# Ambivalence in Anorexia: The Role of Perceived Benefits and Burdens in Anorexia Nervosa

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## Declaration

I, Eva Gregertsen, 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.

Date: 18<sup>th</sup> of July, 2021



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### Abstract

*Background*: This project focusses on the egosyntonic nature of anorexia nervosa (AN), referring to the valued nature of the illness by those impacted by it. The egosyntonicity of the illness is highlighted as a key feature of the disorder, and theorised to be a maintaining factor in cognitive models, in that valuing the illness may reduce motivation for recovery (Schmidt & Treasure, 2006; Wolf & Serpell, 1998). As such, gaining insight into the egosyntonic nature of AN may help inform future treatments.

Aims and Methods: This thesis aimed to improve the understanding of the egosyntonic nature of AN, particularly to investigate its value in predicting outcomes of AN treatment, as well as to validate the Pros and Cons of Anorexia Nervosa Scale (P-CAN), a psychometric measure which aims to capture perceived benefits and burdens of the illness. The first objective was to systematically review the evidence base for pre-treatment patient predictors of drop-out and outcome in AN treatment. Then, a narrative review was undertaken to better understand egosyntonicity. Following this, a cross-sectional study was conducted to validate the P-CAN in a sample of adolescent and adult female outpatients, inpatients or daypatients, undergoing either treatment or monitoring at an eating disorder clinic. It was hypothesised that greater endorsement of benefits of AN would be linked with greater illness severity and lower motivation, whereas greater endorsement of the burdens of AN was hypothesised to be linked with greater motivation. The study also aimed to investigate whether there was a link between endorsement of pros and cons of AN and confidence in one's ability to recover, and whether binge-purge and restrictive subtypes differed on endorsement of pros and cons. Finally, it was hypothesised that motivation would mediate the relationship between endorsement of pros and eating disorder pathology. Lastly, a longitudinal study examined the predictive value of the P-CAN, as well as explored its links with autism traits, in a sample of adolescent and adult female outpatients undergoing treatment for AN. It was predicted that greater motivation, lower eating disorder pathology, lower endorsement of pros, greater endorsement of the "hatred" con, and lower autism traits would predict better outcome.

*Results*: The systematic review and meta-analysis demonstrated that admission BMI, binge-purge subtype, lower motivation and greater eating disorder pathology predicted drop-out and/or outcome. The narrative review established that individuals with AN endorse a range of benefits linked with their illness, whilst also recognising cons, thus likely leading to ambivalence towards recovery. The cross-sectional study established the concurrent validity of the P-CAN, whilst also demonstrating that the link between endorsement of perceived benefits and eating disorder pathology was partially mediated by motivation. Further, the relationship between both decisional balance and self-efficacy and eating disorder pathology was fully mediated by motivation. In the longitudinal study, endorsement of the "hatred" con, motivation and eating disorder

pathology predicted outcome. Lastly, a positive relationship was found between autism traits and perceived benefits of AN.

*Conclusions:* These findings suggest that egosyntonicity may play a role in impacting eating disorder pathology through its effect on motivation. Enhancing endorsement of the "hatred" con and motivation could be useful in therapy. A key limitation was the small sample size in the longitudinal study. Future research should examine the predictive value of the P-CAN sub-scales in a sufficiently large sample.

### **Impact Statement**

This thesis examines the egosyntonic (valued) nature of anorexia, and provides further insight into the important role which egosyntonicity plays in this illness. Highlighting the importance of egosyntonicity is impactful in the clinical realm in that it those who suffer with anorexia often display ambivalence towards recovery due to the valued nature of the illness. Positive therapeutic outcomes may be enhanced when clinicians fully consider the ways in which anorexia may be valued by the person with the illness, and understand reluctance towards recovery as a normal part of the illness, as opposed to being due to stubbornness or 'resistance' on part of the patient. This thesis moves the discipline forward by providing deepened knowledge on egosyntonicity, which can be applied in the clinical realm.

Further, the findings of this thesis suggests that egosyntonicity may play an enhanced role for those patients who are also impacted by greater autism traits. This finding provides further understanding of autism in anorexia, and carries with it important clinical applications. Specifically, therapeutic outcomes may be enhanced if therapy is altered to address the specific pros endorsed by those with autism.

Moreover, this thesis further establishes the validity of the Pros and Cons of Anorexia Nervosa Scale, which is a helpful tool that can be used in both a clinical and research context. The Pros and Cons of Anorexia Nervosa Scale captures perceived benefits and burdens of anorexia, and may help clinicians gain a better understanding of ways in which patients value their disorder, as well as which costs patients may identify which clinicians may wish to further entrench.

Additionally, this thesis provides further evidence for the integral role of motivation in treatment for anorexia, and also highlights the need for dismantling studies to gain a better understanding of how motivation may be manipulated in the treatment context, which in turn could lead to improved outcomes.

Further, this thesis provides novel evidence for the role of feeling negative affect towards one's illness in treatment response, wherein more positive treatment outcomes were seen in those expressing greater hatred towards their illness at the start of therapy. This finding is impactful in that it demonstrates a means through which clinicians may improve outcome; that is, by helping patients make the cognitive shift that their illness is an enemy as opposed to a friend or guardian.

Lastly, this thesis highlights issues within the current literature base, namely small sample sizes and inconsistent definitions of drop-out and outcome, providing important considerations for future research.

In conclusion, the findings of this thesis provide insight into anorexia which may benefit researchers, clinicians and patients alike.

Components of this work have been published in peer-reviewed academic journals. Two papers have been published as a result of this thesis, with another one under review (Gregertsen et al., 2017; 2018; under review). The published version of the narrative review contained in this thesis has gained over 16,000 views to date. Furthermore, parts of this thesis were presented in an invited article on egosyntonicity for a subscription newsletter run by the National Eating Disorders Information Centre. This newsletter is intended for clinicians, carers and those impacted by eating disorders. Lastly, components of this thesis have also been disseminated at several international eating disorder conferences and via an invited article for Eating Disorders Review, a clinical jourstenal for eating disorder professionals.

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## Chapter 1 Predicting Drop-Out and Outcome in Anorexia Nervosa Treatment

"And so I went through the looking glass, stepped into the netherworld, where up is down and food is greed, where convex mirrors cover the walls, where death is honour and flesh is weak. It is ever so easy to go. Harder to find your way back."

Marya Hornbacher: Wasted: A Memoir of Anorexia and Bulimia

The chapter that follows is a systematic review and meta-analysis of pre-treatment patient characteristics as predictors of outcome and drop-out in anorexia nervosa treatment for adolescents and adults (AN). This chapter is a version of a manuscript previously published in *Psychiatry Research* (2018) with the same title as Gregertsen et al., 2018.

#### 1.1 Anorexia Nervosa

Anorexia nervosa (AN) is a debilitating eating disorder, characterised by restricted energy intake leading to a significantly low body weight, intense fear of gaining weight, and disturbed body image and/or undue influence of body weight or shape on self-evaluation (American Psychiatric Association [APA], 2013). The disorder has been classified into two subtypes: a restricting subtype (wherein weight loss is accomplished primarily through restricted food intake and/or excessive exercise) and a binge-purge (BP) subtype (wherein episodes of binge eating and purging behaviour occur regularly). Of note, in cases wherein all of the criteria for AN are met, except the criterion pertaining to significantly low body weight, patients are diagnosed with atypical AN, which falls under the Other Specified Feeding or Eating Disorder (OSFED) category in the 5<sup>th</sup> edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*. Risk factors for AN include perfectionism, obsessive-compulsive personality traits, and early onset anxiety disorders, and the illness is known to show co-morbidity with depression, anxiety disorders, social phobia, obsessive-compulsive disorder, borderline personality disorder, avoidant personality disorder, and substance abuse (Anderluh et al., 2003; Fairburn & Harrison, 2003; Felted et al., 2008; Halmi et al., 1991; Halmi et al., 2003).

AN is associated with a range of psychosocial impairments, including depression, anxiety, low self-esteem, social withdrawal, and self-harm (Fuss et al., 2014; Godart et al., 2000; Goldstein & Givon, 2019; Jacobi et al., 2004; Strumia et al., 2001; Treasure & Schmidt, 2013). Moreover, as the disorder develops, it can cause both reversible and irreversible physiological damage, such as low blood pressure, slow or irregular heartbeat, electrolyte imbalances, stomach ulcers, skin disorders, and, in severe cases, osteoporosis, liver disease, or even death (Meczekalski et al., 2013; Miller, 2013; Winston & Stafford, 2000). Specifically, patients with AN have a morality rate six times higher than that of the general population, making it the most deadly type of eating disorder (Papadopoulos et al., 2009). According to the APA, 5% of people with AN die within the first 4 years of diagnosis, whereas the mortality rate is 20% for those who suffer with the illness for a duration of 20 years or longer (APA, 1994). 'Natural' causes of death in AN patients include malnutrition, organ failure, or severe heart problems; however, an estimated 20% of AN deaths are the result of suicide (Arcelus et al., 2011). Factors associated with mortality include older age,

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longer eating disorder duration, history of suicide attempts, diuretic use, eating disorder severity, and alcohol misuse (Button et al., 2010; Huas et al., 2010; Keel et al., 2003). Compared to other psychiatric illnesses, AN ranks as the most lethal, its estimated six-fold increased risk of death being four times that of the mortality rate for clinical depression, three times the mortality rate for bipolar disorder, and two times the mortality rate for schizophrenia, making it not only the most deadly type of eating disorder, but the most deadly psychiatric disorder (Arcelus et al., 2011).

Most commonly, female adolescents or young women are afflicted by AN, with 0.3-3% of young women impacted by the illness, and AN ranks as the third most prevalent chronic disease found in adolescent girls (Hoek & Van Hoeken, 2003; Nicholls & Bryant-Waugh, 2009). Lifetime prevalence, defined as the proportion of individuals having the disorder at any point in their life (Smink et al., 2012), is estimated to be between 2.0% and 3.0% for women, and 0.24% for men (Isomaa et al., 2009). However, it should be noted that there is evidence to suggest that AN in males may more frequently go undetected as compared to in females (Raevuori et al., 2008). Mean age of onset is around 19 years for females, with the mean age for males not yet having been established (Hudson & Pope, 2007).

#### 1.2 Treating Anorexia Nervosa

A range of therapies have shown efficacy in the treatment of AN, including enhanced cognitive-behavioural therapy (CBT-E), AN-focused Maudsley Model of Anorexia Nervosa Treatments of Adults (MANTRA), Specialist Supportive Clinical Management for Eating Disorders (SSCM), and family-based therapy (FT-AN) 17

(National Institute for Health and Care Excellence [NICE], 2004). AN patients receive therapy as either an inpatient, daypatient, or outpatient, usually dependent on severity of the illness. However, the most effective treatments only lead to remission for around 50% of sufferers, hence there is an urgent need to improve existing treatments.

#### 1.2.1 Enhanced Cognitive-Behavioural Therapy

Enhanced CBT-E, a "transdiagnostic" form of CBT, has been developed to treat the full range of clinical eating disorders, with the transdiagnostic perspective putting forth that eating disorders are not distinct clinical states but rather have many common features, particularly overevaluation of control over eating, shape, and weight, and that eating disorder patients tend to migrate between eating disorder diagnoses over time (Fairburn et al., 2003; Fairburn & Harrison, 2003). There are two forms of CBT-E; a focused-form targeting eating disorder psychopathology exclusively (CBT-Ef), and a broader form which tackles additional barriers to change, such as interpersonal difficulties, low self-esteem, and clinical perfectionism (CBT-Eb) (Fairburn et al., 2008). CBT-E for underweight patients typically consists of 40 sessions, aiming to reduce the risk to physical health and any other symptoms of the eating disorder, whilst encouraging the patient towards healthy eating and reaching a healthy body weight (NICE, 2004). Treatment typically progresses through stages of twice-weekly, weekly, and fortnightly sessions. Therapy sessions cover nutrition, cognitive restructuring, mood regulation, social skills, body image concern, self-esteem, and relapse prevention, and include a personalised treatment plan based on the processes that appear to be maintaining the disorder. Information is provided to patients about risks of malnutrition and low body weight, and patients are asked to monitor their 18

dietary intake and associated thoughts and feelings, as well as to complete homework, which aims to help the patient practice in their daily life what they have learned in sessions. CBT-E also aims to enhance self-efficacy.

Fairburn et al. (2013) examined the effect of CBT-E in 99 adult AN patients, demonstrating that two-thirds of patients completed the 40-week treatment intervention, with these patients showing significant reductions in eating disorder pathology and clinically significant weight gain at the end of treatment. Similarly, CBT-E has been found to be an effective treatment for adolescents with AN (Cowdrey & Davis, 2016; Dalle Grave et al., 2013). Attrition rates of 36% and 37% were reported in these studies (Fairburn et al., 2013; Dalle Grave et al., 2013). More promisingly, the ANTOP study conducted by Zipfel et al. (2014) reported a 19% drop-out rate for CBT-E treatment of AN; however, whilst less dramatic than previously reported figures and figures reported for other therapies, having one fifth of patients drop out of therapy is still a considerable issue.

#### 1.2.2 Maudsley Model of Anorexia Nervosa Treatment of Adults

The MANTRA model demonstrates a radical departure from classical CBT models for AN, wherein weight and shape concerns are considered the central psychopathology of the illness, and are accordingly the main focus of therapy (Murphy et al., 2010; Pike et al., 2003). In contrast, proponents of the MANTRA model argue that whilst on the surface patients with AN mainly appear to worry about aspects of their eating disorder, these worries are simply symptomatic of deeper and more troubling concerns (Schmidt et al., 2014). A mixed-methods study by Sternheim et al.

(2012) explored catastrophic worry in a sample of 44 eating disorder patients (29 of which were diagnosed with AN), using Thematic Analysis to assess the worry content extracted using the Catastrophic Interview, a systematic interview procedure aimed at "externalising" the worrisome cognitions of an anxious individual (Davey & Levy, 1998; Vasey & Borkovec, 1992). The study found that underlying worries rarely pertained to eating disorder-related themes (1%) and more commonly concerned interpersonal difficulties (42%), negative self-perception (22%), and experience of negative emotions (20%), supporting the notion put forth by the MANTRA model. However, it is worth mentioning that other factors could have influenced the types of worry reported by the participants of the study, for example, social desirability, lack of awareness, or wanting to protect the eating disorder from outside influence by minimising its presence. Moreover, the model suggests that AN typically develops in people displaying sensitive/anxious and perfectionist/obsessional traits. The model posits that AN is maintained by four broad factors, including (1) a rigid, detail-focused and perfectionist information processing style; (2) socioemotional impairments (such as avoidance of the experience and expression of emotions in the context of close relationships); (3) beliefs about the function of AN in the patient's life; and (4) close others unintentionally maintaining the illness through high levels of expressed emotion or by accommodation and enabling behaviours (Schmidt et al., 2014). With this rationale in mind, MANTRA, which typically consists of 20 sessions, aims to motivate the patient and encourage them to work with the practitioner, with particular emphasis on the patient de-identifying with their 'anorexic identity' and developing a 'non-anorexic identity' in its place. When the person is ready, topics covered within sessions include nutrition, symptom management, and behaviour change. Family 20

members or carers are usually involved to help the patient understand their condition and the issues it causes, as well as to promote behaviour change.

The MOSAIC study, a multi-centre randomised controlled trial (RCT) comparing MANTRA with SSCM in 142 outpatients with broadly defined AN, found that both treatments resulted in significant improvements in Body MassIndex (BMI) and reductions in eating disorder symptomatology (Schmidt et al., 2015). Results showed that both treatments resulted in significant and comparable improvements in BMI and eating disorder symptoms. In terms of MANTRA, it was demonstrated that at 6 months post-treatment, 11% of MANTRA patients had recovered, 65% had partially recovered, whilst 24% had not yet recovered, wherein recovery was defined as BMI >18.5 and scoring a Global Score of <2.27 on the Eating Disorder Examination (EDE). When followed up 12 months post-treatment, 22% of MANTRA patients had recovered, 62% had partially recovered, and 16% were still battling the illness. At 24 months, the follow-up data demonstrated that improvements in BMI, eating disorder symptoms, distress levels and clinical impairment were still maintained or even further improved. In terms of attrition, a 25% drop-out rate was reported (Schmidt et al., 2015).

#### 1.2.3 Specialist Supportive Clinical Management

SSCM, originally developed to serve as a comparison treatment for CBT and interpersonal therapy (IPT), combines principles of clinical management and supportive psychotherapy (McIntosh et al., 2006). Clinical management is conceptualised as good-quality care, delivered by a competent practitioner with or

without the addition of any specific treatment regimen, emphasising the generic role of health professionals in doing no harm, ensuring safety, and delivering education, care, and support (Fawcett et al., 1987; Joyce, 1995). Supportive psychotherapy is a psychotherapeutic approach integrating various schools of thought to provide psychodynamic, cognitive-behavioural, therapeutic support, including and interpersonal conceptual models and techniques, and aims to assist the patient through use of praise, reassurance, and advice (Peele & Razavi, 2006). SSCM focuses on both eating disorder issues and broader issues of concern to the individual, with the rationale behind SSCM being that improvements in domains outside the core pathology can impact patient well-being and disease burden, ultimately helping increase the patient's quality of life, which will then further motivate and enable the patient to make progress on their eating disorder pathology. SSCM, which typically comprises 20 or more weekly sessions, assesses, identifies, and regularly reviews key problems for the patient, and includes physical health monitoring and establishing a weight range goal, encouraging the patient towards a healthy body weight and healthy eating. A core aim within SSCM is to develop a positive relationship between the patient and clinician, as well as to help patients recognise the connection between their symptoms and their disordered eating behaviour, and to restore weight in so doing. Sessions provides patients with psychoeducation, nutritional education, and advice, alongside with other components that the patient themselves decide should be included as part of their therapy. Considering that many components of SSCM and CBT and MANTRA overlap – such as providing psychoeducation, nutritional advice, and focusing on weight gain goals – it may help explain why SSCM has been shown to

perform similarly to CBT-E and MANTRA in terms of treatment response, despite SSCM originally being used as a control group in an RCT examining CBT and ITP.

In the previously mentioned MOSAIC study, SSCM was included as a comparison to MANTRA. Data collected at 6 months post-treatment demonstrated that 13% those who received SSCM patients were recovered, 58% were partially recovered, and 29% were not yet recovered. These rates were not significantly different from those for MANTRA, so both treatments were of similar effectiveness. Following up the SSCM patients at 12 months post-treatment demonstrated recovery rates of 16%, partial recovery rates of 65%, with 18% of SSCM patients still meeting full diagnostic criteria for AN (Schmidt et al., 2015). As with MANTRA, clinical improvements were maintained or even increased at the 24 month follow-up. However, 41% of SSCM patients did not complete treatment. More promisingly, a study by Touyz et al. (2013), examining treatment for severe and enduring AN demonstrated a 9.4% attrition rate (3/32 patients) for those patients receiving SSCM, whereas Carter et al. (2011) reported a 31% attrition rate (5/16 patients). In terms of outcome, Carter et al.'s (2011) study demonstrated that 75% of SSCM patients showed a good outcome at posttreatment. However, at long-term follow-up (5 years post-treatment), the number of SSCM patients reporting a good outcome had reduced to 42%.

#### 1.2.4 Family-Based Therapy

FBT (also sometimes referred to as the Maudsley method or Maudsley Family Therapy), which is typically delivered to children and adolescents, takes an agnostic view of the eating disorder; specifically, clinicians do not try and analyse why the

eating disorder developed. In this regard, FBT rejects the conceptualisation that the family is a direct cause of the patient's eating disorder, and instead, works to empower families and utilises parents as resources in treatment, as opposed to viewing the family as an impasse to recovery, or a possible reason for why the eating disorder came to fruition in the first place (Loeb & le Grange, 2009). As such, FBT, which typically comprises of 18-20 sessions over a year, emphasises the role of the family in helping the patient recover, without apportioning blame onto the patient or their family members or caregivers. Sessions include psychoeducation about nutrition and the effects of malnutrition. Early in treatment, the parents or carers are supported in taking a central role in helping the patient manage their eating, though this role is temporary. In line with this, FBT comprises three phases: the first phase aims to establish a good therapeutic alliance with the patient and their family and focuses on re-feeding and weight restoration; the second phase aims to support the patient to establish independence appropriate for their level of development, and the final phase focuses on plans for when treatment ends including relapse prevention, as well as addresses how the patient may access support when treatment is stopped.

A review conducted by Smith and Cook-Cottone (2011) examined the effectiveness of FBT for adolescents with AN. The earliest study included in the review was conducted by Russell and colleagues (1987), and demonstrated that 62% of AN patients receiving FBT obtained a "good" or "intermediate" recovery, as determined by the Morgan-Russell outcome categories, wherein "good" and "intermediate" categories indicated that the patient had achieved normal weight and was menstruating, although amenorrhea (lack of menstruation) is no longer a criterion for

AN in the updated DSM-5 (APA, 2000; Morgan & Hayward, 1988). Promisingly, five-year follow-up results demonstrated that over 75% of FBT patients reported having no eating disorder symptoms(Eisler et al., 2007). A study by le Grange et al. (1992) including both males and females (12-17 years) indicated that patients receiving two different forms of FBT (either conjoint family sessions or separate supportive sessions for the patient and counselling for the parents) increased from 77.9% of average body weight to 94.1% of average body weight, a statistically significant difference, alongside improvements in eating attitudes on the Morgan-Russell Average Outcome measure. In 2000, le Grange and colleagues, examined FBT in a sample of 40 adolescents with AN (11-17 years), demonstrating that 37% of patients had a "good" outcome, 25% had an "intermediate" outcome, and 37.5% had a "poor" outcome. A pilot study by Paulson-Karlsson et al. (2009) showed promising results in a sample of 32 female patients with a mean age of 15.4 years. According to the study, data collected at 18-month and 36-month follow-up indicated that 72% and 78% of patients had achieved recovery, respectively. Further validation for FBT was conducted by Robin and colleagues in 1994, and then replicated in 1999 (Robin et all, 1994; 1999). In the initial study, 73% of AN patients receiving FBT reached the 50<sup>th</sup> percentile of BMI for their age and/or were menstruating after treatment. At postassessment, this figure had increased to 89%, with 67% of FBT patients meeting the dual criteria of reaching the 50<sup>th</sup> percentile of BMI and menstruating. In the replication study, 80% of adolescent females receiving FBT had achieved their ideal weight at 1year follow-up (Robin et al., 1999). Further, Lock et al. (2006) demonstrated that, when assessed at long-term follow-up, 89% of their sample were above 90% ideal body weight, with 74% scoring in the normal range on the EDE, after receiving either 25

a short or long course of FBT. More recently, Chen et al. (2016) investigated FBT in a sample of 22 females (18-26 years) with AN or atypical AN. After receiving treatment, 68% of patients were no longer underweight, with this reducing slightly at 12-months post-treatment, with 59% of patients now classified at a healthy weight. Despite several promising studies, it should be noted that these results are not always consistent, with patients achieving a "good outcome" ranging from 37% to 90% in the literature (Eisler et al., 1997; Grange et al., 2000). One important factor which may help explain these inconsistent findings is the family itself. In Eisler et al'.s (2007) paper, the authors note that in their clinical experience they have found there is a small group of families who do not engage well, wherein the carers often feel particularly burdened by the problem and are generally self-blaming. As such, carers may alternate between being intensely involved in treatment and feeling completely overwhelmed by the enormity of the task and thus disengaging from treatment, which may in turn influence treatment outcome. In terms of attrition, drop-out rates from FBT range from 10% to 41% (Chen et al., 2016; Eisler et al., 1997; le Grange et al., 1992; Lock et al., 2006; Paulsson-Karlsson et al., 2009; Robin et al., 1994). Overall, outcomes for FBT are better than for adult treatments, suggesting that prognosis may be better for younger patients.

#### 1.2.5 The Status Quo of Anorexia Nervosa Treatment

Despite the range of therapies developed to treat AN, the disorder is notoriously difficult to treat, with between 31-50% of inpatients, and 23-57% of outpatients, dropping out prematurely (Carter et al., 2006; Carter, et al, 2004; Carter et al., 2012; Halmi, 2005; Schnicker et al., 2013), and only half of all patients receiving treatment 26

achieving full recovery, when considering therapies as an aggregate (Steinhausen, 2002). Furthermore, according to a report published in 2017 by the eating disorder charity B-EAT, 66.3% of their AN respondents experienced relapse after treatment, with patients having received inpatient treatment reporting the highest rates of relapse (77.6%) (B-EAT, 2017). A recent systematic review and meta-analysis by Berends et al. (2018) showed a more optimistic figure, estimating the overall rate of relapse for patients with AN to be 31%, based on their analysis of 16 studies which included various modes of outpatient and inpatient therapy. However, this still indicates that a third of those who are assessed as recovered at end of treatment will fail to maintain their recovered status, an even more worrisome figure considering the fact that recovery rates at the end of treatment are already relatively unimpressive. The highest risk of relapse occurred during the first year after discharge, and factors associated with relapse included weight and shape concerns, low desired weight, BP subtype diagnosis, high levels of exercise, poor psychosocial and/or global functioning, and a history of abuse and/or suicide attempts (Berends et al., 2018). Furthermore, whilst several trials have been conducted assessing the efficacy of various treatments, less is known about who might respond best to treatment in terms of clinical characteristics.

#### 1.3 Systematic Review and Meta-Analysis Rationale

Considering the low efficacy of current treatments, identification of predictors of dropout and outcome is essential in the quest for improving AN treatment, as pinpointing variables related to drop-out or poor treatment response could facilitate more specialised interventions for those who are identified at an early stage as at risk for a poor outcome. Furthermore, identification of prognostic factors can lend important 27

insight into the mechanisms of AN, which can help inform and improve upon current interventions. Based on the work by Waller et al. (2009), there is evidence to suggest that good early treatment response, meaning that patients show improvements early on in treatment, can predict later outcome, which highlights the need to create positive behavioural change early on.

Despite recent trends to attempt to identify commonalities across eating disorder diagnoses in order to inform trans-diagnostic treatment approaches (Dalle Grave et al., 2013; Fairburn et al., 2003; Wade et al., 2006), some researchers suggest there are likely to be specific outcome predictors for AN, compared to other eating disorders (Birmingham et al., 2009), which calls for the need to carry out a focused, AN-specific review. A recent review and meta-analysis conducted by Val and Wade (2015), whilst comprehensive in scope, rendered a gap in the literature in that predictors were assessed in terms of their relation to AN, bulimia nervosa (BN), and binge eating disorder (BED) as an aggregate, as opposed to individually. The problematic nature of this resides in the fact that AN differs from BN and BED both in terms of symptomatology, aetiological factors, and criteria for good outcome. With regards to outcome, the issue of weight particularly demonstrates why assessing eating disorders as an aggregate is troublesome, as weight gain is a critical aspect of good outcome for AN yet may indicate a poor outcome or neutral outcome for other eating disorders. Further highlighting issues arising from assessing eating disorders as an aggregate, there is some evidence that predictors differ for the different diagnoses. For example, Val and Wade (2015) hypothesised that lower levels of depression would be associated with a more positive prognosis in eating disorders; however, upon further scrutiny,

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this finding was only to be applicable for BN patients, with studies examining AN patients finding no association between depression and success within treatment (Le Grange et al., 2014; Speranza et al., 2007). Considering these issues, predictors may be best understood if the disorder is considered on an individual basis, as predictive variables pertaining to eating disorders may not necessarily apply trans-diagnostically. Moreover, the illness can be severe and enduring for many, highlighting further the need for a review identifying prognostic factors. However, whilst reviewing AN on an individual basis as opposed to trans-diagnostically allows for a better understanding of predictors, one issue which still remains is the disparate definitions of both dropout and outcome within the literature, with few studies demonstrating a consensus as to how these outcomes are defined, thereby rendering comparison problematic Furthermore, another issue to consider is the risk that what may be perceived as recovery from AN (e.g. weight gain) may in some cases actually be the result of an individual transitioning from one eating disorder to another (e.g. from AN to BN or BED, with binge eating resulting in weight gain). It is worthwhile noting that some studies have responded to this issue by using a composite to define good and poor outcome, e.g. BMI > 18.5 and scores within 1 SD of healthy norms of the Eating Disorder Examination Questionnaire (EDE-Q).

Considering the most recent reviews pertaining to AN specifically, one review of 35 studies examined sociodemographic predictors of treatment, finding only weak evidence to support the predictive value of variables on outcome (Bulik et al., 2007). A second review of seven studies, attempting to identify predictors of drop-out, concluded that evidence in support of the presence of robust predictors of drop-out

from AN treatment was both conflicting and scarce (Waller et al., 2009). The only factor shown to consistently predict drop-out based on this review was the presence of binge-purge behaviours (Waller et al., 2009). Clearly, an updated review integrating the past decade of research would be useful to elucidate more clearly the predictive value of variables on drop-out and outcome in AN treatment. Specifically, examining variables which can be identified at baseline, thus informing treatments from the beginning, would be useful.

#### 1.4 Objectives

While multiple studies have investigated potential predictors of drop-out and outcome in treatment of AN, development of a cohesive and up-to-date picture of the research literature has yet to be achieved. As such, the current review and meta-analysis aims to systematically investigate the existing AN literature and present a comprehensive summary of the evidence for predictors of drop-out and treatment outcome in patients with AN, as well as to highlight the strengths and limitations within the current literature.

#### 1.5 Methods

#### 1.5.1 Information Source and Search Strategy

The current study was conducted and reported in accordance with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA, Moher et al., 2009). The primary search strategy utilised multi-field searches within four databases, PsychInfo, Medline, Embase, and PubMed. All four databases were searched from the beginning 30 of the databases to July 2021 using the following terms: (anorexia) and (treatment OR therapy OR psychotherapy) and (response OR outcome OR drop-out OR attrition OR premature termination OR treatment acceptance) and (predictor OR predict). Hand searches of bibliographies of identified studies and relevant reviews were conducted to identify any additional pertinent studies not identified in the electronic search.

#### 1.5.2 Inclusion/Exclusion Criteria

Empirical studies that (a) were published in English in a peer reviewed journal, examining (b) pre-treatment patient variables as predictors of outcome and/or dropout in (c) treatment with (d) a formal diagnosis of AN restrictive or BP subtype, or atypical AN, in cases wherein BMI was <19, according to DSM-III, -IV, or -5 or ICD-9 or -10 (International Statistical Classification of Diseases and Related Health Problems International Classification) criteria were included. Studies reporting results from individuals without a formal diagnosis of AN according to DSM or ICD criteria were excluded. Of note, broadly defined AN (defined as either atypical AN or Eating Disorder Not Otherwise Specified depending on which year the relevant study was conducted and which diagnostic manual was used) included individuals whose disorders fulfilled, but not all, of the features of AN, for example in instances wherein all the criteria of AN were met except the weight criterion (APA, 2013; Thomas et al., 2009; World Health Organisation, 1992). Furthermore, only studies examining adolescents and adults aged 16 and up were included.

#### 1.5.3 Study Selection

Search outputs from the three databases were first cross-referenced for duplicates which were removed before examining the results. Then, abstracts were assessed against inclusion criteria, as well as to determine whether they broadly pertained to the review questions. The full-text of all remaining studies was then reviewed to determine eligibility for inclusion in the meta-analysis, including effect size calculation. If studies did not present sufficient data to calculate an effect size, the authors of the relevant study were contacted in order to attempt to attain the necessary data to calculate effect sizes. To check its reliability, a second blinded rater (N.K.) was provided with a random sample of 100 of the 1262 articles identified in the primary search and evaluated these against the criteria for inclusion. A third blinded rater (S.A.) examined an additional 147 articles. There was perfect (i.e. 100%) agreement achieved upon comparing the initial and the second and third (blinded) rater decisions regarding which articles met criteria for inclusion in the review. Presented in Figure 1-1 is a flow diagram of the selection process guided by the PRISMA guidelines.

#### 1.5.4 Quality Assessment of Included Studies

The methodological quality of included studies was assessed in accordance with the STROBE statement (see Table 1-1). The STROBE checklist comprises 22 items assessing the quality of scientific articles. The checklist was utilised to calculate the percentage of STROBE criteria met by each paper, known as the STROBE score. Presented in Table 1-1 are these scores in descending order. Following the method of previous reviews (Olmos, Antelo, Vazquez, Smecuol, Maunno, & Bai, 2008; Teti,

Rebok, Rojas, Grendas, & Daray, 2014), overall quality assessment from A-C was used in place of a sum score (Jüni, Altman, & Egger, 2001). The three categories of global quality assessment include: A) the study met more than 80% of STROBE criteria, (B) the study met between 50–80% of STROBE criteria, or (C) the study fulfilled less than 50% of STROBE criteria.

#### 1.5.5 Data Extraction

For each category of predictor of drop-out and outcome, data was extracted from all studies featuring that predictor. This included the study type (ie. prospective or randomised control trial), the number of participants included in the analysis for that specific predictor, treatment method, definition of the outcome variable, and the predictor measure. Characteristics of the studies included in the meta-analyses are presented in Table 1-2.

#### 1.5.6 Grouping Effects

In some instances, multiple effect sizes for one predictor of outcome were calculated from the same study, as the result of a single predictor having been used to predict more than one type of outcome (e.g. eating disorder pathology and BMI). As it is not recommended to include multiple effects from a single study when conducting metaanalyses as this would increase the likelihood of a single study having undue influence on results (Scammaca et al., 2014), effects of a predictor were combined into an aggregate effect size in instances where multiple types of outcome were presented for a single predictor.

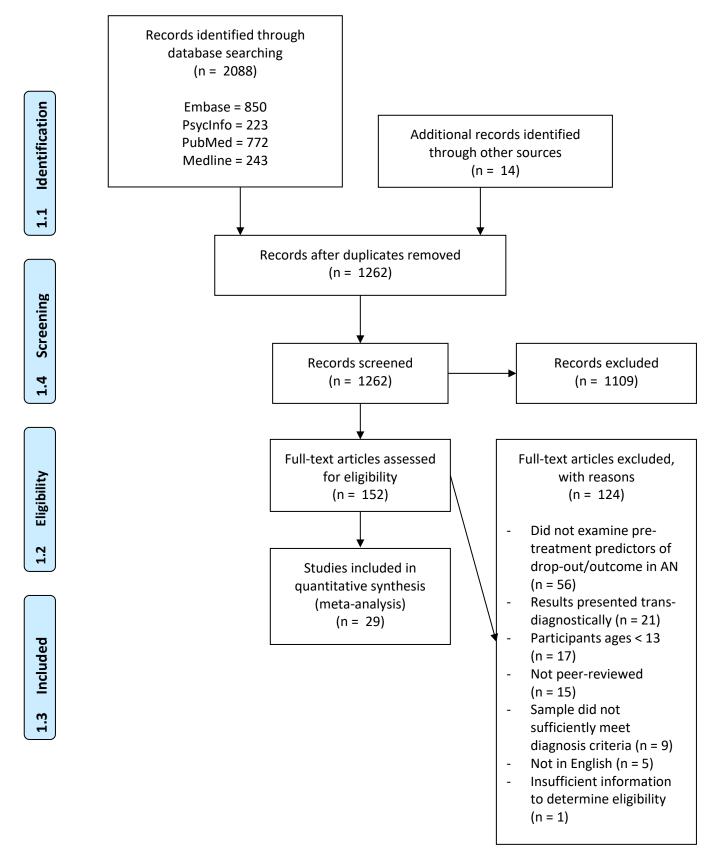


Figure 1-1. PRISMA flow diagram of study selection.

Table 1-1. Percentage of STROBE<sup>a</sup> quality criteria met ("STROBE score") for 29

First author (Date)	STROBE score (%)	Overall quality
		assessment <sup>b</sup>
Hubert et al. (2013)	88%	А
Goddard et al. (2013)	86%	А
Abd Elbaky et al. (2014)	85%	А
Kahn & Pike (2001)	85%	А
Le Grange et al. $(2014_{a,b})$	85%	А
Wild et al. (2016)	77%	В
Calugi et al. (2014)	76%	В
Jordan et al. (2014)	76%	В
Mewes et al. (2008)	76%	В
Sly et al. (2013)	76%	В
El Gnoch et al. (2013)	75%	В
Lockwood et al. (2012)	75%	В
Mekori et al. (2017)	75%	В
Marcoulides & Waller	73%	В
(2012)		
McHugh et al. (2007)	73%	В
Lock et al. (2012)	73%	
Hartmann et al. (2007)	71%	В
Hartmann et al. (2010)	71%	В
Ngo & Iseerlin (2014)	71%	В
Pham-Scottez et al.	71%	В
(2012)		
Bewell & Carter (2008)	68%	В
Wales et al. (2016)	68%	В
Thaler et al. (2016)	66%	В
Kastner et al. (2015)	64%	В
Surgenor et al. (2004)	63%	В
Zeeck et al. (2005)	63%	В
Doyle et al. (2010)	62%	В
Fassino et al. (2001)	62%	В
Gowers & Smyth (2004)	59%	В

studies included in the meta-analysis, ordered by STROBE score.

<sup>a</sup>Strengthening the reporting of observational studies in epidemiology <sup>b</sup>Scale of A-C

Furthermore, due to the disparity of definitions of drop-out and outcome within the literature, we opted not to include a narrow definition of drop-out and outcome to

ensure the review be as inclusive as possible. Thus, specific outcome/drop-out definitions per study are presented in Table 1-2.

# 1.5.7 Statistical Analysis

#### 1.5.7.1 Effect Sizes

Due to correlation coefficients having been shown to best enable interpretation of the practical significance of an effect (Field, 2001), as well as having been previously utilised in similar meta-analyses of predictors of outcome in eating disorders (Vall & Wade, 2015), an effect size expressed as the correlation coefficient, r, was calculated for each predictor variable for drop-out and outcome by entering the reported or obtained statistical outcomes into an effect size calculator. For a study to be included in the analysis, sufficient statistics for an effect size to be calculated had to be provided. Effect sizes were calculated for both significant and non-significant findings alike.

#### **1.5.7.2** Publication Biases

To determine the effect of the "file-drawer problem", referring to the tendency of positive results to be published over negative or non-confirmatory results, the "fail safe N" was calculated for each meta-analysis, wherein the "fail safe N" denotes the number of additional 'negative' studies (studies in which the effect was zero) that would be needed to increase the P-value for the meta-analysis above 0.05 (Rosenthal, 1979). In instances wherein this estimate is larger than the number of studies included

Author name & year	Design	N	Inpatient or outpatient	Treatment	Outcome measure	Predictor measure	R (95% CI)
Studies assessing w depression predicts							
Surgenor et al. (2004)	Prospective	213	Inpatient	Not described	Any self-discharge from hospital against medical advice, or simply leaving the inpatient setting resulting in the designation of absent without leave	BDI	-0.01 (-0.14:0.13)
Zeeck et al. (2005)	Prospective	133	Inpatient	CBT + psychodynamic	Any one-sided (team or patient) decision for premature termination of treatment before the planned regular discharge date	Presence of a current major depressive episode	-0.26 (-0.43:-0.08)
Lockwood et al. (2012)	Prospective	40	Outpatient	CBT	Any case where the patient decided to terminate therapy before the 10 <sup>th</sup> session, either by notifying the therapist or by failing to attend two consecutive appointments without communication (despite written prompting)	Depression subscale of BSI	-0.05 (-0.34:0.25)
Marcoulides & Waller (2012)	Prospective	37	Outpatient	СВТ	Leaving treatment for whatever reason (e.g. dropping out, moving out of an area) before the 20 <sup>th</sup> session	Depression subscale of BSI	0.05 (-0.26:0.36)
Hubert et al. (2013)	Prospective	359	Inpatient	Multi-disciplinary	Not completing a therapeutic contract (ie. not reaching discharge weight)	Presence of depression during hospitalisation	0.04 (-0.06:0.15)
Abd Elbaky et al. (2014)	RCT	63	Outpatient	CBT-AN or SSCM	Not described	BDI	0.16 (-0.08:0.39)
Calugi et al.(2014)	Prospective	63	Inpatient	CBT	Not described	Diagnosis of a Major Depressive Episode	0.05 (-0.19:0.29)
Jordan et al. (2014) 27	Prospective	56	Outpatient	Psychotherapy	Completing <15 of 20 scheduled sessions over 6 months for any reason	HDRS	0.17 (-0.09:41)

# Table 1-2. Characteristics of studies included in the meta-analyses.

					(including medical reasons, psychiatric reasons, logistical withdrawal, progress withdrawal (early improvers who did not wish to continue) and patient-initiated withdrawal)		
Studies assessing w	hether Axis I or	II comor	bidity predicts d	lrop-out			
Surgenor et al. (2004)	Prospective	213	Inpatient	Not described	Any self-discharge from hospital against medical advice, or simply leaving the inpatient setting resulting in the designation of absent without leave	Presence of any additional Axis I or Axis II disorder	0.21 (-0.04:0.44)
Pham-Scottez et al. (2012)	Prospective	64	Inpatient	Multi-disciplinary	Any discharge before normal treatment program termination (the planned day of discharge)	Presence of a personality disorder	-0.03 (-0.17:0.10)
Lock et al. (2016)	RCT	86	Outpatient	Long or short-term family therapy	Participating in less than 80% of the assigned therapy	Co-morbid psychopathology (K-SADS)	-0.13 (-0.34:0.08)
Studies determining predicts drop-out	whether genera	l psycho	pathology				
Zeeck et al. (2005)	Prospective	133	Inpatient	CBT + psychodynamic	Any one-sided (team or patient) decision for premature termination of treatment before the planned regular discharge date	SCL-R-90 Global Severity Index	0.06 (-0.11:0.23)
El Gnoch et al. (2013)	Prospective	53	Inpatient	CBT-E	Not completing the treatment program	BSI Global Severity Index	-0.14 (-0.39:0.12)
Abd Elbaky et al.(2014)	RCT	63	Outpatient	CBT-AN or SSCM	Not described	SF-12 Mental Health Component	-0.21 (-0.43:0.04)
Studies determining	whether eating		pathology pred				
Surgenor et al. (2004)	Prospective	213	Inpatient	Not described	Any self-discharge from hospital against medical advice, or simply leaving the inpatient setting resulting in the designation of absent without leave	EAT mean score	0.11 (-0.03-0.24)

Marcoullides & Waller (2012)	Prospective	37	Outpatient	СВТ	Leaving treatment for whatever reason (e.g. dropping out, moving out of an area) before the 20 <sup>th</sup> session	EDE-Q global score	0.17 (-0.15:0.45)
El Gnoch et al. (2013)	Prospective	53	Inpatient	CBT-E	Not completing the treatment program	EDE global score	-0.20 (-0.44:0.07
Sly e al. (2013)	Prospective	90	Inpatient	Not described	Any termination of treatment ended via a unilateral decision either by service users or staff	EDE-Q global score	0.12 (-0.09:0.31)
Abd Elbaky et al. (2014)	RCT	63	Outpatient	CBT-AN or SSCM	Not described	EDE global score	0.28 (0.04:0.50)
Jordan et al. (2014)	Prospective	56	Outpatient	Psychotherapy	Completing <15 of 20 scheduled sessions over 6 months for any reason (including medical reasons, psychiatric reasons, logistical withdrawal, progress withdrawal (early improvers who did not wish to continue) and patient-initiated withdrawal)	EDE global score	0.01 (-0.24:0.26)
Studies assessing w	vhether BMI pred	icts dro	p-out				
Surgenor et al. (2004)	Prospective	213	Inpatient	Not described	Any self-discharge from hospital against medical advice, or simply leaving the inpatient setting resulting in the designation of absent without leave	Admission BMI	-0.21 (-0.33:-0.08)
Zeeck et al. (2005)	Prospective	133	Inpatient	CBT + psychodynamic	Any one-sided (team or patient) decision for premature termination of treatment before the planned regular discharge date	Admission BMI	-0.11 (-0.27:0.05)
Mewes et al. (2008)	Prospective	100	Inpatient	СВТ	Prematurely aborting treatment for the patient's own reasons or staff-initiated discharge due to a persistent lack of motivation or compliance	Admission BMI	-0.16 (-0.35:0.03)

(2012)       terminate therapy before the 10 <sup>th</sup> session, either by notifying the therapist or by failing to attend two consecutive appointments without communication (despite written promunication (despite written promunication (despite written program termination (the planned day of discharge)       Admission BMI       -0.03 (planted)         Pham-Scottex et al. (2012)       Prospective       64       Inpatient       Multi-disciplinary       Any discharge before normal treatment program termination (the planned day of discharge)       Admission BMI       -0.03 (planted)         El Gnoch et al. (2012)       Prospective       53       Inpatient       CBT-E       Not completing the treatment program       Baseline BMI       -0.10 (planted)         Hubert et al. (2013)       Prospective       359       Inpatient       Multi-disciplinary       Not completing a therapeutic contract (ie. not reaching discharge weight)       Admission BMI       -0.13 (planted)         Sily et al. (2013)       Prospective       90       Inpatient       Not described       Any termination of treatment ended via a unilateral decision either by service users or staff       Admission BMI       -0.13 (planter)         Jordan et al. (2014)       Prospective       56       Outpatient       Psychotherapy       Completing <15 of 20 scheduled sessions over 6 months for any reason (including medical reasons, logistical withdrawal) progress withdrawal (early improvers who did not withdrawal)       -0.13 (psychoeducation)         Thaler	0.22 (-0.01:0.42)	Having the binge/purge subtype	Any discharge pursued by patients prior to reaching their target weight of 90% of an ideal body weight and maintaining it for a 2 week minimum	Multi-disciplinary	Inpatient	81	Prospective	Kahn & Pike (2001)
(2012)terminate thrapy before the 10th session, either by notifying the thrapy before the 10th session, either by notifying the thrapist or by failing to attend two consecutive appointments without communication (despite written prompting)Admission BMI-0.03 ( e.0.03 ( e.0.03 ( discharge)Pham-Scottex et al. (2012)Prospective 5364InpatientMulti-disciplinary discharge)Any discharge before normal treatment program termination (the planned day of discharge)Admission BMI-0.03 ( e.0.03 ( discharge)El Gnoch et al. 						· · · · · · · · · · · · · · · · · · ·		
(2012)terminate therapy before the 10th session, either by notifying the therapist or by failing to attend two consecutive appointments without communication (despite written prompting)Admission BMI-0.03 (Pham-Scottex et al. (2012)Prospective64InpatientMulti-disciplinary Official consecutive appointments without communication (despite written prompting)Admission BMI-0.03 (Pham-Scottex et al. (2012)Prospective53InpatientCBT-ENot completing the treatment program (ie. not reaching discharge weight)Admission BMI-0.10 (Hubert et al. (2013)Prospective359InpatientMulti-disciplinaryNot completing the treatment program (ie. not reaching discharge weight)Admission BMI-0.13 (Sly et al. (2013)Prospective90InpatientNot described a unilateral decision either by service users or staffAdmission BMI-0.13 (Jordan et al. (2014)Prospective56OutpatientPsychotherapyCompleting r15 of 20 scheduled sessions over 6 months for any reason (including medical reasons, psychiatric reasons, logistical withdrawal, progress withdrawal (early improvers who did not wish to continue) and patient-initiatedAdmission BMI-0.13 (	0.17 (-0.03:0.37)	Admission BMI	Completing <5 weeks of treatment	,	•		•	, , , , , , , , , , , , , , , , , , ,
(2012)terminate therapy before the 10th session, either by notifying the therapist or by failing to attend two consecutive appointments without communication (despite written prompting)Admission BMI-0.03 (Pham-Scottex et al. (2012)Prospective64InpatientMulti-disciplinaryAny discharge before normal treatment program termination (the planned day of discharge)Admission BMI-0.03 (El Gnoch et al. (2013)Prospective53InpatientCBT-ENot completing the treatment programBaseline BMI-0.10 (Hubert et al. (2013)Prospective359InpatientMulti-disciplinaryNot completing a therapeutic contract (ie. not reaching discharge weight)Admission BMI-0.13 (-0.23)Sly et al. (2013)Prospective90InpatientNot describedAny termination of treatment ended via a unilateral decision either by serviceAdmission BMI0.05 (-	-0.13 (-0.37:0.13)	Admission BMI	sessions over 6 months for any reason (including medical reasons, psychiatric reasons, logistical withdrawal, progress withdrawal (early improvers who did not wish to continue) and patient-initiated	Psychotherapy	Outpatient	56	Prospective	
(2012)terminate therapy before the 10th session, either by notifying the therapist or by failing to attend two consecutive appointments without communication (despite written prompting)terminate therapy before the 10th session, either by notifying the therapist or by failing to attend two consecutive appointments without communication (despite written prompting)Pham-Scottex et al. (2012)Prospective64InpatientMulti-disciplinaryAny discharge before normal treatment program termination (the planned day of discharge)Admission BMI-0.03 ( 0.03 ( 	0.05 (-0.16:0.25)	Admission BMI	a unilateral decision either by service	Not described	Inpatient	90	Prospective	Sly et al. (2013)
<ul> <li>(2012)</li> <li>terminate therapy before the 10<sup>th</sup> session, either by notifying the therapist or by failing to attend two consecutive appointments without communication (despite written prompting)</li> <li>Pham-Scottex et al. Prospective 53 Inpatient CBT-E</li> <li>Not completing the treatment program Baseline BMI</li> </ul>	-0.13 (-0.23:-0.03)	Admission BMI		Multi-disciplinary	Inpatient	359	Prospective	
<ul> <li>(2012) terminate therapy before the 10<sup>th</sup> session, either by notifying the therapist or by failing to attend two consecutive appointments without communication (despite written prompting)</li> <li>Pham-Scottex et Prospective 64 Inpatient Multi-disciplinary Any discharge before normal treatment Admission BMI -0.03 (program termination (the planned day of program termination (the planned</li></ul>	-0.10 (-0.35:0.17)	Baseline BMI	Not completing the treatment program	CBT-E	Inpatient	53	Prospective	
(2012) terminate therapy before the 10 <sup>th</sup> session, either by notifying the therapist or by failing to attend two consecutive appointments without communication	-0.03 (-0.26:0.21)	Admission BMI	program termination (the planned day of	Multi-disciplinary	Inpatient	64	Prospective	
Lockwood et al. Prospective 40 Outpatient CRT Any case where the patient decided to Initial RMI 0.04 (	0.04 (-0.26:0.33)	Initial BMI	session, either by notifying the therapist or by failing to attend two consecutive appointments without communication	СВТ	Outpatient	40	Prospective	Lockwood et al. (2012)

Surgenor et al. (2004)	Prospective	213	Inpatient	Not described	Any self-discharge from hospital against medical advice, or simply leaving the inpatient setting resulting in the designation of absent without leave	Having the binge/purge subtype	0.14 (-0.00:0.27)
Zeeck et al. (2005)	Prospective	133	Inpatient	CBT + psychodynamic	Any one-sided (team or patient) decision for premature termination of treatment before the planned regular discharge date	Having the binge/purge subtype	0.07 (-0.10:0.23)
Bewell et al. (2008)	Prospective	127	Inpatient		Discharge before reaching a BMI of 20	Having the binge/purge	0.16 (-0.02:0.32)
El Gnoch et al. (2013)	Prospective	53	Inpatient	CBT-E	Not completing the treatment program	subtype Having the binge/purge subtype	0.00 (-0.26:0.27)
Hubert et al. (2013)	Prospective	359	Inpatient	Multi-disciplinary	Not completing a therapeutic contract (ie. not reaching discharge weight)	Having the binge/purge subtype	0.01 (-0.1:0.11)
Abd Elbaky et al. (2014)	RCT	63	Outpatient	CBT-AN or SSCM	Not described	Having the binge/purge subtype	0.36 (0.10:0.57)
Jordan et al. (2014)	Prospective	56	Outpatient	Psychotherapy	Completing <15 of 20 scheduled sessions over 6 months for any reason (inclluding medical reasons, psychiatric reasons, logistical withdrawal, progress withdrawal (early improvers who did not wish to continue) and patient-initiated withdrawal)	Having the binge/purge subtype	0.12 (-0.14:0.37)
Studies assessing w	hether illness du		redicts drop-out		ł		
Surgenor et al. (2004)	Prospective	213	Inpatient	Not described	Any self-discharge from hospital against medical advice, or simply leaving the inpatient setting resulting in the designation of absent without leave	Number of years since first diagnosis	0.04 (-0.10:-0.17)
Zeeck et al. (2005)	Prospective	133	Inpatient	CBT + psychodynamic	Any one-sided (team or patient) decision for premature termination of	Illness duration	-0.11 (-0.27:0.06)

					treatment before the planned regular discharge date		
Marcoullides & Waller (2012)	Prospective	37	Outpatient	CBT	Leaving treatment for whatever reason (e.g. dropping out, moving out of an area) before the 20 <sup>th</sup> session	Illness duration	-0.02 (-0.32:0.29)
Pham-Scottex et al. (2012)	Prospective	64	Inpatient	Multi-disciplinary	Any discharge before normal treatment program termination (the planned day of discharge)	Illness duration	0.20 (-0.04:0.42)
Sly et al. (2013)	Prospective	90	Inpatient	Not described	Any termination of treatment ended via a unilateral decision either by service users or staff	Illness duration	-0.09 (-0.29:0.11)
Abd Elbaky et al. (2014)	RCT	63	Outpatient	CBT-AN or SSCM	Not described	Illness duration	0.18 (-0.06:0.41)
Jordan et al. (2014)	Prospective	56	Outpatient	Psychotherapy	Completing <15 of 20 scheduled sessions over 6 months for any reason (inclluding medical reasons, psychiatric reasons, logistical withdrawal, progress withdrawal (early improvers who did not wish to continue) and patient-initiated withdrawal)	Illness duration (years)	0.08 (-0.17:0.33)
Studies assessing v	vhether previous	treatme	nt predicts drop	-out	·		
Surgenor et al. (2004)	Prospective	213	Inpatient	Not described	Any self-discharge from hospital against medical advice, or simply leaving the inpatient setting resulting in the designation of absent without leave	Having previously received inpatient treatment in an eating disorders unit	-0.07 (-0.20:0.06)
Pham-Scottex et al. (2012)	Prospective	64	Inpatient	Multi-disciplinary	Any discharge before normal treatment program termination (the planned day of discharge)	Number of previous hospitalisations	0.07 (-0.17:0.31)
Hubert et al. (2013)	Prospective	359	Inpatient	Multi-disciplinary	Not completing a therapeutic contract (ie. not reaching discharge weight)	Number of previous hospitalisations	0.17 (0.07:0.27)

Sly et al. (2013)	Prospective	90	Inpatient	Not described	Any termination of treatment ended via a unilateral decision either by service users or staff	Number of previous treatments for AN	-0.01 (-0.21:0.19)
Jordan et al. (2014)	Prospective	56	Outpatient	Psychotherapy	Completing <15 of 20 scheduled sessions over 6 months for any reason (including medical reasons, psychiatric reasons, logistical withdrawal, progress withdrawal (early improvers who did not wish to continue) and patient-initiated withdrawal)	Previous treatment (ED or any psychiatric)	-0.08 (-0.33:0.18)
Studies assessing w	hether age at or	iset pred	dicts drop-out				
Zeeck et al. (2005)	Prospective	133	Inpatient	CBT + psychodynamic	Any one-sided (team or patient) decision for premature termination of treatment before the planned regular discharge date	Age at onset	0.01 (-0.16:0.18)
Pham-Scottex et al. (2012)	Prospective	64	Inpatient	Multi-disciplinary	Any discharge before normal treatment program termination (the planned day of discharge)	Age at onset	0.04 (-0.20:0.28)
Hubert et al. (2013)	Prospective	359	Inpatient	Multi-disciplinary	Not completing a therapeutic contract (ie. not reaching discharge weight)	Age at onset	-0.03 (-0.13:0.07)
Studies assessing w			predicts drop-or				
Surgenor et al. (2004)	Prospective	213	Inpatient	Not described	Any self-discharge from hospital against medical advice, or simply leaving the inpatient setting resulting in the designation of absent without leave	Age at admission	0.06 (-0.08:0.19)
Zeeck et al. (2005)	Prospective	133	Inpatient	CBT + psychodynamic	Any one-sided (team or patient) decision for premature termination of treatment before the planned regular discharge date	Age at admission	-0.11 (-0.2:0.06)
Marcoullides & Waller (2012)	Prospective	37	Outpatient	СВТ	Leaving treatment for whatever reason (e.g. dropping out, moving out of an area) before the 20 <sup>th</sup> session	Age at admission	0.04 (-0.30:0.31)

El Gnoch et al.	Prospective	53	Inpatient	CBT-E	discharge) Not completing the treatment program	Age at admission	0.19 (-0.07:0.43)
(2013)	<b>D</b> <i>i</i>	0.50			N		
Hubert et al. (2013)	Prospective	359	Inpatient	Multi-disciplinary	Not completing a therapeutic contract (ie. not reaching discharge weight)	Age at admission	0.15 (0.05:0.25)
Jordan et al. (2014)	Prospective	56	Outpatient	Psychotherapy	Completing <15 of 20 scheduled sessions over 6 months for any reason (including medical reasons, psychiatric reasons, logistical withdrawal, progress withdrawal (early improvers who did not wish to continue) and patient-initiated withdrawal)	Age at admission	-0.32 (-0.54:- 0.07)
Sly et al. (2013)	Prospective	90	Inpatient	Not described	Any termination of treatment ended via a unilateral decision either by service users or staff	Age at admission	-0.06 (-0.26:0.14)
Thaler et al. (2016)	Prospective	89	Inpatient	CBT, SSCM & psychoeducation	Completing <5 weeks of treatment	Age at admission	-0.04 (-0.25:0.16)
Studies assessing w	hether motivation	n predic	ts drop-out				
Gowers & Smyth (2004)	Prospective	42	Outpatient	СВТ	Not remaining in treatment at 6 weeks	Being categorised in a "higher motivation" group based on 6 motivational questions	-0.43 (-0.65:- 0.15)
Sly et al. (2013)	Prospective	90	Inpatient	Not described	Any termination of treatment ended via a unilateral decision either by service users or staff	ANSOCQ	-0.15 (-0.34:0.06)
		~ ~	0.1.1.1.1.1.1	CBT-AN or SSCM	Not described	ANSOCQ	-0.08 (-0.31:0.16
Abd Elbaky et al. (2014)	RCT	63	Outpatient		Not described	ANOOOQ	-0.00 (-0.01.0.10
			•		Improved versus not improved groups:	Minor depression	0.02 (-0.28:0.32)

					least 50% of their BMI under the threshold of 17.5 and 30% improvement on MROAS		
Le Grange et al. (2014)	RCT	63	Outpatient	CBT or SSCM	EDQoL, MCS, BDI	BDI	0.32 (0.08:0.53)
Kastner et al. (2015)	Prospective	213	Inpatient	Not described (multi-site)	BMI gain	PHQ-9	-0.08 (-0.21:0.05)
Wild et al. (2016)		184	Outpatient	Focal psycho-dynamic psycho-therapy (FPT) or enhanced cognitive behavior therapy (CBT- E) or optimized treatment- as-usual (TAU-O) approach	Global outcome (recovered, partial syndrome, full syndrome) defined by BMI and PSR. Recovered = PSR 1 or 2 and BMI $\geq$ 17.5; full syndrome = PSR 5 or 6 and BMI < 17.5	Depression co-morbidity	0.08 (-0.06:0.23)
Studies assessing	whether psychopa	athology	predicts poorer	outcome			
Fassino et al. (2001)	Prospective	40	Inpatient or outpatient	Psychotherapy	Improved versus not improved groups: Considered improved if recovered at least 50% of their BMI under the threshold of 17.5 and 30% improvement on MROAS	Mild anxiety	0.23 (-0.09:0.51)
Goddard et al. (2013)	Multi-centre cohort study	107	Daypatient and inpatient	Not described (multi- centre study)	EDE-Q	DASS	0.58 (0.43:0.69)
Wild et al. (2016)		184	Outpatient	Focal psycho-dynamic psycho-therapy (FPT) or enhanced cognitive behavior therapy (CBT- E) or optimized treatment- as-usual (TAU-O) approach	Global outcome (recovered, partial syndrome, full syndrome) defined by BMI and PSR. Recovered = PSR 1 or 2 and BMI $\geq$ 17.5; full syndrome = PSR 5 or 6 and BMI < 17.5		0.10 (-0.05:24)
Studies assessing	whether eating dis	sorder p	athology predicts	s poorer outcome			
Goddard et al. (2013)	Multi-centre cohort study	107	Daypatient and inpatient	Not described (multi- centre study)	EDE-Q		0.54 (0.39:0.66)

Le Grange et al. (2014)	RCT	63	Outpatient	CBT or SSCM	EDQoL, MCS, BDI	EDE global score	0.24 (-0.01:0.46)
Wales et al. (2016)	Prospective	79	Inpatient	Individual psychodynamic therapy + group therapy (CBT, addressing abnormal exercise, mindfulness, psychoeducation, pilates & self-esteem)	Positive versus non-positive outcome: Considered positive outcome if BMI of 17.5 kg/m <sup>2</sup> achieved within individual time frame	EDE-Q global score	0.05 (-0.17:0.26)
Wild et al. (2016)		184	Outpatient	Focal psycho-dynamic psycho-therapy (FPT) or enhanced cognitive behavior therapy (CBT- E) or optimized treatment- as-usual (TAU-O) approach	Global outcome (recovered, partial syndrome, full syndrome) defined by BMI and PSR. Recovered = PSR 1 or 2 and BMI $\geq$ 17.5; full syndrome = PSR 5 or 6 and BMI < 17.5	EDI	0.18 (0.04:0.32)
Studies assessing w			mission predicts	•			
Fassino et al. (2001)	Prospective	40	Inpatient or outpatient	Psychotherapy	Improved versus not improved groups: Considered improved if recovered at least 50% of their BMI under the threshold of 17.5 and 30% improvement on MROAS	Initial BMI	0.22 (-0.08:0.49)
Hartmann et al. (2007)	Prospective	85	Inpatient	CBT + psychodynamic	Reaching a BMI of 17.5	Admission BMI	0.24 (0.03:0.43)
Mewes et al. (2008)	Prospective	100	Inpatient	CBT	BMI gain	Admission BMI	0.20 (0.00:0.38)
Doyle et al. (2010)	Prospective	65	Outpatient	FBT	Remitted versus non-remitted: Considered remitted if 95% of IBW achieved at end of treatment	Baseline %IBW	-0.47 (0.64:025)
Hartmann et al. (2010)	Prospective	113	Inpatient or daypatient	Multi-modal therapy (psychodynamic psychotherapy, body therapy, relaxation	Weight gain	Admission BMI	-0.63 (-0.73:0.50)

				therapy, art therapy, symptom oriented behavioural interventions, & family therapy)			
Ngo & Isserlin (2010)	Retrospective	49	Daypatient	Individual & group therapy incorporating psychoeducational, cognitive-behavioral & are therapy	Reaching minimum 92.5% IBW by discharge	Being >= 85% IBW	-0.21 (-0.46:0.07)
Wildes et al. (2011)	Prospective	154	Inpatient or daypatient	CBT or DBT	BMI >= 18.5, no binge/purge in past 28 days, EDE global within two standard deviations of community norms	Admission BMI	-0.25 (-0.39:- 0.10)
Goddard et al. (2013)	Multi-centre cohort study	107	Daypatient and inpatient	Not described (multi- centre study)	EDE-Q	Admission BMI	0.10 (-10:0.28)
Ngo & Isserlin (2013)	Prospective	49	Daypatient	Psychoeducation, CBT & art therapy	Success versus failure: Success defined by minimum 92.5% IBW achieved at discharged; failure defined by (1) failure to reach 92.5% IBW at discharge, (2) admission to inpatient setting any time after discharge from daypatient setting, or (3) readmission to the daypatient setting	Admission BMI	-0.21 (-0.46:0.07)
Le Grange et al. (2014)	RCT	63	Outpatient	CBT or SSCM	EDQoL, MCS, BDI	Admission BMI	-0.18 (0.41:0.07)
Kastner et al. (2015)	Prospective	213	Inpatient	Not described (multi-site)	BMI gain	Admission BMI	0.50 (0.39:0.59)
Wales et al. (2016)	Prospective	87	Inpatient	Individual psychodynamic therapy + group therapy (CBT,	Positive versus non-positive outcome: Considered positive outcome if BMI of	Admission BMI	-0.20 (-0.45:-0.06)

				addressing abnormal exercise, mindfulness, psychoeducation, pilates & self-esteem)	17.5 kg/m <sup>2</sup> achieved within individual time frame		
Wild et al. (2016)		184	Outpatient	Focal psycho-dynamic psycho-therapy (FPT) or enhanced cognitive behaviour therapy (CBT- E) or optimized treatment- as-usual	Global outcome (recovered, partial syndrome, full syndrome) defined by BMI and PSR. Recovered = PSR 1 or 2 and BMI $\geq$ 17.5; full syndrome = PSR 5 or 6 and BMI < 17.5	Admission BMI	-0.34 (-0.46:-0.21)
Mekori et al. (2017)	Prospective	30	Inpatient	(TAU-O) approach Structural nutritional rehabilitation programme & multimodal treatment	BMI at follow-up 1 year post-discharge	Admission BMI	0.28 (-0.09:058)
Studies assessing w			type predicts po	orer outcome			
Ngo & Isserlin (2010)	Retrospective	49	Daypatient	Individual & group therapy incorporating psychoeducational, cognitive-behavioural & are therapy	Reaching minimum 92.5% IBW by discharge	Having the binge/purge subtype	-0.08 (-0.35:0.21)
Wildes et al. (2011)	Prospective	154	Inpatient or daypatient	CBT or DBT	BMI >= 18.5, no binge/purge in past 28 days, EDE global within two standard deviations of community norms	Having the binge/purge subtype	0.34 (0.19:0.47)
Le Grange et al. (2014)	RCT	63	Outpatient	CBT or SSCM	EDQoL, MCS, BDI	Having the binge/purge subtype	0.23 (-0.02:0.45)
Wales et al. (2016)	Prospective	87	Inpatient	Individual psychodynamic therapy + group therapy (CBT, addressing abnormal exercise, mindfulness, psychoeducation, pilates & self-esteem)	Positive versus non-positive outcome: Considered positive outcome if BMI of 17.5 kg/m <sup>2</sup> achieved within individual time frame	Having the binge/purge subtype	0.07 (-0.14:0.28)
Wild et al. (2016)		184		,		Having the binge/purge subtype	0.02 (-0.13:0.16)

Studies assessing w Fassino et al.	Prospective	40	Inpatient or	Psychotherapy	Improved versus not improved groups:	Years of disease	0.02 (-0.28:0.31)
(2001) (2001)			Considered improved if recovered at least 50% of their BMI under the threshold of 17.5 and 30% improvement on MROAS		0.02 ( 0.2010.01)		
Doyle et al. (2010)	Prospective	65	Outpatient	FBT	Remitted versus non-remitted: Considered remitted if 95% of IBW achieved at end of treatment	Illness duration	0.32 (0.08:0.52)
Le Grange et al. (2014)	RCT	63	Outpatient	CBT or SSCM	EDQoL, MCS, BDI		0.28 (0.03:0.49)
Wales et al. (2016)	Prospective	87	Inpatient	Individual psychodynamic therapy + group therapy (CBT, addressing abnormal exercise, mindfulness, psychoeducation, pilates & self-esteem)	Positive versus non-positive outcome: Considered positive outcome if BMI of 17.5 kg/m <sup>2</sup> achieved within individual time frame	Illness duration (months)	-0.07 (-0.28:0.13)
Studies assessing w Fassino et al. (2001)	hether age of or Prospective	nset pre 40	dicts poorer outc Inpatient or outpatient	come Psychotherapy	Improved versus not improved groups: Considered improved if recovered at least 50% of their BMI under the threshold of 17.5 and 30% improvement on MROAS	Age of onset	0.04 (-0.26:0.34)
Wales et al. (2016)	Prospective	87	Inpatient	Individual psychodynamic therapy + group therapy (CBT, addressing abnormal exercise, mindfulness, psychoeducation, pilates & self-esteem)	Positive versus non-positive outcome: Considered positive outcome if BMI of 17.5 kg/m <sup>2</sup> achieved within individual time frame	Age of onset	-0.10 (-0.30:0.11)
Studies assessing w	hether age at ac		n predicts poorer	outcome			
Fassino et al. (2001)	Prospective	40	Inpatient or outpatient	Psychotherapy	Improved versus not improved groups: Considered improved if recovered at	Age at admission	-0.07 (-0.23:0.36)

					least 50% of their BMI under the threshold of 17.5 and 30% improvement on MROAS		
Godart et al. (2009)	Prospective	139	Inpatient	Psychoanalytic	BMI at discharge	Age at admission	0.14 (-0.03:0.30)
Wildes et al. (2011)	Prospective	154	Inpatient or daypatient	CBT or DBTBMI >= 18.5, no binge/purge in past 28Agedays, EDE global within two standard deviations of community norms		Age at admission	0.31 (0.16:0.34)
Le Grange et al. (2014)	RCT	63	Outpatient	CBT or SSCM	EDQoL, MCS, BDI	Age at admission	0.19 (-0.06:0.42)
Wales et al. (2016)	Prospective	87	Inpatient	Individual psychodynamic therapy + group therapy (CBT, addressing abnormal exercise, mindfulness, psychoeducation, pilates & self-esteem)	Positive versus non-positive outcome: Considered positive outcome if BMI of 17.5 kg/m <sup>2</sup> achieved within individual time frame	Age at admission	-0.12 (-0.32:0.09)
Studies assessing w	hether motivatio	n predic	ts poorer outcom	ne			
McHugh et al. (2007)	Prospective cohort study	65	Inpatient	Individual, group, & family therapy + nutritional & medical treatment	Overall improvement (including weight gain, QoL)	ANSOCQ	-0.39 (0.15:0.58)
Bewell et al. (2008)	Prospective	127	Inpatient		Reaching a BMI of 20	Singe item regarding readiness to change	-0.24 (-0.38:- 0.05)
Goddard et al. (2013)	Multi-centre cohort study	107	Daypatient and inpatient	Not described (multi- centre study)	EDE-Q	Confidence in ability to change	-0.51 (-0.64:0.36)
Le Grange et al. (2014)	RCT	63	Outpatient	CBT or SSCM	EDQoL, MCS, BDI	ANSOCQ	-0.12 (-0.36:0.13)
Wales et al. (2016)	Prospective	52	Inpatient	Individual psychodynamic therapy + group therapy (CBT,	Positive versus non-positive outcome: Considered positive outcome if BMI of	ANSOCQ	0.02 (-0.25:0.28)

addressing abnormal	17.5 kg/m <sup>2</sup> achieved within individual
exercise, mindfulness,	time frame
psychoeducation, pilates	
& self-esteem)	

ANSOCQ = Anorexia Nervosa Stages of Change Questionnaire; BDI = Beck Depression Inventory; BSI = Brief Symptom Inventory; DASS = Depression Anxiety Stress Scales; EAT = Eating Attitudes Test; EDE = Eating Disorder Examination; EDE-Q = Eating Disorder Examination Questionnaire; EDI = Eating Disorder Inventory; EDQoL = Eating Disorder Quality of Life; HDRS = Hamilton Depression Rating Scale; K-SADS = Kiddie-Sads; MROAS = Morgan Russell Outcome Scale; PHQ-9 = Patient Health Questionnaire-9; SCR-90 = Symptom-Check-List-00-; SF-we = Short Form-12 Health Status Questionnaire

in the meta-analysis, there is a greater likelihood that the calculated meta-analytic effect is robust to this type of publication bias.

#### **1.5.7.3** Method of Meta-Analysis

Only predictor variables featured in at least three studies were included in the metaanalysis. A random effects model, which assumes that data being analysed are drawn from a hierarchy of different populations, was used, thus allowing inferences to generalise beyond just those studies included in analysis. As per the Hedges and Vevea method of meta-analysis (Hall & Brannick, 2002), effect sizes were first transformed into a standard *z* metric before scores were averaged. Importantly, each effect was weighted based on study sample size with this method. Heterogeneity was measured by the Q statistic, which is computed by summing the squared deviations of each study's effect estimate from the overall effect estimate, with each study's contribution weighted by its inverse variance (Cochran, 1954). Inverse variance weights each variable in proportion to its variance, meaning that larger studies, which yield smaller standard errors, will have more 'weight' than smaller studies.

#### 1.6 Results

# 1.6.1 Predictors of Drop-Out and/or Outcome

Criteria for inclusion for the meta-analysis were met by 29 studies, wherein included studies assessed at least one predictor variable for which there were sufficient data presented or obtained to calculate an effect size, and the predictor was featured in at least two other studies. Given in Table 1-2 are the characteristics of the studies

included in the meta-analysis. Presented in Table 1-3 are the results of the metaanalysis, wherein each predictor variable's relationships with drop-out and negative outcome are presented.

	ĸ	Mean r	Variance	95% CI	Z	р	Q	Ρ	Failsafe n
Predictors of drop-out									
Greater depressive symptoms	8	-0.05	0.00	-0.15:0.06	-1.24	.210	11.99	.101	0
Greater anxiety symptoms	4	-0.03	0.00	-0.15:0.09	-0.46	.650	2.92	.404	0
Axis I or II co-morbidity	4	0.06	0.00	-0.12:0.23	0.65	.522	8.18	.017	0
Greater general psychopathology	3	-0.07	0.08	-0.25:0.10	-0.82	.413	3.59	.166	0
Greater eating disorder pathology	6	0.09	0.00	-0.02:0.20	1.55	.120	7.35	.196	0
Higher admission BMI	9	-0.12	0.00	-0.18:-0.06	-3.93	.000	6.02	.645	15
BP subtype	8	.012	0.00	0.04:0.19	2.99	.003	10.13	.181	22
Longer illness duration	7	0.02	0.00	-0.06:6.11	0.52	.601	7.32	.302	0
Number of previous hospitalisations	5	0.03	0.00	-0.09:0.15	0.48	.628	9.47	.050	0
Higher age at onset	3	-0.01	0.03	-0.01:0.07	-0.30	.767	0.34	.842	0
Higher age at admission	9	0.03	0.00	-0.08:0.14	0.56	.574	23.54	.003	0
Greater motivation	3	-0.21	0.10	-0.38:0.01	-2.03	.042	3.69	.158	4
Predictors of outcome									
Greater depressive symptoms	4	0.07	0.12	-0.10:0.23	0.85	.394	8.44	.038	0
Greater general psychopathology	3	0.32	0.02	-0.05:0.62	1.69	.092	21.04	.000	21
Greater eating disorder pathology	4	0.23	0.00	0.04:0.47	2.27	.023	16.73	.001	28
Higher admission BMI	12	07	0.00	-0.29:0.16	-0.60	.549	189.93	.000	6
BP subtype	5	0.13	0.00	-0.03:0.28	1.58	.114	12.70	.013	7
Longer illness duration	4	0.15	0.11	-0.03:0.28	1.58	.114	8.39	.078	2
Higher age	5	0.09	0.19	-0.07:0.25	1.10	.273	13.03	.011	2
Greater motivation	5	-0.27	0.00	-0.44:0.08	-0.28	.006	15.28	.044	36

Table 1-3. Results of meta-analysis for each predictor variable.

# 1.6.1.1 Drop-out

Displayed in Figures 1-2, 1-3, and 1-4 are the forest plots for the three significant predictors of drop-out. Motivation demonstrated a small but significant negative relationship with drop-out (r = -0.21, 95% CI [-0.38, 0.01], p = .042), wherein drop-outs demonstrated lower levels of motivation at baseline than those who completed treatment. The associated Nfs was adequate (i.e., Nfs > Nstudies). Notably, studies were just as robust in detecting findings whether motivation was measured by 6 motivational questions or the more sophisticated and comprehensive ANSOCQ. Furthermore, there was a significant, small effect of AN subtype on drop-out (r = 0.12, 95% CI [0.04, 0.19], p < .005), whereby AN patients with the BP subtype were more likely to leave treatment prematurely than their restricting counterparts. Additionally, admission BMI demonstrated a small, negative relationship with drop-out (r = -0.12, CI [-0.18, 0.06], p < .005). The associated Nfs added confidence to these two findings.

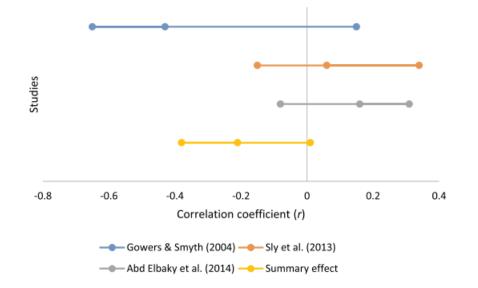


Figure 1-2. Forest plot of the correlation coefficient (r) with corresponding 95% Cis for the correlation between motivation and drop-out from all eligible studies. 54

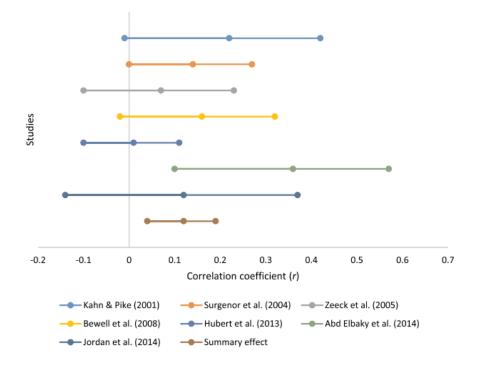


Figure 1-3. Forest plot of the correlation coefficient (r) with corresponding 95% Cis for the correlation between binge-purge subtype and drop-out from all eligible studies.

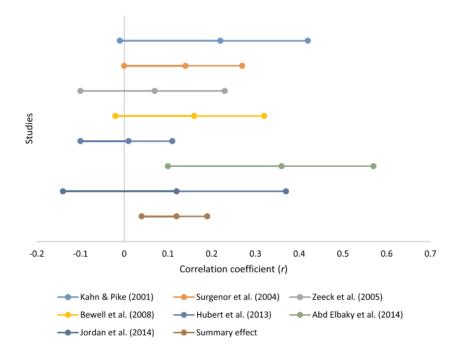


Figure 1-4. Forest plot of the correlation coefficient (r) with corresponding 95% Cis for the correlation between BMI and drop-out from all eligible studies.

The remaining predictors demonstrated negligible to non-existent associations which failed to reach significance: eatinorg disorder pathology (r = -0.09, CI [-0.02, 0.20], p > .05), age (r = 0.03, CI [-0.08, 0.14], p > .05), general psychopathology (r = -0.07, CI [-0.25, 0.10], p > .05), depressive symptoms (r = -0.05, CI [-0.15, 0.06], p > .05), previous hospitalisations (r = 0.03, CI [-0.09, 0.15], p > .05), age at onset (r = -0.01, CI [-0.01, 0.07], p > .05), and Axis I or II comorbidity (r = 0.03, CI [-0.20, 0.26], p > .05).

# 1.6.1.2 Outcome

Displayed in Figures 1-5 and 1-6 are the forest plots for the two significant predictors of outcome. Motivation demonstrated a small but significant negative relationship with outcome (r = -0.27, 95% CI [0.44, 0.08], p = .006), with patients demonstrating higher motivation for recovery at baseline showing better outcomes, with the estimated Nfs adding confidence to the finding. Moreover, severity of eating disorder pathology was shown to have a significant small, positive relationship with outcome (r = 0.23, 95% CI [0.04, 0.47], p = .023), wherein AN patients with greater eating disorder symptoms at baseline showed poorer outcomes at discharge, with the estimated Nfs adding confidence that this finding is not due to the file drawer effect. Further, BP subtype demonstrated a small positive association trending towards significance (r = 0.13, 95% CI [-0.01, 0.33], p = .057, wherein those who suffered from the BP subtype of AN tended to show poorer outcomes than their restricting counterparts.

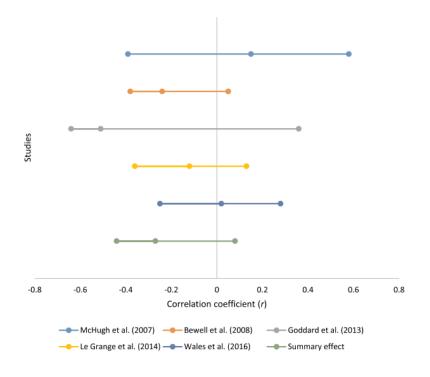


Figure 1-5. Forest plot of the correlation coefficient (r) with corresponding 95% Cis for the correlation between motivation and outcome from all eligible studies.

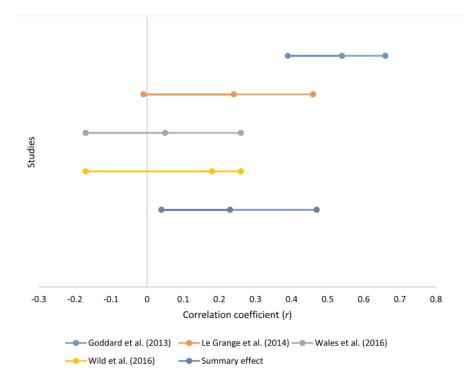


Figure 1-6. Forest plot of the correlation coefficient (r) with corresponding 95% Cis for the correlation between eating disorder pathology from all eligible studies.

The remaining potential predictors demonstrated small to negligible associations which were not significant: general psychopathology (r = 0.32, CI [-0.06, 0.62], p > .05), illness duration (r = 0.15, CI [-0.03, 0.26], p > .05), admission BMI (r = -0.07, CI [-0.29, 0.16], p > .05), age (r = 0.09, CI [-0.07, 0.25], p > .05), and depressive symptoms (r = 0.07, CI [-0.10, 0.23], p > .05).

# 1.7 Discussion

The aim of this systematic review and meta-analysis was to identify and quantify the predictive value of factors associated with drop-out and outcome for patients receiving therapy for AN. Consistent with conclusions from other reviews that our current understanding of AN predictors is limited as findings are sparse and inconsistent, few pre-treatment patient variables were found to predict drop-out or outcome on a reliable basis, and the divergent variables and methods between studies make drawing definite conclusions difficult (Bulik et al., 2007; Vall & Wade, 2015; Wallier et al., 2009). Nevertheless, there is some evidence for the predictive validity of the following pre-treatment variables, shown to predict higher risk of drop-out within the current meta-analysis: 1) lower motivation; 2) having the BP subtype of AN; and 3) having a lower BMI at start of treatment. Furthermore, regarding outcome, the following variables measured prior to treatment showed significant associations with poorer response to therapy: 1) greater eating disorder pathology and 2) poorer motivation.

# 1.7.1 Clinical Implications

There are several clinical implications to be considered regarding the aforementioned findings. Firstly, considering the predictive validity of baseline motivation on dropout and outcome, increasing motivation may be an important strategy to facilitate the likelihood of patients remaining in treatment, as well as improving their engagement with treatment and efforts to change (Vitousek et al. 1998; Ward et al., 1996). Whilst the results of attempts to increase motivation through motivational interviewing (MI) have showed mixed success rates (Dray & Wade, 2012; Knowles et al., 2013; Macdonald et al., 2012), it may be that patients who stay within treatment are generally those who are already relatively motivated to recover, and that those patients who would have benefited most from techniques aimed to enhance motivation simply do not remain in treatment for long enough for motivation enhancement strategies to take an effect. As such, and considering that drop-outs can be differentiated from treatment completers in terms of motivation at baseline, it seems essential to consider a patient's motivation for recovery at assessment stages, so that patients who are determined to be at risk for drop-out or poor outcome due to low motivation for recovery are quickly identified. With such protocols in place, therapy can be tailored to include a component aimed at assessing and increasing motivation at an early stage in treatment. Another important note to make is the methodological issues pertaining to studies investigating MI in AN, which may help explain the mixed results for MI, despite clear evidence that motivation impacts treatment outcome. Rieger et al. (2015) highlighted that many of these studies are hampered by small sample sizes, inadequate comparison groups (for example, the majority of the participants in the waitlist control

condition also accessing treatment, the participants in the active treatment control condition also receiving motivational elements, and/or the participants in the active treatment control condition having higher motivational levels at the start of treatment), and no assessment of treatment fidelity, which is of particular concern given that the therapists are often relatively inexperienced or have received very brief training in MI. Considering these issues, alongside the present findings which underscore the importance of enhancing motivation, methodologically sound studies are clearly needed to further investigate MI in AN. Furthermore, regarding therapeutic techniques, motivational interventions could be helped by better understanding and targeting mechanisms through which motivation may be impacted. For instance, a key feature of AN is its valued nature; that is, the fact that many patients value aspects of their illness, and targeting this feature of the illness in therapy could help to improve motivation and thus outcome and drop-out rates.

Secondly, having the BP subtype of AN was also linked with drop-out. Individuals with the BP subtype of AN have been shown to demonstrate higher levels of impulsivity than their restrictive counterparts, which could be one reason why these individuals are more likely to terminate treatment prematurely (Klump et al., 2000). Furthermore, there is evidence which suggests that those individuals diagnosed with the BP subtype are more likely to demonstrate borderline personality traits, which may impede therapeutic relationships (Selby et al., 2010). However, it should be noted that Axis II pathology did not emerge as a significant predictor of drop-out in our meta-analysis. As such, it is unlikely that poorer therapeutic relationships can fully explain why those suffering with the BP subtype may be more likely to drop out. Lastly, those

diagnosed with the BP subtype may have more mixed motivation for change than their restrictive counterparts, as they may desire to change their bingeing behaviours but not their weight control behaviours, which could affect drop-out rates. Our finding suggests that clinicians and care team staff should take particular care to consider AN subtype in terms of treatment conditions and take particular effort to engage and retain AN-BP patients in care as they are more likely to drop out than their restrictive (AN-R) counterparts. This similarly applies to patients demonstrating a lower BMI. Patients with a lower BMI may be more likely to drop out from treatment for numerous reasons. For instance, lower BMI can be considered an indicator of illness severity; thus, the more severely underweight the patient is, the more psychologically ingrained their illness may be, thus decreasing their likelihood of treatment adherence. In such cases, the patient may either fail to desire recovery due to deeply identifying with their disorder, or may not consider recovery an achievable option due to the degree to which they feel their illness is in control of them, both circumstances leading to increased likelihood for drop-out. The notion that those individuals who experience greater eating disorder pathology may more strongly identify with their disorder is supported by the work of Serpell et al. (2004), who found that AN individuals reporting greater eating disorder pathology endorsed more perceived benefits of AN. Of importance, more severely underweight patients are at highest medical risk if they do not receive effective treatment; thus, it is especially important that efforts are made to prevent these patients from dropping out.

Moreover, considering that eating disorder pathology measured at baseline predicted how well patients fared in treatment, it seems important to identify AN patients with

more severe eating disorder psychopathology at assessment, as these patients are less likely to have successful outcomes from therapy. Having such assessments in place may increase treatment success for these at-risk patients in that clinicians may decide to implement more intensive or frequent treatment for patients displaying more extreme eating disorder pathology.

Furthermore, based on qualitative research into reasons for drop-out in AN treatment, suggestions have been made within the literature for how premature disengagement may be prevented (Eivors et al., 2003). Firstly, Eivors et al. (2003) posed that, particularly in the early stages of treatment, clinicians should seek a shared understanding of the meaning of the illness with the patient, viewing it as a 'coping mechanism', albeit a faulty one, rather than a means of self-destruction. Such a focus may increase a feeling of collaboration between therapist and patient, which may help motivate the patient to carry on with treatment. Secondly, the authors suggested that it may be of benefit to have one therapist focusing on longer-term psychotherapeutic aims, whilst food intake and weight is monitored by another member of the care team. The rationale behind this suggestion is that if one of the objectives of therapy is to develop a sense of self distinct from that defined by eating behaviour, whilst also encouraging weight gain, a dual role for the therapist wherein both these facets are monitored by the same individual may not be conducive to this process.

In terms of the previously mentioned review by Vall and Wade (2015) wherein a transdiagnostic approach was used when examining predictors (with studies investigating BED and BN being included in the analysis), simple baseline predictors associated with better outcome included higher BMI, fewer binge-purge behaviours, 62

greater motivation to recover, lower weight/shape concern, fewer co-morbidities, better interpersonal functioning, and fewer familiar problems. Of these variables, only motivation and greater eating disorder pathology (wherein weight and shape concern would be a sub-category of eating disorder pathology) was demonstrated as significant when AN was analysed on an individual basis. However, it should be noted that our review considered only patient characteristics, and as such, variables such as familial problems were not included in our analysis. Moreover, in terms of drop-out., Vall and Wade (2015) found that greater binge-purge behaviour and lower motivation for recovery predicted greater drop-out from treatment, which echoes the findings from the current chapter, with the exception that our analysis also demonstrated that lower BMI was linked with drop-out.

# 1.7.2 Limitations of Current Research

There are still considerable gaps and inconsistencies in the AN literature which limit the extent to which definite conclusions can be drawn. Thus, it seems necessary that a higher degree of replication and consistency among findings are achieved before empirical results can warrant changes to clinical practice and treatment approaches.

Firstly, across the studies assessed herein, outcome measures varied considerably, with some studies using change in BMI as a measure of outcome, others using a certain BMI threshold which needed to be reached to be considered recovered, and others still using aggregate scores of BMI and eating disorder pathology measures, or eating disorder pathology measures alone without considering BMI. Needless to say, such disparate definitions of treatment outcomes are problematic, as they render

comparison across studies a difficult task. Despite the clear necessity for agreement amongst researchers and clinicians (and patients) on what defines recovery, there is no current "global consensus" on this definition, thus perpetuating the status quo wherein outcome measures vary widely within the AN literature (Bachner-Melma et al., 2006; Jarman & Walsh, 1999; Kordy et al., 2002). One solution to this problem would be to compare studies according to outcome measures used; however, the current dearth of studies examining predictors in AN renders this problematic for meta-analysis.

Similarly, drop-out has also been poorly defined in the AN literature. To exemplify, one study within this review defined drop-out as "patients self-discharging against medical advice or simply leaving inpatient setting resulting in the designation of absent without leave" and specifying that inherent to the definition of drop-out was that treatment had ended as a result of the patient's unilateral decision (Surgenor et al., 2004), whereas other studies considered patients to have dropped out when they were discharged by the therapist as a result of not complying with treatment or reaching their target weight, with still others defining drop-out as attending less than a certain percentage of treatment sessions. Another issue to be considered is that patients sometimes require hospital admission for medical stabilisation. In such instances, hospitalised patients may be recorded as drop-outs in certain studies, whereas other studies may allow brief hospitalisations as part of the outpatient treatment. Thus, it seems necessary, although challenging, that researchers adopt definitions of drop-out and outcome which are similar enough to allow valid cross-study comparison. A

reporting drop out, and put forth a suggested framework for how drop-out from eating disorder treatment might ideally be reported (Mahon, 2000). Specifically, Mahon (2000) emphasised the importance of agreeing on a multi-dimensional definition of drop-out wherein three important facets are considered. Firstly, the author distinguished between patients who leave regular treatment with a therapist, and patients who leave the treatment-phase of a controlled study, termed treatment-phase attrition, rather than drop-out, in this framework. Secondly, the author emphasised how to qualify a patient as a drop-out, noting that having attended at least one therapy session is an important criterion (Garfield, 1994), and further suggesting that treating drop-out as a continuous variable and reporting on the number of therapy sessions attended relative to the amount of treatment expected in order for the patient to improve would allow for comparison of levels of dropping out (early versus late) and of treatment types. Lastly, it was noted that a final task would be deciding whose viewpoint to use in deciding whether the termination of therapy was in fact early, as patients and clinicians may disagree upon this point (for instance, a patient might leave therapy having genuinely received all the help they wanted, thereby considering themselves a completer, wherein their therapist would have liked them to achieve more, thereby considering the patient a drop-out) (Mahon, 2000). Arguing that there is limited evidence as to the difference between types of dropping out regarding outcome, clinical differences, and predictor variables (Waller, 2009), Sly (2009) suggested adopting an overarching definition of 'premature termination of treatment' (PTT) to include all patients who withdraw from treatment due to a unilateral decision made either by themselves or staff. Sly (2009) further proposed that drop-out should then be categorised according to two factors: who initiated the termination (patient-65

initiated versus staff-initiated), and the timing of the termination (early versus late). Expanding on the notion of describing drop-out sufficiently with an even more descriptive framework, Dejong et al. (2012) proposed a reporting structure for drop-out, including reporting reasons for dropping out, wherein reasons should be classified within the following categories: clinical (wherein patients are withdrawn for medical/therapeutic reasons, for example being hospitalised due to continued weight loss); logistical (wherein patients are withdrawn for practical/logistic reasons such as moving to another city); progress (wherein patients are withdrawn by mutual agreement between patient and clinician due to good therapeutic progress and based on predefined targets, e.g. BMI > 18.5 and symptom score within one standard deviation of the population mean); and patient-initiated withdrawal (wherein the patient discontinues without agreement from the clinician).

Furthermore, treatment methods in the studies within this review varied considerably, with treatment forms including CBT, SSCM, psychodynamic therapy, dietary counselling, and interpersonal psychotherapy, in various combinations, both within inpatient and outpatient treatment. In some studies, the treatment was poorly specified. One approach to this challenge could be narrowing the scope of the review by considering only one mode of therapy at a time when systematically reviewing predictors of drop-out and outcome in AN treatment. However, due to the paucity of studies found in this particular area, there would unlikely to be enough studies for sufficient analysis. Thus, in order to overcome this issue and allow for cross-comparison, emphasis should be placed on adequate description of treatment methods used in each specific study. This way, the reader is ensured awareness of how

treatment methods may have differed, and can consider how such variations across studies may hold relevance for results.

Another issue which warrants mentioning is the disparity across studies in how some baseline predictors were measured. For example, in terms of depression and anxiety, some studies measured depression/anxiety on a present/absent basis as determined by a clinical diagnosis of a depressive episode or anxiety disorder, whereas others measured depression/anxiety on a spectrum using scales such as the Beck Depression Inventory (BDI), or the anxiety sub-scale of the Brief Symptom Inventory (BSI). In terms of motivation, the majority of studies captured the variable using the Anorexia Stages of Change Questionnaire (ANSCOQ), a psychometric scale based on the transtheoretical model of change developed specifically for AN to capture readiness for change, whereas one study included only a single item in order to determine motivation. One approach to overcome this issue in future research would be to provide clear and stringent measurement criteria to determine whether a predictor variable is eligible for inclusion (e.g. depression being defined as presence of a minor or major depressive episode, or motivation as determined by a psychometrically-sound scale such as the ANSOCQ or Readiness and Motivation Questionnaire (RMQ)); however, due to the withstanding paucity of studies in the literature, we opted for a more inclusive approach in the current review.

Another issue to consider is the range of severities and presentations within AN. As for any clinical disorder, no case presents exactly the same. This variation may produce difficulties in assessing treatment success. For instance, if recovery is defined as achieving a BMI of 18.5, a severely underweight patient who made significant 67

increases in BMI yet did not meet the 18.5 threshold may be considered unsuccessful in treatment, despite making greater headway during treatment in terms of change in BMI than his or her less severely underweight counterparts. Further, certain studies include only more severe patients whereas others include much milder presentations, which may render cross-comparison difficult. Issues pertaining to range of presentation and severity may best be overcome by ensuring clinical presentation is adequately assessed and described, so that patients with vastly different presentations are less likely to be grouped together in analysis, and clinical presentation within the sample can be considered upon interpreting the results.

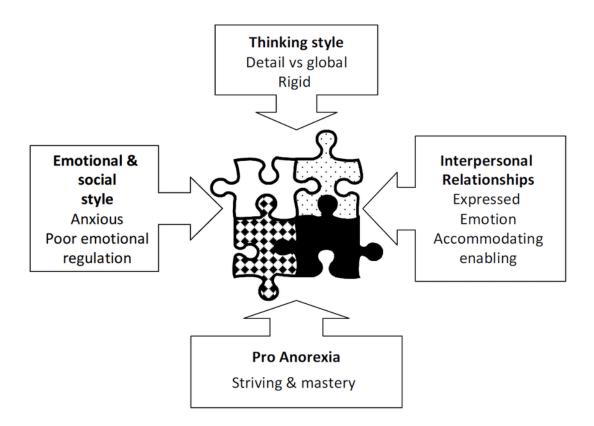
Further issues warranting mention are those of a statistical nature. Firstly, due to the relatively low prevalence of AN, as well as high drop-out rates during treatment, large samples in empirical studies are often difficult to obtain. Thus, the majority of current studies may be afflicted by low power, and perhaps lack of significant findings, or failure to replicate previously identified significant findings, can often be explained by type II errors in the current literature. The implication for future research is in this case both obvious yet difficult to execute; larger samples are required if the relationship between pre-treatment predictors and drop-out and outcome in AN treatment is to be properly elucidated. The best way to achieve this is likely to be using carefully designed multi-centre studies. Moreover, as meeting eligibility criteria for the meta-analyses necessitated sufficient data be provided (either via the paper or via the authors) to allow a "clean" effect size to be determined (wherein a "clean" effect size refers to the effect of a variable irrespective of other variables), a number of papers were excluded due to missing data. Most frequently, data pertaining to insignificant

findings, or data pertaining to "clean" effect sizes (e.g. correlations coefficients between the predictor and outcome calculated in order to determine eligibility for inclusion in multiple regression analysis) were omitted. As such, it is recommended that future studies present such data to allow comparison of effects across studies. Furthermore, considering that the overall effect sizes for pre-treatment predictors of drop-out and outcome identified are small, it is possible that identifying and quantifying pre-treatment factors is not particularly informative in predicting drop-out and outcome in treatment for AN. More recent studies have begun to examine the impact of factors measured early in therapy as opposed to at baseline, such as rate of weight gain or therapeutic alliance (Waller, 2009). Moreover, considering the small effect of pre-treatment patient variables investigated so far, previously unexamined pre-treatment patient variables, particularly those related to motivation, such as egosyntonicity (the valued nature of the illness), may be worth examining.

# **1.8 Underpinning Theoretical Framework**

There have been several maintenance models of AN put forth, including the cognitiveinterpersonal model proposed by Schmidt and Treasure (2006) which highlights interpersonal or cognitive variables which are thought to maintain the illness. As seen in the figure below, Schmidt and Treasure's (2006) model outlines four maintenance factors of an interpersonal or cognitive nature, pertaining to thinking style, emotional and social style, interpersonal relationships, and pro-anorexia beliefs. Pro-anorexia beliefs are thought to maintain the disorder in that individuals impacted by AN may not wish to let go of the benefits which they perceive AN as providing them with. A review of the empirical literature conducted by Treasure and Schmidt (2013) found 69

accumulating evidence to support their model. Specifically, they found evidence to suggest that a strong eye for detail and weak set shifting are inherited vulnerabilities to AN, which may also be further enhanced in the ill state. Moreover, wide-ranging impairments in socio-emotional processing were found in individuals with AN, including impaired signalling of, interpretation and regulation of emotion, and bias in attention towards critical and domineering faces and away from compassionate faces (Treasure & Schmidt, 2013). Furthermore, some of these traits are present in family members, with the shared familiar traits accentuating family members' tendency to react to the frustrating and frightening symptoms with higher expressed emotion (e.g. criticism, hostility, and overprotection) (Treasure & Schmidt, 2013). However, this review did not examine the evidence for the fourth factor highlighted within this model, that is, pro-anorexia beliefs, possibly because the evidence pertaining to this factor is more sparse, with the majority of research in this area being qualitative rather than quantitative in nature. Nevertheless, egosyntonicity has been highlighted as a key feature of AN, and may help explain lack of motivation for recovery and ambivalence toward engaging with therapy. As such, Chapter 2 examines the current literature base as it pertains to egosyntonicity, offering a narrative review on egosyntonicity and a more in-depth look at this concept, with Chapters 3 and 4 presenting quantitative research examining egosyntonicity.



*Figure 1-7. Schmidt & Treasure's cognitive-interpersonal maintenance model for AN (from Schmidt & Treasure, 2006).* 

# **1.9** Rationale for the Thesis

This thesis expands the current understanding of pre-treatment patient predictors of AN by exploring a novel variable which has yet to be examined, that is, egosyntonicity as well as its opposite, egodystonicty (referring to ways in which the illness is in conflict, or dissonant, with the needs and goals of the individual). To give the reader a thorough understanding of this concept, Chapter 2 offers a complete examination of the current literature base relating to egosyntonicity and egodystonicity. The crosssectional study in Chapter 3 validates the Pros and Cons of Anorexia Nervosa Scale (P-CAN), a psychometric measure developed to capture perceived pros and cons of 71

AN, in a sample of clinically diagnosed AN outpatients, to address the limitations within Serpell et al.'s (1999; 2004) previous work, wherein the scale was developed and validated. Further, this chapter uses modelling to explore the relationship between endorsement of pros of AN, motivation, and eating disorder pathology. Lastly, the prospective design of Chapter 4 addresses the gap in the current research; that is, the lack of longitudinal studies examining egosyntonicity and egodystonicity and its potential impact on treatment outcome.

## 1.10 Aims and Overview of the Current Thesis

An overview of this entire project follows. The first aim of the current thesis was to critically examine and review the current evidence base as it pertains to pre-treatment patient characteristics predicting drop-out and outcome in AN. As such, the current chapter describes a systematic review and meta-analysis examining pre-treatment patient characteristic as predictors of drop-out and outcome in AN treatment (a version of this chapter has been published as Gregertsen et al. 2018).

The second aim was to offer a systematic exploration of the underpinning literature pertaining to egosyntonicity and egodystonicity, which is presented in Chapter 2 (a version of this chapter has been published as Gregertsen et al., 2017).

Thirdly, this thesis aimed to validate the P-CAN, as well as test the hypothesis that endorsement of pros of AN impacts upon eating disorder pathology through its effect on motivation, presented in the cross-sectional study in Chapter 3. For this crosssectional study, a diverse and clinically diagnosed sample of AN outpatients was recruited. The cross-sectional study further established the P-CAN as a sound psychometric tool, as well as indicating that greater endorsement of pros may be linked with greater eating disorder pathology partially through its effect on motivation, supporting cognitive maintenance models of AN (Schmidt & Treasure, 2006; Wolf & Serpell, 1998).

Fourthly, to fill the gap in the research base, this thesis aimed to examine the predictive value of endorsement of pros and the "hatred" con of AN, to determine whether the P-CAN would predict treatment outcome in a sample of AN outpatients. Finally, the thesis aimed to explore the link between egosyntonicity/egodystonicty and autism traits. As such, Chapter 4 presents the final study of the thesis, which employed a longitudinal design to examine the predictive validity of endorsement of pros and the "hatred" con of AN, alongside the variables previously established to predict outcome in Chapter 1. This study followed AN outpatients for 6 months, using multiple regression analysis to determine predictors of outcome variables (eating disorder pathology, motivation, endorsement of pros, endorsement of the "hatred" con, and autism traits). The link between egosyntonicity/egodystonicity and autism was also examined on a cross-sectional basis.

Lastly, of note, Chapter 1 and 2 have both been published, with Chapter 3 currently being under review. As the published versions of these chapters have been edited for readability and brevity, they differ slightly from those presented herein. Regardless, the main findings and key takeaways in each of the chapters remain the same for both versions.

## Chapter 2 The Egosyntonic Nature of Anorexia Nervosa

"I have come to realise that hunger feels more like home than any tangible structure ever has, or probably ever will. I know now that creating absence is my way of coping with absence."

Kris Kidd: I Can't Feel My Face

The chapter that follows is a narrative review on egosyntonicity/egodystonicity in AN. This chapter is a version of a manuscript previously published in *Frontiers* (2017) with the same title as Gregertsen et al., 2017.

The systematic review and meta-analysis of the current research literature (Chapter 1) demonstrated four pre-treatment patient variables associated with drop-out and/or outcome in AN treatment: admission BMI, eating disorder pathology, subtype, and motivation. Whilst identifying BMI, eating disorder pathology, and subtype at assessment stages is key in order to tailor treatment to those at risk for drop-out or low engagement (for instance by providing more intensive treatment to patients identified as at risk), understanding and tackling motivation within the therapeutic context may be especially important, as this variable could be addressed in the early stages of treatment in order to improve outcomes. With this in mind, the concept of motivation will be explored in more detail.

#### 2.1 Motivation to Change

Motivation can be defined as "the desire to act in service of a goal", in this context, that goal being recovery from AN. Motivational approaches in the field of AN are based on different conceptualisations of motivation, and include the Transtheoretical Model of Change (TTM) (Prochaska et al., 1977) and Self-Determination Theory (SDT) (Deci & Ryan, 1985).

#### 2.1.1 The Transtheoretical Model of Change

## 2.1.1.1 Stages of Change

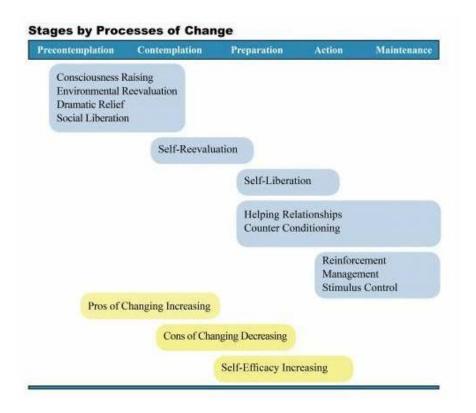
The TTM, which is the most frequently cited theoretical framework in the behaviour change literature, was developed by Prochaska and colleagues in 1977, and is based on the analysis of a number of different theories of psychotherapy, hence the use of the word "transtheoretical" in its name. The model posits that behavioural change is not a coincidence but rather a process wherein individuals transition through five stages; that is, precontemplation (not thinking about change); contemplation (thinking about change); preparation (intention to change soon); action (actively making changes); and maintenance (working to prevent relapse) (see Figure 2-1.). In some iterations of the model, a sixth stage is incorporated, capturing "relapse" (DiClemente et al., 1985; Prochaska et al., 1993; Velicer et al., 1985; Velicer et al., 1992). Furthermore, some versions of the TTM also refer to a "termination" stage, which refers to a stage wherein individuals have no desire to return to their unhealthy behaviours and are sure they will not relapse. These stages are not fixed, and it is possible to transition to a previous stage.



Figure 2-1. Transtheoretical Model of Change (Prochaska & Velicer, 1992)

## 2.1.1.2 Processes of Change

The TTM's main goal is to explain how health behaviour change occurs, and, to this end, ten processes of change, presented in Figure 2-2., capture the techniques and strategies that individuals may use to change behaviour, including overt and covert activities which individuals engage in to modify their experiences and environments with the end of goal of modifying their behaviour (Procashka & Velicer, 1997; Prochaska et al., 1988). These ten processes include: 1); consciousness-raising (increasing awareness via information, education, and personal feedback); 2) dramatic relief (feeling fear, anxiety, or worry because of the unhealthy behaviour, or feeling inspiration and hope when hearing about how people are able to change to healthy behaviours; 3) self re-evaluation (realising that the healthy behaviour is an important part of who one desires to be); 4) environmental re-evaluation (realising how one's unhealthy behaviour affects others and how one could have more positive effects by changing); 5) social liberation (realising that society is supportive of the healthy behaviour); 6) self-liberation (believing in one's ability to change and making commitments and re-commitments to act on that belief); 7) helping relationships (finding people who are supportive of the change); 8) counter-conditioning (substituting unhealthy ways of thinking and acting with healthy ways); 9) reinforcement management (increasing the rewards that come from positive behaviour and reducing those that come from negative behaviour); and 10) stimulus control (using reminders and cues that encourage healthy behaviour and avoiding places and situations that do not). Health researchers have since extended Prochaska and DiClemente's (1984) original ten processes of change with an additional twenty-one processes, presented in Table 2-1. below (Bartholomew et al., 2006).



*Figure 2-2. Processes of change across stages (Prochaska et al., 1994)* 77

Process of Change	Layman Term	Description
1. Risk comparison	Understand the risks	Comparing risks with similar dimensional
		profiles: dread, control, catastrophic
		potential and novelty
2. Cumulative risk	Get the overall	Processing cumulative probabilities
	picture	instead of single incident probabilities
3. Qualitative and	Consider different	Processing different expressions of risk
quantitative risks	factors	
4. Positive framing	Think positively	Focusing on success instead of failure
5. Self-examination	Be aware of your	Conducting an assessment of risk
relate to risk	risks	perception, e.g. impact on others
6. Re-evaluation of	Know the outcomes	Emphasising positive outcomes of
outcomes		alternative behaviours and re-evaluating
		outcome expectancies
7. Perception of	Focus on benefits	Perceiving advantages of the healthy
benefits		behaviour and disadvantages of the risk
		behaviour
8. Self-efficacy and	Get help	Mobilising social support, skills training
social support	I	on coping with emotional disadvantages
		of change
9. Decision making	Decide	Focusing on making the decision
perspective		6 6
10. Tailoring on time	Set the tie frame	Incorporating personal time horizons
horizons		
11. Focus on	Prioritise	Incorporating personal factors of highest
important factors		importance
12. Trying out new	Try it	Changing something about oneself and
behaviour	2	gaining experience with that behaviour
13. Persuasion of	Persuade yourself	Promoting new positive outcome
positive outcomes	J	expectations and reinforcing existing ones
14. Modelling	Build scenarios	Showing models to overcome barriers
e		effectively
15. Skill	Build a supportive	Restructuring environments to contain
improvement	environment	important, obvious and socially supported
		cues for the new behaviour
16. Coping with	Plan to tackle	Identifying barriers and planning
barriers	barriers	solutions when facing these obstacles
17. Goal setting	Set goals	Setting specific and incremental goals
18. Skills	Adapt your strategies	Restructuring cues and social support;
enhancement	1 7	anticipating and circumventing obstacles;
		modifying goals
19. Dealing with	Accept setbacks	Understanding that setbacks are normal
barriers	r	and can be overcome
20. Self-rewards for	Reward yourself	Feeling good about progress; reiterating
success		positive consequences
21. Coping skills	Identify difficult	Identifying high-risk situations; selecting
	situations	solutions; practicing solutions; coping
		with relapse

Table 2-1. Bartholemew et al.'s (2006) additional processes of change

#### 2.1.1.3 Self-Efficacy

Another key element within the TTM which appears to further explain why health behaviour changes occur is self-efficacy (see Figure 2-2.). Self-efficacy, drawn from Bandura's (1986) social cognitive theory, reflects the confidence which individuals have in changing their behaviour. In his research, Bandura established that greater self-efficacy led to greater behaviour change (Bandura, 1977). Ajzen (2002) highlights the similarity between the concept of self-efficacy and perceived behavioural control, underlining the integrative nature of the TTM which combines various behaviour change theories.

## 2.1.1.4 Decisional Balance

The final component of TTM is decisional balance (DB), which refers to the weighing of pros (advantages) and cons (disadvantages) of the behaviour. Decision making has been conceptualised by Janis and Mann (1977) as a "DB sheet" of comparative potential losses and gains, wherein whichever side outweighs the other will inform the individual's motivation either towards or away from the targeted behaviour (Prochaska & Diclemente, 1983). TTM research has demonstrated two important relationships between pros, cons, and stages of change across 48 behaviours and over 100 populations studied (Hall et al., 2008). Firstly, cons of changing outweigh the pros in the Precontemplation stage. That is to say, an individual with AN who is in the Precontemplation stage might more heavily endorse the downsides of recovery over the benefits of recovery (e.g. "I will lose my sense of control" versus "I will reestablish social relationships"). Secondly, the pros outweigh the cons in the Action stage. As such, an individual with AN who is in the Action stage will more heavily endorse the upsides of recovery versus the costs of recovery (e.g. "I will get my health 79

back" versus "I will lose my coping mechanism"). Thus, during the change process, individuals gradually increase the pros of change and decrease the cons, forming a more positive balance towards the behaviour, with attitudes being one of the core components explaining behaviour and behaviour change in various research domains (Bagozzi et al., 1989).

## 2.1.1.5 Applications of the Transtheoretical Model of Change

The TTM has been validated and applied to a variety of behaviours, including dietary behaviour, contraceptive use, exercise behaviour, and smoking behaviour (Grimley et al., 1993; Hellman, 1997; Prochaska et al., 1994). Moreover, "stage-based" approaches derived from the TTM, wherein the current stage of change informs the intervention technique, have demonstrated widespread utility (Cabral et al., 1996; Calfas et al., 1997; Campbell et al., 1994; Weinstein et al., 1998). In terms of AN, Rieger et al. (2000), developed a scale to measure stages of change specifically in AN, the ANSOCQ, which was briefly mentioned in Chapter 1. Using this scale, two studies with Spanish adolescent patients demonstrated that stages of change predicted necessity of hospitalisation and weight maintenance (Amettler et al., 2005; Serrano et al., 2004). Moreover, a positive short-term prediction of weight gain based on stages of change was also demonstrated in a German sample (Hillen et al., 2015). These results were echoed in a prospective cohort study by Green et al. (2017), which demonstrated that stages of change predicted weight gain in an outpatient sample. Furthermore, Wade et al. (2009) found that five out of six motivational sub-scores (but not the ANSCOQ total score) predicted changes over six weeks in eating disorder pathology as measured by the EDE in an adolescent and adult inpatient sample.

Additionally, Pauli et al. (2017) found that stages of change predicted probability and remission of drop-out, albeit not BMI increase, at 9 months follow-up, in a sample of 92 adolescent outpatients. In terms of correlates with stages of change at admission, Hillen et al. (2015) found that those with lower BMI and longer illness duration demonstrated greater motivation. It should be noted that these results differ from the results of the meta-analysis conducted in the previous chapter, which found that lower BMI led to greater drop-out. It is possible that there are two groups of severely underweight patients; those whose illness is so heavily entrenched that they fail to engage with therapy, and those who are extremely fed up with their illness due to the longevity and severity of it and realisation that illness will never deliver on its false promises. Understanding that low BMI may lead to either greater motivation for recovery – or lack of engagement with therapy – depending on which of these two groups the patient falls in may help explain differing findings when it comes to BMI and treatment outcome.

## 2.1.2 Self-Determination Theory

An alternate approach to motivation is found in SDT, which is a macro-theory of human motivation, emotions, and personality that has been under development for 40 years following the seminal work of Deci and Ryan (1985), and concerns people's inherent growth tendencies and innate psychological needs. Humanistic psychology, which concerns itself with examining a person's whole psyche and personal achievement for self-efficacy and self-actualisation, has been influential in the development of SDT (Koole et al., 2019). As such, SDT focuses on the degree to which human behaviour is self-motivated and self-determined. The theory originally

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developed from studies conducted in the 1970s comparing extrinsic and intrinsic motives for behaviour, and from a growing understanding of the integral role which intrinsic motivation played in behaviour (Deci, 1971; Lepper et al., 1973).

## 2.1.2.1 Controlled versus Autonomous Motivation

Similar to TTM, SDT addresses the processes behind behaviour change, with a key component of SDT being the differentiation between types of motivation; specifically, "controlled motivation" versus "autonomous motivation" (see Figure 2-3) (Deci & Ryan, 1985; Deci & Ryan, 2000). "Controlled motivation" includes "introjected motivation" (e.g. guilt, shame, anxiety, and internal compulsion) and "external motivation" (e.g. expectations, rewards, and punishments administered by the patients' environments). Conversely, "autonomous motivation" includes "identified motivation" (e.g. personal values and commitment), "integrated motivation" (e.g. a motivation is fully integrated within oneself) and "intrinsic motivation" (e.g. interest, pleasure, and enjoyment). AN-specific examples of autonomous motivation might include wanting to recover because recovery aligns with one's own personal values (identified motivation), or because recovery will improve one's life (intrinsic motivation), whereas desiring recovery due to external pressures from family or friends, or because falling below a certain weight will result in hospitalisation, are examples of extrinsic motivation. According to SDT, regardless of how ready the patient is to change, action resulting in sustained change occurs only if the attempt at change is autonomously – preferably intrinsically – motivated (Deci & Ryan, 1985; Deci & Ryan, 2000).

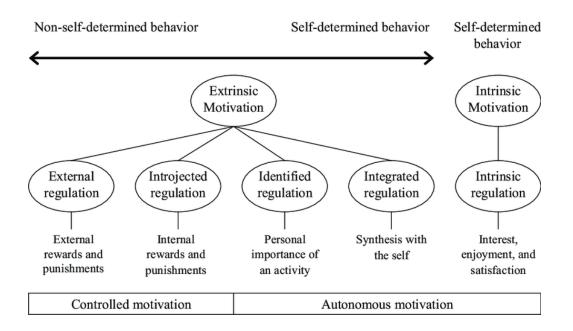


Figure 2-3. Controlled versus Autonomous Motivation (Self-Determination Theory; Deci & Ryan, 1985).

In line with this, intrinsic motivation has been shown to be positively associated with more learning, greater persistence of learning, and greater engagement in learning activities in the therapeutic context, though not specifically in treatment for AN (Choi & Medalia, 2010; Deci & Ryan, 1999; Medalia & Richardson, 2005; Vansteenkiste et al., 2004). Moreover, as intrinsically motivated behaviours are repeated without external rewards or constraints, they are more likely to be maintained. For instance, an inpatient who is motivated to restore weight in order to reach a certain weight goal which will allow them to be discharged from hospital (extrinsic motivation) may fail to further restore weight or even maintain weight once released into community care, as the external reward for gaining weight (hospital release) is no longer present, highlighting the importance of intrinsic motivation in recovery. Promisingly, research into clinical populations suggests that intrinsic motivation is not only dynamic, in that

it changes over time, but also malleable, meaning that it can be manipulated in order to improve outcomes (Nakagami et al., 2010).

#### 2.1.2.2 Intrinsic Psychological Needs

Deci and Ryan expanded on their early work differentiating between motivation types by further proposing three main intrinsic needs involved in self-determination (Deci & Ryan, 1991; Deci & Ryan, 1995). According to the authors, these three basic psychological needs motivate individuals to initiate behaviour in that having these needs met enhances autonomous motivation with these three psychological needs including the universal and innate need for autonomy, competence, and relatedness (Ryan & Deci, 2000).

## 2.1.2.2.1 Autonomy

Autonomy refers to the desire to be the causal agent of one's own life and act in harmony with one's integrated self. Interestingly, Deci found that offering extrinsic rewards for behaviour that is intrinsically motivated undermines the intrinsic motivation originally felt, perhaps because offering external rewards undermines autonomy (Deci, 1971). Echoing this notion, situations that give autonomy as opposed to taking it away appear to increase motivation. For example, studies investigating choice found that increasing a participant's options and choices similarly increased their intrinsic motivation (Zuckerman et al., 1978). In AN, the need for autonomy may reflect the autonomy to control one's own life, as opposed to the illness controlling one's life, but may also reflect the resistance one may feel when one is coerced into treatment, or even involuntarily placed into an inpatient program. As such, AN can be experienced as both an act of autonomy (by defying the wishes of

others and controlling one's own behaviours) and an act of being stripped of autonomy (when one feels powerless over the illness).

## 2.1.2.2.2 Competence

The second psychological need, competence, refers to the need to seek to control the outcome and experience mastery (White, 1959). Deci (1971) demonstrated that providing people with unexpected positive feedback on a task increased people's intrinsic motivation to complete the task, with the author theorising that this was due to the positive feedback fulfilling people's need for competence. In terms of AN, individuals may often experience a heightened sense of competence during the initial stages of AN, due to reaching weight loss goals and being successful in adhering to a strict dietary regiment. Moreover, in these beginning stages when weight loss is not yet severe, individuals with AN may even receive positive feedback on their ability to lose weight and their appearance from others in their environment. Thus, in recovery, other areas of competence (for example, competence in restoring weight and recovering from AN) may need to be reinforced in order to replace the sense of competence attained from AN (in particular from controlling/reducing weight), in order to reinforce intrinsic motivation for recovery.

## 2.1.2.2.3 Relatedness

The third psychological need, relatedness, refers to the will to interact with, be connected to, and experience caring for others (Baumeister & Leary, 1995). Of note, in AN, those by impacted by the illness often receive increased care as a result of the illness; thus, in recovery, it is important that care and attention is not withdrawn as a result of the individual showing improvements. Further, as AN often has a negative

impact on social relationships (Dalmaso et al. 2016), this innate psychological need could be an important component towards initiating change.

## 2.1.3 Motivation in Anorexia Nervosa

AN may differ from other psychological or physical illnesses in terms of motivation in that the disease is typically valued by those impacted by it, as compared to other illnesses – such as chronic fatigue or depression – which are more egodysotonic in nature. Still, it should be noted that AN is not the only psychological or physical disease that brings with it perceived benefits; for example, individuals with depression may view their illness as valid excuse to avoid taking on challenges, which then cushions them against any threat of failure. Nevertheless, it is likely that AN is experienced as more egosyntonic than most other psychological and physical illnesses which in turn may impact motivation. Considering the AN literature, low motivation has been shown to not only be associated with poorer outcome and greater drop-out rates, as demonstrated in Chapter 1 (Abd Elbaky et al., 2014; Bewell et al., 2006; Goddard et al., 2013; Gowers et al., 2004; le Grange et al., 2014; McHugh et al., 2007; Sly et al., 2013) but also with relapse (Carter at al., 2012; Mander et al., 2013). Furthermore, readiness to change not only significantly predicted treatment outcome, even after controlling for level of eating disorder symptomatology at admission and AN subtype in a sample of 127 AN patients, but was also found to fully mediate the relationship between baseline eating disorder symptoms and later treatment outcome (Bewell et al., 2008). Clinical features linked with low motivation include laxative abuse, greater depression, greater body dissatisfaction, and greater eating disorder pathology, whereas greater motivation for change has been found in patients with

lower BMI and longer illness duration (Hillen et al., 2015; McHugh, 2007; Pauli et al., 2017). The notion that lower BMI patients may demonstrate greater motivation for recovery is supported by a study by Bennett et al. (2015) who theorised that severely underweight AN patients may be more motivated to survive, after discovering that cooperativeness in therapy peaked when patients were at their lowest weight, and decreased as their weight increased. Interestingly, in a prospective study by Hillen et al. (2015), an inverse relationship between physical eating disorder symptoms (as measured by percentage expected body weight [%EBW]) and cognitive eating disorder symptoms (as measured by the Eating Disorder Inventory-2 [EDI-2]) was demonstrated in a sample of 40 adolescent inpatients. This relationship has also been described by Berner et al. (2013) who reported greater drive for thinness and greater body dissatisfaction in higher BMI patients in a sample of 238 inpatients, with the authors suggesting that higher BMI patients may exhibit more pronounced eating disorder-specific psychopathology as a result of comparing themselves to thinner eating disorder patients (particularly in an inpatient setting) or desiring a lower weight. As such, patients experiencing stronger eating disorder pathology such as drive for thinness and body dissatisfaction may lack motivation for change as they associate recovery with weight gain which they believe will further increase their poor body image. Furthermore, as put forth by Paul et al. (2017), it may be that patients within the first phase of weight loss are not yet confronted with the disadvantages of their illness and are therefore determined to lose more weight, demonstrating lesser motivation to change. Conversely, those with a lower BMI and longer illness duration may be more motivated towards recovery as they have likely experienced more starvation-associated symptoms leading to greater psychological strain, as compared 87

to patients with better health states. Considering clinical features further, it is likely that depression (and possibly other comorbidities) is linked with low motivation because comorbidity may increase the desire for the patient to hold onto their eating disorder. For example, patients with depression may use their eating disorder as a means to distract from their depressive feelings, and may thus be more reluctant to let go of their eating disorder than patients without comorbid illnesses in an attempt to avoid depressive feelings and other symptoms of their comorbid illness that the eating disorder can help manage.

Regarding social factors, Malmendier-Muehlschelegel et al. (2016), who investigated friendship quality and motivation to change in a sample of 30 AN inpatients (aged 12-20, mean age: 15.07) demonstrated a link between higher quality friendships and greater motivation for change. The authors theorised that friendships may help increase motivation by way of social support, and also that greater readiness to change could also help facilitate fulfilling friendships. Unfortunately, as previously mentioned, interpersonal difficulties and social isolation are commonly associated with AN, with premorbid friendship difficulties often playing a role in AN development (Arcelus et al., 2013). Of note, AN has demonstrated an estimated 37% co-morbidity with autism spectrum disorder (ASD) (Westwood & Tchanturia, 2017), wherein social difficulties are marked (Bellini, 2008). Furthermore, once AN becomes entrenched, those who suffer from AN may actively choose to socially isolate. Reasons for this include low mood, life becoming consumed by the eating disorder leaving little space for other interests, or because social situations commonly involve food consumption. This causes difficulty in that those impacted by AN may have fears

surrounding either being "caught" declining food (thus making their eating disorder more visible to others), being pressured into consuming food, or losing control when in a situation where food is offered. As such, social isolation may not only play a role in the development of AN, but can also be exacerbated by AN, in addition to having a negative effect on motivation to change.

Wishing to gain insight into the social difficulties which those with AN may experience, a qualitative study by Patel et al. (2016) examined socioemotional functioning in a sample of 20 patients with AN, uncovering several themes pertaining to difficulties in socioemotional functioning for these individuals. Firstly, patients in the study reported reduced social capital, in that they did not have friends prior to admission to treatment, or that they lost friends in the process of the illness, with the dissolving of friendships often being attributed to repeated admissions and consequent restrictions and difficulty in maintaining contact. Moreover, many reported experiencing interpersonal adversity, which included teasing, bullying, and competitiveness. Many also described a fear of missing out in this context, with feeling left out of friendship circle and events – often due to the eating disorder or being hospitalised – compounding the sense of exclusion and rejection. Further, these three themes (friendships dissolving, interpersonal adversity, and fear of missing out) led to a reduction in the size of the participants' social networks. Moreover, patients described others' perceptions as being hugely important, which would often lead to patients avoiding spontaneous communication. Patients also described sensitivity to perceived negative affect from others, with fear of judgement being consistent amongst the sample. Further, a heightened rejection sensitivity and distrust in others

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was described. Considering the link between social factors and motivation in AN, considering and addressing these social difficulties could be of great importance.

It should also be noted that difficulties with motivation may often affect caregivers and social interactions, in that carers may often view low motivation as defiance or ill will on part of the patient, and become fatigued with the lack of progress in recovery, which can in turn affect the relationship between patient and carer. This is an especially important aspect to consider given that social factors can act as protective variables against the eating disorder, and as such, maintaining good quality relationships may be integral to the recovery process.

Lastly, personality features associated with a greater motivation to change in AN patients include higher self-esteem and a more active coping style (Pauli et al., 2017). It has been theorised that these constructs may be linked with higher self-efficacy, in that patients with higher self-esteem and more active coping strategies demonstrate greater motivation to change because they feel more capable of initiating change. Conversely, patients who lack self-esteem and possess maladaptive coping strategies may demonstrate low motivation to change simply because they feel recovery is not a goal which they are capable of reaching. This notion is in line with the previously discussed TTM, which outlined self-efficacy as an important component of change (Prochaska et al., 1977).

Some current limitations which warrant mentioning in terms of how treatments have included motivation in their formulation and treatment is traditional treatments' (with the exception of FBT) focus on the individual as opposed to systematic factors. 90

Considering the previously discussed theories pertaining to motivation, wherein the environment is considered to impact motivation (for example, through stimulus control) as well as the importance of social factors, it seems important to not only consider the individual but the individual's environment when addressing motivation in therapy.

Having understood the negative effect of low motivation on drop-out, treatment outcome, and relapse, as well as the malleability of motivation and its effect on learning in the therapeutic context, it becomes clear that understanding possible mechanisms behind motivation could be important in improving treatment outcomes for those suffering with AN. In particular, illuminating the means by which autonomous motivation for recovery could be achieved may be of great importance. As autonomous motivation is described as motivation which is driven internally by one's own values and enjoyment, it could be argued that, in addition to the social, clinical and personality features previously addressed, patients' own attitudes towards their illness (which may be affected by both the external environment and internal values) could play a significant role in fostering or inhibiting autonomous motivation. That is, if a patient perceives AN as adding value to his or her own life, or as being aligned with his or her own personal values, he or she may fail to derive this kind of autonomous motivation for recovery, and instead seek to maintain their illness. In line with this, Mulkerrin et al. (2006) demonstrated that AN patients experienced difficulty finding balance in relating to and acting on their personal values, with AN being experienced as a mixed-fit with values, with these patients exhibiting ambivalence both towards recovery and towards AN. The authors posited

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that these were important patient themes to consider in the promotion of AN recovery. Furthermore, a review by Abbate-Daga (2013) examining resistance to treatment in eating disorders put forth three mechanisms related to patients' evaluation of their illness which may contribute to low motivation; specifically, positive and negative reinforcement of symptoms, positive valuation of symptoms, and perceived benefits of AN.

#### 2.2 Positive and Negative Reinforcement of Symptoms

People with AN often receive positive reinforcement from the successful attainment of thinness, wherein extreme dietary restraint and compensatory behaviours are reinforced both internally (through achieving a sense of self-worth, specialness, and accomplishment) and externally (through receiving compliments from others for weight loss efforts or self-restraint). External reinforcement may be significant in the early stages of illness, when the sufferer has lost significant amounts of weight but is not yet alarmingly thin (Garner & Bemis,1983; Vitousek et al., 1998). According to Slade (1982), this positive reinforcement becomes heightened when the person with AN perceives their AN behaviour as the only area in life at which they are successful, with perceived failure attached to all other areas of functioning, which may often turn into a vicious cycle, as the more sufferers focus on attaining thinness, the more they neglect other areas of life and the less successful they are in these areas as a result. Furthermore, negative reinforcement of behaviours may occur as a result of avoidance of negative affect and experience, such as avoidance of intimate relationships, the responsibilities of adult life, and strong emotions, as a result of the numbing effect of AN on affect (Garner & Bemis, 1983; Slade, 1982).

## 2.3 Positive Valuation of Symptoms

Regarding positive valuation of symptoms, which has also been suggested to impede motivation and maintain eating disorder behaviours, a study by Shafran et al. (2003) investigated the difference between people with eating disorders and healthy controls in how they perceived symptoms of dietary restraint. Participants included 44 meeting DSM-IV criteria for an eating disorder (10 with AN, 12 with BN, and 21 with atypical eating disorder) and 80 controls with no history of an eating disorder. Participants were presented with ambiguous eating disorder scenarios describing physiological symptoms linked with starvation and dietary restraint, and asked to complete sentences (e.g. "You have not eaten all day and you are very hungry. You think "). Responses were categorised by researchers as either 'positive', 'negative', or 'neutral/mixed', with results demonstrating that the eating disorder group was significantly more likely to give a positive valuation to dietary restraint symptoms, specifically in scenarios pertaining to hunger, heightened satiety, and dizziness. However,  $X^2$  analyses with a continuity correction indicated that the only significant difference between clinical and non-clinical groups pertained to dizziness. As such, the researchers posited that the hypothesis that eating disorder patients view their symptoms in a positive light, as had been clinically observed, was only partially met. However, it is worth noting that this study included a trans-diagnostic sample,

as opposed to a sample with only AN patients, who may differ from BN and atypical eating disorder patients in their positive valuation of their symptoms.

## 2.4 Perceived Benefits of Anorexia Nervosa

AN symptoms and behaviours are considered to be markedly more egosyntonic due to behaviours more typically associated with other eating disorders, such as bingeing and purging, sometimes being experienced as distressing, shameful, and egodystonic (Hamburg et al., 1996). Conversely, dietary restraint and thinness, hallmark features of AN, may be egosyntonic in that they are lauded by society, often experienced as consistent with personal goals and values such as discipline and self-control, and often ascribed additional meanings, such as thinness being linked with constructs like 'intelligence', 'beauty', and 'virtue' (Vitousek & Hollon, 1990).

In an attempt to systematically explore the meaning which patients with AN ascribe to their anorexic behaviour, a research team based in Norway interviewed 18 women (14 outpatients, four inpatients), aged 20 to 34, who had within the past two years been diagnosed with AN, using Qualitative Thematic Analysis to assess the interview data (Nordbø et al., 2006). The sample comprised 18 patients, all diagnosed with AN (*DSM-IV* criteria). These studies revealed diverse ways in which AN was experienced as helping the patients achieve goals, or manage difficult experiences.

Thirteen themes relating to the ways in which AN was valuable to the patients emerged. Firstly, patients endorsed the notion of AN as a means of achieving a sense of stability and security; by organising their day through stringent time schedules and rules, the sufferer obtains a sense of structure in their life ("It's simply a way of handling everyday life. To manage to get up in the morning, manage to go to bed and manage a new day after that again. Simply to get a grip on yourself and what's inside you. If you lose your eating problem, you'll lose this too. That's pretty much what I'm afraid of. How on earth am I then going to manage my everyday life?"). Moreover, AN was described as a way of evading negative emotions and experience; when the sufferer's everyday life is characterised by a myopic fixation on body, food, and weight, there remains little energy to focus on other difficulties or problems ("Things were chaotic, the job, the school, all my relationships ... It's quite related to the eating disorder I guess, but I thought that as long as I had the eating disorder, I didn't need to focus on those things. Then I was thinking about food instead"). Furthermore, AN was reported as a mechanism by which an inner sense of strength, mastery and skilfulness could be achieved; as the individual with AN loses weight, he or she may experience a sense of mastery and self-control for having managed to adhere to a strict diet and reach weight loss goals ("When I notice 'ok, I've lost two kilos', 'now I've lost three' ... the stronger and stronger I get to handle the things coming up. It's hard to explain, but it is as if the smaller I get, the stronger I get mentally"). Additionally, feeling worthy of compliments and attaining confidence was reported as a benefit of AN; losing weight makes the individual feel attractive and successful, which may be reinforced by positive feedback received externally regarding appearance and dieting performance, thereby 95

increasing self-confidence. Moreover, AN was viewed as a means of communication; a sickly appearance and pathological behavioural patterns may communicate a feeling of distress to others which the individual is unable to express with words ("It was the body's way to tell that I had a problem, a mental problem. That you don't feel good about yourself"). Further, AN was described as a means of prompting care from others ("You're so tiny and vulnerable, and you get extra care. People are more considerate. When you're used to performing well and feeling the pressure from high expectations, then suddenly people are more like 'Relax, it's not that important really"). Moreover, forging a new, favoured identity was identified as benefit of AN ("When I was 14, I felt other people started to dislike me. They talked behind my back and so on. They day I decided to reduce my weight, it was about being a better person. Because then people wouldn't dislike me anymore. I lost a lot of weight. I got so tiny ... I wanted to change completely, but I didn't know how to do it. So then I got thinner because I thought it would make me a better person. Then it wasn't me anymore. I wasn't the old Ann anymore, I was new"). Lastly, two patients described AN as a means of starving oneself to death, perceiving starvation as a less brutal way of dying as compared to suicide ("When I came home from hospital, I thought, "Fuck! If I don't manage to commit suicide, then I'm going to starve myself to death! That was my project").

In a similar study by Serpell et al. (1999), AN patients' attitudes towards their own illness were assessed by exploring recurrent themes within two letters which patients had been asked to write their illness as part of therapy, one addressing their AN as a friend and another addressing it as an enemy. Serpell et al.'s (1999) sample 96

comprised 18 AN patients. The sample included 11 patients with the restricting subtype and seven with the BP subtype.

Upon comparison of Nordbø et al. (2006)'s and Serpell et al.'s (1999) studies, five themes pertaining to the ways in which AN was perceived as valuable to patients were common to both studies, suggesting these themes may be particularly important to AN patients, and could therefore be particularly relevant to the therapeutic context if attempting to tackle perceived benefits. Specifically, these themes were 'security/control'; 'avoidance'; 'mental strength/skill'; 'communication', and 'confidence'.

In terms of benefits which were not identified in Nordbø et al. (2006)'s study, Serpell et al's (1999) study found a theme of 'attractiveness' wherein looking slim, appearing more attractive, and getting attention from the opposite sex was described as a benefit of the disorder ("When I'm out socialising, I feel more men are interested in me and I feel as though this has a lot to do with you"). Moreover, the theme of 'difference' described how feeling different from the others, being special or superior because of the disorder, and/or the feeling of having a special secret was experienced as a benefit of AN ("You make me feel special by making me different. You give me something none of my friends or family have"). Lastly,, the 'fitness' theme pertained to the increased fitness experienced as a result of AN. Lastly, the 'period' theme described the loss of periods where this was perceived as a benefit ("You've stopped my periods and that's save me those two days of pain and the week of inconvenience every month").

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A study which employed the same design as Serpell et al. (1999) but within an adolescent population (n = 27) demonstrated many similarities and a few notable differences between adolescent and adult AN patients (Freedman et al., 2006). Specifically, compared to their adult counterparts, adolescents tended to place greater value on the sense of feeling 'looked after' by the disorder as well as relishing more the increased attention from others that they felt resulted from having AN. In contrast, they did not perceive loss of periods as a benefit.

Interestingly, upon in-depth reading of the letters, it appeared to the researchers that patients could be grouped into two categories – those for whom attractiveness was an overwhelming motivating factor for AN, and those who completely omitted it when describing its motivators or benefits. Such a finding is of importance in that AN is largely conceptualised within the media as an overzealous attempt at reaching a slim cultural ideal, and in the apeutic contexts wherein this notion is adopted and tackling and debunking beauty myths becomes a highly placed goal within therapy. This goal may have little effect on the patient if attractiveness was not a motivator in developing and/or a factor in maintaining their AN in the first place. Moreover, attractiveness is likely to be more important in the early stages of the illness when individuals with AN have not lost extreme amounts of weight and are still getting positive feedback from others. As such, it becomes clear that it is important not only to understand the *degree* to which the egosyntonic nature of anorexia may be an impediment to recovery, but also to examine the idiosyncratic meaning AN holds for each patient. A further point to consider is that some patients who described their 98

illness as a method of avoiding emotions or helping to cope with emotions or distress also highlighted the negative theme of AN stifling their emotional life, clearly demonstrating the marked ambivalence AN patients often experience regarding their disorder. This is an ambivalence which can be capitalised upon in the therapeutic context if understood correctly, and also helps explain the indecisiveness AN patients often demonstrate in considering change.

#### 2.5 Perceived Burdens of Anorexia Nervosa

Serpell et al.'s (1999) study allowed not only for a deeper understanding of the perceived benefits of AN but also explored also the negative effects of the disorder which patients would identify. As previously mentioned, 10 themes in this domain emerged; specifically, the analysis revealed different life domains which the patients perceived their disorder as impacting negatively, as well as negative feelings held towards their illness, demonstrating that despite the egosyntonic nature of AN, patients are still able to recognise various ways in which the disorder causes detriment to themselves, their life, and their loved ones. For instance, patients described elements of feeling cheated or tricked by the disorder in that it had made false or empty promises ("You pretend to be my friend, but I do not achieve anything with you"), as well as feeling anger and hatred towards it and frustrated by constantly having to battle it ("I'm sick and tired of you ruling my life. You make me devious, unfriendly and unhappy, and very lonely".). In terms of life domains which patients identified as being negatively impacted by the disorder, these included social (including loss of friends, family, social life, and/or career prospects) ("I hate you for what you have

done; ruined friendships, relationship, and career prospects") and health domains ("Were you responsible for the length of time it took me to get pregnant? The perforated gastric ulcer?"). Further, AN was deemed by patients as having a negative impact on emotions in that it made patients feel numb (where this was perceived negatively) ("You suffocated all my natural emotions, clouded all my responses"), as well as leaving them stifled or even taken over by the disorder ("There are times when I think you've engulfed me and when people look at my body, they don't see me any more, only you"). Patients also expressed that they were tired of thinking about food incessantly ("I hate you because you keep bothering me when I have so many far more interesting things to think about"), and that their life and time was being wasted as a result of having the illness ("You've stopped me doing things I should have done and wanted to do"). Lastly, patients identified the psychological symptoms of the disorder such as depressive symptoms as a perceived cost of AN ("And sometimes if you've stopped me eating for a really long time, my hunger makes me feel unhappy as if nothing could comfort me"), and also described the upset and hurt which the disorder had caused to family members and friends as a negative effect of the illness ("Do you realise the worry you have caused [partner] and the rest of my family?").

Notable differences between adult and adolescent populations as shown by Freedman et al. (2006) in terms of perceived costs included adolescents describing a higher degree of psychological distress in relation to the illness, and a greater sense of having been fooled by the disorder. Further, adolescents did not describe as much frustration with food preoccupation or being controlled by food.

#### 2.6 Understanding Ambivalence towards Recovery

In an attempt to understand ambivalence towards recovery in AN, a study investigated the experiences and understandings of those with AN who desired to maintain their eating disorder and examined how these understandings may impact upon treatment experience (Williams & Reid, 2010). Participants (*n* = 14) were recruited via pro-anorexia websites, wherein individuals are encouraged to express positive beliefs about their eating disorder in an online, anonymous environment. Qualitative data was collected and analysed utilising interpretative phenomenological analysis (IPA). Among the identified themes was 'ambivalence and conflict about anorexia'. Ambivalence was expressed as being underlined by the paradoxical notion of AN providing participants with a sense of control, yet as the disease began to overtake their thoughts and behaviour, it began to *divest* them of control, rather than provide them with it. This conflict created further ambivalence regarding whether AN was a controllable, functional tool, or a disease that was out of their control and needed to be extinguished.

Within the framework of AN being a functional tool, several functions were described, including AN as a way of attaining a sense of strength, achievement, and success, as a coping mechanism, as a way of feeling safe, as an expression of emotion, as an escape from negative situations, affect, and puberty, as a pathway toward happiness, as a tool to punish the self or others, or at its most extreme, as a panacea, with one participant stating, "Thinness will fix everything". These responses echo the research of Serpell et al. (1999) and Norbø et al. (2006), further

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solidifying the notion of the egosyntonic nature of AN as a key component in the maintenance of the disorder.

In terms of recovery, marked ambivalence was expressed, with one participant describing both wanting to recover and not wanting to recover in the very same sentence. The potential lethality of AN was highlighted as a reason to strive for recovery. In this vein, it seems that AN patients may desire AN so long as its advantages are perceived to outweigh its disadvantages, and as soon as consequences of AN are considered to drastically outweigh benefits (such as AN becoming lifethreatening or taking control over the patient's life), recovery may become a more appealing prospect. However, one limitation to consider is that individuals suffering with AN who seek out pro-anorexia websites, from which this sample was recruited, may hold particularly positive views regarding their illness, which is what fuels them to seek out communication with likeminded individuals in a pro-anorexic online community, and their views may therefore not necessarily be representative of individuals with AN who would not seek out such a community. Nevertheless, the responses found in this study overlap with responses of individuals with AN recruited not from pro-anorexic websites but rather from clinical settings (Nordbø et al., 2006; Serpell et al., 1999).

In another study attempting to elucidate mechanisms behind AN patients' attitudes toward recovery which employed a descriptive, qualitative design, 36 women (23 outpatients, 11 inpatients, and two treatment completers) treated for AN within the past two years at four clinical institutions in Norway were interviewed regarding 102

their own perception of what might interfere with their wish to recover (Nordbø et al., 2012). Seven themes surrounding interference with recovery were extracted, with the second highly endorsed theme (n = 27) being 'appreciating the benefits'. This referred to a decreased wish to recover as the positive aspects of living with AN were given more weight than, or considered to exceed, the negative aspects. Specifically, patients identified the positive feelings which AN evoked such as feeling secure or having a purpose in life as hindrance to their wish for recovery. Moreover, the high accompanied by being extremely undernourished, and the success they felt as a result of their AN, the support and care they received from others, and AN being a protected area in which they could always succeed in even if failing in all other areas of life, were identified as interfering with motivation for recovery. These findings add a directive subjective link between AN patients' positive experiences of their illness and the patient's reluctance toward recovery, supporting the notion that the positive value of AN symptoms makes a significant contribution to maintaining AN (Vitousek et al., 1998).

# 2.7 Perceived Benefits and Burdens of Anorexia Nervosa and Stages of Change

A framework for understanding ambivalence about change is put forth in the previously described transtheoretical model of change (TTM), wherein individuals are grouped into distinct stages of readiness to change, including precontemplation, contemplation, action, and maintenance (Prochaska et al., 1992). To recap, processes of change, referring to the cognitive, affective, and behavioural activities that

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individuals employ to change problems and work toward new lifestyles, are also described in this model (Prochaska et al.,1988). Among such activities of a cognitive nature, DB, which we previously defined as identifying and evaluating positive and negative effects of health or risk behaviours, has received special attention.

In an integrative study investigating perceived advantages and disadvantages of health-related behaviours across stages of readiness to change, including smoking, quitting cocaine, weight control, reducing high-fat diets, stopping delinquent behaviour, safer sex, condom use, radon gas exposure, acquisition of exercise, and physicians' preventive practice with smokers, it was demonstrated that advancement from precontemplation to contemplation was characterised by an increase in perceived disadvantages, with little change to perceived advantages, in these behaviours (Prochaska et al., 1994). Conversely, progressing from contemplation to action was marked by a decrease in perceived advantages (Prochaska et al., 1994). These two patterns of findings are labelled respectively the strong and weak principles of change, and were supported by the meta-analysis conducted by Hall et al. (2008) which examined DB.

In an effort to discover the extent to which these findings generalise to eating disorders, a simple DB scale was developed for eating disorders, by adapting a DB scale originally developed for weight loss (simply by altering the words 'if I lost weight' to 'if I gained weight'). Results demonstrated support for the strong principle of change, but not the weak principle (Blake et al., 1997). In line with this, Cockell and colleagues (2003) investigated the differences between individuals with 104

AN who did not want to change (i.e. precontemplators) and those who were seriously considering recovery (i.e. contemplators). In order to capture these differences, a DB scale developed specifically for AN was used (Cockell et al., 2002). This scale comprises three sub-domains; Burdens, Benefits, and Functional Avoidance, wherein Functional Avoidance reflects the use of AN to avoid dealing with other issues, which can be viewed as either a burden or benefit. Results from Cockell et al's (2002) study demonstrated that AN patients who were seriously contemplating change identified more costs to the disorder and had greater insight into how it served as a means of avoidance, as compared to those who were not contemplating change, consistent with the strong principle of change. However, the extent to which individuals endorsed benefits of having AN did not vary across preaction stages of change, failing to support the weak principle of change. Associations between DB scores and symptom severity indices suggested that insight about the function of AN was linked with greater distress.

The study's findings demonstrate that greater endorsement of the consequences of AN, as well as greater insight into how AN functions as a form of escape from life's responsibilities, is linked with more seriously contemplating change, highlighting that patients' perception of the burdens of their disorder, as well as recognising the avoidance AN brings with it, may play a role in recovery. To move from precontemplation to contemplation, it is possible that recognising the negative effects of AN is essential. A relevant concept here is the notion of hot versus cold cognition, coined originally to discriminate between cognition mediating processes which are affective in nature (hot) as compared to those which are affect-free (cold) 105

(Abelson, 1963). Whilst patients may be able to recognise and acknowledge negatives of AN, an emotional component may be missing, wherein either patients do not feel that these negatives will apply to them as an individual (e.g. despite high mortality rates in AN, the patient does not believe that their AN is severe enough to put them at risk of death), or are simply apathetic to consequences. As such, "feeling" the consequences of AN (e.g. becoming genuinely worried about health risks) as opposed to simply "knowing" them, may be necessary to move from precontemplation to contemplation.

In line with Cockell et al.'s (2003) study, Rieger and colleagues (2002) demonstrated a link between the ANSOCQ and the Concerns about Change Scale (CCS), a psychometric scale developed to capture a wide range of concerns that may interfere with changing dysfunctional behaviour (Bemis, 1986; Vitousek et al., 1995). Many of the items included in this scale are designed to capture the respondent's perception of positive aspects of their dysfunctional behaviour, with the measure being developed to be applicable across a range of conditions, including AN. Interestingly, whilst the scale was not developed for eating disorders or AN specifically, many of the sub-scales echo concerns raised by AN patients in the work by Nordbø et al. (2006) and Serpell et al. (1999). Specifically, sub-scales pertaining to concerns about interpersonal loss ("I'm afraid that people will stop worrying about me if I change"), personal loss pertaining to accomplishment ("I may lose a feeling of pride in myself if I change"), identity ("This problem is an important part of my identity"), disinhibition of expression ("I wouldn't be able to express how I feel if I change"), and avoidance of negative affect ("I'd have nothing to take away the pain 106

if I change") overlap with the 'prompting care', 'mental strength/skill', 'identity', 'communication', and 'avoidance' themes of Nordbø et al.'s (2006) and Serpell et al.'s (1999) studies. In Rieger et al.'s (2002) study, AN patients who demonstrated less readiness to change on the ANSOCQ expressed greater concerns about change on the CCS. Moreover, Rieger et al.'s (2002) study also demonstrated that the crossover between the benefits and burdens of AN (as measured by the DB scale) occurs between the contemplation and preparation stages, consistent with previous studies across a diverse range of behaviours (Prochaska et al., 1994). This is a noteworthy finding as it indicates that to decide to recover (ie. to be in the preparation stage) requires that the individual perceives the disadvantages of AN to be outweighing its advantages. Another noteworthy finding from this study is the result that movement into the action stage required a significant reduction in endorsement of perceived benefits of AN, whereas changes in the perceived burdens were negligible in propelling the individual into the action stage, thus underscoring the importance of egosyntonicity in AN.

## 2.8 Benefits and Burdens of Anorexia Nervosa and Symptom Severity

Another important question which researchers have attempted to address is whether perceived attitudes towards their illness are linked not only to AN patients' readiness for change or reluctance toward recovery but to symptom severity. With this aim in mind, Serpell et al. (2004) recruited 233 women with AN and measured eating disorder symptomatology as well as perceived attitudes towards AN, captured by the Pros and Cons of Anorexia Nervosa Scale (P-CAN). The P-CAN, developed from

the qualitative research by Serpell et al. (1999) described previously, comprises six sub-scales describing perceived pros of (Safe/Structured; Appearance; Fertility/Sexuality; Fitness; Communicate Emotions/Distress; and Special/Skill) and four describing cons (Trapped; Guilt; Hatred; and Stifles Emotions). Results demonstrated that strongly held beliefs about the disorder's positive function were associated with more severe AN, exemplified by a high drive for thinness and greater body dissatisfaction. Of note, AN severity correlated with the pros but not the cons of AN, suggesting that an important distinction between severely ill patients and their less severely ill counterparts is endorsement of the *positive* facets of their illness (Serpell, Teasdale, Troop, & Treasure, 2004). In this vein, suggestions that tackling the egosyntonic nature of AN may be a key component of therapy for these patients is supported (Schmidt & Treasure, 2006; Treasure, 1999). However, one limitation of this study which warrants mentioning is that diagnostic information was based on self-report for the majority of the sample, due to participants predominantly having been recruited from a volunteer register as opposed to in a clinical setting.

Similarly, Gray (2008) investigated the relationship between the CCS and symptom severity in a sample of 230 females diagnosed with an eating disorder, wherein 96 participants met criteria for AN, 52 participants met criteria for BN, and 82 participants met criteria for EDNOS. Results showed a significant relationship between concerns about change and eating disorder symptoms, as measured by the EDI-2 Drive for Thinness and Body Dissatisfaction sub-scales, wherein those with greater concerns about change also showed greater drive for thinness and higher body dissatisfaction. If we consider concerns about change as the flipside of 108

endorsing positive aspects of AN, this is in line with the findings of Serpell et al. (1999). Furthermore, consistent with the notion that egosyntonicity may be especially marked in AN patients as opposed to other eating disorder groups and is a hallmark feature of the disorder, the AN group scored significantly higher on the CCS scale than both BN and EDNOS groups.

# 2.9 Benefits and Burdens of Anorexia Nervosa and At-Risk Populations

Understanding the egosyntonic nature of AN, and its links to attitudes towards recovery and illness severity, a pertinent question arises regarding the origin of proanorexia attitudes, specifically, whether such attitudes precipitate the disorder as a risk factor, or develop as an artefact of the illness. With this question in mind, Bailey and Frampton (submitted) administered the P-CAN in a healthy, albeit high-risk, undergraduate population, asking participants to fill in the P-CAN from the imagined perspective of someone with AN. Results were then compared to P-CAN results from previous AN samples (Serpell et al, 2003; Serpell et al., 2004). Contrary to the researchers' hypotheses, perceived cons of having AN in the healthy sample were significantly lower than in the AN adult sample, as well as significantly lower on the Con sub-scales of Guilty and Hatred when compared to AN adolescents, suggesting that someone without AN might not be able to fully comprehend how lifeconsuming and detrimental the illness can be without having experienced it firsthand. This implies that prevention programs may be served by emphasising the negative aspects of AN, which a healthy at-risk population may not fully grasp. Furthermore, for the Pro sub-scales Fertility/Sexuality and Communicate

Emotions/Distress, the healthy sample expressed less endorsement than AN adults and adolescents, suggesting that these positive perceptions may be disorder-specific, and that endorsement of these perceived advantages may perpetuate the disorder rather than precipitate it. Unexpectedly, however, for the Appearance and Fitness sub-scales, the healthy sample scored higher than the AN samples, indicating that the healthy sample believed that that physical aspects of AN, regarding fitness and appearance, are highly valued by those with AN. This further supports the notion that the general public holds an idea of AN as a disorder mainly concerning the wish to reach an ideal weight and shape, which is misguided, with AN serving functions those impacted by the illness far beyond maintaining or striving towards a certain beauty ideal. Noting this gap between the outsider's perspective and the AN sufferer's true experience regarding non-appearance-related maintenance factors is important because it challenges the central role many cognitive theories ascribe to the importance of weight and shape in the cause and maintenance of AN (Fairburn et al., 1999; Garner & Bemis, 1982; Vitousek & Hollon, 1990). A further point to make in this regard is that at-risk populations who view AN as a means of obtaining a perfect appearance may be failing to understand that once ingrained in the disorder increasingly extreme weight loss goals are necessary to obtain satisfaction with one's appearance, thereby making a "perfect" appearance a goal which can never be reached. Lastly, healthy participants and AN adults scored similarly on the Special sub-scale, and there were no differences between the healthy sample and AN samples on the Safe/Structured sub-scale. These findings do not contradict research highlighting these aspects as key facets of AN (Gale et al., 2006; Serpell et al., 2004; Serpell et al., 1999), but rather imply that perceiving these aspects as positive 110

features of AN is not necessarily disorder-specific. As such, prevention programs, largely currently focusing on body image and body dissatisfaction, may be served by targeting other aspects of AN which at-risk populations regard as positive aspects of the disorder.

# 2.10 Methods of Overcoming the Egosyntonic Nature of Anorexia Nervosa

Our emerging understanding of specific perceived advantages of AN which patients may endorse and how these weigh up against perceived consequences, potentially playing a role in ambivalence and illness severity, highlights the need to develop methods to counteract this theorised barrier to recovery. Firstly, it is apparent that whilst the egosyntonic nature of AN could be argued to be a core facet of the illness and therefore universal to most AN patients, how this egosyntonic nature presents itself is specific and unique depending on the patient considered, and uncovering this idiosyncratic nature within each patient could be crucial to the therapeutic process. In this vein, psychometric measures developed to capture attitudes toward AN such as the P-CAN might be used within a clinical context to give the therapist an overview of which pros and cons of AN the patient endorses and does not endorse, and to work toward finding healthy mechanisms to replace positive functions of AN, as well as solidifying or elaborating negative attitudes already endorsed by the patient. For example, if the patient identifies that AN plays a key function in allowing the patient to evade emotions, the therapist may wish to teach the patient to learn acceptance of the fact that emotions are an unavoidable part of life, or emotion regulation or distress tolerance strategies to employ whenever faced with high

emotional distress (such as those which form part of dialectical behaviour therapy). Furthermore, if the patient identifies the health risks of AN as a strongly endorsed consequence, the therapist may choose to educate the patient on specific health risks associated with AN as demonstrated by scientific evidence, in order to further ingrain this endorsement. Something to be considered, however, in this regard is the patient's stage of change. According to research investigating the TTM, wherein a sample of smokers were examined, results suggested that precontemplators process less information about their negative behaviour as well as experience fewer emotional reactions to the negative aspects of the behaviour targeted for change (Prochaska & DiClemente, 1983). Extrapolating these concepts to AN, this may suggest that introducing information on health risks to AN patients who are in the precontemplation stage of change may be futile, as these patients may not be ready to fully process information which is incongruent with the idea that their illness is ultimately beneficial to their life, rather than predominantly detrimental to it. However, it should be noted that the previously mentioned results from Rieger et al.'s (2002) suggests that movement from the precontemplation to the contemplation stages in fact necessitates an increases awareness of the burdens of AN, which might be partly achieved by the therapist exploring with the patient any health risks that may arise as a consequence of the condition. In Prochaska and DiClemente's (1983) research, contemplators, on the other hand, proved to be the most likely to be responsive to feedback and education as sources of information about their behaviour targeted for change. As such, considering not only which particular benefits and consequences of their illness AN patients endorse and do not endorse -

but also wherein they fall on the spectrum *overall* in terms of readiness to change – seems pertinent in the development of suitable intervention efforts.

Another point to consider regarding the egosyntonicity of AN is how the functions of AN may either overlap or be in dissonance with the patient's values, wherein values can be defined as things which people place a strong sense of meaning or importance unto (Hayes et al., 2006). For example, adhering to a strict and extreme diet may align with a patient's value of pushing oneself to extremes in striving for perfection, yet overarching personal values – including those of a spiritual, interpersonal, or career-related nature – may resultantly be neglected or compromised in striving to achieve AN-related goals, highlighting once more internal contradictions which AN sufferers may experience whilst deciding whether their disorder is overall beneficial or detrimental and whether recovery is a desired outcome. In line with this, a qualitative study was conducted exploring personal values among individuals with AN, with a particular focus on the overlap between participants' values and their AN (Mulkerrin et al., 2016). Themes were identified through IPA (Smith & Osborn, 1999). Among emerging themes, 'perceived congruence' and 'perceived incongruence' demonstrate how participants experienced a mixed fit between AN and their personal values, with AN both clashing and converging with values which they internalised. Regarding perceived congruence, participants described how AN was experienced both physically (through extreme thinness) and behaviourally (through severe restraint and dietary restriction) as a manifestation of some of their core values, including will power, achievement, hard work, discipline, and selfcontrol. Conversely, regarding perceived incongruence, participants described both 113

AN's sabotaging effect on their ability to act in accordance with their values, as well as the paradoxical experience of AN seemingly being aligned with their values yet in reality compromising them. Most prominent among values experienced as incongruent with AN were interpersonal values, such as having close friendships and family relationships, caring for others, and having fun and socialising, which were described as being overtly compromised by AN. Further, AN was described as both a means of attaining control but also a means through which the sufferer spirals *out* of control, highlighting its paradoxical nature. Additionally, and perhaps unsurprising given the aforementioned experiences of AN both converging and clashing with personal values, themes were also identified wherein participants expressed both ambivalence toward AN and ambivalence toward recovery. Regarding ambivalence toward AN, participants described experiencing an internal battle in that AN was a safe and familiar option, similar to the 'guardian' theme of Serpell et al.'s (2004) research, yet simultaneously a tormenting and dangerous presence. Distinct from this, participants' accounts of the ambivalent feelings they held toward recovery seemed underlined by wanting to keep certain valued aspects of AN (for example, increased confidence and more positive body image due to extreme thinness) whilst letting go of all egodystonic symptoms, providing support for the role of endorsement of pros of AN in maintaining the disorder. Lastly, a final theme identified which holds important clinical implications in the attempt to overcome the egosyntonic nature of AN was the theme of 'values as a beacon of hope', wherein participants described focusing on non-eating disorder values as a tool for addressing ambivalence and facilitating motivation to change. Thus, through value-clarification and uncovering personally held values which are incompatible 114

with AN behaviours (for example, placing importance on friendship and spending time with friends yet having to avoid social situations because of AN due to food being involved), patients may be enabled to see how overarching personal values are being compromised by their disorder, and how ultimately if they want to live a life truly aligned with their core values, it is necessary to move on from their eating disorder.

Recognising and understanding the egosyntonic nature of AN not only has clinical implications related to tailoring treatment but also pertaining to how less 'compliant' patients may be viewed by clinicians, which can affect therapeutic outcomes. Often, AN patients who demonstrate high treatment resistance are labelled non-compliant, and may eventually be subjected to staff-initiated discharge from treatment on the basis of not complying with treatment plans or failing to reach target weights. However, if clinicians keep in mind the demonstrated and robust egosyntonic nature of the disorder, with many patients viewing their illness as an accomplishment rather than an affliction (Casper, 1982), non-compliance might almost be expected, and should be considered an actual symptom or artifact of the illness, rather than some sort of malfeasance or misconduct on part of the patient. As such, a useful paper by Vitousek et al. (1998) on enhancing motivation for change in treatment-resistant eating disorders emphasised the importance of appreciating the degree to which the desire for thinness and self-control is egosyntonic. Furthermore, the authors highlighted the problematic nature of attaching surplus meaning to resistance toward recovery. Resistance is to be expected given that the therapist is "proposing to fix one of the few domains of the person's life which they do not regard as broken" (p. 115

399) As Vitousek et al. (1998) suggest, "It is professionally irresponsible to be offended when anorexic patients act anorexic, just as it would be to interpret an obsessive-compulsive client's hand washing as a personal affront" (p. 399). The clinical danger here is in labelling patients as non-compliant and therefore not suited for treatment, when their resistance toward treatment could be considered natural and even somewhat logical upon regarding the great value which patients perceive their disorder as providing them with, as well as personal values which patients perceive their AN as aligning with. Reframing resistance as a comprehensible response to threat gives both therapists (Garner & Bemis, 1982) and patients (Russell & Meares, 1997) an alternative narrative which may promote empathy and decrease conflict. This reframe might be done by therapists being aware of and acknowledging the functional role which AN may play in the individual's life (Gremillion, 2003; Vitousek et al., 1998).

# 2.11 Current Treatments

With respect to current treatments, the degree to which they target the egosyntonic nature of the illness varies across treatments. As discussed in Chapter 1, the main psychological treatments for AN include CBT-E, MANTRA, and SSCM.

# 2.11.1 Targeting Egosyntonicity in Enhanced Cognitive Behavioural Therapy

Regarding CBT-E, often considered the mainline treatment for eating disorders, as discussed in Chapter 1, a transdiagnostic approach is adopted, built on the premise that all eating disorders share two core psychopathologies; (1) over-evaluation of weight and shape, and (2) the control of weight and shape. Whilst over-evaluation of

weight and shape certainly can be argued to be a hallmark of AN, both quantitative and qualitative research into the egosyntonic nature of AN demonstrate that AN serves as a multi-faceted functional tool for sufferers, and as such, the functional nature of AN in patients' lives may be far more complex than the illness simply being a means of attaining a thin body coveted as a result of overvaluing weight and shape. Whilst CBT-E does incorporate narratives wherein pros and cons of being underweight are explored, for example through letter writing addressing AN as both a friend and an enemy, thus targeting ambivalence, such activities are usually not proposed until Stage 3 of therapy (sessions 10–17) wherein the main maintaining mechanisms of the eating disorder are addressed. At this point, psychoeducation about the risks of eating disorders and prescription of meal plans and homework may have gone on deaf ears to unmotivated candidates whose concerns about letting go of a central part of their identity and their best discovered coping mechanism to date have yet to be addressed.

# 2.11.2 Targeting Egosyntonicity in Maudsley Model of Anorexia Nervosa Treatments of

Showing a radical departure from classical CBT, MANTRA, a cognitiveinterpersonal treatment for AN discussed in Chapter 1, has been built on the basis of a cognitive-interpersonal maintenance model which posits that AN typically arises in sensitive/anxious and perfectionistic/obsessive individuals, and is maintained by four broad factors: (1) a rigid, detail-focused, and perfectionistic information processing style; (2) impairments in socioemotional domains; (3) pro-anorexic beliefs; and (4) high levels of expressed emotion or accommodation and enabling in close others, 117

with starvation intensifying all these problematic factors. The model is contrasted to CBT-E in that it departs from the notion that weight and shape concerns are *the* central psychopathology of the disorder, arguing that although patients with AN mainly worry about aspects of their eating disorder, these worries are simply symptomatic of more profound and troubling problems. The proposition that weight and shape concerns are not necessarily the core psychopathology of AN is consistent with the previously cited research of Serpell et al. (1999), as patients described not only controlling their weight and shape as the sole central benefit of their illness, but rather endorsed a range of beneficial aspects, most commonly benefits pertaining to attaining safety and structure from AN rather than a desired appearance. Furthermore, in the work of Nordbø et al. (2006), mention of appearance was conspicuously missing, although patients did report feeling more worthy of compliments which may have been appearance-related. As MANTRA is developed based on a model incorporating pro-anorexic beliefs as one of its four key maintenance factors, treatment serves to target the ambivalent nature of the illness in many ways. Firstly, the clinician takes a warm and empathic, reflective, responsive, and collaborative position, in the style of motivational interviewing (Miller & Rollnick, 2002), rather than warning, lecturing, or even threatening patients regarding health risks of their illness, which may make patients "defend" their AN. Furthermore, in the early phase of treatment (sessions 1–4), pro-anorexic beliefs are addressed and motivation for change is built. Patients' pro-anorexia beliefs which ascribe the illness its own unique meaning are explored through therapeutic writing exercises wherein the value of AN in the person's life is investigated and questioned.

As a helpful addition, patients' personal values and how AN has changed these are also addressed.

# 2.11.3 Targeting Egosyntoncity in Supportive Specialist Clinical Management

Regarding SSCM, originally developed as a control treatment in a CBT and interpersonal therapy for AN trial and, wherein surprisingly its efficacy was equivalent to that of CBT, the therapy's central focus is on symptoms, with the main aim of therapy being the resumption of normal eating. Whilst a behavioural approach wherein clear goals are set and antecedents for problem behaviours are examined is helpful in terms of teaching AN patients when they are at risk for engaging in eating disordered behaviours and how to combat such situations, failure to explore the egosyntonicity of AN and thus the patient's motivation may leave the patient with a series of helpful tools that they simply do not care to use, as a result of still being in the contemplative stage of change. Furthermore, the psychological mechanism of symptoms is left unexplored in this type of therapy. If psychological mechanisms for symptoms are not understood (for example, the patient derives a feeling of significance from being at an extremely low weight and engaging in restrictive dieting which most others simply could not sustain), then the core psychopathology (feeling insignificant) remains unaddressed, and the patient will be more likely to reengage with eating disordered behaviours in order to obtain the perceived benefit of AN to tend their underlying wound. Whilst SSCM does incorporate psychoeducation, which may solidify patients' endorsement of cons of AN, it is hypothesised based on preliminary evidence as well as the model upon which MANTRA was built, that it is patient's endorsement of the *benefits* of AN that is a 117

crucial factor in maintaining the disorder. Thus, emphasising the downfalls of AN without exploring and dismantling the patient's perceived benefits may be of limited use. Furthermore, a myopic focus on eating disorder behaviours as opposed to the *meaning* of these behaviours may leave the patient feeling unheard; as such, exploring AN's egosyntonicity is not only important in terms of finding healthy mechanisms through which the patient can derive that which he or she previously derived from AN, but also because it allows the patient the opportunity to express the unique significance which AN holds for them, facilitating understanding and rapport between patient and clinician.

# 2.12 Conclusion

In summary, several models have been put forth to explain how motivation may fuel behaviour change (Deci & Ryan, 1985; Prochaska et al., 1977), and motivation has been shown to predict both drop-out and outcome in AN research (Amettler et al., 2005; Pauli et al, 2017; Serrano et al., 2004; Wade et al., 2009). In understanding reluctance towards behavioural change in AN, it is important to recognise that people with AN often receive positive reinforcement for their symptoms (Slade, 1982), and may also positively value their symptoms (Shafran et al., 2003). Moreover, people with AN endorse a range of perceive benefits associated with their illness, demonstrating its hallmark egosyntonic nature (Nordb et al., 2006; Serpell et al., 1999), although people with AN recognise cons as well (Serpell et al., 1999). Considering these perceived pros and cons, it is not surprising that individuals with AN experience feeling ambivalent towards recovery (Williams & Reid, 2010).

Further unpacking this ambivalence, it has been demonstrated that AN patients who seriously contemplate change identify more costs to the disorder than their precontemplative counterparts (Cockell et al., 2002), and that those who endorse more benefits of AN demonstrate greater symptom severity (Serpell et al., 2004). There are several methods to overcoming egosyntonicity, some of which are used in current treatments, particularly MANTRA. Lastly, a tool which can be used to capture egosyntonicity and egodystonicity is the P-CAN (Serpell et al., 2004), which will be discussed more in-depth in the following chapter.

# Chapter 3 Psychometric Properties and Validity of the Pros and Cons of Anorexia Nervosa Scale: An Exploration of Anorexia Nervosa Patients' Endorsement of Pros and Cons of Their Illness and Severity, Subtype, and Motivation

"I am too big and too small and too much and not enough and too frightened to change and too sad to stay the same."

Nancy Tucker: The Time in Between: A Memoir of Hunger and Hope

# 3.1 Introduction

The egosyntonic nature of AN has been highlighted by a number of researchers as a possible maintaining factor in AN, and has been investigated using both qualitative and quantitative methods. The narrative review of research in this area (Chapter 2) examined the current evidence base for the role egosyntonicity plays in AN, finding that AN provides several perceived benefits for those impacted by the illness, including providing a sense of security, control, and skilfulness, functioning as a means to communicate distress as well as a means to avoid negative emotions and experience, increasing feelings of confidence and fitness as well as specialness, allowing avoidance of periods, prompting care from others, providing a new identity, and even the possibility of death, where death is considered desirable (Nordbø et al., 2006; Serpell et al., 1999). In contrast, perceived costs of the disorder include feeling stifled, guilty, and trapped by the illness, as well as feeling hatred towards it (Serpell

et al., 1999). In the qualitative study conducted by Williams and Reid (2010), people with AN expressed ambivalence towards recovery, in that AN provided participants with a sense of control, yet paradoxically, divested them of control as the illness grew more entrenched. Furthermore, Nordbø et al. (2012) highlighted that appreciating the benefits of AN was the second most endorsed impediment to recovery in their qualitative study. In terms of quantitative research, stronger identification of the costs of AN, as well as weaker endorsement of concerns about change, has been linked with greater readiness to recover (Blake et al., 1997; Cockell et al., 2003; Rieger et al., 2002). Furthermore, a link between stronger endorsement of the pros of AN and greater eating disorder pathology (indicated by higher EDI sub-scale scores) has been demonstrated in the initial validation study of the P-CAN, a measure designed to capture both perceived pros and cons of the illness (Serpell et al., 2004).

#### 3.1.1 Intrinsic Motivation

The endorsement of pros of AN is thought to maintain the disorder through its effect on motivation, in that the valued nature of AN to those afflicted with it may decrease their motivation for recovery. Particularly, intrinsic motivation – wherein desire for recovery is motivated by intrinsic rewards (such as improving one's quality of life) as opposed to external rewards (such as appeasing one's family and friends) – has been highlighted as integral in achieving sustained change, according to SDT (Deci & Ryan, 1985, 2000). This line of thinking has been echoed in research demonstrating that higher intrinsic motivation is linked with greater engagement, persistence and learning within the therapeutic context (Choi et al., 2010; Deci et al., 1999; Medalia & Richardson, 2005; Vansteenkiste et al., 2004). Moreover, high internality has been 123

associated with increased BMI in inpatients with AN (van der Kaap-Deeder et al., 2014), as well as lower preoccupation with shape and weight, binge-eating symptoms, and general psychiatric distress at discharge in a sample of BN patients receiving group therapy (Mansour et al., 2012). Taken together, these findings emphasise the significance of internality within the treatment context, which may be influenced by patients' perceived benefits and burdens of their illness. To wit, when those afflicted with AN perceive their illness as improving their life to some extent (for example, by providing them with a sense of control and security, or any other of the perceived benefits identified by Nordbø et al. [2012] and Serpell et al. [1999]), they may not be intrinsically motivated to recover, resulting in poor engagement with treatment and persistence of symptoms.

# 3.1.2 Confidence

Another aspect conceptually linked with motivation, which has received relatively little attention within the research literature thus far, is confidence. Confidence refers to the expectation people have about their ability to make changes or execute a behaviour, and is related to the concept of self-efficacy, described in Chapter 2 (Bandura, 1977; Treasure & Schmidt, 2001). Confidence in one's ability to change has been associated with behaviour change and better outcome in a range of health behaviours, such as physical activity in multiple sclerosis and smoking cessation (Diclemente et al., 1985; Motl et al., 2009). It follows that confidence may be helpful in recovery from eating disorders, in that recovery can be a challenging process which may require a level of confidence in one's ability to overcome the various difficulties encountered during the challenging recovery process. In terms of research examining 124

confidence in eating disorders, one study found that confidence was the strongest predictor of treatment outcome in individuals with BN enrolled in a guided self-help treatment (Steele et al., 2011), whilst another study, investigating individuals with AN and BN seeking inpatient care, found that confidence predicted the length of treatment, as well as reductions in drive for thinness and body dissatisfaction (Pinto et al., 2008). Lastly, Iyar et al. (2019) found that confidence was linked with lower post-treatment symptom severity, in a sample of 59 adult women receiving inpatient treatment for eating disorders. It is possible that confidence could be linked with egosyntonicity, in that an individual who highly values his or her illness may feel less confident in their ability to recover due the ambivalence he or she may be experiencing; however, this relationship has yet to be examined within the literature. Furthermore, according to the TTM discussed in Chapter 2, transitions between stages of behaviour change are the functions of other important dimensions of health behaviour change, such as decision making (ie. weighing the pros and cons of change) and self-efficacy (ie. confidence in one's ability to change) (Cockell et al., 2002).

# 3.1.3 Anorexia Nervosa Subtypes

A point which warrants mentioning when considering AN is the distinction between AN-BP and AN-R subtypes, briefly outlined and discussed in Chapter 1. The division of AN into two categories was first introduced in the 4<sup>th</sup> edition of the *DSM* (APA,1994), following research which indicated existing differences between women with AN-BP and AN-R on measures of lability of mood, suicidality, substance abuse, and impulsivity (APA, 1994; Wilson & Walsh, 1991). In a review by DaCosta and Halmi (1992) which included 12 studies examining differences between restrictive 125

and BP subtypes, it was concluded that BP subtypes demonstrated elevated behaviour impulsivity, measured by frequency of self-injurious behaviours, suicide attempts, substance abuse, and stealing, in addition to also demonstrating greater levels of mood lability and depression (Braun et al., 1994; Bruce et al., 2003; Casper et al., 1980; Favaro & Santonastaso, 1996; Garfinkel, 1981; Rosval et al., 2006; Shisslak et al., 1990). Further, longitudinal studies investigating the course and outcome of AN have reported that purging may be linked with more severe outcome measured by rates of recovery and mortality (Deter & Herzog, 1994; Herzog et al., 1997; Hsu, 1988; Steinhausen & Glanville, 1983; Vandereycken & Pierloot, 1983). More recent research has compared personality traits and cognition within subtypes, finding that AN-BP patients demonstrate more impulsive traits, higher novelty seeking, higher emotional dysregulation, higher extravagance, and greater reward sensitivity, meaning a greater tendency to detect, pursue, learn from, and derive pleasure from positive stimuli (Claes et al., 2010; Claes et al., 2002; Díaz-Marsá et al., 2007; Goodnight, 2018; Tasca et al., 2009; Vervaet et al., 2003). Those diagnosed with the restrictive subtype, on the other hand, demonstrate higher self-directedness, higher compulsiveness, and higher conscientiousness (Claes et al., 2002; Claes et al., 2010; Diaz-Marsa et al., 2008; Tasca et al., 2009; Vervaet et al., 2003). Considering these differences, it is possible that AN-BP and AN-R patients also differ in terms of endorsement of perceived benefits and burdens of their illness; however, these potential differences have yet to be investigated.

# 3.1.4 Egodystonicity in Anorexia Nervosa

As described in Chapter 2, despite the egosyntonic nature of AN, individuals suffering from AN do not fail to recognise the various burdens that come alongside the disorder, also labelled egodystonic aspects of the disorder. Specifically, Serpell et al. (1999) found that common themes pertaining to burdens of AN included feeling trapped by the illness, feeling hatred towards the illness, feeling guilty about the illness' effect on loved ones, and feeling emotionally numbed by the illness. Moreover, individuals suffering with AN recognised that social and health domains were negatively impacted by the illness. Research into the egodystonic aspect of AN has thus far been limited; however, preliminary evidence suggests that individuals with AN who are seriously contemplating change identify more costs to the disorder (Cockell et al., 2003). As such, perceived burdens of AN may play a role in motivation for recovery; however, it has yet to be established whether identifying costs of the illness is linked with intrinsic motivation specifically, which is thought to be key in behavioural change. In terms of illness severity, Serpell et al. (2004) found no relationship between cons of AN and eating disorder pathology and BMI, an interesting finding considering that more severely ill patients are likely to experience more negative effects of the illness, particularly in terms of health and social costs. Uncovering the relationship between perceived cons and intrinsic motivation, as well as understanding its relationship with severity, could help elucidate the role of perceived burdens in AN, which could further inform therapeutic techniques.

#### 3.1.5 Cognitive Maintenance Models of Anorexia Nervosa

As demonstrated, there has been some increased attention in empirical studies investigating egosyntonicity in AN in the past decades, and in line with this, models highlighting egosyntonicity regarding the illness as a maintenance factor have been put forth, as briefly discussed in Chapter 1. Firstly, Wolf and Serpell (1998) proposed a cognitive model which highlighted how positive beliefs about the value or function of the disorder served to maintain the illness. In formulating the model, the authors addressed three key elements pertaining to a cognitive model for AN: 1) the 'core' anorexic beliefs (e.g. core beliefs about thinness and self-worth being intertwined, e.g. 'if I'm thin, I'm special; if I'm fat, I'm worthless'); 2) the 'general' cognitive psychopathology (for example, low self-worth and lack of self-efficacy), and 3) the meaning of the illness to patient, or beliefs about AN. In terms of beliefs about AN, the authors emphasised the importance of meta-cognitions, meaning the beliefs and actions pertaining to the regulation and interpretations of a person's own cognitions, in the maintenance of emotional disorders (Metcaffe & Shimamura, 1994; Teasdale, 1985; Wells, 1996). The authors proposed that meta-cognition in the form of proanorexia beliefs may be involved in maintaining the disorder, particularly the ambivalent approach to treatment commonly seen in AN patients. According to the model, pro-anorexia meta-cognitions (such as "if I didn't have AN, my whole world would fall apart, I wouldn't be able to cope") increase resistance to treatment, whilst anti-anorexia meta-cognitions (such as "anorexia stops me from having a life") might increase readiness to change.

More recently, as discussed in Chapter 1, Schmidt and Treasure (2006) proposed a cognitive-interpersonal model, which highlighted four factors as being influential in maintaining AN. To recap, these four factors included: 1) a rigid thinking style, 2) interpersonal relationships containing high expressed emotion and accommodating and enabling behaviours, 3) an emotional and social style characterised by high anxiety and poor emotional regulation, and 4) pro-anorexia beliefs. In terms of pro-anorexia beliefs, the authors argue that the existence of pro-anorexia websites where some individuals with the illness present AN as a positive lifestyle choice highlights the pervasiveness and intensity of such beliefs. Building on this model, the evidence-based treatment MANTRA (described and discussed in Chapter 1 and 2) has been developed, and incorporates addressing pro-anorexia beliefs as an integral component of treatment.

Moreover, in outlining their cognitive-interpersonal model of AN, Schmidt and Treasure (2006) stress the lack of emphasis on weight and shape concerns in AN in their model, which stands in stark contrast to cognitive-behavioural models of AN wherein weight and shape concerns are believed to be the crux of the disorder. Specifically, the authors point out that, in contrast to BN, AN is not bound to Western culture, in that there are many descriptions of AN from non-Western cultures, wherein psychopathology and justification for weight loss is not based on thin body ideals or concerns about weight (Keel et al., 2003). It should also be noted that the pursuit of thinness can fulfil broader needs than desiring an attractive appearance. For instance, according to Rieger et al. (2001), AN will likely be present in those cultures where the control of body shape or weight has cultural currency, which may relate to cultural

values of thinness being regarded as attractive but may also reflect cultural values wherein lower weight is indicative of self-control, achievement, or spirituality, which echoes some of the benefits of AN endorsed in Serpell et al.'s (1999) and Nordbø et al. (2006) studies. Considering further the lack of emphasis on weight and shape concern in Schnidt and Treasure's (2006) model, it should also be noted thateven in cases where gaining a thin ideal due to desiring an attractive appearance is the affected individual's true and only concern at the beginning of their illness, once the disorder takes hold, a wide range of benefits of the disorder (secondary gains) may present themselves, and weight and shape concerns may no longer be the primary reason for engaging in the disordered behaviour. This lack of emphasis on weight and shape concern echoes the evidence from Serpell et al.'s (1999) and Nordbø et al. (2006), wherein gaining a sense of safety and structure is highlighted as the key benefit of the disorder, as opposed to gaining an improved appearance through thinness. (However, it should be noted that there is a limit to what can be learned from asking patients themselves what they think predated their disorder or maintains it [Vitousek et al., 1991], which is how this evidence was collected.) Further, a study by Machado and Ferreira (2014) which aimed to identify specific life events preceding the onset of eating disorder symptoms in a sample of 86 AN patients (compared with 86 healthy controls) found no specific life event emerging as a specific proximal trigger for AN, including critical comments about weight, shape and/or eating,, with 46.5% of AN respondents reporting no critical comments by family about weight or shape. However, it should be noted that lack of criticism from family does not exclude the presence of self-criticism about one's body. Nevertheless, even in cases where AN originally develops as a response to a negative body image or critical comments about 130

weight, focusing on negative body image (as opposed to focusing on larger problems which may be more difficult to solve) may still be a maladaptive coping mechanism to avoid larger, more complex issues. Further, studies investigating the meaning of AN to those with the condition also highlight the wide range of benefits which patients perceive their disorder as providing them with, which are far more complex than just attaining a thin ideal (Nordbø et al., 2006; Serpell et al., 1999).

# 3.1.6 Validation of the Pros and Cons of Anorexia Nervosa Scale

The P-CAN (discussed in Chapter 2), which aims to identify these various benefits, alongside the numerous costs of the disorder, was originally validated within a population of 233 adult females with AN, recruited from four sources: two eating disorder services in London and Arizona, a volunteer register maintained at the Eating Disorders Research Unit, Institute of Psychiatry, London, and an advertisement appearing on an eating disorder website maintained by the first author (Serpell et al., 2004). Initial results examining the reliability of the P-CAN, in terms of the consistency of the measure, have demonstrated promising results.

Three types of consistency can be measured: consistency across time (test-retest reliability), across items within a scale or sub-scale (internal consistency), and across different researchers (inter-rater reliability). In terms of the P-CAN, moderate to high internal consistency (q = .68 - .89) and good test-retest reliability (r = .60 - .85) have been shown (Serpell et al., 2004).

However, the validity of the P-CAN has yet to be fully established. Validity refers to the extent to which the scores from a measure represent the variable they intend to capture. Different types of validity include face validity, content validity, criterion validity, and discriminant validity. Face validity refers to the extent to which a measurement appears "on its face" to capture the construct of interest. For example, most people would expect a self-esteem questionnaire to include items about about whether a person perceives themselves as having good qualities. Content validity, on the other hand, is the extent to which a measure adequately "covers" the construct of interest. For instance, if a researcher conceptually defines anxiety as involving both negative thoughts and activation of the nervous system, a measure of anxiety should include both negative thoughts and feelings of nervousness. Both face validity and content validity are typically not assessed quantitatively but rather by carefully checking the measurement against the conceptual definition of the construct.

Criterion validity, on the other hand, is the extent to which individuals' scores on a measure are correlated with other variables that one would expect them to be associated with, referred to as the criterion variable. For example, one might expect a measure of test anxiety (the construct) to correlate with performance on a school exam (the criterion variable). When both these variables are measured at the same time, this is referred to as *concurrent* validity, whereas *predictive* validity refers to when the criterion is measured at some point in the future (after the construct has been measured). Criteria can also include measures of the same construct, which is known as *convergent* validity. Conversely, discriminant validity, is the extent to which scores on a measure are *not* correlated with measures of variables that are conceptually distinct. In terms of the P-CAN, only its concurrent validity has been tested, wherein 132

an association between the Pro sub-scale and a measure of eating disturbance was demonstrated.

Specifically, the original validation study determined that higher Pro sub-scale scores correlated with higher scores on the Body Dissatisfaction and Drive for Thinness Eating Disorder Inventory (EDI) sub-scales. However, other measures of illness severity did not yield support for the hypothesis that endorsement of the pros of AN would be linked with illness severity, as there was no significant correlation between BMI and the pros of AN. Interestingly, eating disorder pathology as measured by the EDI was only associated with positive functions and did not appear to be linked with the cons of AN, suggesting that having a more severe illness is associated with stronger endorsement of pros, but not necessarily with a weaker endorsement of cons of the disorder. This finding lends support to suggestions that addressing the egosyntonic facets of AN should be an essential part of therapy (Treasure, 1999).

Considering the promising initial results of the validation of the P-CAN, Serpell et al. (2004) suggested that a further assessment of concurrent validity should be made by administering the P-CAN alongside measures of motivation recently developed for use in AN (Geller & Drab, 1999; Rieger et al., 2000) or with measurements of patients' concerns regarding change (Vitousek et al., 1995). In regards to limitations in Serpell et al.'s (2004) initial study, a methodological issue which warrants mentioning is that diagnostic information was lacking for the majority of participants, as accurate diagnostic details relied on self-report for 78% of participants, due to these participants being recruited via a volunteer register and an eating disorder website, as opposed to 133

a clinic where diagnostic information was accessible via clinical records. As such, further validation of the measure is clearly warranted using a sample of patients with established *DSM* diagnoses of AN. Recruiting participants with established diagnoses from a clinical setting will also ensure that data on BMI is accurately measured by a clinician, as opposed to via self-report. Lastly, considering established differences between the restricting and BP subtypes of AN patients in terms of treatment engagement among other factors (Herzog et al., 1996), and also taking into account that endorsing egosyntonic facets of AN is theorised to be a maintaining factor of the disorder, the authors also suggested that examining whether these subtypes would also differ in terms of their endorsements of egosyntonic and egodystonic aspects of AN could also be clinically useful.

# 3.1.7 The Current Study

As such, the current study aims to replicate and extend upon Serpell et al.'s (2004) research by establishing the concurrent validity of the P-CAN in a sample of clinically diagnosed patients with *DSM-5* AN, specifically examining the relationship between endorsement of pros and eating disorder symptoms, BMI, as well as a number of motivational measures. Moreover, the study aims to explore the link between the P-CAN and confidence in one's ability to recover and AN subtype diagnosis, as well as the relationship between endorsement of cons of AN and eating disorder symptoms, BMI, and intrinsic motivation. Lastly, the study aims to examine whether the relationship between endorsement of pros and eating disorder symptoms is mediated by motivation. Examining this model is especially important because valuing specific

facets of AN may be an integral mechanism through which reluctance to recover, and thus eating disorder symptoms, is maintained. Clarifying the relationship between endorsement of pros and motivation could be of significant clinical relevance, in that understanding mechanisms through which ambivalence towards recovery is maintained could inform more effective treatments. The study employs a crosssectional within-subjects design.

In terms of establishing the concurrent validity of the P-CAN, the following predictions were made:

- Firstly, based on preliminary evidence from the original validation study (Serpell et al. 2004), it is hypothesised that participants' scores on the P-CAN – Pro subscales will be positively correlated with eating disorder pathology (as measured by the Eating Disorder Examination Questionnaire (EDE-Q).
- 2) Further, despite Serpell et al.'s (2004) study failing to find a relationship between endorsement of pros of AN and (self reported) BMI, it is hypothesised that P-CAN – Pro sub-scale scores will be negatively correlated with BMI when investigated within a clinically diagnosed sample wherein BMI is obtained from clinical records as opposed to self-reported.
- 3) In line with Wolf and Serpell's (1998) cognitive model and Schmidt and Treasure (2006) cognitive-interpersonal model, it is hypothesised that P-CAN – Pro subscales will be negatively correlated with readiness for change (as measured by the ANSOCQ and RMQ – Action sub-scale), and positively correlated with

precontemplation and concerns about change (as measured by the RMQ – Precontemplation sub-scale and the CCS).

- 4) Drawing on Vanseteenkiste and colleagues' (2004) SDT, it is hypothesised that P-CAN – Pro sub-scales will be negatively correlated with intrinsic motivation to recover (as measured by the RMQ – Internality sub-scale).
- 5) Based on previous research (Blake et al., 1997; Cockell et al., 2003; Rieger et al., 2002), it is hypothesised that the P-CAN Con sub-scales will be negatively correlated with readiness to change (as measured by the ANSOCQ and RMQ Action sub-scale), and positively correlated with precontemplation and concerns about change (as measured by the RMQ- Precontemplation sub-scale and CCS).

Moreover, the study aims to answer the following research questions:

- 6) Is there a link between endorsement of pros and cons of AN (measured by the P-CAN) and confidence in one's ability to recover (measured by the RMQ Confidence sub-scale)?
- 7) Do BP and restrictive subtypes differ in terms of endorsement of pros and cons (measured by the P-CAN)?
- 8) What is the relationship, if any, between endorsement of cons of AN (measured by the P-CAN – Con sub-scales) and eating disorder symptoms (measured by the EDE-Q), BMI, and intrinsic motivation (measured by the RMQ – Internality subscale)?
- Further, based on cognitive models highlighting endorsement of pros as a maintenance factor in AN (Treasure & Schmidt, 2006; Wolf & Serpell, 1998), it
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is hypothesised that motivation (measured by the ANSOCQ) will mediate the relationship between endorsement of pros (measured by the P-CAN Pro scale) and eating disorder symptoms (measured by the EDE-Q).

10) Lastly, based on TTM which posits that both DB and self-efficacy may jointly contribute to motivation, it is hypothesised that motivation (measured by the ANSOCQ) will mediate the effect of DB (measured by subtracting the P-CAN – Con Global score from the P-CAN – Pro Global score) and self-efficacy (measured by the RMQ – Confidence sub-scale) on eating disorder pathology (measured by the EDE-Q).

#### 3.2 Method

# 3.2.1 Participants

In the current study, the sample comprised 100 female outpatients, daypatients, and inpatients suffering from a *DSM-5* diagnosis of AN, aged 16 to 69 years (M = 25.7, SD = 11.53). To obtain a heterogenous sample with varied levels of illness severity, as well as to achieve the target sample size, BMI threshold was not used as an exclusion criterion in this study. That is, individuals meeting *DSM-5* criteria for AN diagnosis pertaining to restriction, intense fear of weight gain, and body image disturbance, but whose weight was currently within the normal range were included in the sample. It should be noted that reasons behind being at a healthy weight at the time of participation may have varied across participants; for instance, some participants may have gained weight due to success within their current treatment, whereas others may have developed their eating disorder at a higher weight, therefore 137

still being at a healthy weight despite significant and rapid weight loss. This point does raise some potential limitations in the data (in that those participants for whom higher weight was indicative of a lesser severity of illness and those whose illness was still developing have not been distinguished between) and, whilst beyond the scope of this project, futures studies may benefit from more valid measures of weight status (for example, weight change in the previous four weeks) to discern between such individuals. Mean BMI for participants was 16.6 (SD = 2.04), with BMIs ranging from 12.6 to 21.8. 64% of participants were diagnosed with the restricting subtype, 24% of participants were diagnosed with BP subtype, and for 12% of participants, information regarding subtype was missing. Participants were undergoing either monitoring or treatment in five NHS eating disorder services (EDS) within the UK, including Truro Health Park EDS, Cornwall, St. Ann's Hospital EDS, London, and three additional eating disorder services located within North East London Foundation NHS Trust. Treatment comprised of various types of therapy (including CBT-E, MANTRA, and FBT), specialist nurse monitoring, dietetic sessions, psychiatric appointments, medical input, or some combination of these, whereas monitoring typically comprised specialist nurse monitoring and dietetic sessions. Participants were initially approached by a member of their care team to discuss potential participation, and then contacted by the researcher if interest in participating was expressed.

# 3.2.2 Procedure

Ethical approval for the study was given by the local Research Ethics Committee (reference number: 216529). Potential participants were first provided with an

information sheet, which included the description of the study, the risk and the benefits, confidentiality, and informed consent, and each participant was given a 24 hour cooling off period to deliberate whether they wanted to partake in the study. Once the cooling off period was over, those who wished to participate provided informed consent. Participants who experienced any discomfort whilst completing the survey were advised to contact the researchers for debriefing, as well as speak to their treatment team if desired. No requests for debriefing were made. Once informed consent was given, participants completed a questionnaire pack, consisting of the P-CAN, EDE-Q, ANSOCQ, and CCS, as well as basic demographic questions including age, ethnicity, marital/relationship status, and employment status. Completion of the pack took approximately 30 minutes. Some participants received a link to an online survey, administered via University College London's online Opinio tool, whilst others completed a paper-based survey at their eating disorder clinic in conjunction with a monitoring or therapeutic session. As reimbursement for their time and participation, participants received £10.

# 3.2.3 Measures

#### **3.2.3.1** Pros and Cons of Anorexia Nervosa Scale

The P-CAN measured participants' endorsements of the pros and cons of their illness. The measure comprises two scales, Pros and Cons, which contain six and four subscales respectively. Participants indicated their feelings about 50 positive or negative statements regarding their AN on a five-point Likert-scale (Agree strongly to Disagree strongly). The statements pertained to the following sub-scales: Safe/Structured (four

items, e.g. "Anorexia helps me get through life"); Appearance (four items, e.g. "I feel that I am more attractive as a result of my anorexia"; Fertility/Sexuality (four items, e.g. "Anorexia allows me to avoid the disruption of having periods"); Special/Skill (five items, e.g. "Anorexia lifts me above others"); Fitness (four items, e.g. "I feel fitter as result of my anorexia"); Communicate Distress/Emotions (five items, e.g. "Anorexia expresses my inner anguish"); Trapped (four items, e.g. "I feel unable to escape from my anorexia"); Guilt (five items, e.g. "I feel bad that my anorexia is a concern to others"); Hatred (six items, e.g. "I wish my anorexia would go away and leave me alone!"); and Stifles Emotions (five items, e.g. "Anorexia has numbed my emotions"). Sub-scale scores were obtained for each participant by averaging their score on each sub-scale. A Global Pro score was obtained by averaging all six Pro sub-scales. The P-CAN's sub-scales have demonstrated moderate to high internal consistency ( $a_x = .68 - .89$ ) and good test-retest reliability (r = .60 - .85), when administered one week apart (Serpell et al., 2004).

#### **3.2.3.2 Eating Disorder Examination Questionnaire**

The EDE-Q (Fairburn & Beglin, 1994) assessed participants' severity of illness. The self-report questionnaire comprises 28 questions measuring eating disorder symptoms, including Restraint, Eating Concern, Shape Concern, and Weight Concern. Participants are asked to rate a range of behaviours on a 6-point Likert scale, based on the past 28 days. Items include questions such as "Have you been deliberately trying to limit the amount of food you eat to influence your shape or weight (whether or not you have succeeded)?" (Restraint sub-scale), "Has thinking about food, eating or calories made it very difficult to concentrate on things you are interested in (for

example, working, following a conversation, or reading)?" (Eating Concern subscale), "Have you had a definite desire to have a totally flat stomach?" (Shape Concern sub-scale), and "Has your weight influenced how you think about (judge) yourself as a person?" (Weight Concern sub-scale). Global scores were obtained by summing the four sub-scales scores and dividing the resultant total by the number of sub-scales. In terms of internal consistency, the following coefficients have been demonstrated previously within eating disorder samples; .64 for the Restraint sub-scale, .68 - .73 for the Eating Concern sub-scale, .85 - .87 for the Shape Concern sub-scale, and .76 for the Weight Concern sub-scale (Byrne et al., 2010; Mond et al., 2004).

# 3.2.3.3 Anorexia Nervosa Stages of Change Questionnaire

The ANSOCQ (Rieger et al., 2000) measured participants' readiness to recover. The 20 items comprising the questionnaire addressed aspects of eating behaviour, weight and body shape, emotional and relationship problems, and methods of weight control. Derived from Prochaska and DiClemente's stages of change model (1982), five response options were given for each item, reflecting the stages of change proposed by this model: pre-contemplation (e.g. "As far as I am concerned, I do not need to gain weight"), contemplation (e.g. "In some ways I think that I might be better off if I gained weight"), preparation (e.g. "I have decided that I will attempt to gain weight"), action (e.g. "At the moment I am putting a lot of effort into gaining weight"), and maintenance ("I am working to maintain the weight gains I have made"). Participants chose one or more options which best described their attitudes toward a change in the symptom mentioned. Scores were obtained by dividing the total score by the number of items. The scale has demonstrated good internal consistency (.90) and one-week

test-retest reliability (.89) (Rieger et al., 2000). Furthermore, the scale has been shown to predict weight gain within treatment, eating disorder symptoms at discharge, and hospital admission (Ametller et al., 2005; Castro-Fornieles et al., 2007; Rieger et al., 2000).

# 3.2.3.4 Readiness and Motivation Questionnaire

The Readiness and Motivation Questionnaire (RMQ) assesses precontemplation, action, confidence in ability to change, and internality (the extent to which change, when happening, is for external versus internal reasons). Two motivational stage scores (precontemplation and action/maintenance) are provided for each of four symptom domains (restriction, bingeing, compensatory strategies, and cognition). Participants are asked to rate their behaviour on a scale ranging from 0% to 100%. based on the past 28 days. Example items from each symptom domain include "How much of you has wanted to restrict your eating?" (precontemplation, restriction), "How much of you has been actively working to reduce your bingeing?" (action/maintenance, bingeing), "If you were to reduce the amount you made yourself sick, how much of this would be for you (versus for others)?" (internality, compensatory strategies), and "If you decided to reduce your fear of weight gain, how confident are you in your ability to do so?" (confidence, cognition). Total scores were obtained by averaging across 12 symptom scores for each of the four domains (precontemplation, action/maintenance, confidence, and internality). Internal consistency for the RMO has been demonstrated as low to moderate, with coefficient alphas for the four sub-scales being .55 for the precontemplation sub-scale, .66 for the action sub-scale, .80 for the internality sub-scale, and .77 for the confidence subscale (Geller et al., 2013). However, these low to moderate internal consistencies were expected, given that readiness differs according to symptom domain. Acceptable test-rest reliability has also been demonstrated, giving the following results: r = .73 (precontemplation), r = .73 (action), r = .81 (internality), and r = .80 (confidence) (Geller et al., 2013).

# 3.2.3.5 Concerns about Change Scale

The 112-item Concerns about Change Scale (CCS) (Bemis, 1986; Vitousek et al., 1995) measured participants' concerns about change. The scale was devised to measure concerns about change in addictions and anxiety disorders as well as eating disorders. Presented with self-statements, participants indicated their agreement on a five-point Likert-scale (1 = The statement does not reflect my concerns at all to 5 =The statement very strongly reflects my concerns). The scale yields 17 sub-scales reflecting themes of reasons for resisting change, including Unable to Change (e.g. "It is not within my power to change"), Unworthy of Change (e.g. "I think I need this problem to punish myself"), Concern about Risks Involved in Change (e.g. "I may go crazy if I change"), Concern about Sexuality (e.g. "I may have to deal with my sexuality if I change"). Concern about Maturity (e.g. "In many ways, this problem simplifies the difficulties of adult life"), Concern about Interpersonal Loss (e.g. "I'm afraid that people will stop worrying about me if I change"), Concern about Personal Loss (Accomplishment) (e.g. "I may lose a sense of self-control if I change"), Concern about Personal Loss (Hedonic) (e.g. "I may not have as much fun if I change"), Concern about Reaction of Others (e.g. "I'd have to give up all my friends if I change"), Sense of Identity (e.g. "This problem is an important part of my identity"), 143

Avoidance of Negative Affect (e.g. "I wouldn't have anything to help me forget my problems if I change"), Avoidance of Responsibility (e.g. "I'd have no excuse for my failures if I change"), Disinhibition of Expression (e.g. "I wouldn't be able to express how I feel if I change"), Goal Attainment (e.g. "The problem gets me things I want"), Symptom of Deeper Underlying Problem (e.g. "The problem is just covering up a deeper, more serious problem"), Unpleasantness of Change Process (e.g. "The process of change would be too painful for me to bear"), and Failure to Recognise Problem as a Problem (e.g. "I don't want to change this part of my life"). Scores were obtained by tallying items loading on each of the sub-scales in order to create a profile of concerns. Designed to be administered across diagnostic categories, the CCS has been demonstrated to possess strong high internal consistency among individuals with eating disorders, with Cronbach's alphas ranging from .81 to .91 (Vitousek et al., 1995). Further supporting the scale's validity, individuals with AN have been found to score significantly higher than individuals with BN, agoraphobia, and specific phobia on four out of eight sub-scales.

# 3.2.4 Statistical Analysis

# 3.2.4.1 Statistical Tests Examining Internal Consistency

To assess the homogeneity of the P-CAN sub-scales, Cronbach's alpha coefficients were calculated for each of the Pro and Con sub-scales. Item-total correlations were also calculated for each sub-scale.

# 3.2.4.2 Statistical Tests Examining Concurrent Validity and Novel Relationships

Upon initial examination of the data it was determined that the majority of variables were not normally distributed, as assessed by the Shapiro-Wilk test (p < .05). For this reason, the non-parametric Spearman's rank-order correlation coefficient (two-tailed) was used to calculate correlations between the P-CAN and the EDE-Q, ANSCOQ, CCS, RMQ, as well as BMI, in order to establish convergent validity and explore novel relationships.

Spearman's correlations assume (a) that you have continuous or ordinal variables; (b) that these two variables represent paired observations, and (c) that there is a monotonic relationship between your two variables. To test this third assumption, scatterplots for each relationship were produced and visually inspected. No non-monotonic relationships were discovered, thus meeting the assumption. While significance levels were important to facilitate interpretation of the results, emphasis was also placed on the size of the correlation coefficients whilst interpreting the findings. To interpret the size of correlation coefficients, Cohen's (1988) definitions of small (r = .10), medium (r = .30) and large (r = .50) effect sizes were used. In order to reduce type 1 error, a significance level of 1% (0.01) was applied.

# 3.2.4.3 Statistical Tests Exploring Differences Between Binge-Purge and Restricting Subtypes

To explore differences on P-CAN scores between BP and restrictive subtypes, a Mann-Whitney t-test was performed. The Mann-Whitney U test holds four assumptions; (a) that you have a continuous or ordinal dependent variable; (b) that your independent 145

variable (IV) is categorical with two groups; (c) that you have independence of observations (meaning that there is no relationship between the observations in each group of the IV or between the groups themselves), and (d) that the two distributions (i.e. the distribution of scores for both groups of the IV) have the same shape. To test this fourth assumption, a population pyramid was generated for each relationship and visually inspected. Distribution of pros and cons scores were not similar across subtypes. Thus, as the fourth assumption was violated, the Mann-Whitney U test was used to compare mean ranks (as opposed to medians, which can only be compared when this assumption is met).

# 3.2.4.4 Statistical Tests Examining the Relationship between Endorsement of Pros, Motivation and Eating Disorder Symptoms

To test the sixth hypothesis, Baron and Kenny's (1986) method for mediation analysis was performed, with motivation as the independent variable (measured by ANSOCQ), eating disorder symptoms as the dependent variable (measured by the EDE-Q Global Score), and endorsement of pros (measured by the average of all six Pro sub-scales) as the mediator. Path c' should be non-significant after controlling for a mediator for a fully mediated pathway to occur (see figure 3-1).

#### 3.3 Results

#### 3.3.1 Sample Characteristics

Presented in Table 3-1 are the sociodemographic and clinical characteristics of the current sample.

# **1 Direct pathway**

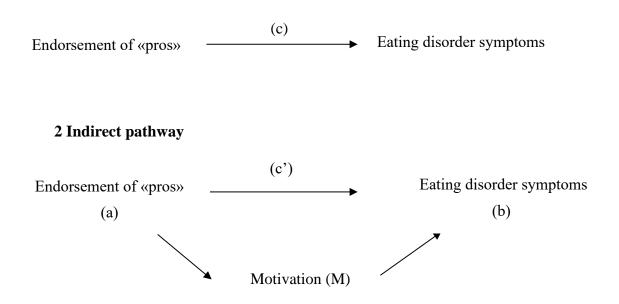


Figure 3-1. Mediation model of the indirect effect of endorsement of pros on eating disorder symptoms via motivation.

# 3.3.2 Internal Consistency

Internal consistency was calculated for each of the 10 sub-scales of the P-CAN using Cronbach's alpha (Cronbach, 1951). Internal consistency for the sub-scales was demonstrated as good to excellent, with coefficient alphas ranging from .75 to .91 (see Table 3-2).

## 3.3.3 Concurrent Validity

Concurrent validity of the P-CAN was examined through the associations between the 10 sub-scales and instruments assessing theoretically related constructs. Specifically, correlations were calculated between sub-scale scores on the P-CAN and eating disorder symptoms (assessed by the EDE-Q), readiness to change (assessed by the ANSOCQ and the RMQ – Precontemplation and Action sub-scales), concerns about 147

Age (years): M (SD)	25.7 (11.43)
BMI: M (SD)	16.6 (2.04)
Anorexia subtype (n, %)	
BP subtype	24 (24%)
Restrictive subtype	64 (64%)
No subtype diagnosis provided	12 (12%)
Education (n, %)	
Some secondary school	22 (22%)
Secondary school graduate	60 (60%)
University graduate	12 (12%)
Postgraduate	6 (6%)
Relationship status (n, %)	
Single	77 (77%)
In a relationship	19 (19%)
Married	4 (4%)
Employment status (n, %)	
Full-time	15 (15%)
Part-time	22 (22%)
Unemployed	63 (63%)
Ethnicity	
White	85 (85%)
Mixed/multiple ethnic groups	6 (6%)
Asian/Asian British	6 (6%)
Other ethnic group	2 (2%)

Table 3-1. Sociodemographic and clinical variables of patients at admission (n = 100)

Table 3-2. Internal consistency of the P-CAN sub-scales.

Sub-scale	Safe	Fertility	Appearance	Special	Fitness	Communicate Distress	Guilt	Trapped	Hatred	Stifles Emotions
Alpha coefficient	.91	.84	.77	.84	.77	.82	.75	.75	.82	.84

change (assessed by the CCS), intrinsic motivation (assessed by the RMQ – Internality sub-scale), and BMI (see Table 3-3). Table 3-3 presents the mean, standard deviation, and range of scores obtained in the questionnaires used to assess concurrent validity, alongside mean, standard deviation and range.

Instrument/Veriah	la N	Maan	Standard Da	viation	Damas	
EDE-Q, ANSCOQ,	RMQ, CCS,	and BMI (n	= 100)			
Table 3-3. Means,	standard de	viations, and	l range of sc	cores for p	participants	on the

Instrument/Variable	Ν	Mean	<b>Standard Deviation</b>	Range
EDE-Q – Restraint	100	3.28	2.00	.00 - 6.00
EDE-Q –	100	3.37	1.48	.00 - 6.00
Eating Concern				
EDE-Q –	100	4.22	1.73	.00 - 6.00
Shape Concern				
EDE-Q –	100	3.69	1.75	.00 - 6.00
Weight Concern				
EDE-Q Global	100	3.64	1.58	.13 - 5.84
BMI	100	16.64	2.04	12.6 - 21.8
ANSCOQ	100	2.58	.78	1.1 - 4.65
RMQ –	100	50.26	23.85	0-100
Precontemplation				
RMQ – Action	100	43.78	24.2	0 - 100
RMQ – Internality	100	54.14	24.39	0 - 100
RMQ – Confidence	100	40.67	22.01	0 - 100
CCS –	97	16.34	6.96	6-30
Unable to change				
CCS –	98	16.19	7.51	6-30
Unworthy of change				
CCS –	98	14.47	6.18	6-30
Concern about Risks				
CCS –				
Concern about	98	9.67	5.57	6-30
Sexuality				
CCS – Concern	98	13.74	6.93	6-30
about Maturity				
CCS – Concern about	98	12.55	6.61	6-30
Interpersonal Loss				
CCS – Concern about				
Personal Loss	98	17.65	7.43	6-30
(Accomplishment)				

CCS - Concern about				
Personal Loss	98	11.00	5.22	6 – 18
(Hedonic)				
CCS – Concern about	97	7.95	4.39	6 - 28
Reaction of Others				
CCS –	98	15.70	7.09	6-30
Sense of Identity				
CCS – Avoidance	97	17.84	7.09	6 - 30
of Negative Affect				
CCS – Avoidance	96	14.44	6.65	6-30
of Responsibility				
CCS – Disinhibition	97	14.01	6.59	6-30
of Expression				
CCS –	98	14.86	6.63	6-30
Goal Attainment				
CCS –				
Symptom of a Deeper	97	17.42	7.25	6-30
Underlying Problem				
CCS - Unpleasantness				
of Change Process	98	18.46	7.23	6-30
CCS –				
Failure to Recognise	98	14.73	6.43	6 - 30
Problem as a Problem				

# **3.3.3.1 Eating Disorder Symptoms**

Eating disorder symptoms were assessed using the Restraint, Eating Concern, Shape Concern, and Weight Concern sub-scales, as well as the Global EDE-Q Score. Higher scores on each of these sub-scales indicate greater eating disorder symptomatology. Participants' scores on the EDE-Q are consistent with published norms for AN samples (Aardoom et al., 2012; Jennings & Phillips, 2017; Mantilla & Birgegaard, 2016; Passi et al., 2003). Utilising a cut-off of >2.09 as a marker of clinical significance, as suggested by Rø et al. (2015) as the optimal cut-off score for AN 150

populations, 71% (n = 71) scored in the clinically significant range on the Restraint sub-scale, 80% (n = 80) scored in the clinically significant range for the Eating Concern sub-scale, 87% (n = 87) scored in the clinically significant range on the Shape Concern sub-scale, and 78% (n = 78) scored in the clinically significant range on the Weight Concern sub-scale. In terms of the Global scale, 81% (n = 81) scored in the clinically significant range. It was predicted that positive correlations between P-CAN – Pro sub-scales and the EDE-Q sub-scales and Global scale would be found.

As shown in Table 3-4, significant correlations emerged between the P-CAN – Pro sub-scales and EDE-Q Global scales. As predicted, the results indicate that higher endorsement of pros as assessed by the Pro sub-scales was linked with greater eating disorder symptomatology, with three of six Pro sub-scales correlating positively with EDE-Q Global scores. Specifically, the EDE-Q Global Scale was strongly correlated with the Appearance sub-scale (r = .51, p = < .001) and moderately correlated with the Safe/Structured (r = .49, p < .001) and Communicate Distress (r = .33, p < .001) sub-scales.

P-CAN	EDE-Q –	EDE-Q –	EDE-Q –	EDE-Q –	EDE-Q	BMI
Sub-scale	Restraint	Eating	Shape	Weight	-	
		Concern	Concern	Concern	Global	
Safe/Structured	.57**	.49**	.30**	.40**	.49**	.13
Special	.36**	.32**	.15	.25*	.31**	.18
Appearance	.54**	.37**	.41**	.47**	.51**	.35**
Fertility/Sexuality	.21*	.29**	.26*	.22*	.27**	04
Fitness	.22*	.21*	.16	.22*	.22*	.11
Communicate	.25*	.42**	.23*	.29**	.33**	-0.12
Trapped	.46**	.45**	.44**	.39**	.48**	-0.84
Guilt	01	.019	.08	06	01	-0.72
Hatred	30**	36**	21*	33**	32**	25
Stifles Emotions	.28**	.33**	.37**	.32**	.35**	05

Table 3-4. Correlations between P-CAN sub-scales and EDE-Q sub-scales, EDE-Q Global Scale and BMI (n = 100)

p = <.05; \*\*p = <.001

## 3.3.3.2 BMI

It was predicted that BMI would be negatively correlated with P-CAN – Pro subscales. Contrary to our expectations, results demonstrated no relationship between the P-CAN and BMI, with the exception of the Appearance sub-scale, which was moderately correlated with BMI in a positive direction (r = .35, p = .001) (see Table 3-4). As such, patients with a higher BMI were more likely to endorse the Appearance pro.

## 3.3.3.3 Readiness to Change

Readiness to change was assessed using the ANSCOQ and the RMQ – Precontemplation and Action sub-scales. Higher scores on the ANSCOQ and RMQ – Action sub-scale indicate greater readiness to change, whereas higher scores on the RMQ – Precontemplation sub-scale indicate greater precontemplation, or lower readiness to change. It was predicted that P-CAN – Pro sub-scales would be negatively correlated with the ANSCOQ and RMQ – Action sub-scale, and positively correlated with the RMQ – Precontemplation sub-scale.

For the ANSCOQ, average scores could be rounded to range from 1 (corresponding to the Precontemplation stage) to 5 (corresponding to the Maintenance stage). On the basis of these rounded average scores, 4% of the participants in the sample were classified in the Precontemplation stage, 46% were classified in the Contemplation stage, 36% were classified in the Preparation stage, 12% were classified in the Action stage, and 2% were classified in the Maintenance stage. As shown in Table 3-5, two out of six Pro sub-scales correlated negatively with the ANSCOQ, partially supporting our prediction. Specifically, the ANSCOQ was strongly correlated with the 152

Safe/Structured sub-scale (r = -.55, p < .001) and moderately correlated with the Appearance sub-scale (r = -.39, p < .001), meaning that participants who endorsed these two pros showed lesser readiness to change.

Table 3-5. Correlations between P-CAN sub-scales and ANSOC and RMQ sub-scales (n = 100).

P-CAN	ANSCOQ	RMQ –	RMQ –	RMQ –	RMQ -
sub-scales		Precontemplation	Action	Internality	Confidence
Safe/Structured	55**	.59**	33**	30**	32**
Special	24*	.43**	15	20*	12
Appearance	39**	.37**	19	21*	19
Fertility/Sexuality	17	.39**	15	22*	07
Fitness	28*	.32**	21*	31**	12
Communicate	22*	.37**	18	26**	18
Distress					
Trapped	26*	.27**	08	03	23*
Guilt	.20*	10	.27**	06	.05
Hatred	.53**	57**	.43**	.28**	.20
Stifled	22*	.30**	00	16	12

p = <.05; \*\* p = <.001

In terms of endorsement of cons, it was hypothesised that greater scores on P-CAN – Con sub-scales would be linked with greater readiness to change. Partially supporting this hypothesis, a strong positive correlation was found between the Hatred sub-scale and ANSCOQ (r = .53, p < .001). This means that participants who expressed more hatred towards anorexia showed greater readiness to change.

In terms of the RMQ – Precontemplation sub-scale, in line with our prediction, five out of six Pro sub-scales were significantly positively correlated with greater precontemplation. Specifically, the Precontemplation sub-scale demonstrated a strong correlation with the Safe/Structured scale (r = .59, p < .001), and moderate correlations 153 with the Special (r = .43, p < .001), Appearance (r = .37, p < .001), Fertility/Sexuality (r = .39, p < .001), and the Fitness (r = .32, p < .001) sub-scales, meaning that those with more pros of anorexia were more likely to be in precontemplation, or have lower readiness to change.

Regarding endorsement of cons, the Precontemplation sub-scale was strongly negatively correlated with P-CAN – Hatred sub-scale (r = .-57, p < .001), in line with our hypothesis. This means that participants who strongly hated anorexia were less likely to be in precontemplation (i.e. more likely to be considering change or actively changing).

For the RMQ – Action sub-scale, only one out of six P – CAN – Pro sub-scales were negatively correlated with Action sub-scale, partially supporting our prediction. Specifically, the Action sub-scale was moderately negatively correlated with the Safe/Structured sub-scale (r = -.33, p = .001).

For con endorsement, one out of four P-CAN – Con sub-scales were significantly correlated with the RMQ – Action sub-scale in a positive direction, partially supporting our prediction. Specifically, the Action sub-scale was moderately correlated with the Hatred sub-scale (r = .43, p < .001), meaning that participants who were in action were more likely to feel hatred towards the disorder.

#### **3.3.3.4** Concerns about Change

Concerns about change was assessed by the CCS. Higher scores indicate greater concerns about change. It was predicted that the P-CAN – Pro sub-scales would be

positively correlated with the CCS sub-scales as having more concerns about change is likely to be related to seeing the disorder as having more benefits. Conversely, it was predicted that the P-CAN – Con sub-scales would be negatively correlated with the CCS sub-scales as having less concerns about change is likely to be related to seeing the disorder as having more disadvantages.

As presented in Table 3-6, the majority of the Pro sub-scales were significantly correlated with the CCS sub-scales in a positive direction. Thus, as predicted, greater endorsement of pros was associated with greater concerns about change.

Regarding the link between the P-CAN – Con sub-scales and CCS sub-scales, several significant relationships were demonstrated, in mixed directions. Commonly, greater endorsement of the Trapped and Stifles Emotions cons was linked with greater concern about change, with the majority of the CCS sub-scales being associated with these cons. Moreover, greater endorsement of the "hatred" con was associated with lesser concern about change, for the majority of the CCS sub-scales.

# 3.3.3.5 Intrinsic Motivation

Intrinsic motivation was assessed by the RMQ – Internality sub-scale. Higher scores indicate higher intrinsic motivation. It was predicted that the Pro sub-scales would be negatively correlated with the RMQ – Internality sub-scale.

As shown in Table 3-5, none of the Pro sub-scales were correlated with the RMQ – Internality sub-scale, contrary to this prediction.

CCS sub-scales	Safe/	Special	Appearance	Fertility/	Fitness	Communicate	Trapped	Guilt	Hatred	Stifles
	Structured			Sexuality		Distress				Emotions
Unable to change	.54**	.24**	.25*	.24*	.35**	.33**	.32**	07	31**	.31**
Unworthy of change	.58**	.32**	.12	.22*	.20*	.38**	.35**	.14	30**	.42**
Concerns about risk	.50**	.32**	.29**	.27**	.36**	.40**				
involved in change										
Concern about sexuality							.04	.05	19	.29**
Concern about maturity	.30**	.36**	.17	.37**	.24*	.48**	.22*	01	24*	.29*
Concern about interpersonal loss	.24**	.45**	.33**	.25*	.25*	.38**	.24*	.02	20	.19
Concern about personal loss	.58**	.48**	.50**	.36**	.32**	.38**	.22*	01	24*	.29*
(accomplishment)										
Concern about personal loss (hedonic)	.43**	.30**	.37**	.35**	.43**	.21*	.08	-0.80	29**	.16
Concern about reaction of others	.11	.12	.24*	.44**	.17	.17	04	.04	10	.12
Problem provides sense of identity	.59**	.54**	.44**	37**	.27**	.41**	.36**	.01	36**	.28**
Avoidance of negative affect	.54**	.32**	.29**	.24*	.33**	.60**	.21*	.04	31**	.52**
Avoidance of responsibility	.36**	.36**	.26*	.29**	.25*	.47**	.33**	.13	25*	.31**
Means of disinhibition of expression	.51**	.31**	.27**	.34**	.40**	.59**	.23*	06	31**	38**
Goal attainment	.54**	.42**	.44**	.35**	.33**	.34**	.25*	02	46**	.32**
Symptom of deeper underlying problem	.45**	.16	.27**	.21*	.24*	.49**	.15	.00	28**	.32**
Unpleasantness of change process	.55**	.35**	.44**	.32**	.44**	.37**	.39**	03	30**	.34**
Failure to recognise	.58**	.32**	.36**	.33**	.38**.	.16	.09	12	52**	.20
problem as a problem										
* <i>p</i> = < .05; ** <i>p</i> = < .001										

# Table 3-6. Correlations between P-CAN sub-scales and CCS sub-scales (n = 100)

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#### 3.3.4 Exploring Novel Relationships (Research Questions 6 to 9)

# 3.3.4.1 Relationship between the P-CAN and Confidence in One's Ability to Recover

Confidence in one's ability to recover was assessed by the RMQ – Confidence subscale (see Table 3-5). Higher scores indicate greater confidence in one's ability to recover. In terms of P-CAN – Pro sub-scales, the RMQ – Confidence sub-scale was significantly negatively correlated with the Safe/Structured sub-scale, demonstrating a moderate effect (r = -.32, p = .001). This means that participants who felt that the disorder kept them safe and helped to structure life expressed lesser confidence in their ability to recover. There were no significant relationships found between endorsement of cons as measured by the P-CAN – Cons sub-scales and confidence.

## 3.3.5 Relationship between the P-CAN and Subtype Diagnosis

Mean differences on the P-CAN between BP and restrictive subtypes were compared using a Mann-Whitney U test. Mean rank, *U* statistics, *z* scores, and significance level for each P-CAN sub-scale are presented in Table 3-7. No significant differences between subtypes were found.

# 3.3.5.1 Relationship between Endorsement of Cons and Eating Disorder Symptoms, BMI and Intrinsic Motivation

Exploring the relationship between endorsement of cons and eating disorder symptoms (as measured by the EDE-Q), it was found that three out of four P-CAN – Con sub-scales were significantly correlated with the EDE-Q Global Scale, albeit in different directions (see Table 3-4). Specifically, the EDE-Q Global Scale was moderately correlated with the Trapped (r = .48, p < .001) and Stifles Emotions (r =

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Sub-scale	Mean rank	$oldsymbol{U}$	Z score	Р
Safe/Structured	R = 40.15	489	-2.612	.009
	BP = 56.10			
Appearance	R = 40.70	525	-2.288	.022
	BP = 54.65			
Fertility	R = 42.47	638	-1.222	.222
	BP = 49.92			
Special	R = 43.27	690	737	.461
	BP = 47.77			
Fitness	R = 41.01	545	-2.103	.035
	BP = 53.81			
Communicate	R = 44.18	748	193	.847
	BP = 45.35			
Trapped	R = 45.91	678	857	.391
	BP = 40.73			
Guilt	R = 44.31	756	114	.910
	BP = 45.00			
Hatred	R = 49.06	476	-2.742	.006
	BP = 32.33			
Stifled	R = 43.56	708	565	.572
	BP = 47.00			

Table 3-7. Results of Mann-Whitney U test comparing P-CAN scores between restrictive (n = 64) and BP (n = 24) subtypes.

.35, p = .001) sub-scales, both in a positive direction, meaning that participants who felt trapped by the disorder or that it stifled their emotions tended to be more severely unwell. Moreover, the EDE-Q Global Scale was moderately negatively correlated with the Hatred sub-scale (r = .33, p < .001). As such, participants with less severe illness expressed greater hatred towards it.

In terms of BMI, there was no relationship between endorsement of cons and BMI (see Table 3-4). It is also worth noting that BMI did was not significantly linked with any measures of motivation (p = >.05).

Regarding intrinsic motivation, the RMQ – Internality sub-scale was not significantly correlated with any of the four Con sub-scales (see Table 3-5).

# 3.3.6 Relationship between Endorsement of Pros, Motivation, and Eating Disorder Symptoms

As presented in Table 3-8, endorsement of pros significantly predicted eating disorder symptoms at path c, and motivation at path a. After endorsement of pros was controlled for, motivation significantly predicted eating disorder symptoms at path b. Lastly, after controlling for the mediator (motivation), endorsement of pros remained a significant predictor at path c'. However, the standardised regression coefficients from endorsement of pros reduced from .53 to .26. Bootstrapped 95% confidence intervals were generated using Process (Hayes, 2013) in order to the test the significance of the mediated pathway (a x b). As confidence intervals did not contain zero (.37 - .88), the mediated pathway was significant, suggesting that motivation was a significant partial mediator of the relationship between endorsement of pros and eating disorder symptoms.

Table 3-8. Results of a mediation analysis of the relationship between endorsement of pros and eating disorder symptoms, mediated by motivation (n = 100)

			95% CI(B)			
Pathways	В	SE (B)	Lower	Upper	β	
Path c:						
Endorsement of pros to ED symptoms	1.21	.19	.82	1.59	.53**	
Path a:						
Endorsement of pros to motivation	52	.10	71	32	46**	
Path b and c':						
Motivation to ED symptoms	-1.19	.15	-1.50	88	59**	
Endorsement of pros to ED symptoms	.59	.17	.25	.93	.26**	
** <i>p</i> < .001.						

# 3.3.7 Relationship between Decisional Balance, Self-Efficacy, Motivation, and Eating Disorder Symptoms

As displayed in Table 3-9, DB and self-efficacy significantly predicted eating disorder symptoms at path c, and motivation at path a. After DB and self-efficacy was controlled for, motivation significantly predicted eating disorder symptoms at path b. Lastly, after controlling for the mediator (motivation), DB and self-efficacy became insignificant at path c'. Bootstrapped 95% confidence intervals were generated using Process (Hayes, 2013) in order to the test the significance of the mediated pathway (a x b). As confidence intervals did not contain zero (..04 - .11), the mediated pathway was significant, suggesting that motivation was a significant full mediator of the relationship between DB and self-efficacy and eating disorder symptoms.

		CI(B)			
Pathways	В	SE (B)	Lower	Upper	р
Path c1 and c2:					
DB to ED symptoms	.11	.03	.05	.17	***
Self-efficacy to ED symptoms	03	.01	03	01	***
Path a:					
DB to motivation	06	.01	09	03	***
Self-efficacy to motivation	.02	.00	.01	.02	***
Path b and c1' and c2':					
Motivation to ED symptoms	-1.26	.18	-1.61	90	***
DB to ED symptoms	.03	.03	02	.09	.248
Self-efficacy to ED symptoms	01	.01	02	.00	.219
*** <i>p</i> < .001.					

Table 3-9. Results of a mediation analysis of the relationship between decisional balance and self-efficacy and eating disorder symptoms, mediated by motivation (n = 100)

## 3.4 Discussion

The egosyntonic nature of AN is a key facet of the illness which may play a paramount role in treatment success and motivation for recovery. Assessment measures are needed to identify potential barriers to benefiting from treatment in this population. The P-CAN represents one such measure, designed to capture endorsement of various pros and cons of AN that may be held by an individual suffering from the disorder.

The primary objective of this study was to further validate the P-CAN in a clinically diagnosed sample. To this end, concurrent validity was examined through the associations between the Pro and Con sub-scales and theoretically related measures. A secondary objective was to explore the relationship between endorsement of pros and cons and confidence in one's ability to recover, as well the relationships between endorsement of cons and eating disorder severity and motivation for recovery, and finally, to compare endorsement of pros and cons profiles within AN subtypes. This section will discuss the major findings of the study, highlight methodological strengths and limitations of the study, as well as propose directions for future research

# 3.4.1 Summary and Integration of Findings

Overall, the findings of the current study suggest that the P-CAN may be a valid and useful tool for identifying factors that may interfere with behavioural change, with all but one hypothesis receiving partial support, providing further evidence of the concurrent validity of the scale.

Internal consistency among the Pros and Cons sub-scales was generally high, with coefficients ranging from .75 to .91. Coefficients of .80 suggest acceptable internal consistency (Anastasi, 1988).

Concurrent validity was investigated through the relationship between the P-CAN – Pro sub-scales and the EDE-Q, BMI, ANSOCQ, CCS, and RMQ, as well as the relationship between the Con sub-scales and RMQ, ANSCOQ, and CCS. It was hypothesised that the Pro sub-scales would be strongly related to indicators of eating disorder pathology, motivation for change, intrinsic motivation, and confidence in one's ability to recover, whilst the Con sub-scales would be linked with motivation for change.

Eating disorder severity was measured through EDE-Q scores and BMI. Consistent with our hypothesis, it was demonstrated that individuals with higher levels of eating disorder symptomology were more likely to endorse benefits of AN, echoing previous research (Serpell et al., 2004). However, contrary to our prediction, most Pro sub-scales were not significantly linked with BMI (with the exception of the Appearance sub-scale), a relationship which Serpell et al. (2004) also failed to demonstrate. The finding that endorsement of pros is linked with eating disorder symptoms but not with BMI may be explained by the previously discussed observation that higher BMI might index both less *and* more severe illness (wherein some patients with higher BMI are in the midst of recovery whereas others may have developed their eating disorder at high BMI but are still losing weight), thus rendering BMI a variable which may not be the best reflection of illness severity.

An interesting finding is that BMI and the Appearance pro were positively correlated, meaning that the lower the patient's BMI, the less likely they were to endorse improved appearance as a benefit of AN. This finding stands in stark contrast to the notion often portrayed in the media that AN is ultimately about achieving a thin ideal; it seems that at some point in the AN patient's weight loss trajectory, the individual with AN may recognise that weight loss is no longer serving to improve their appearance, yet continue to engage in restrictive eating behaviour due to the other functions which AN may serve for the individual or because the behaviour has become 'locked in'. It is also possible that those individuals who are somewhat underweight but not frighteningly so are still receiving positive feedback for their appearance from their external environment, making endorsement of the Appearance pro more likely.

Readiness for change was assessed through the ANSCOQ and the RMQ – Precontemplation and Action sub-scales. As measured by the ANSCOQ, it was demonstrated that individuals with greater readiness to change were less likely to endorse pros of AN. Similarly, the RMQ – Precontemplation sub-scale correlated significantly with five out of six Pro sub-scales, with those who expressed greater precontemplation being more likely to endorse benefits of AN. However, only the Safe/Structured sub-scale was significantly correlated with the RMQ – Action subscale. Notably, the RMQ measures action by what percentage of the individual is taking action towards change (e.g. "In the past two weeks, how much of you has been actively working to eat more?") whereas the ANSCOQ measures stages of change (e.g. ticking "I am working to maintain a current eating pattern which includes 3 standard size meals and a snack each day" to indicate the action stage), which may

explain the differing findings between the two scales. Taken together, the results suggest that AN patients who endorse benefits of AN demonstrate lesser readiness for change, consistent with our hypothesis, as well as with Prochaska et al.'s (1994) weak principle of change. This finding contrasts with the research of Cockell et al. (2003) who failed to find support for the weak principle of change in their AN sample. However, it should be noted that Cockell et al.'s (2003) study did demonstrate that precontemplators endorsed more benefits of AN (as compared to those in the action and contemplation stages) but not significantly so. As such, it is possible that the current study's larger sample size allowed for greater detection of significance. Furthermore, Cockell et al.'s (2003) study examined stages of change as categories (e.g. precontemplators versus contemplators versus action) whereas this study measured readiness to change on a continuous scale, which may also account for the differing findings.

Our hypothesis that individuals identifying stronger costs to their disorder would show lesser readiness to change was partially supported. As measured by the ANSCOQ, patients who expressed greater hatred towards their illness as well as greater guilt for the pain which their illness caused their friends and family demonstrated greater readiness to change. However, those who felt stifled and numbed by their disorder were less ready to change. As measured by the RMQ – Precontemplation sub-scale, endorsement of feeling trapped and numbed by one's illness was linked with being in the precontemplation stage of change, whereas those who expressed hatred towards their disorder were less likely to be precontemplators. Finally, hatred and guilt were once more demonstrated to be associated with the action stage of change, as measured

by the RMQ – Action sub-scale. These results are consistent with the results of Cockell et al. (2003) which demonstrated that identifying costs of one's illness was associated with readiness for change, consistent with Prochaska et al.'s (1994) strong principle of change. However, it should be noted that only two cons of AN were associated with greater readiness to change, specifically feeling hatred towards one's illness and feeling guilt about the suffering the illness may be causing loved ones. Interestingly, this latter con taps into what may considered extrinsic motivation. Thus, it is possible that this readiness to change is externally motivated rather than internally. Conversely, feeling trapped and numbed by one's disorder were actually associated with lesser readiness to change. The "trapped" con may be tapping into feeling powerless over one's disorder, which may lead patients to feel that change is impossible as the disorder is too entrenched. Feeling numb, on the other hand, may instil a feeling of apathy, where the patient is not motivated to make any changes, as there are no negative feelings spurring them on to do so, due to the numbness their disorder may have caused them. This function of AN can be considered both a pro and a con of AN, as some individuals may feel it is beneficial to have their feelings numbed, particularly those that are experienced as overwhelming.

Consistent with what was predicted, concerns about change was positively linked with endorsement of pros, meaning that participants who expressed greater concerns about change were also more likely to endorse benefits of AN. However, greater endorsement of the "trapped" and "stifles emotions" cons was also linked with greater concerns about change. Thus, it seems that the degree to which the patient values their disorder, as well as the degree to which they are feeling trapped and numbed by their

disorder, may increase concerns about change. Lastly, those individuals who endorsed the "hatred" con showed lesser concern about change, again demonstrating the importance of viewing the illness as one's enemy, rather than part of one elf when overcoming concerns regarding change.

In terms of the exploratory section of this study, results showed that AN patients who endorsed the "trapped" and "stifles emotions" cons of AN showed greater eating disorder symptoms, meaning that patients with greater eating disorder pathology were more likely to feel trapped and numbed by their disorder. However, those AN patients who endorsed the "hatred" con showed lesser eating disorder symptoms. The finding may seem counterintuitive as first, in that patients who report greater eating disorder pathology would likely be experiencing more suffering due to their disorder, which might cause greater feelings of hatred towards it. However, it might be that those patients who have come to view their illness as an enemy as opposed to a friend or guardian report lesser eating disorder pathology due to possibly being further in their recovery process. Recognising that one's illness is not one's friend or guardian but rather an enemy which must be fought against may be an important cognitive shift within the treatment process that may lead to progress towards recovery. This cognitive shift can also be referred to as "externalising", a strategy which originally stems from narrative therapy (Carr, 1998) but is also used in FBT. A central tenet of narrative therapy is that the person is not the problem – the problem is the problem. As such, through externalisation, the eating disorder is viewed as being something that is *affecting* the person as opposed to being a *part* of the person, which may be an essential step towards wanting to recover and, in turn, reducing symptoms.

Further, motivation was demonstrated to partially mediate the relationship between endorsement of pros and eating disorder symptoms, thus partially supporting our last hypothesis. This novel finding suggests endorsing benefits of AN may impact upon eating disorder symptoms partially through its influence on motivation, which carries with it important clinical implications and supports the cognitive models discussed in the introduction (Treasure & Schmidt, 2006; Wolf & Serpell, 1998). However, given that motivation was only a partial mediator in the relationship between endorsement of pros and eating disorder symptoms, it should be noted that there are other pathways in which endorsement of pros might exert its influence on eating disorder symptoms, either directly or indirectly, and future research could usefully identify these. Variables which may mediate the relationship between endorsement of pros and eating disorder symptoms include those of a therapeutic nature (such as therapeutic alliance which may be impeded when the patient strongly values his or her disorder, as this may place patient and therapist "at odds"), or those of an individual nature (such as confidence in one's ability to recover, which may be reduced by strong endorsement of pros as the patient may recognise their lack of drive for recovery due to not having enough compelling reasons to do so and thus lose confidence in their ability to successfully recover), as well as those of a clinical nature (such as other comorbidities, which may make the eating disorder's egosyntonic aspect particularly useful for the patient, for instance in its ability to reduce anxiety).

Lastly, motivation was demonstrated to fully mediate the relationship between DB and self-efficacy and eating disorder pathology, in support of our hypothesis. This novel finding suggests that DB and self-efficacy may impact eating disorder pathology

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through its effect on motivation, a finding which could be relevant to the clinical context.

# 3.4.2 Clinical implications

There are several clinical implications that warrant mention in light of these findings. Firstly, our findings demonstrate the internal and concurrent validity of the P-CAN, adding validity to its usefulness within the clinical context. Furthermore, our study shows that endorsement of benefits of AN is linked with greater eating disorder pathology, lesser readiness to change, lesser confidence in one's ability to change, and greater concerns about change. Most importantly, our results indicate that endorsement of pros may exert its influence on eating disorder symptoms partially through its direct effect on motivation. Considering these findings, identifying the degree to which, and the specific ways in which the patient values their disorder could prove essential within the treatment context, as endorsement of pros seems to be linked with a host of factors that are likely to impede recovery, such as lacking confidence, or lacking motivation for recovery in and of itself. Furthermore, considering the finding that endorsement of pros may impact upon eating disorder pathology partially through its influence on motivation, it is suggested that motivation enhancement techniques might benefit from specifically targeting endorsement of pros.

It is also important to note that patients reporting greater endorsement of the "hatred" con show lesser eating disorder pathology, greater readiness to change, and lesser concerns about change, whereas endorsing the "trapped" and "stifles emotions" cons seem to be linked with lower motivation. This latter finding also has important clinical

implications, in that addressing feelings of being trapped and number by AN may be important in increasing a sense of self-efficacy and the motivation to tackle AN in treatment.

To identify how the egosyntonic nature may present itself within a particular patient, the P-CAN, as well as letter-writing tasks addressing the illness as both a friend and an enemy, may be used. These complementary approaches provide the therapist with an overview of which pros and cons of AN the patient endorses and does not endorse, with the goal of finding healthy mechanisms to replace positive functions of AN, as well as solidifying or elaborating negative attitudes already endorsed by the patient. However, this may not apply to the "trapped" con, as solidifying this belief may cause the patient to feel further entrenched by their disorder. To exemplify, if the patient identifies that AN allows him or her an escape from his or her emotions, the therapist may wish to teach distress tolerance strategies as a replacement for the AN's impact on distress. Further, if the patient identifies health risks as a negative aspect of AN, the therapist might offer to provide information on health risks associated with AN, or organise investigations such as bone density measurement, to further strengthen this endorsement. Moreover, making the cognitive shift of viewing AN as an enemy as opposed to a friend or guardian may be imperative to desiring and working towards recovery. As previously mentioned, the technique of externalising has been used in FBT, wherein a metaphor is often used to paint a picture of an external force having invaded the patient and hijacked their brain. For many patients and carers, externalisation of the disorder makes sense because the individual may appear to become a "different person" whilst under the influence of the eating disorder.

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Externalisation may help mobilise the patient to fight back against the eating disorder by viewing it as separate from the self, and can also put patients and carers on the same team fighting a common enemy, that is, the eating disorder. For those who do not like to view the eating disorder as an external force, similar but alternative strategies include thinking of the patient as having two aspects of their own self, a "healthy self" and an "eating disorder self" (Beebe et al., 2012), or abandoning the metaphor altogether and explaining eating disorder behaviours as symptoms of starvation (Vitousek, 2005). Related to externalising is the notion of the eating disorder voice (EDV) (Pugh et al., 2018), or "anorexic voice" in the case of AN (Tierny & Fox, 2010), which a significant number of eating disorder patients experience. The EDV, or "anorexic voice," describes a hostile second- or third-person commentary related to eating, shape, and weight (Pugh & Waller, 2016) and is experienced as internally generated yet separate from the self (Fox et al., 2012). A method for working with this experience is the Voice Dialogue (Stone & Stone, 1989), which involves direct communication between a facilitator and parts of the self to increase awareness, understanding, and separation from inner voices. A study by Chua Yi Ling et al. (2012), which qualitatively examined the experience and acceptability of Voice Dialogue in patients with AN, found that the majority of participants found Voice Dialogue helpful and acceptable for exploring their EDV. As such, Voice Dialogue may be another useful method in making the cognitive shift of viewing one's eating disorder as a separate entity rather than a part of oneself.

Whilst considering pros and cons, it may also be useful to explore the patient's longterm pros versus long-term cons; for example, AN may provide an immediate escape

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from current emotional stressors, but impact the patient's life goals and health negatively when considered on a long-term basis. A task such as writing letters to a friend in five years' time, on in which the person has recovered from AN and the other in which AN is still present (Schmidt et al., 2014), can be a helpful way to elucidate these differences. It is common for pros to be short term or immediate whilst cons are often longer term. When this is the case, it can be useful to discuss the ways in which our behaviour tends to be more impacted by immediate rewards and teaching techniques to keep longer term goals in mind.

Another important avenue to explore with the patient in order to tackle egosyntonicity is to consider personal values. Initially, the pros of AN which the patient endorses may seem aligned with his or her values; however, upon further scrutiny, patient and therapist may come to the conclusion that they are in fact opposed. For instance, a patient who expresses that AN fits with his or her religious beliefs in that he or she feels closer to God through purity and restraint may come to realise upon further inspection that AN in fact limits his or her closeness to God due to obsession with weight or shape, leaving little room for spirituality. As such, through valuesclarification and uncovering personally held values which are not compatible with AN behaviours, patients may discover how their overarching values are being compromised by their disorder, and how ultimately if they wish to live a life truly aligned with their values, recovery is a necessary pathway (Mulkerrin et al., 2016).

Finally, considering that the relationship between self-efficacy and eating disorder pathology was fully mediated by motivation (when including DB as a co-variate), improving self-efficacy may be an important target within the treatment context. For 171

instance, by addressing the underlying fear of failure in therapy, AN patients can begin confronting their fears by taking small steps, while receiving support from their clinician and other helpers. For example, a patient may be challenged to begin replacing eating disorder behaviour with healthier alternatives, such as taking a walk or calling a friend when an urge to engage in disordered eating behaviour or body checking surfaces. As the patient finds success in selecting healthier options to the eating disorder, their self-esteem can be strengthened and they can be challenged to take bigger risks, which each victory increasing their self-efficacy.

# 3.4.3 Limitations of the Current Research

The current study has contributed to the AN literature, and corroborates findings from previous research demonstrating the link between endorsement of pros and cons and eating disorder pathology and readiness for change. The study is novel in its investigation of pros and cons of AN and its relationship with readiness to change, intrinsic motivation, confidence in one's ability to change, and concerns about change, as well as investigating the indirect effect of endorsement of pros on eating disorder symptoms through motivation. With regards to methodology, all variables included in this study were measured through scales which have been demonstrated by previous research to have good psychometric properties. Furthermore, all participants had received a clinically confirmed *DSM-5* diagnosis of AN, and BMI was reported by clinicians.

Nevertheless, there are a number of limitations which should be considered upon interpreting the results of the current study. Firstly, in order to increase the sample size

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in the current study, data was collected from a number of different treatment sites. Limitations which follow as a result include less control and increased variability in the way measures were presented and administered. However, this limitation is mitigated by the fact that the measures were self-report questionnaires, thus being less prone to being influenced by the context of administration, as compared to, for example, interviews. Further, given that the study used a cross-sectional design, the direction of any causal relationships between variables cannot be determined. For example, it cannot be established whether endorsement of the "hatred" con led to lesser eating disorder pathology, whether lesser eating disorder pathology led to greater endorsement of the "hatred" con, or whether a third unknown variable led to both. This limit applies to the mediation analyses conducted in the study as well; is for example possible that low motivation reduces self-efficacy, rather than low self-efficacy reducing motivation. As such, a longitudinal design is necessary to begin to test out causal links between these variables.

# 3.4.4 Future Directions

The results of this study suggest that the P-CAN shows promise as an instrument to assess pros and cons that individuals may endorse regarding their eating disorder. Obtaining profiles of endorsement of pros and cons about change provides valuable information about the nature of the patient's illness, and these profiles may be instrumental in identifying potential barriers to treatment, thus increasing the efficacy of interventions.

However, further examination of t P-CAN is necessary. For example, the results of this study showed that scores on the P-CAN – Con subscales which tapped into feeling stifled and numbed by the illness were associated with *lower* ANSOCQ scores, which may indicate the need for future research aimed at modification of the P-CAN, for example, modifying the wording of the items so that they are unambiguously pros or cons and then using factor analysis to identify where these items load. Moreover, the validity of the P-CAN warrants further investigating. Specifically, an area of interest is the predictive validity of the P-CAN, as well as how the endorsement of pros and cons of AN may change over time. In terms of validating predictive validity, the next step is to investigate the relationship between the P-CAN and treatment outcome, as opposed to just examining how the P-CAN is associated with acute symptoms as was done in the current study. Accordingly, the study described in the following chapter aims to determine the degree to which endorsement of pros and cons predict outcome in a sample of AN patients commencing therapy.

# Chapter 4 Ambivalence in Anorexia: The Predictive Validity of Benefits and Burdens of Anorexia Nervosa on Treatment Outcome and the Impact of Autistic Features

"No two eating disorders are the same.

No two individuals are the same.

No two paths to recovery are the same.

But everyone's strength to reach recovery IS the same."

Brittany Burgunder: Safety in Numbers

# 4.1 Introduction

Predictors of treatment outcome within AN treatment have been extensively researched, though studies are typically characterised by small sample sizes and disparate definitions of both relapse and recovery across studies. The systematic review and meta-analysis of research in this area (Chapter 1) aimed to summarise and integrate the current research literature, concluding that our current understanding of AN predictors is limited due to findings being sparse and inconsistent, echoing the conclusions of previous reviews (Bulik et al., 2007; Vall & Wade, 2015; Waller et al. 2009). Furthermore, novel variables of interest were not included in the analysis due to a lack of suitable studies. One such variable which has been receiving increased attention recently in the AN literature is ASD (hereafter 'autism').

#### 4.1.1 Autism in Anorexia Nervosa

#### 4.1.1.1 The Link between Autism and Anorexia Nervosa

Autism is a pervasive developmental condition characterised by marked difficulties with social interaction and communication, as well as repetitive, stereotyped interests and behaviours, with approximately 1% of the population meeting criteria for the condition (APA, 2013; Brugha et al., 2012). The reported gender ratio for autism is four males to one female; however, in non-referred samples, there are only two to three males for every female with autism, suggesting that many females are not referred, thus failing to receive a diagnosis (Loomes et al., 2017). Interest in the potential link between AN and autism began with the suggestion that a shared underlying genetic vulnerability may interact with environmental factors to manifest as AN (Gillberg, 1983). It is thought that missed or delayed diagnosis of autism, particularly in females, could leave them vulnerable to the development of AN, which may obscure the identification of autism when manifested as extreme rigidity or excessive interest in calories or exercise (Lai & Baron-Cohen, 2015).

A systematic review and meta-analysis by Westwood et al. (2015) found that 20-35% of women with AN met criteria for autism, which is a significant overrepresentation as compared to the 1% in the general population. Previous qualitative research has suggested that restrictive eating difficulties in women with autism, although often labelled as AN, may deviate from traditional AN presentations (Kinnaird et al., 2019). Specifically, participants described how commonly assumed motivations, such as a desire for weight loss, low self-esteem, and poor body image, were less relevant in the development of their illness compared to the need for control, sensory difficulties,

social confusion, organisational problems surrounding cooking and food shopping, exercise as a method of stimulation, and the eating disorder acting as a special interest. As such, it is also possible that AN patients with co-morbid autism may also present differently in terms of egosyntonicity. For example, the values which AN patients with autism may attach to AN may be different because their food restriction and exercise are underpinned by different motivations. For example, food restriction may be motivated by feeling discomfort with the texture of certain foods, as opposed to because the patient fears eating the food will result in weight gain.

# 4.1.1.2 Understanding Autism in Anorexia Nervosa

More recently, a qualitative study by Brede et al. (2020) aimed to better understand how AN develops and persists in individuals with autism, with the goal of deriving a theoretical model of restrictive eating difficulties in autism. Based on semi-structured interviews with women with autism, six main themes emerged pertaining to 1) 'sensory sensitivities'; 2) 'social interaction and relationships'; 3) 'self and identity'; 4) 'difficulties with emotions'; 5) 'thinking styles'; and 6) 'need for control and predictability'.

#### 4.1.1.2.1 Sensory Sensitivities

In terms of sensory sensitivities, almost all participants described experiencing foodspecific sensitivities pertaining to food temperature, smell, taste, texture, or mixing of different foods, which limited the range of foods they would eat. Moreover, some participants reported aversion related to noise, touch, and certain lighting, which in turn affected eating behaviour, in that some participants used the effect of starvation on their body to numb these uncomfortable sensations. Moreover, heightened

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sensitivity to sensory stimuli also pertained to internal sensations. For some, the internal sensations linked with eating, such as the sensations of digesting food or bloating, caused distress, therefore causing them to avoid eating to prevent these sensations. Conversely, several participants described hyposensitivity to internal sensations, causing difficulty in sensing the internal state of the body. As such, they had difficulty interpreting eating-related sensations, such as satiety and hunger. This caused some to miss meals, and others to overeat without realising and subsequently to restrict due to discomfort.

# 4.1.1.2.2 Social Interaction and Relationships

All participants described having long-standing difficulties with communication and social interaction, which impacted their eating in that restricting their eating was described as a means of coping with social difficulties. Moreover, social difficulties impacted restrictive eating in that several women described initially restricting their food intake when they skipped lunch in school canteens due to wanting to avoid bullies, not having anyone to sit with, or feeling overwhelmed by the sensory or social environment.

# 4.1.1.2.3 Self and Identity

Further, participants described lacking a sense of self, feeling different, and not fitting in as a central component of developing their eating disorders, as well as dieting or focusing on appearance to fit in with peers, or gain a sense of identity. Interestingly, most women with autism emphasised that weight loss was not the initial aim of their eating disorder behaviour, but rather a secondary and unintended effect, so that

assumptions by others that body image issues drove their eating disorder behaviours made these women feel even more alienated and poorly understood.

## 4.1.1.2.4 Difficulties with Emotions

Participants' accounts also suggest that women with autism who also have AN may use eating disorder behaviours in order to number or distract themselves from overwhelming and confusing emotions.

# 4.1.1.2.5 Thinking Styles

Further, participants described several autistic thinking styles contributing to AN in autistic women, including rigid thinking, obsessive and intense interests, and literal thinking, which made them more susceptible to developing rules around food and eating, and/or made it more difficult to shift their focus away from these rules once established.

# 4.1.1.2.6 Need for Control and Predictability

Lastly, participants described experiencing rigid thinking and difficulty coping with change, which they considered to be linked with their autism. These difficulties in turn elicited a need for predictability and control, with this need being met through controlling food intake, sometimes in a ritualised manner.

#### 4.1.1.3 Barriers in Treating Anorexia Nervosa in Women with Autism

Another recent qualitative study by Babb et al. (2021) interviewed 15 women with autism with experience with AN, finding that women with autism faced a range of barriers when in treatment for AN, often accentuated by a lack of autism understanding within eating disorder services, with seven sub-themes emerging from the results.

Firstly, many women felt that their behaviours and traits were mischaracterised by some staff as driven by their eating disorder, leading to these women being labelled as 'naughty' or 'resistant' ('pre-autism diagnosis' theme). Specifically, autism-related traits, such as lack of flexibility or difficulties communicating, were often misinterpreted by staff as lack of engagement with treatment, and coping mechanisms adopted to appease sensory sensitivities were misjudged as eating disorder behaviours. Further, some autistic women felt that their autism diagnosis, once received, was still not taken into consideration in their treatment ('post-autism diagnosis' theme). Moreover, most women with autism reported negative experiences of CBT ('challenges of CBT' theme), describing it as inaccessible and ineffective. Lastly, many women with autism described how social demands impacted their ability to engage with treatment when offered group therapy ('challenges of group therapy' theme).

## 4.1.1.4 Autism as a Predictor of Treatment Response in Anorexia Nervosa

To date, three studies have examined the potential impact of autistic traits on treatment outcome in eating disorder groups (though these studies were not eligible for inclusion in our meta-analysis in Chapter 1). Of note, autism is considered a dimensional condition, representing the extreme end of a continuum of social competence and sensory processing that extends throughout the general population (Mandy et al., 2018). As such, autistic traits in non-autistic individuals can be considered to be a milder version of autistic symptoms seen in someone with a clinical diagnosis of autism. The largest study examining autism in girls with restrictive eating disorders undergoing treatment found that higher autism scores were associated with less change

in the self-report EDE-Q sub-scale scores of weight concern, shape concern and global scores, although it should be noted there was no difference in Morgan Russell Outcomes at discharge for those with high and low autism traits (Stewart et al., 2017). Furthermore, Nielsen and colleagues (2015) found that the presence of autism in an AN sample contributed to poorer outcomes in mental, psychosexual and socioeconomic state, as measured by the Morgan Russell Outcome scale. Lastly, Tchanturia and colleagues (2016) examined the impact of symptoms associated with autism in relation to Cognitive Remediation Therapy (CRT). Results demonstrated that the patients scoring low on autism symptoms showed significant improvement in cognitive rigidity and self-reported ability to change following CRT intervention, as compared to patients scoring high on autism symptoms, who showed no improvements on any outcome measure. This finding is interesting considering that CRT specifically targets aspects of cognitive processing, yet was not a more efficacious eating disorder treatment modality for individuals with autism. However, it is important to note that CRT in this study was delivered in a group setting, which may have contributed to poor responses in the elevated autism group in line with Babb et al'.s (2021) research, which highlighted that individuals with autism found group therapy particularly challenging due to the social demands. Furthermore, it is possible that cognitive rigidity in autism is different than cognitive rigidity in AN without autism, in that it may be less flexivle and more fixed. As such, inflexibility in AN may be more malleable, which may explain why AN patients without autism benefit more from CRT. Tt Taken together these findings suggest that elevated autism symptoms may be linked with poorer response to some existing eating disorder treatments, confirming what was suggested by Babb and colleagues (2021). For this reason, we included a 181

measure of autistic traits in the current study to examine their impact on therapy outcome as well as their relationship to the pros and cons of AN.

## 4.1.2 Predicting Treatment Outcome in Anorexia Nervosa

In terms of the systematic review and meta-analysis presented in Chapter 1, two variables did emerge as significant predictors of outcome in AN treatment within our meta-analysis, specifically, greater eating disorder pathology and poorer motivation for recovery. It is also important to note that severity of symptoms is likely to increase over time, and as such, early intervention is likely to be important, in order to treat the illness before it becomes severe and entrenched (Flynn et al., 2020). Considering motivation and eating disorder pathology and how they may be implicated in impeding progress within treatment, motivation stands out as particularly clinically important due to its malleability (Nakagami et al., 2010). Eating disorder symptoms are also malleable, in that they can be treated within therapy, but it unlikely for these symptoms to reduce within therapy if the patient has poor motivation to engage with therapy to begin with. Another important consideration is that a patient with little to no motivation to recover may attend therapy to appease loved ones, but fail to engage, resulting in a poor outcome. This is not only negative for the patient themselves, but also for motivated patients on the waitlist who may have benefited more from therapy than the unmotivated patient. This is not to say that unmotivated patients should be left to wait until motivation for recovery suddenly strikes them, but that poor motivation needs to be understood and directly addressed. Only when the mechanisms behind lack of motivation within AN treatment are properly understood can the patient and therapist work together to enhance motivation, a goal which possibly should be

attempted before commencing traditional therapy, considering that traditional therapy such as CBT requires hard work and engagement which may prove difficult for patients lacking in motivation. Of course, motivation to change is not a dichotomous 'all or nothing' variable, but is likely to be a complex dynamic process which is affected by the interaction between therapist and patient as well as by patterns of symptoms and their severity.

To understand the utility of deconstructing poor motivation, our focus turns to the egosyntonic nature of AN, discussed in-depth in Chapter 2, wherein our narrative review demonstrated that AN provides a range of perceived benefits for those suffering from the disorder, which may in turn decrease motivation for recovery. As such, this variable has been highlighted by a multitude of researchers as a possible culprit in maintaining AN. One measure for capturing egosyntonicity is the P-CAN, which captures endorsement of both pros and cons of AN (Serpell et al., 2004). Results from Chapter 3, wherein we aimed to validate the P-CAN within a sample of clinically diagnosed AN patients, demonstrated that endorsement of pros was linked with greater eating disorder pathology, lower readiness to change, greater concerns about change, lower intrinsic motivation, and lower confidence in one's ability to change. Providing further insight into the relationship between endorsement of pros and motivation, motivation was demonstrated to partially mediate the relationship between endorsement of pros and eating disorder symptoms, supporting the hypothesis that endorsement of pros of AN may impact upon eating disorder symptoms via its influence upon motivation. Interestingly, in terms of burdens of AN, the "hatred" con was the only con significantly linked with lower eating disorder

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pathology, greater readiness to change, and lower concerns about change, suggesting that making the shift from perceiving the disorder as an enemy (as compared to a friend or a guardian), or externalising the disorder, may be more important towards achieving recovery than identifying actual *costs* of the disorder (such as health costs, social costs, etc). However, this study was cross-sectional in nature, and the direction of relationships between variables cannot be determined without the use of a prospective design (as suggested by Schmidt & Treasure, 2010 ; Wolf & Serpell, 1998).. The current study incorporates such a design to build a model of how the pros and cons of AN predict treatment outcome.

## 4.1.3 The Current Study

As such, the aim of the current study is to build upon the previous research literature investigated in Chapter 1, to determine whether it is possible to replicate the emerging predictors of outcome within AN treatment (eating disorder pathology and motivation), as well as to further evaluate the egosyntonic nature of AN using the P-CAN, this time examining whether or not endorsement of pros and the "hatred" con predicts treatment response in individuals with AN undergoing outpatient psychological therapy. Subsidiary aims are: (i) to investigate the relationship between autistic traits and P-CAN scores, and ii) to examine the potential association between autistic traits and treatment outcome. Based on these aims, several hypotheses and research questions were proposed.

1) Based on the systematic review and meta-analysis conducted in Chapter 1, it is hypothesised that lesser eating disorder symptoms (as measured by the

EDE-Q) would predict better outcome (as measured by change in EDE-Q and BMI) at the six-month follow-up.

- Similarly, based on the systematic review and meta-analysis conducted in Chapter 1, it is hypothesised that higher motivation/lower precontemplation (as measured by the RMQ – Precontemplation sub-scale) would predict better outcome at the six-month follow-up (as measured by change in EDE-Q and BMI).
- 3) Thirdly, based on cognitive models of AN (Schmidt & Treasure, 2006; Wolf & Serpell, 1998), alongside the preliminary cross-sectional evidence from Serpell et al. (2004) and the empirical study presented in Chapter 3, it is predicted that lesser endorsement of Pros (as measured by the P-CAN Pro scale) would predict better treatment outcome at the six-month follow-up (as measured by change in EDE-Q and BMI).
- 4) Further, considering the preliminary evidence of the empirical study presented in Chapter 3, wherein endorsement of the "hatred" con was linked with lower eating disorder symptoms and greater motivation, it is hypothesised that endorsement of the "hatred" con (as measured by the P-CAN – Hatred Con sub-scale) would predict better outcome at the six-month follow-up (as measured by change in EDE-Q and BMI).
- 5) Additionally, based on the preliminary evidence of the three studies presented in this chapter (Nielsen et al., 2015, Stewart et al., 2017, Tchanturia et al, 2016.), as well as the qualitative research by Babb et al., (2021), it was hypothesised that patients scoring lower on autism traits (as measured by the Broader Autism Phenotype Questionnaire [BAPQ]) would have better

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outcomes at the six-month follow-up (as measured by change in EDE-Q and BMI).

6) Lastly, we posed the following research question: Is there a relationship between endorsement of pros and cons (as measured by the P-CAN) and autism traits (as measured by the BAPQ)?

## 4.2 Method

### 4.2.1 Participants

An *a priori* power calculation for a linear multiple regression was conducted. With five predictors (eating disorder pathology, motivation, endorsement of pros, endorsement of the "hatred" con, and autism traits), an effect size of .46, and 80% power, a sample size of 35 was required for sufficient power, according to G\*Power3. The effect size was determined based on the squared multiple correlation (.31), wherein correlations for eating disorder symptoms and motivations were estimated based on the meta-analysis of Chapter 1 (r = 0.23 and r = 0.27, respectively). For the three remaining predictors, which were either previously untested in the literature, or where the literature did not provide sufficient evidence to calculate an effect size, in the case of autism, we estimated a small correlation of r = 0.25 based on the size of the motivation and eating disorder pathology correlation coefficients. In the current study, the initial sample comprised 45 patients, however, due to drop-out and not meeting eligibility criteria at start of treatment, the final sample consisted of 30 outpatients, aged 16 to 46 years (M = 23.8, SD = 8.24). Eligibility criteria for the study included meeting the diagnostic criteria for AN with the exception that a BMI cut off of 19 was adopted as in other treatment studies (McIntosh et al, 2005; Wade et al., 186

2011). Additional eligibility criteria required that the patient was aged 16 years and over and was female. Male patients were excluded because they only represent approximately 10% of clinic samples, resulting in insufficient power for gender differences to be explored. There was no exclusion based on lower limit of BMI or comorbidity in order to make the study as inclusive as possible. Mean BMI for the participants was 16.3 (SD = 1.1), with BMIs ranging from 14.3 to18.8. Participants were undergoing treatment within four NHS EDS within the UK, including Cornwall, and services in North East London, Essex and Kent, all of which provided by North East London Foundation NHS Trust. Participants were invited to participate if they were about to commence any psychological therapy (including CBT-E, MANTRA, and FBT). Initially, participants were initially approached by a care team member to discuss participation. Those who expressed interest in participating were then contacted by the researcher.

### 4.2.2 Description of Treatment

At recruitment, participants were about to begin an evidence-based therapy such as CBT-E, MANTRA or family therapy, at an outpatient eating disorder service. CBT-E typically consists of up to 40 sessions over 40 weeks, with twice-weekly sessions in the first two or three weeks. CBT-E covers nutrition, cognitive restructuring, mood regulation, social skills, body image concern, self-esteem and relapse prevention. A personalised treatment plan is created based on the processes that appear to be maintaining the eating problem. CBT-E includes self-monitoring of dietary intake and associated feelings and thoughts, as well as homework. MANTRA typically consists of 20 sessions, with weekly sessions for the first 10 weeks. MANTRA covers nutrition,

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symptom management, and behaviour change. Family therapy typically consist of 18 to 20 sessions over one year, and includes psychoeducation about the nutrition and the effects of malnutrition, while emphasising the role of the family in helping the person to recover. In line with NICE guidelines, FBT tended to be offered to 16-18 year olds whilst MANTRA and CBT-E was commonly offered to those 18 plus. It should be noted that the majority of participants included in this study underwent CBT. Due to the small sample size with most participants belonging to the CBT group, it was not possible to investigate differences between treatments; however, this might be useful to examine in future.

## 4.2.3 Procedure

Ethical approval for the study was granted by the local Research Ethics Committee (reference number: 216529). Eligible patients were contacted about participation at any time between admission to the service and their first therapy session. Potential participants were first provided with an information sheet, and given a 24-hour cooling off period to consider whether they wanted to participate in the study. Once the cooling off period was over, participants provided their informed consent. Participants were advised to get in touch with the researchers for debriefing if they experienced any discomfort whilst completing the survey; however, no requests for debriefing were made. Upon providing informed consent, participants completed a questionnaire pack, consisting of the P-CAN, EDE-Q, RMQ, and BAPQ, as well as basic demographic questions, with completion of the pack taking approximately 30 minutes. Some participants received a link to an online set of measures, administered via Opinio, an online survey tool, whilst others completed a paper-based questionnaire pack at their

eating disorder clinic before or after a monitoring or therapeutic session. 10% of participants (3/30) completed the paper-based version whereas the remaining 90% (27/30) completed the measures online. The participants were followed up six months after commencing treatment to complete a follow-up questionnaire pack completed online comprising of the P-CAN and EDE-Q. As reimbursement for their time and participation, participants received £10 for completing the first batch of questionnaires and £10 for completing the follow-up measures.

## 4.2.4 Measures

## 4.2.4.1 Pros and Cons of Anorexia Nervosa Scale

The P-CAN measured participants' endorsement of the pros and cons of their illness. (See Chapter 3 for a comprehensive description of the scale).

## 4.2.4.2 Eating Disorder Examination Questionnaire

The EDE-Q measured participants severity of eating disorder symptoms. (For a comprehensive description of this scale, see Chapter 3.)

## 4.2.4.3 Readiness and Motivation Questionnaire

The RMQ – Precontemplation sub-scale measured readiness to change. (See Chapter 3 for a comprehensive description of the sub-scale). The RMQ was used to measure readiness to change (as opposed to the ANSCOQ) due to the measuring demonstrating stronger correlations with the P-CAN in the cross-sectional study conducted in Chapter 3.

### 4.2.4.4 Broader Autism Phenotype Questionnaire

The BAPQ measured the participants' autism symptoms. The measure consists of three sub-scales; Aloofness, Rigidity, and Pragmatic Language. Participants indicated agreement with 36 statements on a six-point Likert scale (Very rarely to Very often). Items include statements such as "I like being around other people" (reverse scored, Aloofness sub-scale), I am comfortable with unexpected changes in plans" (reverse scored, Rigidity sub-scale) and "I find it hard to get my words out smoothly" (Pragmatic Language sub-scale). Sub-scale scores were obtained for each participant by averaging their score on each sub-scale. A global score was obtained by averaging all three sub-scales. The BAPQ's sub-scales have shown high internal consistency (q = .85 - .91) (Hurley et al., 2007).

## 4.2.5 Statistical Analyses

All analyses were conducted using version 26 of SPSS.

#### 4.2.5.1 Statistical Tests to Assess the Effectiveness of Outpatient Treatment

In order to assess the effectiveness of outpatient treatment, three different analyses were performed. Firstly, paired sample *t*-tests were used to compare both BMI and EDE-Q scores at baseline and follow-up. Paired sample t-tests contain four assumptions, with the first two pertaining to study design. These first two assumptions include having a continuous dependent variable (BMI and EDE-Q) and the independent variable (in this case, time of assessment) being categorical with two related groups (in this case, baseline versus follow-up). The third assumption states that there should be no significant outliers in the differences between the two groups.

There were no outliers in the data, for either BMI or EDE-Q, as assessed by the inspection of a boxplot for values greater than 1.5 box-lengths from the edge of the box. Lastly, the test assumes that the distribution of differences in the dependent variable between the two groups should be approximately normally distributed. Shapiro-Wilks tests for both BMI (p = .79) and EDE-Q (p = .37) confirmed that this assumption was met. Secondly, pre-post effect sizes were calculated for all measures. Thirdly, outcome was assessed on for each participant based on the criteria of clinical significance, described below (Jacobsen et al., 1984; Jacobsen & Truax, 1991).

### 4.2.5.2 Clinical Significance

The concept of clinical significance is a construct used to assess clinically meaningful changes as a result of therapy. Consisting of a two-part criterion, a patient has to both a) show a reliable change, i.e. statistically significant improvement and b) cross the cut-off point for a clinically significant change to qualify as clinically improved after treatment.

## 4.2.5.2.1 The Criterion of Statistical Significance/Reliable Change

To classify a patient as having demonstrated a statistically significant change (i.e. that the observed change is not based on chance or measurement errors), an individual minimal pre-post change is necessary. As such, the reliable-change index (RCI) has to be exceeded. The RCI is computed by dividing the difference between pre-treatment and post-treatment scores by the standard error of the difference between the two scores. A measure for the reliability of the measurement (Cronbach's alpha) is also included in this formula.

### 4.2.5.2.2 The Criterion of Clinical Significance

A reliable change is considered to be a prerequisite for a clinically meaningful change, and a cut-off is defined in order to assess whether a patient should be assigned to the healthy or clinical group at follow-up. For the current study, the cut-off point to be considered healthy was an EDE-Q Global score <2.09 (Rø et al., 2015). According the cut-off, participants could be classified into five different groups:

1) Normative: participants with normative scores both at admission and

- discharge
- 2) Deteriorated: statistically significant worsening (RCI  $\leq$ 1.96) participants; clinical significance is not of interest as the result is clearly unwanted.
- Unchanged: participants with scores\_above cut-off at admission and statistically non-significant changes at follow-up
- Reliably improved: statistically significant improvement (RCI≥1.96)\_of participants between pre- and post-measurement.
- 5) Clinically significantly improved: patients with statistically significant improvement and symptoms within the normal range at follow-up.

## 4.2.6 Statistical Tests to Examine Predictors of Treatment Outcome

Hypotheses 1-5, aimed at exploring the predictive value of pre-treatment variables, were preliminarily analysed by determining the bivariate correlations between change in BMI at follow-up, change in EDE-Q score at follow-up, and each of the predictor variables, as the correlation matrices would inform which variables would be included in the regression model. To examine the unique contributions of each predictor

variable, two standard multiple regressions were conducted for each dependent variable (change in BMI and change in EDE-Q score).

## 4.2.6.1 Assumptions Testing for Multiple Regression Models

There are eight assumptions of a multiple regression analysis. The first two assumptions pertain to study design, and include (a) having a continuous or dependent variables, and (b) having two or more independent variables, which can either be continuous or categorical. In this case, both dependent variables (BMI and EDE-Q) and all independent variables were continuous.

## 4.2.6.1.1 Assumption Testing – Model Predicting BMI Change

Moreover, multiple regression analysis assumes independence of observations, which can be tested using the Durbon-Watson statistic, which should approximate 2 to indicate that there is no correlation between residuals. In our model predicting BMI change, the Durbon-Watson statistic was 2.21., indicating that this assumption was met. Furthermore, there needs to be a linear relationship between (a) the dependent variable and each of the independent variables, and (b) the dependent variables and the independent variables collectively. This first part of this assumption can be tested by plotting the studentised residuals against the (unstandardised) predicted values. If the residuals form a horizontal band, the relationship between the dependent variable and independent variables is likely to be linear, which was the case for the change in BMI model. The second part of this assumption can be tested by generating partial regression plots. Visual inspection of the plots for the BMI change model demonstrated linear relationships in all three plots; thus, the assumption of linearity

was met. The fifth assumption of multiple regression analysis is that the variance is equal for all values of the predicted dependent variable, referred to as homoscedasticity. To check for heteroscedasticity, residual plots showing the studentised residuals against the unstandardised predicted values were visually inspected. A fanning effect was found upon visual inspection of the residual plot for the BMI change model, thus violating the assumption of homoscedasticity. To correct for this violation, a square root transformation was performed on the dependent variable. The sixth assumption of multicollinearity was assessed in two ways. Firstly, correlation coefficients between the independent variables were inspected to ensure that none of the variables had correlations greater than 0.7. Moreover, the Tolerance statistic was consulted. As the independent variables showed no correlations greater than 0.7 and no Tolerance value greater than 0.1 (Tolerance = .99 for both variables), this assumption was met. The seventh assumption of a multiple regression states that there should be no significant outliers, high leverage points or highly influential scores. Examining the studentised deleted residuals identified one potential outlier, with a studentised deleted residual score greater than 3. However, as this case did not exhibit high leverage (leverage = 0.05) or high influence (Cook's Distance = 0.28), we opted to include the case in our analysis. To determine whether any cases exhibit high leverage, one general rule of thumb is to consider leverage values less than 0.2 as safe, 0.2 to less than 0.5 risky, and values of 0.5 and above as dangerous (Huber, 1981). We identified two cases with risky leverage scores, but as neither were determined to be influential as measured by Cook's Distance (Cook's Distance = <1for both cases), they were included in the analysis. Inspection of all Cook's Distance values determined that our data contained no influential cases, as there was no Cook's 194

Distance values above 1 (Cook & Weisberg, 1982). Thus, we considered the seventh assumption met. The final assumption, the assumption of normality, assumes that the errors in prediction – the residuals – are normally distributed, which can be assessed by inspection of a histogram with a superimposed normal curve and a P-P Plot. Visual inspection of the histogram and P-P plot demonstrated normality.

# 4.2.6.1.2 Assumptions Testing – Model Predicting Change in Eating Disorder Symptoms

In our model predicting EDE-Q change, the Durbon-Watson statistic was 1.95, indicating that the assumption of independence of observations was met. Moreover, inspection of the residual plots and partial regression plots indicated that there was a linear relationship between the dependent variable and each of the independent variables, as well as the dependent variable and the independent variable collectively. There were no inter-correlations about 0.7 and the Tolerance value equalled .98 for both independent variables; thus, multicollinearity was not an issue. We identified one outlier (studentised deleted residual = 3.4), but this case did not demonstrate high leverage (leverage = 0.06) or influence (Cook's Distance = 0.28), and as such, it was included in our analysis. One case demonstrated high leverage (leverage = 0.39) categorised as risky, and as this case also demonstrated high influence (Cook's Distance = 1.13), this case was excluded from the regression model. No additional cases demonstrated high influence. The assumption of normality was met.

### 4.3 Results

A total of 45 outpatients with AN initially completed the baseline measures for this study. Three patients were determined not to meet eligibility criteria at the start of treatment due to an increase in BMI from recruitment to start of treatment, and a further 12 patients dropped out of treatment; as such, a total of 30 participants were included in the analyses. Participants had a mean age of 23.3 (SD = 7.54), and a mean BMI of 16.1 (SD = 1.1) at the start of treatment. The sociodemographic and clinical characteristics of the sample are presented in Table 4-1.

## 4.3.1 Body Mass Index

BMI significantly increased from  $16.3 \pm 1.1 \text{ kg/m}^2$  at start of treatment to  $17.8 \pm 1.7$  at follow-up (ES = 1.02; Table 4-2). This is slightly higher than the results of the MOSAIC trial, wherein mean BMI increase was 0.93 (MANTRA = 1.06; SSCM = 0.80) at six months follow-up (Schmidt et al., 2015). One-third of participants (10/30) moved from the underweight range to the healthy range (BMI > 18.5). 86.7% of participants (26/30) increased their BMI during treatment, whereas 13.3% of participants (4/30) decreased their BMI.

### 4.3.2 Eating Disorder Symptoms

For the Global score and Restraint and Eating Concern sub-scales of the EDE-Q, statistically significant improvements were found (see Table 4-2). The effect size of the change in the Global score of the EDE-Q was 0.61. 20% of participants (6/30)

Table 4-1. Sociodemographic and clinical variables           Age (years): M (SD)	23.3 (7.54)				
BMI: M (SD)	16.3 (1.1)				
Anorexia subtype (n, %)					
BP subtype	7 (23%)				
Restrictive subtype	23 (77%)				
Education (n, %)					
Some secondary school	3 (10%)				
Secondary school graduate	16 (53.3)				
University graduate	10 (33.3)				
Postgraduate	1 (3.3)				
Relationship status (n, %)					
Single	20 (66.7%)				
In a relationship	7 (23.3%)				
Married	3 (10)				
Employment status (n, %)	- ( - )				
Full-time	4 (13.3%)				
Part-time	7 (23.3%)				
Unemployed	19 (63.3%)				
Ethnicity	× ,				
White	20 (80%)				
Mixed/multiple ethnic groups	2 (6.7%)				
Asian/Asian British	3 (10%)				
Other ethnic group	1 (3.3%)				
EDE-Q: M (SD)	4.28 (1.52)				
RMQ – Precontemplation sub-scale: M (SD) P-CAN: M (SD)	59.47 (16.68)				
Safety/Structure	0.58 (0.94)				
Appearance	-0.14 (1.13)				
Fertility	-0.38 (1.05)				
Special	-0.24 (1.15)				
Fitness	-0.52 (0.89)				
Communicate	0.27 (1.17)				
Trapped	1.17 (0.74)				
Guilt	1.33 (0.65)				
Hatred	1.13 (0.67)				
Stifles Emotions	0.51 (1.06)				
BAPQ: M(SD)					
Aloof	3.31 (1.03)				
Rigid	3.31 (0.83)				
Pragmatic Language	3.39 (0.97)				

	Pre-treatment M (SD)	6 months t(df) follow-up M		Р	ES (Cohen's d)
		(SD)			
BMI	16.70 (1.15)	18.11 (1.73)	-3.92 (29)	.016	1.02
EDE-Q	4.35 (1.50)	3.32 (1.87)	3.21 (29)	.003	0.61
Global					
EDE-Q	4.01 (2.07)	2.66 (2.02)	2.98 (29)	.008	1.10
Restraint					
EDE-Q Eating	3.95 (1.4)	2.77 (1.71)	2.66 (29)	.017	0.78
Concern					
EDE-Q Shape	4.56 (2.14)	3.96 (1.89)	0.56 (29)	.588	0.30
Concern					
EDE-Q	4.33 (1.89)	3.68 (1.75)	0.95 (29)	.356	0.35
Weight					
Concern					

Table 4-2. Pre-post results for BMI and EDE-Q

showed clinically significant changes with regards to the EDE-Q Global score, whereas 13.3% of participants (4/30) showed reliable change. 60% of participants remained unchanged (18/30) and 6.7% (2/30) deteriorated.

## 4.3.3 Autism Traits

Based on the cut-off scores established by Sasson et al. (2013), 43.33% (13/30) of participants scored in the clinical cut-off range for aloofness, 63.33% (19/30) scored within the clinical cut-off range for pragmatic language, and 26.67% (8/30) scored within the clinical cut-off range for rigidity. Finally, 53.33% (16/30) scored within the clinical cut-off range for rigidity. Finally, 53.33% (16/30) scored within the clinical cut-off range for heir global BAPQ score. These scores are notably higher than the estimated 20-35% of individuals with AN who also have autism (Westwood et al., 2015); however, as this scale is not clinical diagnostic tool, this may be an issue of insufficient specificity.

### 4.3.4 Predictors of BMI Change

Hypotheses 1-5, pertaining to change in BMI, were addressed preliminarily by determining the bivariate correlations between BMI change and each of the predictor variables. As displayed in Table 4-3, change in BMI demonstrated a significant moderate positive relationship with shape concern (as measured by the EDE-Q shape concern sub-scale) as well as a moderate positive relationship with endorsement of the "hatred" con (as measured by the P-CAN - Hatred sub-scale) which was trending towards significance (p = 0.52). This suggests that those with greater shape concern and greater endorsement of the "hatred" con demonstrated greater increase in BMI at the six-month follow-up. Precontemplation, endorsement of pros, and autism traits failed to demonstrate a significant relationship with BMI change, and these variables were thus excluded from any further analysis.

To examine the unique contributions of each predictor variable, a multivariate linear regression was conducted. Shape concern and endorsement of cons were significant or trending towards significance and therefore entered into the regression.

As displayed in Table 4-4, the final regression model accounted for 20% of the variance in change in BMI, F(2,29) = 3.38, p = .049,  $R^2 = .20$ , with one significant predictor, endorsement of the "hatred" con. Endorsement of the "hatred" con uniquely accounted for 15.6% of variance, with participants expressing more hatred towards the disorder reporting a greater weight gain at follow-up.

	1	$\frac{\text{or variables } (n=30)}{1  2 \qquad 3  4  5  6}$			6	7	8	9	10	11	
			-		-			-	-		
1. BMI change	-										
2. EDE-Q change	.29	-									
3. EDE-Q Global	.17	.56**	-								
4.EDE-Q Restraint	01	.43*	.88**	-							
5. EDE-Q Eating Concern	.29	.62**	.85**	.72**	-						
6. EDE-Q Shape Concern	.40*	.36*	.71**	.45*	.58**	-					
7. EDE-Q Weight Concern	.15	.48**	.89**	.66**	.71**	.72**	-				
8.RMQ Precontemplation	35	39*	.10	.11	11	.20	.16	-			
9. P-CAN Pros	09	04	.38*	.23	.36*	.36	.40*	.39*	-		
10. P-CAN Hatred	.36	.11	.16	.04	.18	.22	.28	38*	21	-	
11. BAPQ	.04	16	.05	.09	.14	01	03	27	.45*	.05	-

Table 4-3. Bivariate correlations between BMI change and EDE-Q change at followup and predictor variables (n = 30)

\* *p* = < .05; \*\* *p* = < .001

	95% CI(B)					
Independent variables	В	SE (B)	Lower	Upper	В	$sr^2$
$R^2 = .2, , F_{chng}(2, 29) = 3.38. p = .049$						
Shape concern	.14	.13	11	.40	.20	3.8%
Hatred	.91	.40	.10	1.72	.40**	15.6%

Table 4-4. Results of standard multiple regression analysis predicting change in BMI (n = 30)

\* p = <.05; \*\* p = <.001

# 4.3.5 Predictors of Change in Eating Disorder Examination-Questionnaire Scores

Hypotheses 1-5, pertaining to change in EDE-Q scores, were initially addressed by determining the bivariate correlations between change in EDE-Q Global score and each of the predictor variables. As displayed in Table 4-3, change in EDE-Q Global score demonstrated a medium positive correlation with baseline eating disorder pathology (as measured by the EDE-Q) and a medium negative correlation with baseline precontemplation (as measured by the RMQ – Precontemplation sub-scale). This suggests that those with higher levels of eating disorder pathology at baseline and those with lower baseline precontemplation showed greater improvement in eating disorder symptoms at the six-month follow up. The P-CAN (specifically the Global Pro scale and Con – Hatred sub-scale), alongside the BAPQ global score, demonstrated no significant relationship with change in EDE-Q score, and these variables were therefore excluded from any further analysis. This suggested that endorsement of pros and the "hatred" con and autism traits did not significantly predict improvements in eating disorder symptoms.

To examine the unique contributions of each predictor variable, a multivariate linear regression was conducted. Eating disorder pathology and precontemplation were significantly related with eating disorder pathology change and were therefore entered into the linear regression analysis.

As displayed in Table 4-5, the final regression model accounted for 44% of the variance in change in EDE-Q, F(2,29) = 6.93, p = .003,  $R^2 = 323$ . EDE-Q global score uniquely accounted for 27.3% of variance, with participants demonstrating greater eating disorder pathology at baseline reporting greater change at follow-up, whereas Precontemplation accounted for 29.7% of unique variance, with those reporting higher levels of precontemplation (i.e. low motivation) demonstrating lesser change at follow-up.

*Table 4-5. Results of standard multiple regression analysis predicting change in ED symptoms (n = 29)* 

			95%	CI(B)		
Independent variables	В	SE (B)	Lower	Upper	В	$sr^2$
$R^2 = .44$ , $F_{chng}(2, 28) = 10.91$ . $p = .$	000					
EDE-Q	.66	.19	.29	1.03	.55**	27.3%
Precontemplation	07	.02	11	03	57**	29.7%

\*\* = *p* < .001

# 4.3.6 Relationship between P-CAN and Autism Traits Measured by the BAPQ (Research Question 6)

To examine the relationship between the P-CAN – Pros and Cons sub-scales and the BAPQ sub-scales, a series of bivariate correlations were performed, and are displayed

in Table 4-6. Four significant correlations were demonstrated. Specifically, the BAPQ – Pragmatic sub-scale showed a positive moderate relationship with the Fertility Pro scale, r = .48, p = .005, the Communicate Pro sub-scales, r = .37, p = .036, and the Stifles Emotions Con sub-scale, r = .35, p = .044, meaning that participants who demonstrated higher pragmatic traits were more likely to endorse the fertility and communicate pros, as well as the stifles emotions con. Further, there was a positive moderate correlation between the BAPQ – Aloof sub-scale and the Communicate Pro sub-scale, r = .35, p = .045, meaning that participants who reported greater aloof traits were more likely to endorse the communicate pro. As displayed in Table 4-4, there was a positive medium correlation between the P-CAN Pros sub-scale and BAPQ – global score, suggesting that those with more autism traits displayed greater egosyntonicity.

P-CAN sub-scale	BAPQ – Aloof sub-scale	BAPQ – Pragmatic sub-scale	BAPQ – Rigid sub-scale
Safe/Structured	.29	.19	.32
Appearance	.20	.17	.17
Fertility	.21	.48**	.09
Fitness	.09	.25	.27
Special	.02	.32	.13
Communicate	.35*	.37*	.30
Trapped	28	.25	.07
Guilt	05	13	02
Hatred	07	03	.14
Stifles Emotions	.04	.35*	.26

*Table 4-6. Correlations between P-CAN and BAPQ at baseline* (n = 30)

\* p = <.05; \*\* p = <.001

### 4.4 Discussion

## 4.4.1 Summary and Integration of Findings

The aim of the current study was to replicate and extend the literature on significant predictors of treatment outcome in outpatient females with AN. Our first hypothesis proposed that eating disorder pathology would be negatively correlated with and would uniquely predict improved outcome. Contrary to this prediction, higher eating disorder pathology predicted greater EDE-Q change. However, eating disorder pathology did not predict BMI change. Secondly, it was hypothesised that higher motivation / lower precontemplation would be positively correlated with and uniquely predict better outcome. Partially in line with this prediction, lower precontemplation predicted greater EDE-Q change but not BMI change. Thirdly, we hypothesised that endorsement of pros would be negatively correlated with and uniquely predict outcome. Contrary to this prediction, endorsement of pros did not predict BMI or EDE-Q change. Further, we predicted that endorsement of the "hatred" con would be positively correlated with and uniquely predict better outcome. Partially in line with this prediction, greater endorsement of the "hatred" con predicted greater BMI change, but did not predict EDE-Q change. Lastly, it was hypothesised that autism traits would be negatively correlated with and predict better outcome. This hypothesis was not supported by our results. The study adds to the eating disorder literature in that is, to the best of the author's knowledge, the first study to investigate the role of endorsement of pros and cons in predicting outcome.

As stated, contrary to our first prediction, *higher* eating disorder pathology at baseline predicted greater change in eating disorder pathology at follow-up, meaning that those participants who demonstrated greater eating disorder pathology at the start of treatment made most progress in terms of reduction of eating disorder symptoms. It is important to note that eating disorder pathology change was simply measured by comparing EDE-Q scores at the start of treatment and at follow-up, without taking into account whether participants fell into a "healthy" or "clinical" status at the six-month follow-up. This decision was due to our relative small sample size, which did not allow for comparison of multiple groups. Considering this method of analysis, it is possible that participants with higher eating disorder pathology at baseline may have made greater reductions in eating disorder symptoms, without necessarily having achieved lower scores at follow-up than those who reported lower eating disorder pathology at baseline. In line with this, we found no significant relationship between eating disorder pathology at start of treatment and eating disorder pathology at end of treatment, r =.32, p = .075. Our finding contrasts with previous studies which have demonstrated that higher eating disorder pathology predicts poorer outcome (Goddard et al., 2013; Le Grange et al., 2014; Wales et al., 2016; Wild et al., 2016). However, the majority of these studies used categorical outcome measures conditioned upon achieving a certain BMI (e.g. positive versus non-positive outcome, wherein positive outcome necessitated achieving a BMI of above 17.5) or a mix of outcome measures (EDQoL, MCS, BDI). None of these studies examined change in EDE-O score, and only one study used EDE-Q as an outcome measure. As such, while the results of the current study might suggest that higher eating disorder pathology leads to better outcome, a more plausible explanation may be that patients who report greater eating disorder 205

pathology at baseline may be able to make greater reductions in eating disorder symptoms during therapy due to experiencing high levels of eating disorder pathology at start of treatment, and as such, having more room to improve than their lower eating disorder pathology counterparts.

Partially supporting the hypothesis of this study, higher motivation in the form of lower precontemplation on the RMQ predicted greater eating disorder change at follow-up, meaning that those participants who reported greater motivation at baseline made greater progress in reduction of eating disorder symptoms than their lower motivation counterparts. This finding echoes the results of previous studies across daypatient, inpatient and outpatient samples (Goddart et al., 2013; Le Grange et al., 2014; Pauli et al., 2017; Thaler et al., 2016). Previous studies examined whether motivation predicted outcome at end of treatment, whereas our study is the first to examine motivation after six months of treatment. As such, this finding suggests that differences in motivation predict differences in outcome even in the relatively early stages of treatment. Importantly, early change is likely to predict later outcome (Waller et al., 2009). However, greater precontemplation did not predict BMI change, which is inconsistent with the previous research of Rieger et al. (2000), wherein pretreatment motivation as measured by the ANSCOQ predicted weight gain up to eight weeks of inpatient treatment, with motivation at discharge predicting BMI over the subsequent six months. It is possible that measuring individuals' stage of change (e.g. precontemplation vs. contemplation vs. preparation vs. action) may be a more useful method of assessing motivation as opposed to simply measuring level of precontemplation, which could explain the differing findings.

Contrary to our third hypothesis, greater endorsement of pros did not predict change in eating disorder pathology at follow-up. This finding contrasts with the cognitive interpersonal model of AN which suggests that pro-AN beliefs may play a role in maintaining AN (Schmidt & Treasure, 2006). However, due to our relatively small sample size, endorsement of pros was computed as a global score, as opposed to examining the predictive validity of each pro on an individual basis ("safe/structured", "appearance", "special", "fertility", etc). It is possible that endorsement of specific pros may contribute to maintaining the disorder, and as such, that these pros need to be examined individually. For instance, the aspect of attaining and maintaining a feeling of control has long been considered a central tenet of AN, and in Serpell et al.'s (2004) study, the authors concluded that the "safe/structured" pro could perhaps best be understood in terms of control. As such, it is possible that this pro, or others, would emerge as a significant predictor of outcome if examined on an individual basis, as some pros may play a greater role in maintaining the disorder than others.

Partially supporting our fourth prediction, greater endorsement of the "hatred" con predicted greater BMI change at follow-up (but not EDE-Q change). This finding suggests that an important factor in influencing treatment response, particularly increase in weight, could be whether the patient feels negative affect towards the illness, thus, no longer viewing the illness as a friend or a guardian, but rather as an enemy or a negative force in one's life.

Inconsistent with our fifth hypothesis, greater autism traits did not predict change in eating disorder pathology at follow-up. This result contradicts the findings of Stuart et al. (2017), Nielsen et al. (2015), and Tchanturia et al. (2016) who found that greater autism traits predicted poorer outcome (as measured by EDE-O change, Morgan Russell outcomes, and change in cognitive rigidity, respectively). Of note, autism was measured differently in all four studies. The Stuart et al. (2017) relied on reports from parents, in addition to self-report, whereas Nielsen et al. (2015) examined patients with a current diagnosis of autism. Tchanturia et al. (2016) measured autism via self-report (Autism-Spectrum Quotient) as well as a semi-structured interview (Autism Diagnostic Observation Schedule) conducted by a trained researcher. As such, it is possible that relying solely on self-report to measure autism traits might explain our differing findings, and that autism traits should be measured on a more thorough basis (relying on multiple measures or presence/absence of diagnosis) in future studies in order to effectively examine its predictive value. Furthermore, studies such as Stewart et al. (2017) examined inpatients rather than outpatients, which also may explain the dissimilar results.

Finally, in regards to our research question regarding the links between autism traits and pros and cons of AN, we found that participants with greater autism traits reported greater endorsement of the "fertility" and "communicate" pros, as well as greater endorsement of the "stifles emotions" con. This finding suggests that individuals with AN who present with higher autism traits may present differently in terms of egosyntonicity, as well as their identification of costs, in that they may show greater endorsement of the abovementioned benefits and burdens. As a reminder, the 208

"fertility" pro pertains to the benefit of avoiding periods as a result of AN, whereas the "communicate" pro pertains to the benefit of being able to communicate distress through one's eating disorder. It is possible that AN individuals with higher autism traits may experience periods as particularly uncomfortable, due to heightened sensitivity of bodily sensations; thus, the avoidance of periods may be perceived as a greater benefit of AN in these individuals as compared to their lower autism traits counterparts. Additionally, due to communication difficulties linked with autism traits, individuals with greater autism traits may be more likely to find it beneficial to use AN as a means of communicating distress as compared to those with lower autism traits. This finding echoes the qualitative research of Brede et al. (2020) who aimed to better understand how AN develops and persists in women with autism, finding many themes which overlapped with the research of Serpell et al. (1999), such as gaining a sense of identity as well as a sense of structure and control through AN. In regards to identification of costs, the "stifles emotions" con, linked with greater autism traits, refers to the numbing of emotions through AN. While this is categorised as a con in the P-CAN, it is possible that some individuals with AN may consider this a benefit. This is consistent with Serpell et al.'s (1999) qualitative study wherein this function of AN was considered both a pro and a con. Echoing this notion, Brede et al.'s (2020) study demonstrated that the phenomenon of experiencing numbed emotions as a result of eating disorder behaviours was described as a positive aspect of AN in individuals with autism. As such, we suggest that individuals with AN reporting higher autism traits may more commonly endorse this aspect of AN due to the overwhelming and confusing emotions they may experience as a result of autism, and that they may regard numbed emotions as a benefit as opposed to a burden.

## 4.4.2 Clinical Implications

Several clinical implications warrant mentioning in light of our findings. First of all, our findings contribute further evidence to the importance of motivation in recovering from AN (Goddart et al., 2013; Le Grange et al., 2014; Pauli et al., 2017; Thaler et al., 2016). With this emerging robust finding, interventions that aim to increase motivation have increasingly been advocated for within eating disorder treatment, with some eating disorder services now using models of motivation to structure and inform treatment options, such as motivation enhancing interventions (Geller et al., 2001; Touyz et al., 2003; Treasure et al., 2001). Motivation enhancing interventions can be broadly divided into three main categories: 1) those that offer a list of principles to guide practice; 2) those that focus on the application of Motivational Interviewing (MI), and 3) those that add motivation enhancing techniques to other, more established therapies. The first category, drawing on a range of psychotherapeutic techniques and approaches, emphasises key principles for clinicians working with ambivalence, including empathy, curiosity, collaboration, transparency, maximising autonomy, and acceptance (Garner et al., 1982; Geller et al., 2007; Goldner et al., 1989; Sallas, 1985; Vitousek et al., 1998). The second category, MI, is a psychological intervention that not only endorses many of these principles, but also outlines specific methods to increase motivation to change. This approach aims to enhance the client's commitment to change by eliciting "change talk", for example by exploring pros and cons of change. In eating disorders, it has been suggested that this can be examined by connecting the client with two hypothetical parts of themselves: the "anorexic minx" and the healthy person who desires change (Treasure et al., 2008). Lastly, in recent 210

years, some psychological treatments for eating disorders have begun to incorporate techniques that specifically aim to increase motivation, such as the exploration of pros and cons of change, the development of a narrative about a preferred future, the examining of function of symptoms, and setting realistic goals for change (Eivors et al., 2005; Fairburn., 2008; Lask et al., 2007; Waller et al., 2007; Wilson et al., 1993). However, despite the robust finding of motivation's impact on outcome, evidence is currently lacking to support the use of motivation enhancing interventions in treatment for eating disorders (Knowles et al., 2012). Thus, we suggest that while lack of motivation is clearly an important barrier to recovery, the current methods for increasing motivational approach is embedded likely being more effective than the stand-alone motivation treatments investigated in Knowles et al. (2012). Furthermore, dismantling studies are necessary to fully understand the role of motivation in treatment.

Moreover, our data suggests that endorsement of the "hatred" con predicts increase in BMI at follow-up. This finding indicates that an important cognitive factor within therapy may be no longer viewing the illness as a friend or guardian, but rather experiencing hatred towards it. As such, clinicians should be cognizant of the patient's overall attitude towards their illness, and consider that those who do not display negative affect towards their illness may be more resistant to treatment and thus need more specialised care. Moreover, clinicians may wish to help move the patient towards a cognitive shift wherein the illness is no longer viewed as a friend, perhaps by exploring ways in which the illness negatively impacts the patient, or by using 211

externalising techniques or chair work to help the individual separate their identity from that of the 'anorexic voice' (Chua Yi Ling et al., 2021).

Further, the results of this study indicate that AN individuals with higher autism traits may differ from their lower autism traits counterparts in terms of egosyntonicity, specifically in regards to the avoidance of periods, using their illness as a means of communicating distress, and numbing of emotions. As such, clinicians would benefit from taking special care to explore the function of AN in individuals with high autism traits, as these functions may not only differ from AN individuals low in autism traits, but are also be more difficult to replace. For example, AN individuals with high autism traits may experience more overwhelming emotions, as well as struggle with learning techniques to manage these emotions. As such, it may be of particular importance for a clinician to identify whether AN serves to numb emotions, and if so, to ensure techniques for managing emotions are taught and practised, perhaps more so than with non-autistic patients. This notion is supported by Brede et al. (2020) wherein autistic women identified one challenge of CBT being that clinicians assumed skill sets that patients did not yet have (possibly including managing emotions), which resulted in poor results. Similarly, clinicians may benefit from focusing on enhancing communication techniques for individuals with AN displaying high autistic traits. Focusing on communication can be beneficial in multiple ways; firstly, in that increasing communication may result in AN no longer being the primary method of expressing anguish, and secondly, in that increasing communication is likely to improve outcome in therapy, in that these patients will be better able to communicate their struggles and have improved therapeutic alliance. Lastly, exploring the effect of 212

internal sensations, and how to better cope with uncomfortable internal sensations (for instance, the experience of having periods if the patient finds this distressing) could prove beneficial in therapy.

## 4.4.3 Strengths and Limitations of the Current Research

The current research has contributed to the AN literature, and replicates findings from previous research demonstrating the predictive value of motivation in treatment outcome. As far as we know, the study is novel in its exploration of pros and cons of AN and its relationship with treatment outcome and autism traits. Regarding methodology, all variables within this study were measured using validated psychometric scales which have been previously demonstrated to have sound psychometric properties. Lastly, verified BMIs were obtained by clinicians rather than self-report, and all participants had received a clinically confirmed *DSM-5* diagnosis of AN.

Having said that, there are a range of limitations which need to considered when interpreting the findings of the study. Firstly, data was collected from three different treatment sites, resulting in less control and increased variability in the way measures were administered. The use of multiple sites was necessary due to the difficulty in recruiting individuals with AN for this type of research (Brockmeyer et al., 2019). However, since the measures used in this study were self-report measures, rather than behavioural or experimental measures, it is unlikely that this limitation had a significant effect on the results. Moreover, for a number of reasons discussed in the following chapter, this study contained a sample size lower than that indicated in the 213

power calculation, reducing the power of the study and increasing margin for error. Further, the findings of the study are limited in that they cannot be generalised to a clinical presentation of autism, given that no clinical diagnoses of autism were made. Both the small sample size and lack of autism diagnoses were due to resource limitations of the project. Furthermore, this study was impacted by recruitment difficulties, which will be detailed in the following chapter, as well as recruitment being curtailed due to the onset of the COVID-19 pandemic.

## 4.4.4 Future Directions

The results of this research study suggest that motivation is an important factor in benefiting from therapy to treat AN. However, considering the demonstrated ineffectiveness of motivation enhancing techniques, more research is needed to understand the mechanisms which underpin motivation in AN, and how they can be used in order to improve outcome within therapy. Moreover, further examination of the predictive validity of the P-CAN is warranted, particularly examining the individual impact of pros and cons in a larger study containing sufficient power to examine these benefits and burdens on an individual basis. Lastly, we suggest that differences in endorsement of pros and cons are further explored in a larger AN sample which includes AN individuals with and without a confirmed diagnosis of autism.

## **Chapter 5** General Discussion

"Never underestimate the power of desire. If you want to live badly enough, you can live. The great question, at least for me, was: How do I decide I want to live?"

Marya Hornbacher: Wasted – A Memoir of Anorexia and Bulimia

This general discussion presents an overview of the key findings of this thesis. Future research and clinical implications are also discussed.

## 5.1 Overview of Thesis: Findings and Limitations

The broad aim of this thesis was to examine the role egosyntonicity plays in AN. To recap, the first aim of the thesis was to systematically and critically investigate the existing AN literature and present a comprehensive summary of the evidence for predictors of drop-out and treatment outcome in patients with AN, alongside highlighting the strengths and limitations within the current literature base. The second aim was to elucidate the nature of egosyntonicity in AN, reviewing both qualitative and quantitative research pertaining to egosyntonicity, and to present methods to overcome this impediment to recovery in AN treatment. The third aim was to replicate and extend upon Serpell et al.'s (2004) research by establishing the concurrent validity of the P-CAN. The fourth aim was to investigate the relationship between endorsement of pros and cons of AN and eating disorder symptoms, BMI, and intrinsic motivation, as well as explore the link between the P-CAN and confidence in one's ability to recover and AN subtype diagnosis. The fifth aim was to examine whether the 215

relationship between endorsement of pros and eating disorder symptoms is mediated by motivation. Finally, to fill a gap in the literature, this thesis had the final aim of evaluating whether endorsement of pros and cons could predict treatment response in individuals with AN undergoing outpatient psychological therapy. Lastly, this thesis aimed to investigate whether patients scoring higher on autism symptoms present differently in terms of egosyntonicity than their lower scoring counterparts.

This thesis employed both a cross-sectional and longitudinal design to examine the role of egosyntonicity in AN. The thesis began with a systematic review and metaanalysis of the existing research base which demonstrated inconsistent results as well as difficulties in comparing studies, due to lack of consistency regarding definition of outcome. Few pre-treatment patient characteristics emerged as significant, which led to the hypothesis that previously unexplored variables may impact response to treatment. One such variable may be egosyntonicity, which has been highlighted as a key feature of AN, yet has received relatively little attention within the research sphere. A narrative review was conducted to examine the nature of egosyntonicity, demonstrating that AN provides those impacted by it with a range of perceived benefits, with endorsement of these perceived benefits being tentatively linked with greater eating disorder pathology (Serpell et al., 2004). Considering these findings, a cross-sectional study was undertaken to further establish the concurrent validity of the P-CAN, a psychometric scale which measures both perceived benefits and costs of AN. The P-CAN demonstrated sound psychometric properties and numerous links with variables of interest. Following this, a longitudinal study was undertaken to examine the predictive value of the P-CAN. This study found that the Con – Hatred 216

sub-scale of the P-CAN predicted outcome, alongside eating disorder pathology and motivation were shown to predict outcome. A summary of key findings is found in the below paragraphs and briefly in Table 5-1.

Chapter	Method	Key finding(s)	Implication for Thesis
1	Meta-analysis	29 studies included in meta- analysis. Lower motivation, BP subtype, and lower BMI linked with greater drop-out. Greater eating disorder pathology and poorer motivation linked with poorer response to therapy. Inconsistent definitions of drop-out and outcome.	Investigate the role of previously unexplored variables in addition to eating disorder pathology and motivation in terms of treatment response. Clearly define outcome, using multiple measures (both BMI and eating disorder
2	Narrative review	AN provides a range of perceived benefits to those impacted by it, alongside perceived burdens, which can be measured by the P-CAN. Endorsement of pros tentatively linked with eating disorder pathology.	pathology) Need to further establish the validity of the P-CAN, as well as investigate whether the relationship between endorsement of pros and eating disorder pathology is partially mediated by motivation.
3	Cross-sectional study	P-CAN demonstrates good validity. Endorsement of pros, mediated by motivation, is linked with greater eating disorder pathology. Greater DB (pros outweighing cons) and lower self-efficacy, fully mediated by motivation, is linked with greater eating disorder pathology	Need to examine whether endorsement of pros and cons predicts treatment outcome. Relationship between autism traits and endorsement of pros and cons is also of interest.
4	Longitudinal study	Endorsement of "hatred" con, eating disorder pathology and motivation predict treatment response. Individuals demonstrating greater autism traits show greater endorsement of pros.	Further research is needed to examine endorsement of individual pros and their relationship to outcome.

Table 5-1. Key findings of thesis by chapter

The design and methodology of this thesis offer several contributions to the current research literature on egosyntonicity in AN. The study recruited participants from 217

clinics across the UK with a confirmed diagnosis of AN, improving upon the design of Serpell et al.'s (2004) study, wherein 78% participants did not have a confirmed diagnosis. Furthermore, all BMI measures included in the study were obtained by clinicians, as opposed to via self-report, thereby addressing another of the shortcomings of Serpell et al.'s (2004) study. With the vast majority of other studies on egosyntonicity existing only as qualitative studies, this project's quantitative design allowed for previously theorised relationships to be explored quantitatively, thereby allowing for statistical testing of these claims that were generated from qualitative studies. Furthermore, the use of more advanced statistical techniques allowed for mediation to be examined.

In the meta-analysis in Chapter 1, it became evident that drawing clear conclusions about pre-treatment patient predictors of drop-out and outcome was challenging for a range of reasons. Firstly, there is a lack of consistency in outcome measures across studies, with a total of 11 outcome measures being used across the 14 outcome studies included in the analysis. This is an issue which has been highlighted by other authors (Bachner-Melma et al., 2006; Jarman & Walsh, 1999; Kordy et al., 2002). The issue of disparity of definitions similarly applied to drop-out, a concern which has been raised by Mahon (2000) and Sly et al. (2013), who have made suggestions for how to more clearly define and categorise drop-out. Similarly, the way baseline characteristics were measured varied considerably (for instance, in terms of depression, some studies measured depression on a present/absent basis whereas others measured depression on a spectrum). Further, a range of treatment methods were used in the included studies, including CBT, SSCM, psychodynamic therapy, 218

dietary counselling, and interpersonal psychotherapy, in various combinations, both within inpatient and outpatient settings. Clearly, drop-out from treatment or from therapy will be defined differently in these different settings. Additionally, severity and presentations of AN were likely to vary across studies, which could produce difficulties in assessing treatment success, as a severely underweight patient who made significant increases in BMI during treatment, yet did not achieve a healthy weight may be considered a treatment failure according to certain outcome definitions. Lastly, the majority of the included studies were characterised by low sample size, with the average sample size across studies being 96 and the median sample size being 79, limiting the power to detect statistically significant differences.

The systematic review and meta-analysis evaluated the range of work conducted in the field, and the inconsistencies raised in this review echo the concerns of previous authors (Mahon, 2000; Sly et al., 2013; Waller et al., 2009). As mentioned, previous recommendations have been made to address these issues (such as suggestions made to categorise drop-out into various sub-categories), but these recommendations have yet to be adopted on a widespread basis. Whilst most variables failed to predict dropout or outcome on a reliable basis, a few variables did emerge as significant predictors in the meta-analysis. As such, the main findings of this chapter were that lower motivation, having the BP subtype of AN, and having a lower BMI at the start of treatment was linked with higher drop-out, whereas greater eating disorder pathology and lower motivation were linked with poorer response to treatment.

The inconsistencies highlighted in this review helped shape the design for later chapters. To address the issue of disparity of definition of outcome, two different outcome measures were used in the longitudinal study; BMI and eating disorder pathology, which were analysed separately, as opposed to as an aggregate. We preferred to examine each outcome measure separately to provide greater clarity for readers on the effect of predictors on specific aspects of outcome, and to also provide greater ease for fellow researchers who wish to make comparisons with other studies in the future. Whilst we did choose to categorise participants in terms of clinically significant change to ascertain how many made significant progress within therapy, we opted not to use clinically significant change categories as our outcome measure, as cut-off points may discount significant progress made within therapy that fails to reach non-clinical status (perhaps due to presenting with a particularly high level of illness at the start of treatment) and can thus sometimes be considered arbitrary. Further, we ensured that therapeutic approaches were adequately described, as several studies in our review failed to provide adequate description of treatment methods. Lastly, we included eating disorder pathology and motivation in our analysis as our review suggested these variables were significant predictors of outcome in AN treatment. The systematic review and meta-analysis contribute to future work in that it highlights issues to consider when undertaking research which examines predictors of drop-out and treatment outcome in AN, and also provides evidence for the significance of BMI, motivation, eating disorder pathology, and subtype in predicting outcome and/or drop-out.

The narrative review in Chapter 2 examined the current research literature on egosyntonicity in AN, and presented methods to overcome this impediment to recovery. The review found that AN provided a range of perceived benefits for individuals impacted by AN, including providing a sense of security, control, and skilfulness, functioning as a means of communicating distress and avoiding negative emotions and experience, increasing feelings of confidence as well as specialness, allowing the avoidance of periods, prompting care from others, and providing a new identity (Nordbø et al., 2006; Serpell et al., 1999). Conversely, perceived burdens included feeling stifled, guilty, and trapped by the illness, as well as carrying hatred towards it (Serpell et al., 1999). A tentative link was demonstrated between endorsement of perceived benefits and greater ED pathology, as well as between perceived costs and greater readiness to recover (Blake et al., 1997; Cockell et al., 2003; Rieger et al., 2002; Serpell et al., 2004). The narrative review contributes to the thesis in that it provides a theoretical underpinning for the cross-sectional and longitudinal studies within this thesis.

Chapter 3 describes a cross-sectional validation study. The results of this study demonstrated the sound psychometric properties of the P-CAN, as well as further establishing its concurrent validity. Perceived benefits of AN were demonstrated to be linked with greater eating disorder pathology, lesser readiness for change, and greater concerns about change, whereas perceived costs were associated with lesser eating disorder pathology, greater readiness to change, and lesser concerns about change (with the exception of the "Stifled" and "Numbs Emotions" costs which often demonstrated a reverse relationship to that of the other cons). The key finding from 221

the cross-sectional study was that the relationship between endorsement of pros and eating disorder pathology was partially mediated by motivation. This finding, suggesting that egosyntonicity may impact upon eating disorder pathology through its effect on motivation, is an important contribution to the literature, in that it suggests that the mechanism through which endorsement of pros may maintain or exacerbate eating disorder symptoms is by lowering motivation for recovery. This finding is also consistent with the interpersonal-cognitive model by Schmidt and Treasure (2006) first introduced in Chapter 1, which purports that pro-anorexia beliefs is a maintenance factor in AN. Understanding the role egosyntonicity plays in impacting pathology through its effect on motivation could be significant to discovering how to help individuals with AN, both research and clinical settings. For example, in the clinic context, altering endorsement of pros and cons may be a necessary precursor to increasing motivation. Furthermore, the relationship between both DB and selfefficacy and eating disorder pathology was fully mediated by motivation, suggesting that targeting self-efficacy in the treatment context may improve therapeutic outcomes through its effect on motivation. This chapter contributes to both the research programme outlined in this thesis and the wider field in that it highlights the importance of egosyntonicity within AN, as well as further establishing the validity of the P-CAN, a useful tool both within clinical and research settings.

The results of the cross-sectional study are researched further in the longitudinal study. In response to a lack of longitudinal research on egosyntonicity, and considering the finding that endorsement of pros impacted eating disorder pathology partially via its effect on motivation, the longitudinal study in Chapter 4 was conducted to explore the 222

predictive value of the P-CAN in a sample of outpatients undergoing treatment for AN, alongside variables previously demonstrated to predict outcome, specifically motivation and eating disorder pathology. A secondary aim of this chapter was to examine the relationship between the P-CAN and autism traits, and to determine whether autism traits would predict outcome, as had been demonstrated in a handful of previous studies (Nielsen et al., 2015; Stewart et al., 2017; Tchanturia et al., 2016). Participants' progress was measured at 6 months.

Considering the results of our longitudinal study, our central findings provide further support for the mounting evidence that motivation plays a key role in achieving progress within therapy for individuals with AN, and that the impact of differences between motivated individuals and their less motivated counterparts on outcome can be seen as early as six months into treatment. Moreover, we found that endorsement of the "hatred" con (but not pros) also predicted greater treatment response. Interestingly, this finding does not support the interpersonal-model put forth by Schmidt and Treasure (2006), wherein pros of AN, which proved insignificant in our results, are theorised to maintain the disorder. Further, we found that individuals with more autism traits more strongly endorsed perceived benefits of AN. It is possible that those with higher autistic traits struggle more with a sense of self and fitting in, which thus leads them to take on their eating disorder as a part of their identity and identifying more with it to a greater extent. This could mean that these individuals therefore are more likely to value their disorder. Furthermore, those with autistic features are more rigid in their thinking, meaning their view of their eating disorder could be more black and white, possibly making them more likely to see it as "all good" as opposed to a 223

mix of good and bad. Lastly, Brede et al.'s (2020) qualitative study suggested that their eating disorder helped autistic individuals cope with stressors related to being autistic, by distracting them and numbing difficult emotions and sensations and providing control and predictability. As such, it is likely that these individuals more strongly endorse benefits of AN because they encounter increased difficulties which AN, albeit in a maladaptive way, can help them manage. Considering this finding, this chapter contributes to the field by providing additional insight into the important role egosyntonicity may play in AN individuals with greater autism traits, suggesting that this factor might be especially important to consider in an AN treatment context where the individual also has a diagnosis of autism. As such, this finding could provide clues as to how to tailor intervention for these individuals, and encourages clinicians to consider the role of egosyntonicity for these individuals. This and other clinical implications will be discussed later in this this chapter. However, when considering these findings, it is important to note that conclusions should be tentative due to the study being underpowered.

# 5.1.1 Recruitment Difficulties

As demonstrated by the systematic review and meta-analysis conducted in Chapter 1, a key limitation of the current AN research literature is that the majority of longitudinal studies examining predictors of outcome are characterised by low sample sizes, thus limiting power. However, despite our awareness of this issue, and several attempts made to mitigate against the difficulty of recruiting large samples in this population, such as including multiple treatment centres, it was not possible to recruit as large a sample as planned. The onset of the Covid-19 pandemic further limited recruitment, 224

as all research activities were halted at our recruitment clinics following the onset of the pandemic. The issue of small sample sizes in AN research has been addressed by previous researchers, with Brockmeyer et al. (2019) highlighting the urgent need for adequate clinical trials with large enough samples of AN patients. The dearth of largescale research studies investigating AN arises for a multitude of reasons, including limited funding for AN research (Schmidt et al., 2016), low prevalence rates of AN, high rates of drop-out, and high treatment ambivalence in the population (Abbate-Daga et al., 2013; Williams & Reid, 2010). To exemplify the difficulty in recruiting a substantial AN sample, it took four years and 10 participating recruitment clinics to recruit 242 eligible participants with AN for the ANTOP study conducted by Zipfel et al. in 2014. This was a study funded by a large grant, with several staff working full time on the project. In terms of our project, we experienced that recruitment for our cross-sectional study was relatively easy which lulled us into a false sense of security about the feasibility of recruiting a decent size sample for the longitudinal study. The majority of patients approached to partake in our cross-sectional study agreed to participate, whereas nearly a third of patients approached to partake in our longitudinal study declined. Moreover, several patients who were eligible to participate in the longitudinal study were not approached due to their clinician feeling they would not be willing to participate or that approaching them about research participation would be inappropriate at the present time. Naturally, it was at the clinician's discretion to determine whether approaching a patient about research participation would be appropriate. However, it is important to consider ethical issues regarding these patients not being given an opportunity to provide a much needed and valuable contribution to knowledge which may benefit themselves and others. Further, clinicians voicing the 225

needs of their patients may also entail a degree of paternalism as opposed to a more patient-centred approach to care. As such, wherever possible without impeding care, we suggest that approaching participants regarding research opportunities not only benefits the research community but also provides the patient with a voice should they want to use it, as well as a opportunity for self-reflection in some cases. For instance, in our study, many participants expressed that completing the P-CAN gave them useful insight into their own feelings about their illness. For these reasons, we urge that patients should not be excluded from being approached about research opportunities wherever possible, including severely ill patients whose perspective is just as important as others A further issue to note is that a handful of participants who were recruited to our study whilst on the waiting list had to excluded due to their BMI being in the healthy range by the time their treatment commenced (thus, failing to meet all eligibility criteria), either due to improvement in eating disorder symptoms or due a change in eating disorder symptoms (ie. changing from restricting to bingeing). A further consideration with regards to recruitment for the longitudinal study concerns logistical issues. Firstly, patients on waiting lists were often approached and agreed to participate during monitoring, but were then picked up for treatment without notification from the treatment team to the researcher, meaning baseline measures were not able to be taken. Further, those on waiting lists who were recruited to the study often dropped out during monitoring, likely as a result of service pressures which resulted in extended waiting times. A further logistical issue concerns staff changes leading to temporary vacancies in the assistant psychologist post, resulting in no one in post to support recruitment for a period of three months. Lastly, a key difference between those approached for the cross-sectional study and those approached for the 226

longitudinal study was that to be eligible for the longitudinal study they needed to be within two weeks of starting therapy, whereas those eligible for the cross-sectional study were still eligible if they had already started therapy. It seems likely that eligible patients who were just commencing treatment were more likely to be in the precontemplation or contemplation stages of change, possibly increasing their ambivalence towards the value of research. Furthermore, they may have been uncertain whether they would remain in therapy, thus making them reluctant to participate in a longitudinal study where they would be asked to complete questionnaires 6 months down the line, perhaps fearing they would disappoint the researcher by dropping out. Moreover, patients at this stage of treatment may be more likely to be grappling with their newly given diagnosis or their decision to commence (or re-commence) therapy, which made them less likely to want to participate in a research study, due to likely experiencing an already overwhelming emotional load. Conversely, those who were further along in therapy may be more comfortable with their diagnosis and/or treatment, making them more likely to participate in a study, especially if they were experiencing less ambivalence towards recovery, which may perhaps have enhanced their desire to help others impacted by AN as well. In fact, many expressed their interest in participating in and contributing to research on the subject precisely in pursuit of this goal. Taken together, these issues highlighted herein may provide insight into the dearth of large studies examining treatment in AN, and pinpoint issues which need consideration when undertaking research in AN treatment.

### 5.2 Future Research

Considering the entire project from a broad lens, it is possible to make several recommendations for future research. Firstly, it is possible that the P-CAN failed to predict treatment outcome due to pros and cons being scored as an aggregate, as opposed to examining each pro and con on an individual basis, as particular perceived benefits or burdens of AN may impact response to treatment more heavily than others. The study was not sufficiently powered to examine all ten pros and cons separately, but a future study with a larger sample size could explore this. The link between egosyntonicity and treatment response warrants further research particularly considering the finding of Chapter 3, which suggested that endorsement of pros impacted upon eating disorder pathology partially through its effect on motivation. As such, we recommend that future research investigates the P-CAN sub-scales individually; however, an important caveat which warrants mentioning is the large sample size necessitated in order to sufficiently power such an analysis. For example, if each pro and con is to be examined separately, a sample of 100-150 participants needs to be recruited, not accounting for drop-out (Wilson et al., 2007). As such, echoing the words of Brockmeyer and colleagues, we reiterate the urgent need for sufficiently large studies in AN research, while fully understanding and acknowledging the many barriers to achieving such a task (Brockmeyer et al., 2019). Moreover, considering the finding that there may be a link between higher autism traits and greater egosyntonicity, we suggest that this relationship is further explored in an AN sample including individuals both with and without a confirmed autism diagnosis, as our study did not use autism diagnoses but merely measured autism traits on a continuum (Mandy et al., 2018). This way, the specific role egosyntonicity may play for those individuals with AN who are also impacted by autism can be properly elucidated. Furthermore, a qualitative study interviewing individuals with AN with and without autism exploring how the pros and cons may differ could be beneficial.

## 5.3 Clinical Implications

One of the major takeaways from this project is the role of motivation in treatment response for people with AN, which carries with it important clinical implications. The role of motivation in AN has been receiving increased attention and support in recent decades, and importantly, literature from other clinical fields such as schizophrenia and other psychiatric illnesses, have demonstrated that this variable can be manipulated, and that this can improve response to treatment (Choi & Medalia, 2004; Hettema et al., 2005; Nakagami et al., 2010). However, in terms of eating disorders, motivational enhancement techniques have failed to demonstrate impressive results in the literature, with most studies finding no differences between groups who received motivational enhancement techniques in addition to therapy compared to those who received treatment as usual (Dean et al., 2007;Dunn et al., 2006; Katzman et al., 2010; Treasure et al., 1999; Knowles et al., 2013; Wade et al., 2009), although it should be noted that Dean et al. (2008) found a higher percentage of MI patients (88%) were inpatient or daypatient treatment at follow-up compared to CBT patients (44%) Nevertheless, whilst motivation is demonstrably an important factor in treatment response, our efforts to enhance it in a clinically meaningful way through targeted techniques have yet to be demonstrated to be successful in a robust

manner, suggesting we may need further understanding of which factors underpin motivation in order to enhance it and have a positive effect on treatment outcome. Considering the effect that endorsement of pros appeared to have on eating disorder pathology through its relationship with readiness to change, we cautiously suggest that one factor which may impact upon motivation, and in turn, eating disorder pathology, is egosyntonicity. Numerous techniques to assess egosyntonicity have been discussed in previous chapters, and include writing letters addressing AN as an enemy and a friend, examining how AN aligns with personal values and drawing out tables examining long-term versus short-term advantages and disadvantages of AN or of change (recovery). In line with our finding, therapeutic interventions to address pros and cons form a core part of MANTRA. For example, an exercise to draw out a table of pros and cons of change can be used to illustrate the fact that cons of change (pros of AN) tend to be short term whilst the pros of change (cons of AN) are likely to be longer term. This can lead to a therapeutic discussion about the need to prioritise longer term goals such as physical health or education/career over the short term goals such as managing anxiety in the immediate term. Examination of the pros and cons can also allow the person with AN to discuss in therapy the ways in which AN functions for them, for example by helping them to manage difficult emotions or avoid demanding situations. This can lead to discussion in therapy of whether AN is a healthy and effective way to achieve these functions, or whether alternative strategies would be preferable. For example, a patient who identifies that AN allows them to communicate their distress to others may decide that, with support from the therapist, they would like to try improving their communication skills so that they can ask for support verbally when it is needed rather than having to use weight loss as a way to 230

communicate this. However, considering that egosyntonicity failed to predict treatment response in our longitudinal study, we also suggest that motivation may need to be targeted in other ways. Drawing upon the motivation literature discussed in Chapter 2, clinicians may wish to focus on enhancing the patient's self-efficacy, as well as discover helpful processes of change, such as consciousness-raising (often achieved through psychoeducation) and helping relationships (identifying people in the patient's life who the patient can rely on for support) (Prochaska & Velicer, 1997; Prochaska et al., 1988). Moreover, exploring intrinsic psychological needs, such as the need for autonomy, competence, and belongingness, and how these may be better fulfilled through recovery (for example, through no longer being controlled by the illness [autonomy], gaining competence from having achieved recovery-related goals and getting positive feedback on these [competence], and improving social relationships [belongingness]) could help increase intrinsic motivation, which is an important factor in behaviour change according to the SDT (Deci & Ryan, 1985). It also important to note that while stand-alone motivational enhancement techniques have been demonstrated to be relatively ineffective in AN treatment, motivational enhancement techniques, when used embedded with previously existing therapies (e.g. MANTRA, CBT), appear to be effective (Knowles et al., 2006). Thus, embedding a motivational stance throughout therapy could be an effective approach to increasing motivation, but we nevertheless need dismantling studies with large samples in order to determine whether this is the correct approach.

Another clinical implication which should be mentioned arises from the finding that endorsement of the "hatred" con predicted treatment response. As has been suggested, 231

this finding could indicate that the overall affect which a patient feels towards their illness could be of clinical importance, wherein the patient experiencing negative affect and considering the illness an enemy as opposed to a friend may be more likely to make improvements within treatment. As such, clinicians may benefit from focusing on the friend versus enemy aspect during treatment, using previously discussed techniques to externalise the eating disorder, and enhancing attitudes and beliefs which may be more likely to shift the patient's perception of their illness to an enemy rather than a friend or guardian.

A further clinical implication which warrants mentioning arises from the link found between higher autism traits and specific perceived benefits and burdens carries with it some clinical implications. To recap, our fourth chapter demonstrated that AN individuals scoring higher on autism traits were more likely to endorse using their illness as a means of avoiding periods as well as a means of communication. Considering the fact that communication difficulties are extremely common in autism, it makes sense that individuals with greater autism traits may be more likely to use AN as a means of communication. Moreover, these individuals were also more likely to endorse AN as a means of stifling emotions, which we, in this context, suggest was perceived as a benefit, despite being a con sub-scale the P-CAN. This finding makes sense in light of the emotional difficulties which have been reported in autism (Mazfesky, 2016). As such, these may be areas which clinicians should be particularly mindful of when treating individuals with AN who demonstrate high autism traits. As perceived benefits may increase reluctance towards for recovery for AN patients with autism due to patients not wanting to let go of these perceived benefits, it may be 232

important for clinicians to find alternative means of achieving these benefits through healthier strategies. Thus, considering the aforementioned findings, improving communication may be an important area of focus within therapy for individuals with AN and high autistic traits, as this was one of the greater endorsed benefits by those with greater autism traits. Moreover, as AN individuals with higher autism traits more strongly endorsed avoiding periods as a benefit of AN, considering interoceptive awareness (IA) within therapy may be important. IA can be broadly defined as the conscious perception of bodily cues such as breathing and heartbeat, and is also related to emotional experiences (Barrett et al., 2004; Wiens, 2005). As individuals impacted by autism experience atypical sensory processing, they may also struggle with IA, meaning that sources of internal discomfort, such as menstruation, cannot be pinpointed leading to feeling "off" without comprehending the reason, or may be heightened (Schauder et al., 2015). This similarly applies to emotions, which may cause feelings of distress, and thus, a desire to stifle them, which AN can provide. IA challenges can be addressed in therapy through a range of techniques, for example through mindfulness and meditation. The notion that there is a need for eating disorder services to identify autistic individuals in their care and adapt treatment accordingly echoes the concerns of previous researchers (Brede et al., 2020).

A final comment that this author would like to make leads us back to the crosssectional study of this thesis. In one of the psychometric measures used in our crosssectional study, an open-ended question was included in the measure, which asked participants to describe any concerns about change which they held which had not been included in the measure. One respondent, who had a successful career in a 233

competitive field of medicine, wrote that without anorexia, her life would no longer have any meaning. As a researcher, this response, which reinforced to me how the egosyntonic nature of this illness can be so detrimental and so powerful, reminded me why I was doing this research, research which could only have been made possible with the clinical and academic guidance of Lucy Serpell, as well as the statistical and clinical guidance of William Mandy. The clinical expertise of the supervisors of this project is a final strength which I would like to highlight, and without the expertise of these individuals, egosyntonicity, and particularly egosyntonicity within autism, may have been left unexplored.

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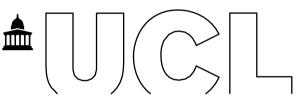
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# Application for inclusion of a research project

All research projects using personal data must be registered with the UCL Data Protection Registration Service **before the data is collected.** This includes projects approved by the Joint Research Office (a partnership between University College London, UCL Hospitals NHS Foundation Trust and the Royal Free Hampstead NHS Trust).

UCL is required by law to comply with the Data Protection Act,1998. UCL, is the Data Controller under the Act, and the Council, as the governing body, is ultimately responsible for implementation. However, students who are intending to process personal data for research purposes where they are the Data Controller, are responsible for any processing under the Act, and UCL is not responsible for any processing of personal data where it is not the Data Controller.

Before completing this form, please refer to our research and data protection website. All sections <u>must</u> be completed before submitting this form to the data protection team.

<b>A.</b> A	PPLICATION DETAILS	
A1.	Project title: AmbivalenceinAnorexia:ThePredictive ValidityofPerceivedAdvantagesand Disadvantages on Treatment Outcome	
a.	Proposed start date: 02.01.2017	Proposed end date: 02.01.2019
<b>B.</b> P	RINCIPAL INVESTIGATOR (S)	
B1.	Principal Investigator (PI): (Please note that a student – undergraduate, postgraduate or research postgraduate cannot be the PI for Ethics purposes).	
a.	Full Name: Dr. Lucy Serpell	
b.	Position held: Senior Lecturer	
с.	School: Psychology & Language Sciences	
d.	Faculty: Brain Sciences	
e.	Department: Clinical, Educational & Health Psychology	
f.	Email: l.serpell@ucl.ac.k	Telephone: 020 76791256
C. D	ATA COLLECTOR (S)	
C1.	Data Collector(s) Details (if Applicant is not the PI e.g. student details):	
a.	Full Name: Eva Cecilie Gregertsen	
b.	Position held: PhD Student	
с.	School: Psychology & Language Sciences	
d.	Faculty: Brain Sciences	
g.	Department: Clinical, Educational & Health Psychology	
h.	Email: eva.gregertsen.15@ucl.ac.uk	Telephone: 07494455102

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# **D. DETAILS OF THE PROJECT**

Please provide a brief summary of the project, including an explanation of the aims, design, methodology and plans for analysis that you propose to use.

The aims of this project are two-fold; (1) to determine the convergent validity of Pros and Cons of Anorexia (P-CAN) scale, and to assess its ability, alongside other previously tested variables, to predict treatment outcome in anorexia nervosa. The first part of the study utilizes a cross- sectional design, and the second part a longitudinal, prospective design. Data will be collected via questionnaires, and analysed using bivariate correlations, ANOVAs, and hierarchical multiple regression.

# **E. DETAILS OF PARTICIPANTS**

Please provide details of the potential participants for this project, including how they will be selected and recruited.

Participants for this project will be anorexia nervosa patients 16 years and up undergoing outpatient treatmentattwoparticipatingclinics. Eligibilityforthestudywillbeassessedbyclinicalstaffofthepotential participants' careteam. Patients deemedeligible will be approached by clinical staff who will supply them with an invitation letter including a reply slip wherein participants can register their interest in one or both parts of the study. Those who express their interest in the study will then be contacted by the researcher wherein arrangements will be made for the initial session of data collection. In this session, before administering any questionnaires, participants will be supplied with an information sheet and informed consent will be taken via the participant's signature.

# F. DETAILS OF THE DATA BEING PROCESSED

Please describe the details of the personal data that is being collected, including the methods of data collection and analysis.

In order to be able to link baseline responses with 6 months post-treatment responses, as well as clinical data relevant to the participant, names of participants will be collected upon the initial meeting between researcher and participant. However, this personal data will be stored in a file separate to the question naire-related data where in participants will only be identified by their unique identity code. The personal data will not be used in any analysis.

# **G. SHARING (DISCLOSURE)**

Please describe how the outcomes of the research will be disseminated (for example provide an explanation as to where, and how, will the results be published, or other mechanisms you will be using to share the potential participants personal data).

The outcomes of the research will be disseminated by being included within a PhD dissertation, as well as being published a peer-reviewed journal. However, no personal data will be included in any of these write- ups.

# **H. CONSENT**

Consent requirements for research projects can vary widely. Whether you are intending to use a consent form, information sheet, or verbally, it is recommended to assure compliance with the Data Protection Act and with ethical requirements.

Please include the information sheet and consent forms you will be using for this project, and or protocol. If you are not including an information sheet and consent form, please explain how the consent will be recorded?

### I. DATA STORAGE

Please describe the arrangements you will make for the security of the data, including how and where it will be stored. i.e. UCL network, \*encrypted USB stick, \*encrypted laptop etc.

The data will be stored in the Research Data Storage service, wherein files are accessible only to named project members. Furthermore, any paper-based data will be kept in a locked storage facility within an office at UCL. Personal data will be stored in Data Safe Haven.

\*Advanced Encryption Standard 256 bit encryption which has been made a security standard within the NHS)

### Data Safe Haven – Identifiable Data Handling Solution

Will the personal identifiable data collected and processed as part of this research be stored in the UCL Data Safe Haven (mainly used by SLMS divisions, institutes & departments)?

<u>YES</u>/NO

\*\*If no please ensure that you have explained how you will ensure that the data is held securely?

Further information on the Data Safe Haven service is available at:<u>http://www.ucl.ac.uk/isd/itforslms/services/handling-sens-</u> data/tech-soln

## J. INTERNATIONAL TRANSFER

Will identifiable data be transferred outside the UK as part of this study? YES / NO

The eighth principle of the Data Protection Act 1998 prohibits the transfer of personal data to countries or territories outside the European Economic Area (which consists of the 27 EU member states, Iceland, Liechtenstein and Norway).

At the time of writing the following countries have also been deemed adequate for the purposes of the 8th principle Andorra, Argentina, Canada, Faroe Islands, Guernsey, Isle of Man, Israel, Jersey, New Zealand, Switzerland and Uruguay.

The Data Protection Officer has produced guidance on the transfer of data overseas and particular to the United States. This is available from the Data Protection webpages at:<u>https://www.ucl.ac.uk/finance/legal/dp-data-transfer</u>

If you intend to transfer data to a country not mentioned above, please supply details of adequate safeguards below:

Use of cloud computing, or the transfer of personal data to other orgainsations providing a specific service e.g. transcriptions services.

If you are intending to use, or are considering using a cloud service (defined as access to computing resources, on demand, via network), or plan on using a third party orgainsation to deliver a service that will involve the transfer of personal data, you should ensure that there is an agreement in place which provides adequate levels of protection so that UCL can meets its obligations and protects the rights of the participants involved.

Please supply further details below, or seek advice by contacting the UCL Data Protection team data-protection@ucl.ac.uk.

## **K. NOTIFICATION**

(Please note that notification is a prerequisite for registration)

Have you informed your department's Data Protection Coordinator about your project? <u>YES</u>/NO

# L. ETHICS

If you are seeking ethics approval for your research, please provide the relevant project ID Number below.

Any questions regarding ethical approval should be directed to the relevant Ethics Committee or Governance Administrator.

L1.	UCL Ethics Project ID Number:	
a.	Joint Research Office Project ID Number: 16/01	66
b.	Other Project ID Number: 21652	29 (IRAS)
lf you a	re not seeking ethical approval for your project, please	explain why below:
M. (	CHECKLIST	
		riate supporting documentation that may be applicable from the list
below.		······································
M1.	Documents to be included with the application form	Yes if attached. No if not relevant
a.	Participant information sheet (s)	Yes
b.	Participant consent form (s)	Yes
с.	Parent/guardian information sheet (s) and consent form (s) for research involving participants under the age of 18	No
d.	Questionnaire	No
g.	Advertisement of project	No
h.	Other interview format (s)	No
i.	Other documentation being used to invite/inform participants about the research	Yes

**Approval** We may have some questions about the information you provide, but you will normally be provided with a registration number within 5 working days of submitting the form. However, the period leading up to meetings of the Ethics Committee is always very busy, and you should allow more time for your application to be processed. It is therefore very important to check in good time whether you need to register your project.

Please note that Data Protection Registration numbers will NOT be issued when you submit an application form in person to the Data Protection Team.

Submit this form electronically and send to <u>research.data-protection@ucl.ac.uk</u> together with supporting documentation that you are intending to use. Please include 'Data Protection Registration' in the subject field.

This form will be returned to you with the appropriate registration number, which you may quote on your Ethics Application Form, or any other related forms.

Data Protection Registration (Office use only)	
UCL Data Protection Registration Number	Date issued

Welcome to the Integrated Research Application System

#### IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

1. Is your project research?
Is your project research?

2. Select one category from the list below:		
0		
Clinical trial of an investigational medicinal product		
Clinical investigation or other study of a medical device		
Combined trial of an investigational medicinal product and an investigational medical dev	ice	
O Other clinical trial to study a novel intervention or randomised clinical trial to compare ir	nterventior	ns in clinical practice
Basic science study involving procedures with human participants		
Study administering questionnaires/interviews for quantitative analysis, or using mixed qua	ntitative/q	ualitative methodology
Study involving qualitative methods only		
2a. Please answer the following question(s):		
a) Does the study involve the use of any ionising radiation?	Yes	💽 No
b) Will you be taking new human tissue samples (or other human biological samples)?	Yes	💽 No
c) Will you be using existing human tissue samples (or other human biological samples)?	Yes	💽 No

3. In which countries of the UK will the research sites be located? (Tick all that apply)

✓

17/1 0/0250
Wales
Northern Ireland
$\odot$
0
3a. In which country of the UK will the lead NHS R&D office be located:
0
4. Which applications do you require?
IMPORTANT: If your project is taking place in the NHS and is led from England select 'IRAS Form'. If your project is led from Northern Ireland, Scotland or Wales select 'NHS/HSC Research and Development Offices' and/or relevant Research Ethics Committee applications, as appropriate.
For NHS/HSC R&D Offices in Northern Ireland, Scotland and Wales the CI must create NHS/HSC Site Specific
Information forms, for each site, in addition to the study wide forms, and transfer them to the PIs or local
collaborators.

Most research projects require review by a REC within the UK Health Departments' Research Ethics Service. Is your study exempt from REC review?

🔿 Yes 🛛 💿 No

5. Will any research sites in this study be NHS organisations?

💿 Yes 🛛 🔿 No

5a. Are all the research costs and infrastructure costs (funding for the support and facilities needed to carry out research e.g. NHS Support costs) for this study provided by a NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC), NIHR Patient Safety Translational Research Centre or a Diagnostic Evidence Co-operative in all study sites?

🔿 Yes 🛛 💿 No

Please see information button for further details.

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) Support and inclusion in the NIHR Clinical Research Network Portfolio?

**IRAS Form** Reference: 17/1 0/0250 The NIHR Clinical Research Network provides researchers with the practical support they need to make clinical studies happen in the NHS e.g. by providing access to the people and facilities needed to carry out research "on the ground". must complete a NIHR Clinical Research Network (CRN) Portfolio Application 6. Do you plan to include any participants who are children? No O Yes 7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves? Yes No Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK. 8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales? Yes No 9. Is the study or any part of it being undertaken as an educational project? Yes No Please describe briefly the involvement of the student(s): 9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

Yes No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

Yes No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

Yes No

### Integrated Research Application System

Application Form for Research administering questionnaires/interviews for quantitative analysis or mixed methodology study

#### **IRAS Form (project information)**

Please refer to the E-Submission and Checklist tabs for instructions on submitting this application.

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting <u>Help</u>.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms) Predictors

Please complete these details after you have booked the REC application for review.

REC Name: London-South East

REC Reference Number: 17/LO/0250 Submission date: 23/01/2017

## **PART A: Core study information**

1. ADMINISTRATIVE DETAILS		
A2-1. Educational projects		
A1. Full title of the	e research:	
		]
	Title Forename/Initials Surname Miss Eva C. Gregertsen	
Address	Miss Eva C. Gregertsen	
	1-19 Torrington Place	
Post Code	WC1E 7HB	
E-mail		
Telephone	eva gregertsen 15@ucl.ac.uk	
Give details of t	he educational course or degree for which this research is being undertaken:	

Date: 23/01/2017

Reference:

PhD Clinical, Educational & Health Psychology

Name of educational establishment: UCL

Academic supe	ervisor 1	
	Title Forename/Initials Surname Dr. Lucy Serpell	
anneland contac	ct details of academic supervisor(s):	
	1-19 Torrington Place	
Post Code E-mail	WC1E 7HB	
Telephone	l semell@ucl.ac.uk	
Academic supe	ervisor 2	
Address	Title Forename/Initials Surname Dr. William Mandy	
Post Code	WC1E 7HB	
E-mail Telephone	w mandv@ucl.ac.uk	
Student(s)	Academic supervisor(s)	
Student 1 Miss	Eva C. Gregertsen	

Please state which academic supervisor(s) has responsibility for which student(s):

Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Dr. Lucy Serpell

A copy of a <u>current CV</u> for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

 $^{\circ}$ 

Student

A3-1. Chief Investigator:

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Post	Title Forename/Initials Surname Dr. Lucy Serpell	
	DClinPsy	
ORCID ID	DhD Dovahalagiaal Approaches to Uaalth	
Employer	UCL	
Post Code Work E-mail	WC1E 7HB	
* Personal E-mail * Personal Telephone/Mo	bile 02076791256	
* This information is option consent.	al. It will not be placed in the public domain or disclosed to any other third party without prior	
A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?		

This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.

Title Forename/Initials Surname Miss Suzanne Emerton

Address 1st Floor Maple House (Suite B)

A5-1. Research reference numbers. Please give any relevant references for your study:

Applicant's/organisation's own reference number, e.g. R & available):	& D (if 16/0166
Sponsor's/protocol number:	
Protocol Version:	
Protocol Date:	
Additional reference number(s):	
Ref.Number Description	Reference Number
Data Protection Registration Number	Z6364106/2016/12/06 health research

Reference:

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Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

🔵 Yes 🛛 💿 No

Please give brief details and reference numbers.

### 2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

**A6-1. Summary of the study.** Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.

Can Pre-Treatment Patient Variables Predict Treatment Outcome in Cognitive-Behavioural Therapy for Anorexia Nervosa?

Anorexia nervosa (AN) is notoriously difficult to treat, and linked with detrimental physical and psychological effects, and even death in severe cases, and several studies have attempted to identify factors which may predict treatment outcome in order to inform and improve upon models of intervention. It has been suggested that one of the greatest hindrances to recovery may be the disorder's egosyntonic nature, meaning that individuals suffering anorexia nervosa often value the disorder and see it as serving important functions.

Determining patient variables which predict successfulness within therapy is important because knowledge of such variables can help tailor treatment and identify those who may be particularly resistant toward recovery at an early stage.

In this vein, the current study aims firstly to validate the P-CAN, a scale used to measure positive and negative attitudes to anorexia and secondly to determine whether patients' attitudes towards their own illness (the degree to which they view it as positive/negative) can predict their outcome in treatment.

Potential benefits of this study are improved models of intervention and better understanding of resistance to AN treatment.

The study will employ a prospective, longitudinal design.

In the first part, participants will complete the P-CAN alongside other measures at a single time point in order to validate the measure. In part 2, participants will be asked to fill out a series of questionnaires aiming to capture key predictors of treatment outcome, and the study will be longitudinal in nature, with measures being taken at the beginning of treatment as well as 6 months post-treatment.

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The study will be self-funded by the student conducting the study, and will be recruiting at the Eating Disorders Service, Truro Health Park in Cornwall and The Hope Wing, Porters Avenue Health Centre in London.

A6-2. Summary of main issues. Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, HRA, or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

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#### Consent:

Informed consent will be obtained from all participants by supplying participants with an information sheet describing the purpose and nature of the research, as well as what will be asked of those who choose to participate. Those eligible for participation will not be coerced to participate, and will be informed that participation is optional and that partaking or not partaking in the study will have no effect on their treatment. As minors will be invited to participate, competence to consent without the need for parental permission or knowledge for these participants will be assessed according to the Gillick's competence standard. As such, minors will be considered Gillick competent if they are considered to have fully understood what will be required of them should they choose to participate in the study, including potential risks and burdens. This will be assessed by asking these participants whether they understand the full purpose and nature of the study, what it involves, and its benefits, risks, and burdens.

Risks, burdens, and benefits:

The risks and burdens of this study are considered to be minimal, as it does not involve allocating participants to specific interventions. Nevertheless, the participants are at risk of experiencing anxiety or distress due to the nature of the questions they are asked to complete, specifically those pertaining to mental health status or other sensitive areas. This risk is minimised by the fact that all participants' responses will be anonymous, and as such, the participants' answers will not be known to the treating clinician, researcher, or others. Furthermore, participants will be advised to seek out relevant support services should they experience significant distress as a result of answering these questions, and will also be advised that they can drop out of the study at any time without having to provide a reason for doing so. Thus, participants who experience distress can drop out at any time distress should become too great. The risk of distress is further minimised by the fact that questionnaires will be filled out in a clinical setting, where participants may be more likely to expect, and therefore feel more comfortable with, questions of this nature.

### Confidentiality:

Person-identifiable information will be not be stored in the data. However, there is a minimal risk that a participant could inform the researcher of information that cannot be kept confidential, due to the participant or others being at serious risk. In such an instance, the researcher would inform the principal supervisor, a clinician at the relevant clinic, of the information divulged, so that the principal supervisor can make an informed decision on how to proceed based on the amount of risk posed to the participant or others.

Potential organisational and legal issues have been considered, and the researcher has determined that the current study does not raise issues in these domains.

3. PURPOSE		NON OF 1	TUE DEC	EADOL
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A7. Select the appropriate methodology description for this research. Please tick all that apply:			
Case series/ case note review			
Case control			
Cohort observation			
Controlled trial without randomisation			
Cross-sectional study			
Database analysis			
Epidemiology			
Feasibility/ pilot study			

A10. What is the principal research question/objective? Please put this in language comprehensible to a lay person.

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their own illness - i.e. the degree to which they feel their illness serves a functional purpose with positive rewards, or is detrimental and brings with it negative consequences - predicts how well they fare in treatment.

A11. What are the secondary research questions/objectives if applicable? Please put this in language comprehensible to a lay person.

The secondary research objectives of the study are to determine the extent to which other previously tested factors (such as anorexia subtype, motivation to change, symptom severity, autism character traits, and BMI at admission) predicts treatment outcome for anorexia patients. Furthermore, the study aims to assess the validity of a measurement of attitudes towards one's eating disorder by comparing it with other previously validated measures.

A12. What is the scientific justification for the research? Please put this in language comprehensible to a lay person.

The research is considered worthy of undertaking because it aims to further deepen knowledge in an area within the psychological community wherein significant gaps in knowledge still define the status quo. Despite the necessity for empirical studies documenting factors related to outcome in AN treatment, robust and consistent findings have been sparse, with few studies investigating predictors of outcome specifically, and contradictory findings existing across these studies. By undertaking the project, a better understanding of factors which may impede response to treatment will be gained, in turn helping to inform and improve upon intervention. Understanding predictive factors relating to treatment euterme will also provide a deepener understanding of AN on a theoretical level. The project answers an important

**A13. Please summarise your design and methodology.** It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.

Part 1:

NULL HYPOTHESIS - The P-CAN will not be significantly linked with measures aiming to tap into similar constructs.

STUDY DESIGN AND METHODOLOGY – We have chosen a cross-sectional design because all measures need to be administered at the same time point if the validity of the P-CAN is to be properly assessed.

WHAT WILL HAPPEN TO THE PARTICIPANTS – Anorexia nervosa patients will be informed of the study by receipt of an invitation letter which will be given to them by a member of their caregiving team, wherein they will be given a minimum of 24 hours to decide if they wish to participate. Potential participants' interest will be documented by a reply slip included in the invitation letter wherein the potential participant will fill in their name and contact details in order to register their details. The completed reply slip will be passed onto the researcher, and the researcher will contact the participant in order to arrange a session at the participant's convenience. During the arranged meeting with the researcher, the participant information sheet will be provided and informed consent obtained. Then, the participant will complete a survey, which should take approximately 1 hour to fill out. The survey includes questions about eating disorder symptoms, anorexia nervosa type, motivation to change, and attitudes towards their illness. We will also ask for some demographic information (e.g., age).

BROAD TIMETABLE OF RESEARCH – Preparations (obtaining ethics, preparing questionnaires) October 2016 – January 2017; Recruitment in outpatient clinics February 2017 – June 2017; Administering questionnaires: February 2017 – June 2017; Data analysis: June 2017; Preparing the final report: June 2017 – July 2017

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SAMPLING AND SAMPLE SIZES – The participants will be identified by clinical staff at the participating clinic who will screen their records and approach eligible individuals about the study and consent forms at or around their point of admission. Individuals who wish to participate will contact the researcher by phone or email to arrange a meeting to discuss the study. 120 participants will ideally participate in the study, which is deemed sufficient for the analysis based on similar published validation studies considered to have enough power.

Part 2:

NULL HYPOTHESIS - No significant predictors of treatment outcome will be found.

STUDY DESIGN AND METHODOLOGY – We have chosen a prospective cohort study because in order to be able to establish the predictive validity of pre-treatment patient variables on therapy outcome we need to follow the participants over time.

#### Reference:

#### 17/1 0/0250

WHAT WILL HAPPEN TO THE PARTICIPANTS - Anorexia nervosa patients will be informed of the study around admission by receipt of an invitation letter which will be given to them by a member of their caregiving team, wherein they will be given a minimum of 24 hours to decide if they wish to participate. Potential participants' interest will be documented by a reply slip included in the invitation letter wherein the potential participant will fill in their name and contact details in order to register their details. The completed reply slip will be passed onto the researcher, and the researcher will contact the participant in order to arrange a session at the participant's convenience. At two different time points (once after admission to their outpatient clinic and once 6 months post-treatment), the participant will complete a survey, which will take approximately 1 hour to complete. During the arranged meeting, the participant information sheet will be provided and informed consent obtained. The survey includes questions about eating disorder symptoms, anorexia nervosa type, motivation to change, autism character traits, attitudes towards their illness, and eating disorder-related quality of life. We will also ask for some demographic information (e.g., age).

Furthermore, the researcher undertaking this study will have access to the minimal clinical details necessary to complete the study, such as BMI pre- and post-treatment.) In the case that the participating clinic already administers certain scales included in the questionnaire, such as the EDE-Q or the EDQoL, at beginning of treatment/6 month follow-up, these scales will not be included in the questionnaire, and the researcher will obtain these details from clinical records, with consent from the participant.

BROAD TIMETABLE OF RESEARCH – Preparations (obtaining ethics, preparing questionnaires): October 2016 – January 2017; Recruitment in outpatient clinics: February 2017 – January 2019; Administering questionnaires: February 2017 – June 2019; Data analysis: June 2019 – August 2019; Preparing the final report: September 2019 – December 2019

SAMPLING AND SAMPLE SIZES - The participants will be identified by clinical staff at the participating clinic who will screen their records and approach eligible individuals about the study and consent forms at or around their point of admission. Individuals who wish to participate will contact the researcher by phone or email to arrange a meeting to discuss the study, or their contact details will be passed onto the researcher if preferred. 58 participants will ideally participate in the study, which is deemed sufficient for the analysis based on was calculations using G Power, using the A Priori: Compute Required Sample Size function for Multiple Regression (F tests), wherein n order to achieve an effect size of 0.25 with 0.8 power, it was determined that a minimum of 58 participants was necessary.

Both parts:

HOW WE DEAL WITH RESEARCHER BIAS AND RESEARCHER EFFECTS – As neither part of the study includes an intervention nor observational components, researcher bias and researcher effects are not considered key issues here. Therefore, no procedures have been put in place to detect and compensate for any possible researcher effects or bias.

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A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

Design of the research Management of the research × Undertaking research the Analysis results of ~ Dissemination of findings 

Give details of involvement, or if none please justify the absence of involvement.

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is acceptable and imposes a minimal burden. Service users and carers will be actively involved in the dissemination of findings in that results will be fed back to those who express an interest in the findings of the project. Furthermore, the research findings will be discussed with members of the public who will thus be given the opportunity to express their views on the research and its results.

### 4. RISKS AND ETHICAL ISSUES

#### **RESEARCH PARTICIPANTS**

A15. What is the sample group or col	hort to be studied in this research?
S <u>ele</u> ct all that apply:	
Blood	
Cancer	
Cardiovascular	
Congenital Disorders	
Dementias and Neurodege	nerative Diseases
Diabetes	
Ear	
Eye	
Generic Health Relevance	
Infection	
□ Inflammatory and Immune Syste	em
Injuries and Accidents	5
Mental Health	
Metabolic and Endocrine	
Musculoskeletal	
Gender:	Female participants only
Lower age limit: 16	Years
	Years

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

The principal induction oritoria are (1) formale (2) patients with a DCM // diagnostic of aperavia parvase (2) aged 16 years

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

The principal exclusion critera are:

# RESEARCH PROCEDURES, RISKS AND BENEFITS

	<b>i-clinical intervention(s) or procedure(s) that will be received by participants as part of the</b> clude seeking consent, interviews, non-clinical observations and use of questionnaires.
Please complete the column	s for each intervention/procedure as follows:
1. Total number of interv	rentions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/pro the total would be routine	cedure would be routinely given to participants as part of their care outside the research, how many of ?
3. Average time taken pe	r intervention/procedure (minutes, hours or days)
4. Details of who will con	nduct the intervention/procedure, and where it will take place.
Intervention or procedure	1234
Seeking consent	1 0 15 The patient's therapist or other clinician (nurse, dietician, psychiatrist, etc) a the
	specific clinic will be conducting this procedure, and it will take place at the out- patient clinic where the patient is undergoing treatment.
Administering the Eating Disorders Examination -	Administering the Broader Autism Phenotype Questionnaire
Questionnaire	Administering the Eating Disorder Quality of Life Scale
Administering the Readiness and Motivation Questionnaire	
Administering the Anorexia Nervosa Stages of Change scale	
Administering the Concerns about Change Scale	

Administering the Pros and Cons of Anorexia scale

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2 2 20 Eva Greger	undergoing treatment.	
tsen, PhD studen t, or a clinicia	1 0 20 Eva Gregertsen, PhD student, or a clinician at the Cornwall Clin this procedure, and it will take place at the out-patient clinic undergoing treatment.	0
n at the Cornw all Clinic will be	1 0 20 Eva Gregertsen, PhD student, or a clinician at the Cornwall Clin this procedure, and it will take place at the out-patient clinic undergoing treatment.	-
conduc ting this proced ure, and it will take place at the out- patient clinic	1 0 20 Eva Gregertsen, PhD student, or a clinician at the Cornwall Clinic w procedure, and it will take place at the out-patient clinic where the treatment.	-
	2 0 20 Eva Gregertsen, PhD student, or a clinician at the Cornwall Clinic v procedure, and it will take place at the out-patient clinic where the treatment.	-
	1 0 20 Eva Gregertsen, PhD student, or a clinician at the Cornwall Clin this procedure, and it will take place at the out-patient clinic undergoing treatment.	
where the patient is	1 0 20 Eva Gregertsen, PhD student, or a clinician at the Cornwall Clin this procedure, and it will take place at the out-patient clinic undergoing treatment.	

A21. How long do you expect each participant to be in the study in total?

For the cross-sectional part of the study, participants will be considered released from the study as soon as they have

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For the longitudinal portion of the study, it is expected that each participant be in the study for 6 months total.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

The potential risks and burdens for research participants are that they may experience anxiety or distress due to the nature of the questions being asked, as the questions will touch upon mental health status and other sensitive areas that could upset participants. This risk is minimised by the fact that all participants' responses will be anonymous, and as such, the participants' answers will not be known to the treating clinician, researcher, or others, which may reduce likelihood of distress. Furthermore, participants will be advised to seek out relevant support services should they experience significant distress as a result of answering these questions, and will also be advised that they can

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

Yes ONO

If Yes, please give details of procedures in place to deal with these issues:

Questionnaires administered in the project will include topics that might be sensitive, embarrassing, or upsetting to the participants, and in order to deal with these issues, participants will be informed that all answers they provide are completely anonymous, and that they can drop out of the study any time they wish, in the informed consent sheet. Furthermore, the questionnaires will be administered in a clinical setting wherein participants may expect to be asked questions of this nature. Moreover, the Chief Investigator is clinically trained and therefore equipped to deal with any potential distress exhibited by the participant; in such cases where participants experience discomfort or upset, they will be advised to contact the Chief Investigator, Dr. Lucy Serpell, via e-mail or via telephone. Further, they will be advised that they can also access support from Beat's helpline and will bne provided with their website

A24. What is the potential for benefit to research participants?

A26. What are the potential risks for the researchers themselves? (if any)

### RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).

In order to identify potential participants, clinical staff at the participating clinics will screen their records and provide eligible individuals with information about the study and an invitation letter including a reply slip. Potential participants will be given a minimum of 24 hours to decide if they want to take part. Potential participants' interest will be documented through the reply slip included in the invitation letter wherein the potential participant will fill in their name and contact details in order to register their details. The completed reply slip will be passed onto the researcher, and the researcher

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A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?
Please give details below:
The identifiable personal information that will be used to identify potential participants will derive from the RIO electronic care records system. However, only a member of the patient's existing clinical care team will have access to patient records in order to identify potential participants, check whether they must the inclusion criteria or make the initial
A27-3. Describe what measures will be taken to ensure there is no breach of any duty of confidentiality owed to patients, service users or any other person in the process of identifying potential participants. Indicate what steps have been or will be taken to inform patients and service users of the potential use of their records for this purpose. Describe the arrangements to ensure that the wishes of patients and service users regarding access to their records are respected.
Please consult the guidance notes on this topic.
Clinical staff will screen records for relevant information to inform eligibility such as age, gender and diagnosis. Contact details of participants who express an interest in partaking in the study will be given to the researcher after participants
A27-4. Will researchers or individuals other than the direct care team have access to identifiable personal information of any potential participants?
A27-5. Has prior consent been obtained or will it be obtained for access to identifiable personal information?
If Yes, please give details below.
The researcher will be given contact details of service users who wish participate, once they have been screened by clinicians. Potential participants' interested after being approached by a member of their care team will be registered through an invitation letter which includes a reply slip where potential participants fill in name and contact details. It is necessary for the researcher to have this information so that they can contact the participant during their involvement in the study. The researcher will assign a number to each participant and this number will be recorded on all research materials whether paper or electronic. The document linking participant names to numbers will be held securely by the researcher. Participants will be made aware that the researcher will have access to the minimum information necessary to carry out the study (which may include identifiable personal information as the study is longitudinal in nature and the researcher will need to be able to link questionnaires completed at separate time points) in the information letter and prior consent to access personal identifiable information (other than contact details) as part of
A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?
◯ Yes
A29. How and by whom will potential participants first be approached?

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will be no consequences to the participant should she choose to leave the study prematurely.

A30-1. Will you obtain informed consent from or on behalf of research participants?	
If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material).	
Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.	
If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.	
Please enclose a copy of the information sheet(s) and consent form(s).	
A30-2. Will you record informed consent (or advice from consultees) in writing?	

A31. How long will you allow potential participants to decide whether or not to take part?

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? (e.g. translation, use of interpreters)

Due to the use of empirically validated psychometric measures, which do not lend themselves to translation, persons who might not adequately understand English in written form will not be considered eligible to participate; thus, no arrangements to cater to individuals with these needs have been made.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.

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The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.

O The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.

O The participant would continue to be included in the study.

CONFIDENTIALITY

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In this section, personal data means any data relating to a participant who could potentially be identified.	It includes
pseudonymised data capable of being linked to a participant through a unique code number.	

Storage and use of personal data during the study
A36. Will you be undertaking any of the following activities at any stage (including in the identification of potentia participants)?( <i>Tick</i> as appropriate)
Access to medical records by those outside the direct healthcare team Access
to social care records by those outside the direct social care team Electronic
transfer by magnetic or optical media, email or computer networks Sharing of
personal data with other organisations
Export of personal data outside the EEA
Use of personal addresses, postcodes, faxes, emails or telephone numbers
Publication of direct quotations from respondents
Sublication of data that might allow identification of individuals Use
of audio/visual recording devices
Storage of personal data on any of the following:
Manual files (includes paper or film)
NHS computers
Social Care Service computers
Home or other personal computers
University computers

Private company computers Laptop computers

#### Further details:

Appropriate access controls on both NHS and university computers will be in place, in the form of smartcards and usernames and personal passwords, such that access is restricted only to those who need access. Further, a procedure of logging out anytime the researcher should leave the NHS or university computer for any period of time will be in place.

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A37. Please describe the physical security arrangements for storage of personal data during the study?

Porconal data collected during the study will be securally stored on a password protostad university computer.

**A38.** How will you ensure the confidentiality of personal data? Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.

In order to ensure confidentiality, pseudonymisation of data will be utilised. As per the Data Protection Act 1998, which states that data should be adequate, relevant, and not excessive, we will only be collecting the minimum amount of personal data needed to fulfil the study's purpose, and not hold more information than what is required for our purpose. As such, all identifiable information (ie. participant name) will be replaced with a unique, abstract identifier, thus allowing separate data sets to be linked to the same individual whilst retaining confidentiality.

A40. Who will have access to participants' personal data during the study? Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.

Names and contact details will be collected by the researcher in order to remain in contact with study participants.

Reference:

number.

Specifically, those who will have access to participants' personal data during the study include:

Storage and use of data after the end of the study

A41. Where will the data generated by the study be analysed and by whom?

The data concreted by the study will be analyzed on a narrow protected institution computer by the student researcher

A42. Who will have control of and act as the custodian for the data generated by the study?

 Post
 Title Forename/Initials Surname Miss
 Serpell

 Post
 Senior Lecturer

 Qualifications
 BA Psychology

 PhD Clinical Psychology
 PhD Clinical Psychology

 Post Code
 WC1E 7HB

 Work Email Work Telephone
 I.serpell@ucl.ac.uk

A43. How long will personal data be stored or accessed after the study has ended?

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Less than 3 months

3 – 6 months

6 – 12 months

A44. For how long will you store research data generated by the study?

A45. Please give details of the long term arrangements for storage of research data after the study has ended. Say where data will be stored, who will have access and the arrangements to ensure security.

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to. After the retention period is over, data will be destroyed by permanently deleting all data files pertaining to the study.

INCENTIVES AND PAYMENTS
A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?
If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined. Participants will be paid 10 pounds per hour on the basis that participation in the study will take time and effort and may include uncomfortable questions. In the first part of the study, it is expected that we will pay for 120 hours (120 participants x 1 hour each). In the second part of the study, it expected that we will pay for 116 hours total (58 participants x 2 hours each).
A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or
incentives, for taking part in this research?
A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?
○ Yes  No
NOTIFICATION OF OTHER PROFESSIONALS
A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?
If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.
A49-2. Will you seek permission from the research participants to inform their GP or other health/ care professional?
It should be made clear in the participant's information sheet if the GP/health professional will be informed.
PUBLICATION AND DISSEMINATION
A50. Will the research be registered on a public database?
OYes  ● No
Please give details, or justify if not registering the research.

The research will be not be registered on a public database as the study is not a clinical trial and no suitable register has been identified.

Reference:

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publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:
Peer reviewed scientific journals
Internal report
Conference presentation
Publication on website
Other publication

A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?

Identifiable personal data will not be used.

A53. Will you inform participants of the results?

💿 Yes 🛛 🔿 No

Please give details of how you will inform participants or justify if not doing so.

Participants interested in the findings of the study will be provided feedback on the outcome of the research to which

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? Tick as appropriate:
Independent external review
Review within a company
Review within a multi-centre research group
Review within the Chief Investigator's institution or host organisation
Review within the research team
Review by educational supervisor
Other

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports,Date: 23/01/201728216529/1064573/37/223

Reference:

together with any related correspondence.

A56. How have the temperature the second sec	ne statistical aspects of the research been reviewed? Tick as appropriate:
Review by in	dependent statistician commissioned by funder or sponsor Other
review by inc	Jependent statistician
$\checkmark$	
Review by co	ompany statistician
	statistician within the Chief Investigator's institution Review
by a statistic	ian within the research team or multi-centre group Review
by education	al supervisor
	Title Forename/Initials Surname Dr. William Mandy
	Di. William Walky
Department	Clinical, Educational and Health Psychology
Institution	UCL
Post Code	WC1E 6BT
Telephone	
Fax	
N 4 - 1- 11 -	w.mandy@ucl.ac.uk
Mohile	
Please enclose a	copy of any available comments or reports from a statistician.

A57. What is the primary outcome measure for the study?

A58. What are the secondary outcome measures? (if any)

**A59. What is the sample size for the research?** How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.

178

Total UK sample size:

Total international sample size (including UK): 178 Total in European Economic Area:

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collect data from 58 participants.

A60. How was the sample size decided upon? If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.

The sample size for the cross-sectional component of the study was determined by reviewing similar cross-sectional correlational validation studies to determine what is a reasonable sample size for such studies.

A61. Will participants be allocated to groups at random?

🔵 Yes 🛛 💿 No

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

In order to obtain the primary and secondary outcomes of this study, the data will be analysed using binary correlations and multiple regression analysis. With regards to the component of the study which aims to validate the P-CAN, internal consistency and reliability co-efficients will be calculated, and concurrent validity will be examined through correlational analysis. To explore associations among predictors and outcome variables, bivariate correlations between predictor variables and outcome measures (BMI, EDE-Q, EDQoL) will be calculated. Three separate multiple regression models will be calculated for each outcome variable with the relevant predictors (those deemed significant in the binary correlational analysis) included. Missing data will be dealt with as appropriate e.g. by withdrawing the participant's data altogether, or by imputation for minor missing data.

The reason for the choice of the study design statistical analysis plan was that similar prospective studies analysing the predictive validity of pre-treatment factors in anorexia nervosa typically utilised multiple regression analysis.

6. MANAGEMENT OF THE RESEARCH

**A63. Other key investigators/collaborators.** Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.

Post	Title Forename/Initials Surname Dr Ian Frampton
Qualifications Employer	Clinical Psychologist Cornwall Partnership NHS Foundation Trust Eating Disorders Service
Post Code Telephone Fax	Truro Health Park Infirmary Hill, Truro TR12I∆
Mohile	ianframpton@nhs.net

Date: 23/01/2017

30

17/1 0/0250

Post	Title Forename/Initials Surname Dr Natalie Kanakam	
Qualifications	Assistant Psychologist	
Employer	North East London NHS Foundation	
	The Hope Wing	
	Porters Avenue Health Centre	
Post Code	234 Porters Avenue	
Telephone Fax		
Γdλ		
Mohile		
	Title Forename/Initials Surname Carly Thornton	
Post		
Qualifications		
Employer	Cornwall Partnership NHS Foundation Trust	
	Eating Disorders Service	
	Truro Health Park	
Post Code	Infirmary Hill Truro	
Telephone		
Fax		
	carly.thornton@nhs.net	

## A64. Details of research sponsor(s)

A64-1. Sponsor		
0		
Lead Sponsor		
0		
0		
Status: ONHS or HSC care organisation	on	Other social care provider
Academic		(including voluntary sector or private organisation)
O Pharmaceutical industry		
Medical device industry		Other
Local Authority		
		If Other, please specify:
Date: 23/01/2017	31	216529/1064573/37/223

Commercial status: Non-

Commercial

**Contact person** 

IRAS F	orm
--------	-----

Reference:

17/I **೧**/೧୨5೧

Name of organisation Given name	n University College London Tabitha	
Family name	Kavoi	
Address	Joint Research Office, UCL, Gower Street	
Town/city	London	
Is the sponsor based Yes No	outside the UK?	
A65 Has external fund	ing for the research been secured?	

Funding secured from one or more funders

External funding application to one or more funders in progress

No application for external funding will be made

A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1)? Please give details of subcontractors if applicable.

🔵 Yes 💿 No

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

🔵 Yes 🛛 💿 No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

17/I 0/0250

Title Forename/Initials Mr. Sandeep	Surname Sandhu
North East London NH	S Foundation Trust
Research and Developr	
Goodmaves Hospital, I	Maggie Lilley Suite
Barley Lane, Ilford Esse	
IG3 8YB	
	Mr. Sandeep North East London NH Research and Develop Goodmayes Hospital, I

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/02/2017 Planned end date: 01/07/2019

A71-1. Is this study?

 $^{\circ}$ 

A71-2. Where will the research take place? (Tick as appropriate)	
England	
Scotland	
Wales	
Northern Ireland	

A72. Which organisations in the UK will host the research? Please indicate the type of organisation by ticking the box and give approximate numbers if known:
NHS organisations in England 2
NHS organisations in Wales
NHS organisations in Scotland
HSC organisations in Northern Ireland

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GP practices in Wales	
GP practices in Scotland	
GP practices in Northern Ireland	
<ul> <li>Joint health and social care agencies (eg</li> <li>community mental health teams)</li> <li>Local authorities</li> <li>Phase 1 trial units</li> <li>Prison establishments</li> </ul>	
Probation areas	
Independent (private or voluntarv sector)	
Total UK sites in study:	2

A73-1. Will potential participants be identified through any organisations other than the research sites listed above?

🔵 Yes 🛛 💿 No

A74. What arrangements are in place for monitoring and auditing the conduct of the research?

A76. Insurance/ indemnity to meet potential legal liabilities

<u>Note:</u> in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? *Please tick box(es) as applicable.* 

<u>Note</u>: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrengements and provide evidence.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the <u>design</u> of the research? *Please tick box(es) as applicable.* 

#### Reference:

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authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

✓

NHS indemnity scheme will apply (protocol authors with NHS contracts only) Other

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the <u>conduct</u> of the research?

<u>Note</u>: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

Please enclose a copy of relevant documents.

A78. Could the research lead to the development of a new product/process or the generation of intellectual property?

 $\bigcirc$ 

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PART C: Overview of research sites

Research site <ul> <li>NHS site</li> <li>Country: England</li> </ul>		Investigator Na Forename Middle name	ame
0			
O Country: England			
Country: England		Midule name	Lucy
		Family r Email	Serpell name <sup>l</sup> serpell@ucl.ac.uk
Organisation name	NORTH EAST LONDON NHS FOUNDATION TRUST	Country	DClinPsy PhD
Post Code	TANTALLON HOUSE GOODMAYES HOSPITAL SITE BARLEY LANE ILFORD ESSEX		
● NHS site		Forename Middle name	lan
Country: England		Email	ianframpton@nhs.net
Organisation name	CORNWALL PARTNERSHIP NHS FOUNDATION TRUST	Qualification (MD)	UNITED KINGDOM
Post Code	ST AUSTELL CORNWALL		
(	Organisation name	Organisation CORNWALL PARTNERSHIP NHS name FOUNDATION TRUST ST AUSTELL CORNWALL	Middle name         Country: England       Email         Organisation       Qualification (MD)         Organisation name       CORNWALL PARTNERSHIP NHS FOUNDATION TRUST         ST AUSTELL CORNWALL

37

17/I N/0250

## PART D: Declarations

D1. Declaration by Chief Investigator

- 1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
- 2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
- **3.** If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
- 4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
- 5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
- 6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
- 7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
- 8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
- **9**. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
  - 0
  - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS
     R&D offices (where the research requires NHS management permission) in accordance with the NHS
     Code of Practice on Records Management.

May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.

May be seen by auditors appointed to undertake accreditation of RECs (where applicable).

Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.

May be sent by email to REC members.

 $\bigcirc$ 

#### **IRAS Form**

#### Reference:

#### 17/1 0/0250

- 10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
- 11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

#### **Contact point for publication**(*Not applicable for R&D Forms*)

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

**Chief Investigator** 

17/1 0/0250

<ul> <li>Sponsor</li> <li>Study co-ordinator</li> <li>Student</li> </ul>	
Access to application	for training purposes (Not applicable for R&D Forms)
Optional – please tick as	s appropriate:
This section was signed	electronically by Lucy Serpell on 20/01/2017 11:02.
Job Title/Post:	Senior Lecturer
Organisation:	UCL
Email:	Lucy@serpell.com

#### 17/1 0/0250

#### D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

- 1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
- 2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
- **3**. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
- 4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
- 5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
- 6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

Please note: The declarations below do not form part of the application for approval above. They will not be considered by the Research Ethics Committee.

- 7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.
- 8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by Miss Tabitha Kavoi on 20/01/2017 13:22.

IRAS Form	Reference:	IRAS Version 5.4.2
	17/1 ∩/∩250	
Job Title/Post:	Research Management and Governance Manager	
Organisation:	University College London	
Email:	randd@uclh.nhs.uk	

3. Declaration for st	udent projects by academic supervisor(s)
	proved both the research proposal and this application. I am satisfied that the scientific content of actory for an educational qualification at this level.
. I undertake to fulfi ramework for Health	I the responsibilities of the supervisor for this study as set out in the Research Governance and Social Care.
Academics sonsibilits Declaration of Helsin supervisors as appro	for ensuring that this study is conducted in accordance with the ethical principles underlying the ki and good practice guidelines on the proper conduct of research, in conjunction with clinical priate.
Job Title/Post:	Senior Lecturer
. Φ <b>tare</b> i <del>setipo</del> nsibilit elevant guidelines re Email: upervisors as appro	y for ensuring that the applicant is up to date and complies with the requirements of the law and elating to security and confidentiality of patient and other personal data, in conjunction with clinical priate.
Academic supervis	or 2
Job Title/Post:	Senior Lecturer
Organisation:	UCL
organioution.	



## PARTICPANT INVITATION LETTER

Validation of the Pros and Cons of Anorexia Scale: Student Study

Dear eligible participant,

At your local clinic, we are recruiting participants for a UCL-based research project aiming to validate a psychometric scale which captures anorexia patients' attitudes towards their own illness. The research study is a student study conducted as part of a PhD. We are writing to ask you whether or not you would be interested in taking part in this research because your care team has suggested that you may be suitable.

If you decide to take part, it would involve one 1 hour session at your local clinic (arranged at your convenience, potentially before or after a therapy session already scheduled) where you would be paid 10£ an hour for your participation. You will complete a survey which includes questions about eating disorder symptoms, anorexia nervosa type, motivation to change, and attitudes towards your illness. We will also ask for some demographic information (e.g., age) so we can accurately describe the general traits of the individuals who participate in the study. Furthermore, the researcher undertaking this study will have access to the minimal clinical details necessary to complete the

study, such as your current BMI. Should you choose to withdraw from the study, this access by the researcher will be immediately revoked.

At this stage we merely want to know whether you would be interested in taking part. If you are, then we will get in touch with you and discuss things in more detail. We have also included a detailed information sheet about the project for you to read. You are under no obligation at all to take part.

Yours sincerely,

Eva Cecilie Gregertsen

eva.gregertsen.15@ucl.ac.uk

## PROS AND CONS OF ANOREXIA study reply slip

Please contact me about this project

Please do not contact me about this project

Name: \_\_\_\_\_

Telephone number: \_\_\_\_\_

Email address:

Participant Invitation Letter Study 1 version 1.0 (30.11.2016) page 2 of 2



## PARTICPANT INVITATION LETTER

## Validation of the Pros and Cons of Anorexia Scale: Student Study

Dear eligible participant,

At your local clinic, we are recruiting participants for a UCL-based research project aiming to

validate a psychometric scale which captures anorexia patients' attitudes towards their own illness. The research study is a student study conducted as part of a PhD, and will be conducted by Eva Cecilie Gregertsen from the Clinical, Educational & Health Department at UCL. I am writing to ask you whether or not you would be interested in taking part in this research because your care team has suggested that you may be suitable.

If you decide to take part, it would involve one 1 hour session at your local clinic (arranged at your convenience, potentially before or after a therapy session already scheduled) where you would be paid £10 an hour for your participation. You will complete a survey which includes questions about eating disorder symptoms, anorexia nervosa type, motivation to change, and attitudes towards your illness. We will also ask for some demographic information (e.g., age) so we can accurately describe the general traits of the individuals who participate in the study. Furthermore, the researcher undertaking this study will have access to the minimal clinical details necessary to complete the **Participant Invitation Letter North East London Site Study 1** version 2.0 (08.03.2017) page 1

of 2 216520

study, such as your current BMI. Should you choose to withdraw from the study, this access by the researcher will be immediately revoked.

At this stage we merely want to know whether you would be interested in taking part. If you are,

Participant Invitation Letter North East London Site Study 1 version 2.0 (08.03.2017) page 2 of 2 216520

then we will get in touch with you and discuss things in more detail. We have also included a detailed information sheet about the project for you to read. You are under no obligation at all to take part.

Yours sincerely,

Natalie Kanakam

Assistant psychologist at The Hope Wing, Porters Avenue Health Centre

Participant Invitation Letter North East London Site Study 1 version 2.0 (08.03.2017) page 2 of 2 216520

## PROS AND CONS OF ANOREXIA study reply slip

Please contact me about this project

Name:

Telephone number:

Email address:

Participant Invitation Letter North East London Site Study 1 version 2.0 (08.03.2017) page 3 of 2 216520



# Validation of the Pros and Cons of Anorexia Scale: Student Study Brief introduction to our study

We invite you to take part in our research study, which examines the validity of a psychometric scale measuring anorexia patients' attitudes towards their illness. The study will not involve any intervention of any kind, and is being conducted as part of a PhD thesis for a student enrolled at University College London.

Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please read this information letter carefully. You are free to decide whether or not to take part in the study, and if you choose not to participate, it will not affect the care you receive from your team.

## Why is the research being conducted?

The research is being conducted in order to validate the Pros and Cons of Anorexia Nervosa scale (P-CAN), a questionnaire-based measurement which intends to capture the attitudes individuals with anorexia hold towards their illness (e.g. the degree to which they view their illness as serving a positive function in their life as opposed to causing them harm). As such, we are recruiting patients from two outpatient clinics to participate. In particular, the study is interested in determining whether the P-CAN is associated with other relevant factors, such as motivation to change and eating disorder symptoms. Currently, only one study has been conducted examining how other relevant factors associate with scores on the P-CAN, and this study aims to provide further information on the validity of the P-CAN, in order to determine its usefulness within both a clinical and research-based context.

## What would taking part involve?

At one time point, you will complete a survey, which will take approximately 1 hour to complete. The survey includes questions about eating disorder symptoms, anorexia nervosa type, motivation to change, and attitudes towards your illness. We will also ask for some demographic information (e.g., age) so we can accurately describe the general traits of the individuals who participate in the study. Furthermore, the researcher undertaking this study will have access to the minimal clinical details necessary to complete the study, such as your current BMI. Should you choose to withdraw from the study, this access by the researcher will be immediately revoked.

Surveys will be administered at your outpatient clinic when most convenient for you. You will also be paid 10£ per hour for your participation.

## What are the possible benefits to taking part?

There are no identified possible benefits for taking part in the research. However, the study does provide wider benefits in that it validate a measurement scale which may have clinical utility, and as such, some indirect benefits might be foreseeable for participants in the form of possible improved

treatment conditions in the future.

#### What are the possible disadvantages and risks of taking part?

The possible disadvantage of taking part in the study is that you may experience some discomfort due to the nature of the questions being asked. However, participants can be assured that the nature of the questions will not be more sensitive than typical questions asked in a clinical context, and all answers will be kept completely confidential.

#### **Further supporting information**

If you at any time point wish to withdraw from the study, you may do so without having to provide any explanation as to why you wish to withdraw, and all your participant data collected prior to your withdrawal will be excluded from the analysis and destroyed. Withdrawal from the study will not have any effect on the care you receive from your clinical team.

Your information will be kept confidential by being securely stored on a password -protected university computer only accessed by the researcher, and all data collected by or information provided by you to the researcher will be kept confidential from your clinical team. However, as a a participant you should be aware that under circumstances where the researcher is led to believe that you may be in danger of harming others or yourself, the researcher is legally obligated to inform a clinician or relevant authorities.

The results of the study will be disseminated through publication in a relevant journal article. Participants who wish to learn the results of the study will be provided with a summary sheet of the research, and the thesis once fully completed can be provided should you express an interest in accessing it.

This study is self-funded by the researcher, and has been reviewed by a review panel at University College London.

Information Letter version 1.0 (23.11.2016) page 2 of 2

Your General Practitioner will be notified of your involvement in this study.

Contact details for the Chief Investigator and supervisor are provided below. Please do not hesitate to contact the Chief Investigator if you have any questions or concerns.

Chief Investigator: Dr. Lucy Serpell

University College London / Clinical, Educational & Health Psychology Department

Tel: 020 7679 1256

l.serpell@ucl.ac.uk

Student Researcher: Eva Cecilie Gregertsen

University College London / Clinical, Educational & Health Psychology Department

Tel:

eva.gregertsen.15@ucl.ac.uk



## PARTICPANT INVITATION LETTER

## Validation of the Pros and Cons of Anorexia Scale: Student Study

Dear eligible participant,

At your local clinic, we are recruiting participants for a UCL-based research project aiming to validate a psychometric scale which captures anorexia patients' attitudes towards their own illness. The research study is a student study conducted as part of a PhD, and will be conducted by Eva Cecilie Gregertsen from the Clinical, Educational & Health Department at UCL. I am writing to ask

Participant Invitation Letter North East London Site Study 1 version 2.0 (08.03.2017) page 1 of 2 216520

you whether or not you would be interested in taking part in this research because your care team has suggested that you may be suitable.

If you decide to take part, it would involve one 1 hour session at your local clinic (arranged at your convenience, potentially before or after a therapy session already scheduled) where you would be paid £10 an hour for your participation. You will complete a survey which includes questions about eating disorder symptoms, anorexia nervosa type, motivation to change, and attitudes towards your illness. We will also ask for some demographic information (e.g., age) so we can accurately describe the general traits of the individuals who participate in the study. Furthermore, the researcher undertaking this study will have access to the minimal clinical details necessary to complete the study, such as your current BMI. Should you choose to withdraw from the study, this access by the researcher will be immediately revoked.

At this stage we merely want to know whether you would be interested in taking part. If you are, then we will get in touch with you and discuss things in more detail. We have also included a

Participant Invitation Letter North East London Site Study 1 version 2.0 (08.03.2017) page 2 of 2 216520

detailed information sheet about the project for you to read. You are under no obligation at all to take part.

Yours sincerely,

Natalie Kanakam

Assistant psychologist at The Hope Wing, Porters Avenue Health Centre

Participant Invitation Letter North East London Site Study 1 version 2.0 (08.03.2017) page 2 of 2 216520

# PROS AND CONS OF ANOREXIA study reply slip

Please contact me about this project

Name:

Telephone number: \_\_\_\_\_

Email address: \_\_\_\_\_\_ Participant Invitation Letter North East London Site Study 1 version 2.0 (08.03.2017) page 3 of 2 216520



## Validation of the Pros and Cons of Anorexia Scale: Student Study Brief introduction to our study

We invite you to take part in our research study, which examines the validity of a psychometric scale measuring anorexia patients' attitudes towards their illness. The study will not involve any intervention of any kind, and is being conducted as part of a PhD thesis for a student enrolled at University College London (UCL), Eva Cecilie Gregertsen.

Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please read this information letter carefully. You are free to decide whether or not to take part in the study, and if you choose not to participate, it will not affect the care you receive from your team.

## Why is the research being conducted?

The research is being conducted in order to validate the Pros and Cons of Anorexia Nervosa scale (P-CAN), a questionnaire-based measurement which intends to capture the attitudes individuals with anorexia hold towards their illness (e.g. the degree to which they view their illness as serving a positive function in their life as opposed to causing them harm). As such, we are recruiting patients from two outpatient clinics to participate. In particular, the study is interested in determining whether the P-CAN is associated with other relevant factors, such as motivation to change and eating disorder symptoms. Currently, only one study has been conducted examining how other relevant factors associate with scores on the P-CAN, and this study aims to provide further information on the validity of the P-CAN, in order to determine its usefulness within both a clinical and research-based context.

Participant Information Sheet Study 1 version 3.0 (02.05.2017) page 1 of 4 216529

At one time point, you will complete a series of questionnaires, which will take approximately 1 hour to complete. The questionnaires include questions about eating disorder symptoms, anorexia nervosa type, motivation to change, and attitudes towards your illness. Specifically, the questionnaires administered will be the Pros and Cons of Anorexia Scale, the Eating Disorder Examination Questionnaire, the Anorexia Nervosa Stages of Change Questionnaire, the Concerns about Change Scale, and the Readiness and Motivation Questionnaire. We will also ask for some demographic information (e.g., age) so we can accurately describe the general traits of the individuals who participate in the study. **Furthermore, the researcher undertaking this study will have access to the minimal clinical details necessary to complete the study, specifically your current Body Max Index and Anorexia Nervosa subtype diagnosis.** This access will not be

given to the researcher unless you consent to it, and should you choose to withdraw from the study, this access by the researcher will be immediately revoked.

Surveys will be administered at your outpatient clinic when most convenient for you. You will also be paid  $\pm 10$  per hour for your participation.

## What are the possible benefits to taking part?

There are no identified possible benefits for taking part in the research. However, the study does provide wider benefits in that it validate a measurement scale which may have clinical utility, and as such, some indirect benefits might be foreseeable in the form of possible improved treatment conditions in the future.

## What are the possible disadvantages and risks of taking part?

The possible disadvantage of taking part in the study is that you may experience some discomfort due to the nature of the questions being asked. However, you can be assured that the nature of the questions will not be more sensitive than typical questions asked in a clinical context, and all answers will be kept completely confidential. Further, debriefing can be offered to anyone who experiences discomfort during completion of the survey.

Specifically, if you do experience any discomfort during completion of the survey, you are advised to contact the Chief Investigator, Dr. Lucy Serpell, via e-mail (<u>l.serpell@ucl.ac.uk</u>) or via telephone (020 7679 1256).

You may also wish to contact Beat, a support service which offers helplines, message boards, and online support groups. Please refer to <u>https://www.b-eat.co.uk/support-services</u> for further details.

Participant Information Sheet Study 1 version 3.0 (02.05.2017) page 2 of 4 216529

### Do I have to take part?

No, if you at any time point wish to withdraw from the study, you may do so without having to provide any explanation as to why you wish to withdraw, and all your participant data collected prior to your withdrawal will be excluded from the analysis and destroyed. Withdrawal from the study will not have any effect on the care you receive from your clinical team.

## **Expenses and payments**

You will be paid £10 hour per hour of participation. You will receive your payment in cash directly after each session after having completed the series questionnaires mentioned above.

# Will my details be kept confidential?

Your information will be kept confidential by being securely stored on a password-protected university computer only accessed by the researcher, and all data collected by or information provided by you to the researcher will be kept confidential from your clinical team. However, as a participant you should be aware that under circumstances where the researcher is led to believe that you may be in danger of harm or of harming others or yourself, the researcher is legally obligated to inform a clinician or relevant authorities.

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We will ask for your consent to notify your GP of your involvement in this study.

## Will you tell my parents about my participation in this study?

It is welcome for you to discuss your participation in this study with your parents; however, it is not mandatory, and you need only do so if you feel comfortable.

How will my data from this study be stored and used in the future?

Data collected during the study will be securely stored on a password-protected university computer in the Clinical, Educational & Health Psychology Department at UCL, accessed only by the student researcher and Chief Investigator. The personal data will be stored in a file separate to the questionnaire-related data. Data will not be maintained outside the study unit.

Data may be used for future research, in conjunction with protocols set out for ethically approved research, but any data including personally identifiable information such as your name will be destroyed upon the completion of this study.

## What will happen to the results of the study?

The results of the study will be disseminated through publication in a relevant journal article. You will not be identified in any publication. If you wish to learn the results of the study will be provided with a summary sheet of the research, and the thesis once fully completed can be provided should you express an interest in accessing it.

Participant Information Sheet Study 1 version 3.0 (02.05.2017) page 3 of 4 216529

This study is self-funded by the researcher, and has been reviewed by a review panel at University College London. The study has been organised by Eva Cecilie Gregertsen.

# Who has reviewed this study?

A review has been undertaken and a favourable Ethics opinion has been granted by Research Ethics Committee .

Contact details for the Chief Investigator and supervisor are provided below. Please do not hesitate to contact the Chief Investigator if you have any questions or concerns.

# What if there is a problem?

"What if there is a problem" or "What happens if something goes wrong?"

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your research doctor if you would like more information on this.

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Alternatively you can contact Somerset Partnership NHS Foundation Trust Patient, Advice and Liaison team on 01278 432022 or email <u>pals@sompar.nhs.uk</u>

In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to the Chief Investigator, Dr. Lucy Serpell, who is the Chief Investigator for the research and is based at the Clinical, Educational & Health Psychology Department at UCL. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

# **Further supporting information**

If you at any time point wish to withdraw from the study, you may do so without having to provide any explanation as to why you wish to withdraw. All identifiable data collected from you will be destroyed; however, data which is not identifiable to the research team may be retained. Withdrawal from the study will not have any effect on the care you receive from your clinical team.

Your information will be kept confidential by being securely stored on a password-protected university computer only accessed by the researcher, and all data collected by or information provided by you to the researcher will be kept confidential from your clinical team. However, as a participant you should be aware that under circumstances where the researcher is led to believe that you may be in danger of harming others or yourself, the researcher is legally obligated to inform a clinician or relevant authorities.

Participant Information Sheet Study 1 version 3.0 (02.05.2017) page 4 of 4 216529

The results of the study will be disseminated through publication in a relevant journal article. If you wish to learn the results of the study will be provided with a summary sheet of the research, and the thesis once fully completed can be provided should you express an interest in accessing it.

# **Contact details**

Chief Investigator: Dr. Lucy Serpell

University College London / Clinical, Educational & Health Psychology Department Tel: 020 7679 1256

l.serpell@ucl.ac.uk

Student Researcher: Eva Cecilie Gregertsen

University College London / Clinical, Educational & Health Psychology Department

Tel:

eva.gregertsen.15@ucl.ac.uk

Local collaborator/research staff details:

Dr. Jasmin Langdon-Daly

Participant Information Sheet Study 1 version 3.0 (02.05.2017) page 5 of 4 216529

# CAMHS Community Eating Disorder Service

jasmin.daly.13@ucl.ac.uk

Participant Information Sheet Study 1 version 3.0 (02.05.2017) page 5 of 4 216529



## Validation of the Pros and Cons of Anorexia Scale: Student Study Brief introduction to our study

We invite you to take part in our research study, which examines the validity of a psychometric scale measuring anorexia patients' attitudes towards their illness. The study will not involve any intervention of any kind, and is being conducted as part of a PhD thesis for a student enrolled at University College London (UCL), Eva Cecilie Gregertsen.

Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please read this information letter carefully. You are free to decide whether or not to take part in the study, and if you choose not to participate, it will not affect the care you receive from your team.

# Why is the research being conducted?

The research is being conducted in order to validate the Pros and Cons of Anorexia Nervosa scale (P-CAN), a questionnaire-based measurement which intends to capture the attitudes individuals with anorexia hold towards their illness (e.g. the degree to which they view their illness as serving a positive function in their life as opposed to causing them harm). As such, we are recruiting patients from two outpatient clinics to participate. In particular, the study is interested in determining whether the P-CAN is associated with other relevant factors, such as motivation to change and eating disorder symptoms. Currently, only one study has been conducted examining how other relevant factors associate with scores on the P-CAN, and this study aims to provide further information on the validity of the P-CAN, in order to determine its usefulness within both a clinical and research-based context.

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# What would taking part involve?

At one time point, you will complete a series of questionnaires, which will take approximately 1 hour to complete. The questionnaires include questions about eating disorder symptoms, anorexia nervosa type, motivation to change, and attitudes towards your illness. Specifically, the questionnaires administered will be the Pros and Cons of Anorexia Scale, the Eating Disorder Examination Questionnaire, the Anorexia Nervosa Stages of Change Questionnaire, the Concerns about Change Scale, and the Readiness and Motivation Questionnaire. We will also ask for some demographic information (e.g., age) so we can accurately describe the general traits of the individuals who participate in the study. **Furthermore, the researcher undertaking this study will have access to the minimal clinical details necessary to complete the study, specifically your current Body Max Index and Anorexia Nervosa subtype diagnosis.** This access will not be

given to the researcher unless you consent to it, and should you choose to withdraw from the study, this access by the researcher will be immediately revoked.

Surveys will be administered at your outpatient clinic when most convenient for you. You will also be paid  $\pm 10$  per hour for your participation.

## What are the possible benefits to taking part?

There are no identified possible benefits for taking part in the research. However, the study does provide wider benefits in that it validate a measurement scale which may have clinical utility, and as such, some indirect benefits might be foreseeable in the form of possible improved treatment conditions in the future.

## What are the possible disadvantages and risks of taking part?

The possible disadvantage of taking part in the study is that you may experience some discomfort due to the nature of the questions being asked. However, you can be assured that the nature of the questions will not be more sensitive than typical questions asked in a clinical context, and all answers will be kept completely confidential. Further, debriefing can be offered to anyone who experiences discomfort during completion of the survey.

Specifically, if you do experience any discomfort during completion of the survey, you are advised to contact the Chief Investigator, Dr. Lucy Serpell, via e-mail (<u>l.serpell@ucl.ac.uk</u>) or via telephone (020 7679 1256).

You may also wish to contact Beat, a support service which offers helplines, message boards, and online support groups. Please refer to <u>https://www.b-eat.co.uk/support-services</u> for further details.

Participant Information Sheet Study 1 version 3.0 (02.05.2017) page 2 of 4 216529

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## **Expenses and payments**

You will be paid £10 hour per hour of participation. You will receive your payment in cash directly after each session after having completed the series questionnaires mentioned above.

# Will my details be kept confidential?

Your information will be kept confidential by being securely stored on a password-protected university computer only accessed by the researcher, and all data collected by or information provided by you to the researcher will be kept confidential from your clinical team. However, as a participant you should be aware that under circumstances where the researcher is led to believe that you may be in danger of harm or of harming others or yourself, the researcher is legally obligated to inform a clinician or relevant authorities.

Participant Information Sheet Study 1 version 3.0 (02.05.2017) page 3 of 4 216529

We will ask for your consent to notify your GP of your involvement in this study.

## Will you tell my parents about my participation in this study?

It is welcome for you to discuss your participation in this study with your parents; however, it is not mandatory, and you need only do so if you feel comfortable.

How will my data from this study be stored and used in the future?

Data collected during the study will be securely stored on a password-protected university computer in the Clinical, Educational & Health Psychology Department at UCL, accessed only by the student researcher and Chief Investigator. The personal data will be stored in a file separate to the questionnaire-related data. Data will not be maintained outside the study unit.

Data may be used for future research, in conjunction with protocols set out for ethically approved research, but any data including personally identifiable information such as your name will be destroyed upon the completion of this study.

## What will happen to the results of the study?

The results of the study will be disseminated through publication in a relevant journal article. You will not be identified in any publication. If you wish to learn the results of the study will be provided with a summary sheet of the research, and the thesis once fully completed can be provided should you express an interest in accessing it.

Participant Information Sheet Study 1 version 3.0 (02.05.2017) page 3 of 4 216529

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If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your research doctor if you would like more information on this.

Participant Information Sheet Study 1 version 3.0 (02.05.2017) page 4 of 4 216529

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## **Further supporting information**

If you at any time point wish to withdraw from the study, you may do so without having to provide any explanation as to why you wish to withdraw. All identifiable data collected from you will be destroyed; however, data which is not identifiable to the research team may be retained. Withdrawal from the study will not have any effect on the care you receive from your clinical team.

Your information will be kept confidential by being securely stored on a password-protected university computer only accessed by the researcher, and all data collected by or information provided by you to the researcher will be kept confidential from your clinical team. However, as a participant you should be aware that under circumstances where the researcher is led to believe that you may be in danger of harming others or yourself, the researcher is legally obligated to inform a clinician or relevant authorities.

Participant Information Sheet Study 1 version 3.0 (02.05.2017) page 4 of 4 216529

The results of the study will be disseminated through publication in a relevant journal article. If you wish to learn the results of the study will be provided with a summary sheet of the research, and the thesis once fully completed can be provided should you express an interest in accessing it.

# **Contact details**

Chief Investigator: Dr. Lucy Serpell

University College London / Clinical, Educational & Health Psychology Department Tel: 020 7679 1256

l.serpell@ucl.ac.uk

Student Researcher: Eva Cecilie Gregertsen

University College London / Clinical, Educational & Health Psychology Department

Tel:

eva.gregertsen.15@ucl.ac.uk

Local collaborator/research staff details:

Dr. Jasmin Langdon-Daly

Participant Information Sheet Study 1 version 3.0 (02.05.2017) page 5 of 4 216529

# CAMHS Community Eating Disorder Service

jasmin.daly.13@ucl.ac.uk

Participant Information Sheet Study 1 version 3.0 (02.05.2017) page 5 of 4 216529



Centre Number:

Study Number:

Participant Identification Number for this trial:

## **CONSENT FORM**

Title of Project: Validation of the Pros and Cons of Anorexia Scale Name

of Researcher: Eva Cecilie Gregertsen

Please initial box

- 3. 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.

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.

4. I agree to my General Practitioner being informed of my participation in the study.

5. I agree to take part in the above study.		
Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.

Version 1 (08.13.2016)



# PARTICPANT INVITATION LETTER

Validation of the Pros and Cons of Anorexia Scale: Student Study

Dear eligible participant,

At your local clinic, we are recruiting participants for a UCL-based research project aiming to examine how different factors may relate to treatment outcome in anorexia nervosa outptients. The research study is a student study conducted as part of a PhD. We are writing to ask you whether or not you would be interested in taking part in this research because your care team has suggested that you may be suitable.

If you decide to take part, it would involve two 1 hour sessions (once around admission to your outpatient clinic and once 6 months post-treatment) at your local clinic where you would be paid 10£ per hour for your participation. You will complete a survey which includes questions about eating disorder symptoms, anorexia nervosa type, motivation to change, autism character traits, and attitudes towards your illness. We will also ask for some demographic information (e.g., age) so we can accurately describe the general traits of the individuals who participate in the study.

Furthermore, the researcher undertaking this study will have access to the minimal clinical details necessary to complete the study, such as your BMI pre- and post-treatment. Should you choose to withdraw from the study, this access by the researcher will be immediately revoked.

At this stage we merely want to know whether you would be interested in taking part. If you are, then we will get in touch with you and discuss things in more detail. We have also included a detailed information sheet about the project for you to read. You are under no obligation at all to take part.

Yours sincerely,

Eva Cecilie Gregertsen

eva.gregertsen.15@ucl.ac.uk

# PROS AND CONS OF ANOREXIA study reply slip

Please contact me about this project

Please do not contact me about this project

Name: \_\_\_\_\_

Telephone number: \_\_\_\_\_

Email address:

Participant Invitation Letter Study 2 version 1.0 (30.11.2016) page 2 of 2



# Predictors of Treatment Outcome in Anorexia Nervosa: Student Study Brief introduction to our study

We invite you to take part in our research study, examining how different factors may relate to treatment outcome in anorexia nervosa outpatients. The study will not involve any intervention of any kind, and is being conducted as part of a PhD thesis for a student enrolled at University College London.

Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please read this information letter carefully. You are free to decide whether or not to take part in the study, and if you choose not to participate, it will not affect the care you receive from your team.

# Why is the research being conducted?

The research is being conducted to foster a better understanding of which specific patient factors may impede or facilitate a successful outcome in anorexia nervosa patients undergoing treatment, and as such, we are recruiting patients from two outpatient clinics to participate. In particular, the study is interested in whether a patient's attitudes towards their illness (e.g. the degree to which they view their illness as serving a positive function in their life as opposed to causing them harm) can be linked to how well they respond to their treatment. Currently, there is a poor understanding of which variables predict successfulness in treatment in the eating disorder literature, and this study aims to provide greater clarity on this topic, which we in turn hope can provide useful information that may inform and improve upon treatment models for anorexia nervosa patients in the future.

# What would taking part involve?

At two different time points (once after admission to your outpatient clinic and once post- treatment), you will complete a survey, which will take approximately 1 hour to complete. The survey includes questions about eating disorder symptoms, anorexia nervosa type, motivation to change, autism character traits, and attitudes towards your illness. We will also ask for some demographic information (e.g., age) so we can accurately describe the general traits of the individuals who participate in the study. Furthermore, the researcher undertaking this study will have access to the minimal clinical details necessary to complete the study, such as your BMI pre- and post-treatment. Should you choose to withdraw from the study, this access by the researcher will be immediately revoked.

Surveys will be administered at your outpatient clinic when most convenient for you. You will also be paid 10£ per hour for your participation.

# What are the possible benefits to taking part?

There are no identified possible benefits for taking part in the research. However, the study does provide wider benefits in that it aims to inform and improve upon treatment for anorexia nervosa and as such, some indirect benefits might be foreseeable for participants in the form of possible

improved treatment conditions in the future.

### What are the possible disadvantages and risks of taking part?

The possible disadvantage of taking part in the study is that you may experience some discomfort due to the nature of the questions being asked. However, participants can be assured that the nature of the questions will not be more sensitive than typical questions asked in a clinical context, and all answers will be kept completely confidential.

## **Further supporting information**

If you at any time point wish to withdraw from the study, you may do so without having to provide any explanation as to why you wish to withdraw, and all your participant data collected prior to your withdrawal will be excluded from the analysis and destroyed. Withdrawal from the study will not have any effect on the care you receive from your clinical team.

Your information will be kept confidential by being securely stored on a password-protected university computer only accessed by the researcher, and all data collected by or information provided by you to the researcher will be kept confidential from your clinical team. However, as a participant you should be aware that under circumstances where the researcher is led to believe that you may be in danger of harming others or yourself, the researcher is legally obligated to inform a clinician or relevant authorities.

The results of the study will be disseminated through publication in a relevant journal article. Participants who wish to learn the results of the study will be provided with a summary sheet of the research, and the thesis once fully completed can be provided should you express an interest in accessing it.

This study is self-funded by the researcher, and has been reviewed by a review panel at University College London.

Information Letter Study 2 version 1.0 (23.11.2016) page 2 of 2

Your General Practitioner will be notified of your involvement in this study.

Contact details for the Chief Investigator and supervisor are provided below. Please do not hesitate to contact the Chief Investigator if you have any questions or concerns.

Chief Investigator: Dr. Lucy Serpell

University College London / Clinical, Educational & Health Psychology Department Tel: 020 7679 1256

l.serpell@ucl.ac.uk

Student Researcher: Eva Cecilie Gregertsen

University College London / Clinical, Educational & Health Psychology Department Tel: 07494455102

eva.gregertsen.15@ucl.ac.uk



# Predictors of Treatment Outcome in Anorexia Nervosa: Student Study Brief introduction to our study

We invite you to take part in our research study, examining how different factors may relate to treatment outcome in anorexia nervosa outpatients. The study will not involve any intervention of any kind, and is being conducted as part of a PhD thesis for a student enrolled at University College London (UCL), Eva Cecilie Gregertsen.

Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please read this information letter carefully. You are free to decide whether or not to take part in the study, and if you choose not to participate, it will not affect the care you receive from your team.

## Why is the research being conducted?

The research is being conducted to foster a better understanding of which specific patient factors may impede or facilitate a successful outcome in anorexia nervosa patients undergoing treatment, and as such, we are recruiting patients from two outpatient clinics to participate. In particular, the study is interested in whether a patient's attitudes towards their illness (e.g. the degree to which they view their illness as serving a positive function in their life as opposed to causing them harm) can be linked to how well they respond to their treatment. Currently, there is a poor understanding of which variables predict successfulness in treatment in the eating disorder literature, and this study aims to provide greater clarity on this topic, which we in turn hope can provide useful information that may inform and improve upon treatment models for anorexia nervosa patients in the future.

Participant Information Sheet Study 2 version 2.0 (08.03.2017) page 1 of 4 216529

## What would taking part involve?

At two different time points (once after admission to your outpatient clinic and once post- treatment), you will complete a series of questionnaires, which will take approximately 1 hour to complete. The questionnaires include questions about eating disorder symptoms, anorexia nervosa type, motivation to change, autism character traits, and attitudes towards your illness. Specifically, the questionnaires administered will be the Eating Disorder Examination Questionnaire, the Anorexia Nervosa Stages of Change Questionnaire, the Pros and Cons of Anorexia Scale, and the Broader Autism Phenotype Questionnaire. We will also ask for some demographic information (e.g., age) so we can accurately describe the general traits of the individuals who participate in the study. Furthermore, the researcher undertaking this study will have access to the minimal clinical details necessary to complete the study, including your Body Mass Index pre- and post-treatment, illness duration, and scores on eating disorder symptom questionnaires administered by care staff at admission and 6 months follow-up. This access will not be given to the researcher unless you

consent to it, and should you choose to withdraw from the study, this access by the researcher will be immediately revoked.

Surveys will be administered at your outpatient clinic when most convenient for you. You will also be paid  $\pm 10$  per hour for your participation.

## What are the possible benefits to taking part?

There are no identified possible benefits for taking part in the research. However, the study does provide wider benefits in that it aims to inform and improve upon treatment for anorexia nervosa and as such, some indirect benefits might be foreseeable in the form of possible improved treatment conditions in the future.

## What are the possible disadvantages and risks of taking part?

The possible disadvantage of taking part in the study is that you may experience some discomfort due to the nature of the questions being asked. However, you can be assured that the nature of the questions will not be more sensitive than typical questions asked in a clinical context, and all answers will be kept completely confidential. Further, debriefing can be offered to anyone who experiences discomfort during completion of the survey.

Specifically, if you do experience any discomfort during completion of the survey, you are advised to contact the Chief Investigator, Dr. Lucy Serpell, via e-mail (<u>l.serpell@ucl.ac.uk</u>) or via telephone (020 7679 1256).

You may also wish to contact Beat, a support service which offers helplines, message boards, and online support groups. Please refer to <u>https://www.b-eat.co.uk/support-services</u> for further details.

Participant Information Sheet Study 2 version 2.0 (08.03.2017) page 2 of 4 216529

### Do I have to take part?

No, if you at any time point wish to withdraw from the study, you may do so without having to provide any explanation as to why you wish to withdraw, and all your participant data collected prior to your withdrawal will be excluded from the analysis and destroyed. Withdrawal from the study will not have any effect on the care you receive from your clinical team.

## **Expenses and payments**

You will be paid £10 hour per hour of participation. You will receive your payment in cash directly after each session after having completed the series questionnaires mentioned above.

# Will my details be kept confidential?

Your information will be kept confidential by being securely stored on a password-protected university computer only accessed by the researcher, and all data collected by or information provided by you to the researcher will be kept confidential from your clinical team. However, as a participant you should be aware that under circumstances where the researcher is led to believe that you may be in danger of harm or of harming others or yourself, the researcher is legally obligated to inform a clinician or relevant authorities.

Participant Information Sheet Study 2 version 2.0 (08.03.2017) page 3 of 4 216529

We will ask for your consent to notify your GP of your involvement in this study.

## Will you tell my parents about my participation in this study?

It is welcome for you to discuss your participation in this study with your parents; however, it is not mandatory, and you need only do so if you feel comfortable.

How will my data from this study be stored and used in the future?

Data collected during the study will be securely stored on a password-protected university computer in the Clinical, Educational & Health Psychology Department at UCL, accessed only by the student researcher and Chief Investigator. The personal data will be stored in a file separate to the questionnaire-related data. Data will not be maintained outside the study unit.

Data may be used for future research, in conjunction with protocols set out for ethically approved research, but any data including personally identifiable information such as your name will be destroyed upon the completion of this study.

## What will happen to the results of the study?

The results of the study will be disseminated through publication in a relevant journal article. You will not be identified in any publication. If you wish to learn the results of the study will be provided with a summary sheet of the research, and the thesis once fully completed can be provided should you express an interest in accessing it.

Participant Information Sheet Study 2 version 2.0 (08.03.2017) page 3 of 4 216529

This study is self-funded by the researcher, and has been reviewed by a review panel at University College London. The study has been organised by Eva Cecilie Gregertsen.

# Who has reviewed this study?

A review has been undertaken and a favourable Ethics opinion has been granted by Research Ethics Committee. Contact details for the Chief Investigator and supervisor are provided below. Please do not hesitate to contact the Chief Investigator if you have any questions or concerns.

# What if there is a problem?

# "What if there is a problem" or "What happens if something goes wrong?"

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your research doctor if you would like more information on this.

In the unlikely event that you are harmed by taking part in this study, compensation may be available.

Participant Information Sheet Study 2 version 2.0 (08.03.2017) page 4 of 4 216529

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to the Chief Investigator, Dr. Lucy Serpell, who is the Chief Investigator for the research and is based at the Clinical, Educational & Health Psychology Department at UCL. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

# **Further supporting information**

If you at any time point wish to withdraw from the study, you may do so without having to provide any explanation as to why you wish to withdraw. All identifiable data collected from you will be destroyed; however, data which is not identifiable to the research team may be retained. Withdrawal from the study will not have any effect on the care you receive from your clinical team.

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University College London / Clinical, Educational & Health Psychology Department Tel: 020 7679 1256

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Student Researcher: Eva Cecilie Gregertsen

University College London / Clinical, Educational & Health Psychology Department

Tel:

Participant Information Sheet Study 2 version 2.0 (08.03.2017) page 5 of 4 216529

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# Predictors of Treatment Outcome in Anorexia Nervosa: Student Study Brief introduction to our study

We invite you to take part in our research study, examining how different factors may relate to treatment outcome in anorexia nervosa outpatients. The study will not involve any intervention of any kind, and is being conducted as part of a PhD thesis for a student enrolled at University College London (UCL), Eva Cecilie Gregertsen.

Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please read this information letter carefully. You are free to decide whether or not to take part in the study, and if you choose not to participate, it will not affect the care you receive from your team.

#### Why is the research being conducted?

The research is being conducted to foster a better understanding of which specific patient factors may impede or facilitate a successful outcome in anorexia nervosa patients undergoing treatment, and as such, we are recruiting patients from two outpatient clinics to participate. In particular, the study is interested in whether a patient's attitudes towards their illness (e.g. the degree to which they view their illness as serving a positive function in their life as opposed to causing them harm) can be linked to how well they respond to their treatment. Currently, there is a poor understanding of which variables predict successfulness in treatment in the eating disorder literature, and this study aims to provide greater clarity on this topic, which we in turn hope can provide useful information that may inform and improve upon treatment models for anorexia nervosa patients in the future.

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At two different time points (once after admission to your outpatient clinic and once post- treatment), you will complete a series of questionnaires, which will take approximately **30 minutes each** to complete. The questionnaires include questions about eating disorder symptoms, anorexia nervosa type, motivation to change, autism character traits, and attitudes towards your illness.

Specifically, the questionnaires administered will be the Eating Disorder Examination Questionnaire, the Anorexia Nervosa Stages of Change Questionnaire, the Pros and Cons of Anorexia Scale, and the Broader Autism Phenotype Questionnaire. We will also ask for some demographic information (e.g., age) so we can accurately describe the general traits of the individuals who participate in the study. Furthermore, the researcher undertaking this study will

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have access to the minimal clinical details necessary to complete the study, including your Body Mass Index pre- and post-treatment, illness duration, and scores on eating disorder symptom questionnaires administered by care staff at admission and 6 months follow-up. This access will not be given to the researcher unless you consent to it, and should you choose to withdraw from the study, this access by the researcher will be immediately revoked.

Surveys may be completed at your local clinic, at home, or online via a weblink sent to your e- mail. You will also be paid £10 per session of participation.

## What are the possible benefits to taking part?

There are no identified possible benefits for taking part in the research. However, the study does provide wider benefits in that it aims to inform and improve upon treatment for anorexia nervosa and as such, some indirect benefits might be foreseeable in the form of possible improved treatment conditions in the future.

## What are the possible disadvantages and risks of taking part?

The possible disadvantage of taking part in the study is that you may experience some discomfort due to the nature of the questions being asked. However, you can be assured that the nature of the questions will not be more sensitive than typical questions asked in a clinical context, and all answers will be kept completely confidential. Further, debriefing can be offered to anyone who experiences discomfort during completion of the survey.

Specifically, if you do experience any discomfort during completion of the survey, you are advised to contact the Chief Investigator, Dr. Lucy Serpell, via e-mail (<u>l.serpell@ucl.ac.uk</u>) or via telephone (020 7679 1256).

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You may also wish to contact Beat, a support service which offers helplines, message boards, and online support groups. Please refer to <u>https://www.b-eat.co.uk/support-services</u> for further details.

#### Do I have to take part?

No, if you at any time point wish to withdraw from the study, you may do so without having to provide any explanation as to why you wish to withdraw, and all your participant data collected prior to your withdrawal will be excluded from the analysis and destroyed. Withdrawal from the study will not have any effect on the care you receive from your clinical team.

#### **Expenses and payments**

You will be paid £10 hour per hour of participation. You will receive your payment in cash directly after each session after having completed the series questionnaires mentioned above.

## Will my details be kept confidential?

Your information will be kept confidential by being securely stored on a password-protected

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university computer only accessed by the researcher, and all data collected by or information provided by you to the researcher will be kept confidential from your clinical team. However, as a participant you should be aware that under circumstances where the researcher is led to believe that you may be in danger of harm or of harming others or yourself, the researcher is legally obligated to inform a clinician or relevant authorities.

## Will you tell my GP about my participation in this study?

We will ask for your consent to notify your GP of your involvement in this study.

## Will you tell my parents about my participation in this study?

It is welcome for you to discuss your participation in this study with your parents; however, it is not mandatory, and you need only do so if you feel comfortable.

## How will my data from this study be stored and used in the future?

Data collected during the study will be securely stored on a password-protected university computer in the Clinical, Educational & Health Psychology Department at UCL, accessed only by the student researcher and Chief Investigator. The personal data will be stored in a file separate to the questionnaire-related data. Data will not be maintained outside the study unit.

Data may be used for future research, in conjunction with protocols set out for ethically approved research, but any data including personally identifiable information such as your name will be destroyed upon the completion of this study.

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#### What will happen to the results of the study?

The results of the study will be disseminated through publication in a relevant journal article. You will not be identified in any publication. If you wish to learn the results of the study will be provided with a summary sheet of the research, and the thesis once fully completed can be provided should you express an interest in accessing it.

### Who is organising and funding this study?

This study is self-funded by the researcher, and has been reviewed by a review panel at University College London. The study has been organised by Eva Cecilie Gregertsen.

## Who has reviewed this study?

A review has been undertaken and a favourable Ethics opinion has been granted by Research Ethics Committee. Contact details for the Chief Investigator and supervisor are provided below. Please do not hesitate to contact the Chief Investigator if you have any questions or concerns.

## What if there is a problem?

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#### "What if there is a problem" or "What happens if something goes wrong?"

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask your research doctor if you would like more information on this.

In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to the Chief Investigator, Dr. Lucy Serpell, who is the Chief Investigator for the research and is based at the Clinical, Educational & Health Psychology Department at UCL. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

#### **Further supporting information**

If you at any time point wish to withdraw from the study, you may do so without having to provide any explanation as to why you wish to withdraw. All identifiable data collected from you will be destroyed; however, data which is not identifiable to the research team may be retained. Withdrawal from the study will not have any effect on the care you receive from your clinical team.

Withdrawal from the study will not have any effect on the care you receive from your clinical team.

Your information will be kept confidential by being securely stored on a password-protected university computer only accessed by the researcher, and all data collected by or information provided by you to the researcher will be kept confidential from your clinical team. However, as a a **Participant Information Sheet Study 2** version 3.0 (21.08.2017) page 4 of 4 **216529** 

participant you should be aware that under circumstances where the researcher is led to believe that you may be in danger of harming others or yourself, the researcher is legally obligated to inform a clinician or relevant authorities.

The results of the study will be disseminated through publication in a relevant journal article. If you wish to learn the results of the study will be provided with a summary sheet of the research, and the thesis once fully completed can be provided should you express an interest in accessing it.

This study is self-funded by the researcher, and has been reviewed by a review panel at University College London.

Your General Practitioner will be notified of your involvement in this study.

Contact details for the Chief Investigator and supervisor are provided below. Please do not hesitate to contact the Chief Investigator if you have any questions or concerns.

Chief Investigator: Dr. Lucy Serpell

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Centre Number:

Study Number:

Participant Identification Number for this trial:

## **CONSENT FORM**

Title of Project: Predictors of Treatment Outcome in Anorexia Nervosa - Student Study

Name of Researcher: Eva Cecilie Gregertsen

Please initial box

1.	I confirm that I have read the information sheet dated (version) 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 the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.
- 4. I agree to my General Practitioner being informed of my participation in the study.
- 5. I agree to take part in the above study.

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.



Centre Number:

Study Number:

Participant Identification Number for this trial:

## **CONSENT FORM**

Title of Project: Predictors of Treatment Outcome in Anorexia Nervosa - Student Study

Name of Researcher: Eva Cecilie Gregertsen Name of Participant Date

Signature

Name of Person taking consent

Date

Signature

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.

#### Please initial box

- I confirm that I have read the information sheet dated 30.01.2017 (version 2.0) 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.
- 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... The

future studies will be REC approved.

- 4. I agree to my General Practitioner being informed of my participation in the study.
- 5. I agree to take part in the above study.

Name of Participant

Signature

Name of Person

Date

Signature taking consent