tr>
</tbody>
</table>

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Demographics V2 03072017
Appendix 41 Payment Address Form (Chapter 4)

Participant ID Number:

In order for us to send you your £5 gift voucher, please complete this form and return it in the provided prepaid envelope. Do not forget to keep the information sheet, the informed consent, the mindfulness and distract techniques and support number sheet. You do not need to write down your name or any other identifiable information as these questionnaires are anonymous.

Please write down the postal address you would like your £5 gift voucher to be delivered to.

<table>
<thead>
<tr>
<th>Address</th>
<th>Postcode</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Feedback Meeting of Results

We will also be holding a feedback meeting presenting the findings of the study in the future. If you are interested in attending, please tick here ☐ to consent to us sending you (on the same contact information above) details of the meeting.
### Appendix 42: Frequencies of item endorsement (Chapter 4)

#### Item 1

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
</tr>
</thead>
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<td></td>
<td></td>
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</tr>
<tr>
<td>1</td>
<td>4</td>
<td>3.2</td>
<td>3.3</td>
</tr>
<tr>
<td>2</td>
<td>4</td>
<td>3.2</td>
<td>6.6</td>
</tr>
<tr>
<td>3</td>
<td>12</td>
<td>9.5</td>
<td>16.4</td>
</tr>
<tr>
<td>4</td>
<td>18</td>
<td>14.3</td>
<td>31.1</td>
</tr>
<tr>
<td>5</td>
<td>84</td>
<td>66.7</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>122</td>
<td>96.8</td>
<td>100.0</td>
</tr>
<tr>
<td>Missing</td>
<td>868</td>
<td>4</td>
<td>3.2</td>
</tr>
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</tr>
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</table>

#### Item 2

<table>
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</tr>
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<tr>
<td>1</td>
<td>3</td>
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<td>8</td>
<td>6.3</td>
<td>8.9</td>
</tr>
<tr>
<td>3</td>
<td>30</td>
<td>23.8</td>
<td>35.3</td>
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<tr>
<td>4</td>
<td>36</td>
<td>28.6</td>
<td>66.4</td>
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<tr>
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<tr>
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<td>92.1</td>
<td>100.0</td>
</tr>
<tr>
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<td>888</td>
<td>10</td>
<td>7.9</td>
</tr>
<tr>
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#### Item 3

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<td>1</td>
<td>6</td>
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<td>5.2</td>
</tr>
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<td>22</td>
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</tr>
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<td>3</td>
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<td>28</td>
<td>22.2</td>
<td>100.0</td>
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<tr>
<td>Total</td>
<td>116</td>
<td>92.1</td>
<td>100.0</td>
</tr>
<tr>
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<td>10</td>
<td>7.9</td>
</tr>
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#### Item 4

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<td>100.0</td>
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#### Item 5

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<th>Cumulative Percent</th>
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<td>64</td>
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<tr>
<td>Total</td>
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<td>6.3</td>
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#### Item 6

<table>
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<th>Cumulative Percent</th>
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<tr>
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<td>2.4</td>
<td>2.5</td>
</tr>
<tr>
<td>2</td>
<td>3</td>
<td>23.0</td>
<td>26.4</td>
</tr>
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<td>23.5</td>
<td>50.4</td>
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# Appendix 43 Thematic Analysis Frequencies (Chapter 4)

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Appendix 44 Frequencies (Chapter 4)

Table 1.
“Question 2) How long did the pilot PES-PD questionnaire take to complete?” Frequency

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<td>Mean (time)</td>
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<td>Std. Deviation</td>
<td>13.687</td>
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Table 2.
“a) I felt the length of the questionnaire was... “Frequency

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
<th>Valid Percent</th>
<th>Cumulative Percent</th>
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<td>7.9</td>
<td>7.9</td>
<td>7.9</td>
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<td>Just fine</td>
<td>43</td>
<td>34.1</td>
<td>34.1</td>
<td>42.1</td>
</tr>
<tr>
<td>Long</td>
<td>41</td>
<td>32.5</td>
<td>32.5</td>
<td>74.6</td>
</tr>
<tr>
<td>Too long</td>
<td>31</td>
<td>24.6</td>
<td>24.6</td>
<td>99.2</td>
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<tr>
<td>Too short</td>
<td>1</td>
<td>.8</td>
<td>.8</td>
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<tr>
<td>Total</td>
<td>126</td>
<td>100.0</td>
<td>100.0</td>
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</table>
Appendix 45 PES-PD Domains (Chapter 4)

Cognitive Factors
I believe I will be able to get a job
I worry I will be negatively judged by my work colleagues and/or manager.
I worry that if I disclose (tell people) my mental health difficulties or personality disorder diagnosis, I will be fired.
I believe I will be able to keep a job
When I think about work my self-critical thoughts (doubts/judgements) get in the way
I would not stay in a job if it went against my values

Behavioural Factors
I work longer than I am expected (more than my contracted hours).
I act impulsively at work.
I find it hard to get motivated in the morning to go to work/go to an interview.
I would quit my job without thinking about the consequences.
I say/do things at work without thinking about the consequences.

Interpersonal Factors
I am able to ask for what I want in the workplace (e.g. ask for time off).
I know my personal limits and I am able to say ‘no’ in the workplace.
I am able to imagine what another person might be thinking or feeling at work.
I know when to share personal information about myself with my manager/supervisor.
I understand how people respond to me (their thoughts and feelings about me) when I share my own thoughts and feelings at work.
I find it easy to socialise with people at work.
I find it easy to interact with my work colleagues.
I am able to discuss things with colleagues and/or managers, when I have conflicts with them.

Emotion Regulation
When I am emotional, I find it difficult to get on with doing my work.
I am quick to show emotions at work.
I am able to talk about how I am feeling with other people at work.
Feeling low in mood stops me from going to work.
I am able to manage strong emotions while I am at work.
I find it difficult to calm down when I am emotional at work.

Vitality
If I use alcohol and/or drugs it stops me from doing my work (e.g. hungover, currently intoxicated).
My physical health gets in the way of my ability to work.
If I am sleepy, I am able to go to work.
If I feel low in energy I go to work.

Supports – What gets in the way of getting help
I need help to problem solve the practical steps to seeking, getting, and keeping a job (e.g. financial support, transportation, the process in how to get a job).
I am self-sufficient at work (or similar situation); I do not need to rely on my manager for advice or instructions.
I need ongoing support from NHS mental health services with regard to employment.
I need the emotional support of friends and family for me to be able to work.
When I am absent from work due to my mental health, I need reassurance from my manager.
I am able to ask for adjustments to be made to my working environment for my mental health needs.
Appendix 46 Ethical Approval Letter Psychometric Evaluation (Chapter 5)

30 April 2018
Dr Janet Feigenbaum
Goodmayes Hospital
Barley Lane
IG3 8XP

Dear Dr Feigenbaum

Study title: Preparedness for Employment Scale for Personality Disorder (PES-PD): Psychometric Evaluation of a New Scale
REC reference: 18/YH/0183
IRAS project ID: 243606

The Proportionate Review Sub-committee of the Yorkshire & The Humber - Leeds East Research Ethics Committee reviewed the above application on 27 April 2018.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above

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research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

**Conditions of the favourable opinion**

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

**Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.**

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, [www.hra.nhs.uk](http://www.hra.nhs.uk) or at [http://www.rdforum.nhs.uk](http://www.rdforum.nhs.uk).

Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites (‘participant identification centre’), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

**Sponsors are not required to notify the Committee of management permissions from host organisations.**

**Registration of Clinical Trials**

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

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Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion”).

Summary of discussion at the meeting

- Recruitment arrangements and access to health information, and fair participant selection

The Sub-Committee queried whether the researchers would continue to collect data until they had data on two hundred and fifty of each category of participant, or if, once they had sufficient numbers from a given category, they would stop any further participants of that category completing the questionnaire.

*Student Investigator Miss Li-Ling Song explained that the researchers would continue to collect data until they had recruited two hundred and fifty participants for each category. They appreciated this may mean that some groups were overrepresented, however all questionnaires were included and analysed. The data collected was reviewed on a monthly basis. This meant they will be able to monitor the number of participants recruited to each category and target recruitment for groups that were underrepresented, while paring back their recruitment for the already over-represented group. For example, if they found that participants without PD traits who did not non-identify with having mental health difficulties, were underrepresented they would increase their recruitment activity in public places, such as libraries.*

The Sub-Committee was satisfied with this response.

- Informed consent process and the adequacy and completeness of participant information

Clause 7 on the Consent Form referred to EMPOWER, but did not explain who they were. The Sub-Committee suggested that “sponsor” is used instead or that it was explained who EMPOWER were.

A revised Consent Form was submitted. The term “Research Team” had been added to Clause 7 to clarify who EMPOWER were. A description of EMPOWER had already been included in the Participant Information Sheet.

The Sub-Committee was satisfied with this response.

Approved documents

The documents reviewed and approved were:

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<th>Version</th>
<th>Date</th>
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<td>Copies of advertisement materials for research participants [Appendix B Psychometric Evaluation PES-PD Poster V1 06.04.2018]</td>
<td>Version 1</td>
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<tr>
<td>Copies of advertisement materials for research participants [Appendix A Social Media Messages V1 06.04.2018]</td>
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**Membership of the Proportionate Review Sub-Committee**

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

**Statement of compliance**

A Research Ethics Committee established by the Health Research Authority
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

18/YH/0183 Please quote this number on all correspondence

Yours sincerely

pp

Dr Rhona Bratt
Chair

Email: nrescommittee.yorkandhumber-leedseast@nhs.net

A Research Ethics Committee established by the Health Research Authority
Yorkshire & The Humber - Leeds East Research Ethics Committee

Attendance at PRS Sub-Committee of the REC meeting on 27 April 2018

Committee Members:

<table>
<thead>
<tr>
<th>Name</th>
<th>Profession</th>
<th>Present</th>
<th>Notes</th>
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</thead>
<tbody>
<tr>
<td>Dr Rhona Bratt</td>
<td>Retired Multimedia Project Manager</td>
<td>Yes</td>
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<tr>
<td>Mrs Ann Kay</td>
<td>Retired Special Needs Coordinator</td>
<td>Yes</td>
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<tr>
<td>Dr Andrew Poliard</td>
<td>Consultant Anaesthetist</td>
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Also in attendance:

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<tr>
<th>Name</th>
<th>Position (or reason for attending)</th>
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<tr>
<td>Ms Katy Cassidy</td>
<td>REC Manager</td>
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Preparedness for Employment Scale for people with Personality Disorders (PES-PD)

This questionnaire looks at things that might get in the way of a person thinking about, looking for, getting, and keeping employment. If you have never worked, or are not currently working, then please consider how you might feel if you were to look for or be at work. For each statement please circle a number between 0 (never) and 10 (always).

Part 1) This section contains statements about some of the challenges to thinking about, looking for, getting, and keeping employment.

At this moment in time…

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<th>1. I believe I will be able to get a job.</th>
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<th>3. I act impulsively at work.</th>
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<th>4. I find it hard to get motivated in the morning to go to work/go to an interview.</th>
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<th>5. I worry I will be negatively judged by my work colleagues and/or manager.</th>
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<th>6. When I am emotional I find it difficult to get on with doing my work.</th>
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<th>7. I know when to share personal information about myself with my manager/Supervisor.</th>
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### Preparedness for Employment Scale for people with Personality Disorders (PES-PD)

8. I am quick to show emotions at work.

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9. I would quit my job without thinking about the consequences.

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10. I would not stay in a job if it went against my values.

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11. I worry that if I disclose (tell people) my mental health difficulties or personality disorder diagnosis, I will be fired.

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12. I find it easy to socialise with people at work.

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13. I am able to talk about how I am feeling with other people at work.

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14. I am able to imagine what another person might be thinking or feeling at work.

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15. I believe I will be able to keep a job.

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16. Feeling low in mood stops me from going to work.

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17. I know my personal limits and I am able to say ‘no’ in the workplace.

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IRAS Number: 243606
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<tr>
<td>18. I am able to ask for what I want in the workplace (e.g. ask for time off).</td>
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<td>19. I find it easy to interact with my work colleagues.</td>
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<td>20. If I use alcohol and/or drugs it stops me from doing my work (e.g. hungover, currently intoxicated). (If you do not use alcohol and/or drugs then please circle N/A).</td>
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<td>21. I am able to discuss things with colleagues and/or managers, when I have conflicts with them.</td>
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<td>22. My physical health gets in the way of my ability to work.</td>
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<td>23. I say/do things at work without thinking about the consequences.</td>
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<td>24. I am able to manage strong emotions while I am at work.</td>
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<td>25. If I am sleepy I am able to go to work.</td>
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<td>26. I find it difficult to calm down when I am emotional at work.</td>
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27. If I feel low in energy I go to work.

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28. I understand how people respond to me (their thoughts and feelings about me) when I share my own thoughts and feelings at work.

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29. When I think about work my self-critical thoughts (doubts/judgements) get in the way.

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Part 2: This section contains statements that look at the different kinds of support a person might need when ‘thinking about’, looking for, getting and keeping employment. At this moment in time…

1. I need help to problem solve the practical steps to seeking, getting, and keeping a job (e.g. financial support, transportation, the process in how to get a job).

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2. I am self-sufficient at work (or similar situation); I do not need to rely on my manager for advice or instructions.

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3. I need ongoing support from NHS mental health services with regard to employment.

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4. I need the emotional support of friends and family for me to be able to work.

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</table>

5. When I am absent from work due to my mental health I need reassurance from my manager. (If this does not apply to you please circle N/A).

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N/A

PES-PD V 1 06.04.2018
IRAS Number: 243606

623
6. I am able to ask for adjustments to be made to my working environment for my mental health needs.

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
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</tbody>
</table>
## Appendix 48 PES-PD (Paper Version) V1 (Chapter 5)

### PES-PD Demographics Form

**PLEASE RETURN THIS FORM**

**Section 1: Personal Information (please tick one box per question, unless otherwise stated)**

<table>
<thead>
<tr>
<th>What is your sex?</th>
<th>What is your ethnic group? (please tick one)</th>
<th>What is your legal marital status or same-sex civil partnership status? (please tick one)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>White</td>
<td>Married/Civil Partnership</td>
</tr>
<tr>
<td>Female</td>
<td>Mixed/multiple ethnic groups</td>
<td>Separated</td>
</tr>
<tr>
<td>Transgender</td>
<td>Asian/Asian British</td>
<td>Divorced</td>
</tr>
<tr>
<td>A-gender</td>
<td>Black/African/Caribbean/Black British</td>
<td>Single/unmarried</td>
</tr>
<tr>
<td>Bi-gender</td>
<td>Other ethnic group</td>
<td>Cohabiting</td>
</tr>
<tr>
<td>Inter-gender</td>
<td></td>
<td>Widow/Widower</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td></td>
<td>Prefer not to answer</td>
</tr>
</tbody>
</table>

**Age**

<table>
<thead>
<tr>
<th>_ _ years</th>
<th>Are you eligible for employment in the UK?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td></td>
</tr>
</tbody>
</table>

### Section 2: Mental Health

**Please indicate whether you self-identify with having a mental health condition (Please tick one)**

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Prefer not to answer</th>
</tr>
</thead>
</table>

### Section 3: Employment Status

**Please indicate your current employment status (Please tick the answer that best describes your current situation).**

<table>
<thead>
<tr>
<th>Internship (unpaid)</th>
<th>Voluntary Employment (unpaid)</th>
<th>Internship (paid)</th>
<th>Paid Employment</th>
<th>Retired</th>
<th>Unable to work</th>
<th>Signed off sick/unfit for work due to mental health (certified by GP)</th>
<th>Self-employed</th>
<th>Sheltered/Supported Employment</th>
<th>Job Training/Apprentice</th>
<th>Unemployed</th>
<th>Looking for work</th>
<th>Student</th>
<th>At home and not looking for work (e.g. looking after home and/or family).</th>
</tr>
</thead>
</table>

### Section 4: Educational Status

**What is your highest completed level of education (Please tick one answer)**

<table>
<thead>
<tr>
<th>Primary education or less</th>
<th>Secondary education (e.g. GCSEs/O-Levels)</th>
<th>Tertiary/further education (e.g. AS, A-Levels)</th>
<th>Higher Education (Undergraduate degree, postgraduate degree)</th>
<th>Other education (e.g. City &amp; Guilds, NVQ)</th>
</tr>
</thead>
</table>

The EMPOWER study is funded by the National Institute for Health Research (NIHR) Programme Grant for Applied Research (RP-PG-1212-20011)

PES-PD Version 1 06.04.2018

IRAS number: 243808
**PES-PD Demographics Form**

<table>
<thead>
<tr>
<th>Please tick one that best describes your situation:</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am involved in a community employment/vocational rehabilitation programme (e.g. employment support programme)</td>
</tr>
<tr>
<td>I am involved in an inpatient employment/vocational rehabilitation programme</td>
</tr>
<tr>
<td>I am not involved in any employment/vocational rehabilitation programme but access mental health services</td>
</tr>
<tr>
<td>I am not involved with any employment /vocational rehabilitation programme or mental health services</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Where in the world are you from?</th>
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<tbody>
<tr>
<td>UK</td>
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<tr>
<td>Europe</td>
</tr>
<tr>
<td>North America</td>
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<td>South America</td>
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<td>Africa</td>
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<td>Australasia</td>
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<td>Indian Subcontinent</td>
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<td>North Asia</td>
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<tr>
<td>South East Asia</td>
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<tr>
<td>Other</td>
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</tbody>
</table>
Appendix 49 Psychometric Evaluation Information

Sheet (Chapter 5)

Study Title: A psychometric evaluation of the Preparedness for Employment Scale for people with Personality Disorders (PES-PD)

Welcome! Thank you for showing interest in our study. Please read this participant information sheet before you take part in our study. If there is anything you are unclear about or if you have any questions, please do contact us.

Who are we looking for to participate?

As you can see from the study title this questionnaire is for people with a personality disorder. However, in order for us to understand how well the scale works, we would like people from different backgrounds to complete it. This means we are not only looking for people with characteristics similar to people with personality disorders, but also people without personality disorder characteristics who are seeking employment, are employed or are unemployed.

Who we are

We are the EMPOWER Research Team, funded by the National Institute for Health Research (NIHR). Our aim is to develop and evaluate a new intervention; Dialectical Behavioural Therapy-Skills for Employment (DBT-SE). EMPOWER intends to increase wellbeing and employment for people with a personality disorder and people with characteristics consistent with people with personality disorder.

Purpose of this study

One way of helping to increase wellbeing and employment is to identify areas in which individuals may require extra support. In order to achieve this, we have devised a questionnaire; the Preparedness for Employment Scale for people with Personality Disorders (PES-PD). We want to find out whether the PES-PD has good psychometric properties. In other words, whether the questionnaire measures what it is supposed to measure (i.e. one’s preparedness for getting and keeping employment). We hope the PES-PD will:

i) Help people with a personality disorder or people who have characteristics consistent with people with a personality disorder to make decisions about when to enter employment.

ii) Help clinicians/employment staff to identify what type of support that these people may need in order to seek, gain and keep employment.

iii) Allow us to measure the outcome of interventions designed to help people gain and retain employment.

Do I have to take part?

No. This study is voluntary. If you decide that you would like to take part and you complete the questionnaires you are letting us know that you are giving consent to take part. You are however free to stop completing the questionnaires at any time.

Unfortunately, you cannot take part if have participated in previous focus groups related to this study, or have completed previous versions of this questionnaire, or taken part in the previous pilot study. Doing so may influence the results of the study.

Who will know you are taking part in the study?

None of the questionnaires will require your personal information (e.g. your name) therefore, no one will know you are taking part in the study. All data will be stored in accordance with local NELFT and national NIHR information governance policies. Furthermore, in accordance with current NELFT Records Management Policy and the UK policy framework for health and social care research, the study will keep the data for a period of 20 years in the secure NHS research archiving system. The study will conduct all activities in accordance with the Data Protection Act 1998 and NELFT Data Protection Policy. Access to the data is restricted and only members of the research team will have access to it.

Can I withdraw my data?

As personal information that can identify you is not required to complete the questionnaires, once you have submitted the online questionnaires, the study will not be able to withdraw your data (as we have no means to trace you to the completed packs).

What will happen if you do choose to take part in the study?
If after reading this information sheet and you feel like you have had enough time to consider the study, you want to take part then please complete the questionnaires in this pack. The questionnaire pack will contain:

An informed consent statement page (for you to keep);
Three questionnaires: the Standardised Assessment of Personality – Abbreviated Scale (SAPAS); The Preparedness for Employment Scale for people with Personality Disorders (PES-PD); and a demographics form
A study charity donation form (to return to us).

Prepaid envelope

The questionnaires will take approximately 15 minutes to complete. In exchange for you completing a questionnaire pack, the study will donate £1 on your behalf to a charity of your choice. The charity options are: Young Minds: Child & Adolescent Mental Health, Mental Health Foundation, or Rethink. There will be a prepaid envelop in which you can return the questionnaires and charity form to the study (Documents 2 and 3).

**What are the possible benefits of taking part in the study?**
By taking part we hope that you will gain helpful insight into your feelings and thoughts about employment which you may find useful. You may also find it helpful to know the information gathered will better inform the development of the questionnaire (PES-PD), which will subsequently help clinicians and people in their planning of their employment support. You may also feel you have positively contributed to the community by donating £1 to your chosen charity.

**What are the possible disadvantages of taking part in the study?**
We anticipate there will be little disadvantage to you in participating in the study. However, people who have had recent experiences of finding it difficult to obtain a job, losing a job or are having current difficulties at work may experience some discomfort as the questionnaire may touch upon these areas. Everyone undertaking the questionnaires will be provided with a self-help and support sheet on how to cope if you are feeling distressed (please see the self-help link when you start the online questions). If you find the distress is ongoing, we encourage you to contact your GP or healthcare professional.

**What will happen to the results of the research study?**
will present the anonymised results of the psychometric evaluation of the PES-PD in a doctoral thesis, which will be published in a scientific journal and presented at national or international conferences. Once the scale is fully developed, it will be given to NHS Trusts across the UK.

The EMPOWER study was reviewed by the National Institute for Health Research [YH/0183] has granted the study ethical approval.

Contact Details:
If you wish to contact us to discuss any of the information further, then please contact us on the details below:
Research Team, Principle Investigator: Programme Manager: Dr Telephone: Address:
Appendix 50 Social media (Chapter 5)

NELFT Facebook page & EMPOWER Facebook page
We are looking for participants to complete our preparedness for employment questionnaire. Anyone who is interested in invited to participate (if you are over 18). Upon completion of your questionnaires we will donate £1 on your behalf to a mental health charity https://preparednessforemplomentscale.com
Do you feel highly emotional on a daily basis? Have you ever found it hard to get along with colleagues and managers/supervisors? You may be interested in completing our Preparedness for Employment Scale: https://preparednessforemplomentscale.com
Are you interested in mental health and employment? Help us develop a preparedness for employment questionnaire for people with personality disorders by taking part online (you do not need to have a diagnosis of personality disorder to participate we need all types of people): https://preparednessforemplomentscale.com. If you take part, we will donate £1 on your behalf to a mental health charity.

PD Forum/Organisation websites
Do you feel highly emotional on a daily basis? Have you ever found it hard to get along with colleagues and managers/supervisors? You may be interested in completing our Preparedness for Employment Scale for personality disorders: https://preparednessforemplomentscale.com. For your participation we will donate £1 on your behalf to a mental health charity.

Do you feel highly emotional on a daily basis? Have you ever found it hard to get along with colleagues and managers/supervisors? Help us develop a preparedness for employment questionnaire for people with personality disorders by taking part online: https://preparednessforemplomentscale.com. For your participation we will donate £1 on your behalf to a mental health charity.

Do you feel highly emotional on a daily basis? Have you ever found it hard to get along with colleagues and supervisors? Help us develop a preparedness for employment questionnaire for people with personality disorders by taking part online: https://preparednessforemplomentscale.com. We will donate £1 on your behalf to a mental health charity.
We are looking for people who are willing to complete some online questionnaires about employment and wellbeing which we hope will help us to improve services for assisting people with mental health difficulties to obtain and retain employment.

We are developing an employment questionnaire for people with personality disorders – it would only take about 15 minutes to complete. For your participation, we’ll donate £1 on your behalf to a mental health charity (Young Minds: Child & Adolescent Mental Health, Mental Health Foundation, or Rethink).
If you’re interested please click on this link below: https://preparednessforemplomentscale.com
If you would like to know more about the study please click on the link above or contact the study team on EMPOWER@nelft.nhs.uk.
Thank you for considering taking part in our study!

Other Mental Health Organisation Websites/Forums
We are looking for people who are willing to complete some online questionnaires about employment and wellbeing which we hope will help us to improve services for assisting people with mental health difficulties to obtain and retain employment.

We are developing an employment questionnaire for people with personality disorders; however, we are looking for people from all backgrounds to complete it. That means you do
not need to have a diagnosis of personality disorder – you just need to have an interest in completing the online questionnaires. The questionnaires will only take about 15 minutes to complete online.

For your participation, we’ll donate £1 on your behalf to a mental health charity (Young Minds: Child & Adolescent Mental Health, Mental Health Foundation, or Rethink). If you’re interested, please click on this link below:
https://preparednessforemplomentscale.com
If you would like to know more about the study, please click on the link above or contact the study team on EMPOWER@nelft.nhs.uk.
Thank you for considering in taking part.

(Li-Ling Song, PhD student University College London)

NELFT & EMPOWER Twitter account
Are you interested in mental health and work? Help us develop a preparedness for employment questionnaire by taking part online: https://preparednessforemplomentscale.com
For your participation, we will donate £1 on your behalf to a mental health charity.
Characters: 263

Have you ever found it hard to get along with colleagues and managers/supervisors? Help us develop a preparedness for employment questionnaire by taking part online:
https://preparednessforemplomentscale.com
Characters: 216

Help us develop a preparedness for employment questionnaire by taking part online: https://preparednessforemplomentscale.com. Anyone who is interested is invited to participate (so long you are 18+)’ We will donate £1 on your behalf to a mental health charity
Characters: 268

PD Organisations Twitter Accounts
Do you feel highly emotional on a daily basis? Help us develop a preparedness for employment questionnaire by taking part online: https://preparednessforemplomentscale.com
Characters: 273

Have you ever found it hard to get along with colleagues and managers/supervisors? You may be interested in completing our Preparedness for Employment Scale for people with PD:
https://preparednessforemplomentscale.com
Characters: 223

Mental Health Organisations
Are you interested in mental health and work? Complete our online questionnaires and we will donate £1 on your behalf to a mental health charity
https://preparednessforemplomentscale.com
Characters: 194

Do you feel highly emotional on a daily basis? Have you ever found it hard to get along with colleagues and managers/supervisors? Help us develop a preparedness for employment questionnaire by taking part online: https://preparednessforemplomentscale.com
Characters: 262
Appendix 51 Psychometric Evaluation Informed Consent form (Chapter 5)

Please keep this form for your information, you do not need to return this with the other completed questionnaires.

1) I confirm that I have read and understood the information sheet about the PES-PD. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.

2) I confirm that by completing the measures and returning them I have given consent to participate.

3) I understand the completion of the measures will not include any information that could personally identify me.

4) I understand that my participation is voluntary and that I am free to stop taking part at any time, without giving reason.

5) I understand that there are no personal identifiers used in this study, therefore once I have returned the questionnaires I cannot withdraw my data.

6) I understand that if I experience any distress from completing the measures or have any concern for my safety, there is a self-help sheet I can use. I also understand I can contact the research team (contact information is found in the participant information sheet).

7) I understand that relevant sections of my data collected in the study may be looked at by individuals from the EMPOWER Research Team or from NHS Trusts.

8) I am 18 years or older.

9) I have not participated in previous focus groups related to this study, taken part in the pilot PES-PD study or completed a version of the PES-PD before.

10) I consent to all of the above statements.
Appendix 52 Poster/Flyer (Chapter 5)

Participants needed for a new online Employment and Mental Health Questionnaire

What does preparedness for employment mean to you? Are you interested in taking part in research? Would you like the study team to donate £1 on your behalf to a charity?

We are evaluating a questionnaire that will help to identify the challenges and supports needed for seeking, getting, and keeping employment for those with a diagnosis of a personality disorder.

In order for us to understand how well the scale works, we would like people from different backgrounds to complete it. This means we are not only looking for people with characteristics similar to people with personality disorders, but also people without personality disorder characteristics who are seeking employment, are employed or are unemployed.

For your participation, the study will donate £1 on your behalf to a charity of your choice: Young Minds: Child & Adolescent Mental Health, Mental Health Foundation, or Rethink.

The EMPOWER study is funded by the National Institute for a Health Research (NIHR) Programme Grant for Applied Research (RP-PG-1212-20011) IRAS Number: 243606 PES-PD Poster Version 2 15.05.2018

If you would like more information or if you are interested in taking part, please tear off the website link and contact details below:

https://PreparednessforEmploymentScale.com

Contact: Leng Song on 0300 555 1213. Email: EMPOWER@nelft.nhs.uk

*some Android phones will need to install a QR code reader

Follow us on: 

@LengSong1/PES_PD @PESPD
Appendix 53 Goodness of Fit Indices (Chapter 5)

The Model Chi-Square ($\chi^2$) is the most traditional index for goodness-of-fit. It measures the degree of discrepancy between the sample and fitted covariances matrices (Hu & Bentler, 1995). Although most popular amongst researchers, a considered limitation is its sensitivity to sample size. In other words, small samples increase the likelihood that the Chi-Square ($\chi^2$) is unable to discriminate between good fitting models and poor fitting model (Hu & Bentler, 1995). On the contrary, Chi-Square ($\chi^2$) usually rejects the model when there are large samples (Kenny & McCoach, 2003). Due to this restriction, researchers tend to report alternative goodness-of-fit statistics and a minimum number of indices as recommended by (Bentler & Bonett, 1980).

The RMSEA, is considered as ‘one of the most informative indices’ (Tabri & Elliott, 2012a) and is an alternative index to evaluate model fit, due to its sensitivity to the number of estimated parameters in the model (i.e. factor loadings, factor variance, factor covariance and error variance).

The SRMR is the square root of the discrepancy between the sample covariance matrix and the model covariance matrix (Diamantopoulos & Siguaw, 2000). It is a positively biased measure, and that bias is greater for small samples and for low degrees of freedom (df) studies (Hooper, Coughlan, & Mullen, 2008).

The last index, CFI, assumes that all latent variables (items) are uncorrelated and compares the sample covariance matrix with this (null) model (Hu & Bentler, 1995). The CFI does not vary much with sample size, however this measure is less variable with larger sample sizes (Hooper et al., 2008). It is generally included in all SEM programs and one of the most widely reported goodness-of-fit statistic due to its sample size insensitivity (Tabachnick & Fidell, 2007).
Appendix 54 PD Correlation Matrix (Chapter 5)

634


Appendix 55 PD EFA (Chapter 5)

Table 1.

<table>
<thead>
<tr>
<th>Factor</th>
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LR test: independent vs. saturated: chi2(153) = 2393.00 Prob>chi2 = 0.0000

Table 2.

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## Appendix 56 Modification Indices (Chapter 5)

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EPC = expected parameter change
# Appendix 57 NPD Correlation Matrix (Chapter 5)

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### Table 1.

*NPD EFA Eigenvalues and Variance*

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LR test: independent vs. saturated: $\text{chi}^2(406) = 2653.37 \text{ Prob}>\text{chi}^2 = 0.0000$

### Table 2.

*NPD EFA Eigenvalues and Variance after Rotation*

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LR test: independent vs. saturated: $\text{chi}^2(190) = 1584.55 \text{ Prob}>\text{chi}^2 = 0.000$
Appendix 59 Final 11-item PES-PD (Chapter 5)

This questionnaire looks at things that might get in the way of a person thinking about, looking for, getting, and keeping employment. If you have never worked, or are not currently working, then please consider how you might feel if you were to look for or be at work. For each statement please circle a number between 0 (never) and 10 (always).

At this moment in time…

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<th>9</th>
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<tr>
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<td>I am able to talk about how I am feeling with other people at work.</td>
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<tr>
<td>3</td>
<td>I am able to discuss things with colleagues and/or managers when I have conflicts with them.</td>
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<tr>
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<td>I am able to imagine what another person might be thinking or feeling at work.</td>
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<tr>
<td>7</td>
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8. I am able to manage strong emotions while I am at work.

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9. If I am sleepy, I am able to go to work.

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10. If I feel low in energy, I go to work.

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11. Feeling low in mood stops me from going to work.

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Appendix 60 Box Plots (Chapter 5)

Figure 1. Outliers
Appendix 61 ANOVA Results Outliers removed

(Chapter 5)

Table 1.
Descriptive Statistics

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<td>12.838 - 14.936</td>
</tr>
<tr>
<td></td>
<td></td>
<td>N</td>
<td>456</td>
<td>0</td>
<td>16 - 425</td>
</tr>
<tr>
<td>PD</td>
<td>Unemployed</td>
<td>Mean</td>
<td>43.49</td>
<td>.00</td>
<td>40.85 - 46.03</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SD</td>
<td>16.977</td>
<td>-.078</td>
<td>15.162 - 18.705</td>
</tr>
<tr>
<td></td>
<td></td>
<td>N</td>
<td>180</td>
<td>0</td>
<td>12 - 156</td>
</tr>
<tr>
<td></td>
<td>Employed</td>
<td>Mean</td>
<td>58.11</td>
<td>-.02</td>
<td>56.43 - 59.70</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SD</td>
<td>14.893</td>
<td>-.028</td>
<td>13.793 - 15.945</td>
</tr>
<tr>
<td></td>
<td></td>
<td>N</td>
<td>338</td>
<td>1</td>
<td>15 - 310</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>Mean</td>
<td>53.03</td>
<td>.01</td>
<td>51.56 - 54.49</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SD</td>
<td>17.114</td>
<td>-.033</td>
<td>16.004 - 18.108</td>
</tr>
<tr>
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<td></td>
<td>N</td>
<td>518</td>
<td>0</td>
<td>16 - 488</td>
</tr>
<tr>
<td>Total</td>
<td>Unemployed</td>
<td>Mean</td>
<td>64.98</td>
<td>.03</td>
<td>63.08 - 66.78</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SD</td>
<td>21.389</td>
<td>-.049</td>
<td>20.174 - 22.644</td>
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<td></td>
<td></td>
<td>N</td>
<td>514</td>
<td>0</td>
<td>16 - 485</td>
</tr>
<tr>
<td></td>
<td>Employed</td>
<td>Mean</td>
<td>61.48</td>
<td>-.03</td>
<td>59.95 - 62.95</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SD</td>
<td>16.042</td>
<td>-.017</td>
<td>14.969 - 17.067</td>
</tr>
<tr>
<td></td>
<td></td>
<td>N</td>
<td>460</td>
<td>0</td>
<td>16 - 427</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>Mean</td>
<td>63.33</td>
<td>.00</td>
<td>62.17 - 64.50</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SD</td>
<td>19.122</td>
<td>-.019</td>
<td>18.349 - 19.887</td>
</tr>
<tr>
<td></td>
<td></td>
<td>N</td>
<td>974</td>
<td>0</td>
<td>974 - 974</td>
</tr>
</tbody>
</table>

a. Unless otherwise noted, bootstrap results are based on 1000 bootstrap samples

Table 2.
Levene’s Test of Equality of Error Variancesab

<table>
<thead>
<tr>
<th>Levene Statistic</th>
<th>df1</th>
<th>df2</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>FullPES-PD Score</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Based on Mean</td>
<td>4.733</td>
<td>3</td>
<td>976</td>
</tr>
<tr>
<td>Based on Median</td>
<td>4.862</td>
<td>3</td>
<td>976</td>
</tr>
<tr>
<td>Based on Median and with adjusted df</td>
<td>4.862</td>
<td>3</td>
<td>932.549</td>
</tr>
<tr>
<td>Based on trimmed mean</td>
<td>4.868</td>
<td>3</td>
<td>976</td>
</tr>
</tbody>
</table>

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.

a. Dependent variable: Full_Scale_Score

b. Design: Intercept + NPD_or_PD + EmploymentStatus + NPD_or_PD * EmploymentStatus
Figure 1. Simple Main effects of PD Status Groups, no outliers

Figure 2. Simple Main effects of Employment Status, no outliers
Table 3.  
*Simple main effects by PD Status Groups (Univariate Tests)*

<table>
<thead>
<tr>
<th>EmploymentStatus</th>
<th>Sum of Squares df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
<th>Partial Eta Squared</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unemployed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contrast</td>
<td>127923.484</td>
<td>1</td>
<td>127923.484</td>
<td>589.862</td>
<td>.000</td>
</tr>
<tr>
<td>Error</td>
<td>210364.167</td>
<td>970</td>
<td>216.870</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contrast</td>
<td>14525.974</td>
<td>1</td>
<td>14525.974</td>
<td>66.980</td>
<td>.000</td>
</tr>
<tr>
<td>Error</td>
<td>210364.167</td>
<td>970</td>
<td>216.870</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Each F tests the simple effects of NPD_or_PD within each level combination of the other effects shown. These tests are based on the linearly independent pairwise comparisons among the estimated marginal means.

Table 4.  
*Bootstrap for Pairwise Comparisons*

<table>
<thead>
<tr>
<th>EmploymentStatus</th>
<th>(I) NPD_or_PD</th>
<th>(J) NPD_or_PD</th>
<th>Mean Difference (I-J)</th>
<th>Bias</th>
<th>Std. Error</th>
<th>Sig. (2-tailed)</th>
<th>95% Confidence Interval</th>
<th>Bootstrap*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unemployed</td>
<td>NPD</td>
<td>PD</td>
<td>33.071</td>
<td>-.004</td>
<td>1.510</td>
<td>.001</td>
<td>30.122</td>
<td>36.109</td>
</tr>
<tr>
<td></td>
<td>PD</td>
<td>NPD</td>
<td>-33.071</td>
<td>.004</td>
<td>1.510</td>
<td>.001</td>
<td>-36.109</td>
<td>-30.122</td>
</tr>
<tr>
<td>Employed</td>
<td>NPD</td>
<td>PD</td>
<td>12.730</td>
<td>.038</td>
<td>1.630</td>
<td>.001</td>
<td>9.727</td>
<td>15.951</td>
</tr>
<tr>
<td></td>
<td>PD</td>
<td>NPD</td>
<td>-12.730</td>
<td>-.038</td>
<td>1.630</td>
<td>.001</td>
<td>-15.951</td>
<td>-9.727</td>
</tr>
</tbody>
</table>

a. Unless otherwise noted, bootstrap results are based on 1000 bootstrap samples
Table 5.

*Simple main effects by Employment status* (Univariate Tests)

<table>
<thead>
<tr>
<th>NPD_or_PD</th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
<th>Partial Eta Squared</th>
</tr>
</thead>
<tbody>
<tr>
<td>NPD</td>
<td>Contrast</td>
<td>2927.606</td>
<td>1</td>
<td>2927.606</td>
<td>13.499</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Error</td>
<td>210364.167</td>
<td>970</td>
<td>216.870</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PD</td>
<td>Contrast</td>
<td>25096.478</td>
<td>1</td>
<td>25096.478</td>
<td>115.72</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Error</td>
<td>210364.167</td>
<td>970</td>
<td>216.870</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Each F tests the simple effects of EmploymentStatus within each level combination of the other effects shown. These tests are based on the linearly independent pairwise comparisons among the estimated marginal means.

Table 6.

*Bootstrap for Pairwise Comparisons*

<table>
<thead>
<tr>
<th>NPD_or_PD</th>
<th>(I) EmploymentStatus</th>
<th>(J) EmploymentStatus</th>
<th>Mean Difference (I-J)</th>
<th>Bias</th>
<th>Std. Error</th>
<th>Sig. (2-tailed)</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>NPD</td>
<td>Unemployed</td>
<td>Employed</td>
<td>5.724</td>
<td>-.022</td>
<td>1.551</td>
<td>.001</td>
<td>2.592 - 8.661</td>
</tr>
<tr>
<td></td>
<td>Employed</td>
<td>Unemployed</td>
<td>-5.724</td>
<td>.022</td>
<td>1.551</td>
<td>.001</td>
<td>-8.661 - -2.592</td>
</tr>
<tr>
<td>PD</td>
<td>Unemployed</td>
<td>Employed</td>
<td>-14.618</td>
<td>.021</td>
<td>1.574</td>
<td>.001</td>
<td>-17.622 - -11.520</td>
</tr>
<tr>
<td></td>
<td>Employed</td>
<td>Unemployed</td>
<td>14.618</td>
<td>-.021</td>
<td>1.574</td>
<td>.001</td>
<td>11.520 - 17.622</td>
</tr>
</tbody>
</table>

a. Unless otherwise noted, bootstrap results are based on 1000 bootstrap samples
Appendix 62 Tests of Normality (Chapter 5)

<table>
<thead>
<tr>
<th>PD Group</th>
<th>Employment Status</th>
<th>Statistic</th>
<th>df</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>NPD</td>
<td>Unemployed</td>
<td>.072</td>
<td>335</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Residual for Full PES-PD Score</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Employed</td>
<td>.048</td>
<td>122</td>
<td>.200*</td>
</tr>
<tr>
<td></td>
<td>Residual for Full PES-PD Score</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PD</td>
<td>Unemployed</td>
<td>.048</td>
<td>181</td>
<td>.200*</td>
</tr>
<tr>
<td></td>
<td>Residual for Full PES-PD Score</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Employed</td>
<td>.037</td>
<td>342</td>
<td>.200*</td>
</tr>
<tr>
<td></td>
<td>Residual for Full PES-PD Score</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* This is a lower bound of the true significance.

Figure 1. Normal Q-Q Plot of Residual Full PES-PD Score (Non-PD and Unemployed)
Figure 2. Normal Q-Q Plot of Residual Full PES-PD Score (Non-PD and Employed)

Figure 3. Normal Q-Q Plot of Residual Full PES-PD Score (PD and Unemployed)
Figure 4. Normal Q-Q Plot of Residual Full PES-PD Score (PD and Employed)
Appendix 63 ANOVA (with Outliers) Output (Chapter 5)

Table 1.

**Descriptive Statistics**

<table>
<thead>
<tr>
<th>NPD or PD</th>
<th>Employment Status</th>
<th>Statistic</th>
<th>Bias</th>
<th>Std. Error</th>
<th>95% Confidence Interval</th>
<th>95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>NPD</td>
<td>Unemployed</td>
<td>Mean</td>
<td>76.61</td>
<td>.01</td>
<td>.67</td>
<td>75.22</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SD</td>
<td>12.881</td>
<td>-.032</td>
<td>.481</td>
<td>11.948</td>
</tr>
<tr>
<td></td>
<td></td>
<td>N</td>
<td>335</td>
<td>0</td>
<td>15</td>
<td>305</td>
</tr>
<tr>
<td>NPD</td>
<td>Employed</td>
<td>Mean</td>
<td>70.84</td>
<td>.01</td>
<td>1.38</td>
<td>68.16</td>
</tr>
<tr>
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<td></td>
<td>SD</td>
<td>15.441</td>
<td>-.121</td>
<td>1.227</td>
<td>13.039</td>
</tr>
<tr>
<td></td>
<td></td>
<td>N</td>
<td>122</td>
<td>0</td>
<td>10</td>
<td>103</td>
</tr>
<tr>
<td>NPD</td>
<td>Total</td>
<td>Mean</td>
<td>75.07</td>
<td>.01</td>
<td>.63</td>
<td>73.86</td>
</tr>
<tr>
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<td>SD</td>
<td>13.832</td>
<td>-.032</td>
<td>.505</td>
<td>12.848</td>
</tr>
<tr>
<td></td>
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<td>N</td>
<td>457</td>
<td>0</td>
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<td>426</td>
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<tr>
<td>PD</td>
<td>Unemployed</td>
<td>Mean</td>
<td>43.55</td>
<td>.03</td>
<td>1.24</td>
<td>41.19</td>
</tr>
<tr>
<td></td>
<td></td>
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<td>16.951</td>
<td>-.103</td>
<td>.873</td>
<td>15.113</td>
</tr>
<tr>
<td></td>
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<td>N</td>
<td>181</td>
<td>-1</td>
<td>12</td>
<td>156</td>
</tr>
<tr>
<td>PD</td>
<td>Employed</td>
<td>Mean</td>
<td>58.10</td>
<td>.01</td>
<td>.78</td>
<td>56.53</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SD</td>
<td>14.857</td>
<td>-.035</td>
<td>.552</td>
<td>13.791</td>
</tr>
<tr>
<td></td>
<td></td>
<td>N</td>
<td>342</td>
<td>1</td>
<td>15</td>
<td>315</td>
</tr>
<tr>
<td>PD</td>
<td>Total</td>
<td>Mean</td>
<td>53.07</td>
<td>.04</td>
<td>.69</td>
<td>51.78</td>
</tr>
<tr>
<td></td>
<td></td>
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<td>17.066</td>
<td>-.047</td>
<td>.517</td>
<td>16.015</td>
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<td>0</td>
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<td>493</td>
</tr>
<tr>
<td>Total</td>
<td>Unemployed</td>
<td>Mean</td>
<td>65.01</td>
<td>.06</td>
<td>.93</td>
<td>63.20</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SD</td>
<td>21.385</td>
<td>-.062</td>
<td>.582</td>
<td>20.191</td>
</tr>
<tr>
<td></td>
<td></td>
<td>N</td>
<td>516</td>
<td>-1</td>
<td>15</td>
<td>485</td>
</tr>
<tr>
<td>Total</td>
<td>Employed</td>
<td>Mean</td>
<td>61.45</td>
<td>.00</td>
<td>.72</td>
<td>60.05</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SD</td>
<td>16.012</td>
<td>-.033</td>
<td>.523</td>
<td>14.963</td>
</tr>
<tr>
<td></td>
<td></td>
<td>N</td>
<td>464</td>
<td>1</td>
<td>15</td>
<td>435</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>Mean</td>
<td>63.32</td>
<td>.03</td>
<td>.59</td>
<td>62.15</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SD</td>
<td>19.105</td>
<td>-.038</td>
<td>.385</td>
<td>18.314</td>
</tr>
<tr>
<td></td>
<td></td>
<td>N</td>
<td>980</td>
<td>0</td>
<td>0</td>
<td>980</td>
</tr>
</tbody>
</table>

*Note.* a. Unless otherwise noted, bootstrap results are based on 1000 bootstrap samples.
Table 2.  
Levene's Test of Equality of Error Variances\textsuperscript{a,b} 
\begin{tabular}{lccc}
Source & Levene Statistic & df1 & df2 & Sig. \\
\hline
Full PES-PD & 4.733 & 3 & 976 & .003 \\
Score Based on Mean & 4.862 & 3 & 976 & .002 \\
Based on Median & 4.862 & 3 & 932.549 & .002 \\
Based on Median and with adjusted df & 4.868 & 3 & 976 & .002 \\
Based on trimmed mean & & & & \\
\hline
\end{tabular} 

Note. Tests the null hypothesis that the error variance of the dependent variable is equal across groups.  
\textsuperscript{a}. Dependent variable: Full PES-PD Score  
\textsuperscript{b}. Design: Intercept + NPD or PD + Employment Status + NPD or PD * Employment Status 

Table 3.  
Tests of Between-Subjects Effects\textsuperscript{a} 
\begin{tabular}{lcccc}
Source & Type III Sum of Squares & df & Mean Square & F & Sig. \\
\hline
Corrected Model & 146072.732\textsuperscript{b} & 3 & 48690.911 & 224.949 & .000 \\
Intercept & 3160763.334 & 1 & 3160763.334 & 14602.542 & .000 \\
NPD or PD & 106809.406 & 1 & 106809.406 & 493.453 & .000 \\
Employment Status & 3924.283 & 1 & 3924.283 & 18.130 & .000 \\
NPD or PD * Employment Status & 21027.019 & 1 & 21027.019 & 97.144 & .000 \\
Error & 211258.081 & 976 & 216.453 & & \\
Total & 4287122.000 & 980 & & & \\
Corrected Total & 357330.812 & 979 & & & \\
\hline
\end{tabular} 

Note. \textsuperscript{a}. Dependent variable: Full PES-PD Score  
\textsuperscript{b}. R Squared = .409 (Adjusted R Squared = .407)
Table 4.
Univariate Tests (Bootstrap 1000)

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
<th>Partial Eta Squared</th>
</tr>
</thead>
<tbody>
<tr>
<td>NPD</td>
<td>Contrast</td>
<td>128383.191</td>
<td>1</td>
<td>128383.191</td>
<td>593.123</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Error</td>
<td>211258.081</td>
<td>976</td>
<td>216.453</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PD</td>
<td>Contrast</td>
<td>14587.417</td>
<td>1</td>
<td>14587.417</td>
<td>67.393</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Error</td>
<td>211258.081</td>
<td>976</td>
<td>216.453</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. Each F tests the simple effects of NPD or PD within each level combination of the other effects shown. These tests are based on the linearly independent pairwise comparisons among the estimated marginal means.

Table 5.
Bootstrap for Pairwise Comparisons

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>(I) NPD or PD</th>
<th>(J) NPD or PD</th>
<th>Mean Difference (I-J)</th>
<th>Bias</th>
<th>Std. Error</th>
<th>Sig. (2-tailed)</th>
<th>95% Confidence Interval Lower</th>
<th>95% Confidence Interval Upper</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unemployed</td>
<td>NPD</td>
<td>PD</td>
<td>33.053</td>
<td>-.021</td>
<td>1.418</td>
<td>.001</td>
<td>30.234</td>
<td>35.747</td>
</tr>
<tr>
<td></td>
<td>PD</td>
<td>NPD</td>
<td>-33.053</td>
<td>.021</td>
<td>1.418</td>
<td>.001</td>
<td>-35.747</td>
<td>-30.234</td>
</tr>
<tr>
<td>Employed</td>
<td>NPD</td>
<td>PD</td>
<td>12.737</td>
<td>.001</td>
<td>1.601</td>
<td>.001</td>
<td>9.600</td>
<td>15.841</td>
</tr>
<tr>
<td></td>
<td>PD</td>
<td>NPD</td>
<td>-12.737</td>
<td>-.001</td>
<td>1.601</td>
<td>.001</td>
<td>-15.841</td>
<td>-9.600</td>
</tr>
</tbody>
</table>

Note. a. Unless otherwise noted, bootstrap results are based on 1000 bootstrap samples.
Appendix 64 PES-PD COSMIN checklist scores (Chapter 5)

Score: V = very good; A = adequate; D = doubtful; I = inadequate; N = not applicable

<table>
<thead>
<tr>
<th>Box 1. Internal consistency</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Check whether a scale or a subscale is unidimensional</td>
</tr>
<tr>
<td>2</td>
<td>Perform the analysis in a sample with an appropriate number of patients (taking into account expected number of missing values)</td>
</tr>
<tr>
<td>3</td>
<td>Provide a clear description of how missing items will be handled</td>
</tr>
<tr>
<td>4</td>
<td>For continuous scores: calculate Cronbach’s alpha or Omega for each unidimensional scale or subscale</td>
</tr>
<tr>
<td>5</td>
<td>For dichotomous scores: calculate Cronbach’s alpha or KR-20 for each unidimensional scale or subscale</td>
</tr>
<tr>
<td>6</td>
<td>For IRT-based scores: calculate standard error of theta (SE (θ)) or reliability coefficient of estimated latent trait value (index of (subject or item) separation) for each unidimensional scale or subscale</td>
</tr>
</tbody>
</table>

**TOTAL** Lowest score of items 1-5

Score: V = very good; A = adequate; D = doubtful; I = inadequate; N = not applicable

<table>
<thead>
<tr>
<th>Box 4. Structural Validity</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>For CTT: perform confirmatory factor analysis</td>
</tr>
<tr>
<td>2</td>
<td>For CTT: provide clear information on how the factor analysis will be performed, e.g. software program, method of estimation, whether and how assumptions will be checked, rotation method, criteria for model fit.</td>
</tr>
<tr>
<td>3</td>
<td>For IRT/Rasch: choose a model that fits to the research question</td>
</tr>
<tr>
<td>4</td>
<td>For IRT/Rasch: provide clear information on how the IRT or Rasch analysis will be performed, e.g. software program, which IRT or Rasch model used, method of estimation, whether and how assumptions will be checked, criteria for model fit.</td>
</tr>
<tr>
<td>5</td>
<td>Perform the analysis in a sample with an appropriate number of patients (taking into account expected number of missing values)</td>
</tr>
<tr>
<td>6</td>
<td>Provide a clear description of how missing items will be handled</td>
</tr>
</tbody>
</table>

**TOTAL** Lowest score of items 1-6
**Score:** V = very good; A = adequate; D = doubtful; I = inadequate; N = not applicable

### Box 4. Content Validity

<table>
<thead>
<tr>
<th>Rating</th>
<th>Score: V = very good; A = adequate; D = doubtful; I = inadequate; N = not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>From the perspective of the patients: use an appropriate method for assessing (1) the relevance of each item for the patients’ experience with the condition, AND (2) the comprehensiveness of the PROM, AND (3) the comprehensibility of the PROM instructions, items, response options, and recall period.</td>
</tr>
<tr>
<td>V</td>
<td>From the perspective of professionals: use an appropriate method for assessing (1) the relevance of each item for the construct of interest, AND (2) the comprehensiveness of the PROM</td>
</tr>
<tr>
<td>V</td>
<td>Include professionals from all relevant disciplines</td>
</tr>
<tr>
<td>V</td>
<td>Evaluate each item in an appropriate number of patients or professionals for qualitative studies for quantitative (survey) studies</td>
</tr>
<tr>
<td>NA</td>
<td>Use skilled group moderators or interviewers</td>
</tr>
<tr>
<td>NA</td>
<td>Base the group meetings or interviews on an appropriate topic or interview guide</td>
</tr>
<tr>
<td>NA</td>
<td>Record and transcribe verbatim the group meetings or interview</td>
</tr>
<tr>
<td>V</td>
<td>Use an appropriate approach to analyse the data</td>
</tr>
<tr>
<td>V</td>
<td>Involve at least two researchers in the analysis</td>
</tr>
<tr>
<td>V</td>
<td><strong>TOTAL</strong> Lowest score of items 1-9</td>
</tr>
</tbody>
</table>

### Box 9. Hypotheses Validity (Known-groups)

<table>
<thead>
<tr>
<th>Rating</th>
<th>Score: V = very good; A = adequate; D = doubtful; I = inadequate; N = not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 Formulate hypotheses regarding mean differences between subgroups</td>
</tr>
<tr>
<td>V</td>
<td>2 Provide an adequate description of important characteristics of the subgroups, such as disease or demographic characteristics</td>
</tr>
<tr>
<td>V</td>
<td>3 Perform the analysis in a sample with an appropriate number of patients (taking into account expected number of missing values)</td>
</tr>
<tr>
<td>V</td>
<td>4 Use statistical methods that are appropriate for the hypotheses to be tested</td>
</tr>
<tr>
<td>V</td>
<td>5 Provide a clear description of how missing items will be handled</td>
</tr>
<tr>
<td>V</td>
<td><strong>TOTAL</strong> Lowest score of items 1-10</td>
</tr>
</tbody>
</table>