# A Qualitative Study of The Experiences of People who Use A&E Services following Deliberate Self Harm or Attempted Suicide and Receive No Further Support

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## UCL Doctorate in Clinical Psychology

## Thesis Declaration Form

I 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.

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## Overview

Deliberate self-harm, attempted suicide and Borderline Personality Disorder are problems affecting a significant number of people within the United Kingdom.

Part 1 of this thesis provides a systematic review of Dialectical Behaviour Therapy (DBT) based interventions under the length of six months for these problems. 20 studies were identified assessing the effectiveness or efficacy of the interventions. The nature of the interventions being provided as well as the strength of the evidence for their effectiveness were assessed in the review. Group based skills interventions and six-month implementations of full DBT were reported to have evidence supporting their effectiveness. The need for further research on the effectiveness of shorter implementations of full DBT, in particular RCTs, is highlighted in the conclusions.

Part 2 is a qualitative study exploring the experiences and views of people who repeatedly use Accident & Emergency services (A&E) for self-harm or attempted suicide and do not go on to receive input from mental health services. This was a joint project, conducted with another trainee Clinical Psychologist. Ten service users with past or present experience of visiting A&E for risk to self were interviewed. Using thematic analysis, ten themes were developed, divided into three domains. The first domain focussed on the experiences participants had in A&E, how they interpreted these experiences, and the consequences of these experiences. The second explored the beliefs participants held about themselves, clinicians and the availability of services. The final domain focussed on barriers and facilitators to accessing further care.

Part 3 is a reflection on the process of planning research, recruiting participants, and the journey of reflexivity in the research.

## Impact Statement

The first part of this thesis provides a systematic review exploring the research on Dialectical Behaviour Therapy (DBT) based interventions lasting under six months for deliberate self-harm, attempted suicide and Borderline Personality Disorder. The review examines what interventions are being provided as well as the evidence for their effectiveness. The second part of the thesis is a qualitative study, speaking to people who repeatedly present to A&E services with these difficulties and do not go on to receive any further input from mental health services.

The review was the first to look into the effectiveness of DBT specifically in the context of providing briefer interventions for those at risk to themselves. The findings highlight important areas that could be considered for further research and clinical implementation. Evidence is presented demonstrating the feasibility and effectiveness of DBT skills group (particularly as an adjunctive treatment) and six-month implementations of fully programmatic DBT. Shorter interventions could be beneficial to services in improved cost-effectiveness and to clients in potentially reducing waiting lists and being easier to commit time to.  The need for further studies in all categories of intervention, and in particular the 12-16 session range, is discussed. Most studies on full implementations of DBT were uncontrolled and of low quality. The importance of higher quality controlled trials, including RCTs, to provide higher quality evidence of effectiveness is highlighted.

The qualitative study reported on participants’ experiences of using A&E following self-harm or a suicide attempt. The study reported on beliefs that participants held about themselves, clinicians and availability of services, that they connected with not receiving any further support. Views on barriers and facilitators to accessing care are also reported. A key idea developed concerning participants' perceptions of clinicians and their attitudes towards people who self-harm. This knowledge and understanding could be used by clinicians and policymakers to guide thinking on how to adapt service structures, training and practice to better meet the needs of service users and maximise the opportunities they get to receive further support. People who present multiple times to A&E for self-harm are at increased risk of suicide in the future, therefore learning how to best support them is of great value.

The importance of future research to understand the differences between people who go on to receive further care and those who do not is discussed, so that those at risk of not receiving further care can potentially be identified earlier, and approaches to engaging them adapted. Other areas for research that are suggested include accessible interventions that could be offered quickly to people following a presentation to A&E. This suggestion was informed by the finding that the moment of help-seeking in A&E is a significant one to service users.

The results of the study will be disseminated in written format and with an offer of a presentation to the teams that were involved in the research, and made available in written format to other A&E and psychiatric liaison teams. The results will be further disseminated through publications to maximise the potential benefit of the research. Results will also be disseminated to participants of the study who expressed an interest in hearing about the findings.

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# Part 1. Systematic Review

## Current research on abbreviated DBT-based interventions for Borderline Personality Disorder and suicidal risk – a systematic review

## Abstract

### Aim

The aim of this systematic review was to explore Dialectical Behaviour Therapy (DBT) based interventions under six-months in length. The review summarises the content of the interventions that are being researched as well as the evidence for the effectiveness of those interventions.

### Method

A systematic literature search of PsychInfo, Medline and Embase databases was conducted to identify outcome studies of short-term DBT based interventions for adults affected by deliberate self-harm, suicidal risk or a diagnosis of Borderline Personality Disorder. Studies were assessed for quality, categorised by intervention and their outcomes reviewed.

### Results

A total of twenty studies were identified that matched the inclusion criteria. There were three categories of intervention identified – DBT Skills Groups, 12-16 session implementations of DBT and six-month packages of fully programmatic DBT.

Skills groups and six-month packages are reported to have good evidence supporting their effectiveness. 12-16 session implementations of DBT were not consistently found to be effective.

Across the studies included, the risk of bias due to lack of controlled studies or randomisation means that results should be interpreted tentatively.

## Conclusion

Relevance to clinical practice is discussed, with skills groups as an adjunctive treatment suggested as an intervention that services may wish to consider. Further rigorous research in the area is recommended, particularly around 12-16 session implementations of DBT.

# Introduction

Dialectical Behaviour Therapy (DBT; Linehan, 1993) is an evidence based treatment for Borderline Personality Disorder (BPD), deliberate self-harm (DSH) and suicidality (Panos, Jackson, Hasan, & Panos, 2014). It is a treatment that previously has been delivered over the course of at least one year, and the majority of research has focussed on the 1-2 year timescale. This review will examine research on treatments based on DBT that take place over 6 months or less.

## Deliberate Self Harm, Suicide and Borderline Personality Disorder

DSH is the deliberate and direct attempt by a person to damage their body. It has been found to have a lifetime prevalence in adults of 6.7% (McManus et al., 2014). The biosocial model (Linehan, 1993) suggests that the function of DSH is broadly to reduce the intensity of emotions by people who lack the skills to do so in other non-damaging ways. Specific functions of DSH can include relieving intense emotions, blocking out unpleasant thoughts, easing tension, relieving symptoms of depression, self-punishment, and to give a sense of control (Gratz, 2003). Briere and Gil (1998) found that 40% of people endorse interpersonal functions of DSH, whilst 70% endorsed intrapersonal functions. It has been suggested that the care elicited from others is not the initial purpose of the behaviour, but may serve as a positive reinforcer of it (Linehan, 1993).

5821 people died by suicide in the United Kingdom in 2017 (Office for National Statistics, 2017), 10.1 per 100000 population. The risk of death by suicide in the year following a presentation to hospital for DSH is 66 times that of the general population (Hawton, Zahl, & Weatherall, 2003). A review of risk factors for suicide found that suicide attempts are predicted primarily by suicidal ideation, which is in turn predicted by factors that include the presence of mental health difficulties.

BPD is a diagnosis defined by the DSM-5 (American Psychiatric Association, 2013) as being characterised by features including emotional instability, impulsive behaviour (including DSH) and unstable relationships. 69-80% of people with a diagnosis of BPD report engaging in DSH (McMain, Guimond, Barnhart, Habinski, & Streiner, 2017), and are at significantly higher risk of suicide, when compared with the general population (Pompili, Girardi, Ruberto, & Tatarelli, 2005). It is worth noting that the diagnostic category of BPD has been critiqued as lacking validity (Paris, 2005), particularly in relation to diagnostic overlap with other personality disorder diagnoses (Zanarini et al., 1998). Despite this the diagnostic category was retained and continues to be used both clinically and in research.

NICE guidelines (National Institute for Health and Care Excellence, 2009, 2013) recommend a range of interventions for DSH and BPD. These include inpatient treatment for people at the highest risk of harm, community treatment and psychological interventions, including cognitive behavioural therapy (CBT) and DBT. With appropriate treatment 85% of people diagnosed with BPD have been found to remit over the course of 10 years (Gunderson et al., 2011).

## DBT

DBT (Linehan, 1993) is a psychological intervention for BPD, DSH and Suicidality. DBT is based on the biosocial model of BPD (Linehan, 1993). This model suggests that emotional dysregulation arises from emotional vulnerability transacting with an invalidating environment. Behavioural responses to affective and cognitive dysregulation are understood as attempts to control emotions. Invalidating environments have the effect of preventing people acquiring the skills to understand and managing these emotions. As a result, the behavioural responses may provide temporary relief, but lead to further invalidation and reinforce the emotional dysregulation.

The initial target of DBT is people's life-threatening behaviours, followed by therapy interfering behaviours and then individual therapy goals related to improving quality of life. This is achieved in fully programmatic DBT (Linehan, 1993) by achieving five functions –

1- motivating participants
2- teaching skills
3- generalising those skills to participants' environments
4- motivating and improving the skills of therapists
5- structuring the participant's environment to encourage skills usage.

These functions are usually provided through four 'modes' – group skills training, individual psychotherapy, telephone coaching, and DBT consultation. In group skills training, clients meet weekly to learn skills from four modules - mindfulness, distress tolerance, interpersonal effectiveness and emotion regulation. These skills are then practised in between sessions. In individual psychotherapy, validation and problem-solving skills are used to support the client to use the skills in overcoming difficulties in their own lives and structuring their environments. Telephone coaching allows clients to generalise their skills use through seeking support in using skills to manage problems as they arise. In DBT consultation, therapists meet each other to monitor and develop their adherence to the DBT model. Studies that include all modes and functions of DBT will be referred to in this review as ‘fully programmatic’.

In meta-analyses, randomised control trials (RCTs) have demonstrated DBT to be superior to treatment as usual (TAU) for suicidal behaviour and ideation, episodes of DSH and depression (DeCou, Comtois, & Landes, 2019; Hawton et al., 2016; Panos et al., 2014). DBT is the only psychological therapy explicitly recommended by NICE guidelines for BPD (National Institute for Health and Care Excellence, 2009).

The emphasis on skills in DBT is supported by evidence that skills improvement fully mediates changes in suicidal behaviour and depression over the course of therapy and partially mediates changes in DSH (Neacsiu, Rizvi, & Linehan, 2010). Evidence suggests that DBT skills delivered as a standalone intervention can be effective in treating symptoms and behaviours of Axis-I mental health conditions (Valentine, Bankoff, Poulin, Reidler, & Pantalone, 2015).

Due to the multiple formats of intervention and length of the intervention, DBT is a resource intensive intervention. With an emphasis in public health services on cost-efficiency (National Health Service, 2014) it is therefore worth considering whether a less resource intensive intervention based on DBT would be feasible, efficacious and effective. DBT for adolescents (DBT-A) delivers all modes of adult DBT over a shorter period of 20 weeks. Meta-analysis evidence based on a sample size of 71 people found that DBT-A was not superior to TAU in reducing repetition of self-harm (Hawton et al., 2015). However, a recent large RCT (n=173) found DBT-A to be efficacious in the reduction of suicidal attempts and non-suicidal self-injury (McCauley et al., 2018).

### Aims of This Review

This review had two aims. Manualised DBT takes place over the course of one year, and includes all of the specified modes (Linehan, 1993). Any intervention which takes place over less time or does not include all modes, will not be manualised DBT. The first aim of this review was therefore be to report what the intervention content is in research of six-month or shorter, DBT-based interventions for adults with a diagnosis of BPD or at risk of suicide and DSH. The review also considered to what extent these interventions delivered the intended functions of DBT.

The second aim of the review was to consider the evidence regarding the efficacy and effectiveness of the interventions studied. Primary outcomes of interest were suicidality, DSH and BPD symptomatology. Secondary outcomes were depression, anxiety, hopelessness and general psychopathology.

# Method

## Inclusion Criteria

The following inclusion and exclusion criteria were applied to studies for inclusion in this review –

1) The target population of the study was
    a. Over 18 years of age
    b. Selected on the basis of either: BPD diagnosis, BPD symptoms, DSH or suicidality
    c. Not selected on the basis of a secondary diagnosis in addition to those above (e.g. trauma, psychosis, learning disability)
2) The study was investigating the outcomes of an intervention described by the study as either fully programmatic DBT or being comprised of at least one mode of DBT.
3) The intervention was based in a community setting.
4) The intervention took place over a time period of greater than a single session, and less than six months.
5) The study used a quantitative methodology.
6) Outcomes were related to DSH, suicidality and/or psychological wellbeing.
7) The study was written in English.
8) The study was published in a peer-reviewed journal.

The rationale for criterion 1 was to produce results applicable to primary care and low-intensity mental health services. Clients of these services may not meet criteria for a diagnosis of BPD. The criteria are therefore intended to capture clients who would be likely to receive a shorter DBT based intervention if it were widely available.

The rationale behind criteria 2 and 3 was to be broad, as preliminary literature searches showed that studies used elements of DBT in different ways, ranging from use of select skills modules all the way to the full DBT package. A number of published studies were based on providing a single session of information giving about DBT skills. The criterion of ‘greater than a single session’ was intended to exclude these studies. A number of studies were identified where final data were collected at six months, but the intervention continued. The aim for this review was to look at interventions that were completed in six months or under, therefore these studies were excluded.

### Search Terms

The databases Medline, PsychINFO and Embase were searched for articles matching the inclusion criteria. The initial search terms were intended to identify studies that were related to both a) DSH/Suicide/BPD and b) DBT. The search terms used were intentionally broad, as preliminary searches with more narrow terms were found to miss studies known to be relevant to the review. Full search terms used for each database can be found in Appendix A.

### Effect Size Calculation

Effect sizes were not reported by all studies included in this review. Where sufficient data was provided, effect sizes were calculated and reported. For studies with a repeated-measures design, Cohen’s d is calculated using the method described by Morris & DeShon (2002).

# Results

## Results of Search

Following the initial searches, records were combined, automatically deduplicated using Endnote and then manually screened (see Figure 1 for details or exclusions at each stage). This was initially done based on just titles. Subsequent screens focussed on abstracts and ensuring the source was a peer-reviewed journal, followed by a full text assessment. Reasons for exclusions at the stage were interventions being over six months in length, interventions taking place in an inpatient setting and primary diagnostic criteria for the study being post-traumatic stress disorder.

A total of 20 studies matched criteria for inclusion. The studies formed three categories, on the basis of style of intervention. The three main clusters were skills group only (n=7), fully programmatic DBT condensed to 12-16 sessions per mode (n=6), and fully programmatic DBT condensed to a timescale of six months (n=7).

One study (Mohamadizadeh, Makvandi, Pasha, Bakhtiarpour, & Hafezi, 2017) was excluded despite appearing to match the inclusion criteria due to the publishing journal currently being under investigation for “suspected misconduct in manuscript publishing” (“Acta Medica Mediterranea - International Journal of Clinical Medicine,” n.d.).

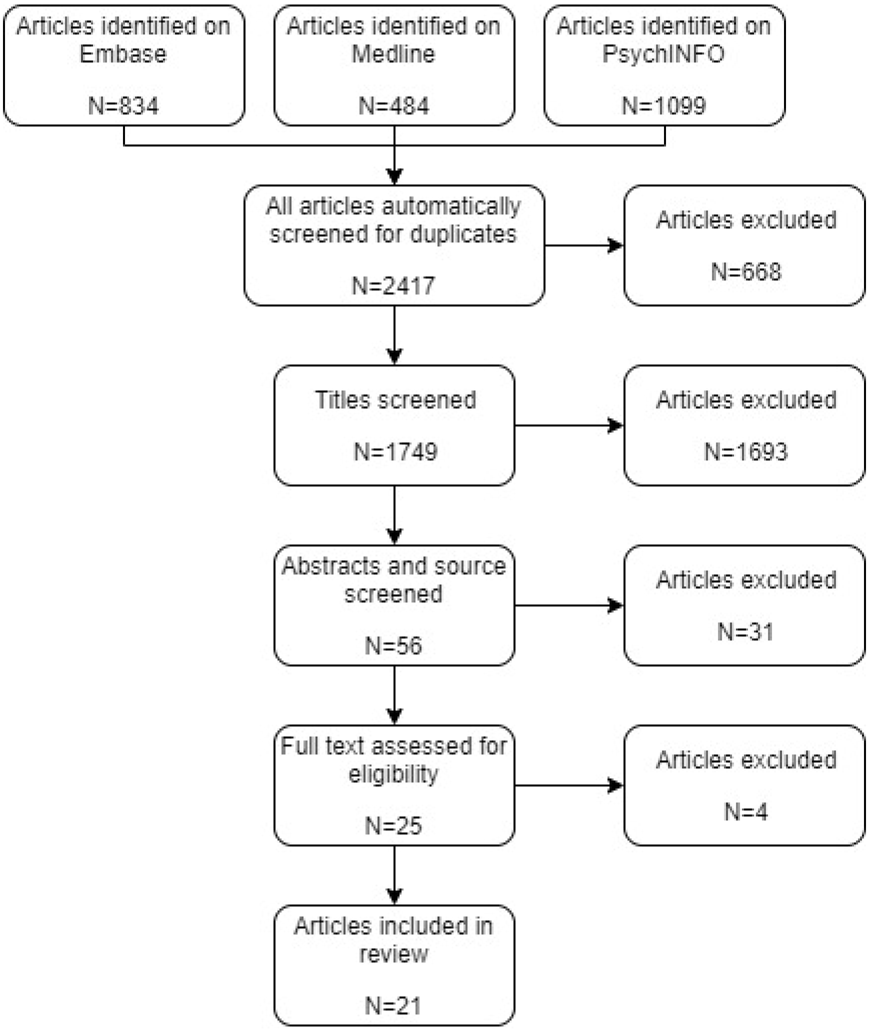

*Figure 1. Details of quantities of studies identified and excluded at each stage of selection.*

## Quality Assessment

From the results of the search, the designs of studies included randomised controlled trials (RCTs), unrandomised cohort controlled trials (CCTs), and cohort studies. A quality evaluation tool that was suitable for use with this range of designs was therefore desirable. The Effective Public Health Practice Project (EPHPP; Thomas, Ciliska, Dobbins, & Micucci, 2004) is a tool designed for the evaluation of public health research using any quantitative design. It is therefore well suited to the breadth of designs found in the papers selected for this review (see Appendix B for details of the evaluation tool).

The EPHPP incorporates ratings for studies on the basis of selection bias, study design, controlling for confounding variables, blinding, data collection methods and withdrawals and dropouts. Guidance is given on whether a study should receive a strong, moderate or weak rating in each category. No exclusion criteria were applied based on quality ratings, but the ratings were considered when evaluating the he conclusions of the review (See Table 1 for study ratings).

*Table 1. Included study quality ratings.*

| **Studies (Grouped by Intervention Category)** | **Selection bias** | **Study design** | **Confounders** | **Blinding** | **Data collection methods** | **Withdrawal and dropout** |
|---|---|---|---|---|---|---|
| ***Skills Groups*** | | | | | | |
| Dixon-Gordon et al. (2015) | Moderate | Strong | Strong | Strong | Strong | Strong |
| Feliu-Soler et al. (2014) | Moderate | Strong | Strong | Moderate | Strong | Moderate |
| Soler et al. (2009) | Strong | Strong | Strong | Moderate | Strong | Weak |
| Kramer et al. (2016) | Strong | Strong | Strong | Moderate | Strong | Moderate |
| McMain et al. (2017) | Strong | Strong | Strong | Moderate | Strong | Moderate |
| Meaney-Tavares and Hasking (2013) | Moderate | Moderate | Strong | Weak | Strong | Moderate |
| Sambrook et al. (2007) | Weak | Moderate | Strong | Weak | Weak | Moderate |
| ***12-16 Sessions*** | | | | | | |
| Andreasson et al. (2016) | Strong | Strong | Strong | Moderate | Strong | Weak |
| McQuillian et al. (2005) | Moderate | Moderate | Strong | Weak | Strong | Moderate |
| Moen et al. (2012) | Weak | Strong | Strong | Moderate | Strong | Moderate |
| Pistorello et al. (2017) | Moderate | Strong | Weak | Weak | Strong | Moderate |
| Simpson et al. (2004) | Moderate | Strong | Strong | Strong | Strong | Strong |
| Soler et al. (2005) | Moderate | Strong | Strong | Strong | Strong | Moderate |
| ***6 Months*** | | | | | | |
| Blennerhasset et al. (2009) | Moderate | Moderate | Strong | Weak | Strong | Strong |
| Brassington et al. (2006) | Moderate | Moderate | Strong | Weak | Strong | Strong |
| Goodman et al. (2016) | Moderate | Strong | Weak | Weak | Strong | Weak |
| Koons et al. (2001) | Strong | Strong | Strong | Weak | Strong | Moderate |
| Linehan et al. (2008) | Weak | Strong | Strong | Strong | Strong | Moderate |
| Rizvi et al. (2017) | Strong | Moderate | Strong | Weak | Strong | Moderate |
| Stanley et al. (2007) | Moderate | Moderate | Strong | Weak | Strong | Strong |

### Skills Groups

A total of seven studies (see Table 2 for characteristics) were found which included skills training as the only client-facing DBT mode, and were completed over a period of six months or less.

*Table 2. Characteristics of studies of DBT Skills Group Interventions*

| Author | Year | Design | Follow-up | N | Modules of DBT Skills | Control Condition | Outcome Measures |
|---|---|---|---|---|---|---|---|
| Dixon-Gordon et al. | 2015 | CCT | n/a | 19 | Interpersonal Effectiveness, Emotional Regulation (Separate Conditions) | Psychoeducation | DSHI*<br>PAI-BOR**<br>BDI-II** |
| Feliu-Soler et al. | 2014 | CCT | n/a | 35 | Mindfulness Only | General Psychiatric Management | HDRS*<br>BPRS* |
| Kramer et al. | 2016 | RCT | 3-Month | 36 | All Modules | TAU Psychotherapy | OQ-45.2* |
| McMain et al. | 2017 | RCT | 3-Month | 84 | All Modules | TAU + Waitlist | DSH Episodes*<br>DSHI*<br>BSL-23*<br>BDI-II*<br>SCL-90-R* |
| Meaney-Tavares et al. | 2013 | Uncontrolled | n/a | 17 | All Modules | n/a | DSM Criteria Ratings**<br>BDI-II**<br>BAI |
| Sambrook et al. | 2007 | Uncontrolled | n/a | 34 | All Modules | n/a | CORE** |
| Soler et al. | 2009 | RCT | n/a | 59 | All Modules | Standard Group Therapy | Episodes of DSH and Suicide Attempts<br>CGI-BPD**<br>HDRS*<br>HRSA*<br>SCL-90-R*<br>BPRS* |

*Note.* * = significant between groups differences favouring DBT, ** = significant improvement over time in DBT condition
BAI = Beck Anxiety Inventory, BDI-II = Beck Depression Inventory II, BPRS = Brief Psychiatric Rating Scale, BSL-23 = Borderline Symptom Checklist 23, CCT = Cohort Controlled Trial, CGI-BPD = clinical global impression scale for borderline personality disorder , CORE = Clinical Outcomes in Routine Evaluation, DSH = Deliberate Self Harm, DSHI = Deliberate Self Harm Inventory, HDRS = Hamilton Depression Rating Scale, OQ-45.2 = Outcome Questionnaire 45.2, PAI-BOR = Personality Assessment Inventory – Borderline Features, RCT = Randomised Controlled Trial, SCL-90-R = Symptom Checklist-90-Revised, TAU = Treatment as Usual

### Study Design

Of the seven studies identified, four were RCTs (Dixon-Gordon, Chapman, & Turner, 2015; Kramer et al., 2016; McMain et al., 2017; Soler et al., 2009), one was a controlled trial (Feliu‐Soler et al., 2014) and two were uncontrolled pre-post designs (Meaney-Tavares and Hasking, 2013; Sambrook, Abba, & Chadwick, 2007).

Comparison groups in the controlled studies were mostly TAU, with the exception of Soler et al. (2009), who use relational group therapy adapted to focus on the unique experiences of people with a diagnosis of BPD, and Feliu-Soler et al. (2014), who used a general psychiatric management program.

The controlled studies ranged in sample size from 19 (Dixon-Gordon et al., 2015) to 84 (McMain et al., 2017). Two controlled studies (Feliu-Soler et al., 2014; Kramer et al., 2016) stated that their samples sizes (35 and 36) were insufficient, leaving the studies potentially insufficiently powered to detect change. The sample size of one further controlled study was 19 (Dixon-Gordon et al., 2015). In this study power was not commented on, however considering that two larger studies were underpowered, it is likely to have also been.

Three month follow-up data were presented in two studies (Kramer et al., 2016; McMain et al., 2017).

### Participants and Intervention Content

Six studies (Dixon-Gordon et al., 2015; Feliu‐Soler et al., 2014; Kramer et al., 2016; McMain et al., 2017; Meaney-Tavares and Hasking, 2013; Soler et al., 2009) required that participants have a diagnosis of BPD according to DSM-IV criteria (American Psychiatric Association, 1994). Sambrook et al. (2007) did not require a diagnosis of BPD but upon assessment all participants did meet DSM-IV criteria.

A consistent feature of these studies was that skills groups were an adjunctive treatment. In four studies (Dixon-Gordon et al., 2015; Feliu - Soler et al., 2014; Meaney-Tavares and Hasking, 2013; Sambrook et al., 2007) participants were receiving psychiatric care, either as part of the study or externally. In a further two studies (Kramer et al., 2016; McMain et al., 2017) most to all participants were receiving individual psychotherapy from therapists external to the study.

In five studies (Kramer et al., 2016; McMain et al., 2017; Meaney-Tavares and Hasking, 2013; Sambrook et al., 2007; Soler et al., 2009), all four modules of DBT skills training specified in the DBT treatment manual (Linehan, 1993) were included in the intervention. In a number of studies it was specified that the intervention was augmented with self-help guides and handouts, although this should be included in any DBT skills intervention. Kramer et al. (2016) explained that this was provided in order to help with strengthening and generalisation of skills learning, due to the lack of multiple cycles of skills training. All studies ran the skills groups for a single cycle.

Two studies provided individual modules of DBT skills training. Feliu-Soler et al. (2014) provided the mindfulness module and Dixon-Gordon et al. (2015) provided the interpersonal effectiveness and emotion regulation modules to separate groups.

Frequency of treatment was generally weekly. Treatment lengths ranged from 6 weeks (Dixon-Gordon et al., 2015) to 20 weeks (Kramer et al., 2016; McMain et al., 2017).

In all studies, therapy was delivered by clinicians described as trained in DBT. Treatment adherence was rated in two studies (Dixon-Gordon et al., 2015; McMain et al., 2017), and both were found to be adherent to the DBT model. DBT consultation was stated as being available to clinicians in a single study (Sambrook et al., 2007). The remaining studies did not state whether DBT consultation groups were available.

### Outcomes

Across all the studies, completion rates were in the 65-75% range. One study (Soler et al., 2009) reported significantly higher treatment retention than control (65.5% in DBT group, 36.6% in control group). There were no reported deaths by suicide during any of the studies.

Three studies (Dixon-Gordon et al., 2015; McMain et al., 2017; Soler et al., 2009) reported outcomes related to DSH and suicidal behaviour. In one study (McMain et al., 2017), the DBT skills group had significantly greater decreases in DSH and suicide attempts at post-treatment ($d_{ppc2}$=0.036) 3-month follow-up ($d_{ppc2}$=0.014) with small effect sizes. Soler et al (2009) reported no differences in incidences of DSH or attempted suicide. One study (Dixon-Gordon et al., 2015) reported significant group-time interactions in favour of DBT skills groups reducing DSH at post-treatment and follow-up (insufficient data available to calculate effect sizes). Within-group effect sizes for the emotion regulation module were small at post-treatment (d=0.24) and medium at follow-up (d=0.5). Within-group effect sizes for the interpersonal effectiveness module were medium at post-treatment (d=0.51) and small at follow-up (d=0.24). The significance of the within-group effect sizes was not reported.

Four studies reported outcomes related to BPD symptomatology (Dixon-Gordon et al., 2015; McMain et al., 2017; Meaney-Tavares and Hasking, 2013; Soler et al., 2009), using a variety of measures (Borderline Symptom List - Short Version; Bohus et al., 2009; Personality Assessment Inventory-Borderline Features; Jackson & Trull, 2001; Clinical Global Impression Scale for BPD; Perez et al., 2007). Significant between-group differences in favour of DBT skills training were detected by McMain et al. (2017) at end of treatment (lost at follow-up) with a large effect size ($d_{ppc2}$=0.68). Dixon-Gordon et al. (2015) reported significant within-group improvements only in the emotional regulation module condition with large effect sizes post-treatment and follow-up (d=0.85 and 1.38 respectively). No significant group interactions were reported. Soler et al. (2009) detected significant symptom reduction in both the DBT and control condition (insufficient data provided to calculate within-group effect sizes), with no significant differences between groups. Meaney-Tavares and Hasking (2013) reported significant reductions in BPD symptomatology (d=1.02).

Five studies reported outcomes related to changes in depression (Dixon-Gordon et al., 2015; Feliu‐Soler et al., 2014; McMain et al., 2017; Meaney-Tavares and Hasking, 2013; Soler et al., 2009). The remaining three used the Beck Depression Inventory II (BDI-II; Beck, Steer, & Brown, 1996). Two studies (Feliu-

Soler et al., 2014; Soler et al., 2009) utilised the Hamilton Rating Scale for Depression (HRSD; Hamilton, 1986). Dixon-Gordon et al. (2015) reported significant within-group improvements only in the emotional regulation module condition at post-treatment and follow-up with small (d=0.32) and large (d=1.49) effect sizes, respectively. No significant group interactions were reported. Feliu-Soler et al. (2014) reported a significant group-time interaction with a medium effect size, favouring improvement in the DBT skills group ($d_{ppc2}=0.58$). Meaney-Tavares and Hasking (2013) reported significant within-group reductions in depression scores with a large effect size (d=1.13). Soler et al. (2009) reported significantly greater improvement in depression scores in the DBT skills group with a small effect size ($d_{ppc2}=0.337$). They also report significant within-group improvements in the DBT group, but did not provide sufficient data to calculate effect sizes. McMain et al. (2017) reported no significant results related to depression scores at post-treatment or follow-up.

Two studies reported outcomes relating to anxiety (Meaney-Tavares and Hasking, 2013; Soler et al., 2009), measured using the Beck Anxiety Inventory (BAI; Beck, Epstein, Brown, & Steer, 1988) and the Hamilton Rating Scale for Anxiety (HRSA; Hamilton, 1959). Soler et al. (2009) significant within-group improvements in the DBT skills group (insufficient data to calculate effect size) and no significant between-group differences. No significant changes were reported by Meaney-Tavares and Hasking (2013).

All studies except two (Dixon-Gordon et al., 2015; Meaney-Tavares and Hasking, 2013) reported on psychopathology, measured using either the Brief

Psychiatric Rating Scale (BPRS; Derogatis & Melisaratos, 1983), Revised Symptom Checklist (SCL-90-R; Derogatis & Unger, 2010), Outcome Questionnaire (Beckstead et al., 2003) or Clinical Outcomes in Routine Evaluation scale (CORE-OM; Evans et al., 2002). Feliu-Soler et al. (2014) reported significant between-group differences favouring the DBT skills intervention with a medium effect size ($d_{ppc2}$=0.558). Kramer et al. (2016) reported significant between-group differences favouring the DBT skills condition, with small effect sizes (d=0.15-0.25 across various subscales). The difference was lost at follow-up. McMain et al. (2017) reported significant between-group differences favouring the DBT skills group at post-treatment with a medium effect size ($d_{ppc2}$=0.63), which was lost at follow-up. Sambrook et al. (2007) reported significant within-group improvements (insufficient data available to calculate effect size). Soler et al. (2009) detected significant within-group differences only in DBT condition (insufficient data available to calculate effect sizes). There were no significant between-group differences.

McMain et al. (2017) reported that participants in the DBT group showed significantly greater improvements in emotion regulation at post-treatment ($d_{ppc2}$-=1.08) and follow-up($d_{ppc2}$=0.924), measured with the Difficulties in Emotion Regulation Scale (Dan-Glauser & Scherer, 2012) and distress tolerance at post-treatment ($d_{ppc2}$=0.69) and follow-up ($d_{ppc2}$=0.77), measured using the Distress Tolerance Scale (DTS; Simons & Gaher, 2005).

Two studies (Feliu‐Soler et al., 2014; Meaney-Tavares and Hasking, 2013) reported on skill acquisition. Meaney-Tavares et al. (2013) reported that adaptive coping skills increased across a range of domains. Feliu-Soler et al. (2014) found no significant differences in acquisition of skills.

### 12-16 Sessions

The six studies included in this section all contain at least two of the four modes of DBT and interventions lasted from 12-16 sessions per mode (see table 3 for study characteristics).

*Table 3. Characteristics of studies of 12-16 sessions implementations of DBT*

| **Author** | **Year** | **Design** | **Follow-up** | **N** | **DBT Modes Included** | **Control Condition** | **Outcome Measures** |
|---|---|---|---|---|---|---|---|
| Andreasson et al. | 2016 | RCT | 6-Month, 1 year | 108 | All Modes | Assessment and Management | Suicide Attempts<br>BSSI<br>ZAN-BPD<br>HDRS<br>BDI-II<br>BHS |
| McQuillian et al. | 2005 | Uncontrolled | n/a | 87 | All Modes | n/a | BDI-II**<br>BHS** |
| Moen et al. | 2012 | RCT (Both conditions receiving DBT) | n/a | 15 | All Modes | n/a | BEST<br>SCL-90-R** |
| Pistorello et al. | 2017 | Sequential Multiple Assignment Randomised Trial | n/a | 62 (7 Receiving DBT) | All Modes | n/a | BSSI<br>PAI<br>BHS<br>CGI |
| Simpson et al. | 2004 | RCT (Both conditions receiving DBT) | n/a | 25 | All modes except telephone support | n/a | OAS-M-SI<br>OAS-M-S**<br>BDI-II**<br>STAI** |
| Soler et al. | 2005 | RCT (Both conditions receiving DBT) | n/a | 60 | All modes except individual sessions | n/a | Episodes of DSH and Suicide Attempts<br>HDRS**<br>HRSA**<br>CGI** |

*Note.*

* = significant between groups differences favouring DBT, ** = significant improvement over time in DBT condition

BDI-II = Beck Depression Inventory II, BEST = Borderline Evaluation of Severity Over Time, BHS = Beck Hopelessness Scale, BSSI = Beck Scale for Suicidal Ideation, CGI = Clinical Global Impression Scale, DSH = Deliberate Self Harm, DSHI = Deliberate Self Harm Inventory, HDRS = Hamilton Depression Rating Scale, OAS-M-SI/S = Overt Aggression Scale-Modified Self Injury/Suicidality, PAI = Personality Assessment Inventory, RCT = Randomised Controlled Trial, SCL-90-R = Symptom Checklist-90-Revised, STAI = State-Trait Anxiety Inventory, ZAN-BPD = Zanarini Rating Scale for BPD

### Study Design

Of the six studies included, four were randomised control trials (Andreasson et al., 2016; Moen et al., 2012; Simpson et al., 2004; Soler et al., 2005), one was a cohort study (McQuillan et al., 2005) and one (Pistorello et al., 2017) utilised a sequential multiple assignment randomised trial design (Lei, Nahum-Shani, Lynch, Oslin, & Murphy, 2012). In three of the RCTs (Moen et al., 2012; Simpson et al., 2004; Soler et al., 2005), DBT was provided to both the experimental and control groups. These studies were included as they contained analyses relevant to answering the questions of this review. For the purposes of this review they will therefore be treated as uncontrolled cohort studies. In the single study comparing DBT to a non-DBT group (Andreasson et al., 2016) the control group received an intervention that consisted of assessment, treatment planning and risk management.

Sample sizes of the studies ranged from 17 (Moen et al., 2012) to 108 (Andreasson et al., 2016). Three studies (Andreasson et al., 2016; Moen et al., 2012; Simpson et al., 2004) identified insufficient sample size as a methodological weakness of their study. One study (Pistorello et al., 2017) was an evaluation of the outcomes of a college care pathway, in which 7 participants received DBT.

Only one study (Andreasson et al., 2016) included follow-up analyses, conducted at six months and one year after randomisation. One study (Simpson et al., 2004) collected final data at week 10 of a 12 week intervention with the stated reason to minimise interference of therapeutic termination.

### Participants and Intervention Content

Five studies had inclusion criteria related to BPD diagnostic criteria. Four of these (McQuillan et al., 2005; Moen et al., 2012; Simpson et al., 2004; Soler et al., 2005) screened for eligibility on the basis of meeting DSM-IV (American Psychiatric Association, 1994) criteria for diagnosis, and one (Andreasson et al., 2016) required participants to meet two of the DSM-5 (American Psychiatric Association, 2013) criteria for BPD, due to the assumed lower severity of the target population. One study (Pistorello et al., 2017) recruited students at risk of DSH or suicide.

Four studies (Andreasson et al., 2016; McQuillan et al., 2005; Moen et al., 2012; Pistorello et al., 2017) provided fully programmatic DBT, with two adapted from the DBT-A manual (Rathus & Miller, 2002). Simpson et al. (2004) did not specify if telephone support was provided, and Soler et al. (2005) did not include individual sessions but did include telephone support.

One study (McQuillan et al., 2005) provided an intensive programme, where participants had group and individual therapy 4 days per week for three weeks. The remaining studies provided 12 (Simpson et al., 2004) to 16 weeks (Andreasson et al., 2016) of treatment with sessions scheduled on a weekly basis.

In all studies except one (Moen et al., 2012) treatment was provided by trained DBT therapists, although in one study treatment began before training had finished (Andreasson et al., 2016). The core professions of the therapists included psychologists, nurses and psychiatrists.

One study (Pistorello et al., 2017) reported on adherence to DBT treatment. They found that all therapists achieved an ‘adherent’ rating for at least one tape.

### Outcomes

In five studies (McQuillan et al., 2005; Moen et al., 2012; Pistorello et al., 2017; Simpson et al., 2004; Soler et al., 2005), completion rates ranged from 70-83%. One study (Andreasson et al., 2016) reported a lower completion rate in the DBT group (40% vs 90% in the control group). No deaths by suicide were reported by any study.

Two studies (Andreasson et al., 2016; Simpson et al., 2004) reported outcomes related to suicidality. Andreasson et al. (2016) reported no significant between or within group changes in suicide attempts or suicidality, rated by the Beck Scale for Suicidal Ideation (BSSI; Beck, Kovacs, & Weissman, 1979). Simpson et al. (2004) reported significant reductions in suicidality only in the group receiving DBT and placebo medication, measured by the suicidality subscale of OAS-M (insufficient data available to calculate the effect size). Data for pooled groups was unavailable.

Three studies (Andreasson et al., 2016; Simpson et al., 2004; Soler et al., 2005) reported outcomes related to DSH. Andreasson et al. (2016) and Soler et al. (2005) reported no significant differences in DSH episodes, and Simpson et al. (2004) reported no significant changes on the self-injury subscale of the Overt Aggression Scale (OAS-M; Yudofsky, Silver, Jackson, Endicott, & Williams, 1986).

Two studies (Andreasson et al., 2016; Moen et al., 2012) reported on outcomes related to BPD symptoms, measured using the Borderline Evaluation of Severity over Time (Pfohl et al., 2009) and the Zanarini Rating Scale for BPD

(Zanarini et al., 2003). Both reported no significant within or between-group differences.

Four studies (Andreasson et al., 2016; McQuillan et al., 2005; Simpson et al., 2004; Soler et al., 2005) reported outcomes related to depression. Significant pre-post treatment improvement on the BDI-II were reported by McQuillian et al. (2005) with a medium effect size (d=0.60) and Simpson et al. (2004) in the medication placebo group only (insufficient data available to calculate effect size). Soler et al. (2001) reported significant pre-post treatment improvements on the HRSD in both placebo and active medication groups (insufficient data to calculate effect sizes). Andreasson et al. (2016) reported no significant improvements on the HRSD or BDI-II. A single study (McQuillan et al., 2005) reported significant improvements in hopelessness with a small effect size (d=0.26), measured by the Beck Hopelessness Scale (BHS; Beck, Weissman, Lester, & Trexler, 1974).

Two studies (Simpson et al., 2004; Soler et al., 2005) reported outcomes related to anxiety, measured using the HRSA and the State-Trait Anxiety Inventory (Spielberger, Sydeman, Owen, & Marsh, 1999). Both reported significant pre-post intervention improvements. Both studies found this effect in groups taking placebo medication, whilst Soler et al. (2005) also found this in the group taking active medication. Insufficient data was available to calculate effect sizes.

Three studies (Moen et al., 2012; Pistorello et al., 2017; Soler et al., 2005) reported outcomes related to psychopathology, measured by the Clinical Global Impression Scale (CGI; Guy, 1976) and SCL-90-R. Moen et al. (2012) an overall effect of improvement over time, across both active and placebo medication groups. Soler et al. (2001) reported significant pre-post treatment improvements in both placebo and active medication groups. Both studies provided insufficient data to calculate effect sizes. Pistorello et al. (2017) reported that five of seven participants achieved ‘sufficient response’ to treatment, defined as a score of 2 or greater on the improvement subscale and 3 or greater on the severity subscale of the CGI (no statistical analysis was conducted).

### Six Months

The seven studies included in this section (see table 4 for study characteristics) all provide fully programmatic DBT for a period of six months, half of standard length (Linehan, 1993).

*Table 4. Characteristics of studies of 6-month implementations of fully programmatic DBT*

| Author | Year | Design | Follow-up | N | Control Condition | Outcome Measures |
|---|---|---|---|---|---|---|
| Blennerhasett et al | 2009 | Uncontrolled | n/a | 11 | n/a | BPD Diagnosis<br>CORE**<br>SCL-90-R** |
| Brassington et al | 2006 | Uncontrolled | n/a | 10 | n/a | Episodes of DSH<br>MCMI-III-BPD**<br>MCMI-III**<br>SCL-90-R** |
| Goodman et al | 2016 | RCT | 6-Month | 91 | TAU | Suicide attempts**<br>BSSI**<br>BDI-II**<br>BAI*<br>BHS** |
| Koons et al. | 2001 | RCT | n/a | 28 | TAU | Suicide attempts**<br>BSSI*<br>BPD Diagnostic Criteria**<br>BDI-II*<br>HDRS**<br>HRSA |
| Linehan et al | 2008 | RCT (Both conditions receiving DBT) | n/a | 24 | n/a | Episodes of DSH**<br>OAS-M-S<br>HDRS** |
| Rizvi et al | 2017 | Uncontrolled | n/a | 50 | n/a | Episodes of DSH and Suicide Attempts**<br>BSL-23**<br>BDI-II**<br>BSI** |
| Stanley et al | 2007 | Uncontrolled | n/a | 20 | n/a | Episodes of DSH**<br>DSH Urges**<br>Suicidal Ideation**<br>BDI-II**<br>HDRS<br>BHS** |

Note. * = significant between groups differences favouring DBT, ** = significant improvement over time in DBT condition
BAI = Beck Anxiety Inventory, BDI-II = Beck Depression Inventory II, BHS = Beck Hopelessness Scale, BSI = Brief Symptom Inventory , BSL-23 = Borderline Symptom List 23, BSSI = Beck Scale for Suicidal Ideation, CORE = Clinical Outcomes in Routine Evaluation, DSH = Deliberate Self Harm, DSHI = Deliberate Self Harm Inventory, HDRS = Hamilton Depression Rating Scale, HRSA = Hamilton Rating Scale for Anxiety, MCMI-III = Millon Clinical Multiaxial Inventory, OAS-M-S = Overt Aggression Scale-Modified Suicidality Subscale, PAI = Personality Assessment Inventory, RCT = Randomised Controlled Trial, SCL-90-R = Symptom Checklist-90-Revised, STAI = State-Trait Anxiety Inventory

### Study Design

Of the seven studies identified, four were uncontrolled cohort studies (Blennerhassett, Bamford, Whelan, Jamieson, & Wilson O'Raghaillaigh, 2009; Brassington & Krawitz, 2006; Rizvi, Hughes, Hittman, & Oliveira, 2017; Stanley, Brodsky, Nelson, & Dulit, 2007) and three were RCTs (Goodman et al., 2016; Koons et al., 2001; Linehan, McDavid, Brown, Sayrs, & Gallop, 2008). Of the RCTs, one (Linehan et al., 2008) was an RCT of medication, with both groups in the study receiving DBT. Analyses relevant to the question of this paper were conducted. It will be treated as a cohort study for the purposes of this review.

In both RCTs with a non-DBT control group (Goodman et al., 2016; Koons et al., 2001), the control group contained an active treatment. Goodman et al. (2016) used a multidisciplinary TAU as control. Koons et al. (2001) provided non-DBT one to one therapy, including CBT, psychodynamic and 'eclectic' therapy.

The sample sizes of the studies ranged from 8 (Blennerhassett et al., 2009) to 20 (Stanley et al., 2007) in the cohort studies and 24 (Linehan et al., 2008) to 91 (Goodman et al., 2016) in the RCTs.

Most studies collected data only at the start and completion of the intervention. Exceptions were Goodman et al. (2016), who collected data at 6 month follow up, and Linehan et al. (2008) who collected data at 21 weeks of treatment, rather than at the end. The reason for this is not given.

### Participants and Intervention Content

Six studies (Blennerhassett et al., 2009; Brassington & Krawitz, 2006; Koons et al., 2001; Linehan et al., 2008; Rizvi et al., 2017; Stanley et al., 2007) included people meeting DMS-IV or DSM-III (American Psychiatric Association, 1980, 1994) criteria for a diagnosis of BPD, either assessed as part of the study or recruiting from existing services for people with BPD. Goodman et al. (2016) included people at high risk of suicide, of whom 50% of the DBT group and 53% of the TAU group met DSM-IV criteria for a diagnosis of BPD. Both trials with a non-DBT control group (Goodman et al., 2016; Koons et al., 2001) included only war veterans.

In all seven studies, fully programmatic DBT was provided for a period of six months. The clinicians providing treatment were described in all but two studies (Linehan et al., 2008; Stanley et al., 2007) as being experienced and fully trained in the provision of DBT. In two studies (Goodman et al., 2016; Koons et al., 2001) therapist tapes were rated for adherence to the DBT model. In one study (Rizvi et al., 2017) treatment was provided by trainee therapists. Koons et al. (2001) reported mean DBT adherence ratings of 3.8, which they stated demonstrated adherence. The recommended cut-off is stated as 4.0 in the adherence manual (Linehan & Korslund, 2003).

### Outcomes

DBT treatment completion rates ranged from 64-95% across all studies. Attendance was reported by two studies. Rizvi et al. (2017) reported that participants who completed treatment attended 24.47 individual sessions and 19.32 group sessions. Goodman et al. (2016) reported that those in the DBT group attended 17.87 weeks, compared with 16.85 weeks in the TAU group, which was not significantly different.

Five studies (Goodman et al., 2016; Koons et al., 2001; Linehan et al., 2008; Rizvi et al., 2017; Stanley et al., 2007) reported outcomes related to suicidality. Koons et al. (2001) reported significant reductions in ‘parasuicides’ (variable combining attempted suicides and DSH) in the DBT group, with a medium effect size (d=0.35). The difference between DBT and TAU groups was non-significant. The same study reported significant reductions in suicidal ideation only in the DBT group with a large effect size (d=0.98). A significant group-time interaction was reported favouring the DBT group ($d_{ppc2}$=0.55). Rizvi et al. (2017) reported significant reductions in suicidality (insufficient data to calculate effect size). Stanley et al. (2007) reported significant reductions in suicidal ideation (insufficient data available to calculate effect size). Two studies (Goodman et al., 2016; Linehan et al., 2008) reported no significant results related to suicidality.

Three studies (Linehan et al., 2008; Rizvi et al., 2017; Stanley et al., 2007) reported outcomes related to DSH. Linehan et al. (2008) reported a significant reduction in DSH incidents (in pooled placebo and active medication groups) with a large effect size (d=1.12). Rizvi et al. (2017) reported significant reductions in DSH frequency (insufficient data to calculate effect size). Stanley et al. (2007) reported significant reductions in DSH episodes and urges (insufficient data available to calculate effect size).

Three studies (Blennerhassett et al., 2009; Koons et al., 2008; Rizvi et al., 2017) reported results related to BPD symptomatology. Koons et al. (2001) reported significant reductions in participants meeting BPD criteria in DBT (d=2.83) and TAU (d=1.13) conditions. There was no significant group-time interaction. Rizvi et al. (2017) reported significant reductions in BPD symptomatology measured by the BSL-23 (insufficient data available to calculate effect size). Blennerhassett et al. (2009) reported no reduction in participants meeting BPD diagnosis criteria.

Five studies (Goodman et al., 2016; Koons et al., 2001; Linehan et al., 2008; Rizvi et al., 2017; Stanley et al., 2007) reported outcomes related to depression. Goodman et al. (2016) reported significant improvements in depression scores (measured using the BDI-II) with no significant differences between groups (insufficient data available to calculate effect sizes). Koons et al. (2001) reported significant reductions in depression scores measured by the HRSD for the DBT condition only, with a large effect size (d=1.12). There was no significant group-time interaction. No significant results were reported in depression scores measured by the BDI-II. Linehan et al. (2008) reported significant reductions in depression scores measured by the HRSD with a large effect size (d=0.8), in pooled active and placebo medication conditions. Rizvi et al. (2017) reported significant reductions in depression scores measured using the BDI-II (insufficient data available to calculate effect size). Stanley et al. (2007) reported significant improvements in depression scores measure by the BDI-II but not the HRSD (insufficient data available to calculate effect sizes).

Two studies (Goodman et al., 2016; Koons et al., 2001) reported outcomes related to anxiety. Goodman et al. (2016) reported significant improvements in anxiety scores (measured using the BAI) with no significant differences between at follow-up, but not post-treatment (insufficient data available to calculate effect sizes). Koons et al. (2001) reported no significant results related to anxiety.

Three studies (Blennerhassett et al., 2009; Brassington & Krawitz, 2006; Rizvi et al., 2017) reported outcomes related to psychopathology. Two studies (Blennerhassett et al., 2009; Brassington & Krawitz, 2006) reported significant improvement on SCL-90-R. Brassington et al. (2009) reported significant improvement on the Millon Clinical Multiaxial Inventory III (Millon, 2004), including on the borderline, depression and anxiety subscales. Rizvi et al. (2017) reported significant improvement on the Brief Symptom Inventory (Derogatis & Melisaratos, 1983). All studies provided insufficient data to calculate effect sizes, however Blennerhassett et al. (2009) described the effect size as ‘large’.

## Discussion

### Interventions Provided and DBT Function Delivery

The DBT based interventions fell broadly into three groups; short term DBT skills groups, 12-16 session programmes, and six-month programmes. In the majority of studies, therapists were described as being trained in DBT. Across the studies included in this review, only three studies reported on therapist adherence to the DBT model. Additionally supervision arrangements were not discussed by any studies. As a result, it is not possible to comment with confidence on the quality of the treatment provided or fidelity to the model. This section of the discussion will therefore focus on the intervention protocols as described by the published studies. It is possible that adequate supervision and DBT consultation was provided to clinicians, and that treatments were adherent to the model and of high quality, but this cannot be assumed.

In the DBT Skills Group category, five of the studies included all skills modules described by Linehan (1993), making it possible to compare and consider the results of the studies. The interventions provided in these studies delivered on the skills teaching function of DBT. Interventions providing only a single module of skills training did not fully deliver on that function. In two studies (Kramer et al., 2016; McMain et al., 2017), DBT skills were adjunctive to individual psychotherapy. As a result, findings from these studies should be considered in the context of potential interactions between the skills training and individual therapy. Additionally, participants in a further two studies were receiving care coordination. In these treatments it is possible that benefits of motivation, generalising skills and structuring the environment are being delivered through these other pathways but are not an explicit aspect of the DBT based intervention. No studies addressed how they may improve the skills of therapists.

In the 12-16 session programmes, four studies (Andreasson et al., 2016; McQuillan et al., 2005; Moen et al., 2012; Pistorello et al., 2017) provided fully programmatic DBT. These studies therefore deliver on all functions of DBT. It may be questioned as to whether skills can be adequately learnt or generalised over the intervention where all sessions were delivered daily over the course of three weeks (McQuillan et al., 2005). In weekly DBT, participants have the opportunity to practice skills and consolidate learning between sessions. In a daily intervention, opportunities for this will be more limited. Simpson et al. (2004) did not deliver on generalisation as there was not telephone support. Soler et al. (2009) did not provide individual sessions, therefore potentially lacked a mechanism to motivate clients. The heterogeneity in the interventions in this category, particularly with McQuillian et al. (2005) and Soler et al. (2009), makes some studies difficult to compare and consider together.

Whilst not all interventions described delivered on generalising of skills, it is worth considering the options available to service users outside of the provided intervention. An example of this is the increasing availability of evidence based mental health smartphone apps (Bush, Armstrong, & Hoyt, 2019). It is conceivable that these could provide a similar in-the-moment function to having a therapist available for telephone consultation.

In the six month category, all studies provided fully programmatic DBT, therefore delivering on all functions of DBT.

A weakness across many studies in this review was a lack of detail provided about the protocol’s of the interventions. This makes it hard for the studies to be recreated. This is less of a problem for studies stating that they provided full-package DBT, however for those that did not it is important to know in detail which aspects were retained or adapted.

## Research Quality

Before discussing the results of the studies it is important to consider the quality of the research, which may affect the validity and generalisability of results. In the quality assessment of the studies, two areas stood out as weaknesses across a number of the studies. The first was the possibility of selection bias, particularly in the 12-16 session and 6-month intervention studies. A potential explanation for this is the high number of small pilot or evaluation studies that were included.

Another area of concern was inadequate blinding of assessors in controlled trials. The only trials rated ‘strong’ for blinding were those where DBT was provided to both the experimental and control conditions. As a result, the risk of results being biased is increased, particularly on assessor-rated measures.

Outside of the skills group interventions, there were only three controlled studies that compared a DBT intervention group to a non-DBT control group. It is therefore difficult to draw conclusions about whether observed change is due to receiving any treatment, or related to elements specific to DBT. The high prevalence of uncontrolled studies combined with poor ratings of researchers blinding further increases the risk of researchers bias unintentionally biasing the results of the studies.

Overall, the generally low quality of trials in relation to risk of selection bias and blinding, combined with the small number of RCTs and high number of uncontrolled studies, mean that the results of this review should be interpreted tentatively. It is possible that results in many of the studies included may be biased towards finding positive results.

## Effectiveness of Treatments

### DBT Skills Groups.

The quality of the studies was generally high and the majority (five of seven) were controlled, however an area of weakness was in the blinding of the researchers. Additionally, two of the controlled studies were non-random. There is therefore the risk of researcher bias, particularly in regard to finding between-groups effects.

Findings related to DSH and suicidal behaviour were mixed, and effect sizes were in the small-medium range. There were few significant between-group differences reported in relation to BPD symptomatology, with the only one reported (McMain et al., 2017) being lost at follow-up. Uncontrolled studies significant reductions with large effect sizes. Findings related to depression were mixed. Significant within-group improvements were consistently reported with a range of effect sizes (were available). Between-group findings were more variable. Significant between-group findings favouring DBT skills for improvements in psychopathology were reported with small-medium effect sizes by the highest quality studies included (Feliu-Soler et al., 2014; Kramer et al., 2016; McMain et al., 2017). These were lost at follow-up by both studies that included follow-up data (Kramer et al., 2016; McMain et al; 2017).

The effectiveness in regards to depression and general psychopathology is supported by previous reports of the helpfulness of DBT Skills as a standalone treatment for axis-I disorders (Valentine et al., 2015). When considering the areas in which evidence in this review was mixed, such as DSH and BPD symptoms, it may be possible that the limited scope of skills groups alone is not sufficient to impact on more severe or long-standing symptoms.

Due to participants in most studies receiving DBT skills in addition to another treatment (either as part of or external to the trial), evidence from this group is generally for DBT skills as an adjunctive treatment. Whilst this may add ecological validity to the results, it limits the ability to isolate effects to DBT Skills groups alone, especially in uncontrolled studies. Soler et al. (2009) was the only study to require that participants not be engaged with any external therapists. In addition, the prevalence of treatment as usual and active control groups suggests that results in this section should generally be interpreted as evidence of effectiveness, rather than efficacy.

### 12-16 Session Interventions.

The studies in this category were of mixed quality, particularly in relation to blinding of researchers, selection bias and reporting of withdrawal and dropout. Additionally only a single study compared DBT to a non-DBT control and generally insufficient data was reported to be able to provide effect sizes.

Across studies in the 12-16 session category, only a single, uncontrolled study of 25 participants (Simpson et al., 2004) found a significant outcome support the use of DBT in relation to suicidality. No significant results were reported in relation to DSH or BPD symptomatology. Significant with-in groups results were reported for improvements in depression, anxiety  and psychopathology scores, however effect sizes were  almost entirely unavailable or unable to calculated with the provided data. The only study (Andreasson et al., 2016) study in this category comparing DBT to a non-DBT control group reported no significant differences in outcomes for participants receiving DBT compared to a control intervention, and no within-group analyses were reported on.

It is surprising that outcomes are less favourable towards DBT than in the Skills Group category, considering that the studies in this category should in theory be providing a more comprehensive psychological intervention. As only uncontrolled studies found evidence supporting the usefulness of 12-16 session DBT, results should be interpreted in terms of feasibility and tentative evidence of effectiveness.

DBT-A is a comparable intervention for adolescents. The findings in this review are consistent with mixed findings in DBT-A meta-analysis (Hawton et al., 2015), although a large RCT which took place after the review has found that it can have significant benefits for adolescents at risk of suicide and DSH (McCauley et al., 2018). It may be possible that a shorter intervention is sufficient for adolescents due to the likelihood that problems and symptoms will have been present for less time and behavioural patterns therefore less strongly reinforced.

### 6 Month Interventions.

The studies in this category were mixed in quality. Blinding, study design and selection bias were consistent areas of weakness. In particular one of the only two RCTs (Goodman et al., 2016) was weak in half of domains assessed. Results reported should therefore be interpreted with the risk of researcher bias held in mind. Sufficient data to calculate effect sizes was not consistently available.

Mixed results were reported regarding suicidality. Three studies reported significant within-group results with variable (but generally unavailable) effect sizes. One study (Koons et al., 2001) reported significant between group differences on suicidal ideation. Significant reductions in DSH were reported by three studies. One study (Linehan et al., 2008) reported a large effect size. No studies comparing DBT to a non-DBT control reported on DSH as a standalone variable. Two out of three studies reported within-group reductions in BPD symptomatology. Koons et al. (2001) reported a large effect size, but not between group differences. Both RCTs reported significant within-group differences in depression scores and one (Koons et al., 2001) on anxiety scores, but no between-group effects. Significant within-group effects were consistently reported with large effect sizes (where available). Three uncontrolled studies reported significant improvements in psychopathology, with no effect size data available.

Within group outcomes demonstrated consistently that people receiving DBT experienced improvement in suicide attempts, episodes of DSH, suicidal ideation, BPD symptoms, general psychopathology and depression were consistently reported. In controlled studies, significant between groups differences favouring DBT were only found for suicidal ideation and self-reported depression. These results are consistent with meta-analytic evidence for one year DBT as an effective treatment (DeCou et al., 2019; Hawton et al., 2016; Panos et al., 2014).

Both RCTs in the 6-month category were based exclusively on veteran populations in the USA. This is a group that faces significantly higher rates of PTSD than the general population (Oster, Morello, Venning, Redpath, & Lawn, 2017) as well as specific life experiences different to those of the general population. Results from Koons et al. (2001) and Linehan et al. (2008) provide evidence supporting the efficacy of DBT in this population, however the ability to generalise this may be limited. The remaining studies were all uncontrolled, therefore can only be interpreted as evidence of feasibility and tentative evidence of effectiveness for a six-month package of DBT.

Limited between-group differences in depression and anxiety (across all intervention categories) are consistent with literature on full package DBT (DeCou et al., 2019; Hawton et al., 2016). A possible explanation for this is that depression and anxiety are not the initial targets of DBT. Whilst these problems may be targeted in later stages of treatment (Linehan, 1993), early stages are focussed initially on life and therapy-interfering behaviours. It is possible that in shorter term DBT, these targets are less likely to be reached. Additionally, in skills-group only interventions there are fewer opportunities for participants to address these areas. It is therefore not necessarily surprising that depression and anxiety rates did not improve significantly when compared with control groups.

Some studies included measures of outcomes which may give some insight in to the mechanisms by which change was made. A number of studies reported on hopelessness, finding positive results in favour of DBT. Hopelessness is a significant risk factor for suicide and suicidal ideation (Hawton, Casañas i Comabella, Haw, & Saunders, 2013), and therefore reductions in hopelessness  may explain some of the reduction in suicidal behaviour. Other factors such as distress tolerance and emotional regulation were evaluated only by single skills-group studies, but improvements were noted. This may suggest that the intended skills can be acquired during engagement in a shorter intervention.

## Limitations of the review

The lack of RCTs comparing a DBT condition to a non-DBT condition has been highlighted previously. Due to the lack of the RCTs it has not been possible to draw conclusions about the effectiveness of DBT in comparison to waitlist, TAU, psychological placebo interventions or other available evidence-based psychological interventions for BPD, DSH or risk of suicide.

Of the twenty studies included, only four collected follow-up data beyond the end of treatment. Collecting comprehensive follow-up data is important in order to accurately understand the efficacy of an intervention and it’s safety outcomes (Llewellyn-Bennett, Bowman, & Bulbulia, 2016). This is of particular importance when working with a population at high long-term risk of suicide (Hawton, Zahl, & Weatherall, 2003) who may be experience long-term mental health difficulties.

The majority of included studies did not report effect sizes, and many did not report sufficient data to calculate them. This was particularly the case for within-group effects, where the correlation between scores at each time point needs to be known in order to calculate the effect sizes (Morris & DeShon., 2002). Understanding the size of the effect is of crucial importance when evaluating whether an intervention is going to be of value to a service-user and cost-effective to provide (Sullivan & Feinn., 2012)

A small number of studies used BPD diagnosis as a dichotomous variable. In addition to previously mentioned critiques of the validity of the BPD construct, use of the dichotomous variable presents challenges. Using the presence of a diagnosis as an outcome variable risks masking changes in participants who were more unwell at the start of the study but made substantial improvement in their psychological wellbeing but continued to meet criteria for diagnosis, whilst overstating changes in participants who made small improvements which moved them out of meeting diagnostic criteria.

The final limitation concerns the search strategy for this review. The search focussed on terms related to BPD. The International Classification of Diseases-10 refers to ‘Emotionally Unstable Personality Disorder’ (EUPD; World Health Organisation, 1992) however this was not included in the search terms for this review. BPD and EUPD are used relatively interchangeably clinically and in research, and it is therefore possible that a small number of papers relevant to the research question were missed due to the term’s omission.

## Clinical Relevance to Current Services

An important consideration is what can be learnt from this review about how shorter or reduced DBT interventions can be of benefit to service users and services. For DBT to deliver on the intended functions, staff need to be trained and have the resources to provide the individual sessions, groups, telephone support and consultation groups. A consideration for services will therefore be whether the benefits demonstrated in research can be provided in a cost-effective manner.

Based on the results of this review, DBT skills groups may be a beneficial adjunctive treatment to provide in services where people are already receiving support for difficulties with suicidal behaviour, DSH or BPD. A potential benefit of providing skills groups only is that it may be a low-resource intervention, relative to fully programmatic DBT. In the only RCT investigating skills groups as a standalone treatment (Soler et al., 2009), the groups were not found to have significant benefits over standard group therapy on DSH or suicide attempts. It is therefore not possible to endorse standalone DBT skills groups on the basis of the provided evidence.

Whilst the evidence for six month implementations of DBT should be interpreted tentatively, due to a lack of RCTs in most populations, it may be an area for consideration in services already providing fully programmatic DBT. This may be an appropriate intervention for service users with lower initial symptom severity or who are unable/unwilling to commit to a full year of therapy. These services will already have the systems in place for providing the intervention. If further research can demonstrate that six months of treatment is sufficient for some clients, then offering an option of a shorter version may improve patient choice and facilitate the provision of more cost-effective services.

In most studies included, the intervention was provided by clinicians who had received specific training in DBT and often described as experienced. An implementation of a lower-intensity DBT programme in services may require additional DBT therapists to be trained. This is an exercise that can be costly and resource intensive. It is therefore encouraging that Rizvi et al. (2017) reported that trainee DBT therapists are able to achieve effect sizes comparable to those found in RCTs, suggesting that it would be feasible and ethical for them to treat clients whilst they are training.

## Future Research Directions

It is notable that outside of the skills group only studies, there are very few adequately powered RCTs comparing DBT to a non-DBT control condition. To justify short-term DBT as an efficacious and effective intervention then a priority must be for more, high quality research to be conducted. This research should randomise participants to either a DBT based intervention or a control group. Control groups that might particularly enhance understanding of the potential benefits of short-term DBT based interventions could be waitlist or placebo interventions to establish the efficacy of the interventions, or TAU and other available psychological interventions to establish the effectiveness. Particularly in the case of fully programmatic interventions it would be of value to compare a shorter intervention to a full year of DBT and include analyses to compare effect sizes with the amount of DBT received. It is encouraging that there is a large trial comparing 6 to 12 month DBT is currently ongoing (McMain et al., 2018).

In the 12-16 session category of interventions, the content of what was provided varied significantly. The format of interventions provided in this category was variable, however DBT-A (Rathus & Miller, 2002) may provide a viable option to use as a manualised template for future research. This would help in providing an evidence base for a consistently delivered intervention.

A further consideration may be around what populations the research is conducted in. For example, both RCTs (Goodman et al., 2016; Koons et al., 2001) of six month DBT focus on veteran populations. It would be of value for future research to ensure that it focusses on populations who are currently using services and having difficulties with DSH, suicide and BPD.

In addition to questions around the efficacy and effectiveness of the interventions, there are other areas that might be of interest. Investigating who shorter versions may be appropriate for would be one of these. A possible hypothesis may be that clients who present with lower initial symptom severity are able to benefit from a smaller dose of therapy.

Another area of interest may be to identify which components of DBT are most important to clinical improvement. Current research suggests that skills groups are a key component (Linehan et al., 2015) and that emotion regulation modules may provide more benefit than interpersonal effectiveness (Dixon-Gordon et al., 2015). Further research of these ideas could aid in producing a shorter intervention that provides maximum benefit.

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# Part 2. Empirical Paper

## A Qualitative Study of The Experiences of People Who Use A&E Services Following Deliberate Self Harm or Attempted Suicide and Receive No Further Support

## Abstract

### Aims

The aim of this project was to gain an understanding of the experiences of people who repeatedly presented to A&E following deliberate self-harm, attempted suicide, or suicidal thoughts without receiving any subsequent further support from mental health services. This was with the intention of generating ideas for how services may be able to better serve the needs of people who could benefit from accessing them.

### Method

A qualitative methodology was used for the study. Ten service users who had present or past experience of the phenomena being investigated were recruited from psychiatric liaison and psychological therapy services. Semi structured interviews were conducted with ten participants. Thematic analysis was used to analyse the data.

### Results

Ten themes divided into three domains were reported. The first domain focussed on the participants’ journey through services from the important moment of seeking help through to the consequences of the experiences they had in A&E. The second domain looked at the negative beliefs that participants reported about themselves, clinicians and availability of services which could affect help-seeking. The third domain looked at participants’ views on barriers and facilitators to accessing care.

## Conclusion

Participants of this study had experiences of seeking help in A&E which connected to further difficulties, both psychologically and in accessing care. Adaptations to services which support clinicians to better understand the needs of people affected by deliberate self-harm, attempted suicide and suicidal thoughts may help with these issues.

## Introduction

Deliberate self-harm (DSH) is an attempt by a person to deliberately damage their body and has a lifetime prevalence of 6.7% in adults (McManus et al., 2014). This is skewed towards women and younger adults. The risk of death by suicide in the year following a presentation to hospital for DSH is 66 times that of the general population (Hawton et al., 2003). In 2017 (Office for National Statistics, 2017), almost 6000 people died by suicide in the United Kingdom.

A presentation to hospital for DSH is associated with a significant increase in risk of suicide when compared with the general population (Hawton et al., 2003), and among those with repeated presentations to hospital, the long-term risk is 2.24 times greater than among those with only a single presentation (Zahl & Hawton, 2004). Suicidal ideation and mental health diagnoses have been reported as being key risk factors for attempted suicide (Ribeiro et al., 2016). In addition to increased risk of suicide, an episode of DSH has a 16% chance of being repeated in the next year and a 23% chance of being repeated in the next 4 years (Owens, Horrocks, & House, 2002). Among those who present to hospital emergency departments in England, the one year re-appearance rate is 21% (Geulayov et al., 2016).

DSH is suggested by Linehan’s (1993) biosocial theory as an attempt by people to manage the intensity of distressing emotions that affect them. This is explained as arising in the context of biological predisposition and an invalidating environment leading to difficulties developing skills in emotional self-regulation. Research by Gratz (2003) suggests additional functions of DSH include easing tensions, self-punishment, a sense of control and to manage thoughts. Briere and

Gil (1998) reported that 70% endorsed intrapersonal functions of DSH and 40% of people endorse interpersonal functions. Whilst eliciting care and support from others is not viewed as a primary function of DSH, caregiving may provide positive reinforcement of the behaviour and therefore maintain it (Linehan, 1993).

People with a diagnosis of Borderline Personality Disorder (BPD) are typically affected by symptoms including emotional instability, distressing patterns of thinking, impulsive behaviour, self-harming behaviour and unstable relationships (American Psychiatric Association, 2013). Whilst BPD is not an explicit focus of this study, a significant majority of people with this diagnosis engage in DSH (McMain et al., 2017), and also are at elevated risk of death by suicide (Pompili et al., 2005).

NICE guidelines (National Institute for Health and Care Excellence, 2013, 2018) recommend psychiatric assessment and a range of interventions for DSH and suicidality. These include inpatient treatment for those most at risk of harm, community treatment and psychological interventions, including cognitive behavioural therapy (CBT) and Dialectical Behaviour Therapy (DBT). Despite the recommendations of treatment, a large proportion of people who self-harm do not go on to receive psychological support (McManus et al., 2014).

For many people, emergency services will be their first contact with health services in relation to mental health. It is therefore crucial that at this point, needs are being identified, assessed and referred to appropriate sources of support for NICE guidelines to be put into practice. Despite this, approximately half of people who present to A&E with a presentation of DSH do not receive a psychosocial assessment (Kapur et al., 2008; Lepping, Woodworth, Roberts, & Turner, 2006), and referrals to appropriate specialist services vary from 11-64% (depending on area) in England (Cooper et al., 2013). Kapur et al. (2008) investigated factors associated with not receiving an assessment and found these included self-cutting and self-discharge.

There has been a limited amount of research investigating factors in A&E that affect patients' help-seeking behaviour and subsequent engagement with services. Horrocks et al. (2005) investigated patient experiences of hospital care after DSH, finding a number of barriers to receiving care including negative attitudes of staff, sense of abandonment and reluctance to engage with care. Other studies have found that many patients do not understand the psychiatric assessment processes and become frustrated by the lack of follow-up (Hunter, Chantler, Kapur, & Cooper, 2013). A study of young people using A&E for DSH found that they experience feelings of shame and unworthiness thus perceiving treatment as punitive (Owens, Hansford, Sharkey, & Ford, 2016).

Health seeking behaviours have been studied in related populations which may help enhance the understanding of people who attend A&E for DSH and suicidal behaviour. Research into help-seeking behaviour specifically in child and adolescent populations has reported barriers including perceptions that the problems experienced are not serious, placing high value on self-reliance and not knowing from where to seek help  (Czyz, Horwitz, Eisenberg, Kramer, & King, 2013; Fortune, Sinclair, & Hawton, 2008; Michelmore & Hindley, 2012; Nada-Raja, Morrison, & Skegg, 2003). Many participants in these studies sought no help at all, including from emergency services. Warm et al. (2002) reported that people who had received care for DSH reported generally low satisfaction with doctors and nurses, but mostly did want to stop self-harming.

Studies have also investigated dropout of therapy in personality disorder services (Chiesa, Drahorad, & Longo, 2000; Hummelen, Wilberg, & Karterud, 2007; Martino, Menchetti, Pozzi, & Berardi, 2012). Factors creating likely disengagement from services included staff not understanding patients, poor evaluation of services by patients, care being perceived as standardised, and clinicians being perceived as unable to handle the emotional states of patients.

## This Study

Evidence cited previously suggests that there are some patients who repeatedly use A&E services for DSH or suicidality but do not receive any ongoing mental health support. This suggestion is backed up by anecdotal reports from NHS services. Given the increased risk to the lives of people who use A&E repeatedly following DSH, it is important for services to adapt to better support the needs of this population.

Only a single study was found focussing on the experiences of people using A&E for DSH, however this did not focus specifically on people who have not received further support with their mental health. Other research on help-seeking behaviour in DSH has included populations where people did not seek help at all.

The aim of this study was to attempt to listen to people who have experience of using A&E for DSH but did not receive further support. Qualitative methods were used to gain insight into their experiences and beliefs affecting help seeking. Due to the limited research available, an open and exploratory approach was used.

This was a joint project, conducted with another trainee clinical psychologist, who was speaking with clinicians and investigating interpersonal processes that may affect the gaps in the care that the patients described are entitled to.

**Research Questions**

1. What experiences do participants have of A&E and other health services?
    a. How do they interpret those experiences?
    b. How do those experiences and interpretations affect future engagement with mental health services?
2. What beliefs do participants hold that may interact with their relationship with services?
3. What views and expectations do participants have about A&E and any other health services encountered?
    a. How could a psychological intervention provide for participants at the point of A&E usage?

# Methods

## Design

The aims of this study were to understand the experiences and views of people who had experience of repeatedly using A&E whilst not engaging with offered mental health interventions. In order to best explore this phenomenon, a qualitative, semi-structured interview methodology was chosen. This was an area that had not been previously explored and whilst we were able to make predictions about likely themes that would develop, these were based only on clinical experience and knowledge from related topics. Usage of semi-structured interviews allowed the researchers to be flexible to what participants reported and explore both the events that people were affected by and the meanings they ascribed to them.

## Joint Project Statement

This project was conducted with another trainee clinical psychologist. Aspects of the project design and data collection were jointly conducted. Analysis and write-up was conducted independently. See Appendix I for details of each researcher's involvement.

## Ethics

Ethical approval for conducting the research was obtained from the West of Scotland Research Ethics Committee 3 (Appendix C).

## Inclusion and Exclusion Criteria

Participants were eligible to participate in the study if they met the following criteria –

1. Had current, or past, experience of having presented to A&E more than once following either DSH or a suicide attempt.
2. At the time of using A&E they were not using any psychological or psychiatric support available to them.
3. They were over 18 years of age.

Participants were excluded if they met the following criteria –

1. They were considered by clinicians or researchers to not have capacity to consent to involvement in research.
2. They were unable to communicate in or understand conversational English.

**Recruitment**

Participants for the research were purposively recruited from two National Health Service (NHS) teams in London - a psychiatric liaison service and a therapy service for people who have received a diagnosis of personality disorder in London. It was expected that participants from psychiatric liaison would have current experience of the phenomenon being investigated, whilst those from the therapy service would have past experience.

The psychiatric liaison service is the team who are contacted when a service user comes to A&E for support related to their mental health. The team will complete an assessment for the service user, signpost to where they can get further support and make appropriate referrals. Participants recruited through this service were initially approached by the clinician working with them, who asked permission to either introduce them to one of the researchers or to pass on contact details if the researcher was not present. This was done whilst they were at A&E, after all routine clinical work had been completed.

The therapy service provided DBT and CBT for people with a diagnosis of BPD. Participants recruited through this service were initially approached by their therapist who asked permission to pass their contact details on to one the researchers.

Initial identification of people who fit the inclusion criteria for the study was done by clinicians in the services. Potential participants were given brief information about the study and asked if they were willing to consent to be contacted by the researchers. Participants who gave consent were contacted by email and telephone, at which point a screening for inclusion and exclusion criteria was conducted. Participants who were eligible to participate in the study were sent the participant information sheet (appendix D) by email and given the opportunity to ask any questions. Potential participants were then given a minimum of one week to consider their involvement in the study. If the participants chose to be involved in the study consent was taken either in writing or recorded over the phone if the interview was not conducted in person (appendix E).

## Data Collection

A semi-structured interview format was used to investigate the research questions (appendix F). The interview guide was developed by the researchers in collaboration with the primary investigator. At the time of development of the interview, the aim of the qualitative study was inform the development of a brief and easy to access psychological intervention for people repeatedly using A&E

services, but not accessing any other services. The researchers felt that to overcome barriers, it was important to understand the experiences that people had with health services and how they had interpreted those. It was also important to hear about ideas service users had about what they expected from services, and what would be helpful for them. Experts by experience (EbEs) were not consulted during the development of the interview.

This resulted in an interview that was divided into two parts. The first part asked about participants' experiences of using A&E for DSH or suicide attempts, the help and support that they had been offered at these times, and the factors that prevented them from using mental health services at the time. Questions and suggestions for follow-up prompts were designed to encourage participants to reflect on how they interpreted the meaning of their experiences, their beliefs about mental health support and the providers of that support, and any impact on them going forward.

In the second part of the interview participants were reminded that part of the reason for the research being done was to develop ideas about a psychological intervention that may be able to support people using A&E for DSH or attempted suicide better in the future. They were invited to reflect on what expectations they have towards services and what could have been more helpful to them. They were also asked more specific questions regarding the nature of any future intervention.

In the interviews, follow up questions were used flexibly in response to what the participants spoke about, and what seemed to the interviewer to be of value to hear more about.

Interviews were conducted either in person at an NHS location convenient to the participant, or over the phone. Interviews all lasted between thirty and sixty minutes. Participants were informed and reminded that they could end the interview early for any reason, however none chose to do so. Seven interviews were conducted by myself, and three by the other researcher. Eight interviews were transcribed verbatim by me and two by the other researcher.

A decision was made early in the project that aside from gender, demographic data would not be collected. This was due to an expectation that the participants in the study might be concerned about confidentiality. As the group we were planning to interview were people reluctant to engage with services, it was intended to place as few potential barriers to engagement as possible.

## Analysis

Analysis followed the Thematic Analysis method described by Braun and Clarke (2006). Thematic analysis is a process which enables researchers to identify, develop, analyse and report themes within a qualitative dataset. Advantages of the method include flexibility, potential to generate unanticipated themes, the accessibility of results, and the suitability of outcomes to informing policy and service development. NVivo 12 software was used for transcription and analysis.

Thematic analysis consists of six phases.

### Phase 1 – Familiarisation with data

This phase began with transcription of interviews. Interviews that were transcribed by the other researcher were read an additional time to ensure that there was equal familiarity with the all transcripts being analysed. During this phase, notes were made on initial ideas for coding and patterns that seemed to be present.

### Phase 2 – Generating initial codes

In this phase, units of meaningful information within each transcript were identified and coded with a short summary (e.g. Impact – Avoided A&E). As many codes as possible were identified. Whilst not all codes would eventually contribute towards the final themes, keeping as much of the detail of the data as possible at this stage was important to staying open to potential theme developments. See appendix G for an NVivo screenshot of the coding process.

### Phase 3 – Searching for themes

This phase begins once all data has been fully coded. The codes that were generated in phase 2 were analysed and grouped into categories that could form the basis for potential themes (see appendix H for photograph of process). Notes were made on relationships between codes and themes that were being developed. An initial thematic map was generated to help visualise the data.

### Phase 4 – Reviewing themes

The initial themes were reviewed and refined, giving consideration to whether the themes were coherent and justified on the basis of the contained extracts and also whether they were justified in relation to the full data-set. In this phase a trainee clinical psychologist not affiliated with the project reviewed the themes against two transcripts and provided feedback.

### Phase 5 – Defining and naming themes

The content of the themes was carefully considered in order that the meaning of the theme was clearly defined and a name that gave a clear idea of the content of the theme was selected.

### Phase 6 – Producing the report

In writing the report themes were presented and illustrated using extracts from the transcripts that were able to describe an important aspect of the theme.

## Epistemology and Methodological Decisions

In their guide to thematic analysis, Braun and Clarke (2006) describe a number of decisions that must be made prior to conducting a thematic analysis. In the interest of methodological and epistemological transparency (Caelli, Ray, & Mill, 2003), the responses to these decisions will be described here.

### Epistemology

A position of critical realism was used for this research. Critical realism suggests that whilst an objective reality exists, any experience or knowledge of that reality is affected by the context of the observer, resulting in multiple equally valid accounts of that reality (Bhaskar, 1998). Fletcher (2017) argues that critical realism avoids pitfalls associated with a rigidly realist or constructivist position. He also argues that it is well suited to healthcare research as it allows for the explanation of events whilst also making practical outcomes and policy suggestions possible.

### What counts as a theme?

The first decision to be made is around what level of coverage an idea needs to have in the data to constitute a theme, and how to report on this. It has been argued that even individual cases can have value, especially when contradictory to an established theory or view (Pyett, 2003). It seemed important in this study to ensure that the perspectives of participants recruited from psychiatric liaison were well represented in the themes despite representing a minority of the total sample due to difficulties with recruitment.

In this light, the primary factor in deciding ‘what is a theme’ was based on what was viewed by the researcher to be of significance to the participants in the study. There is an extent to which this is a subjective interpretation by myself as the researcher, however by following the thematic analysis method described above and ensuring that equal attention is given to each participant and stage of analysis, it was intended that the themes developed represent a genuine account of the data. This is also consistent with the idea that the researcher is an active factor in the data collection and analysis.

In reporting, numbers of participants and the recruitment source are included. The reader should bear in mind that the number of participants who spoke about a theme is not necessarily a direct indicator of its importance or validity.

### Scope of analysis

The second decision to be made is whether the themes aim to capture a broad view of the data or are focussed on a specific aspect. Initially the aim of the research was to focus on participants’ experiences of being offered mental health support and their views on that support. However, it quickly became clear that participants were coming to the interviews with stories important to the topic of their engagement with mental health services that fell beyond the scope of this question. It was therefore decided that analysis would aim to capture the themes in the data as a whole.  Additionally, Braun and Clarke (2006) recommend this approach to areas which are under-researched.

### Bottom-up or top-down?

The third decision is on whether the themes will be bottom-up (driven by the content of the data) or top-down (driven by a pre-established theoretical framework). As this is an under-researched area, a bottom-up approach was well suited to allowing themes to be developed from the content of the data provided by participants. It is worth noting that a theoretical position of 'people's experiences of health services will influence their future engagement in health services' was present in the research and research questions and will therefore have influenced the development of the research protocol and analysis.

### Semantic or Latent themes?

The final decision to be made was whether themes would be at a semantic or latent level. A semantic approach to themes is well suited to research that aims to give an account of the experiences of the participants in the research, whereas a latent approach is useful for understanding the underlying beliefs and contexts underlying what participants say (Braun & Clarke, 2019). For this research, a semantic approach was more suited to the research questions and the goal of generating practical ideas to improve service provision.

## Researcher Position

In qualitative research, the researchers are viewed as active participants in the production of data and development of themes (Braun & Clarke, 2006). Viewed in this context, it is likely that the backgrounds and beliefs of researchers will affect how they interview participants, interpret their answers, select topics to follow up on with further questioning, and how they are experienced by the participant. Equally, the interpretation of data and themes that develop will be impacted by the positions of the researchers involved. It is therefore important to acknowledge the positions of the researchers (Caelli et al., 2003). Throughout the research I attempted to maintain awareness of how my own position might be impacting on the process.

I am a 29 year old, white-British man who, at the time of writing, had eight years' experience of working with adults and young people affected by mental health difficulties. I do not have personal experience of using mental health services.  During and prior to clinical psychology training I have worked with both young people and adults who were affected by DSH and suicidal thoughts. This has included people who were discharged, either voluntarily or through non-engagement, from services without receiving any intervention aimed at improving psychological wellbeing in the long-term.

In training I have been particularly interested by systemic and narrative approaches to understanding mental health as well as acceptance and commitment therapy. Systemic ideas about 'relationship to help' (Reder & Fredman, 1996) have informed my clinical work. They describe the interacting beliefs that clients and clinicians bring to a therapeutic relationship, and the importance of understanding those and any potential problems they may cause. Reder and Fredman (1996) describe patients who make a ‘loud cry of distress’ before disengaging from any further support, which resonates with the topic of this research. Whilst this research only hears from a single part of the system, it is my personal belief that as clinicians with the power and opportunity to be flexible and adaptive, we should be considering how our offers of help may be perceived and interpreted by the people we work with.

This thesis was conducted as a joint project. The other trainee conducting the research was involved with developing the study protocol and interview guides, recruitment and interviewing participants and interview transcription. He is a 31-year-old, Israeli-Jewish man with experience working with adults and young people affected by mental health difficulties. He favours a psychodynamic understanding of mental health.

## Results

In this section the participant sample is described, and the themes developed from the data are reported with direct quotes that highlight and illustrate aspects of the theme.

The sample consisted of a total of ten people (see Table 1) who had experience of repeatedly using A&E services for DSH or suicide attempts and had not subsequently engaged in any mental health services. The sample consisted of three participants from psychiatric liaison and seven from the therapy service. Nine participants were female and one male. Participants were assigned pseudonyms as well as a participant identifier (PL referring to participants recruited from psychiatric liaison and TS to those recruited from the therapy service).

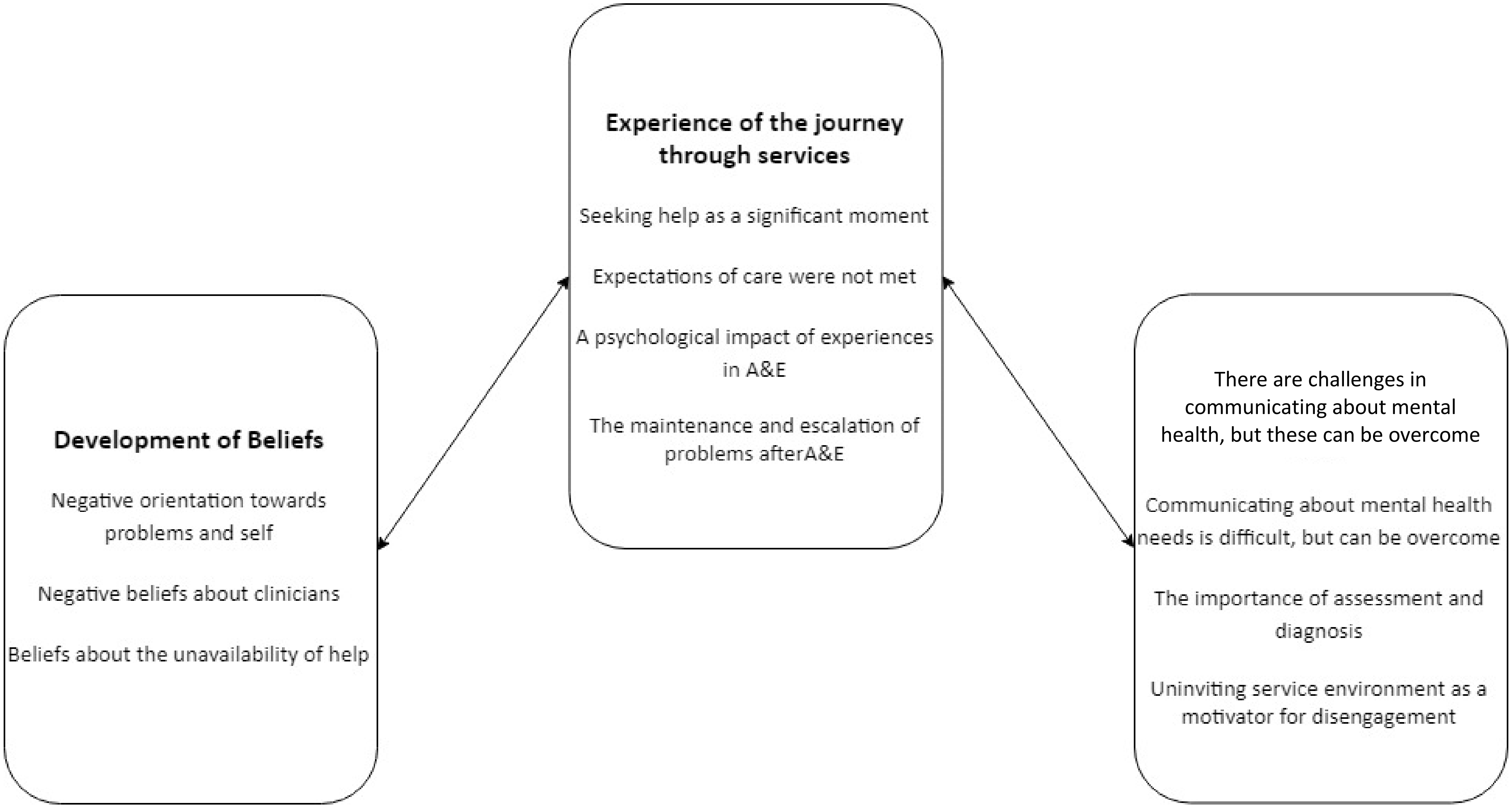
During the analysis, 10 themes were developed, which were categorised into three domains (see Figure 1). When reading, it is important to remember that the themes capture aspects of reality as experienced by the people interviewed for this study. When an event or belief is described, the author is not concerned with objective facts about events, clinicians or services, but rather how the participant experienced reality, something which will be informed by the context of their experiences and beliefs.

*Table 1. Summary of participants*

| Name | Referral Source | Gender |
|---|---|---|
| Angie (PL1) | Psychiatric Liaison | Female |
| Emmanuel (TS1) | Therapy Service | Male |
| Gemma (TS2) | Therapy Service | Female |
| Katie (PL2) | Psychiatric Liaison | Female |
| Louise (TS3) | Therapy Service | Female |
| Miranda (TS4) | Therapy Service | Female |
| Natalie (TS5) | Therapy Service | Female |
| Rachel (TS6) | Therapy Service | Female |
| Sarah (TS7) | Therapy Service | Female |
| Wendy (PL3) | Psychiatric Liaison | Female |

Note. PL – Participant recruited from psychiatric liaison services. TS – Participant recruited from therapy services

*Figure 1. A summary of themes developed from the data*



## Experience of the journey through services

A consistently heard story in the data was of participants seeking help, experiencing varying degrees of dissatisfaction with the treatment they received or the outcomes of visiting A&E, and the aftermath of that. The themes in this section explore significant aspects of that journey.

### Seeking help as a significant moment

All participants spoke about their reasons for seeking help from A&E as being related to either DSH, a suicide attempt or feeling unable to keep themselves safe from one of these. Most participants spoke about this as being in the context of a long history of psychological difficulties.

> *The truth is I've always kind of struggled mentally growing up, even as a kid. But I didn't actually know what it was. So I just kept on going while it was all building up. – Emmanuel (TS1)*

A consistently endorsed idea was one that participants were at a moment where they were *actively* seeking help for the problems that they were experiencing at the time. For this help, they had turned to A&E.

> *I willingly, openly wanted to help myself. – Wendy (PL3)*

> *I just needed help. I needed help because I lost my children to social services. I also went through domestic violence and sexual abuse as well. So I just think I was crying out for help basically. I just needed someone to help me. - Gemma (TS2)*

Some participants spoke about the personal significance of the step that they were taking in seeking help from services.

> *I knew something wasn't right but I just didn't deal with it. This was the day that I'd been brave enough to finally come and sort this problem out. – Sarah (TS7)*

> *I did kind of regret [taking the overdose] and I was like 'oh sh*t I have to do something'. That was such a big thing for me to do … it took so much to actually make a step and go out to seek [help from] people. – Louise (TS3)*

**Expectations of care were not met**

All participants expressed expectations that they had of the care and support that they would receive when using A&E services. The expectations that they spoke about were most commonly to be listened to, respected and treated with caring and kindness.

> *One of the key things I think is consoling and being in touch with how the person's feeling and coming around. – Miranda (TS4)*

> *I don't expect them to do so much but just to listen to me, understand that I might be going through a lot and for 5 minutes or less than that. I think just listening to someone can be so much because, you know, I don't expect them to send referrals left right*

> *and centre, I don't expect them... they've got a lot on their plate... but just to like smile and be friendly. – Louise (TS3)*

Participants described experiences where they did not feel listened to and that undermined their ideas of respect and caring. These included feeling that they were not being taken seriously and that they were being laughed at.

> *Another time I went there and I was sober and I said that I need help and they couldn't help me. I said no look I need to see a psychiatric or something because these are my symptoms. I told them my symptoms, they didn't take me seriously. – Wendy (PL3)*

> *I booked a room in an hotel, and told him 'look, I am following your guidelines and recommendations'. It was an expensive way to keep myself safe. When I told him that, he just laughed at me. – Katie (PL2)*

This perception of inadequate care was reinforced by accounts of mistakes that were made. These included errors on forms, promised referrals that were not followed through on, and medication prescriptions that were misplaced.

> *When I said the yes to low mood, they obviously had to go to the other column and scribbled it all out because they did it wrong and they ticked that I was suicidal and everything, and then I was panicking a bit… and that was just like a little small little mistake, I don't want to criticise, but I just felt like if I didn't say I*

> *wasn't, then they would have put I was suicidal when I didn't want that. – Louise (TS3)*

The importance of these expectations is emphasised by the positivity in the descriptions that some participants gave of times when their expectations were met. Talking about ambulance clinicians, Gemma (TS2) said

> *They were really caring, really reassuring, they'd make sure that they cleaned me up, they'd tell me that I'm not very well and they'd get this dealt with and all that sort of thing. Just reassurance that you're not off your head sort of thing. Yeah. They were just really reassuring and caring. - Gemma (TS2)*

**A Psychological impact of experiences in A&E**

This theme highlights the feelings that participants were left with following their visits to A&E. Nine participants (including all from psychiatric liaison) described some level of emotional reaction towards the services they had used and what they had received. The descriptions of these ranged from disappointment to frustration to devastation.

> *Not positive. Quite the opposite. My last treatment was absolutely devastating. – Katie (PL2)*

> *I just remember being irritated and frustrated that, yeah, they kind of just sent me home like nothing. – Emmanuel (TS1)*

> *I got so angry at the system. – Angie (PL1)*

One participant explained that it was the unmet expectations that caused these feelings.

> *I prepared myself for a situation that will save me, but all they did was get my hopes up. – Angie (PL1)*

Some participants described feeling traumatised by the experiences that they had with A&E services.

> *And then that day I went through all of this. This was all really traumatic for me. It was a big thing for me to go out and admit that. - Sarah (TS7)*

Some participants described feelings associated with specific incidents which were particularly upsetting. One participant described being left untreated for hours.

> *One time I was put in basically, a room, on a mattress on the floor and left there I think for six hours. That was in A&E. That was with no blankets or anything … The other time that I've been there, they left me basically on a bed and left all my cuts open on my legs. So now I've quite deep scarring. They didn't stitch them up or anything so now I suffer with really bad anxiety about my scars. – Gemma (TS2)*

Whilst another describes being upset by a member of staff who she experienced as physically invasive.

> *He stood over me and put his hands on my shoulders. I said to him 'get out of my personal space. I'm asking you nicely please get out my personal space because if you don't I will react inappropriately'... when I tried to go to sessions after that, I was uptight or felt anxious. Having in the back of my mind him barging in again. It is better just to forget about that. – Katie (PL2)*

### The maintenance and escalation of problems after A&E

An experience reported by nine participants (including all from psychiatric liaison) was a maintenance and/or escalation of problems following a visit to A&E. They related this to reduced motivation to seek help as a result of their experiences with A&E services.

> *Unless I was fully on death's door and I really had to, I don't know. Even if I had overdosed I don't feel comfortable going to A&E. – Louise (TS3)*

> *I ended up distancing myself once again because I just felt like, I'm not being helped. I'm not being heard. I'm not being understood. I distanced myself once more. - Emmanuel (TS1)*

Almost all participants spoke about the problems they were experiencing being maintained or worsened as a result of the perceived inadequate care provided to them by services.

> *I kind of got progressively worse. I was trying to find ways to feel relief, if that makes sense. I don't feel like I was supported enough. – Natalie (TS5)*

> *But I have been to A&E beforehand a good few times and it was completely not helped at all and my condition had been prolonged for years because of this which has caused me loads of bad things to happen – Wendy (PL3)*

Despite the reduction in motivation towards help-seeking, we know that all participants did return to A&E services again.

## Development of Beliefs

Participants spoke about beliefs that they had and were developed, in relation to themselves and their problems, the clinicians who they hoped would support them with those problems and about care being something unavailable to them.

### Negative orientation towards problems and self

Nine participants (including two from psychiatric liaison) spoke about a negative perception of themselves and the problems present for them. Some spoke of a feeling of otherness which was related both to their views of mental health as well as their experiences in A&E.

> *I thought I was completely different, and I couldn't explain anything. - Rachel (TS6)*

> *When I have been in A&E it was very much that I was looked at as weird and incapable. Maybe dramatic. – Miranda (TS4)*

> *People thinking that I'm evil when I'm actually suffering, people thinking I'm just choosing to drink. - Wendy (PL3)*

Participants spoke about the reactions that they received from clinicians inviting feelings that the problems they were seeking help for were not significant or deserving of care.

> *In my head when you go to a mental health service, if there's a problem they notice it. Where she was so blasé I was like, I must be fine. There must be nothing. If I had mental health she would be a bit more interested. - Sarah (TS7)*

These were feelings that could be invited simply by being in the A&E environment.

> *In A&E you're seeing other people and you feel incredibly guilty for being there. You're wasting people's time. Why are you here? What are you...the audacity to be here. I'm a liability. – Louise (TS3)*

Almost half of participants compared the treatment of mental health with physical health. This unfavourable comparison could further add to the narrative of mental health difficulties being undeserving of support.

> *I imagine a kind of treatment that is similar to any other physical condition. If someone has heart condition or something like that. Like they treat the "normal people". - Katie (PL2)*

Louise (TS3) explicitly connected ideas expressed by professionals with her difficulties in adapting to the diagnosis she had received and the problems that she experienced.

> *One person saying that they didn't believe that personality disorders exist but because I have got that diagnosis, I feel very uncomfortable with that. That's another thing. I'm doubting it. I'm refusing that and everything. So to get further invalidation from a healthcare professional feeds into that. – Louise (TS3)*

**Negative beliefs about clinicians**

Eight participants (including two from psychiatric liaison) described beliefs they had about clinicians in relation to their skills, personal qualities or both. Clinicians were perceived to be under-skilled and under-trained by some participants.

> *How are you supposed to deal with that if you've not been trained in it? I personally don't think the general nurses, I don't think there's enough of them who are aware of the effects of mental health on people. – Gemma (TS2)*

> *Maybe I'm just assuming and that's just how they're trained to be, like really monotone and not nice, or at least appear not nice. - Louise (TS3)*

Views of A&E clinicians' emotional investment in their work ranged from seeing them as being overworked and therefore lacking the space to connect with patients, to being seen as cold and uncaring.

> *I guess they're stressed and overworked and rushed and not completely in touch with their emotions. I can understand it from both perspectives, but I guess it's still difficult as the patient. – Miranda (TS4)*

> *When I went to that [clinician] in A&E they were there for a pay check. They were there to get their pay and go home. (edited to preserve anonymity) – Sarah (TS7)*

Some participants spoke of views that their experiences were representative of what all services and/or clinicians would be like.

> *I just felt every doctor is going to be the same as them from now on and I'm not doing it. (edited to preserve anonymity) – Sarah (TS7)*

> *This is a typical example of the NHS giving me information but not considering my other needs. And then they wonder why I get frustrated and verbally aggressive. – Katie (PL2)*

### Beliefs about the unavailability of help

Six participants (including all of those from psychiatric liaison), spoke about the idea that getting better, or receiving support was not something that was possible for them.

> *I really thought they are going to save me. And then I understand that I'm not going to be saved and nothing is going to work out for me. I will not be saved. – Angie (PL1)*

Two ideas seemed to inform this view. The first of these was a sense that in order to access care, conformity and playing along with the expectations of the healthcare system is necessary.

> *The ambulance paramedics tell me all the time 'well all we can do is to take you to an A&E'. And when I explain that I don't want to go to A&E, the paramedics say that I am uncooperative. – Katie (PL2)*

> *[They said] 'She either answers it or she doesn't.' It's hard for me to talk about and being a mental health professional you should understand that it's difficult for me to talk about things like that. So they put me in that position of you either answer it or you don't. So I said I don't. (edited to preserve anonymity) – Sarah (TS7)*

The second idea contributing to perception of unavailability of care was an impression developed by some participants that there would be consequences to their involvement in mental health services. These consequences included having police called and being sectioned if they try to use A&E, and losing access to their families if they pursue engagement.

> *Basically what they were trying to say was that it was quite serious and the only option was to put me in a mental hospital, and if they did that I wouldn't get any access to my son. – Natalie (TS5)*

In this situation Natalie (TS5) went home without receiving or engaging in any further support.

## Perceived barriers and facilitators to getting needs met

All participants spoke about factors that can form barriers to, or facilitate, their engagement with services.

### There are challenges in communicating about mental health, but these can be overcome

Eight participants (including all from psychiatric liaison) described difficulties that they had in communicating how they were feeling to other people, including clinicians. Whilst the reasons that participants gave for this were varied, the presence of the phenomenon was consistently described.

> *I don't talk about my feelings openly. Like my deep really how I feel. – Sarah (TS7)*

> *For me because I can be quite eloquent and explain but can never fully iterate what's going on in my head, so what's the point in doing so. – Louise (TS3)*

Reasons that participants gave for this phenomenon included diagnoses of autism spectrum disorder, discomfort with professionals, and a desire to hide their problems or pretend they were not as bad as they were.

> *I would have been like deal with it another day, put the problems under the rug - Sarah (TS7)*

> *I think I didn't want to admit I was as bad as I was in my head. – Rachel (TS6)*

Emmanuel (TS1) wanted to explain how he was feeling but did not have the words or understanding to do so.

> *I literally hadn't known anything about mental health growing up. It wasn't part of my community and my upbringing… It was the first time I went to A&E to say I'm having mental difficulties. I don't know that I expressed that, because I didn't know what the process was, so I just told them that I wasn't sleeping and that I needed help. - Emmanuel (TS1)*

The feeling of difficulty in communicating needs to and speaking with clinicians was something that could be reinforced by experiences that people had with the clinicians they encountered. Louise (TS3) described this process following experiencing a doctor as being invalidating of her experiences.

> *Obvioulsy I shouldn't take one experience and let it paint others. But since then I do not feel compfortable telling people that I'm suicidal in A&E… I guess I must be scared of what they might say, but I guess I'm more scared they won't take me as seriously as how it's affecting me. - Louise (TS3)*

Some participants recruited from the therapy service described how despite finding it difficult to communicate with clinicians, having even a singular experience of talking to someone and feeling comfortable was enough to engage them in services and change their views on being open. In the following quote Sarah (TS7) is describing an assessor who she experienced as helping her feel comfortable to be open.

> *If it wasn't for him I wouldn't have been where I am now. I would have given up on the whole thing… He completely changed my view around on the mental health system. But if it wasn't for him I wouldn't have come and got help. - Sarah (TS7)*

### The importance of assessment and diagnosis

Eight participants (including two from psychiatric liaison) spoke of the importance and complexity of accurate assessment and diagnosis when it comes to providing support to people with mental health difficulties.

> *There's no brain scan [that says] this person has bipolar or this person has schizophrenia. So it’s simply down to one other human being’s idea from research and studies and experience of*

> *what they think you have… The whole thing should be taken seriously. - Wendy (PL3)*

Many participants felt like the assessments they received in A&E and other services they encountered on their pathway were not in depth enough to fully understand them and their problems.

> *There wasn't a doctor there so these two people... I don't know who they were. They done a rough... their words... 'we're going to do a rough mental health assessment'. And I was like 'Really? I don't need rough I need some help'. - Sarah (TS7)*

A number of participants described being given diagnoses that they felt were inaccurate. Angie (PL1) described receiving a diagnosis of avoidant personality disorder.

> *Making you take a personality test and then decide if you're avoidant or you got the other more general one. They got a list and just following it. It turned out they were wrong. – Angie (PL1)*

A number of clients were diagnosed with depression, despite feeling there was more to their presentation than that.

> *They diagnosed me with a circumstantial depression because [redacted for anonymity], that's what made me depressed. I did try to explain that I've had mental issues my whole life… Definitely depression was a part of it, but I explained*

> *different things like maybe PTSD. I wasn't completely aware of all the disorders out there but I knew I had some kind of personality problem and I definitely tried to express that. – Emmanuel (TS1)*

Another participant was given multiple diagnoses but did not feel that these helped her with understanding her experiences and difficulties.

> *I had the diagnosis of borderline personality disorder, anxiety, dysthymic disorder and post-traumatic stress disorder… I didn't really understand the diagnoses that they'd given me. I didn't understand what was actually wrong with me. - Gemma (TS2)*

It is important to note that views on the helpfulness of receiving a diagnosis were not universal throughout the sample. Some participants expressed reservations about being labelled and reflected on the stigma that people with mental health diagnoses can receive from others.

> *I know many people with the same diagnoses being treated exactly the same way. All I get from mental health services is disrespect and I know I'm not the only one. – Katie (PL2)*

One participant reported a smooth process of receiving a diagnosis that they agreed with and did not dispute.

> *I believe I went to my GP and told them I was feeling like depressed and suicidal and things like that. And they gave me an*

> *initial assessment so referred me to having the potential diagnosis of borderline personality disorder. - Miranda (TS4)*

**Uninviting service environment as a motivator for disengagement**

Seven participants (including one from psychiatric liaison) spoke about aspects of the environment and context of A&E as a place which inhibits engagement with services and makes people want to leave. Participants described experiencing A&E as a busy, cold and overwhelming place to be.

> *You get very distracted in A&E because there's too many people. It's big and you don't know where to go. It can feel overwhelming when you already feel a bit stressed. – Natalie (TS5)*

> *It just seemed very brief like they were trying to get rid of me as such so that they could move on to the next case. – Miranda (TS4)*

Participants felt at times that due to the busyness, the priority of the service was to get rid of them, to the detriment of the care that they received.

> *They were quite... I don't want to say dismissive, but they were just... It was just like I was just another person there that they just put me under the umbrella of depression and kept it moving. I didn't feel like I was heard properly or that I was diagnosed thoroughly. I just feel like they were hurrying the process. – Emmanuel (TS1)*

Connected to this, a number of participants described that once they were at A&E they simply wanted to go home, regardless of receiving care.

> *Even if it wasn't the best thing for me to go somewhere I still just would have said no. Just because I wanted to go home and get it over with. – Rachel (TS6)*

Some participants acknowledged the context of what is possible in A&E and the pressures that clinicians are likely to find themselves under, but always in the context of an experience they had which they did not find acceptable.

## Discussion

This study explored the experiences and views of people who make repeated use of A&E services due to DSH or attempted suicide without receiving any further psychological or psychiatric support. The themes developed clustered around the journey people have through A&E and its impact on them, the beliefs that people have and develop that affect the journey, and views on factors that can be barriers or facilitators to the access of support.

### Summary of Results and Links with Previous Research and Theory

In their research on the experiences people using A&E for DSH, Horrocks et al. (2005) reported on themes including difficulties with communication, unmet expectations of care, and negative perceptions of the views of clinicians. In contrast to this study they also reported frequently endorsed themes of positive experiences of support in A&E. An explanation for this could be that the current study focussed specifically on people who did not go on to receive further care after using A&E and the interview was focussed on experiences that contributed to this, whereas Horrocks et al. (2005) were investigating experiences of A&E unconnected from future engagement. It is feasible that the experience of support as overwhelmingly negative could affect the likelihood of going on to receive further support. In a systematic review of views towards services of people who self-harm, common themes found included poor communication, lack of knowledge of staff, and the poor quality of psychosocial assessments (Taylor, Hawton, Fortune, & Kapur, 2009). The themes developed in this study overlapped in many places with the common themes identified in this review.

The perception of many participants of this study that clinicians lack skills, understanding and hold negative attitudes towards people affected by DSH and suicidal thoughts is backed up by research. Rayner et al. (2019) reported that nurses in emergency departments hold negative attitudes and have low empathy towards people who self-harm. Factors associated with negative attitudes include a lack of training and guidelines in managing DSH in the UK, as well as proximity to the front-lines of care (Rees, Rapport, Thomas, John, & Snooks, 2014). Emerson (2010) concluded that additional training and information giving was needed for nurses to combat the stigma against DSH. The cycle of inadequate care and clinician-service user relationships is demonstrated by Krawitz and Batcheler (2006), who reported that clinicians working with people with a diagnosis of BPD are vulnerable to practising in a defensive manner that is not in the best interest of service users, due to a belief that they need to protect themselves from medico-legal repercussions.

The biosocial model of BPD (Linehan, 1993) describes the role of an emotionally invalidating environment in the development and maintenance of DSH as a way of coping. Crowell et al. (2014) reported that a key aspect to the invalidating environment is the rejection of the emotional expressions of the child. A repetition of this dynamic can be seen in the themes reported in this study. Participants reported using A&E as an important moment and cry for help, where they were hoping for and expecting care and support. The efforts and emotions that they were expressing at this time were subsequently invalidated when they received care that was perceived in ways ranging from inadequate to uncaring to hostile.

An aspect that stood out in relation to this, was the experiences participants spoke about of feeling unimportant, not deserving of care, and care being unavailable. Among people who engage in DSH, a common idea is that the problems they are having are not serious enough to warrant care (Czyz et al., 2013; Fortune et al., 2008). This view is associated with having no engagement at all in services (including A&E). It is possible that people who do seek help are vulnerable to the same beliefs, which are then reinforced by experiences they have in A&E.

People with a diagnosis of BPD are vulnerable to a range of cognitive processing biases that lead to them being more likely to hold negative beliefs about themselves and others, attend to negative stimuli, and interpret neutral events in a negative manner (Baer, Peters, Eisenlohr-Moul, Geiger, & Sauer, 2012). As a result of these processing differences, people attending A&E for DSH or attempted suicide may be more likely to form negative memories of their experiences. Once these memories are formed, they will then have disproportionate access to negative memories. This process may be particularly significant when, as discussed previously, people visiting A&E are more likely to encounter a lack of understanding from clinicians, and have decisions made that are not in their best interests.

Ideas from systemic approaches to psychology talk about the relationship to help (Reder & Fredman, 1996) as the interacting beliefs of service users and clinicians about each other, problems and support that impact on help-seeking interactions and therapeutic relationships. The significance of the beliefs and motivations of referrers (who in this context would be A&E services) is emphasised in systemic theories (Palazzoli, Boscolo, Cecchin, & Prata, 1980). Within this model it is understood that beliefs and behaviours of patients, referers, professionals and other aspects of the systems can interact in ways that make them vulnerable to getting stuck in patterns of interaction that are detrimental to engagement with care (Reder, 1986).

The beliefs of service users reported in this study, such as the unavailability of care and the lack of capacity of clinicians to meet their needs, will unavoidably influence any interactions that they have with health services subsequent to the belief development. The ways in which service users respond to these beliefs (for example avoidance of care until crisis as reported in this study) could feasibly contribute to the development of negative attitudes and lack of empathy that clinicians report towards people who self-harm (Rayner et al., 2019), which may in turn impact on the care that they deliver. The interactions of these beliefs and behaviours could understandably lead to vulnerability to getting stuck in patterns of service users receiving support they view as inadequate and not returning to services again until they reach a crisis point, whilst never receiving the further support necessary to break this cycle.

## Limitations of the Research

### Development of the interview and materials

During this study, the interview and information sheets were developed to inform two different projects with related but different research questions. Both projects aimed to directly inform the development of an intervention. Additionally, the study was developed without consultation with EbEs. These features of the development contributed to limitations that are discussed here.

The tightness of the focus of the interview on A&E experiences and perceptions of care was a decision made to try to provide the most useful data possible for the development of the future intervention. This may have limited the possible development of themes relevant to the experiences of people who do not use services, but outside of this scope. For example, the questions did not provide significant opportunity for participants to talk about experiences in their lives outside of mental health services. This may be useful to understanding the ways in which they interact with A&E and mental health services. Including more open questions at that start of the interview may have been a way of supporting participants to talk about different topics.

The researchers were primarily focussed on different research questions. This may have encouraged them to engage with the interview process in different ways, following up on different aspects of what participants said. This could have the impact of making it more difficult to develop themes from an inconsistent data-set. Additionally, it meant the interview schedule was designed to answer both questions, possibly limiting the ability to go in to a high level of depth on either.

Language use, particularly in relation to how people engage with services was inconsistent across the materials and may not have accurately reflected the experiences of people we were talking to. For example 'not accepting support offered', ‘deciding not to use' and ‘prevent people from using' are all used interchangeably but carry different implied assumptions.  The first two examples position not using services as an active choice, whereas the second makes presumptions about something ‘preventing’ engagement. Additionally, a phrase like ‘not accepting support’ may be interpreted as judgemental. This may have impacted on the comfort that potential participants felt towards participating in the study. It may also have closed potential paths of discussion in the interviews, which could have led to different and meaningful themes developing.

By incorporating EbEs in to the development of the study some of these problems could potentially be addressed early in the process. For example, they may have been able to point out language in interview schedules or study documentation that made assumptions that did not fit with their experiences.

### The Sample

In planning the project, it was intended that the majority of participants would be recruited from psychiatric liaison and not currently engaged in any mental health interventions, as they are the people with current experience of the phenomena we were investigating. Difficulties with recruitment resulted in this not being possible, and participants from psychiatric liaison made up only 30% of the sample.  The remaining 70% were individuals who had later gone on to be offered and engage with a local therapy service for people with a diagnosis of personality disorder.

It is possible that there are important differences between people who go on to successfully receive treatment and those who do not. It is not possible to know who those will be, but in a sample recruited from psychiatric liaison you would expect both groups to be reasonably represented. In this study the voices of people who will not go on to receive any treatment, an important demographic for services to learn how to support, are inevitably under-represented.

An issue for consideration in differences between the participants recruited from psychiatric liaison and the therapy service is the impact that receiving treatment might have on how experiences are remembered and reported. Participants who have engaged in therapy will have begun to examine some of the thought and behaviour patterns that they may have been vulnerable to at the time of using A&E. They may find it easier to be reflective on their experiences and things that affected them, however this increased reflectiveness could lead to under-reporting of thoughts and feelings that were present and important at the time of non-engagement with services. It may also have led to genuine shifts in perspectives, with participants reporting their current beliefs, rather than those they held when they were not using therapy.

Another group who are under-represented in the research is men. Out of ten people interviewed only one was male. This is despite men making up approximately one third of people who self-harm and being at significantly higher risk of a successful suicide attempt (McManus et al., 2014).

Generalisability is not a primary concern of qualitative research (Leung, 2015), however it useful to think about which voices were over and underrepresented in order to contextualise what clinical services may be able to learn from the research. Due to the lack of contextual information about the participants in the study (for example age, ethnicity, cultural background) it is not difficult to think about both how these factors might affect interpretation of the results and also to reflect on how are the themes and conclusions might help to understand service users not associated with the study.

It is also worth noting that all participants were English speaking and recruited from a single NSH trust. It is therefore important to interpret the themes in the context of the study being inevitably affected by local cultural factors and issues that may be specific to local services.

As with development of the interview schedule, consulting with EbEs in the development of the recruitment strategy may have made it possible to anticipate and think about how to overcome some of the barriers experienced in recruitment in a way that would fit best with the population we were aiming to speak to.

### Position of the Researcher and Social Desirability

A potential barrier to participants feeling comfortable to disclose some stories may have been the close association between the researchers and the services that they were being asked to speak about in the interviews. Social desirability is something that is thought about extensively in quantitative research, and efforts are made to control for it in many studies (Van de Mortel, 2008). Social desirability controls are, however, inconsistent with the methodology of qualitative research therefore are not used. Despite this Collins et al. (2005) reported very few indications of attempts to give socially desirable responses across over 300 pages of qualitative interview transcripts. Some of the transcripts covered in this study were related to perceptions of nursing care, and therefore may give information relevant to the present study. It is notable that participants did at times caveat answers by saying that they did not want to be critical, or by acknowledging the challenges that clinicians face. It is not possible to know to what extent social desirability or my position as a clinician affected participants' disclosure of information.

## Implications for Future Research

As previously reported, the themes developed in this study are similar to those in studies not specifically recruiting people who have not engaged with services, with a difference noted in a lack of reported positive experiences in A&E. It would be of interest for future research to investigate whether there are any experiences, beliefs or interpretations that differentiate people who use services from those who do not. This research may be more suited to a quantitative methodology, in which a group of people who have engaged with services are compared with a group who have not. This may be beneficial in making it possible to identify people at higher risk of non-engagement after using A&E, and therefore being able to find different ways to support them to reduce the risk of problems worsening or being maintained after or as a result of an A&E visit.

An area that was not addressed by this thesis is social contexts and wider narratives which interact with the beliefs described and experiences interpreted by the participants. This research was intended to generate ideas that services could respond to in a practical way, however qualitative research is well suited to examining the underlying social constructions that inform participants' experiences (Braun & Clarke, 2019).

In line with reported themes that seeking help is a significant moment and opportunity, research could be conducted on how services can best use these moments to develop a positive relationship with the service user. This could have the benefit of demonstrating to service users that their needs are being responded to, as well beginning to equip them with the skills to regulate their emotions in less harmful ways in the future.

Finally, this study focussed on people's experiences of a single clinical pathway through A&E. Similar research expanded to other pathways such as crisis teams or GP surgeries may help to provide further understanding of the phenomenon being investigated.

## Implications for Clinical Practice

The themes that were generated from this study e a pathway through services that was being influenced by beliefs that participants held about themselves, clinicians and services as well as some barriers and facilitators to accessing care.

The significance of the moment of seeking help in A&E, and the potential for belief formation and reinforcement at this time is information that could be of use to services. Adapting service structures and supporting staff to provide helpful and positive experiences to service users at these times may be able to help make the most of these moments. Some areas to focus on may be those discussed in the 'perceived barriers and facilitators to getting needs met' theme category.

Beliefs about the self are not something that can be directly addressed by A&E services, however clinicians could consider the expectations and vulnerabilities that service users may have towards having their feelings invalidated. It may therefore be of benefit if A&E clinicians are supported to provide service users with an experience that is validating of the emotional experiences that they are having, and respectful of the importance of the moment of asking for help. Addressing the attitudes and lack of knowledge and understanding that clinicians have of the problems discussed (Rees et al., 2014) is an important factor in enabling clinicians to take a more empathic and validating stance towards service users. If clinicians can be made aware of how situations and interactions may be interpreted, then they have the opportunity to adapt their practice

It is also worth considering how services can use knowledge that some service users hold beliefs that they are not deserving of support or that support is not available to them. These beliefs could interact with the current political environment where people will hear many messages about the unavailability of services and pressures on A&E. Having materials readily available that clearly inform people of what help they could access, as well as staff who are well informed could go some way to alleviating this challenge.

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# Part 3. Critical Appraisal

The critical appraisal explores two areas which I found particularly challenging and learnt from in the process of doing this research. The first was issues related to the successful planning and execution of a piece of research, and explores some areas that presented challenges in the project written about in part two of this thesis. The second part discusses the importance of reflexivity, and the role of myself as an active part of the research. I explore a number of issues and decisions that I learnt from.

## Challenges in Conducting the Research

In conducting this research I have learnt a significant amount about the process of planning a piece of research, the NHS ethics process, and recruiting. A key learning for me was in considering what is feasible and realistic for a piece of research that is limited by a deadline and resources (both financial and time). At the outset of the project, the plan was to pilot a Dialectical Behaviour Therapy (DBT; Linehan, 1993) based intervention that the target sample of the study may have been able to benefit from directly following a visit to A&E. Part of the process of implementing this was to be a small-scale qualitative project to investigate what barriers potential service users  had experienced in the past, and what would make a potential intervention most helpful to them.

At the stage of developing the project for application to the Joint Research Office (JRO) and for ethics application it became clear that the pilot group part of the project would not be feasible to do within the time and resource scale of a DClinPsy thesis. From this point onwards the ethics application proceeded for the qualitative aspect of the project only. The results were still intended to inform a developing intervention option for people coming though A&E, but this would no longer be a part of the thesis project. Delays in the JRO and ethics process resulted in final ethical approval being granted in late December 2018. Due to the Christmas period delaying getting site access, we did not begin recruitment until mid-January.

Something that I considered late in the process of doing the research was the idea of whether research questions that we were asking necessitated an NHS sample and therefore an NHS ethics application. Whilst there is no definitive answer to this question it made me consider some of the pros and cons of each option more closely. In recruiting from the NHS we gave ourselves the best opportunity to speak to people who would be likely to be impacted by any learning generated by the study. It also meant we could be very confident that the people we were speaking to had the experiences we were seeking to hear about. It was also my experience that the participants we spoke to were very open and engaged, with a lot to say about the topics we were discussing. Using a non-NHS sample would have probably allowed recruitment to begin earlier, and also come from a potentially wider base of people (e.g. online communities) and therefore hear from more people, however the people we spoke to might have had less direct experience of the phenomena we were investigating, and it may not have generated as rich data.

Despite spending all available study days in psychiatric liaison attempting to recruit participants, this process was slow. It took a significant amount of time to recruit enough  participants for the study. There were a number of factors that contributed to the difficulties we had with recruitment. The first of these was engaging potential participants whom we met, in particular through psychiatric liaison. As the study was targeting people who had not wanted to engage in services, this was something we had foreseen happening, however I was surprised by the extent to which we had difficulties recruiting. Due to the participants' vulnerability at the point when we would be meeting them (during a visit to A&E), we felt it was important to give them a week to consider their participation in the study, however in this time the majority of participants were lost to follow up from initial consent to contact.

Shaghaghi et al. (2011) discuss reasons why some populations may be 'hard to reach' including stigma and not wanting to be contacted. The themes that are discussed in the empirical paper demonstrate that the people we were trying to speak to had significant negative experiences of services, which could lead to feelings of stigmatisation. Despite presenting ourselves as students doing research, due to the referral process we were associated with the same services they had negative experiences with. It is understandable that potential participants may not wish to speak to people who they associate with services where they have had negative and stigmatising experiences. Not being associated with clinical services could be another potential benefit of a recruitment strategy that did not involve working through the NHS.

It may have been beneficial at the point of research development to involve service users, particularly when thinking about the recruitment process, information sheets and consent forms (McLaughlin, 2006). Service users may have generated ideas or provided feedback about how to make the study more appealing and/or accessible to the people we wanted to speak to and therefore made recruitment easier.

Another difficulty we encountered was engaging the psychiatric liaison service in recruitment. The experience in this study was that if we were not present in psychiatric liaison, recruitment did not happen. Since the amount of time we were able to spend in the service was limited, we were only able to speak with a small proportion of potential participants who came into contact with the service. We attempted to make the process as quick and unobtrusive to clinicians as possible, however there was unavoidably some burden in holding the study in mind, making time and space to ask patients if they would be interested, collecting the contact details and passing on the information. A less rigorous process could have been feasible, but would have necessitated compromise in the checks that participants were giving informed consent to be contacted by us.

At the time that we were doing the research the psychiatric liaison team were experiencing difficulties with low staffing levels, and increased expectations from commissioners of what they would be providing. It is therefore understandable that our research, which did not provide an immediate and obvious benefit to the team or their clients, was not a top priority of clinicians experiencing considerable other pressures. Another consideration is that the team were involved from an earlier stage, when the research was intended to provide an intervention to their clients. There was a sense of disappointment from members of the team when the decision was made that the intervention would no longer be provided as part of the research, but would instead be arranged at a later date.

Hewison et al. (2012) talk about co-production with practitioners in healthcare research, and the benefits when it comes to ‘buy-in’. At the early stages of the research we did attempt to work with the team to develop the project in a way that would be most supportive and practical to them, however the benefits of this may have been lost when the focus of the project shifted. Additionally, our engagement with the team focussed mainly on the management-level members of the team. It may have been beneficial to focus more on working with the clinicians doing front-line work who we would be relying on to aide us in recruitment.

A particular learning from this process of change and adaptation was the importance of being flexible in my own expectations. I was disappointed when it became clear that the intervention would not be feasible to include in the project, leading to a ‘smaller’ project than was initially planned. Now at the end of the process, I appreciate having had the opportunity to  learn about and conduct a qualitative piece of research in a more in-depth way than would otherwise have been the case.

## The Process of Qualitative Research

### Learning from conducting the analysis

In conducting the analysis there were a number of challenges encountered that in future I would consider in advance and plan for. The first of these was in transcribing. Some of the transcripts were transcribed by myself and some by the other researcher on the project. There were differences in our transcription styles that could inadvertently impact on how coding and themes develop. In future I would plan in advance on specific factors related to transcription, for example in transcribing of pause fillers (e.g. ‘umm’ and ‘err’) and discourse particles (e.g. ‘obviously’ and ‘like’).

A second area of learning was in effective coding. After initial coding of all transcripts I had over 700 codes. There was significant overlap between some codes, and some codes operated on a different level of analysis (for example, summary of what was said vs beginning to interpret the content). As a result an extensive process of recoding was required. Whilst Braun and Clarke (2006) emphasise that recoding is a normal part of the process of thematic analysis, there were clear areas where I could have coded more consistently and more concisely throughout. A possible solution may have been to review the codes and their organisation after coding each transcript, minimising the overlap and consistently refamiliarising myself with the codes that were already being used. This does, however, potentially inhibit the idea of giving equal attention to all the data.

Difficulties with the coding process were further felt when I was sorting the codes in to themes. I was surprised when ideas that I had been confident would develop in to themes were not proving possible to assemble. At this point I went back to the codes, and found that in recoding I had consolidated too much and created codes that were not coherent, and contained quotes expressing quite different ideas. In separating these into different codes I was able to better assemble themes that were well grounded in the data.

Another realisation was that some of my ideas about what themes would develop were based on particularly memorable stories that participants had told in the interviews. I was then attempting to develop themes around these stories, rather than being guided by patterns across the data as a whole. An example is a participant telling a story of being told she would lose access to her child if she engaged in mental health services. I had been struck by this story and become quite focussed on it, with an idea for a theme about experiencing threats from clinicians. This theme was not well grounded in the rest of the data, however aspects of this story and how the participant interpreted the experiences contributed to and illustrated multiple other themes.

## Journey of Reflexivity

Reflexivity in qualitative research refers to the process of the researcher seeking to understand and acknowledge how they have shaped and been shaped by the research process (Palaganas, Sanchez, Molintas, & Caricativo, 2017). Jootun et al. (2009) discuss how it is difficult not to influence and be influenced by the research that you are conducting. Due to this, an ongoing process of reflexivity is a key aspect to rigorous qualitative research. Through being explicit and open about the position of the researcher, a reduction of bias in understanding can hopefully be achieved. Presented here is an account the journey of reflexivity that I went on whilst conducting this project, in particular how my role as a trainee attempting to write a thesis impacted on me.

I am a 29 year old, white-British man without personal experience of using mental health services. I have eight years experience working with both young people and adults who were affected by DSH and suicidal thoughts. This has included people who were discharged, either voluntarily or through non-engagement, from services without receiving any intervention aimed at improving psychological wellbeing in the long-term.

Prior to this research the idea of the researcher as an active participant in the production and analysis of the data was something that I was aware of but had little experience of first hand. My (limited) prior research experience was mostly in quantitative research, and the position of the researcher was not something considered or questioned. It was therefore an adjustment for me to get used to seeing myself not as a passive observer of reality, but as an active ingredient in how reality would be interpreted by this study.

An area where I particularly felt my position as a co-creator of the data in the study was when conducting interviews with participants. Rapley (2001) writes about the process of interviewing as a complex interactional process between the interviewer and interviewee, in which the types of responses that an interviewer gives can have a profound impact on what an interviewee says. I had the interview guide, but the specific decisions of how and when to follow-up on something that seemed important were down to my own judgement. This was particularly the case when the stories that participants were telling differed significantly from what I had expected or prepared for. Initially these decisions were based on a combination on my own judgement of what appeared significant to the interviewee as well as ideas we had prior to starting the research of what themes might emerge.

I noticed that participants would often experience questions differently to how they had been intended. I thought about the journey that a question goes on – from being a topic I as the researcher am curious about, to being formulated as a question in the interview guide, to being asked by me, to being heard and interpreted by the interviewee. The first question of the interview guide was 'Please could you tell me about your experience of being offered support from mental health services during or following a visit to A&E.' This question contained an assumption by me that participants *had* been offered support. What was clear during the interviews was that in many cases they had not been. Most participants treated this question as an invitation to speak about adverse experiences they had with A&E services. In this situation my own beliefs about how services should run had affected the development of the questionnaire in a way that had led to a question that was a poor fit for the experiences of the people I was talking to.

Something that was noticeable to me early on was how I was being perceived by the participants of the research. I was aware that I was a person who, from their perspective, would be closely associated with the services that they were being asked to talk about in the interviews. I noticed a number of times participants would caveat an answer in some way – saying something like 'I'm not trying to criticise'. I wondered to what extent my position was affecting the things they were willing to say. I noticed myself beginning to 'reassure' participants more, reminding them more prior to interviews that it was a space where they could share anything they wanted.

Additionally, I noticed that when participants told stories of difficult experiences, and especially if they became emotional telling them, I would easily slip in to a more 'clinical' position. This is not necessarily a problem, but is not a 'neutral' researcher position. A potentially more problematic example is when participants said something like ‘that shouldn’t have happened’ I would frequently find myself mentally agreeing with them, and sometimes I would express this.

As the interviews continued, despite not moving past the coding stage of analysis, I began to notice patterns and ideas that were consistently coming up in interviews and imagined that these would be likely to form the basis of my themes. During later interviews I noticed an impulse to try to shape the interview in a way that might create data that would add additional endorsements to themes that were forming in my mind, and frustration when they did not. Transcribing interviews as soon as possible after conducting them, and reflecting on how they had gone, was a useful tool to maintain awareness of this and limit its impact on my interviewing. I was able to notice topics that I could have followed up on but did not, or times when I had been too leading in the discussion.

Braun and Clarke (2019) write that reporting numbers of participants ‘reflects an anxiety about the validity of qualitative research practice, to some extent suggesting that somehow our analysis might not be real’. I realised that this was an anxiety that was present for me. It was at this point that I decided to not report numbers of participants endorsing themes and found this to be liberating (note. this decision was later changed following viva feedback, however analysis was conducted from the described perspective). I was then able to focus more easily on what seemed significant within each individual interview.

With this approach, an increased burden of trust is placed upon the reader to believe that the researcher has rigorously analysed the data, following the stated method and not taken an anecdote-led approach. In writing up this project I attempted to demonstrate this by ensuring that quotes were selected in such a way that the voices of all participants were heard at points throughout the themes. This approach was also informed by a belief I hold about the equal value of each person's viewpoint. Despite this it was unavoidable that some participants, who had more to say, featured more heavily in the quotes than others.

It was through this process that I came to understand the importance of reflexivity, and informing the reader of the researcher's position and beliefs. My experiences will have affected the sort of follow-up questions that I initially asked, which will have shaped the initial ideas for themes that I developed. This in turn will have affected how the narrative of each theme developed and therefore what the reader takes away from the research.

As the research and analysis continued I felt an increasing sense of responsibility towards the participants' stories and voices, and to interpret and represent them in a way that would feel truthful. This was something that I grappled with particularly when writing up the theme 'Negative Beliefs About Clinicians'.

The quotes that I felt were important to be included in this theme were highly critical of clinicians, and sometimes in a very personal way. As a clinician myself, having first hand experience of the pressures that services experience, and seeing the impact that a stressful working environment can have on people, there was a part of me that felt a sense of guilt. It was helpful at this point to remind myself of the epistemological position that I was taking, not reporting on 'reality' but reporting participants' experience and interpretation of reality. I felt that it was also important to remind the reader of this, which motivated me to include the line ‘it is important to remember that the themes capture aspects of reality *as experienced* by the people interviewed for this study. When an event or belief is described, the author is not concerned with objective facts of what happened, but rather how the participant experienced it, something which will be informed by the context of their experiences and beliefs.’

### Conclusion

From the process of conducting the empirical study part of the thesis I have learnt a significant amount about the process of planning and conducting research, in particular in the NHS, and also about qualitative analysis and my position as the researcher. In future I will be able to use these experiences and knowledge to guide my approach to research and anticipate barriers.

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# Appendices

## Appendix A – Search Terms

Psychinfo

1. exp Self-Injurious Behavior/ or exp Attempted Suicide/ or exp Suicide/ or exp Suicidal Ideation/

2. exp Borderline Personality Disorder/

3. exp Dialectical Behavior Therapy/

4. ("self harm*" or "self inj* beh*" or "borderline personality disorder" or BPD or suicid* or "suicid* idea*" or DSH).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

5. (dialectical behavior therapy or "dialectic$ therap$" or "dialectic$ behavi$ therap$").mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

6. 1 or 2 or 4

7. 3 or 5

8. 6 and 7

Medline

1. Self-Injurious Behavior/

2. Borderline Personality Disorder/

3. Suicide/ or SUICIDAL IDEATION/ or Suicide, Attempted/

4. 1 or 2 or 3

5. DBT.mp.

6. dialectical behavior therapy.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

7. "dialectic$ therap$".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

8. "dialectic$ behavi$ therap$".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

9. 5 or 6 or 7 or 8

10. 4 and 9

11. "self harm*".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

12. "self inj* beh*".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word,

protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

13. "borderline personality disorder".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

14. BPD.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

15. suicid*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

16. "suicid* idea*".mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

17. DSH.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

18. 11 or 12 or 13 or 14 or 15 or 16 or 17

19. 4 or 18

20. 9 and 19

Embase

1. suicidal behavior/ or suicide/ or automutilation/ or suicide attempt/ or suicidal ideation/

2. borderline state/

3. ("self harm*" or "self inj* beh*" or "borderline personality disorder" or BPD or suicid* or "suicid* idea*" or DSH).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]

4. 1 or 2 or 3

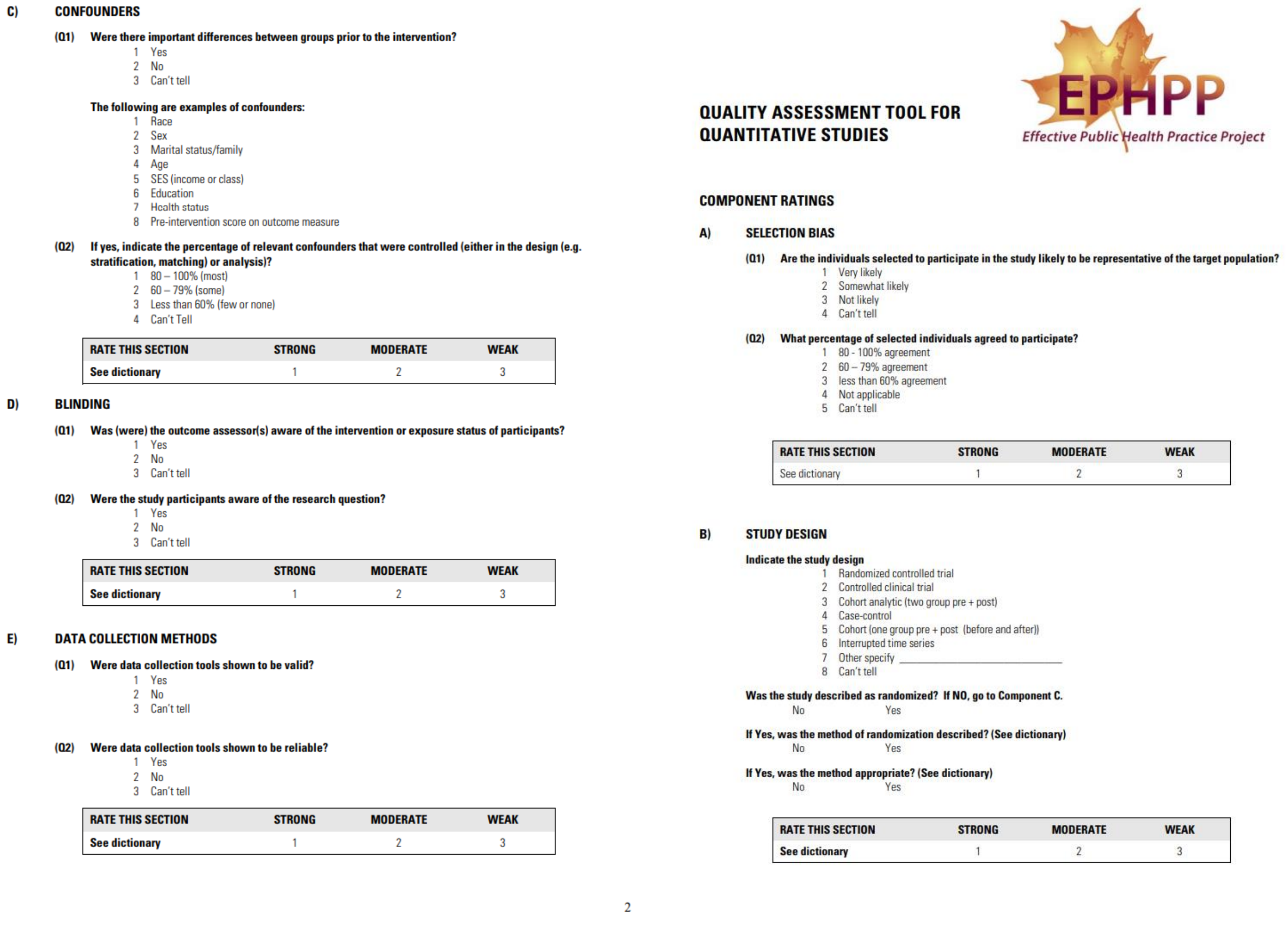
5. (dialectical behavior therapy or "dialectic$ therap$" or "dialectic$ behavi$ therap$").mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]

6. DBT.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]

7. 5 or 6

8. 4 and 7

# Appendix B – The Effective Public Health Practice Project Quality Criteria



## QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES

EPHPP
*Effective Public Health Practice Project*

### COMPONENT RATINGS

**A) SELECTION BIAS**

**(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?**
1 Very likely
2 Somewhat likely
3 Not likely
4 Can't tell

**(Q2) What percentage of selected individuals agreed to participate?**
1 80 - 100% agreement
2 60 – 79% agreement
3 less than 60% agreement
4 Not applicable
5 Can't tell

| RATE THIS SECTION | STRONG | MODERATE | WEAK |
|---|---|---|---|
| See dictionary | 1 | 2 | 3 |

**B) STUDY DESIGN**

**Indicate the study design**
1 Randomized controlled trial
2 Controlled clinical trial
3 Cohort analytic (two group pre + post)
4 Case-control
5 Cohort (one group pre + post (before and after))
6 Interrupted time series
7 Other specify ____________________
8 Can't tell

**Was the study described as randomized? If NO, go to Component C.**
No Yes

**If Yes, was the method of randomization described? (See dictionary)**
No Yes

**If Yes, was the method appropriate? (See dictionary)**
No Yes

| RATE THIS SECTION | STRONG | MODERATE | WEAK |
|---|---|---|---|
| **See dictionary** | 1 | 2 | 3 |

**C) CONFOUNDERS**

**(Q1) Were there important differences between groups prior to the intervention?**
1 Yes
2 No
3 Can't tell

**The following are examples of confounders:**
1 Race
2 Sex
3 Marital status/family
4 Age
5 SES (income or class)
6 Education
7 Health status
8 Pre-intervention score on outcome measure

**(Q2) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?**
1 80 – 100% (most)
2 60 – 79% (some)
3 Less than 60% (few or none)
4 Can't Tell

| RATE THIS SECTION | STRONG | MODERATE | WEAK |
|---|---|---|---|
| **See dictionary** | 1 | 2 | 3 |

**D) BLINDING**

**(Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?**
1 Yes
2 No
3 Can't tell

**(Q2) Were the study participants aware of the research question?**
1 Yes
2 No
3 Can't tell

| RATE THIS SECTION | STRONG | MODERATE | WEAK |
|---|---|---|---|
| **See dictionary** | 1 | 2 | 3 |

**E) DATA COLLECTION METHODS**

**(Q1) Were data collection tools shown to be valid?**
1 Yes
2 No
3 Can't tell

**(Q2) Were data collection tools shown to be reliable?**
1 Yes
2 No
3 Can't tell

| RATE THIS SECTION | STRONG | MODERATE | WEAK |
|---|---|---|---|
| **See dictionary** | 1 | 2 | 3 |

## GLOBAL RATING

### COMPONENT RATINGS

Please transcribe the information from the gray boxes on pages 1-4 onto this page. See dictionary on how to rate this section.

| | | | | | |
|---|---|---|---|---|---|
| **A** | **SELECTION BIAS** | **STRONG** | **MODERATE** | **WEAK** | |
| | | 1 | 2 | 3 | |
| **B** | **STUDY DESIGN** | **STRONG** | **MODERATE** | **WEAK** | |
| | | 1 | 2 | 3 | |
| **C** | **CONFOUNDERS** | **STRONG** | **MODERATE** | **WEAK** | |
| | | 1 | 2 | 3 | |
| **D** | **BLINDING** | **STRONG** | **MODERATE** | **WEAK** | |
| | | 1 | 2 | 3 | |
| **E** | **DATA COLLECTION METHOD** | **STRONG** | **MODERATE** | **WEAK** | |
| | | 1 | 2 | 3 | |
| **F** | **WITHDRAWALS AND DROPOUTS** | **STRONG** | **MODERATE** | **WEAK** | |
| | | 1 | 2 | 3 | Not Applicable |

**GLOBAL RATING FOR THIS PAPER (circle one):**

| | | |
|---|---|---|
| 1 | STRONG | (no WEAK ratings) |
| 2 | MODERATE | (one WEAK rating) |
| 3 | WEAK | (two or more WEAK ratings) |

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

No Yes

If yes, indicate the reason for the discrepancy

1 Oversight
2 Differences in interpretation of criteria
3 Differences in interpretation of study

**Final decision of both reviewers (circle one):**

**1 STRONG**
**2 MODERATE**
**3 WEAK**

### F) WITHDRAWALS AND DROP-OUTS

**(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?**
1 Yes
2 No
3 Can't tell
4 Not Applicable (i.e. one time surveys or interviews)

**(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).**
1 80 -100%
2 60 - 79%
3 less than 60%
4 Can't tell
5 Not Applicable (i.e. Retrospective case-control)

| | | | | |
|---|---|---|---|---|
| **RATE THIS SECTION** | **STRONG** | **MODERATE** | **WEAK** | |
| **See dictionary** | 1 | 2 | 3 | Not Applicable |

### G) INTERVENTION INTEGRITY

**(Q1) What percentage of participants received the allocated intervention or exposure of interest?**
1 80 -100%
2 60 - 79%
3 less than 60%
4 Can't tell

**(Q2) Was the consistency of the intervention measured?**
1 Yes
2 No
3 Can't tell

**(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?**
4 Yes
5 No
6 Can't tell

### H) ANALYSES

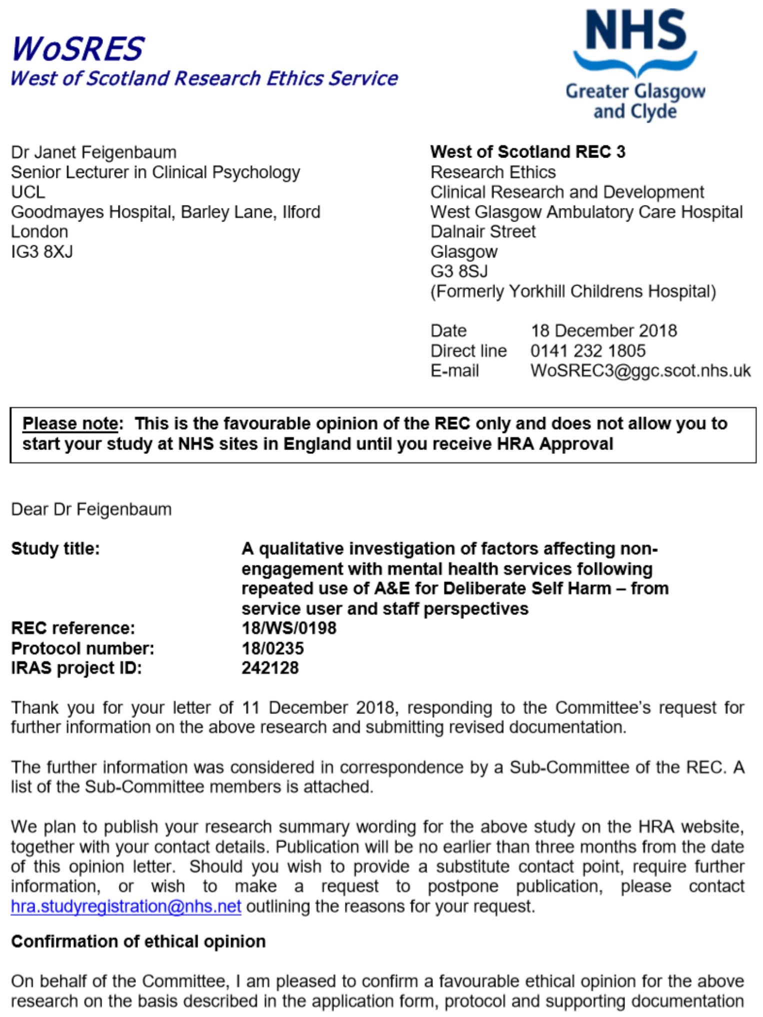
**(Q1) Indicate the unit of allocation (circle one)**
community organization/institution practice/office individual

**(Q2) Indicate the unit of analysis (circle one)**
community organization/institution practice/office individual

**(Q3) Are the statistical methods appropriate for the study design?**
1 Yes
2 No
3 Can't tell

**(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?**
1 Yes
2 No
3 Can't tell

# Appendix C – Ethics Approval



**WoSRES**
*West of Scotland Research Ethics Service*

NHS
Greater Glasgow and Clyde

Dr Janet Feigenbaum
Senior Lecturer in Clinical Psychology
UCL
Goodmayes Hospital, Barley Lane, Ilford
London
IG3 8XJ

**West of Scotland REC 3**
Research Ethics
Clinical Research and Development
West Glasgow Ambulatory Care Hospital
Dalnair Street
Glasgow
G3 8SJ
(Formerly Yorkhill Childrens Hospital)

Date 18 December 2018
Direct line 0141 232 1805
E-mail WoSREC3@ggc.scot.nhs.uk

**Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval**

Dear Dr Feigenbaum

| | |
|---|---|
| **Study title:** | **A qualitative investigation of factors affecting non-engagement with mental health services following repeated use of A&E for Deliberate Self Harm – from service user and staff perspectives** |
| **REC reference:** | **18/WS/0198** |
| **Protocol number:** | **18/0235** |
| **IRAS project ID:** | **242128** |

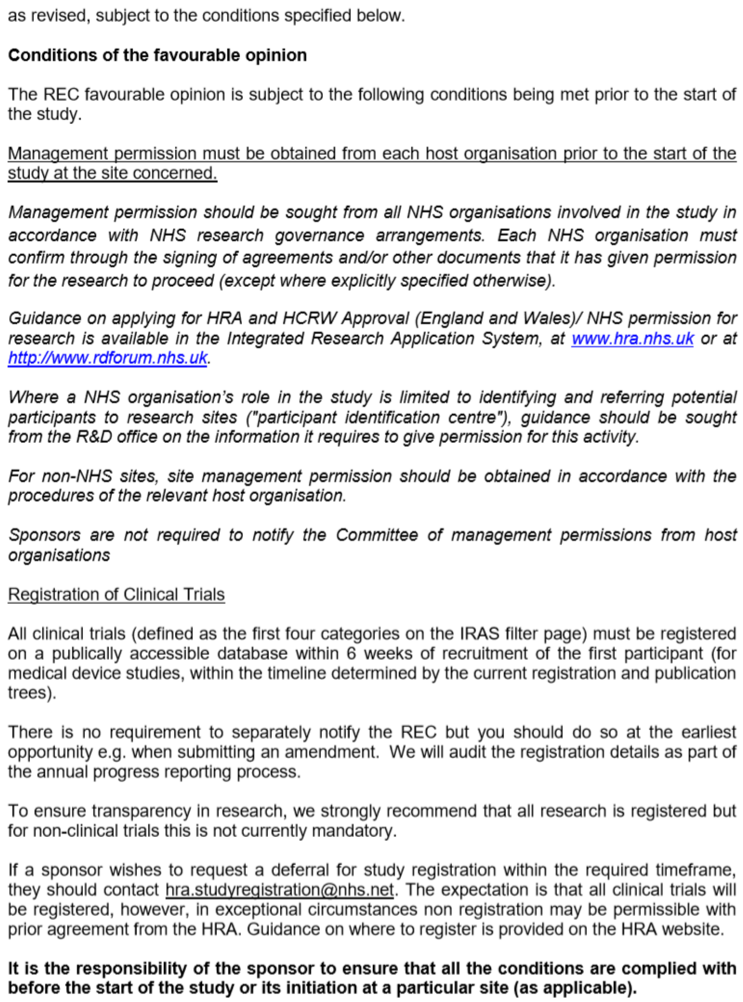
Thank you for your letter of 11 December 2018, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

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 hra.studyregistration@nhs.net outlining the reasons for your request.

**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).*

*Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at 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 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 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).**

**Ethical review of research sites**

NHS 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" above).

**Approved documents**

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

| *Document* | *Version* | *Date* |
|---|---|---|
| Copies of advertisement materials for research participants | 1.2 | 10 December 2018 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Letter] | | 25 July 2018 |
| Interview schedules or topic guides for participants [Interview Schedule - Staff] | 1.2 | 10 December 2018 |
| Interview schedules or topic guides for participants [Interview Schedule - Service User] | 1.2 | 10 December 2018 |
| IRAS Application Form [IRAS_Form_11102018] | | 11 October 2018 |
| Letter from funder [Expenses Confirmation] | | 20 August 2018 |
| Letters of invitation to participant [Contact Details Form] | 1.3 | 10 December 2018 |
| Participant consent form [Consent Form - Service User] | 1.2 | 10 December 2018 |
| Participant consent form [Consent Form - Staff] | 1.2 | 10 December 2018 |
| Participant information sheet (PIS) [PIS - Service User] | 1.3 | 10 December 2018 |
| Participant information sheet (PIS) [PIS - Staff] | 1.4 | 10 December 2018 |
| Research protocol or project proposal [Protocol] | 1.3 | 10 December 2018 |
| Response to Request for Further Information [Response to REC amendments (no date or version)] | | |
| Response to Request for Further Information [Response to REC amendments (no date or version)] | | |
| Summary CV for Chief Investigator (CI) [CV for CI/Academic Supervisor - Dr Feigenbaum] | | |
| Summary CV for student [CV - Itamar Cohen] | | |
| Summary CV for student [CV - Daniel Harris] | | |

**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/

| **18/WS/0198** | **Please quote this number on all correspondence** |
|---|---|

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

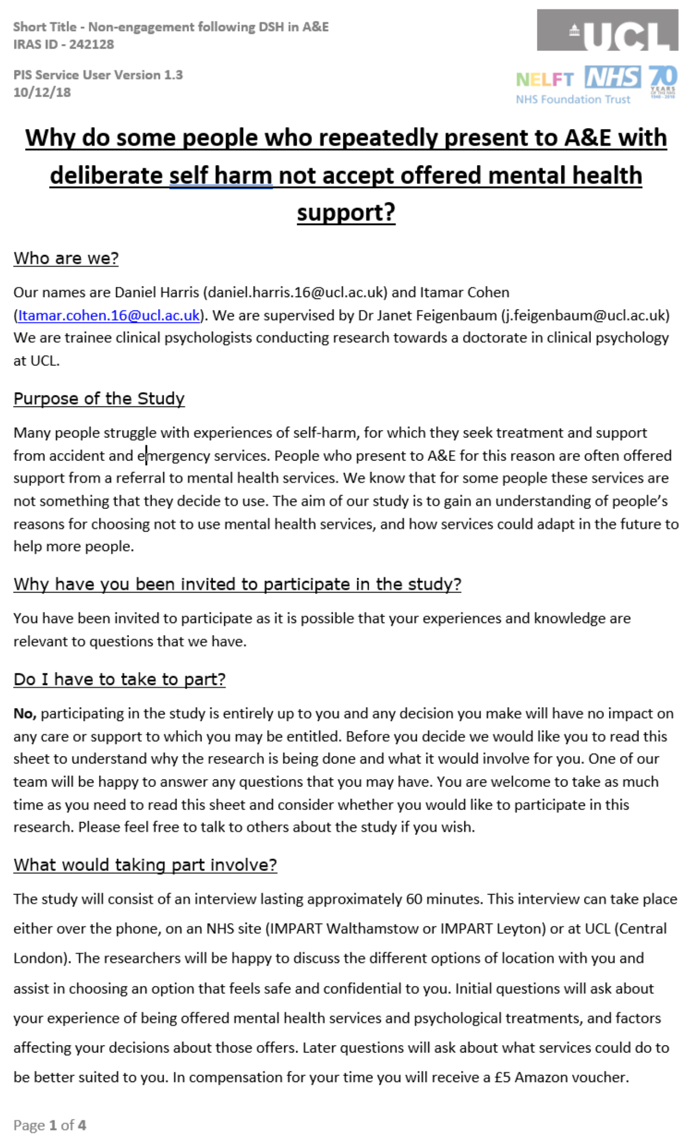
Yours sincerely

[redacted]

*On behalf of*
**Mrs Rosie Rutherford**
**Chair**

| | |
|---|---|
| *Enclosures:* | *List of names and professions of members who were present at the meeting and those who submitted written comments*<br>"After ethical review – guidance for researchers" |
| *Copy to:* | *Mrs Jessica Broni-Tabi*<br>*Ms Fiona Horton, North East London Foundation Trust (NELFT)*<br>HRA.Approval@nhs.net |

# Appendix D – Participant Information Sheet



## Why do some people who repeatedly present to A&E with deliberate self harm not accept offered mental health support?

### Who are we?

Our names are Daniel Harris (daniel.harris.16@ucl.ac.uk) and Itamar Cohen (Itamar.cohen.16@ucl.ac.uk). We are supervised by Dr Janet Feigenbaum (j.feigenbaum@ucl.ac.uk) We are trainee clinical psychologists conducting research towards a doctorate in clinical psychology at UCL.

### Purpose of the Study

Many people struggle with experiences of self-harm, for which they seek treatment and support from accident and emergency services. People who present to A&E for this reason are often offered support from a referral to mental health services. We know that for some people these services are not something that they decide to use. The aim of our study is to gain an understanding of people's reasons for choosing not to use mental health services, and how services could adapt in the future to help more people.

### Why have you been invited to participate in the study?

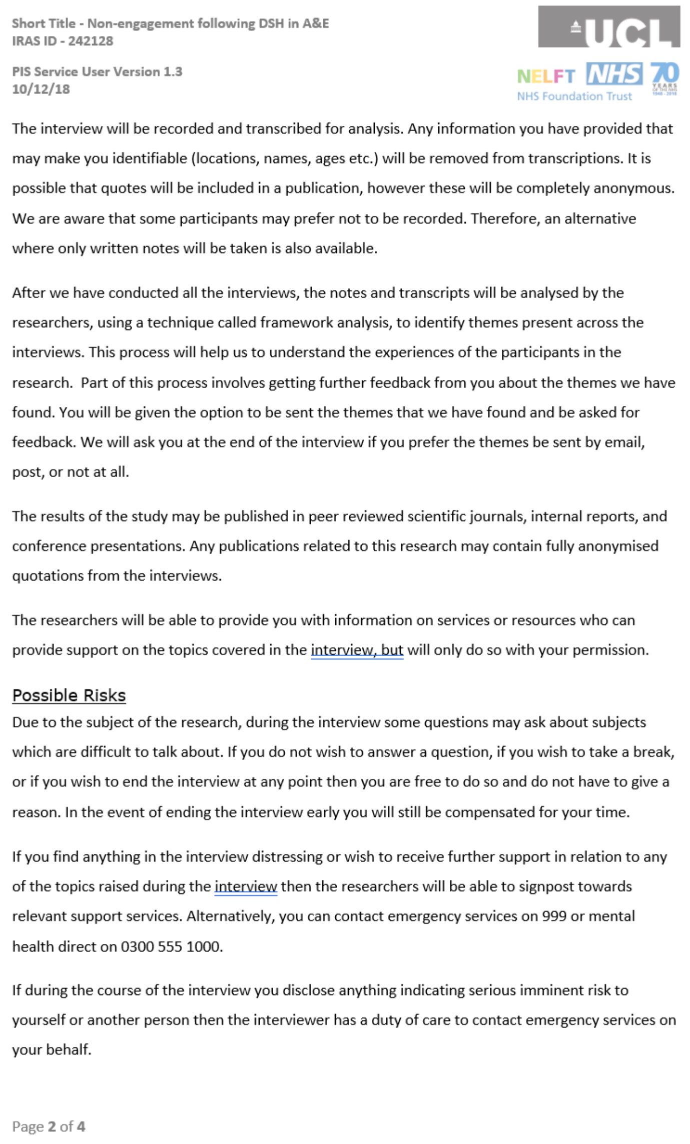
You have been invited to participate as it is possible that your experiences and knowledge are relevant to questions that we have.

### Do I have to take to part?

**No,** participating in the study is entirely up to you and any decision you make will have no impact on any care or support to which you may be entitled. Before you decide we would like you to read this sheet to understand why the research is being done and what it would involve for you. One of our team will be happy to answer any questions that you may have. You are welcome to take as much time as you need to read this sheet and consider whether you would like to participate in this research. Please feel free to talk to others about the study if you wish.

### What would taking part involve?

The study will consist of an interview lasting approximately 60 minutes. This interview can take place either over the phone, on an NHS site (IMPART Walthamstow or IMPART Leyton) or at UCL (Central London). The researchers will be happy to discuss the different options of location with you and assist in choosing an option that feels safe and confidential to you. Initial questions will ask about your experience of being offered mental health services and psychological treatments, and factors affecting your decisions about those offers. Later questions will ask about what services could do to be better suited to you. In compensation for your time you will receive a £5 Amazon voucher.



The interview will be recorded and transcribed for analysis. Any information you have provided that may make you identifiable (locations, names, ages etc.) will be removed from transcriptions. It is possible that quotes will be included in a publication, however these will be completely anonymous. We are aware that some participants may prefer not to be recorded. Therefore, an alternative where only written notes will be taken is also available.

After we have conducted all the interviews, the notes and transcripts will be analysed by the researchers, using a technique called framework analysis, to identify themes present across the interviews. This process will help us to understand the experiences of the participants in the research. Part of this process involves getting further feedback from you about the themes we have found. You will be given the option to be sent the themes that we have found and be asked for feedback. We will ask you at the end of the interview if you prefer the themes be sent by email, post, or not at all.

The results of the study may be published in peer reviewed scientific journals, internal reports, and conference presentations. Any publications related to this research may contain fully anonymised quotations from the interviews.

The researchers will be able to provide you with information on services or resources who can provide support on the topics covered in the interview, but will only do so with your permission.

### Possible Risks

Due to the subject of the research, during the interview some questions may ask about subjects which are difficult to talk about. If you do not wish to answer a question, if you wish to take a break, or if you wish to end the interview at any point then you are free to do so and do not have to give a reason. In the event of ending the interview early you will still be compensated for your time.

If you find anything in the interview distressing or wish to receive further support in relation to any of the topics raised during the interview then the researchers will be able to signpost towards relevant support services. Alternatively, you can contact emergency services on 999 or mental health direct on 0300 555 1000.

If during the course of the interview you disclose anything indicating serious imminent risk to yourself or another person then the interviewer has a duty of care to contact emergency services on your behalf.

## Confidentiality and Rights

If you agree to take part in the study you will need to sign and date the 'Informed Consent' form attached. Your unique registration number will be used in any study documentation make sure you cannot be identified outside the trial. All information, which is collected, about you during the course of the research will be treated as strictly confidential.

Your legal rights will not be affected by agreeing to take part in or withdrawing from the study. You are free to withdraw from the study at any time without giving a reason. If you decide to withdraw from the study this will not affect the standard of your routine care in any way.

You will be informed of any significant new findings that occur during the study as this may change your decision to continue.

## What if something goes wrong?

If anything goes wrong or you have any concerns related to your involvement in this study, then you can contact the principal investigator, Dr Janet Feigenbaum (j.feigenbaum@ucl.ac.uk). Alternatively you can contact your most convenient Patient Advice and Liaison Service (PALS). The closest office is at Whipps Cross Hospital (0208 535 6438, WXpals@bartshealth.nhs.uk). Other PALS departments maybe be more convenient for you and their contact details can be found be going to www.nhs.uk, searching 'PALS' and selecting the top result.

## Data Management Information

UCL is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting Dr Janet Feigenbaum.

The researchers will keep your name, and contact details confidential and will not pass this information to UCL. The researchers will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from UCL and regulatory organisations

may look at your anonymised research records to check the accuracy of the research study. UCL will only receive information without any identifying information.

The researchers will securely store the anonymised data from this study for 20 years after the study ends, in order to ensure regulatory compliance. Any identifiable information (for example contact details forms and consent forms) will be destroyed at the end of the study.

The data protection officer is Lee Shailer (data-protection@ucl.ac.uk).

## Further Information

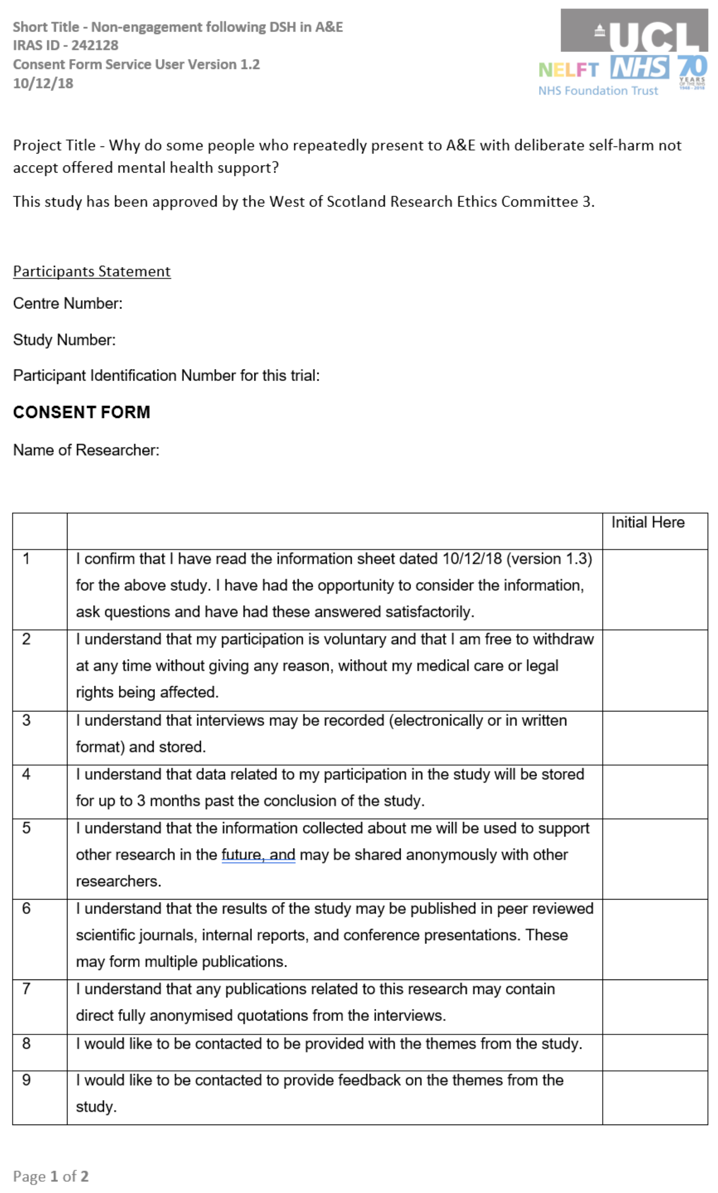
If you decide want support with any of the issues raised in this topic then a directory of psychological therapy services can be found at https://www.nhs.uk/Service-Search/Psychological%20therapies%20(IAPT)/LocationSearch/10008 or you can speak to your GP. If you need access to emergency services then you can call 999 or go directly to your local A&E. To speak anonymously Samaritans can be contacted at any time on 116123. A variety of other helplines can be found at https://www.nhs.uk/conditions/stress-anxiety-depression/mental-health-helplines/.

All data will be collected and stored in accordance with the General Data Protection Regulation (GDPR).

This study has been reviewed and approved by West of Scotland Research Ethics Committee 3.

[Project ID No]: **242128**

# Appendix E – Consent Form



Project Title - Why do some people who repeatedly present to A&E with deliberate self-harm not accept offered mental health support?

This study has been approved by the West of Scotland Research Ethics Committee 3.

Participants Statement

Centre Number:

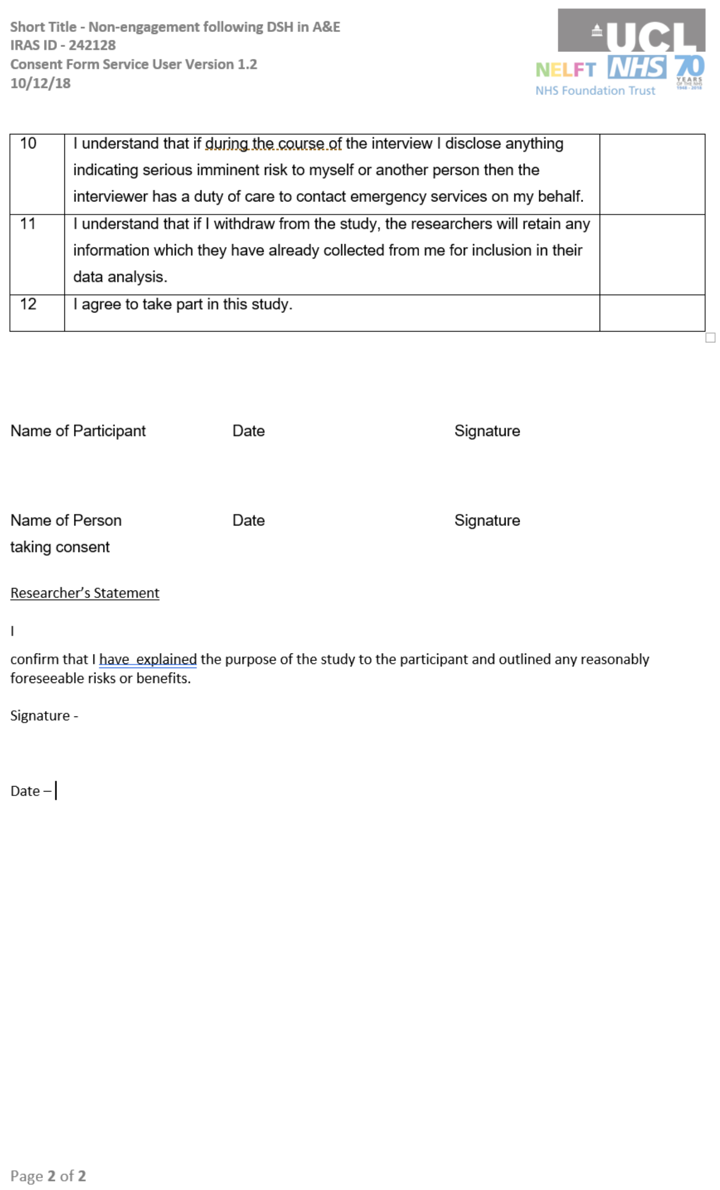
Study Number:

Participant Identification Number for this trial:

**CONSENT FORM**

Name of Researcher:

| | | Initial Here |
|---|---|---|
| 1 | I confirm that I have read the information sheet dated 10/12/18 (version 1.3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | |
| 2 | I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. | |
| 3 | I understand that interviews may be recorded (electronically or in written format) and stored. | |
| 4 | I understand that data related to my participation in the study will be stored for up to 3 months past the conclusion of the study. | |
| 5 | I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. | |
| 6 | I understand that the results of the study may be published in peer reviewed scientific journals, internal reports, and conference presentations. These may form multiple publications. | |
| 7 | I understand that any publications related to this research may contain direct fully anonymised quotations from the interviews. | |
| 8 | I would like to be contacted to be provided with the themes from the study. | |
| 9 | I would like to be contacted to provide feedback on the themes from the study. | |



| | | |
|---|---|---|
| 10 | I understand that if during the course of the interview I disclose anything indicating serious imminent risk to myself or another person then the interviewer has a duty of care to contact emergency services on my behalf. | |
| 11 | I understand that if I withdraw from the study, the researchers will retain any information which they have already collected from me for inclusion in their data analysis. | |
| 12 | I agree to take part in this study. | |

| | | |
|---|---|---|
| Name of Participant | Date | Signature |
| Name of Person taking consent | Date | Signature |

Researcher's Statement

I

confirm that I have explained the purpose of the study to the participant and outlined any reasonably foreseeable risks or benefits.

Signature -

Date –

# Appendix F – Interview Schedule

Hello, thank you for agreeing to speak with me today.

Researcher introduces themselves.

Before we begin can I please confirm that you have read the information sheet and consent form that you have been sent?

- Yes – continue
- No – offer to read the PIS and consent form out loud to the participant, ensure that the participant has access to the PIS and consent form and rearrange the interview for at least 24 hours later, with the explanation of giving them time to consider the content of the PIS. If participant requests to not reschedule the interview, continue as long as they have read or heard the full PIS.

Do you have any questions about any of the information you have been given, or about anything else related to the research?

- Yes – answer questions
- No - continue

Having read the information sheet and consent form are you happy to continue with the interview?

- Yes – Proceed to consent form
- No – End the conversation

*If the interview is taking place over the phone*

Thank you, before we begin I will read the consent form, which is the same as the one you were previously sent (adjust if the consent form was read to them on a previous phone call). After each item of the consent form I will ask if you do or do not consent to it. If you have any questions regarding the contents of the form I will be happy to answer them. If you would like any additional time to consider any of the contents, then I will be happy to reschedule the interview.

- If the participant consents to all items (excluding 7 and 8, which are not crucial to this stage of the study) proceed with the interview. If they do not, end the interview.

*If the interview is in person*

Thank you, before we begin the interview we will go through the consent form, which is the same as the one you were previously sent (adjust if the consent form was read to them on a previous phone call). Please take as much time as you need to read this consent form, signing all items that you consent to. If you have any questions regarding the contents of the form I will be happy to answer them. If you would like any additional time to consider any of the contents, then I will be happy to reschedule the interview.

- If the participant consents to all items (excluding 7 and 8, which are not crucial to this stage of the study) proceed with the interview. If they do not, end the interview.

*All participants*

Thank you. I'll just remind you that if at any time you wish to stop the interview, take a break or ask a question to please just let me know.

As you will have seen/heard from the information sheet, we are conducting the study to further our understanding of factors that prevent people from using current mental health services and also ways that services may adapt to be able better support more people.

Before we begin, I would like to remind you that if you want to take a break or stop the interview at any time, just let me know.

PART A

Please could you tell me about your experience of being offered support from mental health services during or following a visit to A&E.

Possible Prompts and follow up questions – What were you offered? Who offered it to you? How was it offered? What was your initial reaction to being offered X? Did you google, ask anyone or read about the service?

When you were offered this support, what was your experience of the staff members involved?

Prompts – Did you have ideas about what they were thinking? Did you find their attitude helpful or unhelpful? Was there anything they could have done differently that you would have preferred?

When you were offered the support, what did you imagine using it would be like?

Possible prompts – What made you think that?

What, if anything, about the offer seemed helpful to you?

Tell me about your what affected your decision of whether to take up the offer of support from mental health services.

Possible prompts – Pros? cons? was it a difficult decision? Did you discuss it with anybody else? How confident were you in your decision? Did you know anything about the service that was offered to you? If so, what? Do you know anyone else who has used that service or anything similar to it?

What factors ultimately led to you choosing not to take up the offer of support from mental health services?

Possible prompts – Did you have any thoughts about what other people would think if they knew about you using mental health services? What beliefs do you have about people who use mental health services? Is there anything about mental health services that worries you? Did you think that anything bad would happen to you if you used mental health services?

PART B

Part of why we are doing this research is to help us find ways to adapt services to help more people. What could have been done differently when you were offered support from mental health services to make you more likely to use them?

If there were a therapy group or mental health service that you might be willing to use, what features would that group have?

Prompts: Go through main points of concern mentioned previously, asking if they have any ideas about what, if anything, services could do to address that issue.

Are there any issues that you have mentioned that you don't think could be addressed by mental health services?

We also wanted to ask your opinion on some more specific aspects that we were thinking about.

Do you have a preference for, and by who, you were offered support?

What locations for a group would suit you?

- Public? NHS location? Libraries? Health Centres? Community Centres?
- What about X location makes it more suitable to you?

What times of day would suit you best?

- What about those times works best for you?

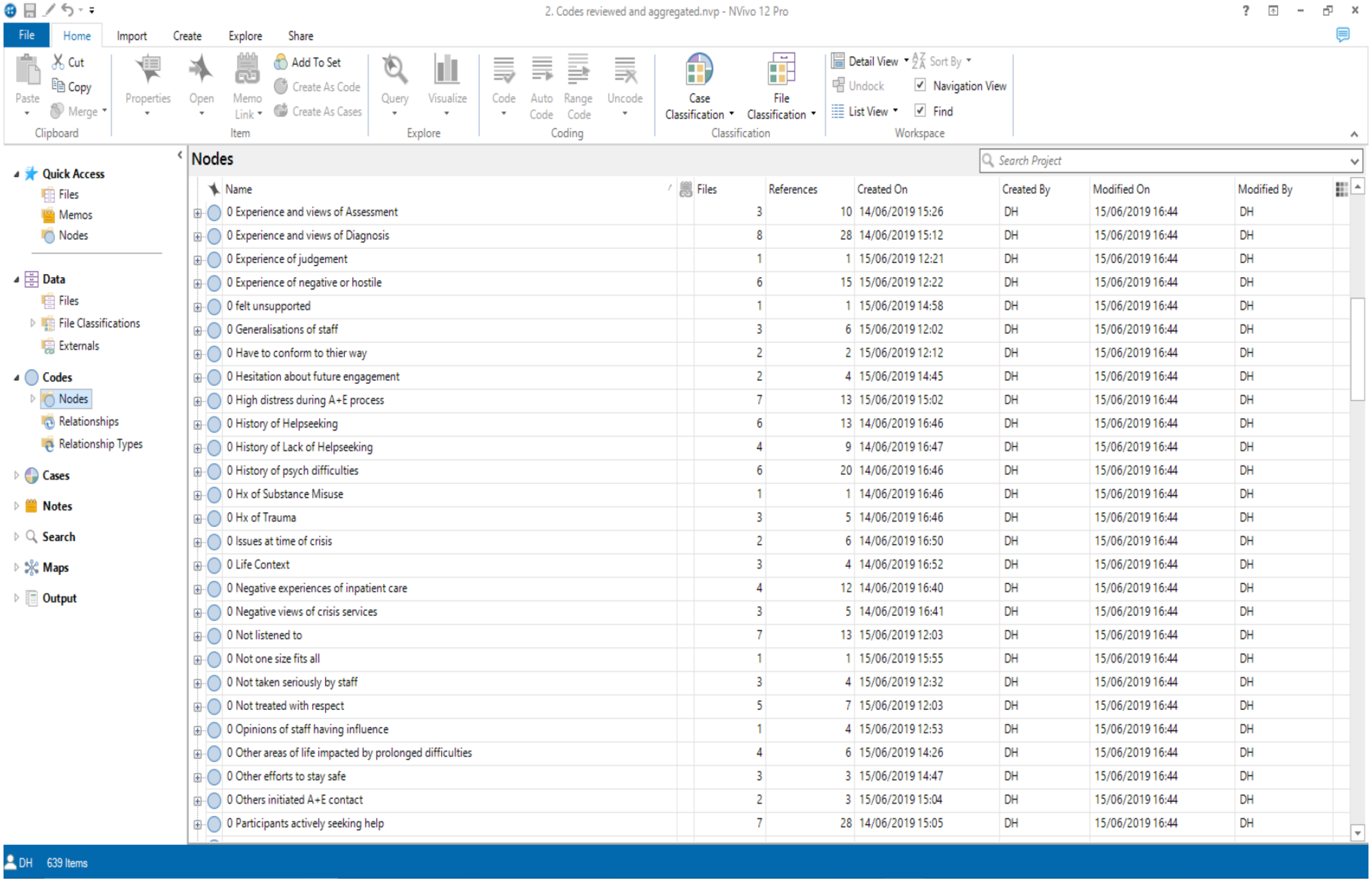
If other formats of support (rather than face to face) were available such as email, telephone or online, would these be more or less helpful to you?

- What about X makes it more or less helpful?

If you were offered self-help reading resources would these be helpful to you?

- What about these makes them helpful/unhelpful to you?

# Appendix G – Nvivo Screenshot

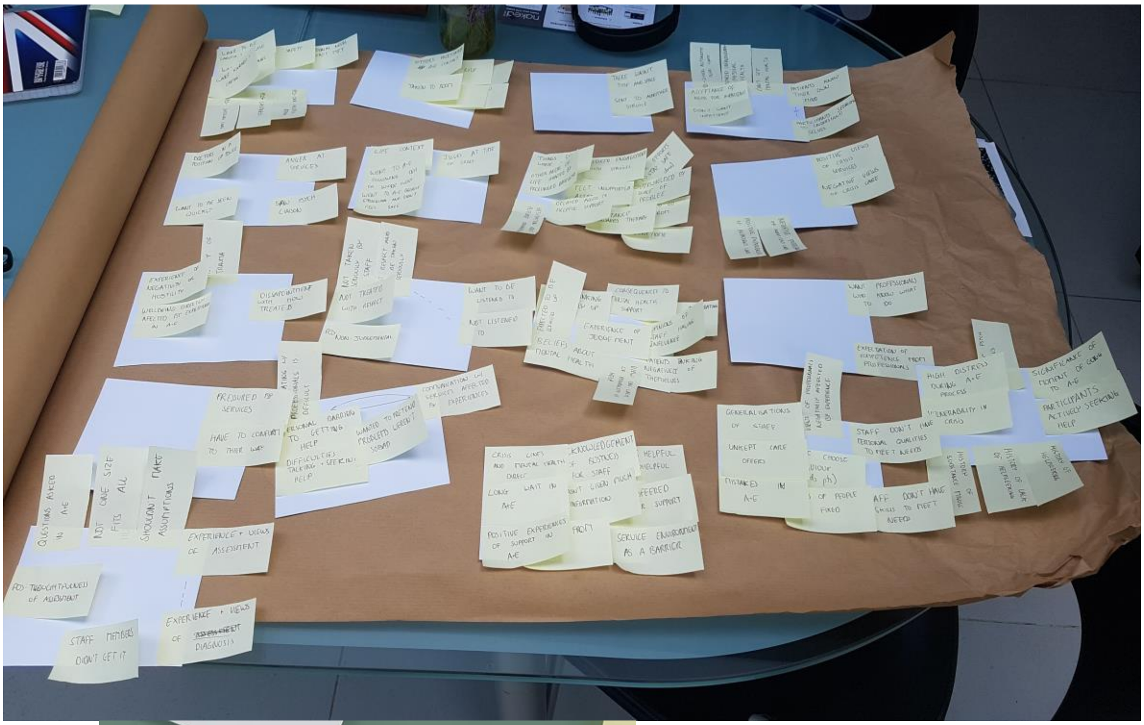


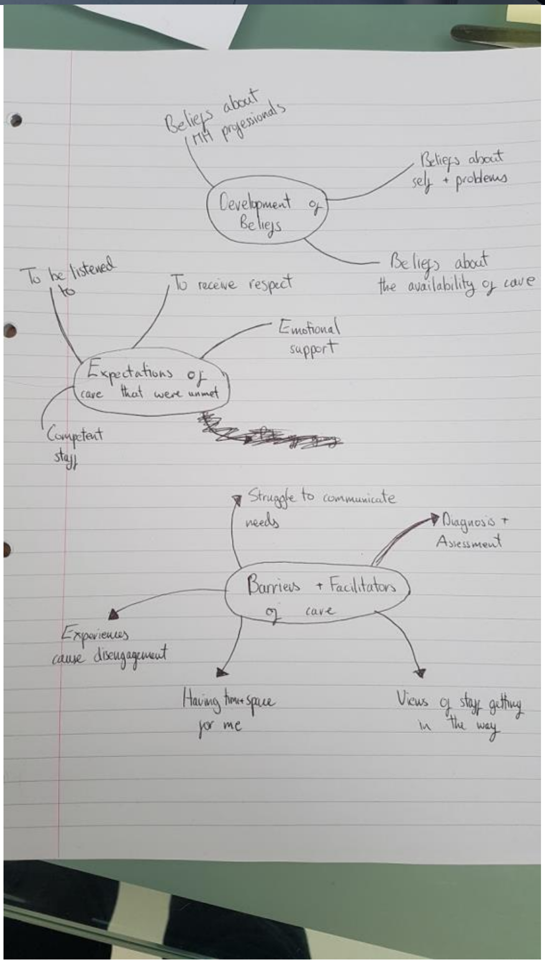
2. Codes reviewed and aggregated.nvp - NVivo 12 Pro

Nodes

| Name | Files | References | Created On | Created By | Modified On | Modified By |
|---|---|---|---|---|---|---|
| 0 Experience and views of Assessment | 3 | 10 | 14/06/2019 15:26 | DH | 15/06/2019 16:44 | DH |
| 0 Experience and views of Diagnosis | 8 | 28 | 14/06/2019 15:12 | DH | 15/06/2019 16:44 | DH |
| 0 Experience of judgement | 1 | 1 | 15/06/2019 12:21 | DH | 15/06/2019 16:44 | DH |
| 0 Experience of negative or hostile | 6 | 15 | 15/06/2019 12:22 | DH | 15/06/2019 16:44 | DH |
| 0 felt unsupported | 1 | 1 | 15/06/2019 14:58 | DH | 15/06/2019 16:44 | DH |
| 0 Generalisations of staff | 3 | 6 | 15/06/2019 12:02 | DH | 15/06/2019 16:44 | DH |
| 0 Have to conform to thier way | 2 | 2 | 15/06/2019 12:12 | DH | 15/06/2019 16:44 | DH |
| 0 Hesitation about future engagement | 2 | 4 | 15/06/2019 14:45 | DH | 15/06/2019 16:44 | DH |
| 0 High distress during A+E process | 7 | 13 | 15/06/2019 15:02 | DH | 15/06/2019 16:44 | DH |
| 0 History of Helpseeking | 6 | 13 | 14/06/2019 16:46 | DH | 15/06/2019 16:44 | DH |
| 0 History of Lack of Helpseeking | 4 | 9 | 14/06/2019 16:47 | DH | 15/06/2019 16:44 | DH |
| 0 History of psych difficulties | 6 | 20 | 14/06/2019 16:46 | DH | 15/06/2019 16:44 | DH |
| 0 Hx of Substance Misuse | 1 | 1 | 14/06/2019 16:46 | DH | 15/06/2019 16:44 | DH |
| 0 Hx of Trauma | 3 | 5 | 14/06/2019 16:46 | DH | 15/06/2019 16:44 | DH |
| 0 Issues at time of crisis | 2 | 6 | 14/06/2019 16:50 | DH | 15/06/2019 16:44 | DH |
| 0 Life Context | 3 | 4 | 14/06/2019 16:52 | DH | 15/06/2019 16:44 | DH |
| 0 Negative experiences of inpatient care | 4 | 12 | 14/06/2019 16:40 | DH | 15/06/2019 16:44 | DH |
| 0 Negative views of crisis services | 3 | 5 | 14/06/2019 16:41 | DH | 15/06/2019 16:44 | DH |
| 0 Not listened to | 7 | 13 | 15/06/2019 12:03 | DH | 15/06/2019 16:44 | DH |
| 0 Not one size fits all | 1 | 1 | 15/06/2019 15:55 | DH | 15/06/2019 16:44 | DH |
| 0 Not taken seriously by staff | 3 | 4 | 15/06/2019 12:32 | DH | 15/06/2019 16:44 | DH |
| 0 Not treated with respect | 5 | 7 | 15/06/2019 12:03 | DH | 15/06/2019 16:44 | DH |
| 0 Opinions of staff having influence | 1 | 4 | 15/06/2019 12:53 | DH | 15/06/2019 16:44 | DH |
| 0 Other areas of life impacted by prolonged difficulties | 4 | 6 | 15/06/2019 14:26 | DH | 15/06/2019 16:44 | DH |
| 0 Other efforts to stay safe | 3 | 3 | 15/06/2019 14:47 | DH | 15/06/2019 16:44 | DH |
| 0 Others initiated A+E contact | 2 | 3 | 15/06/2019 15:04 | DH | 15/06/2019 16:44 | DH |
| 0 Participants actively seeking help | 7 | 28 | 14/06/2019 15:05 | DH | 15/06/2019 16:44 | DH |

# Appendix H – Photograph of theme sorting





## Appendix I – Statement of Joint Working

This empirical project was conducted with another trainee Clinical Psychologist. The project was designed, and interview schedules written together. Both researchers contributed to recruitment and data collection.

In recruitment, seven participants were recruited and interviewed by myself and three by the other researcher. I transcribed all of the interviews conducted by myself in addition to one conducted by the other researcher. They transcribed the remaining two.

Analysis and write-up were conducted separately.