

**EXPERIENCES OF USING PRO-EATING  
DISORDER WEBSITES: A QUALITATIVE  
STUDY WITH SERVICE USERS IN NHS  
EATING DISORDER SERVICES**

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## ABSTRACT

There is a growing professional concern regarding the existence of pro eating disorder (pro-ED) websites. Previous research investigating the impact of pro-ED websites has comprised analyses of website content and experimental exposure of mock pro-ED content with participants from non-clinical populations. The few studies involving the assessment of pro-ED website use in individuals with eating disorders have predominantly used online survey methodology. The findings from these studies suggest that pro-ED websites may have a detrimental impact on emotional and physical wellbeing. The present study sought to explore the function and impact of pro-ED websites in a clinical sample of individuals in treatment for an eating disorder. Participants were recruited through tier two community mental health teams and tier three specialist eating disorder services within two NHS Health Boards in South Wales. Individual face to face interviews were conducted with seven adult females receiving treatment for an eating disorder who had disclosed historic or current use of pro-ED websites. Constructivist Grounded Theory was used to analyse the data. Five key themes were identified within the interview transcripts: fear, cognitive dissonance, social comparisons, shame, and pro-ED website maintaining eating disordered behaviour. Pro-ED websites were often used to reduce a sense of social isolation, fuelled by stigma and shame associated with the eating disorder and use of pro-ED websites. Individuals experienced cognitive dissonance regarding their use of pro-ED websites, and the websites were often used to protect themselves from pressures to recover. The pro-ED websites appeared to offer a sense of support, validation and reassurance, whilst simultaneously reinforcing and maintaining eating disordered behaviour. Websites were often used to motivate food restriction, and were at times used as a method of punishment when individuals experienced self-criticism. The findings are discussed in relation to implications for eating disorder treatment services and recommendations for future research are outlined.

# CONTENTS

<b>CHAPTER ONE: INTRODUCTION .....</b>	<b>1</b>
1.1 OVERVIEW .....	1
1.2 OVERVIEW OF EATING DISORDERS .....	1
1.2.1 Defining eating disorders .....	1
1.2.2 Estimated prevalence .....	3
1.2.3 Impact of eating disorders .....	4
1.2.4 Factors implicated in the cause of eating disorders .....	4
1.3 MODELS OF EATING DISORDERS .....	5
1.3.1 Cognitive behavioural model of eating disorders .....	5
1.3.2 Social comparison theory .....	7
1.4 TREATMENT OF EATING DISORDERS .....	8
1.4.1 Cognitive Behavioural Therapy (CBT) .....	9
1.4.2 Interpersonal Psychotherapy (IPT) .....	9
1.4.3 Prognosis in treatment .....	9
1.5 PRO EATING DISORDER WEBSITES .....	10
1.5.1 Public use of generic websites .....	10
1.5.2 Pro eating disorder (pro-ED) websites .....	10
1.5.3 Analyses of pro-ED website content .....	11
1.5.4 Tips, tricks and ‘thinspiration’ .....	12
1.5.5 Personification of the eating disorder .....	13
1.6 THE IMPACT OF PRO-ED WEBSITES .....	13
1.6.1 Research into the impact of pro-ED websites .....	13
1.6.2 Literature reviews .....	14
1.6.3 Professional and Government responses to pro-ED websites .....	15

1.7 CONCLUSIONS.....	16
1.8 SYSTEMATIC REVIEW .....	17
1.8.1 Aims.....	17
1.8.2 Search methodology.....	17
1.8.3 Study criteria.....	18
1.8.4 Results and quality framework .....	19
1.9 SYNTHESIS OF STUDIES .....	38
1.9.1 Reasons for use of pro-ED websites .....	38
1.9.2 Possible dangers of using pro-ED websites .....	39
1.9.3 Perceived benefits of using pro-ED websites .....	41
1.9.4 Different approaches to pro-ED website use .....	43
1.9.5 Ambivalence .....	44
1.9.6 Conclusions.....	45
1.10 METHODOLOGICAL ISSUES.....	45
1.10.1 Sample sizes.....	45
1.10.2 Potential for biased responses .....	46
1.10.3 Correlational designs .....	46
1.10.4 Limited qualitative data .....	47
1.11 STUDY AIMS .....	47
<b>CHAPTER TWO: METHODOLOGY .....</b>	<b>49</b>
2.1 OVERVIEW .....	49
2.2 DESIGN.....	49
2.2.1 A qualitative design .....	49
2.2.2 Qualitative philosophical underpinnings .....	50
2.3 GROUNDED THEORY .....	51
2.3.1 Constructivist Grounded Theory.....	51

2.3.2 Rationale for using Grounded Theory .....	52
2.4 ENSURING QUALITY.....	53
2.4.1. Publishability Guidelines .....	53
2.4.2 Quality within GT .....	55
2.5 REFLEXIVITY.....	56
2.5.1 Self-reflexivity .....	56
2.6 PARTICIPANTS .....	58
2.6.1 Recruitment context .....	58
2.6.2 Inclusion and exclusion criteria .....	58
2.6.3 Recruitment procedure.....	59
2.6.4 Sample size .....	59
2.7 DATA COLLECTION .....	60
2.7.1 Development of a semi-structured interview .....	60
2.7.2 Procedure .....	60
2.7.3 Transcription .....	61
2.7.4 Participant demographics.....	61
2.8 DATA ANALYSIS.....	62
2.8.1 Coding.....	62
2.8.2 Constant comparative analysis.....	63
2.8.3 Memo writing.....	63
2.8.4 Theoretical sampling.....	64
2.9 CLINICAL GOVERNANCE AND ETHICAL CONSIDERATIONS .....	64
2.9.1 Consent .....	64
2.9.2 Risk .....	65
2.9.3 Conflict of Interest .....	65

<b>CHAPTER THREE: RESULTS .....</b>	<b>66</b>
3.1 OVERVIEW .....	66
3.2 THEME ONE: FEAR .....	68
3.3 THEME TWO: COGNITIVE DISSONANCE .....	73
3.4 THEME THREE: SOCIAL COMPARISONS .....	83
3.5 THEME FOUR: SHAME .....	89
3.6 THEME FIVE: WEBSITES MAINTAINING ED .....	93
3.7 ADDITIONAL FINDINGS .....	100
3.8 SUMMARY OF FINDINGS .....	101
 <b>CHAPTER FOUR: DISCUSSION .....</b>	 <b>103</b>
4.1 OVERVIEW .....	103
4.2 RESEARCH FINDINGS AND THE RELEVANT LITERATURE .....	103
4.2.1 Theme one: FEAR .....	104
4.2.2 Theme two: COGNITIVE DISSONANCE .....	107
4.2.3 Theme three: SOCIAL COMPARISONS .....	111
4.2.4 Theme four: SHAME .....	114
4.2.5 Theme five: PRO-ED WEBSITES MAINTAINING ED .....	117
4.2.6 Additional findings .....	119
4.3 IMPLICATIONS FOR CLINICAL PRACTICE AND SERVICE DELIVERY .....	120
4.3.1 Awareness and assessment of pro-ED website use .....	120
4.3.2 Empathic and non-judgemental approaches within therapy .....	121
4.3.3 Assessing readiness for change and recovery .....	122
4.3.4 Constraints of pro-recovery websites .....	123
4.4 STRENGTHS AND LIMITATIONS OF THE PRESENT STUDY .....	123
4.4.1 Strengths of the research .....	123
4.4.2 Limitations of the research .....	124

4.5 RECOMMENDATIONS FOR FUTURE RESEARCH.....	125
4.6 CONCLUSIONS.....	127

<b>REFERENCES.....</b>	<b>129</b>
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## LIST OF TABLES

Table number	Title	Page number
Table 1	Diagnostic criteria of anorexia nervosa and bulimia nervosa (ICD-10 and DSM-5)	2
Table 2	Summary of studies used for Systematic Review	21-27
Table 3	SURE Quality Framework, cross sectional/correlational studies	28-34
Table 4	Ethical considerations of cross sectional/correlational studies	34
Table 5	SURE Quality Framework, qualitative studies	35-37
Table 6	Participant demographics	62

## LIST OF FIGURES

Figure number	Title	Page number
Figure 1	Transdiagnostic model of eating disorders	6
Figure 2	Constructivist Grounded Theory Model of the function of pro-ED websites	67
Figure 3	Process of using pro-ED websites to reduce cognitive dissonance to protect eating disorder	82
Figure 4	Process of pro-ED websites influencing shame and social isolation	92
Figure 5	The role of pro-ED websites in maintaining eating disorder behaviour	99



## LIST OF APPENDICES

<b>Appendix</b>	<b>Title</b>
Appendix A	Systematic Review Search Results
Appendix B	Research and Development Approval Documentation
Appendix C	Clinician Information Sheet
Appendix D	Participant Information Sheet
Appendix E	Consent to be Contact Form
Appendix F	Initial Interview Schedule
Appendix G	Participant Consent Form
Appendix H	Debriefing Information Sheet
Appendix I	Excerpts of Reflective Journal and Example Memo
Appendix J	Interview Schedule Adaptations
Appendix K	NISCHR Ethical Approval Documentation
Appendix L	Letter to Care Co-ordinator
Appendix M	Summary of Themes

## CHAPTER ONE: INTRODUCTION

### 1.1 OVERVIEW

This chapter aims to outline definitions of various eating disorders and to provide estimates of prevalence and prognosis rates. Psychological models of eating disorders will be presented, including cognitive behavioural perspectives and social comparison models of eating-related difficulties.

The concept of pro eating disorder (pro-ED) websites will be described, and existing research examining the potential impact of pro-ED websites will be presented. A systematic review of existing research related to the function, and impact of pro-ED websites in clinical eating disorder populations will be undertaken. Finally, the rationale and aims of the present study will be presented.

### 1.2 OVERVIEW OF EATING DISORDERS

#### **1.2.1 Defining eating disorders**

Various definitions of eating disorders have been proposed, including those by the American Psychiatric Association (APA) within the Diagnostic and Statistical Manual 5th revision (DSM-5, 2013) and the World Health Organisation (WHO), International Classification of Diseases-10<sup>th</sup> edition (ICD-10, 1992). Both include an abnormal attitude towards eating which leads an individual to change eating habits and behaviour; however, descriptive labels may differ across diagnostic tools. Diagnostic criteria from ICD-10 and DSM-5 are outlined in table one below.

	ICD-10 (WHO)	DSM-5 (APA)
Anorexia nervosa	<p>A. Weight loss, or in children a lack of weight gain, leading to a body weight of at least 15% below the normal or expected weight for age and height.</p> <p>B. The weight loss is self-induced by avoidance of "fattening foods".</p> <p>C. A self-perception of being too fat, with an intrusive dread of fatness, which leads to a self-imposed low weight threshold.</p> <p>D. A widespread endocrine disorder involving the hypothalamic-pituitary-gonadal axis, manifest in the female as amenorrhoea, and in the male as a loss of sexual interest and potency.</p> <p>E. Does not meet criteria A and B of Bulimia nervosa.</p>	<p>Persistent restriction of energy intake leading to significantly low body weight (in context of what is minimally expected for age, sex, developmental trajectory, and physical health).</p> <p>Either an intense fear of gaining weight or of becoming fat, or persistent behaviour that interferes with weight gain (even though significantly low weight).</p> <p>Disturbance in the way one's body weight or shape is experienced, undue influence of body shape and weight on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.</p> <p>Restricting type Binge-eating/purging type</p>
Bulimia nervosa	<p>A. Recurrent episodes of overeating (at least two times per week over a period of three months) in which large amounts of food are consumed in short periods of time.</p> <p>B. Persistent preoccupation with eating and a strong desire or a sense of compulsion to eat (craving).</p> <p>C. The patient attempts to counteract the fattening effects of food by one or more of the following: (1) self-induced vomiting; (2) self-induced purging; (3) alternating periods of starvation; (4) use of drugs such as appetite suppressants, thyroid preparations or diuretics.</p> <p>D. A self-perception of being too fat, with an intrusive dread of fatness (usually leading to underweight).</p>	<p>Recurrent episodes of binge eating, characterised by both of the following:</p> <ul style="list-style-type: none"> <li>• Eating, in a discrete period of time (e.g. within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances.</li> <li>• A sense of lack of control over eating during the episode (e.g. a feeling that one cannot stop eating or control what or how much one is eating).</li> </ul> <p>Recurrent inappropriate compensatory behaviour in order to prevent weight gain, such as self-induced vomiting, misuse of laxatives, diuretics, or other medications, fasting, or excessive exercise.</p> <p>The binge eating and inappropriate compensatory behaviours both occur, on average, at least once a week for three months.</p> <p>Self-evaluation is unduly influenced by body shape and weight. The disturbance does not occur exclusively during episodes of Anorexia Nervosa.</p>

Table 1. Diagnostic criteria of anorexia nervosa and bulimia nervosa (ICD-10 and DSM-5).

Within Europe, ICD-10 criteria are often used in the diagnosis of eating disorders, as reflected in NHS treatment guidance (National Institute for Health and Care Excellence, NICE, 2004). There is some disparity between ICD-10 and DSM-5 diagnoses in regards to compensatory behaviours involved in BN. The DSM-5 distinguishes between purging type BN (self-induced vomiting or laxative misuse) and non-purging type (fasting or excessive exercise). Conversely, the ICD-10 does not make this distinction and all individuals with bingeing and compensatory behaviours may fulfil criteria of BN.

Individuals with other eating related difficulties who do not fulfil criteria for AN or BN may be diagnosed with atypical eating disorder (ICD-10) or Eating Disorder Not Otherwise Specified (EDNOS, DSM-5). For example, a person's weight may remain just above the threshold for AN, or an individual may binge less frequently than specified for BN. Whilst full diagnostic criteria may not be met, the treatment needs of individuals with such diagnoses may be identical to those with a full diagnosis of AN or BN (NICE, 2004).

### **1.2.2 Estimated prevalence**

Eating disorders can occur at any age but most commonly develop during adolescence. Incidence rates from 12 cumulative studies within Western cultures estimated AN to occur in 19 per 100,000 per year in females and two per 100,000 per year in males (Pawluck & Gorey, 1998). BN is estimated to be up to five times more common than anorexia, and atypical eating disorders are more widespread still (NICE, 2004). Whilst eating disorders were traditionally thought to be confined to Western cultures, there is increasing evidence of eating disorders in a range of societies, including Asian cultures, although information regarding specific incidence rates is limited (NICE, 2004).

According to the Health and Social Care Information Centre, 2,560 individuals were admitted to hospital in England for an eating disorder between 2012 and 2013 (Health and Social Care Information Centre, HSCIC, 2014). The most recent figures demonstrated an increase of 8% from 2011 to 2012, when 2,370 hospital admissions were recorded. Hospital admissions were nine times more common for females than males, and whilst one in five individuals were discharged on the same day as admission, one in 17 remained in hospital for longer than six months (HSCIC, 2014).

### **1.2.3 Impact of eating disorders**

Whilst acute physical complications of eating disorders such as low weight are often alarming and are at times fatal, individuals often experience comorbid psychological and longer term physical complications. Such concerns include depression, anxiety, alcoholism, cardio-vascular problems, fertility problems and osteoporosis (Fairburn & Brownell, 2001). Mortality rates related to eating disorders, including suicide, are estimated to range from 5% to over 8% (Polivy & Herman, 2002) and are the highest of any mental health difficulty (Birmingham et al., 2005). Such long term psychological and social consequences may have a profound impact on the individual's relationships, employment and parenting prospects (NICE, 2004), and highlight the personal and financial cost of eating disorders to both the individual and the NHS.

### **1.2.4 Factors implicated in the cause of eating disorders**

It is beyond the scope of this chapter to provide a detailed account of the research on the causes of eating disorders; however the key findings from a systematic review and other robust sources will be outlined.

Common risk factors for eating disordered behaviour identified from longitudinal and cross-sectional studies include gender (females), early childhood eating and gastrointestinal problems, raised concern over weight and shape, negative self-evaluation, genetic factors, perfectionism, and adverse experiences including sexual abuse (Polivy & Herman, 2002; Jacobi et al., 2004). Familial 'faddy' eating habits and unwarranted concern regarding weight have been documented in family members of individuals with eating disorders; such family anxieties may increase an adolescent's risk of developing an eating disorder (Gowers & Shore, 2001).

In a meta-analytic review of both experimental and prospective studies, limited empirical support and contradictory findings were evident for some 'widely accepted' risk factors of eating disordered behaviour, such as sexual abuse and dieting (Stice, 2002). Consistent support emerged for the role of factors such as a thin-ideal internalisation, body dissatisfaction, negative affect and perceived pressure to be thin in the development and maintenance of eating disorders. However, the predictive power of mediating and moderating variables was limited (Stice, 2002).

Methodological limitations of studies included in the review were raised, such as short term follow up periods of prospective studies, divergences in the type and quality of outcome measures, and differences in sample demographics (Stice, 2002). A call was made for further experimental research in to the aetiology of eating disorders (Stice, 2002; Polivy & Herman, 2002); nonetheless, a decade after such a bid, the complex issue of the causes of eating disorders appears to remain poorly understood:

*“Unfortunately, research has not advanced to the point where we know what factors cause an individual to develop an eating disorder”* (Keel et al., 2012, p.390).

### 1.3 MODELS OF EATING DISORDERS

Various theoretical models of eating disorders have been developed, utilising feminist theory, personal construct theory, developmental perspectives and models of self-esteem. Two theories of eating disorders, cognitive behavioural and social comparison are outlined in detail below. Cognitive behavioural theory has been selected as it underpins cognitive behavioural therapy (CBT) for eating disorders, arguably one of the most well researched, well established and effective treatments for eating disorders in Western cultures (Fairburn et al., 2009). Social comparison theory will be described as the author recognises personal preconceptions regarding the importance of social comparisons in eating disorders, and the subsequent role that pro-ED websites are suspected to play in terms of exacerbating such comparisons. Therefore, social comparison theory may hold relevance when considering the function and impact of pro-ED websites.

#### 1.3.1 Cognitive behavioural model of eating disorders

Originating in the 1980's, Fairburn applied principles of learning theory and cognitive theory to understand bulimia nervosa. The work of Fairburn and colleagues over many years has led to a well-developed cognitive-behavioural model of eating disorders which has informed research and practice in the UK. Fairburn (2008) argues that such discrete DSM or ICD eating disorder diagnoses are arbitrary as the majority of individuals with a recognised eating disorder migrate between diagnoses (Fairburn & Harrison, 2003). They propose a transdiagnostic model in which the presentation of anorexia nervosa, bulimia nervosa and atypical eating disorders are expressed through similar attitudes and maladaptive behaviours.

Within this model it is suggested that eating disorders are essentially ‘cognitive disorders’ whereby an individual over-evaluates the importance of shape and weight in terms of their self-worth, and minimises the value of other factors contributing to self-worth, such as work and relationships (Fairburn, 2008).

It is proposed that individuals become preoccupied with their body shape and weight, which results in continual checking of the body. The individual focuses on dissatisfied areas, which leads to body image denigration whereby the individual believes they look fat and repulsive. Self-critical comparisons with others are argued to maintain such low self-esteem and over-concern regarding weight and body shape. Individuals subsequently attempt to limit food intake through adherence to strict and rigid dietary rules (anorexia presentation). However, many individuals are unable to adhere to such strict restrictive eating regimes and therefore may subsequently binge on large amounts of food. Misconceptions regarding the effects of purging behaviour, such as vomiting or use of laxatives as a means of counteracting the impact of binges reinforce such methods (bulimia presentation).

The transdiagnostic model, outlined below in figure one, also highlights the importance of core low self-esteem, interpersonal life factors, and perfectionism as maintaining factors within an eating disorder.

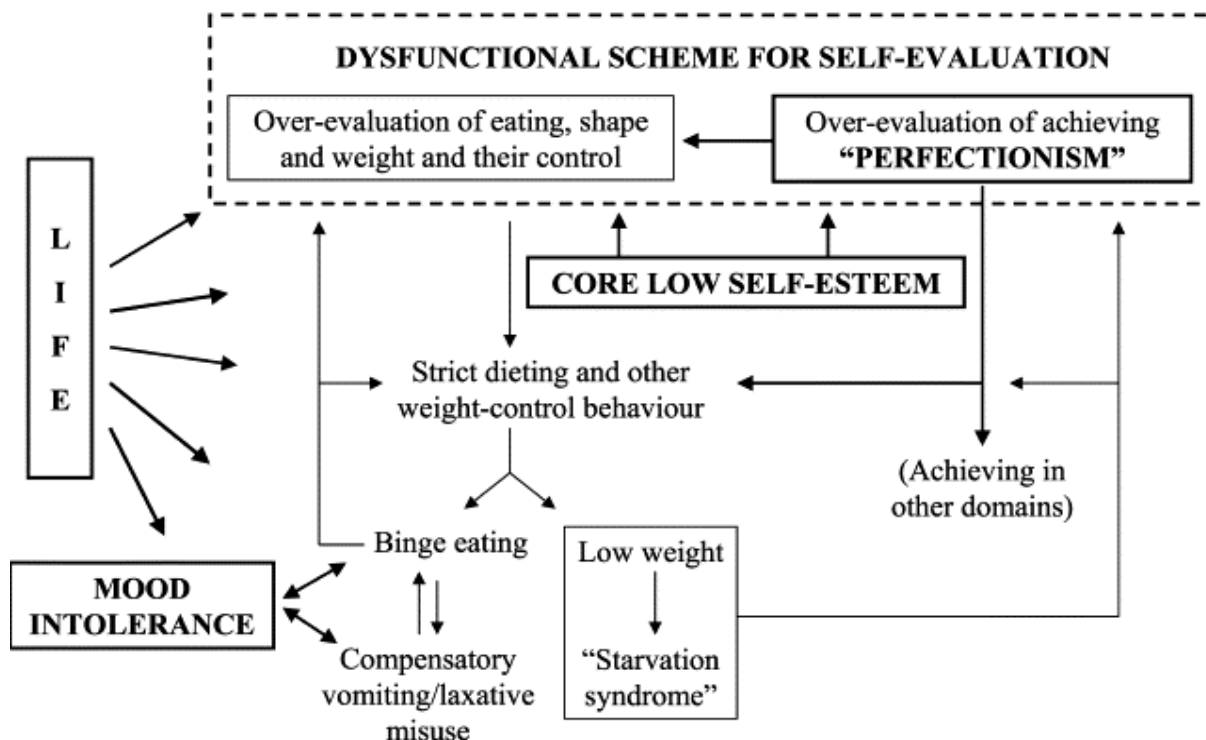


Figure 1. Transdiagnostic model of eating disorders, Fairburn et al., (2003).

### **1.3.2 Social comparison theory**

According to socio-cultural theory, body dissatisfaction and the potential for subsequent eating disordered behaviour is associated with society's unrealistic beauty ideals emphasised by mass media (Thompson, Coover & Stomer, 1999). A body of evidence exists supporting the role of media-exposure to images of extremely thin models and internalisation of idealised images (for example, Stice et al., 1994; Heinberg & Thompson, 1995; Groesz, Levine, & Murnen, 2002).

Social comparison theory (Festinger, 1954, as cited in Bamford & Halliwell, 2009) has been applied to explain how socio-cultural pressure may impact on eating related difficulties, notably focusing on the impact on females rather than males. It is proposed that individuals who choose inappropriate targets for self-comparisons (i.e. idealised 'thin' images) and engage in more frequent comparisons with such targets, have increased vulnerability to socio-cultural appearance pressure (Wood, 1996). Whilst virtually all individuals are exposed to such images within the mass media, it is noted that not all individuals go on to develop disordered eating. Particular vulnerability factors are reported to be poorly understood (Thompson et al., 1999).

Further investigation into moderating and mediating factors appears to have highlighted the potential role of attachment in social comparisons (Bamford & Halliwell, 2009). Within a non-clinical sample, attachment style, social comparisons and eating difficulties were assessed through self-report measures. In individuals who scored more highly on attachment anxiety; (i.e. those who are motivated to engage in close relationships with a tendency to idealise others whilst devaluing themselves), it was found that social comparisons mediated the relationship between attachment anxiety and disordered eating (Bamford & Halliwell, 2009). In contrast to those scoring highly on attachment anxiety, the association was not supported for participants who scored highly on attachment avoidance, (i.e. those who aim to deactivate attachment needs and avoid others).

Findings suggest that attachment may drive social comparisons between the self and culturally idealised 'thin' others. Individuals with high attachment anxiety have a tendency to devalue themselves and idealise others, which may enhance their vulnerability to making social comparisons of a socially constructed 'thin ideal' (Bamford & Halliwell, 2009). This



may be accounted for by increased hyper-vigilance, whereby individuals with high attachment anxiety ‘scan’ their environment for perceived social threats. Such hyper-vigilance may lead to attention biases whereby individuals selectively attend to idealised others. This in turn may fuel body dissatisfaction and subsequent eating difficulties (Bamford & Halliwell, 2009). Authors claim that by reducing social comparisons in individuals who are highly anxious about relationships, eating disordered behaviour may subsequently diminish (Bamford & Halliwell, 2009).

Whilst findings appear intuitive, participants were recruited from a non-clinical sample and potential confounding variables such as depression, anxiety and self-esteem were not controlled for. Conclusions regarding causation cannot be drawn; therefore, future longitudinal research is required to form more robust theories regarding the role of attachment and social comparisons in the development of eating disorders.

## 1.4 TREATMENT OF EATING DISORDERS

NHS guidance on the treatment of eating disorders (NICE, 2004) promotes psychological approaches as the treatment of choice for all diagnostic categories of eating disorder. The guidance highlights the role of patient, and potentially carer preference when deciding on psychological treatment pathways. It is specified that psychological treatment should aim to reduce risk, encourage weight gain and healthy eating, reduce other symptoms related to the eating disorder, and facilitate psychological and physical recovery (NICE, 2004). It should be highlighted that current NICE treatment guidance makes no reference to the existence of, or impact of pro-ED websites. A surveillance review of the guidance was published in December 2013 which recommended a full update of eating disorder treatment guidance (NICE Centre for Clinical Practice, Surveillance Programme, 2013).

Current treatment guidance promotes evidence based self-help approaches as an initial treatment option for BN. Therapeutic interventions such as cognitive behavioural therapy (CBT), interpersonal psychotherapy (IPT) or alternative treatments such as family therapies are recommended as secondary treatment options (NICE, 2004). The guidance recommends that most individuals with AN should be managed on an outpatient basis within services competent in the assessment and management of physical risks involved in AN. Where inpatient re-feeding is required, treatment should be delivered alongside psycho-social

interventions. It is highlighted that there is very limited evidence for the use of pharmacological treatment for AN, whereas anti-depressants, namely Fluoxetine, may be used to reduce symptoms in individuals with BN (NICE, 2004).

#### **1.4.1 Cognitive Behavioural Therapy (CBT)**

Cognitive Behavioural Therapy for eating disorders (CBT-Bulimia Nervosa CBT-BN, Fairburn, 1981; CBT-Enhanced, Fairburn 2008) is based on the cognitive behavioural model of eating disorders presented above. NHS treatment guidance suggests that individuals should be offered between 16 and 20 individual sessions of CBT over a period of four to five months (NICE, 2004).

CBT for eating disorders aims to modify maladaptive beliefs and behaviours that perpetuate the cycle of eating disordered attitudes and behaviour. Treatment comprises both behavioural and cognitive components. Interventions include the monitoring of food intake with the aim of establishing normal eating patterns, setting behavioural experiments to overcome anxiety provoking situations, and cognitive restructuring through challenging rigid unhelpful thoughts regarding perfectionism, self-criticism and rumination about appearance.

#### **1.4.2 Interpersonal Psychotherapy (IPT)**

Originally developed as a treatment for depression (Klerman et al., 1984, cited in NICE, 2004), IPT aims to support individuals to identify and address interpersonal problems. It has since been developed for use with individuals with eating disorders, for example IPT:BN. NICE guidance (2004) highlights that IPT may be presented as an alternative to CBT, however, individuals should be made aware that comparable treatment effects may take up to seven months longer than CBT.

#### **1.4.3 Prognosis in treatment**

Qualitative research has highlighted that individuals often experience ambivalence regarding recovery due to the ego-syntonic and functional nature of eating disorders (Williams & Reid, 2010). Individuals often do not view their behaviour as problematic, resulting in high rates of resistance to treatment for eating disorders (Cooper, 2005). It has been estimated that approximately one third of individuals receiving treatment for an eating disorder will

continue to meet diagnostic criteria five years after initially commencing treatment (Polivy & Herman, 2002). There has been little research into self-cure or recovery from an eating disorder in individuals who do not access formal treatment (Polivy & Herman, 2002).

Few studies have investigated variables associated with prognosis in treatment. A longitudinal study of 60 adolescents receiving treatment for eating disorders found no predictors of treatment duration (Steinhausen, Seidel & Winkler-Metzke, 2000). Whilst the mortality rate at the 11 year follow up was 8.3%, a trend for recovery was observed; 80% of surviving participants had recovered at the 11 year follow up. Participants spent an average of 17% of the 11 year study period in treatment, highlighting the long term nature of eating disorder treatment (Steinhausen et al., 2000).

## 1.5 PRO EATING DISORDER WEBSITES

### 1.5.1 Public use of generic websites

Internet accessibility has increased greatly over recent years; 83% of British households (21 million) were reported to have Internet access in 2013 (Office for National Statistics, ONS, 2013). Moreover, 36 million adults (73%) in Great Britain accessed the Internet daily in 2013; 20 million greater than in 2006 when comparable records began (ONS, 2013).

A distinction has been made between website ‘surfers’ and ‘searchers’. It is noted that when seeking information online individuals are likely to either ‘surf’ websites using website navigation tools, or ‘search’ websites using search engines (Hudson, 2012). The search engine Google accounted for 84% of Internet searches in 2012 and is increasingly becoming the standard point of entry to website pages, potentially rendering Internet navigation skills obsolete (Hudson, 2012). Consequently, search engines such as Google provide timely and direct Internet access for individuals with low confidence in website navigation.

### 1.5.2 Pro eating disorder (pro-ED) websites

There is huge variation in the content and design of websites providing information on and discussing eating disorders for the general population. Some are designed by professional organisations such as the NHS, and charities such as *Beating eating disorders* (B-eat) and the mental health charity, MIND. Others, termed pro anorexia, pro bulimia, or pro eating disorder

(pro-ED) websites appear to promote an attitude that eating disorders are a ‘lifestyle choice’, taking a positive view of the eating disorder, in clear contrast to the view of it as a ‘medical illness’ which needs ‘curing’.

From a review of the literature, many of the published studies into the use and effects of pro-ED websites have utilised content analyses of websites and forums, and experimental designs using non-clinical participants. This work will be outlined to provide background for the systematic review which focuses on evidence from work with clinical populations.

### **1.5.3 Analyses of pro-ED website content**

Discourse analyses, which explore how the use of language constructs social meaning within texts, and content analyses have been conducted on pro-ED websites, forums and message boards. In a review of five ‘pro-ED websites’, using discourse analysis it was found that whilst four paid *‘lip service’* to the notion that eating disorders are bad, the pro-ED content, *“undeniably validates the anorexic ‘lifestyle’ and provides the tools to allow people to continue it and to hide it from their family and friends”* (Lipczynska, 2007, p.546).

The remaining website, named *Pro-Ana Nation* appeared to offer a more balanced position regarding eating disorders. The website acknowledged some benefits of eating disorders, such as pride, but also explicitly stated the severe medical consequences, and provided no information on how to engage in eating disorder behaviour (Lipczynska, 2007). This highlights that whilst websites may superficially appear to be ‘pro-ED’ or ‘pro-recovery’, a deeper analysis of website content is required prior to establishing a website’s intentions and ethos.

In a widely cited content analysis of 180 active pro-ED websites, 91% were publicly available and 79% included interactive features (Borzekowski et al., 2010). It was found that 84% of the pro-ED websites reviewed contained pro anorexia content, with 64% promoting pro bulimia information. In 83% of reviewed sites, overt suggestions on how to engage in eating-disordered related behaviours were present; nonetheless, 38% included pro recovery information or links (Borzekowski et al., 2010).

In 2012 the blog hosting service Tumblr reported that websites and blogs promoting self-harm behaviour, such as pro-ED blogs would be banned from the site (Ryan, 2012).

However, the tenacity of pro-ED website administrators was noted as new websites and blogs with pro-ED content were quickly set up under the pretence of non pro-ED websites (Ryan, 2012).

#### **1.5.4 Tips, tricks and ‘thinspiration’**

Many websites contain ‘tips and tricks’ sections to maintain an eating disorder. The excerpts below are taken from the analysis of nine pro-ED websites (Harshbarger et al., 2009, pp.368-369):

- *Pick one food for the day like an apple. Cut it into eight slices. Eat two slices at breakfast, two at lunch, two at dinner, and you will have two left for a snack! This way your body thinks it is eating four times that day, but in reality you have only had one apple.*
- *When you get the urge to eat, rinse your mouth with strong mouthwash, or brush your teeth. Food would not taste that great so why eat it?*

The analysis also revealed that 11% of comments on the websites related to deception methods to conceal an eating disorder from family, friends and health professionals:

- *Leave dirty dishes around the house (example: pour a little milk in a bowl and put some pieces of cereal in it and say you ate it) people will think you were eating.*
- *Wear nail polish to hide the discolouring in your nails from lack of nutrients.*

The authors highlight that whilst some of the tips were perceived as aggressive and damaging, most were benevolent when taken in isolation. It is argued that the combination of restriction and deception tricks and tips which promote extreme weight loss are detrimental to health (Harshbarger et al., 2009).

Websites have also been shown to include ‘thinspiration’ pages which aim to promote and sustain motivation to restrict food through ‘inspirational’ quotes and photos of emaciated

bodies (Norris et al., 2006) as well as “Thin Commandments” such as *‘Thou shall not eat without feeling guilty’* (Borzekowski et al., 2010).

### **1.5.5 Personification of the eating disorder**

Some individuals appear to personify their anorexia, referring to it as ‘her’ and using the name ‘Ana’ (Williams & Reid, 2007; Gailey, 2009). In a grounded theory analysis of pro-ED message boards it was demonstrated that individuals tend to express ambivalence towards the pro anorexia paradigm (Williams & Reid, 2007). When individuals feel in control of anorexia they view ‘Ana’ as their friend, however, when they do not feel in control of anorexia, ‘Ana’ is their enemy.

Furthermore, through analysis of message boards, a distinction between ‘Ana’ and ‘anorexia’ was observed, whereby ‘Ana’ conceptualises anorexia as a lifestyle choice and ‘anorexia’ is understood in terms of a mental illness (Mulveen & Hepworth, 2006). The authors note that Ana rejects anorexia as a mental illness, a process which appears to empower members to maintain their lifestyle.

## **1.6 THE IMPACT OF PRO-ED WEBSITES**

### **1.6.1 Research into the impact of pro-ED websites**

Experimental studies using non-clinical samples, such as college students have demonstrated that exposure to both mock and real pro-ED websites in comparison to neutral sites may impact adversely on various measures including affect, appearance self-efficacy, self-esteem, perfectionism, drive for thinness, and perceived attractiveness (Theis et al., 2012; Juarez, Soto & Pritchard, 2012; Jett, LaPorte & Wanchisn, 2010; Bardone-Cone & Cass, 2007; Bardone-Cone & Cass, 2006).

In a study of 13 to 17 year old school children, 12.6% of girls and 5.9% of boys reported having visited pro-ED websites (Custers & Van den Bulck, 2009). It appears that the websites may attract vulnerable young people; the girls who had visited the websites reported greater perfectionism, a higher drive for thinness and body image difficulties. Such factors enhance the risk of individuals developing an eating disorder, and it is argued that the additional influence of pro-ED websites may further increase this risk (Custers & Van den Bulck, 2009).

Questionnaire based studies with individuals demonstrating eating disordered behaviour have shown that viewership of pro-ED websites and forums is associated with mental stress (Eichenberg, Flumann & Hensges, 2011); dysregulated eating patterns (Ransom, La Guardia, Woody & Boyd, 2010); greater length of hospital stay and a less favourable prognosis (Talbot, 2010).

In contrast, qualitative analyses of pro-ED website posts suggested that individuals sought the anonymity of the websites as an outlet for their experiences due to fear of stigmatisation, forced treatment or hospitalisation as a result of their eating disordered thoughts and behaviour (Gailey, 2009). The author argued that ‘outrage’ against pro-ED websites should be redirected away from website creators and users. Instead, cultural messages regarding preoccupation with thinness and beauty should be held accountable for eating disorders. It is proposed that treatment services should focus on enhancing empathy, dignity and respect towards such individuals, as opposed to exacerbating suffering through forced feeding practices (Gailey, 2009).

### **1.6.2 Literature reviews**

In a review of seven studies examining the effects of viewing pro-ED websites within the general population, Talbot (2010) proposed that such websites may increase eating disorder related behaviours but may not cause it. Moreover, a systematic review of 26 peer reviewed articles regarding risks of pro-ED websites highlighted three major themes relating to risks of pro-ED websites use. Such websites were found to operate under the pretext of support; they appeared to reinforce disordered eating behaviour and acted as a barrier to recovery (Rouleau & von Ranson, 2011).

Findings in the review suggested that whilst pro-ED websites may be perceived to be supportive by users, the websites essentially appear to exacerbate eating difficulties (Rouleau & von Ranson, 2011). The review authors suggest that further research is required to explore how pro-ED websites may contribute to the development and maintenance of eating disordered behaviour. Therefore, further research is required to understand if and how exposure to pro-ED websites impacts on the causal pathways of eating disordered behaviour.

### **1.6.3 Professional and Government responses to pro-ED websites**

#### *1.6.3.1 Risks of pro-ED websites*

A review paper titled '*Virtually anorexic: Where's the harm?*' conducted at University Campus Suffolk, in partnership with charities B-eat and Childnet International (Bond, 2012), highlights potential risks of pro-ED websites. Identified risks include heightened perfection seeking and the normalisation of dangerous eating practices and extremely underweight body images. It is noted that competition between users appears to encourage harmful behaviours. The websites are argued to fuel isolation from friends and family, which subsequently prevents individuals from seeking recovery. A paradoxical relationship between negative online content and positive online support is also highlighted; such ambiguity appears to prevent individuals from seeking recovery (Bond, 2012).

Similarly, in a Position Paper written by the Royal College of Psychiatrists (RCP) in collaboration with B-eat, the dangers of pro-ED websites are explicitly highlighted (RCP, 2009). The paper draws on existing evidence that pro-ED websites attract individuals with eating disorders as well as vulnerable young people at risk of developing eating disorders. Harmful effects of such usage are noted, such as the amplification of weight and shape concerns and high risk weight loss behaviours.

#### *1.6.3.2 Recommendations*

Recommendations from the papers include an extension of the UK Government's efforts to enhance child Internet safety to incorporate the risks of pro-ED websites (RCP, 2009; Bond, 2012). The UK Council for Child Internet Safety was launched in response to the Byron Review on '*Safer Children in a digital World*', published by the Department for Children, Schools and Families, and the Department for Culture, Media and Sport in 2008 (Byron Review, 2008). It is proposed that any strategy for Internet safety should explicitly recognise the dangers of pro-ED websites, incorporating an independently monitored Code of Practice for Internet providers (RCP, 2009).

Enhanced education and awareness training for young people, health professionals, teachers and families regarding the early signs of eating disorders, the risks of pro-ED websites and Internet safety is recommended (RCP, 2009; Bond, 2012). The papers also argue that making pro-ED websites illegal may criminalise vulnerable people, as websites are likely to be set up



by individuals with an eating disorder (RCP, 2009; Bond, 2012). Influences of general media are noted; the media is encouraged to ‘de-sensationalise’ pro-ED content by not reporting pro-ED websites as headline news, and not reporting how to access the sites (RCP, 2009; Brown, 2012).

Finally, it is acknowledged that individuals with an eating disorder often feel isolated or ashamed, and that the Internet is an accessible and powerful means of gaining support (RCP, 2009; Bond, 2012). Individuals are encouraged to use ‘reputable sources of information and support, such as that provided by B-eat’ (RCP, 2009). Whilst the papers raise the risks of pro-ED websites, recommendations are focused on support targeted towards young people who may be vulnerable to developing an eating disorder. Less attention is paid towards adults in the midst of an eating disorder who currently use pro-ED websites.

## 1.7 CONCLUSIONS

The relationship between pro-ED websites and pathological eating related attitudes and behaviours is complex and merits further investigation. Through experimental research and analyses of website content, it appears that pro-ED websites may have a negative impact on the viewer. However, potential benefits of using pro-ED websites have also been recorded (Gailey, 2009). Whilst analyses of website content and non-clinical experimental research are useful in understanding the impact of pro-ED websites, such methods do not allow conclusions to be drawn about the experiences of individuals who use such pro-ED websites.

The most recent systematic reviews of pro-ED websites were undertaken nearly four years ago and included research based on non-clinical samples (Talbot, 2010) and covert analyses of website content (Rouleau & von Ranson, 2011). The following systematic review will focus specifically on research which explores the opinions of pro-ED website users within a clinical eating disorder population.

## 1.8 SYSTEMATIC REVIEW

### 1.8.1 Aims

The present study aims to explore the functions of, and impact of pro-ED websites on a clinical population of individuals in receipt of treatment for an eating disorder. Therefore, a systematic review has been undertaken to explore the findings and quality of existing research on individuals' experiences of pro-ED websites using participants from a clinical population. The systematic review aims to assess motivations for using the websites, the functions that websites may fulfil and the potential impact of using the websites.

### 1.8.2 Search methodology

An initial screening of titles and abstracts against inclusion criteria outlined below was undertaken in order to identify potentially relevant papers. Relevant papers were identified and full texts of papers were sought. No publication cut-off date was applied.

The Web of Knowledge database was searched on 15<sup>th</sup> and 16<sup>th</sup> August 2013. The database includes the following sources: Web of Science (1900 to present), Citation Index (1926 – present), Current Contents Connect (1998 – present), Derwent Innovations Index (1963 – present), Chinese Science Citation Database (1989 – present), Data Citation Index (1900 – present), and MEDLINE (1950 – present).

The PsycINFO database was searched on 23rd August 2013. The database includes the following sources: Cardiff University Books@Ovid, Cardiff University Full Text Journals, AMED (Allied and Complementary Medicine), EMBASE 1947-Present, HMIC Health Management Information Consortium, ICONDA 1976 to July 2013, Ovid MEDLINE(R) 1946 to August Week 2 2013, Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations August 21, 2013, PsycINFO 1806 to August Week 2 2013, PsycArticles Full Text, and the Joanna Briggs Institute EBP Database.

The Cochrane Library was searched on 23rd August 2013. Academic journals specifically related to eating disorder research, namely the International Journal of Eating Disorders and

European Eating Disorders Review were also searched. A search of 'grey literature' through Google and Google Scholar was also undertaken.

The following key word search terms were used:

- Pro eating disorder AND websites (web\*)
- Pro anorexia AND web\*
- Pro ana AND web\*
- Pro bulimia AND web\*
- Pro mia AND web\*
- Thinspiration

Reference lists of relevant articles were searched to generate further relevant studies for inclusion in the review. The search was repeated on 27 January 2014 to establish any further studies published between August 2013 and January 2014.

### **1.8.3 Study criteria**

#### *1.8.3.1 Inclusion criteria*

- Research (qualitative or quantitative studies) assessing the impact of pro-ED websites within a clinical sample (including individuals with previous or current self-reported eating difficulties and/or individuals in treatment for an eating disorder).
- Studies of individuals defined above with additional historic or current use of pro-ED websites.
- Studies of adolescent and adult participants.

#### *1.8.3.2 Exclusion criteria*

- Content/discourse/IPA/linguistic analyses of pro-ED website content.
- Research into the frequency of usage of pro-ED websites.
- Experimental studies using non-clinical samples (i.e. exposing college students to pro-ED website content).
- Studies focusing solely on the impact of general media (TV/magazines) and social media (Facebook, You Tube, Flickr, MySpace) rather than pro-ED websites.

- Non English language articles, see below.
- Generic eating disorder research which does not focus on pro-ED websites.
- Research focusing on pro-recovery eating disorder websites or general mental health websites.

#### *1.8.3.3 Language*

Only English texts were included. However, it should be noted that including only studies in English language may result in a bias towards significant results; non-English language studies may be more likely to be translated into English if they revealed significant results than those with non-significant findings (Egger et al., 1997). Abstracts in non-English languages without a full text English translation were recorded.

#### *1.8.3.4 Publication status*

All available research on pro-ED websites was searched for inclusion, including peer reviewed journals, book chapters and conference presentations. This is to reduce the potential of publication biases, whereby publication is influenced by the results of a study (Song et al., 2000). The inclusion of published-only studies may over-estimate effects of pro-ED websites.

### **1.8.4 Results and quality framework**

A total of eight studies were included in the systematic review. A diagram of search results is provided in appendix A. Study information is detailed in table two below. Quantitative cross sectional survey studies and qualitative studies were included within the review.

Consequently, two different quality frameworks were required to assess the quality of the studies; the first is relevant to cross sectional surveys and the second was applied to qualitative studies.

A quality framework developed by Cardiff University's Support Unit for Research Evidence (SURE) specifically for cross sectional survey and correlational studies was applied to the studies implementing this methodology (Cardiff University, 2012). Relevant studies were assessed in accordance with the quality framework. In order to weight the clinical significance of findings according to study quality, a numerical scoring system was added to the existing scoring guidance within the quality framework. Studies were rated following discussion with the researcher's research supervisor to enhance reliability of scores:

- ++ (good) = score of 2
- + (mixed) = score of 1
- - (poor) or nr (not reported) = score of 0.

Please refer to table three for quality information for cross sectional survey and correlational studies. The checklist was produced by Cardiff University's Support Unit for Research Evidence (SURE) and is a modified checklist specifically for correlation or cross-sectional studies. The chosen quality framework did not include information on ethical considerations; therefore, ethical issues were added to the checklist within table four.

A qualitative quality framework developed by SURE (Cardiff University) was applied to the qualitative studies within the systematic review. The qualitative quality framework was adapted and updated from the Health Evidence Bulletins Wales (HEBW) checklist with reference to the NICE Public Health Methods Manual (2012) and previous versions of the Critical Appraisal Skills Programme (CASP) checklists. Please refer to table five for qualitative quality framework.

Author, country	Aims	Participant demographics	Participant eating difficulties	Method	Results/main themes	Conclusions
Csipke (2007); UK	To explore phenomenon of pro-anorexia/bulimia websites.	N= 151 participants  97% female, age range 13 to 49 (mean age 22.05, SD=6.60).  41% aged between 16 and 19.  Country of residence: UK (60%); US (25%); Australia and Canada (3.5% each); The Netherlands (3%); and one participant from Germany, Mexico, Korea, Uruguay, and Puerto Rico	Eating Attitudes Test -26 (EAT-26) completed by 78 (52%) participants (not mandatory).  Mean EAT-26 scores 45.34 (suggested cut off of 20 for significant eating concerns).  127 (84%) reported having an ED: 43 (29%) AN, 22 (15%) BN, 17% EDNOS, 22 (15%) both AN and BN, 5 (3%) reported binge eating disorder and 7 (5%) unspecified eating problems.  7% reported they were recovered, 46% reported self-harm behaviour, 37% reported anxiety/panic attacks, 24% reported depression and 24% reported some form of social difficulty, e.g. problematic relationships.	<u>Design</u> 24 item online survey assessing opinion on pro-ED websites, correlational design.  <u>Recruitment</u> Link to study put on SANE (charity), Eating Disorders Association website, Internet pages containing information of interest to young people and two pro-ED websites.  <u>Measures</u> EAT-26 and Pro-Anorexia Website Survey (PAWS): a 24-item questionnaire specifically developed for this study. Questions presented in various formats, free text and rating scale options.  <u>Analysis</u> Pearson correlational analyses of frequency of usage and outcomes; t-tests and chi square to analyse differences between active users and passive users.	Two distinct groups emerged: 'active' participators (n= 69; 45%) and 'passive' observers (n= 52; 34%); middle group excluded from analysis.  'Passives' reported pro-ED sites supported them to maintain restricted eating. 'Actives' described emotional support from others who share experiences and thoughts.  'Actives' believed they had more in common with other visitors and felt better about themselves after visiting the sites than 'Passives'. Subjective self-esteem of 'Actives' reportedly improved after visiting the site more than that of 'Passives'.  'Passives' reported browsing 'tips and tricks' significantly more than 'Actives'. 'Actives' interacted with others, sought emotional support and were more likely to be interested in jokes and diversions and other 'cultural' content.	'Actives' reported improved mental state after visiting pro-ED sites. Evidence of a possible buffering effect through emotional support: reduced impact from potentially damaging pro-ED content.  Silent browsing ('Passives') to sustain eating disorder was found to be mainly harmful. May enhance vulnerability to worsen eating disorder symptoms in absence of beneficial effects of emotional support from websites.  Overall trend of worsening of body image following visiting the sites for both 'Actives' and 'Passives'. Sites helped to maintain disordered eating and discouraged them from recovery.  However, genuine social support is available with a possible positive effect, reduced loneliness and enhanced sense of belonging, reduced fear of rejection through disgust/ embarrassment.  'Active' participation in chat-rooms is often crisis resolution, 'passives' do not utilise this. 'Actives' more likely to motivate each-other to fast, however, some actives said visiting sites led to them seeking treatment.
Peebles et al. (2012: a);	To examine association between levels of	N= 1,291 participants; 1,254 female (97%); 37 male.	800 (86%) self-diagnosed ED, 499 (39%) reported formal diagnosis of ED; 225 AN, 104 BN, 151	<u>Design</u> Cross-sectional online survey of views of pro-ED and pro-recovery website users. Correlational analyses of website usage and	<u>Results</u> Greater perceived support from pro-ED compared to pro recovery sites (60% vs. 16% felt very or extremely supported).	Heavy pro-ED website usage (used daily for at least 12 months) was significantly associated with more extreme weight loss behaviours, harmful post-website usage activities (e.g. diet pill use, self-

United States: Philadelphia	pro-ED website usage, disordered eating behaviours and quality of life.	Adults, average age 22 years.	EDNOS, 8 binge eating. 24.83% were underweight; 20.89% were overweight or obese.  Over 70% of participants had purged, binged, or used laxatives to control their weight; only 12.91% were in treatment.  Mean Eating Disorder Examination Questionnaire (EDE-Q) scores were above the 90th percentile and mean Eating Disorder Quality of Life (EDQOL) scores were in the severely impaired range.  Only 21 (1.6%) completed less than 50% of surveys, 48 (3.7%) completed 50%-80% of surveys. Remaining completed over 80% of surveys.	outcomes.  <u>Recruitment</u> Link on pro-ED websites: 296 sites were contacted following inclusion criteria and asked to post link to the survey.  <u>Measures</u> 193 survey items: demographics, eating information, treatment history, overall health, self-harm, frequency of pro-ED and pro-recovery website usage, EDE-Q and EDQOL scores. Secondary outcomes: number of unhealthy days on Healthy Days Measure and common indicators of health in ED, e.g. hospital admission, missed menses.  <u>Analysis</u> Descriptive statistics. Chi-square, t-test, Pearson correlations, and ANOVA to analyse associations. Tukey test for post hoc comparisons. Multivariate regression analyses used to stratify factors predictive of disordered eating behaviours and impaired quality of life.	Greater sense of community similar to self on pro-ED compared to pro recovery (61% vs. 19% found community like self).  Most important reason for accessing pro-ED sites in last 30 days: motivation for weight loss 37%; weight loss tips 16%; meeting people 5%; tips on hiding the disorder 4%; curiosity 8%; support 6%; help with recovery 0.17%.  Most important reason for accessing pro-recovery sites in last 30 days: motivation for weight loss 14%; weight loss tips 8%; meeting people 2%; tips on hiding the disorder 5%; curiosity 33%; support 29%; help with recovery 3%.  Post pro-ED website use activity: 61% used new weight loss/purging methods; 37% used new laxatives, diet pills or weight loss supplements; 55% changed eating habits.	harm) and greater pathology (EDE-Q and EDQOL scores) in comparison to light usage (less than 1 month) and medium usage (> 1month but < one year). Pro-ED website usage remained significant predictor when other variables (e.g. age, duration of ‘disease’) controlled.  Pro-ED website visitors reported many disordered eating behaviours, although few had been treated.  Causality cannot be inferred due to cross-sectional methodology. However, reported average age of initially visiting pro-ED sites was greater than reported age of onset of eating difficulties; suggesting pro-ED websites may be a later consequence of eating disorder rather than an initial cause of eating disorder.
Peebles et al. (2012: b); United States:	To explore themes of why people visit and continue to use pro-ED websites.	N= 1,291 sample as described in Peebles et al 2012: a.	As above	<u>Design</u> As above  <u>Recruitment</u> As above  <u>Measures</u> Qualitative question on survey:	Many expressed feelings of isolation/“like a freak”; lacked social support outside of websites. Physicians and therapists were described as “faceless doctors” by a subset who felt care providers lacked understanding.	Social isolation, stress and depression influenced website use. Feelings that others (friends, professionals, family) cannot understand their ED supported use of pro-ED sites.  Users described risks and benefits, web ethic reinforced repeated use of sites,

Philade lphia				<p><i>“What role do you think pro-recovery and pro-Ana/pro-Mia websites played in the course of your eating disorder or in your life?”</i></p> <p>An additional free text box was included for further comments or feedback.</p> <p><u>Analysis</u> Thematic analysis, double coded.</p>	<p>Family and friends perceived as unable to understand, resulting in increased isolation. Dangers of pro-ED websites were acknowledged but minimised/ignored.</p> <p>Perceived pro-ED website benefits were reduced isolation and enhanced coping/support, many described pro-ED websites as the only place they could be ‘real’ – websites were only place they could ‘truly connect’ with others.</p>	<p>online behaviours (e.g. diet pills) minimised as less dangerous/risky than when considered in offline context.</p> <p>Pro-ED sites were defended websites: participants said they already had eating disorder before using websites.</p>
Ransom et al., (2010); Canada: Ontario	<p>To explore positive and negative behaviours encouraged on pro-ED forums.</p> <p>To compare forum members’ perceptions of social support in online and offline relationships to age matched control group.</p>	<p>60 pro-ED forum members and 74 undergraduate age matched controls.</p> <p>Forum member participants: all female aged 14 to 30 years old (Mean 20.33, SD 3.22).</p> <p>Residents of United States (51%), UK (22%), other European countries (15%), Canada (7%), Australia (3%), and Asia (2%).</p> <p>Control sample: psychology</p>	<p>Nearly all pro-ED forum members reported some previous restriction of food (98%), dieting (98%), bingeing (90%), purging or vomiting (83%), and exercising more than two hours a day (78%).</p> <p>40% reported having received diagnosis of an ED. All with formal diagnoses had undergone previous treatment and seven were in treatment.</p> <p>Significant differences in mean scores on EAT-26: forum participants reported greater eating problems than controls.</p>	<p><u>Design</u> Survey of 60 pro-ED forum members and comparisons with age matched control group.</p> <p><u>Recruitment</u> Fifteen pro-ED forums were selected for recruitment.</p> <p><u>Measures</u> Assessed support provided on pro-ED forums and perceptions of social support for general and specific life concerns. Controls asked to indicate participation in online forums, (e.g. entertainment, social networking).</p> <p>Modified version of the Significant Others Scale<sup>16</sup> to assess perceived levels of support (both overall and for a significant stressor – eating disorder in forum sample) from several significant relationships.</p>	<p><u>Motivations for using pro-ED forums</u> 65% learned of pro-ED sites through search engines. Motivations to join pro-ED forum: a sense of belonging (77%); social support (75%); to support their choice to continue current eating behaviours (52%).</p> <p><u>Impact of forums</u> How to effectively hide eating behaviours from others (60%), how to fast (57%), employ new weight loss methods (51.7%), use diet pills (47%), use diuretics and laxatives (45%), vomit (23%), use alcohol or drugs to inhibit appetite (22%), and how to engage in self-harm behaviours (22%).</p> <p><u>Positive aspects of forums</u> Encouraged to eat healthily (63%), accept their current weight or body size (63%) and accept their body image (53%), address problematic eating behaviours (58%), increase their calorie intake (37%), consult</p>	<p>Forum members perceived less social support compared to controls, particularly for one of their most significant stressors: eating concerns.</p> <p>Pro-ED forums encourage both adaptive and maladaptive behaviours. Forum members perceived most support to be from fellow forum members, greater perceived support online than offline. However, forums also encourage dysregulated eating behaviours (e.g. laxatives, eating suppressants).</p> <p>Forum members reported a high frequency of direct feedback from other forum members about positive behaviours.</p> <p>Findings suggests that online forums partly serve to supplement offline relationship support, particularly regarding eating concerns when users feel they do not gain adequate support in real-world relationships.</p>



		undergraduates: 18 to 28 years old (Mean 20.23, SD 5 2.0).		<u>Analysis</u> T-tests to assess differences between forum members and controls. Mixed model repeated measures ANOVA to assess differences in perceived social support and stress type of forum members and controls.	with a health professional about their eating concerns (48%), and communicate with loved ones about issues related to eating (31%).	The anonymous nature of online forums may support users to openly discuss negative or shameful behaviours and to feel more understood by like-minded individuals.
Rodgers, Skowron & Chabrol (2012); France	To assess disordered eating among members of a French language online pro-Ana community. To explore motivations for becoming a member and perception of support from other members.	29 females, all French residents.  Mean age 17.4 years (range 12 to 23).  18 in middle or high school, 6 students, 4 employed, 2 unemployed.	All EAT scores above the clinical cut-off point of 30 (mean 65.5).	<u>Design</u> Online survey of pro-Ana website users.  <u>Recruitment</u> Investigator posted message on eight Pro-ED website forums.  <u>Measures</u> French translation of the Eating Attitudes Test (EAT).  Twelve open questions: motivation to join the online community; their level of satisfaction with it; their definition of the pro-Ana movement; the advice and help that they had been given and which parts they had chosen to follow.  <u>Procedure</u> Participants responded to questions/measures above through email.  <u>Analysis</u> Descriptive statistics.	Most frequent methods of finding out about pro-Ana: TV documentaries (24%); searching for weight loss methods online (24%). Reasons for joining pro-Ana websites/forums: weight loss 59%; social support 55%; both weight loss and social support 17%.  Advice/tips received: techniques to avoid eating 72%; decrease feelings of hunger 83%; avoid weight gain 55%; lose weight 93%; vomiting 31%; fasting 24%; severe restriction in order to avoid weight gain 48%; drinking excessive quantities of fluids 27%.  83% agreed pro-Ana offered support. All were aware of health risks of not eating/purging/vomiting but 12 (41%) stated they did not care or that it did not apply to them.  Benefits of membership: emotional benefits e.g. being listened to 72%; satisfaction at weight loss 28%; negative consequences in vague terms e.g. I was better before; a few complications 14%.	All participants demonstrated high levels of eating concerns and eating disorder symptoms. Causality difficult to determine.  Double function of pro-ED websites: pursuit of weight loss and sense of identity: sense of acceptance and relief within online community.  Breadth of responses: identity of pro-Ana community means different things to different people, in contrast to 'tight knit'/ exclusive community as previously portrayed.  Large majority pleased at participation and weight loss; small minority reported negative/painful experiences. Potential difference in experience between active and passive users? May have different perspectives of support/identity within websites – those who actively contribute may feel greater sense of support.

Williams & Reid (2010); UK: Scotland	To explore experiences of people who use pro-ED websites and who want to maintain their eating disorder.	13 females and 1 male.  Aged 18 to 36.  Online focus group, participants living in the USA (5), Canada (2) and one in Spain, South Africa, Australia, New Zealand, Romania and India.	All participants used pro-ED websites from around five times a month to 10–15 times a day; use of pro-recovery websites from never to twice a day.  All participants believed that they had anorexic behaviours at the time of the study and wished to maintain them. Some expressed ambivalence: three participants also wished to recover and five wanted to receive treatment.	<u>Design</u> Qualitative - online focus group of pro-ED forum members.  <u>Recruitment</u> Google search of pro anorexia websites/forums. Potential participants contacted via email addresses posted on sites. Those interested were sent consent forms and study information.  <u>Measures</u> Self-report questionnaire: demographic information, eating disorder history and other mental health problems, eating disorder related internet use, and attitudes to eating disorders, EDE-Q.  <u>Procedure</u> Online focus group (OFG); asynchronous (non-real time) lasting five weeks. Two participants joined after OFG and completed online interviews on same topics.  <u>Analysis</u> Interpretative phenomenological analysis	Two overarching themes ‘ambivalence and conflict about anorexia’ and ‘barriers to recovery’.  Underlying ambivalence was a conflict between the belief that anorexia provided a sense of control yet also, at the same time, was in control of them.  Anorexia as a functional and ego-syntonic role: anorexia as a way of feeling in control, achieving something, coping, feeling safe, expressing emotion, escape, avoid negative feelings.  Despite their involvement in pro-anorexia websites which suggest anorexia is a lifestyle choice, participants described their anorexia as a ‘disease’, ‘disorder’ or ‘illness’ and recognised negative effects on health: ‘  Barriers to treatment: negative attitudes towards treatment from own experiences or listening to others on pro anorexia forums; treatment too heavily focused on only weight gain.	Participants wanted to maintain their anorexia due to its positive consequences e.g. feeling in control and avoiding negative feelings. Relationship with anorexia was likened to a reliable friend.  However, it is also seen as a ‘disease’ and ‘enemy’ with negative health consequences and a feeling of being out of control from the anorexia. This results in ambivalence about whether their anorexia plays a positive or negative role and ambivalence whether to maintain behaviours or recover.  Engagement in pro-ED websites/forums may be a barrier to treatment.
Wilson et al., (2006); USA	Pilot study of pro-ED website usage among adolescents with ED;	76 patient respondents: 72 (94.7%) female, 4 (5.3%) male. Mean age 16.7 (SD 2.5).  106 parent	Patient respondents – duration of eating disorder: less than one year 44%; one to two years 20%; over two years 36%.  Number of	<u>Design</u> Cross-sectional study of 698 families of patients (aged 10–22 years) diagnosed with an eating disorder at Stanford between 1997 and 2004.	<u>Patient survey results</u> 25% reported using both pro-recovery and pro-ED websites. No male patients reported visiting pro-ED sites.  Reasons for visiting pro-ED websites: to maintain motivation for	No significant differences between pro-ED users and non-users on health outcomes, including percentage ideal body weight, incidence of low bone mineral density, number of hospitalisations, or number of missed menses.

	association with health and quality of life. To assess awareness of parents regarding pro-ED.	respondents: 83 (81.4%) female; 19 (18.6%) male. Mean age 48.7 (SD 5.4).	hospitalisations: zero to one 52%; two to three 36%; over four 12%.  Number of missed menses: six and under 43.7%; over six 56.3%.	<p><u>Procedure</u> Potential participants were identified by medical chart review. An initial mailing sent to the parents of 698 patients and each patient aged over 18. All participants aged under 18 recruited through contact with parents. A unique number was assigned to each patient/ parent questionnaire set.</p> <p><u>Measures</u> Question phrasing was pilot-tested on a small group of patients with ED and parents. The parent questionnaire was 46 items, and the patient questionnaire was 56 items including demographics, ED symptoms and severity and information regarding pro-ED website usage.</p> <p><u>Analysis</u> Descriptive statistics, t-tests and Chi square.</p>	<p>weight loss 70.8%; for support 37.5%; to meet others with EDs 37.5%. 96% learned new weight loss or purging methods; 64% learned about diet pills, laxatives, or supplements; and 69.2% reported using new weight loss or purging methods.</p> <p>Reasons for visiting pro-recovery sites: 59.3% for support and 48.1% to meet others with EDs. Pro-recovery site users also reported learning high-risk eating behaviours: 46.4% learned new methods of weight loss or purging at pro-recovery sites.</p> <p><u>Patient health outcomes</u> Users of pro-ED websites had been ill significantly longer than non-users, although no difference with regard to length of time in treatment or age. Pro-ED users spent less time on homework than non pro-ED users.</p> <p><u>Parent survey results</u> 62.5% of parents had no knowledge of pro recovery websites, 52.8% of parents were aware of pro-ED websites. 52% of parents were unaware whether their child visited these sites, and only 27.6% had discussed them with their child.</p>	<p>However, pro-ED users had been ill significantly longer and pro-ED use may be associated with a negative impact on quality of life and promote the learning of maladaptive eating behaviours.</p> <p>Pro-ED users report greater motivation for weight loss than pro recovery website users. Curiosity was a motivation for users of both sites.</p> <p>Use of pro recovery websites also led to individuals learning new weight loss behaviours.</p> <p>Parents had little awareness of the children's use of Pro-ED websites.</p>
Yeshua-Katz & Martin	To explore motivations, benefits and drawbacks of	33 participants, all female.  Mean age 20, range 15 to 33 (SD=4.5).	Participants reported mostly anorexia, rather than bulimia or EDNOS.	<p><u>Design</u> Qualitative: semi-structured online interviews.</p> <p><u>Recruitment</u> Pro-ana blogs searched online,</p>	<p><u>Motives for blogging</u></p> <ol style="list-style-type: none"> <li>1. Social support – not wanting to feel alone, feel misunderstood in offline environment.</li> <li>2. Coping with stigma – cope with/escape from social</li> </ol>	<p>Paradoxically, blogging about anorexia both alleviates and triggers anxiety about living with stigmatised 'illness'.</p> <p>Participation in online community results from psychological and social needs.</p>

(2013)	blogging about having an eating disorder in the context of ED as a stigmatised mental illness.	22 lived in US, 5 UK, 3 Europe, 2 Canada, 1 New Zealand.	<p>Average (mode) length of participants' eating disorder 6.8 years.</p> <p>27 reported living with eating disorder, 6 reported being in recovery.</p> <p>24 defined ED as mental illness, 6 defined as coping mechanism, 3 defined it as lifestyle.</p> <p>All participants were <i>authors</i> of pro-ana blogs.</p>	<p>authors of blogs contacted by email, or invitation to participate left on blog or comments page – 300 blog authors invited to participate, 33 took part in study.</p> <p><u>Interview questions</u> Three sections 1) bloggers experience of their ED, 2) motives for blogging about their ED, 3) perceived benefits and drawbacks of pro ana blogging.</p> <p><u>Procedure</u> Pilot interview conducted, revised interview schedule to enhance comprehensibility. Interviews conducted over telephone (7), Skype (4) or email (23).</p> <p><u>Analysis</u> Grounded theory.</p>	<p>disapproval, blogging offers a different reality.</p> <p>3. Self-expression – venue to express selves/disclose information without judgement/criticism.</p> <p><u>Benefits of blogging</u></p> <ol style="list-style-type: none"> <li>1. Catharsis – blogging improves mood/find relief when others read the blogs they became aware their words reached an audience – sense of community.</li> <li>2. Social support – find similar, supportive others, supportive community, encouragement and validation, unconditional support, no one tries to 'fix' them.</li> </ol> <p><u>Drawbacks of blogging</u></p> <ol style="list-style-type: none"> <li>1. Fear of disclosure – fear of friends/family finding out they blog.</li> <li>2. Encouraging ED – fuelling own ED behaviour (double edged sword) and concerned may encourage other vulnerable people.</li> </ol>	<p>Findings support identity demarginalisation model – active online to compensate for lack of offline resources and support. Pro ana bloggers are stigmatised and expect support from similarly stigmatised others.</p> <p>People attempt to conceal their ED offline and go online to express themselves anonymously.</p> <p>Bloggers concerned about being 'found out' and concerned blog will trigger ED behaviour, particularly in vulnerable young girls and people in recovery.</p> <p>Only 3 participants defined ED as lifestyle, most (24) defined as mental illness – bloggers are trying to find the best way to live with their disorder. Bloggers posted disclaimers and blocked 'wannarexics' teenagers who want to become anorexic.</p> <p>Treatment for ED is notoriously ineffective; diagnosis and treatment should be examined further instead of blaming young women for sabotaging own recovery online – moral panic of pro-ED websites may not be appropriate.</p>
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Table 2. Summary of studies used for Systematic Review.

		Scoring guidance: 2 = good, 1 = mixed, 0 = poor, nr = not reported, na = not applicable				
Quality framework criteria		Csipke (2007)	Peebles et al., (2012a & 2012b)	Ransom et al., (2010)	Rodgers, Skowron & Chabrol (2012)	Wilson et al., (2006)
1. Population	1.1 Is the source population or source area well described?	Age range, gender, country of residence, self-reported eating difficulties, mean EAT-26 score, other reported concerns (e.g. anxiety, self-harm, relationship problems).	Age range, gender, ethnicity, employment status, ED diagnosis and related behaviours, mean EDE-Q and EDQLS scores, BMI, mental health diagnoses and self-harm history recorded.	Age range, gender, ethnicity, country of residence, BMI, eating concerns/behaviours reported in pro-ED user and control participants.	Age range, gender, country of residence, employment status, mean EAT-40 score reported.	Patient gender, ethnicity, mean age, disease length, treatment length, no. hospitalisations, missed menses. Parent gender, ethnicity, mean age.
		<b>2</b>	<b>2</b>	<b>2</b>	<b>1</b>	<b>2</b>
	1.2 Is the eligible population or area representative of the source population or area?	Relatively small sample of 151 from eligible international population of pro-ED website users.	Relatively large sample of 1,291 pro-ED website users from eligible international population of pro-ED users.	Relatively small sample of 60 pro-ED website users and 74 university undergraduates as age matched controls.	Small sample of 29 French users of pro-ED websites.	Cross sectional study of patients with ED and parents at specific children's hospital in US. Not all patient participants were users of pro-ED websites.
		<b>1</b>	<b>2</b>	<b>0</b>	<b>0</b>	<b>0</b>
	1.3 Do the selected participants or areas represent the eligible population or area?	Participants were not screened for eating disorders, 84% reported having an ED, 52% completed EAT-26, mean score above cut off. All reported that they used pro-ED websites, but were not solely recruited through pro-ED websites, e.g. search engine, charity websites; representative of all pro-ED websites users? Not possible to distinguish EDs from non-ED participants. Self-report biases?	Large sample of pro-ED website users with eating difficulties (86% self-diagnosed ED, 36% formal diagnosis of ED), recruited from 296 pro-ED websites.	Relatively small sample size of 60 pro-ED users, all had eating difficulties but only 40% had formal diagnosis of ED. Participants recruited through only 12 websites where forum members permitted access.	Small sample of French pro-ED website users, all EAT-40 scores above clinical cut off.	All patient participants had diagnosis of ED, not all used pro-ED websites (33% disclosed using pro-anorexia and 17% disclosed using pro-bulimia websites), 48% used neither pro-ED nor pro-recovery websites. Low response rate of 10-15%, anonymous survey so could not compare demographics of responders with non-responders.

		<b>1</b>	<b>2</b>	<b>1</b>	<b>0</b>	<b>0</b>
<b>2. Method of selection of exposure (or comparison) group</b>	2.1 Selection of exposure (and comparison) group. How was selection bias minimised?	Initial recruitment through charity website SANE, recruitment slow so expanded to Eating Disorders Association website and pro-ED websites. Data from repeat respondents deleted. Survey instructions not critical of pro-ED websites to promote open/honest responses?	Wide recruitment strategy- 550 English language pro-ED websites identified, 296 met inclusion criteria and were contacted by researchers to post link to survey. IP addresses blocked to ensure anonymity to encourage responses. Estimated response rate by proxy of 43.58% when considering number of hits to websites versus survey responses.	Moderators of 15 pro-ED websites contacted for recruitment – three refused and no response from 12, link posted on 12 websites for recruitment. Selection bias acknowledged, some participants noted they did not wish to participate due to fear of being stigmatised or fear of site closing down. Randomly assigned participant ID numbers and IP addresses blocked to ensure anonymity to encourage responses.	Link to study posted on eight French language pro-ED websites/forums. Participants assured no personal information would be collected and forum names would be not be reported.	Participants selected from medical chart review within hospital. Mailing sent to 698 parents of patients and patients aged >18 at time of mailing. Questionnaires sent through mail or email. Low response rate - 182 completed surveys (76 patients, response rate 10.9%, 106 parents, response rate 15.2%), 52 child-parent pairs in analysis.
	2.2 Was the selection of explanatory variables based on sound theoretical basis?	<b>1</b>	<b>2</b>	<b>1</b>	<b>1</b>	<b>1</b>
		Yes, variables relevant to theoretical background and existing literature.	Yes, related to limited amount of previous research/theory.	Yes, related to limited amount of previous research/theory	Yes, related to previous research/theory	Yes, related to previous research/theory
	2.3 Was the contamination acceptably low?	<b>2</b>	<b>1</b>	<b>1</b>	<b>2</b>	<b>2</b>
		N/A	N/A	N/A	N/A	N/A
	2.4 How well were likely confounding factors identified and controlled?	Confounding variables, e.g. self-harm, anxiety, social concerns identified but not controlled for in correlations.	Confounding factors in correlations e.g. duration of 'disease', mental health diagnoses, self-harm recorded and controlled for in analysis.	Potential confounding variables e.g. other mental health difficulties, previous incidents relevant to perceptions of social support, not identified or controlled.	No confounding factors acknowledged, but survey only, no correlations between eating difficulties and pro-ED website usage made. Nr	High overlap between individuals using both pro-ED and pro-recovery websites. Potential confounding factors not controlled for, e.g. pro-ED users spent less time on homework than non-users, no potential confounding variables reported.

		<b>1</b>	<b>2</b>	<b>0</b>	<b>0</b>	<b>0</b>
	2.5 Were rigorous processes used to develop the questions (e.g. were the questions piloted / validated?)	Pro-Anorexia Website Survey (PAWS): 24 items, questions in various formats (free text, rating scales), two questions omitted during development to enhance user-friendliness. No information given re: pilots of PAWS or validation. Questionnaire copy in appendix. Use of EAT-26, standardised self-report measure.	Online survey, 193 items, disordered eating, quality of life, treatment history, overall health, self-harm, and website usage of both pro-ED and pro-recovery websites. Questionnaire copy available – closed questions (2012a) and one open question regarding role of pro-ED websites in life/eating disorder (2012b). Survey used in previous research of pro-ED usage.	Examples of questions in survey were provided, copy of survey not available. No mention of survey questions piloted.	Twelve open-ended questions, questions available in appendix, no mention of development or piloting of questions.	Designed own survey instrument as no validated measure of website use in adolescents existed. Question phrasing was pilot-tested on a small group of patients with ED and their parents in a clinic setting. Patient and parent questionnaire topics reported, actual questionnaires not available.
		<b>1</b>	<b>2</b>	<b>1</b>	<b>0</b>	<b>1</b>
	2.6 Is the setting applicable to the UK?	Yes – 60% of respondents from UK, majority of remaining from English speaking Western countries e.g. USA, Canada, Australia, potential cultural differences from UK?	Likely - no details of country of residence reported, only ethnicity of respondents. All measures in English language.	Likely to be applicable to UK – 22% of pro-ED sample lived in UK, 51% in US and 15% in Europe, potential cultural differences from UK? Controls from Canadian university sample.	Potentially not, all respondents French residents using French language pro-ED websites/forums, language and cultural differences from UK?	Likely, all English language adolescents living in US, potential cultural differences from UK.
		<b>2</b>	<b>1</b>	<b>1</b>	<b>0</b>	<b>1</b>
<b>3. Outcomes</b>	3.1 Were the outcome measures and procedures reliable?	EAT-26 Garner, Olmsted, Bohr, & Garfinkle, 1982) to measure severity of disordered food related behaviours and thoughts, standardised, free to use and widely used in ED. Not mandatory to reduce length of time for completion to enhance recruitment.	Use of self-report measures: Eating Disorder Examination Questionnaire (EDE-Q) shown to have good validity, specificity and sensitivity, and the Eating Disorder Quality of Life Scale (EDQLS) measure shown to have good construct validity. Secondary outcome	All participants: self-reported BMI, EAT-26, EAT-26, validated widely used measure, reliability of EAT-26 in current sample reported to be .90. DSM-IV diagnoses of ED, treatment history for any ED, modified Significant Others Scale to measure social support.	French translation of EAT-40, good psychometric properties and within the sample reported $\alpha = .87$ .	No validated outcome measures, use of patient and parent survey only. Some objective measures included e.g. no. of days hospitalised, bone mineral density level and missed menses. Other areas more subjective e.g. changes in time spent with friends or on extra-curricular activities.

Time			measures e.g. health indicators e.g. hospitalisation, missed menses.	Pro-ED forum members: specific ED related behaviours and pro-ED website usage. Controls: general Internet forum usage.		
		<b>2</b>	<b>2</b>	<b>2</b>	<b>1</b>	<b>1</b>
	3.2 Were the outcome measurements complete?	52% completed EAT-26	21 respondents (1.63%) answered less than 50% of questions and another 48 (3.72%) were partial completers (50%-80% of questions answered).	10 controls excluded due to EAT-26 scores above clinical cut off, 49% did not report ethnicity. No information provided on additional missing data. Nr	Nr	Nr
		<b>1</b>	<b>2</b>	<b>0</b>	<b>0</b>	<b>0</b>
	3.3 Were all important outcomes assessed?	Many outcomes assessed, e.g. impact of pro-ED sites on attitudes and self-esteem, behaviours e.g. weighing, not exhaustive list but open question inviting additional impacts. Impacts of active use and passive use analysed, but mid group (21%) omitted from analyses. No question regarding whether participants had received treatment for ED.	Many outcomes assessed with validated measures. However, arbitrary distinction between light, medium and heavy pro-ED usage?	Relevant outcomes were assessed, e.g. perceived social support for general stressors and main stressor (ED) and behavioural impacts of pro-ED forum usage.	EAT-40 only outcome measure. Open ended questions to assess impact of pro-ED websites, e.g. what tips/advice have you learned from other members.	Selection of outcomes, e.g. time spent with friends, time spent on homework and clinical indicators e.g. bone density and number of hospitalisations. No measures of depression, anxiety, body image difficulties etc.
		<b>1</b>	<b>1</b>	<b>1</b>	<b>1</b>	<b>1</b>
	3.4 Was there a similar follow-up time in exposure & comparison groups?	No follow up reported Nr	No follow up reported Nr	No follow up reported Nr	No follow up reported Nr	No follow up reported Nr
		<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>
	3.5 Was follow-up time	No follow up reported Nr	No follow up reported Nr	No follow up reported Nr	No follow up reported Nr	No follow up reported Nr



	meaningful?	0	0	0	0	0
4. Analyses	4.1 Was the study sufficiently powered to detect an effect if one exists?	Sample 151 participants, no mention of power analyses.	Large sample of 1,291 respondents.	60 in pro-ED forum sample and 64 age-matched controls, no mention of power analyses.	Small sample, no mention of power analysis.	Numbers too small to perform meaningful chi square analysis on some variables when separating out overlap of pro-ED and pro-recovery use.
		0	2	0	0	0
	4.2 Were multiple explanatory variables considered in the analyses?	Range of variables measured, e.g. anxiety, social/relationship difficulties but these factors were not included in analyses as compounding/additional explanatory variables.	Colinearity of variables assessed, e.g. age and duration of ED. Multivariate analysis showed pro-ED usage predictive of quality of life when additional variables controlled.	Nr	Nr	Nr
		1	2	0	0	0
	4.3 Were the analytical methods appropriate?	All descriptive and inferential statistics reported: Pearson used for correlational analyses and t-tests and Chi-square used to analyse differences between active and passive users, presented at .05 significance level – non parametric test used if results were not normally distributed (Mann Whitney U Test). 30 participants from ‘middle’ section removed from analysis, crucial analysis of potential ambivalent users lost.	All descriptive and inferential statistics reported: associations assessed using chi-square, Student t-test, Pearson correlations, and analysis of variance, followed by Tukey test for post hoc comparisons. Multivariate regression analyses were used to stratify factors predictive of disordered eating behaviours and impaired quality of life. Responses were not weighted in any manner. Significance level was set at .05.	Descriptive statistics used regarding nature of forum use. T-tests to assess differences e.g. BMI of sample and controls. Mixed model repeated measures ANOVA to assess differences in perceived social support for pro-ED forum users and controls, main effects and interactions reported. Subsequent pairwise comparisons for support type (e.g. mother, best friend).	Descriptive statistics, answers to open ended questions were coded and categorised, frequencies and percentages reported. No mention of double coding of open question responses to check reliability.	Associations assessed using chi square, t test and ANOVA. Post hoc comparisons between groups using Tukey test.
		1	2	2	1	1

	4.4 Was the precision of association given or calculable? Is association meaningful?	Association values and statistical significance reported. Clinical implications of associations discussed.	Statistical associations and clinical relevance presented and discussed.	Statistical associations and clinical relevance presented and discussed.	Frequencies reported of categories of open question responses. No associations reported. Nr	Statistical associations and clinical relevance presented and discussed.
		<b>2</b>	<b>2</b>	<b>2</b>	<b>0</b>	<b>1</b>
<b>5. Summary</b>	5.1 Are the study results internally valid (i.e. unbiased)?	Convenience sample of limited size. Respondents may have been dishonest in order to 'protect' pro-ED sites, fear of sites being shut down. Potential for selection bias; those who decided to take part in the study may have different experiences/ opinions of pro-ED websites than those who did not respond. Duplicate responses deleted.	Convenience sample, relatively large size, potential recall biases and potential selection biases. Respondents asked if they had lied on the survey; 227 excluded as admitted to lying e.g. about age or weight, but unable to meet with respondents to verify answers due to online/anonymous responses. Duplicate responses not identified or deleted.	Convenience sample of relatively small size, potential recall biases and potential selection biases. Age matched control group to compare perceived social support and general Internet forum usage.	Convenience sample small size, potential selection and recall biases.	Convenience sample with low response rates, selection biases? Parental concerns over introducing pro-ED websites to children by participating in the research may have led to not providing consent for child to take part. Anonymous survey, unable to verify responses e.g. number of hospitalisations. Recall biases, some participants were seen in clinic for ED several years previously.
		<b>1</b>	<b>1</b>	<b>1</b>	<b>0</b>	<b>1</b>
	5.2 Are the results generalizable to the source population (i.e. externally valid)?	Findings may be generalizable to population of pro-ED website users, international study, however, relatively small sample size.	Relatively large international sample size, results likely have greater generalizability than smaller samples.	Relatively small international sample of pro-ED website users.	Small sample, French users.	All patients were seen in clinic for ED's, may not be representative of people with eating difficulties who use pro-ED websites who are not in formal treatment.
		<b>1</b>	<b>2</b>	<b>1</b>	<b>0</b>	<b>1</b>
	<b>Total quality score</b> (Total = 40; however, 2.3 not applicable to all studies, therefore, maximum score = 38).	<b>21/38</b>	<b>30/38</b>	<b>16/38</b>	<b>7/38</b>	<b>13/38</b>

Table 3. SURE Quality Framework, cross sectional/correlational studies, Support Unit for Research Evidence (SURE), Cardiff University, 2012.

	<b>Csipke (2007)</b>	<b>Peebles et al., (2012a &amp; 2012b)</b>	<b>Ransom et al., (2010)</b>	<b>Rodgers, Skowron &amp; Chabrol (2012)</b>	<b>Wilson et al., (2006)</b>
<b>Ethical considerations</b>	Online recruitment only - cautious of not introducing pro-ED websites to individuals by recruiting through ED clinics/mass media, but subsequently recruited individuals through general websites (not specifically pro-ED websites). Example consent form available. Anonymity: no mention of blocking I.P addresses but participants given option of providing email address if they wanted to be contacted by researcher. Youngest participant aged 13, issues with children consenting, parental knowledge?	Informed consent obtained. Potential participants asked to confirm aged over 18 and give informed consent before directed to survey. No incentives offered to encourage participation. Anonymity: no identifiers collected, no cookies used and IP addresses were not tracked. Participants were able to contact researchers via email. Researchers did not introduce pro-ED websites to participants; all participants recruited through pro-ED websites.	Participants informed of anonymity – no personal information collected, random ID numbers allocated and IP addresses blocked. Specific forum names not published. All recruited through pro-ED websites/forums, no introduction of pro-ED to participants. Researchers unable to access some pro-ED websites for recruitment as they required declaration of eating difficulties before joining. Age range from 14, consent of children, parental knowledge?	Participants assured no personal information would be collected and forums would not be identified. Contact email for researcher provided. All participants recruited through pro-ED websites, no introduction of pro-ED to participants. Age range from 12, consent issues for children, parental knowledge?	Questionnaires only sent to parents and patients who were over aged 18. Informed consent obtained from parents of patients and patients aged 18 and above, younger patients gave assent. Random identification numbers allocated to parent-child pairs to maintain anonymity. Questionnaires sent in post or given to patients at outpatient clinic, completed online or sent in mail. Potential low response rate as parents did not want child to participate in research due to introducing them to potentially harmful pro-ED websites. Authors cite research that surveying adolescents for risk behaviours does not make them more likely to engage in such risk behaviours.

Table 4. Ethical considerations of cross sectional/correlational studies.

		Scoring guidance: Yes, Can't Tell, No	
Quality framework criteria		Williams & Reid (2010)	Yeshua-Katz & Martins (2013)
1	Does the study address a clearly focus question/hypothesis?	Yes	Yes
	<i>Setting</i>	Yes	Yes
	<i>Perspective</i>	Can't Tell	Yes
	<i>Intervention or phenomena</i>	Yes	Yes
	<i>Comparator/control (if any)?</i>	N/A	N/A
	<i>Evaluation/exploration</i>	Yes – exploration	Yes – exploration, 3 questions outlined.
2	Is the choice of qualitative method appropriate?	Yes	Yes
	<i>Is it an exploration of e.g. behaviour/reasoning/beliefs</i>	Yes	Yes
	<i>Do the authors discuss how they decided which method to use?</i>	Not detailed, can't tell	Not detailed, can't tell
3	Is the sampling strategy clearly described and justified?	Yes – online recruitment.	Yes – online recruitment.
	<i>Is it clear how participants were selected?</i>	Yes	Yes
	<i>Do the authors explain why they selected these particular participants?</i>	Yes	Yes
	<i>Is detailed information provided about participant characteristics and about those who chose not to participate?</i>	Yes – but no information on individual choosing not to participate as anonymous.	Yes – but no information on individual choosing not to participate as anonymous.
4	Is the method of data collection well described?	Yes	Yes
	<i>Was the setting appropriate for data collection?</i>	Yes	Yes
	<i>Is it clear what methods were used to collect data?</i>	Yes	Yes
	<i>Is there sufficient detail of the methods used?</i>	Yes	Yes

	<i>Were the methods modified in the study, if yes is this explained?</i>	Yes, email interviews and online focus group.	Yes, email (n=23), Skype (n=4) and telephone (n=7) interviews.
	<i>Is there triangulation of the data (more than one source of data collection?)</i>	No, one source of data – themes checked with second author.	No, one source of data - both authors read and coded transcripts.
	<i>Do the authors report achieving saturation?</i>	No – IPA used.	No
5	<i>Is the relationship between researcher(s) and participants explored?</i>	No	No
	<i>Did the researcher report critically examining/reflecting on their role and any relationship with participants?</i>	No	No
	<i>Were any potential power relationships involved?</i>	Not detailed, can't Tell	Not detailed, can't Tell
6	<i>Are ethical issues explicitly discussed?</i>	Yes	No
	<i>Is there sufficient information on how the research was explained to participants?</i>	Yes	No
	<i>Was ethical approval sought?</i>	Yes	Can't Tell
	<i>Are there any potential confidentiality issues in relation to data collection?</i>	No – anonymous online study.	Yes – Skype/telephone interviews.
7	<i>Is the data analysis/interpretation process described and justified?</i>	Yes	Yes
	<i>Is it clear how the themes and concepts were identified in the data?</i>	No – no memos presented	No – no memos presented.
	<i>Was the analysis was performed by more than one researcher?</i>	Yes	Yes
	<i>Are negative/discrepant results taken into account?</i>	Yes	Can't Tell
8	<i>Are the findings credible?</i>	Yes	Yes
	<i>Are there sufficient data to support the findings?</i>	Yes	Yes – but no diagram of grounded theory.
	<i>Are sequences from the original data presented (e.g. quotations) and</i>	Yes	Yes

	<i>were these fairly selected?</i>		
	<i>Are the data rich (i.e. are the participants' voices foregrounded)?</i>	Yes	Yes
	<i>Are the explanations for the results plausible and coherent?</i>	Yes	Yes
	<i>Are the results of the study compared with those from other studies?</i>	Yes	Yes
9	Is any sponsorship/conflict of interest reported?	No	No
10	<i>Did the authors identify any limitations?</i>	Yes	Yes
	<i>Are the conclusions the same in the abstract and the full text?</i>	Yes	Yes

Table 5. SURE Quality Framework, qualitative studies, Support Unit for Research Evidence (SURE), Cardiff University.

## 1.9 SYNTHESIS OF STUDIES

Studies included in the systematic review will be synthesised below; findings and methodological limitations will be presented.

### 1.9.1 Reasons for use of pro-ED websites

In the largest study of pro-ED website users to date, with a sample of nearly 1,300 individuals, the most frequently cited reasons to access pro-ED websites were motivation for weight loss, weight loss tips, meeting people and curiosity (Peebles et al., 2012a). Similar motivations were also cited in relation to pro-recovery websites, including weight loss tips and tips on hiding the disorder. Interestingly, 29% cited social support as the most important reason to access pro recovery sites, whereas only 6% of respondents cited support as the fundamental motivation for accessing pro-ED sites. With a high quality rating of 30/38, the study appears the most robust to date, and findings suggest that individuals primarily seek pro-ED websites in order to lose weight through learning weight loss tips.

In a relatively small online survey of 60 pro-ED website users, 65% reported that they learned of pro-ED sites through search engines (Ransom et al., 2010). Motivations for joining and using pro-ED websites included a sense of belonging (77%), social support (75%) and to support their choice to continue eating disordered related behaviours (52%).

Rates of social support as a reason to access pro-ED websites differed between two reported studies (6% in Peebles et al., 2012a in comparison to 75% in Ransom et al., 2010). Such a disparity may be accounted for by differences in the quality of the studies (30/38 for Peebles et al., 2012a versus 16/38 for Ransom et al., 2010). Alternatively, the perceived importance placed on social support as a reason for using pro-ED websites may account for differences reported. The majority of individuals surveyed (75%) may feel that support is one of many reasons to access pro-ED websites, whereas few individuals (6%) may believe that social support is the fundamental factor in deciding to use the websites. Moreover, participants were potentially recruited from different ‘types’ of pro-ED websites; labelled as pro-ED forums (Ransom et al., 2010) as opposed to pro-ED websites (Peebles et al., 2012a). Forums may provide greater opportunities for sharing and communicating than standard pro-ED websites, which may explain differences in perceived support received from websites.

Similar findings in terms of motivations regarding weight loss behaviours were evident in a US study focusing on the experiences of 76 adolescents with eating disorders (Wilson et al., 2006). Reasons for visiting pro-recovery websites included support (60%) and meeting others with eating disorders (48%). In contrast, reasons for visiting pro-ED websites included motivation for weight loss (70%), and social support (37.5%).

The studies consistently indicate that individuals report using pro-ED websites as a means to learn weight loss techniques, to meet others with an eating disorder, and to gain a sense of belonging.

## **1.9.2 Possible dangers of using pro-ED websites**

### *1.9.2.1 Self-reported adoption of new high risk weight loss behaviours*

Post pro-ED website use activity was assessed in a large sample of pro-ED website users (Peebles et al., 2012a). It was found that 61% reported using new weight loss or purging methods; 37% used laxatives, diet pills or weight loss supplements; and 55% admitted to changing eating habits. Findings suggest that a proportion of users not only learn new high risk weight loss methods, they also apply what they learn online to their own behaviour (Peebles et al., 2012a).

Similar results were found amongst adolescent patients using pro-ED sites (Wilson et al., 2006). According to self-reports, 96% learned new weight loss or purging methods, 64% learned about diet pills, laxatives or supplements, and 69% reported implementing new weight loss or purging methods as a result of using the websites. This suggests that users' behaviours are influenced by the content of websites. Interestingly, users of pro-recovery websites also reported learning high risk eating behaviours; 46% learned new weight loss or purging methods (Wilson et al., 2006).

Findings are echoed in a sample of 60 pro-ED website users, whereby 60% learned how to effectively conceal eating behaviours from others; 57% learned how to fast, and 47% used diet pills (Ransom et al., 2010). Other concerning behaviours reported include using alcohol or drugs to inhibit appetite (22%) and engaging in self-harm behaviours (22%).



Similarly, in a small survey of 29 French pro-ED website users, 72% noted that they received advice regarding techniques to avoid eating, 83% learned ways to decrease feelings of hunger and 93% viewed weight loss tips (Rodgers et al., 2012). Only one participant reported that they had observed another forum member being advised to eat more to avoid harming herself.

Findings across studies appear to consistently demonstrate that many individuals who use pro-ED websites learn and adopt new high risk weight loss behaviours.

#### *1.9.2.2 Other risk indicators of pro-ED website usage*

Measures of patient health outcomes within an adolescent sample suggested that users of pro-ED websites had been ill significantly longer than non-users, although there were no differences regarding length of time in treatment (Wilson et al., 2006). Also, pro-ED users were found to spend less time on homework than non pro-ED website users. However, no significant differences were found on objective health outcomes, such as body weight, low bone mineral density or missed menses. Authors suggest that whilst pro-ED websites may not directly impact on health outcomes in adolescents, use may be associated with quality of life and may promote the learning of maladaptive behaviours (Wilson et al., 2006).

Similarly, analyses within the most robust study compared outcomes in individuals with heavy pro-ED usage (defined as daily use for at least one year), medium use (use for over one month but less than one year) and light use (use for less than one month) (Peebles et al., 2012a). Correlational analyses demonstrated that heavy use was significantly associated with more extreme and harmful weight loss behaviours such as purging and use of laxatives, as well as greater pathology on clinical measures of eating disorder behaviour and quality of life (EDE-Q and EDQOL) than medium and light website usage. Results suggest a discrepancy in the reported impact of pro-ED websites; whilst many pro-ED users generally appear to report positive influences in terms of social support, more objective measures suggest that intensive use of the sites is associated with risky behaviours and poorer quality of life (Peebles et al., 2012a).

Causality cannot be presumed due to the correlational and cross-sectional methodology, nonetheless, the average age of initial use of pro-ED sites was greater than the reported onset of eating difficulties. Authors suggest a possible progression from the development of eating difficulties into pro-ED websites usage, as opposed to a causal effect whereby pro-ED

website use leads to an eating disorder (Peebles et al., 2012a). Findings also suggest that a subset of individuals who use the websites intensively may be more vulnerable to the negative effects of use. However, it is not known whether such a ‘high usage’ group engaged in more extreme eating disordered behaviour prior to using the websites, or whether use of the sites exacerbated their eating difficulties and further impacted on quality of life. Longitudinal research is required to identify the vulnerability factors which may enhance an individual’s susceptibility to engaging in frequent and intense pro-ED website use.

In addition, whilst the survey involved a large sample, the estimated response rate was 43%, therefore, there may be biases in individuals choosing to respond to the survey. Due to the online nature of the study, it is not possible to conduct comparisons between completers and non-completers so inferences cannot be made regarding those more likely to complete the survey.

#### *1.9.2.3 Minimising dangers and risks*

Whilst the dangers of pro-ED websites were acknowledged by some website users, many were minimised or ignored (Peebles et al., 2012b). Qualitative responses suggested that a ‘web ethic’ was apparent whereby behaviours that would be considered as dangerous offline, such as diet pills, were considered less risky when online. Authors propose that such ‘distorted beliefs’ may reinforce continued pro-ED website use (Peebles et al., 2012b). Furthermore, in support of a potential minimisation of risks, all respondents in an online survey of 29 French pro-ED website users stated that they were aware of health risks associated with restrictive eating and purging. Nevertheless, 41% reported that they felt the risks did not apply to them, or they were not concerned about the risks (Rodgers et al., 2012).

### **1.9.3 Perceived benefits of using pro-ED websites**

#### *1.9.3.1 Social and emotional support*

Findings from the large international survey demonstrated that users felt highly supported by pro-ED websites; 60% reported feeling highly supported by pro-ED websites whereas only 16% reported feeling highly supported by pro recovery websites (Peebles et al., 2012a). Respondents reported that they found a like-minded community on pro-ED websites in contrast to pro-recovery sites.

A qualitative question combined with the above mentioned survey assessed perceptions of the role of pro-ED websites on an individual's eating disorder (Peelbes et al., 2012b). Many respondents reported a sense of isolation, feeling 'like a freak' and lacking social support outside of pro-ED websites. A subgroup of participants described health professionals as 'faceless doctors', perceiving care-givers as non-empathic with a lack of understanding regarding their views. Family and friends were also perceived to have a lack of understanding, which further fuelled a sense of isolation. Participants generally reported that they felt pro-ED websites reduced a sense of isolation and provided support, describing the forum as the only place where they could be 'real' and 'truly connect' with others (Peebles et al., 2012b).

In support of this, a qualitative study involving interviews with 33 authors of pro-ED blogs found that such blogs and websites fulfilled a supportive role which individuals felt was not available in 'offline' relationships (Yeshua-Katz & Martins, 2013). Responses suggested that the stigmatised social perception of eating disorders, in particular anorexia, led to individuals feeling socially isolated in real world environments. Online blogs were argued to provide a safe and non-critical audience whereby individuals gained a sense of community and unconditional support.

Further emotional benefits of visiting pro-ED websites were raised within a French sample of pro-ED website users (Rodgers et al., 2012). Within an online survey, respondents reported positive consequences of using sites, such as a sense of belonging and a perception of being listened to (72%). Results demonstrated that 28% reported satisfaction at weight loss and only 14% reported vague negative effects from websites, for example '*I was better before*'. Whilst findings may suggest that non-English speaking participants perceive pro-ED websites in a similar light to English-speaking respondents, the compromised quality rating of 7/38 may limit the generalisability of findings. For example, information regarding the frequency of use of websites was not collected and the sample was relatively small.

Adding more weight to the notion that individuals turn to pro-ED websites for social support, a survey of 60 pro-ED forum members demonstrated that pro-ED website users reported significantly less perceived social support in offline relationships than age matched controls (Ransom et al., 2010). The difference in social support reported by forum members and

controls was particularly pertinent for their most significant stressors; within the forum group this was their eating concerns.

Authors note that the anonymous nature of pro-ED forums may facilitate open discussions regarding negative or shameful behaviours, where individuals feel a shared sense of understanding which is not readily available in offline, real world relationships (Ransom et al., 2010). As previously noted, the role of stigma and shame in disclosing eating disorder related thoughts and behaviour within offline relationships is echoed in findings from interviews with pro-ED blog authors (Yeshua-Katz & Martins, 2013).

#### *1.9.3.2 Catharsis*

A sense of catharsis was also raised in a qualitative study involving authors of pro-ED blogs. In addition to a sense of support, it was noted that contributing to pro-ED blogs and websites can improve mood and provide a sense of relief (Yeshua-Katz & Martins, 2013). Individuals felt able to post thoughts about their eating disorder that they believed would be judged critically by friends, family or health professionals.

### **1.9.4 Different approaches to pro-ED website use**

In a study of moderate quality (21/38), an online survey of 150 international pro-ED users highlighted disparity between users' online behaviour. An 'Active' user group was found to experience benefits from using the pro-ED websites whereas a 'Passive' user group appeared to endure detrimental effects of the websites (Csipke, 2007).

Such 'Active' users engaged in online discussions with other users and were interested in jokes and other 'cultural content'. The group reported some advantageous effects from receiving emotional support from other online users. 'Active' users reported feeling that they shared more in common with other users and the use of pro-ED websites resulted in improved subjective self-esteem. 'Active' users reported participating in chat-rooms which was appraised as often fulfilling a crisis resolution function.

In contrast, 'Passive' users were silent observers of pro-ED websites and reported browsing tips and tricks sections significantly more than 'Active' users. Such silent browsing to sustain eating disordered behaviour was found to be particularly harmful. Researchers argue that

such direct interaction from others on the website experienced by ‘Active’ users may help to ‘buffer’ the potentially damaging content of the pro-ED websites. On the other hand, ‘Passive’ users who are exposed to pro-ED content in the absence of emotional support may be more vulnerable to the adverse impact of pro-ED websites (Csipke, 2007).

Within the study, 30 participants whose pro-ED website use fell in the ‘middle’ of ‘Passive’ and ‘Active’ groups were excluded from analysis. Therefore, important information regarding individuals who are potentially more ambivalent about pro-ED websites was lost.

Furthermore, whilst 24% of participants reported being depressed, it is unclear whether depression occurred more frequently in ‘Active’ or ‘Passive’ users. It may be that ‘Passive’ users experienced higher levels of depression and consequently were less likely to actively seek support from websites. Alternatively, ‘Passive’ website users may feel more ambivalent about their eating disorder and choose not to immerse themselves within pro-ED websites.

Pro-ED website usage appeared to have an overall detrimental impact on body image; authors argue that the sites generally helped to maintain eating disordered behaviour and discouraged users from recovery. However, it is noted that a genuine sense of support is available for a subgroup of users, with possible positive effects from website usage, for example a sense of belonging and reduced fear of rejection through embarrassment or disgust (Csipke, 2007).

### **1.9.5 Ambivalence**

In a qualitative study, one male and 13 female pro-ED website forum members took part in an online focus group discussing eating disorders, particularly anorexia nervosa (Williams & Reid, 2010). Using Interpretative Phenomenological Analysis, two overarching themes were identified regarding conflict about anorexia and barriers to recovery. Authors refer to a sense that participants experienced an underlying conflict between the beliefs that anorexia provides a sense of control, yet concurrently anorexia is in control of them. Anorexia was viewed as a means to feel in control, gain a sense of achievement, cope with and avoid negative feelings, and express emotions. It was noted that despite participants’ involvement in pro-anorexic websites which promote anorexia as a lifestyle choice, anorexia was also described in the focus group as an illness; *“a disease no different from cancer; a potentially fatal disease”* (p.561).

Such ambivalence led to participants describing anorexia, or ‘Ana’ as both a friend and an enemy, and led to ambivalence as to whether to maintain behaviours or attempt recovery. Involvement in pro-ED websites was viewed as a barrier to treatment; particularly in terms of listening to negative attitudes towards treatment from others online (Williams & Reid, 2010).

### **1.9.6 Conclusions**

Overall, themes emerge regarding the perceived support and mutual understanding that pro-ED websites provide to users who are experiencing eating difficulties. However, it also appears that such websites teach and promote potentially harmful behaviours, such as use of laxatives and diet pills, as well as covert techniques to deceive family and professionals, which users often employ. Risks that are apparent in ‘real life’ may be minimised or ignored in an online environment, and it appears that different levels of website engagement (passive and active use) may impact on outcomes. In contrast, there is some evidence to suggest that pro-ED forums may also encourage positive behaviours, such as healthy eating or acceptance of body image (Ransom et al., 2010).

When findings are considered in the context of previous experimental research, it appears that pro-ED website use may have a detrimental impact on the psychological and physical wellbeing of users (e.g. (Theis et al., 2012; Juarez et al., 2012; Bardone-Cone & Cass, 2007; Bardone-Cone & Cass, 2006). However, users may also perceive various benefits from engaging in an online pro-ED environment.

## **1.10 METHODOLOGICAL ISSUES**

### **1.10.1 Sample sizes**

Sample sizes within survey studies included in the review range from 29 to nearly 1,300, although four of the five surveys utilised samples of less than 200 respondents. Such small sampling limits generalizability of findings to the larger population of individuals using pro-ED websites. Potential selection biases are prevalent across all cross sectional surveys. Due to the anonymous nature of online surveys, and the anonymity of the population of pro-ED website users, it is difficult to assess potential biases in individuals who choose to respond in contrast to those who do not participate in the research.

Furthermore, low response rates add to the problem of potential biases in responding. Response rates as low as 15.2% are reported in the literature (Wilson et al., 2006). Therefore, results may not be representative of the wider population of pro-ED website users. Survey responses also relied on recall of experiences some several years previous, enhancing the risk of recall biases.

### **1.10.2 Potential for biased responses**

The potential issue of participants answering questions favourably in an attempt to ‘protect’ the pro-ED websites from being shut down is raised within some papers (e.g. Csipke, 2007; Ransom et al., 2010). It was noted that some pro-ED website users contacted researchers stating they were reluctant to complete the survey and other similar research due to concerns that the research would stigmatise them or be used to close down the sites that they used. Thus it is difficult to assess the honesty of participant responses within online surveys. However, it is argued that individuals do tend to report negative implications of pro-ED use as well as positive influences, which has been interpreted as participants providing open and honest responses (Ransom et al., 2010).

### **1.10.3 Correlational designs**

Whilst the studies reviewed are open to methodological criticisms, a relatively robust study of nearly 1,300 pro-ED website users provided interesting insights into the perceived effects of pro-ED website use. Authors conclude that greater pro-ED website use is associated with worse outcomes when other factors such as duration of eating difficulties was controlled for (Peebles et al., 2012). However, correlational designs do not allow for conclusions regarding cause and effect to be drawn. Whilst various studies suggest that eating difficulties may precede pro-ED website use, large scale longitudinal studies, or in depth qualitative studies are useful in order to assess and explore the complex relationship between pro-ED website use and pathological eating further.

Furthermore, existing research assessing pro-ED websites usage within clinical eating disorder samples appears to have focused mainly on cross sectional survey and correlational methodology. Whilst such methods provide descriptive data regarding motivations for using pro-ED websites and potential consequences of using sites, the deeper exploration of the functions of sites and how they fit with a person’s understanding of their eating disorder is

not possible. Also, the studies highlight perceptions at a ‘snapshot’ in time, namely how the participant views pro-ED websites at the point at which they fill in the questionnaire. An understanding of the journey through which individuals initially use and continue to use pro-ED websites is not captured.

#### **1.10.4 Limited qualitative data**

Whilst qualitative studies have provided interesting insights into the perspectives of individuals with eating difficulties who use pro-ED websites, at present only two relevant studies appear to have been conducted (Yeshua-Katz & Martins, 2013; Williams & Reid, 2010). Also, to date, interviews have been completed through electronic means such as online focus groups, telephone, email and Skype which may present with different dynamics than face to face interviews. Also, there appears to have been no exploratory studies conducted specifically with individuals who are in active treatment for eating disorders.

### **1.11 STUDY AIMS**

At present there appears to have been no face to face interviews with individuals receiving treatment for eating disorders that have accessed and viewed pro-ED websites. Exploratory work through direct interaction with such individuals is useful in order to understand the underlying function and processes involved in accessing and continuing to view such websites.

The research aims to explore the function of pro-ED websites from the perspective of individuals in receipt of NHS eating disorder services. Through interviewing service users who have used pro-ED websites, the research aims to explore the following:

- The mechanisms by which individuals came to initially view pro-ED websites.
- The functions of pro-ED websites and the processes underlying repeated use of websites.
- The impact of pro-ED websites on thoughts, feelings and behaviour.
- Perceptions regarding the externalisation/personification of ‘Ana’ (anorexia) and ‘Mia’ (bulimia).
- Perceptions of the impact of pro-ED websites on recovery and treatment for eating disorders.



Such exploratory work may help to improve the effectiveness of interventions for individuals with eating disorders. A greater understanding of the mechanisms contributing to an individual initially viewing and continually utilising pro-ED websites is clinically relevant in terms of assessment practices, formulation, intervention and longer term evaluation of treatment for individuals with eating disorders.

## CHAPTER TWO: METHODOLOGY

### 2.1 OVERVIEW

The following chapter provides an overview of the rationale and methodology used within the research. The design and procedures are outlined below.

### 2.2 DESIGN

The study employed a qualitative research design. A purposive sample of individuals in receipt of NHS treatment services for eating disorders within South Wales completed semi-structured interviews. The interviews, which explored participants' use of pro eating disorder (pro-ED) websites, were audio recorded and transcribed. Constructivist Grounded Theory was the approach used in the analysis of the data.

#### **2.2.1 A qualitative design**

As previously noted, much of the research investigating pro-ED websites to date has utilised quantitative methods. Individuals without an eating disorder have been exposed to real or mock pro-ED content in order to measure the impact on factors such as self-esteem, body image and eating related behaviours. Qualitative methods in the form of content and discourse analyses of pro-ED websites and forums have also been undertaken. Whilst analyses of website content are useful in understanding the nature of the material that individuals access online, such methodology does not present opportunities to explore the impact that the websites have on individuals with eating difficulties who access them.

The relationship between pro-ED websites and concerning eating related attitudes and behaviours appears complex and requires further investigation. At present there are no known

published studies describing face to face interviews with individuals receiving treatment for eating disorders that have accessed and viewed the websites. Qualitative designs are suited to exploratory projects (Brown & Lloyd, 2001) and permit the in-depth assessment of phenomena which are not easily quantifiable, such as the psychological impact of pro-ED websites. This work could promote a greater understanding of the mechanisms contributing to an individual initially viewing and continuing to access pro-ED websites, which in turn has potential to enhance clinical practice.

### 2.2.2 Qualitative philosophical underpinnings

Qualitative methodologies are concerned with exploring how individuals experience and make sense of the worlds they live in. Underpinning qualitative methods are the position they hold in relation to epistemology, that is the theory of knowledge; which attempts to answer “*how, and what, can we know*” (Willig, 2008, p.2).

A continuum from positivism to relativism may be presented to illustrate various epistemological positions (Charmaz, 2006). In its purest form, positivism, which suggests there is a simple relationship between the world and our understanding of it, posits that research aims to uncover an objective truth. Through observation, a definite ‘truth’ emerges through the eyes of impartial and unbiased ‘witnesses’. However, it has been acknowledged that such a position fails to account for cultural and social factors influencing the ‘lenses’ through which phenomena are observed (Willig, 2008). Conversely, at the other end of the continuum, extreme relativism proposes that there are no absolute truths (Willig, 2008).

In contrast to positivist and realist positions, social constructionism suggests that human experience is mediated through culture, history and language, and is becoming increasingly influential in the realm of research (Willig, 2008). A social constructionist perspective argues that reality is not merely uncovered; rather it is constructed in the minds of beings. Consequently, various ‘socially constructed’ positions may form multiple realities of an issue. A social constructionist approach to research highlights how the researcher and participant co-construct reality. This results in the development of one *type* of reality, rather than *the objective* reality coming to light.

## 2.3 GROUNDED THEORY

Grounded Theory (GT), a qualitative methodology which aims to produce and develop a model from the data, was used. GT provides an explanatory framework to understand phenomena and so is often used for the exploration of new areas of research (Willig, 2008).

GT originated within the field of sociology (Glaser & Straus, 1967) and has more recently been applied to the study of human behaviour within the realm of psychology (Willig, 2008). GT encompasses “*the progressive identification and integration of categories of meaning from data*” (Willig, 2008, p.35). Its method utilises discovery and induction which is in contrast to more traditional research techniques which commence with hypotheses and use methods of deduction to test such hypotheses (Elliott & Lazenbatt, 2005). Further details of GT are detailed in the analysis section below.

### 2.3.1 Constructivist Grounded Theory

Whilst the GT methodology was originally developed by Glaser and Strauss (1967), the authors subsequently proposed and developed divergent perspectives on the process and application of GT. Purest ‘Glaserian’ theorists suggest that researchers should start with an empty mind, taking a passive position to observe a theory which emerges through the data (Willig, 2008). In contrast, a ‘Straussian’ position may suggest that the researcher begins with a general idea about the direction of the research and goes on to interpret the developing theory (Willig, 2008).

It has been argued that original descriptions of GT which refer to the ‘emergence’ of themes from data imply that a particular ‘truth’ exists which is uncovered by the researcher. However, Charmaz (1990, as cited in Willig, 2008) developed a ‘social constructionist’ version of GT, proposing that categories and theories do not simply ‘emerge’ from the data, “*but are ‘constructed’ by the researcher through interaction with data*” (Willig, 2008, p.45). Constructivist Grounded Theory holds social construction epistemology at its core. The approach highlights the role of the researcher as co-constructor in the research, rather than as a passive observer who brings no influence to the discovery of *an objective reality*.

GT as proposed by Charmaz highlights that the researcher's political, philosophical and personal background influences decisions made throughout the research, such as questions asked of participants, themes attended to and interpreted within the data, and the way in which the methodology is applied. Consequently, it is believed that the researcher develops one particular way of making sense of a phenomenon, rather than uncovering the 'truth' of phenomena.

### **2.3.2 Rationale for using Grounded Theory**

GT is often applied to areas of research where little is known in order to generate preliminary theories of a phenomenon (Strauss & Corbin, 1998). Much of the existing literature in the field of pro-ED websites is descriptive rather than explanatory. There is a paucity of studies examining the impact of pro-ED websites on individuals with an eating disorder.

Consequently, a GT approach was considered suitable for the present study.

Moreover, the research aimed to explore the processes through which individuals use pro-ED websites as well as the perceived influence of the websites in order to develop a theoretical model. It is acknowledged that participants are likely to form a heterogeneous group of individuals and therefore, theoretical sampling within GT can assist in exploring the similarities and differences of experiences of pro-ED websites. GT also allows for interview questions to be tailored according to previous interviews. Such flexibility was considered beneficial in order to investigate individuals' unique perceptions of pro-ED websites in the context of an eating disorder.

In addition, GT is argued to be appropriate for socially constructed experiences (Charmaz, 2003; Goulding, 1998), which may be relevant to the notion of eating disorders and the pro-ED movement. The literature has highlighted socially constructed influences within the development and understanding of eating disorders. For example, anorexia was once viewed as a moral and religious issue; however, following the dominance of the medical model within health care, anorexia evolved to become viewed as a psychiatric or medical disorder (Hepworth, 1999). Similarly, gender role social constructions have been implicated in the development of eating disorders (Piran & Cormier, 2005).

Finally, it has been argued that a ‘fit’ between the epistemological assumptions of chosen methodology and the position of the researcher is important (Willig, 2008). Therefore, due to the researcher’s appreciation of social constructionist approaches, and the role that the researcher may take in exploring such a potentially emotive subject, the constructivist GT approach as developed by Charmaz was applied to the present study. In its endeavour to develop a co-constructed experience of the world from the researcher and participant’s perspective, constructivist GT does not strive to result in a ‘complete’ theory of a phenomenon (Charmaz, 2006); as uncovering *the* objective truth is at odds with its epistemological positioning.

## 2.4 ENSURING QUALITY

Whilst no universally accepted definition of ‘best practice research’ exists, it has been argued that to strive for ‘best practice’ assumes a positivist stance whereby research aims to uncover ‘objective’ facts (Elliott & Lazenbatt, 2005). Nevertheless, particular generic quality criteria have been applied to both quantitative and qualitative research (Elliott, Fischer & Rennie, 1999). The authors suggest that assessing relevant literature, clearly defining research questions, choosing appropriate methods, conducting research in an ethical manner, and presenting appropriately tentative discussion regarding the implications of findings are important to ensure quality across all realms of research.

### 2.4.1. Publishability Guidelines

In the context of qualitative research, a set of proposed publishability guidelines have been developed in an attempt to promote the rigour of qualitative methodologies (Elliott et al, 1999). Authors maintain that the following criteria are non-exhaustive or definitive, but provide guidance to qualitative researchers. The researcher will endeavour to address the following principles during the present research, highlighted in italic font below.

1. *Owning one’s perspective:* authors are advised to specify theoretical orientations, both in advance and as they emerge throughout the research. Authors should attempt to communicate their understanding of the phenomenon within the research, explicitly noting how their values, interests and assumptions impact on their understanding. Any personal experiences of the research topic should be highlighted. This is argued to assist the reader in interpreting the findings and considering potential alternatives. *Issues of*

*reflexivity related to the research are outlined below and are reflected upon within the discussion chapter, as well as in the form of selected entries of the researcher's reflective journal.*

2. *Situating the sample:* researchers are advised to provide details regarding research participants in order to aid readers to judge the relevance of the range of people and situations in relation to the findings. Good practice examples include providing details regarding participants' age, gender, ethnicity and social class. *Demographic information of participants is presented below in order to assist the reader in situating the sample.*
3. *Grounding in examples:* it is recommended that authors provide examples of the data to demonstrate analytic procedures used and to illustrate the understanding developed in light of the analysis. This will allow readers to examine the interpretations of the author and formulate possible alternative meanings from the data. Offering at least one or two examples of each theme is suggested to be good practice. *Anonymised direct quotes are presented in the results section to illustrate the development of themes presented.*
4. *Providing credibility checks:* several methods for checking credibility of themes may be employed, for example, where relevant checking with original informants (see below for respondent validation), using multiple analysts, comparing two or more varied perspectives, or potential 'triangulation' with external factors such as quantitative data. Examples of good practice include asking colleagues with relevant experience in the area of study to review and potentially elaborate on themes identified within the analysis. *A peer Trainee Clinical Psychologist who was undertaking an unrelated research project using constructivist grounded theory was consulted through various stages of analysis. Selected transcripts were coded in collaboration with the colleague, and particular categories were developed through discussion with the Trainee Clinical Psychologist as part of investigator triangulation (Guion, Diehl & McDonald, 2011). Themes were also reflected upon in supervision.*
5. *Coherence:* authors are advised to represent their understanding in a coherent and integrated manner, whilst maintaining nuances in the data. Analysis and findings should be presented within a narrative framework, for example using diagrams and summaries to convey the understanding of the phenomenon under research. *Diagrams are presented*

*within the results section in order to assist the reader in understanding findings in a coherent manner. Findings are presented using various fonts to highlight themes, core categories, categories and sub-categories.*

6. *Accomplishing general vs. specific research tasks:* the researcher is advised to clearly acknowledge whether they are intending to develop a general understanding of a phenomenon or an in-depth specific understanding of a particular case. Limitations of applying findings to additional contexts should be clearly noted. *The researcher acknowledges that the research is likely to explore the experiences of a heterogeneous sample of individuals in treatment for eating disorders. The research strives to develop a general understanding of the impact of pro-ED websites, highlighting similarities and disparities amongst participants' responses. Constructivist GT does not strive to develop the 'complete' and 'true' account of phenomena.*
  
7. *Resonating with readers:* the content of the research and the emerging theory should be communicated clearly in order that readers are able to judge the research as accurately representing the subject under study. The reader should feel that the researcher has captured the experiences of interviewees. *It is anticipated that through adhering to the principles outlined above, and the researcher's respect and gratitude to the participants within the study, the findings and emerging theory should capture the experiences of the interviewees. Quotes are presented throughout the results section to illustrate the participants' experiences.*

#### **2.4.2 Quality within GT**

In terms of ensuring quality specifically within GT methodology, Elliott & Lazenbatt (2005) note that the continuous cycle of data collection and analysis is an essential feature. In order to ensure that emerging categories are embedded in the data, constant comparative analysis, which involves checking back to the raw data, is essential. Memoing is an additional function to ensure quality in GT. Memos aim to limit subjectivity through enhancing the researcher's awareness of personal biases and allow the researcher to check whether memos fit emerging theory.



Authors highlight that features within GT, such as constant comparative analysis and memoing mean that respondent validation; whereby themes are relayed back to original participants to check for agreement is unnecessary and introduces an additional layer of analysis (Charmaz, 2006). Such features of GT will be outlined in greater detail within the analysis section below.

## 2.5 REFLEXIVITY

As previously mentioned, according to quality guidelines, researchers are urged to own their own perspective (Elliott et al., 1999). Similarly, within GT, particularly the constructivist approach, the researcher is encouraged to take a position of reflexivity (Willig, 2008). This may be achieved through disclosure of personal beliefs and relevant experiences related to the research topic. This supports the reader to interpret the presented data in the context of the researcher's experiences and to consider potential alternatives.

Reflexivity was a central aim of the present study; the author's initial assumptions and beliefs about the pro-ED paradigm are outlined below. Throughout the process of data collection and analysis, a reflective journal was kept, as recommended within constructivist GT (Charmaz, 2006) and supervision sessions facilitated transparency and reflexivity. Moreover, following recommendations related to reflexivity within qualitative research (Ahern, 1999) the researcher took part in reflective discussions with peer Trainee Clinical Psychologists in order to highlight issues related to self-reflexivity.

### 2.5.1 Self-reflexivity

As self-reflexivity involves personal reflection the following will be described using a first person narrative.

I am a 28 year old English female in my final year of doctoral training in clinical psychology. I have a background working both academically and clinically within the field of forensic psychology, in the Prison Service and secure hospitals. As a potential consequence of such experiences, I would identify myself as particularly mindful of potential power imbalances within mental health settings. I acknowledge that whilst working from an 'expert' position has the potential to facilitate service user confidence in mental health professionals; such a stance may also fulfil an oppressive, disempowering and potentially abusive role.

I am increasingly influenced by social constructionism in the understanding of mental health difficulties, and particularly view the concept of ‘eating disorders’ as existing on a continuum. It is my belief that people can shift from body image and eating concerns viewed as socially ‘normal’, to more extreme concerns which may become pathologised.

I lean more towards a ‘person centred’ approach whereby service users’ choice and shared decision making are central to recovery and wellbeing, promoting autonomy and equality. I believe that whilst mental health services often strive to work from such principles, my experiences both as an Assistant Psychologist and as a Trainee Clinical Psychologist have highlighted that mental health services are often designed to take the lead and deliver interventions *to* service users, rather than collaborating *with* service users.

I am also aware that within the realm of eating disorder treatment, individuals may ‘receive treatment’ against their will, in extreme cases being admitted to inpatient services and force fed. This presents a moral dilemma; I acknowledge that such practices may be necessary to protect the life of the individual; however, such treatment may also be experienced as particularly abusive and traumatising.

Whilst having no personal experience of eating disorder services, I identify with societal values emphasising the importance of appearance, weight and shape. I have also observed the impact of the intensely perceived pressure to be ‘thin’ and ‘attractive’ in friends and family members.

I initially became interested in the research topic after one of the current project supervisors attended a research fayre and presented pro-ED websites as a potential area of research interest. I was not previously aware of pro-ED websites and was intrigued by their existence. When deliberating whether to proceed with the current research project, I attempted to search for said pro-ED websites with an open mind. I initially felt detached from the websites, viewing the relationship as an ‘academic’ exercise in the name of research. However, the ease of accessibility and the explicit content in the form of text and images was a noticeable shock to me. I noticed experiencing an immediate defensive reaction, judging the websites to be harmful and irresponsible, preying on vulnerable people in the midst of an eating disorder. This position is explicitly acknowledged as I feel it is important to highlight any potential preconceptions regarding the research topic.

## 2.6 PARTICIPANTS

Details of recruitment procedures inclusion criteria are outlined below.

### 2.6.1 Recruitment context

Participants were recruited through NHS mental health services within two Health Boards in South Wales. Some participants were recruited through Tier Two Community Mental Health Teams and other participants were recruited through Tier Three Specialist Eating Disorder Services. There was uncertainty regarding the number of potential participants available for recruitment, therefore, two health boards were approached to broaden the sample.

Health Boards were established in Wales in October 2009 following the merger of many NHS Trusts and Local Health Boards. The merger resulted in a total of seven NHS Wales Health Boards covering the whole of Wales. One of the recruiting Health Boards delivers NHS services to six counties of South Wales, including both rural and urban communities. The second recruiting health board covers four localities, delivering NHS services to approximately 289,400 people, serving the most deprived population in Wales.

The research was reviewed and approved by the NHS Wales Research and Development Research Scrutiny Committee and Research Risk Review Committee within both hosting Health Boards. See Appendix B for Research and Development approval documentation.

### 2.6.2 Inclusion and exclusion criteria

Participant inclusion and exclusion criteria are outlined below.

Inclusion Criteria:

- Adults aged 18 and over.
- In current receipt of NHS eating disorder services.
- A history of and/or present use of pro-ED websites as disclosed to clinicians during assessment/treatment.
- Agreement through clinical judgement of recruiting clinician/multi-disciplinary team that participation in the study would not be detrimental to the participant's health or clinical care.

Exclusion Criteria:

- People who are currently hospitalised due to their eating disorder.
- People who are unable to participate in an interview of 60 minutes.
- Individuals who may pose a risk under the lone worker policy for the relevant health board.
- People with communication difficulties (hearing or significant speech problems).
- People who are unable to speak English.

Only people with sufficient command of spoken and written English were included as no funding for translators or interpreters was available.

### **2.6.3 Recruitment procedure**

Clinicians working in NHS mental health services (Community Mental Health Teams and Tier Three Specialist Eating Disorder Services) who had agreed to support the recruitment of participants were provided with a Clinician Information Sheet, see appendix C. Clinicians were asked to identify individuals from their clinical case-loads who fulfilled inclusion criteria as outlined above.

Clinicians informed identified individuals about the research using a Participant Information Sheet (see Appendix D) and invited them to take part. If an individual expressed an interest in taking part in the research they were asked to sign a Consent to be Contacted Form, refer to Appendix E. The researcher then collected all Consent to be Contacted Forms and made contact with potential participants to discuss the research and arrange a mutually convenient date to conduct the interview. Interviews took place within the NHS premises that participants attended for treatment.

### **2.6.4 Sample size**

Within the field of GT research it has been suggested that in order to attain saturation of themes and categories, an ideal sample size may range between eight to 12 participants (Smith & Osborn, 2003). It is suggested that the number of participants in qualitative research should not exceed 12 because of the difficulty in managing large data sets (Smith & Osborn,

2003). As the target population was thought to be relatively small, a purposive sampling method was used. Seven participants were recruited and took part in the research.

## 2.7 DATA COLLECTION

### 2.7.1 Development of a semi-structured interview

A semi-structured interview was devised to explore participants' experience of pro-ED websites. A Clinical Psychologist working in a Tier Three NHS specialist eating disorder service and a Service User Representative from a research development group for eating disorders in South Wales were consulted with to develop the question ideas. Their input was extremely valuable in thinking through interesting areas to focus on during interviews. Please refer to Appendix F for a copy of the initial interview schedule.

Grounded theory allows for interview schedules to be tailored depending on previous interviews. Therefore, the interview schedule was a guide, but the researcher adapted interview questions depending on analysis of themes and categories from previous interviews, in accordance with theoretical sampling, described below.

### 2.7.2 Procedure

Interviews were conducted with participants at the NHS premises that they attended for treatment. Sessions lasted no longer than one and a half hours. The researcher initially explained the study information and answered any questions. Informed consent was obtained, see Appendix G for the Participant Consent Form, and interviews were conducted individually with the participant.

Interviews were audio recorded with a digital recorder and generally lasted between 45 and 60 minutes. Participants were informed that the recorded interview would be destroyed following transcription, and that all transcripts would be anonymised to assure confidentiality.

Following the interview participants were invited to ask any questions and were provided with a Debriefing Information Sheet, see Appendix H. Participants were given information to

enable them to access a summary of the findings following completion of the study in September 2014 should they wish to do so.

### **2.7.3 Transcription**

All interviews were transcribed within a week of the interview taking place. Interviews took between five and six hours to transcribe, which allowed immersion in the data. Interviews were transcribed verbatim, with pauses and non-verbal content, such as laughs and nods, being included in transcripts. Participants were assigned pseudonyms to protect anonymity.

The author reflected on the process of the research through writing a reflective journal. The journal was updated through significant stages of the research, for example, undertaking the ethics and research governance procedures, and following each interview.

### **2.7.4 Participant demographics**

Participant demographics were recorded and are presented in Table six below. Pseudonyms have not been added to the table in order to protect the anonymity of participants in identifying interview quotes. The table illustrates the heterogeneity of participants in terms of their age and length of eating difficulties. In support of the Transdiagnostic Model of Eating Disorders (Fairburn, 2003), all participants reported that they had undertaken both restricting (anorexia presentation) as well as bingeing and purging (bulimia presentation) behaviours throughout their eating difficulties. Whilst all participants were in receipt of treatment for eating disorders, at the time of interview no participant appeared to be at a weight that would attract a formal diagnosis of anorexia nervosa.

Participant	Age	Ethnicity	Length of eating difficulties	Occupation
1	37	White British	7 years	Managerial
2	20	White British	6 years	University Student
3	38	White British	24 years	Social Worker
4	26	White British	5 years	Retail Assistant
5	34	Central European	15 – 17 years	Social Worker
6	24	White British	14 years	Retail Assistant
7	40	White British	23 years	Catering Manager

Table 6. Participant demographics.

## 2.8 DATA ANALYSIS

The author listened to the audio recording of the interview during the process of transcription. Transcripts were read several times in order for the author to become immersed in the data. The data analysis process is outlined below.

Grounded theory involves the identification of categories within the data which share central characteristics (Willig, 2008). In contrast to content analyses, categories within GT are not pre-defined and are not mutually exclusive; they emerge from the data. Data collection and analyses occur simultaneously in GT.

### 2.8.1 Coding

According to Charmaz (2006), “*Coding means categorizing segments of data with a short name that simultaneously summarizes and accounts for each piece of data*” (Charmaz, 2006, p.43). Initially, open coding was used whereby the data are examined freely. Incident by incident coding (Charmaz, 2006) was used to openly code units of data. This involved the labelling of units of data, for example sentences or parts of sentences using short, action focused words. The aim of open coding is to begin to propose how participants perceive themselves, others and the world (Strauss & Corbin, 1998) in an attempt to portray meanings and actions whilst remaining close to the data (Charmaz, 2006).

Following open coding, focused coding was implemented. Focused codes are more directed and selective than initial open codes (Glaser, 1978 as cited in Charmaz, 2006) and form subcategories. Focused coding becomes a more analytic process in order to categorise data: *“Focused coding means using the most significant and/or frequent earlier codes to sift through large amounts of data”* (Charmaz, 2006, p.57).

Theoretical coding was then implemented which organises subcategories to higher order conceptual categories. Core categories are formed which conceptualise categories. Saturation is achieved when no new categories or concepts emerge from subsequent data collection. Theoretical coding attempts to conceptualise causal relationships between concepts developed through open and focused coding (Jones & Alony, 2011). Theoretical coding is used to develop the emerging theory within grounded theory, and helps, *“to tell an analytic story that has coherence”* (Charmaz, 2006, p.63). Validity in GT is suggested to arise when saturation of themes occurs.

As previously stated, a peer Trainee Clinical Psychologist undertaking an unrelated constructivist GT research project contributed to the open and focused coding of a selected transcript in accordance with quality guidelines. The researcher also consulted with the research supervisor during the process of analysis to enhance the credibility of findings.

### **2.8.2 Constant comparative analysis**

Constant comparative analysis is used to identify similarities and differences within and between categories. It is proposed that sampling, data collection and analysis should be considered to be a continuous cycle rather than distinct procedural steps (Elliott & Lazenbatt, 2005). Constant comparative analysis aims to capture all variance in the data to inform the emerging theory which is ‘grounded’ in the data. Therefore, codes were frequently compared both within and between transcripts.

### **2.8.3 Memo writing**

Memo writing is central to constructivist GT, especially due to its epistemological position where meaning is co-constructed. Definitions of categories are recorded and relationships within and between categories are documented, integrating low order and higher order categories. Memoing is argued to be important in controlling the quality of the data (Elliott &



Lazenbatt, 2005). Memos are used to check whether the concepts and categories fit the emerging theory; memos that do not fit are put aside (Elliott & Lazenbatt, 2005). An example memo and excerpts from the author's reflective journal are presented in Appendix I.

#### **2.8.4 Theoretical sampling**

Theoretical sampling involves further data collection following the development of categories and is fundamental to GT. Theoretical sampling strives to ensure that the emerging theory develops rigor and parsimony (Jones & Alony, 2011). Therefore, interviews were tailored according to categories identified in previous interviews. In line with theoretical sampling, the interview schedule evolved throughout the data gathering process, as outlined in Appendix J.

Constructivist GT aims to produce a theory of a phenomenon in terms of key themes, core categories, categories and sub categories. A diagrammatic representation of such analysis is developed to aid the reader's understanding of the emerging theory.

### **2.9 CLINICAL GOVERNANCE AND ETHICAL CONSIDERATIONS**

The research was reviewed and received favourable ethical approval by the National Institute for Social Care and Health Research (NISCHR) Research Ethics Service for Wales. Please refer to Appendix K for ethical approval documentation. The researcher undertook an Introduction to Good Clinical Practice e-learning course prior to undertaking the research. The course focused on ethical and scientific quality standards in clinical research. Relevant ethical considerations are outlined below.

#### **2.9.1 Consent**

All participants were consenting adults. Participants were informed that participation in the study was entirely voluntary, and that they were free to withdraw at any time.

Care Co-ordinators are responsible for the care of mental health patients under the Mental Health (Wales) Measure. The consent form also sought consent to inform the participant's Care Co-ordinator about their participation in the study. A standardised letter, see Appendix

L, along with the Clinician Information Sheet were sent to the Care Co-ordinator of each participant.

Capacity to consent to the research was assessed by clinicians prior to approaching individuals about participating in the study. Interviews were conducted sensitively and participants were informed that they could pause or terminate the interview at any time. A Debriefing Information Sheet provided details of sources of support following participation in the research.

### **2.9.2 Risk**

Due to the established adverse effect of viewing pro-ED websites within the literature, service users were only approached to participate in the study if they had previously disclosed during assessment and/or treatment that they currently use, or historically accessed pro-ED websites.

Prior to consenting to the research, participants were informed verbally and through the Participant Information Sheet that the researcher would inform the recruiting clinical team of any information suggesting the participant or others were at risk of harm.

### **2.9.3 Conflict of Interest**

At the time of the research, the lead researcher was not working clinically with the recruitment population; therefore, it was believed that no conflict of interest between research and clinical work should arise.

## CHAPTER THREE: RESULTS

### 3.1 OVERVIEW

This chapter will present the Constructivist Grounded Theory developed from the analysis of the seven interview transcripts. For clarity, within this chapter, **THEMES** will be presented in bold capitals, **CORE CATEGORIES** will be presented in underlined capitals, **categories** will be presented in bold lower case, and *sub-categories* will be presented in lower case italics. A list of themes, core categories, categories and sub-categories can be found in Appendix M.

Five themes were constructed following analysis:

- **FEAR**
- **COGNITIVE DISSONANCE**
- **SOCIAL COMPARISONS**
- **SHAME**
- **PRO-ED WEBSITES MAINTAINING ED**

Figure two below represents the Constructivist Grounded Theory model relating to the function and impact of pro-ED websites within a sample of individuals in treatment for an eating disorder. The results will be outlined in greater detail throughout the chapter and interview quotes with pseudonyms will be presented to illustrate the development of the themes and categories.

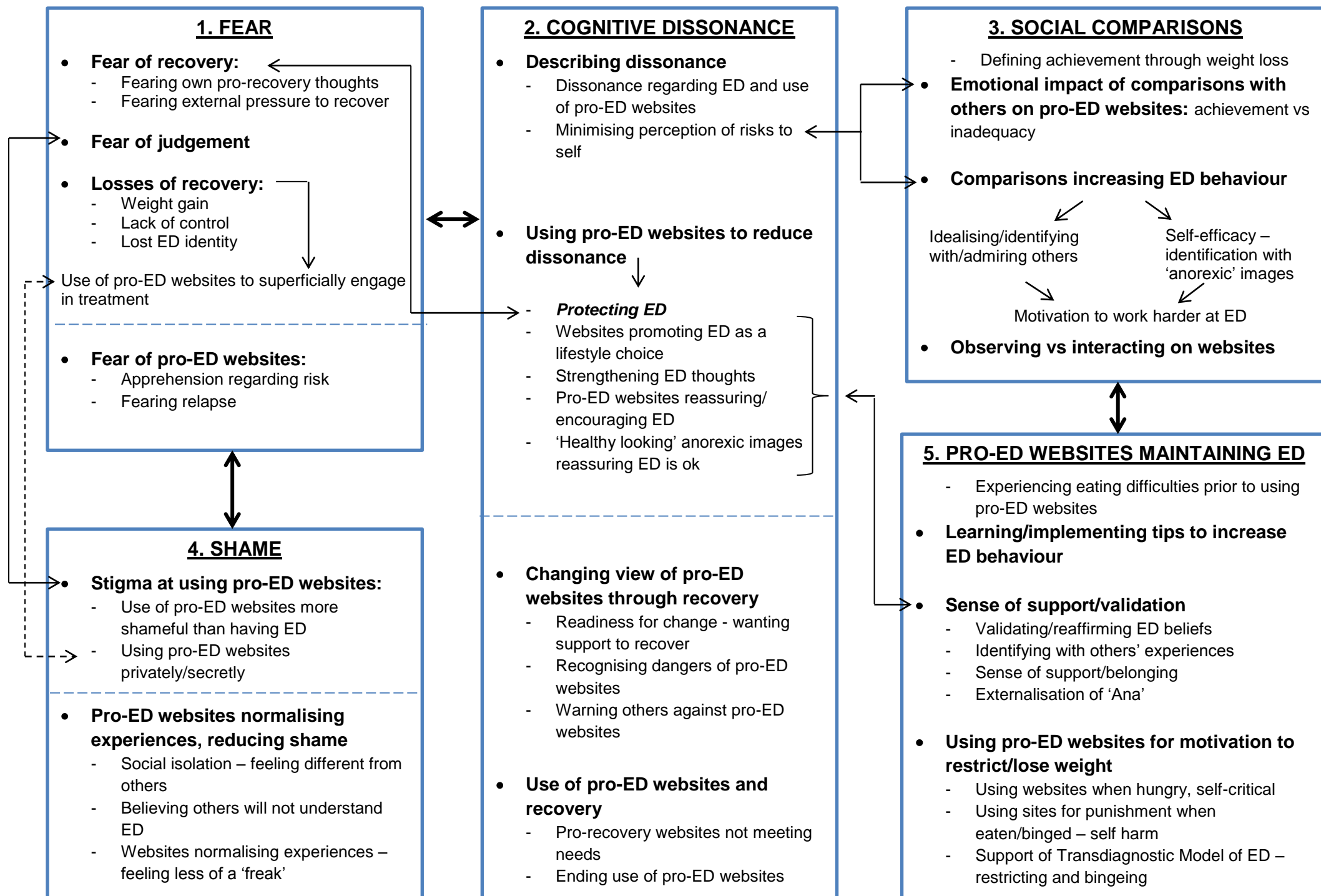


Figure 2. Constructivist Grounded Theory Model of the function of pro-ED websites.

### 3.2 THEME ONE: **FEAR**

The theme of **FEAR** was developed following perceptions that respondents felt and described a sense of fear regarding their eating disorder, their recovery and their use of pro-ED websites. The theme incorporates four core categories: **FEAR OF RECOVERY**; **FEARING JUDGEMENT**; **LOSSES OF RECOVERY**; and **FEAR OF PRO-ED WEBSITES**. The core categories are described in greater detail below, along with **categories** and *sub-categories*.

As outlined below, fear was described differently according to the stage of each participant's journey through recovery. For those who wished to maintain their eating disorder, fear appeared to be associated with the anticipation of recovery. Pro-ED websites appeared to be used to protect individuals from the fear of recovery. For participants who had undergone treatment and appeared to be less entrenched in their eating disorder, the fear they felt prior to engaging in treatment, and the losses associated with their recovery were reflected upon. For those who were further in to 'recovery', participants also appeared to fear pro-ED websites in terms of the influence the websites could have over increasing their risk of relapse.

#### 3.2.1 **FEAR OF RECOVERY**

Fear of recovery conceptualises the anxiety that individuals described about anticipating recovering from their eating disorder. Some participants described **fearing own pro-recovery related thoughts**, which refers to an individual's internal thoughts promoting recovery. At the time of interview, Sophie was actively engaged in treatment and was aiming to overcome her eating disorder, however, she reflected on prior fear related to her internal 'doubt' thoughts.

Sophie: *"I guess like thoughts about why eating like....it kind of made me a better person and I was very stuck in like that was the right thing to be doing so any thoughts I'd have that would kind of oppose that, like um basically, it was pointless to like starve myself and things like that and it wasn't making me feel better, anything like that, if I was having them thoughts and I was kind of afraid of the doubt thoughts."*

Some individuals also reported fear regarding an **external pressure to recover**, reporting that they *feared being pressured in to treatment*. Some individuals appeared to turn to pro-ED

websites in part due to fear that they would be forced to recover if they disclosed their eating practices to others, as Catherine describes below.

Gemma: *“although you’re obviously in the system and you’re in “recovery” and you’re trying to recover, there’s that part of you that actually doesn’t want to, and it kind of fuels that how can I how can I stop, you know how can I stop them making me recover, when maybe you don’t want to.”*

Catherine: *“Finally I felt like I could let it out cause it’s was a really secretive thing and there was no risk in trying to take it away from you, I felt at home like people understood...If I went and said to my mother this is what I’ve been doing the first thing they’re going to do is stop you trying to do it, which is what I didn’t want, so on there no one is going to try and stop you doing it and nobody knows you so nobody could if they wanted to.”*

Other individuals described difficult experiences within treatment services, in particular *feeling threatened or pressurised during treatment.*

Amy: *“I wasn’t always involved with a nice team of people like [therapist], and uh yeah I had quite a tough time at one point and again it was, I was getting shouted at and you know kind of like go on you’ve just got to eat or we’re gonna take this away from you and this away from you, you’re gonna go back in to hospital and it just didn’t work for me and so I felt quite put into a corner.”*

Rachel: *“I’d already started seeing um my therapist and was being told that um I absolutely had to eat three times a day and I really didn’t want to, I didn’t want to eat anything and I was being told if I was to continue with the therapy that that’s what I had to do and because I find it really hard to be told I have to do something and then not do it, um I really struggled with that....I felt um, I don’t know just almost like backed in to a corner... it was kind of like that was my side of the bargain and I found that really hard because it just felt like it was an impossible thing for me to do at that time.”*

### 3.2.2 LOSSES OF RECOVERY

Individuals reflected on the losses associated with their recovery which appeared to underpin the fear of recovery as described above. A fundamental loss associated with recovery from an

eating disorder was **weight gain**. Some individuals who had undergone treatment and had returned to more 'normal' eating practices reflected on the loss of their ideal body image as a result of 'recovery', as described by Amy and Rachel below.

*Amy: "I look back now and it's more jealousy coz I don't have that body image anymore..... my weight's gone up to much more of a healthy weight for me at the moment but I'm just feeling really overweight and there'll be several times when I'll just, I feel so overweight."*

*Rachel: "it's a real battle because I know that from doing the therapy that I've done I get why it's important that I don't slip back in to old habits and eating disorder ways [tearful] but equally I can't accept myself the way that I am and I get really angry at myself for being for asking for help when I did and for and for sort of taking my eye off the ball as it were."*

Subsequent losses associated with recovery from an eating disorder appear to be a *lack of control* and a *lost eating disorder identity*:

*Amy: "I feel like the eating disorder is one thing that I was good at, and now I'm not even good at that anymore, and so sometimes it can have a negative effect because I'd go on these sites and I see everyone doing so much better at their eating disorder than I am. And that can be quite demotivating."*

A fear of recovery and the losses associated with recovery, in addition to a perception of being forced in to treatment, led to some individuals **using pro-ED websites to superficially engage in treatment**. Some participants employed techniques promoted on the pro-ED websites to deceive professionals, friends and families into believing they are working towards recovery, despite actively sabotaging treatment attempts. Using pro-ED websites to superficially engage in treatment is related the second theme of cognitive dissonance, in particular using pro-ED websites to protect the ED, as described in section 3.3 below.

*Gemma: "you know maybe you're, you're not in recovery but if you're recovering and you don't really want to recover in a way you're being forced to it's kind of like I guess people in that situation where you find out what they done and how they deal with things as well."*

*Interviewer: "So tell me a bit more about you say when you're kind of in a position where you're being forced to recover, how do the websites come in, feature in that?"*

*Gemma: “Um it’s like, they kind of give you hints and tips as to how to fool people in to thinking that you are getting better and putting on this front where you’ve got, you don’t want to recover but you want to make people believe that you are, this perception of you so yeah you know if it feels like people are forcing you then you want to kind of please them but you wanna stay the same, like as you are.”*

*Catherine: “once that eating disorder side of your head really takes over it makes you want to go on [pro-ED websites] just so you can prove that the people that are trying to help you are actually trying to sabotage you so when I’m there, say they said well you’re at a healthy weight, my eating disorder’s side of my head will say they’re saying you’re fat...it sort of undermines what they’re doing so I can’t trust them...I think it’s more my head that does that and then they [websites] just sort of motivate that side of me to rebel against whoever is trying to help me sort of thing.”*

### 3.2.3 FEARING JUDGEMENT

This core category refers to the fear of being judged for using pro-ED websites. Individuals appeared to believe that others would not understand their use of pro-ED websites and they would consequently **fear criticism or judgement regarding pro-ED website use**.

Individuals described concern at ‘letting people down’ or being ‘told off’ for using the websites. This fear of judgement is associated with the stigma of pro-ED websites outlined in theme four of shame described in section 3.5 below.

*Rachel: “I never actually discussed my use of them with my therapist because I really believed that I’d get into so much trouble even though I felt that because of, because I’d, by using them it had helped me to get into eating regularly um I really felt that if I if I discussed that with my therapist I’d be in a lot of trouble [laughter].”*

*Gemma: “I think it would be more of they wouldn’t understand why. They wouldn’t understand the reasons why, they’d look at it and go why are you looking at that for, it’s not helpful. It’s kind of like that telling off thing.”*

*Charlotte: “Well work just won’t understand, nobody sort of understands do they, it’s just everybody just says I’m mad [laughs]...but it’s just I won’t tell them because they’d tell them I’ve lost it, [laughingly] my marbles. And they’d think I’ve gone mad.”*



### 3.2.4 FEAR OF PRO-ED WEBSITES

In addition to a fear of recovery, some individuals described a sense of fearing pro-ED websites, with regards to being apprehensive about the content of websites. For participants who were actively working towards recovery and had stopped using pro-ED websites, the fear of pro-ED websites was associated with a **fear of relapse**. Participants appeared anxious regarding the struggle of resisting the temptation to return to the pro-ED websites.

Amy: *“I’ve come off that course and I’m a bit scared and going off into a whole new world where, I still don’t have a proper relationship with food but I’m at a healthy weight.....so now I’m feeling more vulnerable now....I guess the emotional side is dragging me back towards those websites more now because I’m, my emotional thinking is much greater than it was maybe a couple of months ago.”*

Rachel: *“I haven’t looked at them since probably, well [pause] well over a year I’ve not looked at them...I think I’ve just had to try not to think about it, you know that when I get those thoughts I try to distract myself from it so that I don’t end up um becoming obsessed with it....I think if I started to look at them once you’ve done that once it’s easier to then keep doing it again and it just becomes a um an easier thing to do, you know it’s like oh it’ll be ok, it’s just going to help me, it’s not going to, it can’t do any harm.”*

Moreover, some participants described feeling **apprehension at websites supporting high risk behaviour**, such as suicide at a time when they were actively using pro-ED websites.

Amy: *“The only thing that was quite scary was at one point I did get, did feel quite suicidal and....there were noticeable comments to other people that felt the same way, and they were saying well yeah if you feel like you want to do it....you should do it there’s no shame.... I got a bit scared by that because there was one point where I was actually starting to formulate plans and actually becoming quite serious, and that’s one thing you don’t really want to read and that’s, that really did scare me a little bit.*

### 3.3 THEME TWO: COGNITIVE DISSONANCE

The second theme identified within the analysis was COGNITIVE DISSONANCE; individuals appeared to experience conflicting attitudes and beliefs regarding their eating disorder and their use of pro-ED websites. Beliefs appeared to develop both internally and externally through the influence of others. Four core categories were developed from the data: DESCRIBING DISSONANCE; USING PRO-ED WEBSITES TO REDUCE DISSONANCE; CHANGING VIEW OF WEBSITES THROUGH RECOVERY; and PRO-ED WEBSITES AND RECOVERY. Again, **categories** and *sub-categories* are also outlined below.

#### 3.3.1 DESCRIBING DISSONANCE

Many respondents described an inner battle regarding their eating disorder and their use of pro-ED websites; labelled as **dissonance regarding ED and use of pro-ED websites**. Some individuals applied language used within treatment approaches that they had completed, such as ‘rational mind’ and ‘emotional mind’ from Dialectical Behavioural Therapy (DBT). Others talked about experiencing an ‘anorexic’ voice and a ‘normal’ voice, or a ‘logical’ and ‘eating disorder’ mind:

Amy: *“I always think of kind of having an anorexic voice and a normal voice and they almost sometimes they feel like two different people.”*

Sophie: *“I always kind of thought of it as that being my unhealthy side, my eating disorder side and another side....Like I say I’d be scared of the other thoughts I was having, the kind of healthy recovery thoughts I was having.”*

Individuals also described dissonance regarding their use of pro-ED websites. Many participants explained a sense of inner conflict as they found the websites supportive and useful for reaching goals related to the eating disorder, yet had doubts as to whether the websites were helpful in terms of their health. Many individuals described continuing to use pro-ED websites despite feeling guilty.

Rachel: *"I felt like it was a really naughty thing to do, like it was really wrong because I'd heard such negative stuff about it. And also because at that point I didn't really see myself as having an eating disorder at all so it was um I didn't really see that link but I just saw it as a way of being able to get me some ideas of how to how to stop eating."*

Gemma: *"I think that it's a bit of embarrassment as well because although you're looking at it and you really really like looking at these websites and I really get a lot out of it it's part of you that goes I shouldn't be looking at them at the same time and you think that other people would kind of like see it and go why are you looking at that for, and there's kind of like guilt at the same time."*

Catherine: *"it was a mix between being nervous and is this the right thing to do but at the same time being quite excited because it [pro-ED website] was full of people who thought the same as me and it was supportive."*

Whilst many interviewees appeared to acknowledge risks of eating disorders and the use of pro-ED websites, many **minimised the perception of risks to the self**. This appeared to be exacerbated by comparisons made with other websites users (theme three). Participants often considered themselves to engage in less 'extreme' behaviour than other users on the websites. Therefore, the perceived risks of their own behaviour were minimised.

Amy: *"....there's a body of evidence that people can be very thin and still lead a healthy life, you know people telling you you're unwell, you may not be fit to drive, you're not fit to travel and I'm like well I don't know what you're talking about because there's a whole group of people out there that are thinner than me and are doing all these things, so I guess that I'd use that kind of discussion that I'd been building up from the websites as part of an argument."*

Sophie: *"I guess it egged me on a lot like I think the sense of feeling like I didn't really have a problem because I'd always look at the people on there as being like sad, like they had the problem and I was just you know not like them."*

In addition to minimising the perception of risks of ED to the self, one respondent described experiencing a *pressure to meet diagnostic criteria* which may intensify an individual's

eating disordered behaviour and increase the physical and psychological risks of their behaviour. Catherine explained that she believed NHS treatment guidance results in individuals feeling that they need to fulfil diagnostic criteria for anorexia nervosa in order to justify professional help, which exacerbates the risks of their behaviour. Catherine suggests that individuals may turn to pro-ED websites for support as they do not feel that they deserve or justify professional support.

Catherine: *“I think NHS guidelines are worst for making you feel that you don’t have an eating disorder you’re not justified for help because you feel like you have to fit in this category to be classed as anorexic. You’ve got to be so much underweight to fit that box that you feel like you have to get there before you get the help and when you get there you don’t want the help ....I think a lot of people are on there [pro-ED websites] because they don’t feel like they deserve the help professional help because they don’t fit the box.”*

### 3.3.2 USING PRO-ED WEBSITES TO REDUCE DISSONANCE

Following the experience of dissonance outlined above, and the perception of being pressured in to treatment, many respondents described using pro-ED websites to reduce cognitive dissonance about their eating disorder. Participants described using information and support from pro-ED websites in order to reduce the credence of the messages received by others that eating disorders are dangerous and should be ‘treated’.

**Using pro-ED websites to protect ED** was described by many respondents regarding reducing the influence of pressures arguing against eating disorders. Respondents appeared to use pro-ED websites to seek reassurance and strengthen arguments that weight restriction was normal and healthy. The pro-ED websites were used to reduce internal doubts regarding the risks of the eating disorder and to fight against others who argue that food restriction and extreme weight control is dangerous:

Amy: *It [pro-ED website] helps bolster my own opinion and reaffirm my own opinion that that’s right, whereas all the medical people that I’m seeing especially trying to always knock away and say weight loss is bad and all these consequences and you feel like you’re in a corner, and actually then you got this group of people that are saying ‘you’re alright, keep going’ .... you want to be reassured that you’re perfectly healthy being underweight, and everything’s fine, there’s no consequences and so having all of that is kind of like, especially*

*when you get backed in to a corner, you're like actually no I'm alright. So it's almost reassuring the emotional mind."*

*Sophie: "well I'd definitely say it kind of egged me on, in the sense that you know any thoughts I might have been having about why I was doing it or the consequences of it, it kind of it kind of stopped me thinking them so much..... if I was kind of really battling with myself and I'd kind of go on there to kind of dismiss some of the thoughts that the quite good ones that I was having for recovery, but ones that I kind of when I was kind of wanting to be stuck in my eating disordered ways I'd want to shoo them away."*

*Gemma: "you kind of get that, you wanna recover but you don't and then you go back there cos it's kinda like a safe, a safe place where you go right I know that everyone else there knows what I'm going through."*

An **illusion of 'healthy' looking images supporting ED** was identified within the transcripts. Individuals appeared to focus on images of extremely underweight ('anorexic') looking people on the websites who appeared to be 'healthy' as a way of supporting that extreme weight loss is healthy. Images of gaunt looking 'ill' people were often ignored or dismissed as they promoted the notion that eating disorders are dangerous.

*Amy: "..... you know how someone with anorexia can look really gaunt and tired and, just looking very unwell, whereas all these images, all the ones that worked for me were girls looking really nice, you know, healthy complexion and looking as though they were living life to the full even though they were very underweight."*

*Laura: "And the worst is when you see pictures of women or some men as well that look literally like skeletons but they're still able to jog, and you will find things like that and you'd just think wow I'm nowhere anywhere near that, I was at my thinnest I was a size eight to ten, I was nowhere near what they were, and they can still run around then it can't be so bad and it's obviously just me why I can't concentrate as well as I did before."*

### 3.3.3 CHANGING VIEW OF WEBSITES THROUGH RECOVERY

Whilst all respondents were recruited within treatment services for eating disorders, individuals appeared to be at various stages of recovery. Some individuals had completed

treatment and stated that they were continuing to work on their recovery, whereas, others in the sample stated that they were satisfied with their weight loss behaviour and were not intending to 'recover'.

It appeared that all respondents perceived pro-ED websites to be helpful, supportive and functional whilst 'in the middle' of their eating disorder. The websites provided reassurance that the eating disorder was a lifestyle choice rather than an 'illness', which helped individuals to feel more in control of their eating difficulties. For example, whilst Gemma acknowledges some risks of the websites, she consciously chooses to continue to use the websites. In contrast, many of the individuals who have undergone therapy and wish to recover from their eating disorder reflected on their current beliefs about pro-ED websites following treatment. Many stated that the websites are dangerous and help to maintain eating disorders, as Amy and Laura describe below.

Gemma: *"I see them as helpful, I can't really see them as a negative, you know there's that niggling thing at the back of your mind always, you know maybe I shouldn't look at this or you know it's not helping me, but the positives outweigh the negatives."*

Amy: *"I guess looking back on it now there was many unhelpful things that um, giving tips and tricks on how to lose weight and giving that reassurance and people just saying no you can't eat, go even lower, that's not helpful now I realise although it was then."*

Laura: *"But yeah at the same time it was really hard to accept that this is actually not normal because because they would tell you don't worry you know we've been there as well, don't let them tell you you're ill or anything like that it's a lifestyle. So you kind of, makes you feel secure in, you know and at the same time it's so harmful because you just think oh yeah if they all think that then it's got to be right.....all of those sites are just so blimmin dangerous. Um, I couldn't defend them at all."*

Some individuals described a **readiness for change and wanting to help recover** from their eating disorder, in contrast to feeling pressure for forced recovery. Participants described a process whereby they personally decided that they wanted support to recover from there eating disorder.

Laura: *"I started to think that this can actually be deadly and although I didn't really care about it for myself....[leave] your little boy out there without a mum you can't do it so so I knew I had to change something and I was very keen to get help."*

Interviewer: *"And so at what point did you stop using the websites?"*

Laura: *"Umm I stopped using them before that really, I think I stopped using them after a couple of half-hearted attempts because then I started to think more and I thought it's just it's just dangerous what they're saying, it's really dangerous because it gets you into that so much and it makes out it's actually quite alright and it's not and you could die from it."*

Of those who wanted support to recover, many reported **recognising dangers of pro-ED websites**:

Rachel: *"it's a very private thing and something that actually I spose inherently I feel is, was a wrong thing for me to be doing even though I can say that it helped me in a certain way, I also felt it was something that I really shouldn't be looking at that it it's the sort of website that shouldn't really exist."*

The dangers of websites were exacerbated due to the *vulnerability of people with ED*. This was raised in terms of the influence that pro-ED websites may have on individuals who are cognitively and emotionally sensitive due to the effects of the eating disorder. Therefore, pro-ED content is argued to have a more profound impact on individuals with pre-existing difficulties with eating and food.

Amy: *".... you think very differently when you're in the middle of having an eating disorder. Your emotional mind won't let you see these sites with, in a balanced way, it will cling on to it and you might be forced to go down the routes that you won't like when you get there."*

In relation to the dangers raised above, some individuals also described a sense of anger towards pro-ED websites, believing that the websites should be held *accountable for encouraging ED*.

Sophie: *"like now I feel more angry towards them. I think like they are very kinda, it is egging, like I'd never want the difficulties I've got with food on another person, that is technic. that is what they're doing. They're kind of egging other people on kind of like I don't*

*know making kind of people stuck in that kind of behaviour and things um so definitely, you know I guess knowing the effect they have on me I do feel, I don't think they're a good thing."*

Regardless of stage of recovery, all participants noted that they would **warn others against using pro-ED websites** despite some individuals continuing to engage in the websites for personal use. For example, Catherine continues to use the websites yet would not recommend them to other people:

Catherine: *"I wouldn't want to encourage them to do things that are going to make them worse or I'd maybe say to them that I've been on them [pro-ED websites] before but I'm not comfortable to talk about it with them because I don't want to encourage my friends to get ill."*

Interviewer: *"And so if they were curious and started to look for themselves what would you say to them if you knew they were starting to browse the websites."*

Catherine: *"To be careful because it can be very addictive and it can ruin, it depends on what frame of mind but you're in but it ruin your life because it can consume everything....it can become very addictive so I just say to be very careful, yeah probably try and persuade them not to use them."*

Sophie: *"I'd try to get them to stay away from them [pro-ED websites]. I think like there's such a competitive, a competitiveness with eating disorders and always a sense of not being good enough and things like that that I do think anything that kind of eggs on those beliefs they're not going to be good for anyone with an eating disorder. So I wouldn't recommend them."*

#### 3.3.4 PRO-ED WEBSITES AND RECOVERY

The final core category within the theme of cognitive dissonance concerns perceptions of pro-recovery websites and treatment services for ED. Individuals often stated that **pro recovery websites were not meeting their needs** when they required information and support for their eating disorder. Difficulties included *feeling excluded from pro-recovery websites* and finding *patronising/biased information*. It is possible that a reluctance to use pro-recovery websites and a sense that individuals cannot be open on self-help websites may encourage the use of pro-ED websites.



Laura: *"The self-help websites I didn't think they were very good to be honest...the more I was actually looking for self-help through the Internet um I was quite unhappy with what I was finding....a lot of the websites obviously are aimed at much younger people than me...you know it just doesn't help at all because it makes me feel old and it makes me feel even more weird. Um and a few of the pages they're just not very comprehensive...it would be just like an overview and it's like well I know all of that it don't really help me.... I found some of the self-help websites quite even patronising as in literally lecturing you."*

Catherine: *"self-help websites are a bit more, and for good reason you're not allowed to mention number or weight or dress sizes so there a lot more restrictive in what you can talk about on there, where for good reason it could trigger somebody I understand that but you're a lot more restrictive in what you can talk about... I've been on the beat website and self-help website and chat-rooms and something are really bothering you that you want help with you can't actually put them in the conversation".*

For participants who had actively engaged in treatment, many consciously decided to **end the use of pro-ED websites to engage in treatment** either before commencing treatment or during the treatment.

Amy: *"Umm I guess I did stop using them quite a lot because I just needed to, I was trying to motivate myself and go through this DBT programme... I realised there was triggers that I would go down if I went on to that and so I stopped using them."*

Interviewer: *"So was that a conscious decision from the treatment programme to give that a chance?"*

Amy: *"Yeah, yeah I think so, yes try and at least."*

Rachel: *"But then as the therapy progressed that became less of a um less um less of a hold on me that I realised that that wasn't that wasn't the way forward and so I'm not sure exactly when it stopped, perhaps like a year in to therapy you know I wasn't keeping those lists and I wasn't looking back at them [pro-ED websites]."*

Figure three below outlines the process through which individuals fear the losses associated with recovery and experience cognitive dissonance regarding their eating disorder. Their wish to maintain their eating disorder is in conflict with internal pro-recovery related thoughts and

external pressures to recover. Individuals appear to use pro-ED websites to protect their eating disorder through finding evidence which validates and strengthens thoughts supporting the belief that eating disorders are not harmful. Some individuals appear to actively use pro-ED websites to superficially engage in treatment in order to fight and rebel against treatment. In contrast, other participants appeared more ambivalent about treatment and recovery, and continued to secretly use the websites whilst feeling guilty and fearing judgement from their therapist.

It appears that some individuals developed an internal motivation and decided to work towards recovery for personal reasons, for example wanting to get better for their children. Such individuals appeared to consciously decide to stop using the pro-ED websites in order to attempt to engage in treatment and work towards recovery.

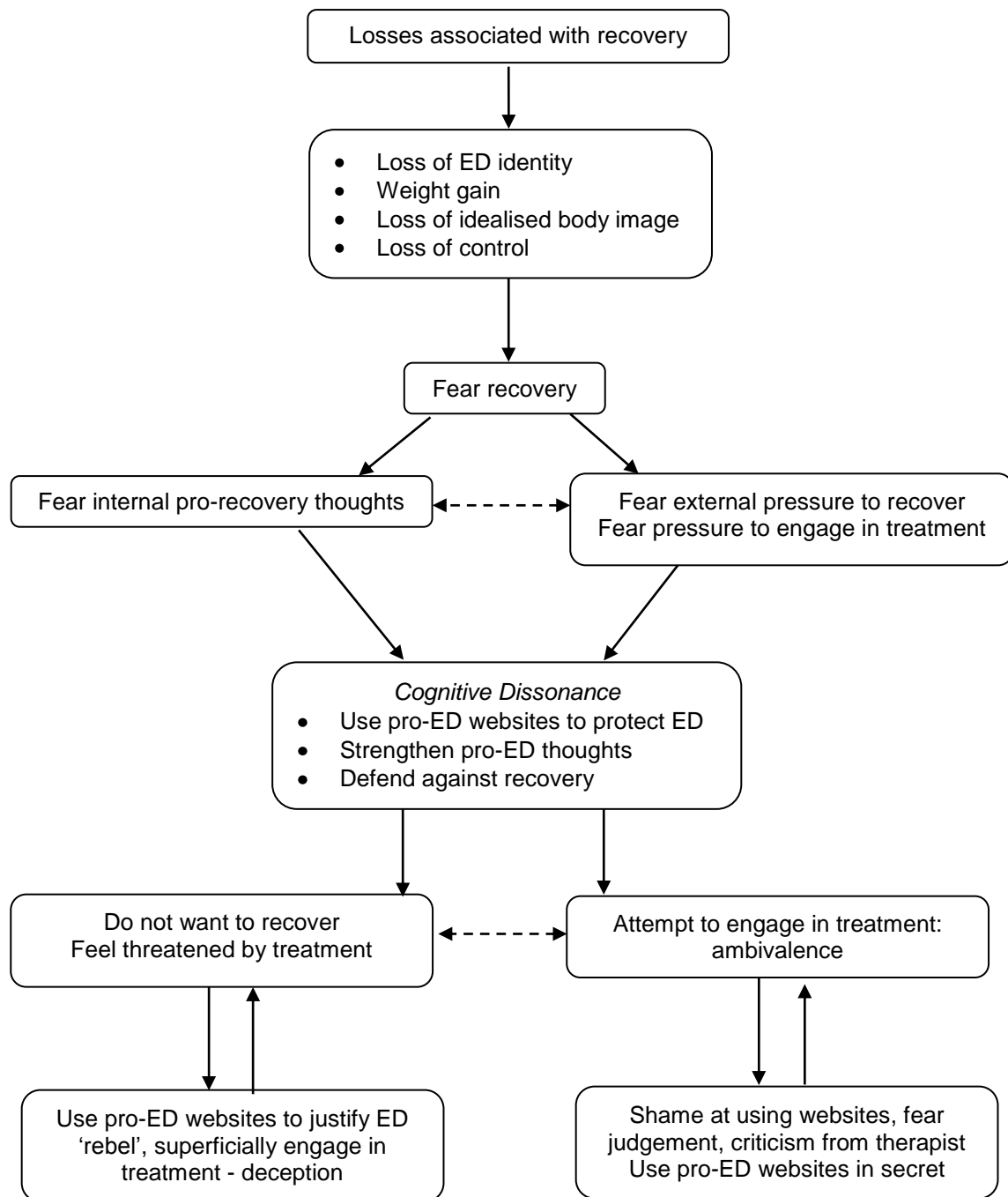


Figure 3. Process of using pro-ED websites to reduce cognitive dissonance to protect eating disorder.

### 3.4 THEME THREE: SOCIAL COMPARISONS

The third theme generated within the analysis relates to SOCIAL COMPARISONS made between participants and other users of pro-ED websites. Within this theme three core categories were identified: EMOTIONAL IMPACT OF COMPARISONS WITH OTHERS ON PRO-ED WEBSITES; COMPARISONS INCREASING ED BEHAVIOUR and IDENTIFICATION WITH USERS. **Categories** and *sub-categories* are outlined below.

#### 3.4.1 EMOTIONAL IMPACT OF COMPARISONS WITH OTHERS ON PRO-ED WEBSITES

The first core category of the social comparison theme relates to the emotional impact of the comparisons that individuals make between themselves and other pro-ED website users. Participants appear to **define personal achievement through weight loss**. Individuals appear to gain a sense of personal success, pride, strength and achievement through weight loss and food restriction.

Amy: "I guess it's all about confidence in body and there was a whole thing of for me, losing that much weight was a kind of a sense of achievement for me."

Sophie: "losing weight and stuff made you better and made you a better person, and all the good things that apparently came along with the losing weight and stuff."

Catherine: "so it's motivation in that sense that they've got to that point that their picture is now on there because people admire how they look, so it motivates you to do it because you think right, one day I want my picture to be one that people look at and think that's what I want to look like."

A **pressure to be thin is reinforced on pro-ED websites**; consequently, comparisons are made to others on the websites and result in either a sense of achievement or a sense of inadequacy.

Gemma: "I think that this comparison thing where people put post pictures of themselves or they post pictures of celebrities and again there's that idealisation of that you have to look a

*certain way and if you feel that you don't look a certain way then it doesn't make you feel great about yourself."*

Laura: *"there's always been like a niggle as in that can't be right. It was still like well I thought I don't have to go to these extremes as they do, if it only helps me to get more like that I'm gonna give it a go and then eventually I started to feel more pressure because I thought they're doing so much better than me, I wasn't nowhere near as thin as they were."*

Comparisons may fluctuate between achievement and inadequacy, depending on the individual's current 'performance' at their eating disorder. *Comparing self negatively to others leads to feeling jealous, inadequate and a failure whereas comparing self favourably to others results in reinforcing ED/enhancing self-esteem and pride.*

Sophie: *"I guess it made me feel like I wasn't...pushing myself enough to kinda lose weight ....sometimes I'd feel a bit like kind of useless when I was on them. I'd kind of be comparing myself to all these other girls who do it and so it kind of went two ways, sometimes it would egg me on and I'd feel good about what I was doing then other times it made me feel like I wasn't doing enough."*

Laura: *"she would video herself and say look that's how my belly looks now, that's how my bum looks now and it just makes you feel really really, I don't know really bad because you're not quite like that and no matter what you do you can't achieve it as quick as they can."*

Amy: *"...the anorexia was very much part of, and, sense of achievement and satisfaction about who I am and so going on and just realising that hey I'm really engaged in this and I'm doing this quite well and there's a whole group of people out there that would be... 'I want to get down to this weight how do I do it', and I'm like I'm there, I'm there at that weight.... again it helped boost my self-esteem."*

### **3.4.2 COMPARISONS INCREASING ED BEHAVIOUR**

The second core category within the theme captures the behavioural impact that such comparisons have on users; comparisons with other users appear to increase eating disorder

related behaviour. Pro-ED websites appear to **fuel comparisons and competition** between users.

Catherine: *“There’s loads of different competitions going on at the same time, fasting competitions, point based competition, they’ve recently started a new one...it’s sort of like set up like a school so you’ve got to weight, imagine the weight you want to lose is then divided in to seven to correspond with seven years of school and then you lose however much you want to lose to move up in certain classes, like restricting, fasting, exercise then you get elected classes as you move up the years, yeah I’ve never seen one like that before.”*

This category refers to individuals comparing the self to others on sites and **admiring/idealising/aspiring to be like others on websites**. Individuals described identifying with and idealising other users who posted about their weight loss. Participants often strived to achieve the body image of other ‘thinner’ users. However, not all participants strived to achieve the body image of the extremely underweight ‘anorexic’ images on the websites.

Charlotte: *“But obviously there’s pictures of people and stuff like that but that doesn’t bother me that’s how I want to look at the end of the day it doesn’t bother me how...you know as thinner people are getting the better they look.”*

**Self-efficacy** refers to the extent to which individuals believed that they were able to achieve such an extreme ‘anorexic’ body image. Some participants strived to achieve the weight of extremely underweight images on the websites whereas others reported that such a weight loss was an unachievable and unrealistic goal. Therefore, they would not relate to or identify with such underweight images.

Two sub-categories were formed, the first being *identifying with extremely thin users and striving to achieve their body image*:

Gemma: *“It’s motivation because you, you see something and you’re like I quite like that or I wish I looked like that and it gives you that motivation to kind of go right that’s what I wanna look like so you have this image in your head of what you want to look like, but you have this ideal like thing in your head that you want to look like and you use those pictures to kind of*

*make yourself be like, lose weight because you want to be that size, you want to look like that.”*

Charlotte: *“It’s normally before and after pictures and obviously they survive like and survive on an apple a day and stuff like that. And they’ve got the before pictures, how they looked and then afterwards then in so many weeks or months they’ve got down to that kind of weight. I think they look good obviously because obviously they’ve lost a lot of weight haven’t they so to me sticking out bones that’s how I want to be.”*

The second sub-category relates to *believing thin images are unattainable, not identifying with extremely thin images*

Rachel: *“I wasn’t looking to become anorexic, I wasn’t looking to be skinny like those girls because I don’t believe I could ever be like that so I had to kind of think well that’s a completely unachievable goal so what I had to do was focus on what I needed to do.”*

Laura: *“Of course when I see pictures of the extreme thin ones that I thought you know that’s scary, but I just thought I, why do I want to go and you know I wouldn’t look like them anyway.”*

Overall, such **comparisons increase motivation to work harder at ED.**

Sophie: *“Like I said I didn’t feel like I was ever doing enough so it would just get more and more, I was never kind of content at oh I’m eating this amount now and that’s enough, it would always be like no I need to cut back more.”*

Laura: *“I think it really fuelled it as in before then it was just like well I know that people are different and some are well they just lose weight quicker or don’t put it on so much and there’s nothing wrong with that basically, but when you see it like that it’s like rubbing it in your face at the same time it’s such a strong pull because it kind of gives you the hope that it is possible if only you try hard enough. So you’ll be skipping even more meals and making yourself even more sick. Because you think you’re not trying enough.”*

Charlotte: *“Looking at those pictures sort of spurred me on a bit more then and I think, ‘Oh God if they can do it I can do it.’ That’s the type of thing that you look at and you think, ‘Well obviously people can lose weight from going on those sites, so perhaps if I try harder and don’t eat anything at all then I might actually get down to how I want to be.’”*

### 3.4.3 IDENTIFICATION WITH USERS

The final core category relates to the extent to which participants identify themselves alongside other website users. Many individuals described **observing versus interacting on websites**. Out of the seven individuals interviewed, only one participant reported that they interacted with others and posted on the websites. Catherine stated that she had made long term friends through pro-ED websites, some of whom had since recovered from their eating disorder. However, Catherine also had the most severe eating disorder within the sample and continued to actively use pro-ED websites. Catherine was determined that she did not wish to recover from her eating disorder and only sought help for her difficulty with fluid restriction.

Catherine: *“because they provide competition and things if you have to update everyday you do interact with people. It’s, it’s not the same as when I first started and made my close friends, you do interact with people because you do post on the different blogs and the different categories.”*

The remaining six participants reported that they only observed the websites, reading blogs and posts. A sub-category emerged whereby individuals described *feeling inferior to other users and anticipated rejection if they interacted on websites* which appeared to explain their decision for not interacting on websites. Some individuals believed that they were not ‘worthy’ of interacting with other pro-ED website users, feeling like an ‘imposter’ on the websites, which resulted in a reluctance to post on the websites.

Sophie: *“I always kind of felt um inferior if anything I’d say, I think that’s one of the main reasons I never really used them properly, like as in never kind of went on them and used them myself, just kind of observed. I always felt like these girls were kind of doing what I kind of wanted to be doing, I wasn’t in the same boat as them if that makes sense?....I guess I kind of felt like an amateur, like kind of wannabe kind of thing.”*



Laura: *“I didn’t put it on there because I didn’t think I could help them much. I could have only put on there that I agreed with the others but then I thought that would have been a bit daft.”*

Whilst Catherine reported to be the only participant who interacted on the websites, she also noted that during the periods when she feels she is not ‘doing well’ at her eating disorder, she believes she is not worthy to post on the sites. This highlights a perception of the conditional nature of acceptance by the pro-ED online community:

Catherine: *“when you’re losing weight then you deserve to be on there, you can be on there where while I’m bingeing and putting on weight, I don’t feel like I deserve to be on there because I’m not fitting it then, and everyone is on there cause they want to lose weight where I’m gaining weight.”*

Individuals also reported *fearing lack of anonymity if posted online* which appeared to influence their choice to secretly observe the websites.

Gemma: *“I just think well again it’s that anonymity thing, you know that it’s anonymous and you know that people can’t find out who you are but it’s always the case of oh maybe someone might find out who I am.”*

Laura: *“because it’s of course anonymous, because that’s probably part of why I never participated because I just wanted to stay behind the screen. I mean it’s nothing I’m particularly proud of when, I never have been, it’s quite disgusting even when you’re in the middle of it...So it’s not really something you would want to sit down and discuss, especially when you’re in the middle of it.”*

### 3.5 THEME FOUR: SHAME

The fourth theme within the analysis refers to the concept of SHAME; shame regarding the eating disorder and shame regarding the use of pro-ED websites. The theme of shame includes two core categories: STIGMA OF USING WEBSITES and WEBSITES NORMALISING ED: REDUCING SHAME, along with **categories** and *sub-categories*.

#### 3.5.1 STIGMA OF USING WEBSITES

Many participants noted that they held beliefs that their **use of pro-ED websites is more shameful than having ED**. Participants described feeling that using pro-ED websites would be perceived by others as less understandable and more morally wrong than having an eating disorder. It appeared that the eating disorder could be viewed as an ‘illness’, potentially attracting empathy from others, whereas using pro-ED website involves choosing to maintain the eating disorder, actively ‘sabotaging’ recovery.

Rachel: *“I just felt it was just like almost worse than the eating disorder itself and that it was like a really like a conscious thing to be promoting my eating disorder and doing what I can to hold on to it... I think they’d be really disappointed and I think that it was, I felt that in some ways the eating disorder could be explained and that you know that people could understand that, but that if I was actually going out looking for, for ways of keeping the eating disorder going that that people wouldn’t understand that.”*

*Preconceptions of pro-ED websites* appeared to fuel a sense of shame, as some participants had been exposed to negative press coverage related to pro-ED websites prior to using the websites. Therefore, the stigmatised nature of pro-ED websites fuelled a sense of shame at using the websites.

Rachel: *“I think I knew about them from things like on the news that were quite negative about them, I don’t think I was really aware of their existence and you’d see in the paper you know about how shocking they are and what a terrible thing they are and um yes so that’s how I knew about them.”*

Shame regarding use of pro-ED websites appears to result in individuals **using websites privately and secretly** in order to reduce a sense of shame. This relates to a fear of judgement at using the websites, noted within the theme of fear above.

Gemma: *“it’s a very secretive thing that you don’t talk about it a lot...it’s kind of like even though you can’t talk to anyone about it coz obviously you can’t say to your, well you can say to your therapist well oh I don’t really it or I don’t like this I don’t like that, but it’s not ideal. You go to people who know, who are on the other side who are on the same side as you, and then you can share your experiences and you can kind of relate to people.”*

### 3.5.2 WEBSITES NORMALISING ED: REDUCING SHAME

This core category relates to the notion that pro-ED websites appear to reduce an individual’s shame regarding their eating disorder through normalising ED experiences. Individuals reported a sense of **social isolation; feeling different from others** regarding their wish to restrict and lose weight rapidly. Individuals appeared to believe that other people would not understand their extreme weight loss behaviours, resulting in a *reluctance to disclose the eating disorder to ‘real’ people*. Therefore, individuals turned to the accessibility and anonymity of the Internet to research weight loss tips and experiences.

Laura: *“I was desperate to learn how to lose weight quick, um of course I knew I couldn’t ask like the doctor or friends or something because it was like mad, so I just typed in things like you know like anorexia or how to lose weight fast in Google and just went on to whichever page came up.... I just wanted to find something where I didn’t have to show my face, where I just got some information about what I thought you know what I wanted to do without being judged.”*

Gemma: *“...there’s that secretive, there’s also that thing of you don’t have any one to turn to so it’s kind of that community as well so you go I can’t talk to anyone about it but I can find out or I can share my experiences with someone else who understands what I’m going through.”*

Catherine: *“It’s just the easiest place to get information if you don’t want your parents to know and if you’re a bit worried about going to the doctor, it’s just the easiest place to get information.”*

**Websites normalising experiences** refers to participants describing how pro-ED websites provide a source of like-minded individuals which helps to reduce feelings of shame and a sense of isolation. Again, pro-ED websites appeared to reassure individuals that their experiences were formed as part of a ‘lifestyle choice’, rather than a medical problem.

Amy: *“it’s almost rather than a shock, it was almost welcomed because it made me feel a bit less like a freak, it was actually my thinking wasn’t just me, there was a group of people out there that also had the same thinking.”*

Laura: *“I felt I’m probably not as weird as I thought I was and as I said because my it’s more like a lifestyle and it’s your choice... I just found it really helpful that there were so many tricks and tips, and no judgement, I think that’s what you’re really scared of when your self-esteem is quite low anyway, um you’re really scared of being judged.”*

Catherine: *“It was comforting to know that I wasn’t the only one thinking the way I was that there were other people who thought exactly the same and it also, I had doubts whether I had an eating disorder or whether it was just a choice that I was making and it sort of put that out of my head that it was an eating disorder it was a choice, it was your choice to not eat it’s not, it’s not that you’re mentally ill, it’s sort, it sort of put that out of my head as well, know that I’m in control and know that it is something that I’m doing rather than an illness.”*

Figure four below outlines the process through which individuals appear to feel a sense of social isolation regarding their desire to rapidly lose weight. Beliefs that others in the ‘real’ world will not understand or support their choices subsequently influences individuals to turn to the Internet for support. Pro-ED websites appear to offer reassurance and normalise experiences around the individual’s eating disorder, reducing a sense of isolation experienced in the ‘real’ offline world. However, the continued use of pro-ED websites exacerbates a sense of being ‘different’ to ‘real’ people, fuelling social isolation. Similarly, social isolation appears to occur when individuals feel inferior to other websites users and are on the periphery of the ‘online community’. Individuals appear to fear judgement from ‘real life’ people as well as pro-ED website users.

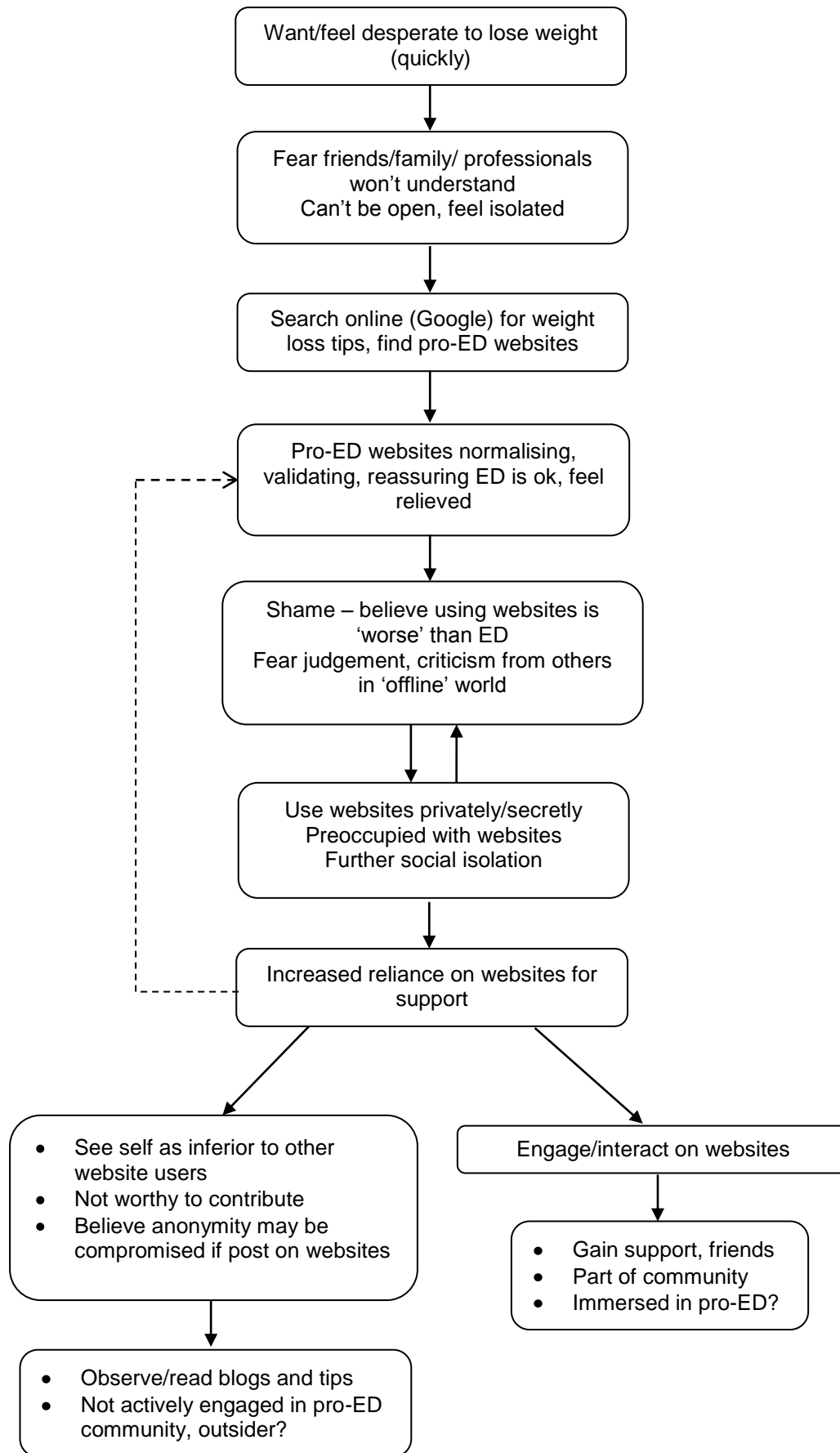


Figure 4. Process of pro-ED websites influencing shame and social isolation.

### 3.6 THEME FIVE: WEBSITES MAINTAINING ED

The final theme from the analysis is WEBSITES MAINTAINING ED which refers to pro-ED websites supporting users to continue eating disordered behaviour.

Sophie: *“I guess using pro ana websites definitely prolonged how long it took me to kind of come away from them kind of feelings and thoughts because they’d be confirming it again. Because the people on the websites are saying like, kind of saying that’s good, like they put their pictures up and say like the willpower that they have and things like that so it’s definitely egging it on.”*

The theme includes three core categories: LEARNING/IMPLEMENTING TIPS TO INCREASE ED BEHAVIOUR; SENSE OF SUPPORT/VALIDATION and USING PRO-ED WEBSITES FOR MOTIVATION TO RESTRICT/LOSE WEIGHT. **Categories** and *sub-categories* are also presented below.

#### 3.6.1 LEARNING/IMPLEMENTING TIPS TO INCREASE ED BEHAVIOUR

Participants reported searching for weight loss tips on pro-ED websites. Many participants reported both learning and often implementing weight loss tips and tricks available online to aid in weight loss or weight control.

Rachel: *“I found that really helpful and then the other thing was where they would have um lists of um of changing your calorie intake to day by day to kind of trick your body into thinking that it’s getting enough um like um, um, so that so as I say you have so many calories this day and that day and I would write them in my diary how many, I’d just put the number in the corner of my diary of how many calories to have that day so based on what I’d read on the websites.”*

Laura: *“I went through all the blogs, but I went if they had something like tips or tricks or something I would go through them and sometimes if, if I couldn’t quite do what they were writing about I would read it again to remind myself and um it’s to this day that I’ve got some of those rules stuck in my head and I just still can’t quite get rid of them, so over a year later..... I learned how to how to throw up and I think yeah I could do that again it would be*

*quite easy. And if you eat a bit of baking powder with it it goes even better because that's one of the tricks on the websites, never forget it."*

Charlotte: *"I just wanted to know what people survive on what to eat daily. You go from like half a cucumber somebody is surviving and an apple and stuff like that. That's what I was looking at if they had any sort of tips to stop be...because I can go for days without eating and obviously I get to a stage where I'm hungry so they say like chew cotton wool and stuff like this which obviously I've never done but it's just looking for tips really more than anything."*

All participants reported that they had been **experiencing eating difficulties prior to using pro-ED websites**. Individuals described feeling desperate to lose weight quickly and had already begun to employ 'abnormal' weight loss methods. Some participants had struggled with an eating disorder for many years prior to using the websites. Many searched for weight loss tips on Google and often 'stumbled' upon pro-ED websites. Therefore, it appears that the pro-ED websites maintain and potentially increase eating difficulties rather than cause an eating disorder.

Sophie: *"I first found out about them, just like Googling things to do with like calorie intake and stuff on the Internet and stumbled upon them."*

Charlotte: *"I've obviously had an eating problem for a long time and then just hearing about, just googled it and they all come up, you just type in Pro Ana sites and all this come up."*

It was noted that *websites encourage and glamorise high risk behaviour*, such as the physical consequences of an eating disorder.

Sophie: *"The websites kind of promotes the unhealthy effects of eating disorders as kind of another good thing like kind of people who are ill and are in hospital or are kind of having all these side effects from their eating disorders like that will get promoted on there....like kind of gets you stuck in the feeling of you know like to be ill from an eating disorder is kind of you're winning at it."*

### 3.6.2 SENSE OF SUPPORT AND VALIDATION

Participants described that pro-ED websites provided a sense of support and validation, a sense of comfort and relief when individuals feel alone and persecuted by others for engaging in eating disordered behaviour. Pro-ED websites appeared to **provide validation**, which involved *reinforcing an ED identity, reaffirming beliefs and attitudes about ED*.

Amy: *“Um I guess it was mirroring very much what I wanted, so there was lots of stuff on there and lots of images of very skinny people, which is what ah yeah I wanna be like that...motivation for you going down the right path and it was kind of everything that my eating disorder was saying to me was written in front of me so it’s more of a reaffirming thing.”*

Sophie: *“I guess at first it was kind of it felt good that there was people on there kind of doing the same thing as me, and it was kind of like validating what I was doing and kind of confirming that it was good what I was doing and I don’t know I guess it felt quite good to like have that kind of shared thing with other people.”*

Laura: *“most of them wouldn’t show any risks they’d just say just don’t listen to it...at that time it actually feels right for you because you think you don’t want to be lectured about what could happen, you don’t want to be lectured about you know um cardiac arrest when you be sick, you don’t want to hear that of course not otherwise it would probably scare you at some point. And they don’t have anything on there; they just say it’s a lifestyle.”*

Individuals also reported **identifying with others’ experiences** through reading blogs and **feeling a sense of support and belonging** from the pro-ED websites, a shared understanding and acceptance from the pro-ED community.

Amy: *“Again, it’s just the reassurance that other people are asking the same... and again I guess it’s that being part or feeling like you’re part of an online community that is on your side.”*

Catherine: *“I just got introduced to people on there and made friends on there, friends that I have now that I always speak to that no longer have eating disorders that we became really*



*good friends so it was just sort of like a bit of a er a family, yeah, so just made me keep going back really.”*

The **externalisation of anorexia as Ana** was also discussed as forming part of pro-ED websites. There was disparity within views on ‘Ana’, some individuals felt that viewing anorexia as Ana was comforting and less stigmatising, whereas others viewed Ana as a threatening concept.

Amy: *“I hate the term anorexia so calling it Ana and you know it’s kind of a way of being then it made it feel a bit more cuddly and nice rather than freakish.”*

Laura: *“That [Ana] is positively weird, I think that was the first things where I started to think whoa hold on there’s something not right...it says don’t forget Ana is always watching you. And I found that positively strange. Woo, that is paranoid. So I mean I found that quite, actually I started to you know they were making out they’re friends and they’re watching you and I thought no, no that is getting a bit too weird, that is scary.”*

### 3.6.3 USING PRO-ED WEBSITES FOR MOTIVATION TO RESTRICT/LOSE WEIGHT

All participants reported that a main reason for using pro-ED websites was to increase motivation to restrict food intake or to maintain other weight loss behaviours.

Amy: *“Umm, I guess I felt renewed motivation [after using pro-ED websites], um, so it would often lead to me restricting more that day or doing some more exercise, it would have a temporary step up of the eating disorder behaviour.....I would try and reduce my daily calorie count for instance it gave me motivation to do that. So if I reduced it down to say 400, 300 calories a day, um I would be able to then, that would be my benchmark then for the period onwards.”*

Sophie: *“it would give me new motivation like be planning like a different like of meal plan that I’d stick to or something, or different, wanting to do be doing more exercise or cutting out certain food groups and things, just new ways to lose weight really.”*

Individuals described **using websites for motivation when hungry, weak or self-critical**. Many participants talked about turning to the websites for renewed motivation to restrict

when they were feeling tempted to eat or binge through hunger, or when their motivation had waned.

Rachel: *“I guess feeling, feeling that I’d let myself down that day would be the trigger, that I’d eaten something or that I’d eaten! And I was feeling really angry with myself for eating and thinking right you’ve got to get a grip on this now and so that would be what would you know, I would know that if I had a look at that that that would give me some ideas of how I could be better the next day.”*

Gemma: *“once your motivation kind of wavers or you think oh you know I’m not quite sure then you can go back to it again and you can get inspiration or you can find out information from there.”*

Catherine: *“When it became, more exhausting to keep losing weight and or say my weight was sticking it was a way of getting tips to boost my weight loss to kick start it again and it keep going and you have days when I thought oh I’m so hungry I just want to eat then I would go on there and have tips on how I could get rid of the hunger pains and what I could do to kick start my weight loss.”*

In addition to using websites for motivation to restrict, some individuals also described using the websites as a form of self-harm behaviour; **using pro-ED websites as punishment when eaten or binged.**

Sophie: *“I guess if it was on days where maybe I hadn’t lost any weight or I’d ate more than I felt comfortable with and then I went on then, it would be almost like I was going on to make myself feel useless. Like I’d be going on to see all these other girls who were clearly doing well and kind of promoting losing weight and not eating and things, and then I’d feel rubbish with myself.”*

Finally, the data appeared to **support the Transdiagnostic Model of eating disorders** as many individuals described both restricting behaviours and bingeing and purging behaviours as restriction was unsustainable in the longer term.

*Amy: “I’ve gone from not so much restricting eating now but I’ve a bit of a problem with over-eating at times.”*

Figure five below demonstrates the pathway that individuals appear to use pro-ED websites as a method of engaging in eating disordered behaviour. Individuals compare themselves with other users and either identify with and strive to achieve an extremely underweight body image, or feel such images are unattainable and consequently ignore ‘anorexic’ images and engage in pro-ED websites for a less extreme weight loss. The figure outlines the cycle whereby comparisons with others resulting in feelings of inadequacy drive individuals to use pro-ED websites to maintain their eating disorder.

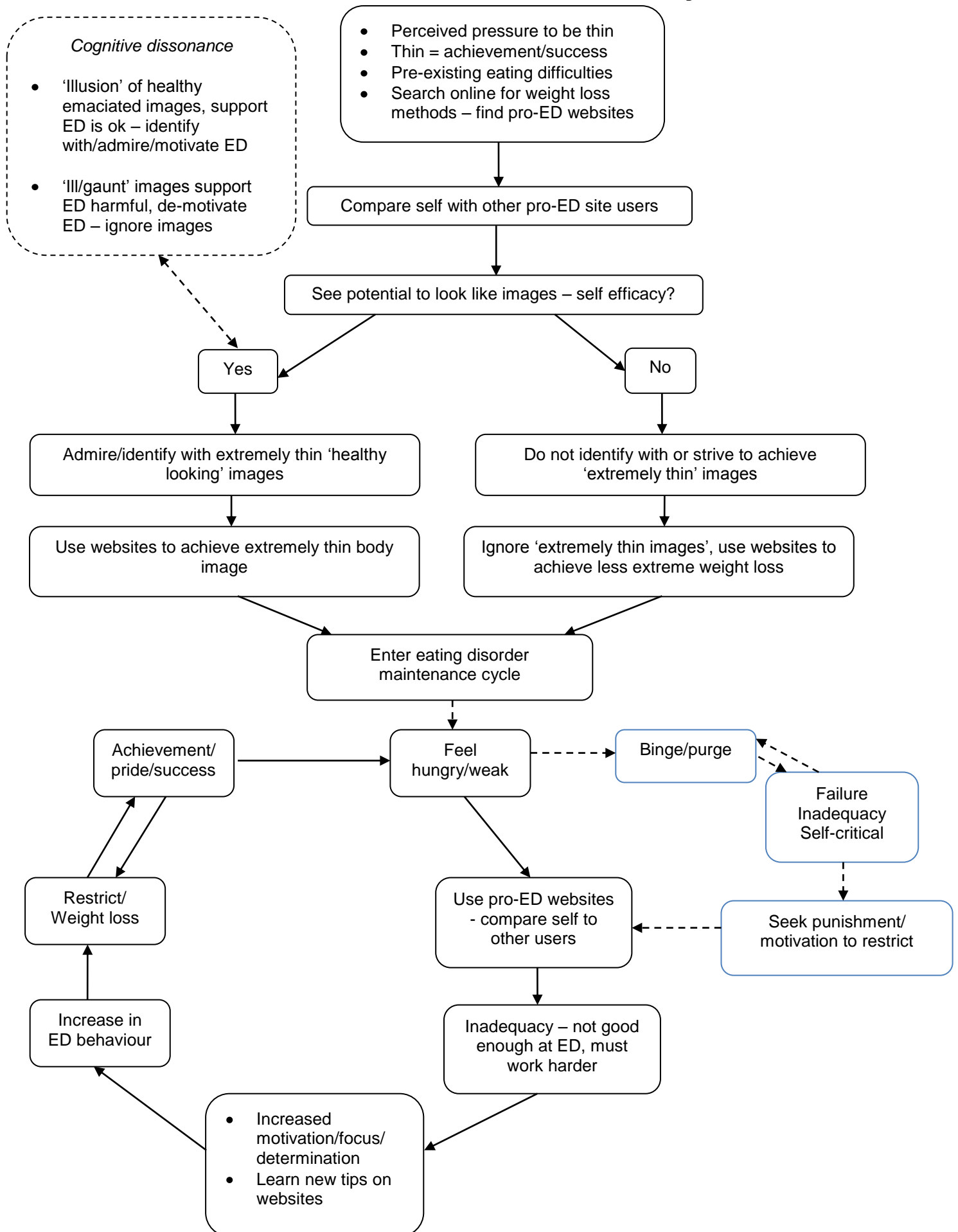


Figure 5. The role of pro-ED websites in maintaining eating disorder behaviour.

### 3.7 ADDITIONAL FINDINGS

A number of additional themes were observed within the data. The additional themes are not directly related to the use of pro-ED websites and do not fit in to the Constructivist Grounded Theory model of the use of pro-ED websites, however, due to clinical implications stemming from the results the additional findings are presented below.

Participants described using a variety of pro-ED websites, with no particular allegiance to one website. Pro-ED websites were perceived to vary in quality, with a **continuum of pro-ED websites** being described from well run to poorly run websites.

Sophie: *“Yeah I’d just browse different ones there was no particular.”*

Catherine: *“the ones that run well with moderator they tend to not let you put tips and tricks sort of thing, so they wouldn’t say someone said how do they make themselves sick they wouldn’t allow that post to go out to teach somebody to do it so not so much like that, on other website that are not as well run, yeah you do get tips and trick.”*

Whilst some respondents reflected on feeling pressurised during treatment as described in the first theme of fear, some participants also described **positive experiences of treatment**. Such positive experiences centred on receiving *empathy and support through non-judgemental therapists*.

Laura: *“I’ve had counselling now um, I’ve had two different counsellors and both of them were very understanding, kind and non-judgemental so I’d say you have to try and find a good counsellor because they actually help you get healthy and they are just as understanding, they won’t judge you. You know um they, they both sit down and make you look at facts so you can just physically look at facts instead of pushing, putting that pressure on that makes you feel insufficient.”*

Participants also reported *implementing skills learned in treatment* in order to cope with eating disorder related thoughts and urges.

Rachel: *“I’ve had to I’ve had to work really hard to distance myself from the thoughts that I have around my eating disorder, which I guess is where the mindfulness comes in.... most of the time when I get that thought I use my mindfulness just to sort of like, just to acknowledge that I’m having that thought and try not to entertain it, it’s just, and seeing it as being an eating disordered thought rather than something that I should be doing. But it does feel like a bit of a battle with it sometimes.”*

Some participants also reported that an approach used on pro-ED websites, *personification of ED can be helpful in treatment*. Personification can allow emotions to be directed towards an external being, rather than internalising problems, which is perceived to be helpful through recovery of an eating disorder.

Sophie: *“When I’ve been speaking to therapists and stuff we’ve always kind of have personified it.....Definitely think I found it helpful, I mean it did kind of, did at one point, all of my actions were being drove from like that kind of Ana or um and that kind of helped me break free of it I guess, challenging it and battling it and separating them.”*

Catherine: *“I think as well for recovery that [personifying as Ana] can help as well because you’ve got some, you’ve got a name this comfort maybe you’ve got a face then you can put to a name that if you want to recover you can get angry at this, this person is who I’m not going to listen to rather than being quite clinical and you’re anorexic and you’ve just distorted thinking about food and weight.”*

### 3.8 SUMMARY OF FINDINGS

The aim of the present study was to explore the perspectives of individuals in treatment for an eating disorder regarding their use of pro-ED website use. Five themes were identified within the analysis, which relate to individuals’ experiences of turning to pro-ED websites, the function that the websites fulfil and the impact of the websites on the individuals’ treatment and recovery. Figure two illustrates the Constructivist Grounded Theory which details how fear, cognitive dissonance, social comparisons, shame are associated with the pro-ED websites’ impact on maintaining an individual’s eating disorder. The theory offers a conceptual understanding including divergent accounts of the use and impact of pro-ED websites. Moreover, figures have been used to illustrate descriptive models of the processes

which appear to drive individuals to use pro-ED websites and the factors which appear to maintain the use of pro-ED websites.

The following chapter will discuss findings in relation to the literature, as well as highlight the clinical implications of the findings and the limitations of the research.

## CHAPTER FOUR: DISCUSSION

### 4.1 OVERVIEW

The discussion chapter outlines the research findings in the context of relevant literature and theory. Implications for clinical practice and service delivery will be discussed and strengths and limitations of the current study will be highlighted. Finally, recommendations for future research will be outlined.

Firstly, it is important to highlight that the research took place within the context of NHS treatment services for eating disorders. Consequently, the author is influenced by a recovery-oriented context, and holds the value that recovery from an eating disorder and the establishment of healthy eating practices would indicate a positive and desired outcome for individuals. However, it is acknowledged that this is a socially constructed perspective and may not be held universally, particularly by those engaging in restrictive eating. Therefore, the results and discussion are outlined with the underlying belief that recovery is an ‘ideal’ for those with an eating disorder. Such a position may sit in conflict with the attitudes of participants and other individuals using pro-ED websites, particularly given the stance that pro-ED websites take of resisting a ‘cure’ for eating disorders.

### 4.2 RESEARCH FINDINGS AND THE RELEVANT LITERATURE

The principle aim of the current study was to explore the function and impact of pro-ED websites amongst a group of individuals in treatment for eating disorders. Particular aims included to explore the mechanisms by which individuals came to initially view pro-ED websites; the functions of pro-ED websites and the processes underlying repeated use of websites; the impact of pro-ED websites on thoughts, feelings and behaviour; perceptions regarding the externalisation/personification of ‘Ana’ (anorexia) and ‘Mia’ (bulimia); and perceptions of the impact of pro-ED websites on recovery and treatment for eating disorders.



Five key themes were identified using a Constructivist Grounded Theory approach to analyse the seven interview transcripts: fear, cognitive dissonance, social comparisons, shame, and pro-ED websites maintaining an eating disorder. The Grounded Theory model is illustrated in figure two. The findings will be discussed in relation to existing psychological theory and literature, and are presented below according to the **THEMES**, **CORE CATEGORIES**, **categories** and *sub-categories* as reported within the results chapter.

#### 4.2.1 Theme one: **FEAR**

The theme of **FEAR** incorporates **FEAR OF RECOVERY**; **FEARING JUDGEMENT**; **LOSSES OF RECOVERY**; and **FEAR OF PRO-ED WEBSITES**. Participants appeared to experience fear associated with the anticipation of recovery from their eating disorder which seemed to be linked with losses associated with recovery. The experience of fear appeared to trigger the use of pro-ED websites, a process outlined in detail below. Furthermore, the manifestation of fear was associated with participants' stage of recovery. Individuals who appeared to be further in to recovery also described a fear of pro-ED websites. The fear of pro-ED websites was due to apprehension regarding the encouragement of high risk behaviour such as suicide, and the influence of websites in terms of risk of relapse.

A **FEAR OF RECOVERY** appeared to relate to individuals both **fearing own pro-recovery related thoughts** in addition to a perceived **external pressure to recover**. A fear of recovery was expressed differently according to the stage of an individual's recovery. Participants who wished to maintain their eating disorder described a current fear regarding the prospect of recovery. For those who had undergone treatment and were actively working towards recovery, individuals reflected on the fear that they experienced prior to engaging in treatment. For those who had undergone treatment, **LOSSES ASSOCIATED WITH RECOVERY** were also reflected upon. Losses primarily included **weight gain**, a sense of a *lost eating disorder identity*, and a *lack of control*.

Previous research has highlighted the ego-syntonic nature of eating disorders (Cooper, 2005); that is the behaviours and values associated with the eating disorder are consistent with the individual's ideal self-image. Individuals tend to view their 'eating disorder' as a functional method of controlling weight and other aspects of their lives (Cooper, 2005). Qualitative research exploring individuals' perceptions of their own eating disorders has highlighted that

anorexia was perceived to be a way of feeling in control, gaining a sense of achievement, feeling safe, expressing emotion, and coping with and avoiding negative feelings (Williams & Reid, 2010).

Moreover, due to the ego-syntonic nature of eating disorders, many individuals do not view the behaviour as problematic, and are likely to resist treatment attempts due to reluctance to ‘give up’ the positive aspects of the eating disorder (Cooper, 2005). Consequently, individuals often experience ambivalence regarding their eating disorder (Williams & Reid, 2010) which reflects the experience of, “*conflicting motivations or feeling two ways about something*” (Miller, 1998, p.123). Therefore, ambivalence about change, driven by the ego-syntonicity associated with eating disorders, supports the core categories of fear of recovery and losses associated with recovery identified within the current sample.

In relation to the fear of recovery outlined above, a number of participants reported **using pro-ED websites to superficially engage in treatment**. Some individuals turned to pro-ED websites in an effort to protect their eating disorder and undermine treatment attempts, by using the content of websites to conceal their eating disorder. This is supported by evidence that pro-ED websites include covert techniques to deceive others, including professionals and families. In an analysis of nine pro-ED websites, it was found that 11% of comments related to deception methods to conceal an eating disorder from family, friends and health professionals (Harshbarger et al., 2009). Moreover, 60% of pro-ED website users within a clinical population reported using websites to learn how to effectively conceal eating disordered behaviours from others (Ransom et al., 2010). The participants in the present study describe how despite being in treatment for an eating disorder, they use pro-ED websites as a means of deceiving others to ‘rebel’ from treatment attempts. For example, some individuals reported using pro-ED websites to learn how to prevent treatment services from making them ‘fat’.

In reference to a fear of pro-ED websites, some participants described **apprehension at websites supporting high risk behaviour**. Previous research has demonstrated that users of pro-ED websites often acknowledge that such websites encourage high risk behaviour such as the use of diet pills or self-harm (Peebles et al., 2012b; Wilson et al., 2006). In a survey of 60 pro-ED website users, 22% reported that they learned how to engage in self-harm behaviours from such forums (Ransom et al., 2010). Furthermore, within a French sample of pro-ED

website users, 14% reported negative consequences of the use of websites in vague terms, such as *I was better before* (Rodgers et al., 2012).

A number of participants in the present study described apprehension regarding the encouragement of high risk behaviour, particularly relating to suicide. However, research included in the systematic review does not appear to highlight such a concern. Pro-ED website user participants within studies included in the review appear to demonstrate a general recognition that the websites promote dangerous behaviours, but do not explicitly express concern or anxiety related to this. Such a discrepancy may be due to differences in sample demographics and research methodology. The current research recruited participants solely through treatment services for eating disorders. Individuals who are actively working towards recovery may have a sense of themselves as being more at risk. Therefore, the promotion of high risk behaviour may have a stronger personal resonance and lead to concern. Also, the present study appears to be the first study in the field of pro-ED websites using face to face interviews as opposed to online surveys, questionnaires and focus groups. Accordingly, individual semi-structured interviews may be more sensitive to individuals' anxieties in addition to the positive aspects of the websites.

**Fear of relapse** was also observed in participants who had undergone treatment programmes, such as DBT, for their eating disorder. Individuals reported that they experienced urges to return to using pro-ED websites which led to anxiety that the use of pro-ED websites would increase their risk of relapse. A nine year prospective study followed 136 individuals with a diagnosis of AN, and 110 participants with a diagnosis of BN. Relapse following treatment occurred in 36% of individuals with AN and 35% in those with BN. It was found that greater body image disturbance and the over-importance of weight and shape contributed to risk of relapse in both disorders (Keel et al., 2005). It could be argued that pro-ED websites reinforce body image disturbances and promote the importance of weight and shape; therefore, continued use may influence the risk of relapse from an eating disorder.

Overall, the theme of fear is congruent with previous research supporting the ego-syntonic nature of eating disorders which underpins a fear of recovery. Pro-ED websites appear to be used by some individuals in treatment to protect them from losing their eating disorder. This is discussed in more detail within the second theme of cognitive dissonance outlined below. Once individuals have more fully engaged in treatment, a fear of pro-ED websites may

emerge in terms of apprehension at the high risk behaviour promoted on the websites and anxiety related to pro-ED websites increasing the risk of relapse.

#### **4.2.2 Theme two: COGNITIVE DISSONANCE**

The second theme constructed within the data refers to **COGNITIVE DISSONANCE**, which relates to descriptions of **dissonance regarding the eating disorder and use of pro-ED websites**. Cognitive Dissonance Theory can be applied to understand individuals' experiences of conflicting beliefs regarding their eating disorder and their use of pro-ED websites. This is outlined within the core category of **DESCRIBING DISSONANCE**.

Cognitive Dissonance Theory was originally developed by Leon Festinger (1957) and focuses on the relationship between various cognitions; that is the thoughts or 'pieces of knowledge' we hold regarding an attitude, emotion, behaviour or value. It is argued that two cognitions are consonant if the cognitions are in agreement with one another. Experimental research has highlighted that individuals prefer to experience consonant cognitions. When cognitions oppose one another, they are labelled as dissonant and lead to psychological discomfort and tension. Such dissonance often leads people to alter their behaviour or attitudes to reduce such inconsistency, a human drive equated to those of hunger or thirst (Festinger, 1957).

Cognitive Dissonance Theory suggests that when two cognitions are discrepant, individuals employ various methods to reduce psychological tension. Individuals can attempt to change cognitions or behaviour in order for them to become consistent; alter cognitions or behaviour to become more similar; or add one or more consonant cognitions to reduce the magnitude of dissonance. Alternatively, the importance of cognitions can be altered to reduce a sense of dissonance. Such cognitive dissonance appears to be supported by literature discussed above regarding the ambivalence experienced by those with eating disorders (Williams & Reid, 2010). Participants within the present study described a sense of conflict or ambivalence over the use of pro-ED websites, including believing that pro-ED websites were helpful in motivating weight loss but were also 'wrong' or 'shameful'. Many participants reported using pro-ED websites despite feeling naughty or guilty for doing so.

Many participants described USING PRO-ED WEBSITES TO REDUCE DISSONANCE about their eating disorder. Pro-ED websites were used to **‘protect’ their eating disorder** in the face of internal doubts and external pressures to recover as discussed above. As described, individuals appeared to use pro-ED websites to gain reassurance that eating disordered behaviour was healthy. Websites tended to promote the concept of eating disorders as being a lifestyle choice, as observed in previous research (Lipczynska, 2007). Websites were used to strengthen ‘pro-ED’ thoughts and fight against the advice of others including professionals, friends and families. Consequently, users were reassured that their behaviour was acceptable and healthy, which served to reduce cognitive dissonance regarding their eating disorder. This is consistent with findings presented within the systematic review whereby 52% of 60 pro-ED users surveyed used pro-ED websites to support their choice to continue current eating behaviours (Ransom et al., 2010).

It has been suggested that pro-ED websites support the normalisation of dangerous eating practices and extremely underweight body images (Bond, 2012). Within the present study, participants noted that some extremely underweight individuals were portrayed as being healthy, for example emaciated individuals were photographed jogging outside looking healthy and happy. Such images served to strengthen beliefs that food restriction was not dangerous.

An **illusion of ‘healthy’ looking images supporting the eating disorder** was apparent whereby individuals would ignore gaunt looking images on the websites. Such ‘ill’ looking images were discounted because they supported ‘medical’ advice, which conflicted with pro-ED beliefs and fuelled cognitive dissonance. Information processing errors known as cognitive distortions have been associated with various emotional difficulties (Dryden & Ellis, 2001). Such cognitive biases include the selective filtering of information, overgeneralising and ‘all or nothing’ thinking. Cognitive distortions related to body image have been identified in individuals with eating disorders (Lee & Shafran, 2004) and are a central feature of Fairburn’s cognitive model of eating disorders (Fairburn, 2008). Consequently, cognitive distortions in the form of selective attention to ‘healthy’ looking images served to reduce cognitive dissonance regarding the potentially harmful physical consequences of eating disorders.

Similarly, whilst risks of dangerous eating practices such as purging and laxative use were acknowledged within the interviews, participants appeared to **minimise perception of risks to the self**. This is supported by previous research suggesting that individuals minimise risks to themselves in the online pro-ED environment. Within qualitative analyses, individuals described a ‘web ethic’ whereby behaviours such as diet pill use were considered dangerous offline, yet within online environments the same behaviours were perceived to be acceptable (Peebles et al., 2012b). Furthermore, within a survey of 29 French pro-ED website users, all were aware of health risks of restrictive eating, however, 41% noted that they ignored such risks or were not concerned about the risks (Rodgers et al., 2012).

Individuals in the current study often minimised the perceived risks of their behaviour, which again reduced a sense of cognitive dissonance, achieving a sense of ‘permission’ to continue to engage in eating disordered behaviour. Comparisons with other website users also minimised the perception of personal risks. Comparisons reinforced a belief that personal behaviour was not as extreme and high risk as other website users. Details regarding social comparisons are outlined in theme three below.

The overall messages promoted within pro-ED websites were used to reduce cognitive dissonance stemming from internal doubts and external pressures regarding the eating disorder and the use of pro-ED websites. The notion of individuals using pro-ED websites to protect their eating disorders appears consistent with findings from a systematic review claiming that pro-ED websites act as a barrier to treatment (Rouleau & von Ranson, 2011). In addition, listening to others on pro-ED forums was reported to be a barrier to recovery within a qualitative research project with pro-ED website users (Williams & Reid, 2010).

A subsequent core category within the theme of cognitive dissonance refers to a perceived CHANGING VIEW OF WEBSITES THROUGH RECOVERY. There was disparity amongst participants regarding the level at which they were engaged in treatment and the extent to which they were working towards recovery. For those who had completed treatment programmes and were actively working towards more ‘normal’ eating patterns, many reflected that they had previously believed the websites to be ‘helpful’ whilst in the midst of their eating disorder. However, these individuals all reflected that they now believe the websites are dangerous and harmful due to the effect they have on reinforcing eating disordered behaviour. None of these participants currently use the websites. This is in

contrast to those participants who did not wish to regain ‘normal’ eating practices and were less engaged in treatment. Whilst they acknowledged some risks of pro-ED websites, they believed them to be helpful and intended to continue to use the websites.

Such a distinction in attitudes towards pro-ED websites may be explained using the Transtheoretical Model of Change (Prochaska & DiClemente, 1992). Originally developed within the realm of addictions research, the model focuses on the stages that individuals are believed to oscillate between when recovering from an addiction, paralleling a revolving door metaphor. It is proposed that individuals often oscillate many times between stages within the cycle of change prior to long term maintenance of recovery is achieved. The stages refer to pre-contemplation (not considering changing the behaviour), contemplation (starting to think seriously about change), preparation (preparing to change the behaviour), action (beginning to attempt to change the behaviour), maintenance (prolonged change of the behaviour) and relapse (relapsing back to the original behaviour). It is argued that relapse may occur several times before long term maintenance is achieved (Prochaska & DiClemente, 1992).

Since its conception, the model has also been applied to field of eating disorders (Ward et al., 1996). It is possible that individuals in a pre-contemplation stage of change may experience treatment attempts as highly threatening, and subsequently use pro-ED websites to protect their status quo. This appears to reflect the current experience of a proportion of the participants interviewed in the present study. However, for other participants, a **readiness for change and wanting help to recover** was described, which may refer to those within a contemplation, preparation or action stage of change.

Although the model is often described in a linear way it is recognised that every individual’s journey of change is different. The ego-syntonic nature of eating disorders along with the experience of ambivalence discussed above is likely to impact on an individual’s fluctuating motivation to change. However, the model may be used to consider how the functions and impact of pro-ED websites on attitudes and behaviours appear to change according to an individual’s motivation to recover.

Those who appeared to be further into action and maintenance stages of change described **recognising the dangers of pro-ED websites**, particularly in relation to the *vulnerability of people with ED*. Participants highlighted that the cognitive and emotional consequences of

eating disorders increases individuals' vulnerability, in line with previous research (Lena, Fiocco & Leyenaar, 2004). Participants argued that such vulnerability exacerbated the harmful influence of pro-ED websites. It should be noted that participants who appeared to be in the preparation and action stages of change reported **ending the use of pro-ED websites to engage in treatment**, either at the outset of treatment or during the process of therapy. The termination of pro-ED website use has not been explored in previous research.

It is important to note that all participants, despite apparent stage of recovery advocated **warning others against using pro-ED websites**. Despite some individuals choosing to continue to use pro-ED websites, all participants stated that they would not recommend the websites to others because they would not wish to encourage other people to develop an eating disorder. This appears consistent with findings suggesting that pro-ED bloggers were concerned that the blog would trigger eating disordered behaviour in vulnerable people and those in recovery (Yeshua-Katz & Martins, 2013). This ethic was apparent in all participants regardless of attitudes towards their own use of the websites.

#### **4.2.3 Theme three: SOCIAL COMPARISONS**

The third theme constructed within the data refers to **SOCIAL COMPARISONS**. Pro-ED websites appear to encourage comparisons with other website users, leading to the **EMOTIONAL IMPACT OF COMPARISONS WITH OTHERS ON PRO-ED WEBSITES**. The theme of social comparisons encompasses the notion that participants draw comparisons between themselves and others on the pro-ED websites, which ultimately fuels eating disordered behaviour.

Individuals appear to **define personal achievement through weight loss** which is incorporated into the Transdiagnostic Model of eating disorders (Fairburn, 2008). The model highlights that for those experiencing eating disorders, the importance of shape and weight in gaining self-worth is over inflated. In addition, the value of other factors contributing to self-worth, such as work and relationships are minimised (Fairburn, 2008).

**A pressure to be thin is reinforced on pro-ED websites** which results in individuals *comparing the self negatively to others on websites*, resulting in feelings of *jealousy, inadequacy and failure*. In contrast, *comparing the self favourably to others* appears to



*reinforce the eating disorder through enhancing self-esteem and pride.* Social Comparison Theory (Festinger, 1954, as cited in Bamford & Halliwell, 2009) can be applied to understand the impact of such comparisons on eating disordered behaviour. It appears that inappropriate targets for self-comparisons, i.e. individuals engaging in eating disordered behaviour and underweight images, are chosen by some individuals who use pro-ED websites. Such frequent comparisons enhance vulnerability to socio-cultural appearance pressure (Wood, 1996), which appears to reinforce a desire to achieve the idealised image. This subsequently results in a sense of failure and inadequacy if unfavourable comparisons are made, or a sense of pride and achievement when favourable comparisons are made.

As a consequence of the emotional impact of comparisons on pro-ED websites, it appears that COMPARISONS INCREASE EATING DISORDERED BEHAVIOUR. Participants described how the **websites fuel comparisons and competition**, which is reflected in the Transdiagnostic Model of eating disorders (Fairburn, 2008). Within the model, self-critical comparisons are argued to fuel low self-esteem and over-concern with weight and body shape, ultimately maintaining eating disordered behaviour.

Moreover, comparisons with others on pro-ED websites also appeared to foster the **admiration and idealisation of others**. Internalisation of such idealised images is a robust risk factor for the development of eating disorders (Stice, 2002). However, not all individuals appeared to identify with such extreme underweight images on pro-ED websites. The concept of **self-efficacy** (Bandura, 1977) was used to account for the extent to which individuals strive to achieve such ‘anorexic’ images. Self-efficacy refers to an individual’s belief in their own capabilities to achieve a particular goal. Individuals who believed that they were unable to achieve a body shape similar to the extremely underweight images described dissociating from the images. Conversely, those who believed that achieving such a body image was a realistic goal appeared to identify with such extreme images, and strived to achieve a similar body shape.

As previously noted, attachment experiences, specifically anxious attachment patterns may drive social comparisons. It has been hypothesised that those with attachment anxiety tend to devalue themselves and idealise others, making them more vulnerable to making such unfavourable self-comparisons (Bamford & Halliwell, 2009). Assessment of attachment style

was not part of the present study but the influence of attachment style on use of pro-ED websites merits future research.

In addition to direct self-to-other comparisons, participants appeared to differ in the extent to which they identified with the general community of pro-ED website users. **Observing versus interacting on websites** relates to the extent to which participants actively contributed to pro-ED websites. Six out of the seven participants reported solely observing on websites; Catherine was the only participant who interacted on the websites. Previous research has demonstrated disparities in the use of pro-ED websites, detailing the difference between ‘Active’ users and ‘Passive’ users (Csipke, 2007). Whilst users from the middle group were excluded from analyses, it was suggested that ‘Passive’ users reported using pro-ED websites to maintain restricted eating, whereas ‘Active’ users utilised emotional support acquired on the websites. It was reported that ‘Active’ users felt better about themselves after using the websites. It was hypothesised that the support gained through active use may have buffered the impact of harmful pro-ED website content. In contrast, ‘silent browsing’ was argued to have a greater detrimental effect due to increased eating disorder symptoms in the absence of emotional support (Csipke, 2007).

In comparison to findings from Csipke (2007), within the present study, the only active website user appeared to be experiencing the most severe eating disorder within the sample. Therefore, whilst Catherine reported that she had formed long-term friendships on websites, she appeared to be the most entrenched in her eating disorder with a recent hospitalisation. Catherine continued to actively use pro-ED websites and engage in regular competitions. Therefore, such ‘active’ use was associated with poorer outcomes in terms of recovery than the ‘passive’ users in the sample. The impact of active use and silent browsing merits more detailed investigation.

In relation to ‘passive’ website use, some participants described *feeling inferior to other users* and *anticipated rejection if they interacted on websites*. It appeared that some individuals perceived themselves to be on the periphery of the pro-ED website community and therefore, engaged in passive rather than active use. Arguably, this could potentially be viewed as a protective factor for recovery as ‘passive’ use individuals appeared to be less immersed in pro-ED phenomena.

The perceived relationship between the self and the wider ‘pro-ED community’ may be understood using principles of Social Identity Theory (Tajfel, 1979). The theory proposes that the groups that individuals belong to are an important source of self-esteem and pride, providing a sense of social identity. Through interaction with group members, group norms, roles and attitudes are defined and are internalised. The developed group norms subsequently influence behaviour (Tajfel, 1979), with individuals aspiring to become a member of the ‘pro-ED’ in-group. However, intra-group marginalisation suggests that in order to maintain the distinctiveness of the group, members of the in-group marginalise those members who do not fully conform to the group’s norms (Abrams et al., 2000). Therefore, individuals may make unfavourable comparisons between themselves and the in-group, with a sense of being inferior and not ‘good enough’ at their eating disorder. This may subsequently lead them to expect to become marginalised from the virtual in-group, resulting in a reluctance to fully engage and interact with the pro-ED community ‘in-group’. Much of the work on social and group behaviour is based on face-to-face interaction; with an increasing focus on online social activity. Consequently, further work is needed to explore the impact of social groups in an online pro-ED context.

Participants also described *fearing a lack of anonymity* if they posted online, reinforcing silent browsing of the websites. The importance of the anonymity of pro-ED websites is supported in the literature (Ransom et al., 2010) due to the opportunity to discuss potentially shameful behaviours anonymously. Shame is discussed within theme four outlined below.

#### **4.2.4 Theme four: SHAME**

The fourth theme of SHAME refers to participants’ experiences of shame at using pro-ED websites, and paradoxically the role that pro-ED websites fulfil in normalising experiences and reducing feelings of shame about their eating disorder. Shame is described as an intense emotion involving the feeling of self-consciousness and a wish to hide oneself (Tangney et al., 1996). Shame is reportedly associated with a sense of being defective and inferior, unlovable and unworthy of respect (Yontef, 1993). The role of shame in eating disorders has been well established throughout previous research (Swan & Andrews, 2003). Self-reports of shame were found to be significantly higher in individuals in treatment for eating disorders than non-clinical controls. Differences in reported shame remained significant on all measures, including shame regarding bodily characteristic, non-physical characteristics,

general behaviour and behaviour around eating (Swan & Andrews, 2003). However, samples were relatively small with less than 75 individuals in each condition.

Shame has been associated with a lack of disclosure in therapy, with 42% of participants in treatment for an eating disorder reporting that they had not disclosed particular information during therapy due to fear of being judged by their therapist (Swan & Andrews, 2003). Participants in the present study described a perceived STIGMA OF USING WEBSITES and described a sense that their **use of pro-ED websites was more shameful than having an eating disorder**. Participants in the present study were engaged in treatment and had acknowledged their use of pro-ED websites with their clinician, yet still experienced a sense of shame at using the websites. Therefore, it is possible that the experience of shame is potentially greater for those individuals who have not sought support for their eating disorder and have not disclosed their use of websites to anyone.

The stigma attached to pro-ED websites has been highlighted within the literature; potential participants have reported a reluctance to take part in research due to fear of being stigmatised (Ransom et al., 2010). Consequently, individuals may under report their use of pro-ED websites as a result of stigma, shame, and fear of judgement. This is supported as participants reported **using websites privately and secretly**. Qualitative research has also highlighted that pro-ED website users search for the anonymity of pro-ED websites to express their eating disorder related attitudes and experiences due to a fear of stigmatisation in the ‘real world’ (Gailey, 2009).

Participants generally reported a sense of **social isolation** and **feeling different from others**, a well-established feature within the field of eating disorder research (Peebles et al., 2012b; Ransom et al., 2010). A belief that others would not understand their weight loss behaviour led to *reluctance to disclose ED to ‘real’ people*. Therefore, participants sought information and support online. The current sample were all recruited within treatment services, therefore, expressing an intention to continue eating disordered behaviour may be considered to be more prohibited and shameful than outside of a treatment context. Some participants reported anxiety regarding letting others down, such as their therapist, or feeling like they may get in to trouble for wanting to continue their behaviour and using pro-ED websites.

In addition to a sense of stigma regarding the use of pro-ED websites, participants also described a perception of WEBSITES NORMALISING THE EATING DISORDER; REDUCING SHAME. As a consequence of feelings of shame and a sense of social isolation in ‘real world’ relationships, individuals reported that **pro-ED websites helped to normalise experiences**. Participants noted that the websites provided reassurance that they were not alone; they described feeling accepted and less of a ‘freak’. Findings are consistent with previous research highlighting that pro-ED websites provide a safe forum for the expression of eating disordered behaviour (Gailey, 2009). Pro-ED websites are argued to facilitate open discussions whereby individuals feel a sense of shared understanding which is not available in ‘offline’ relationships (Ransom et al., 2010).

Previous qualitative research with pro-ED website bloggers also echoes present findings. Participants described motives for blogging which included a drive for social support due to feeling misunderstood in offline environments (Yeshua-Katz & Martins, 2013). A wish to escape social disapproval was also a factor motivating individuals to turn to pro-ED websites. Such findings are in line with the Identity Demarginalisation Model, whereby stigmatised individuals (i.e. those with an eating disorder) experience high levels of motivation to identify with a group of similar others (McKenna & Bargh, 1998). Consequently, individuals sought online support from similarly stigmatised others to compensate for a lack of offline social support (Yeshua-Katz & Martins, 2013).

Although many participants reported that pro-ED websites served to reduce a sense of shame and normalise experiences, some individuals also described further social isolation as a result of becoming preoccupied with pro-ED websites. This is supported by professional guidance provided by B-eat and Childnet International, in that pro-ED websites are argued to fuel social isolation from friends and families (Bond, 2012). A paradoxical relationship between positive online support and negative online content is argued to prevent individuals from seeking recovery (Bond, 2012). Therefore, whilst participants acknowledged that pro-ED websites provided a positive sense of reassurance and normalisation of experiences, the websites appear to reinforce eating disorder principles and further isolate individuals from ‘real life’ sources of support, thus maintaining the eating disorder. The role of pro-ED websites maintaining an eating disorder is outlined in theme five below.

#### 4.2.5 Theme five: **PRO-ED WEBSITES MAINTAINING ED**

The final theme identified within the interview transcripts refers to the notion that the use of pro-ED websites serves to **MAINTAIN EATING DISORDERS**. This is consistent with reviews which suggest that pro-ED websites may reinforce and increase eating disordered behaviour, acting as a barrier to recovery (Talbot, 2010; Roleau & von Ranson, 2011). However, existing experimental research has predominantly exposed non-clinical samples to mock pro-ED websites.

Present findings are also consistent with a high quality study focusing on over 1,200 pro-ED website users within a clinical eating disordered population (Peebles et al., 2012a). Within the sample, heavy pro-ED websites use was significantly associated with more extreme weight loss behaviour and harmful post-website use activities in comparison to light and medium website usage. The association remained when other variables such as age and duration of eating disorder was controlled. This suggests a robust association between pro-ED website use and detrimental outcomes, however, correlations do not allow for causality to be inferred.

Participants described **LEARNING and IMPLEMENTING TIPS TO INCREASE EATING DISORDERED BEHAVIOUR**, which replicates findings from the aforementioned study whereby 61% of pro-ED website users reported employing new weight loss or purging methods (Peebles et al., 2012a). Moreover, 37% used laxatives, diet pills or weight loss supplements; and 55% admitted to changing eating habits following pro-ED website activity (Peebles et al., 2012a). Similar results were found amongst adolescent patients using pro-ED sites (Wilson et al., 2006). However, users of pro-recovery websites also reported learning high risk eating behaviours; 46% learned new methods of weight loss or purging (Wilson et al., 2006).

Whilst it appears that individuals may learn and implement new weight loss tips from pro-ED websites, all participants in the present study reported **experiencing eating difficulties prior to using pro-ED websites**. Participants reported using the search engine Google to find weight loss tips, and ultimately found pro-ED websites. Results are coherent with previous research which highlights that many participants reported having an eating disorder prior to using pro-ED websites (Peebles et al., 2012b). It appeared that the *websites encourage and glamorise high risk behaviour* which is further supported by previous results (Ransom et al.,

2010). Therefore, present findings appear to be supportive of the claim that pro-ED websites may not initially cause eating disordered behaviour, but are likely to reinforce and maintain it (Talbot, 2010).

In addition to learning information on weight loss tips, participants also described experiencing a SENSE OF SUPPORT AND VALIDATION from pro-ED websites. Participants reported that the websites **provide validation** regarding their choice to engage in behaviour that may be considered indicative of an eating disorder. The websites *reinforce an eating disorder identity* and *reaffirm beliefs and attitudes about the eating disorder*, which is associated with the experience of cognitive dissonance, discussed in theme two above. Therefore, the validation received online supports individuals to use pro-ED websites to protect their eating disorder against a perceived pressure to recover. Support and validation were previously identified as benefits of pro-ED websites within both survey and qualitative research with pro-ED website users (Pebbles et al., 2012b; Yeshua-Katz & Martins, 2013).

Participants within the present study described **identifying with others' experiences** and **feeling a sense of support and belonging**. Such experiences are echoed in previous survey research whereby individuals reported greater perceived support and a sense of community from pro-ED websites in comparison to pro-recovery websites (Peebles et al., 2012a). A sense of acceptance and relief at using pro-ED websites has also been documented using survey methodology (Rodgers et al., 2012). Moreover, in a grounded theory analysis of individual experiences of pro-ED blogging, benefits of pro-ED websites included unconditional support and a sense of community within pro-ED websites (Yeshua-Katz & Martins, 2013).

Whilst many participants in the present study reported finding acceptance and a sense of community on pro-ED websites, such experiences are incongruent with the perception of the self as inferior to other users, and the anticipation of rejection outlined in theme three above. It would be interesting to explore such a disparity further.

The **externalisation of anorexia as Ana** was also discussed within the present study. It was found that some individuals related to 'Ana' and found the concept of Ana to be more comforting and less stigmatising than anorexia. In contrast, others found the concept of externalisation bizarre and unhelpful. This highlights divergences in how individuals view

their eating disorder. Some individuals perceive ‘Ana’ as an entity capable of controlling their thoughts and behaviour (Williams & Reid, 2010) whereas others do not relate to such a concept. In the present sample, it appeared that participants who wished to maintain their eating disorder related more to the concept of Ana than those further in to their recovery. It is possible that this disparity may also reflect the degree to which an individual is immersed within the pro-ED community.

The final core category within the theme of pro-ED websites maintaining an eating disorder involves USING PRO-ED WEBSITES FOR MOTIVATION TO RESTRICT AND LOSE WEIGHT. Participants described **using websites for motivation when hungry, weak or self-critical**. Previous survey studies report the principle use of pro-ED websites to be a method of motivating weight loss (Peebles et al., 2012a; Wilson et al., 2006).

Interestingly, a selection of participants in the present study also reported **using pro-ED websites as punishment when eaten or binged**, as a possible method of self-harm. Such findings have not appeared in previous research, suggesting a potential additional mechanism through which pro-ED websites may maintain eating disorders. The role of punishment may be consistent with models highlighting low self-esteem and self-criticism in individuals with eating disorders (Fairburn, 2008).

Finally, the interviews **support the Transdiagnostic Model of eating disorders** (Fairburn, 2008) which argues that discrete DSM or ICD eating disorder diagnoses of anorexia, bulimia and atypical eating disorders are arbitrary. It is proposed that the majority of individuals with a recognised eating disorder migrate between diagnoses (Fairburn & Harrison, 2003).

Participants within the current study described engaging in both restrictive and bingeing and purging eating practices. Restriction was often unsustainable, and individuals consequently migrated towards a bingeing and purging presentation, with some subsequently attempting to restrict food.

#### 4.2.6 Additional findings

Findings which were not directly related to the use of pro-ED websites were presented within the results chapter due to their potential relevance to clinical practice, outlined below. In addition to perceived pressure during treatment as described within the first theme of fear,



some participants also described **positive experiences of treatment**. Positive treatment experiences centred on experiencing *empathy and support through non-judgemental therapists*. Empathy is a well-established factor influencing the efficacy of interventions. A review of 23 qualitative and survey studies relating to recovery from eating disorders found that empathic relationships were essential to recovery (Bell, 2003).

Participants in the present study also reported *implementing skills learned in treatment* in order to cope with eating disorder related thoughts and urges. Skills such as mindfulness and thought challenging were also implemented to resist urges to return to using pro-ED websites once an individual had undergone treatment. Some participants also reported that the *personification of the eating disorder can be helpful in treatment*. It was believed by some participants that externalisation allows for painful emotions such as anger to be directed towards an external being, rather than becoming internalised.

### 4.3 IMPLICATIONS FOR CLINICAL PRACTICE AND SERVICE DELIVERY

To the author's knowledge, the present study provides the first exploration of the use of pro-ED websites for individuals specifically in treatment for an eating disorder. The implications of findings for clinical practice and service delivery are outlined below.

#### 4.3.1 Awareness and assessment of pro-ED website use

Current findings and previous research support the role of pro-ED websites reinforcing and potentially exacerbating eating disorders. Consequently, it follows that the use of pro-ED websites is an important factor which should be assessed and considered during treatment for an eating disorder. This is particularly salient given that the use of pro-ED websites has been described as a barrier to recovery and may undermine therapeutic work through the promotion of superficial engagement and deception during treatment.

Furthermore, despite robust research highlighting the impact of pro-ED websites, current NHS treatment guidance does not refer to the existence of, or impact of pro-ED websites (NICE, 2004). Consequently, it is possible that treatment services potentially underestimate the use of and impact of pro-ED websites. The current research supports previous recommendations made by professional bodies regarding enhanced education and awareness

training for young people, health professionals, teachers and families regarding the risks of pro-ED websites (RCP, 2009; Bond, 2012). A full update of NICE guidance was recommended in 2013 (NICE Centre for Clinical Practice, 2013). Findings from the present research suggest that inclusion of the risks and impact of pro-ED websites may assist in enhancing the efficacy of treatment services for individuals with eating disorders.

Clinicians should be aware of the accessibility of pro-ED websites and develop an understanding of how shame and stigma regarding pro-ED websites may lead to secrecy and reluctance to disclose the use of pro-ED websites. It is important to incorporate the use of pro-ED websites into formulations and intervention plans for individuals with an eating disorder. However, practitioners may be hesitant to ask explicitly about pro-ED website use due to anxiety about informing individuals about the existence of pro-ED websites and encouraging such use. It is anticipated that clinicians routinely assess for high risk behaviours such as laxative use and purging. However, actively avoiding the exploration of pro-ED website use may reinforce the ‘guilty secret’ that individuals using such websites may experience. This is likely to perpetuate shame and secrecy regarding pro-ED websites as the use of website cannot be named. The ethics protocol for the present study reflects clinical anxieties regarding encouraging use of pro-ED websites. The researcher respected ethical considerations and was unable to approach service users about pro-ED website use without prior disclosure of such use. However, the research has begun to draw attention to the impact of shame and secrecy regarding pro-ED website use.

It may be possible to indirectly assess the use of pro-ED websites through asking individuals about general website use and the methods they use to source information and support related to their eating difficulties. An empathic and non-judgemental stance is fundamental for the development of a trusting therapeutic alliance to facilitate the disclosure of pro-ED website use, as outlined below.

#### **4.3.2 Empathic and non-judgemental approaches within therapy**

Current findings highlight the role of shame and fear of judgement regarding the use of pro-ED websites. This seems to exacerbate a sense of social isolation and appears to motivate individuals towards using pro-ED websites. It is important that individuals feel both accepted and understood by treatment services (Bell, 2003) alongside a belief that individuals are

capable of, and are expected to change. Such an approach fits with the dialectic of acceptance and change from Dialectical Behaviour Therapy (DBT, Linehan et al., 1991). The dialectic balances a genuine acceptance of individuals with the view that clients have the capacity to change. DBT was originally developed for the treatment of individuals with a diagnosis of borderline personality disorder, and is gaining increasing credibility as a treatment choice for individuals with eating disorders (Wisniewski & Kelly, 2003; Chen et al., 2008).

Moreover, compassion-focused therapy has been applied to the treatment of eating disorders, with promising preliminary results (CFT-E, Goss & Allan, 2014). Developed from evolutionary and attachment theories of affect regulation, the model focuses on managing the biological and social challenges of recovery from an eating disorder. Authors note that CFT-E encompasses traditional treatment models, such as CBT, which is embedded in affiliative and caring processes. It is argued that the compassion-focused model addresses the high levels of self-criticism and shame which is commonly experienced in individuals with an eating disorder (Goss & Allan, 2014). Therefore, such a treatment approach may reduce the desire to utilise pro-ED websites.

Open, empathic and non-judgemental discussions regarding pro-ED websites across all treatment approaches may help to reduce a sense of shame and fear of disapproval. This may in turn promote a therapeutic alliance whereby individuals feel supported in offline contexts, reducing the need to use online pro-ED resources anonymously. Previous literature has argued that the vindication of pro-ED websites is obstructive and counter-productive. Alternatively, it is suggested that treatment services should focus on enhancing empathy, dignity and respect towards individuals experiencing an eating disorder (Gailey, 2009). However, due to the detrimental impact associated with pro-ED website use, therapists may hold negative preconceptions regarding pro-ED websites. Such preconceptions may present the therapist with an ethical dilemma, which may present a barrier to facilitating open and impartial discussions with clients.

### **4.3.3 Assessing readiness for change and recovery**

Findings in the present study highlight that when individuals feel pressured and threatened into recovery they may use pro-ED websites as a means of protecting their eating disorder, undermining attempts to facilitate change. Therefore, it is important to consider an

individual's readiness for recovery, possibly using the Transtheoretical Model of Change (Prochaska & DiClemente, 1992) as a marker of motivation to change. A treatment programme incorporating a motivational component within eating disorders treatment, named Motivational Enhancement Therapy (MET, Feld et al., 2001) has been developed and assessed. Findings demonstrated that MET enhanced motivation to change, increased self-esteem and reduced depression in individuals with an eating disorder. Therefore, prior motivational work may reduce a fear of recovery and a feared pressure to recover which may underlie the use of pro-ED websites. Such an approach may subsequently enhance readiness to engage in treatment programmes for eating disorders.

#### **4.3.4 Constraints of pro-recovery websites**

Participants within the current sample expressed that they felt excluded from some pro-recovery websites. Criticisms of pro-recovery websites included material being targeted towards younger adolescent females, information appearing biased and discounting any positive aspects of eating disorders, and perceiving the content to be brief, patronising and at times critical of individuals with eating disorders. Participants noted that pro-recovery websites could utilise some positive aspects of pro-ED websites to enhance the credibility of pro-recovery websites. It was suggested that pro-recovery websites could focus on sharing personal experiences in blogs, detailing journeys of recovery, as opposed to factual accounts of eating disorders. Recommendations may enhance the utility of pro-recovery websites, facilitating a sense of support and acceptance which is often sought on pro-ED websites.

### **4.4 STRENGTHS AND LIMITATIONS OF THE PRESENT STUDY**

#### **4.4.1 Strengths of the research**

To the author's knowledge, this is the first study of its kind within the field of pro-ED websites in that the research conducted face to face interviews with individuals who have used pro-ED websites in the context of an eating disorder. In addition, the research focused on the perceptions of individuals specifically in treatment for their eating disorder. Therefore, the study provides novel findings regarding the use of, and impact of pro-ED websites on individuals within treatment services.

The research adhered to quality guidelines (Elliott et al., 1999) and the analysis followed recommendations for undertaking Constructivist Grounded Theory (Charmaz, 2006), including documenting self-reflexivity. The analysis produced an explanatory model regarding the function and impact of pro-ED websites, ultimately meeting the aims and objectives of the study. Supervision and joint working with peer Trainee Clinical Psychologists was used to develop investigator triangulation (Guion et al., 2011), enhancing the validity of the study. Moreover, the constructivist approach to analysis fits with the researcher's theoretical orientation. Constructivist Grounded Theory explicitly notes that the grounded theory model provides *one* conceptualisation of pro-ED websites, rather than *the true account* of the phenomenon.

Furthermore, a service user who had experience of using pro-ED websites and a Clinical Psychologist working in tier three eating disorder services were consulted with during the development of the initial interview schedule. Therefore, various perspectives were taken in to account when considering areas of focus within interviews. Also, Grounded Theory allows for interview schedules to be tailored according to previous responses, in line with theoretical sampling. The flexibility of the interview schedule provided diverse areas for exploration, which subsequently led to rich data.

A comprehensive systematic review of pro-ED website use was undertaken, consequently, the present findings are embedded in the context of relevant theory and literature. Moreover, the current sample presented unique opportunities to capture perspectives of individuals at various stages of treatment and recovery. The sample included individuals who had undertaken treatment as well as those who maintained that they did not wish to recover from their eating disorder. Also, participants ranged in age from 20 to 40, all with enduring eating difficulties lasting from five years to 23 years. Consequently, the research captured a range of similar and diverse perspectives on pro-ED websites, highlighting the complex and idiosyncratic nature of pro-ED website use.

#### **4.4.2 Limitations of the research**

Although the current study presents valuable findings and contributions to the field of pro-ED websites, the study's limitations are outlined below. It must be acknowledged that the sample size within the study did not reach the sample size of eight to 12 participants which has been

recommended to achieve saturation of themes (Smith & Osborn, 2003). The author recognises that the research is likely to have benefited from an increased sample size; however, challenges to recruitment were experienced.

Two Health Boards were used for recruitment in order to maximise the number of potential participants available for inclusion in the study. In addition, the research interviews commenced in August 2013 and a final date for interviews was set at April 2014. Despite the large pool of potential participants and the long time frame for interviews, recruitment relied on the prior disclosure of pro-ED website use by service users. Ethical reasons prevented the researcher from approaching all individuals within the eating disorder service. Also, clinicians involved in recruitment reported that some individuals tentatively agreed to undertake the research but did not take part due to a reluctance to discuss their use of pro-ED websites or deterioration in their eating disorder. Out of the seven participants, six were recruited from one Health Board and one was recruited from the other Health Board. It is difficult to speculate reasons for different rates in the recruitment of participants across the Health Boards. Nevertheless, the successful recruitment of seven participants who were prepared to discuss their use of pro-ED websites was encouraging given the narrow pool of potential participants.

In addition, all participants were female and there was limited ethnic diversity within the sample. Therefore, the research findings cannot be extrapolated to represent all individuals in treatment for an eating disorder who currently use or have previously used pro-ED websites. Notwithstanding the limited sample size, saturation of themes did begin to emerge within interview transcripts. Constructivist grounded theory does not strive to generate a theory representative of all individuals. The present model was constructed in relation to the experiences of the participants who took part in the current study, and therefore, the model may not be generalizable to all individuals in treatment for eating disorders who use pro-ED websites.

#### 4.5 RECOMMENDATIONS FOR FUTURE RESEARCH

The present research offers a preliminary conceptualisation concerning the views of individuals in treatment for eating disorders regarding their use of pro-ED websites. Recommendations for future research to expand on the present study are outlined below.

The systematic review demonstrated that existing research in the field of pro-ED websites has predominantly been undertaken using online survey studies. Whilst online survey methodology permits the investigation of large samples, it does not allow for the in-depth exploration of phenomena. A combination of large quantitative survey studies and qualitative explorations of pro-ED websites is required to gain a more robust understanding of the function and impact of pro-ED websites within clinical populations. However, due to the stigma associated with pro-ED website use, recruitment of representative samples of pro-ED website users may be problematic.

Future qualitative research using samples of individuals within treatment services for eating disorders as well as those who are not involved in treatment services is important to further knowledge in the area. Studies within the systematic review highlight the international nature of pro-ED website use, with participants living across all continents, with the exception of Antarctica. Due to the wide-spread universal nature of pro-ED websites, it may be useful to conduct qualitative analyses on individuals outside of Wales and the UK. Treatment services outside of the NHS may react and respond differently to pro-ED websites, particularly where health-care is not provided by the state. Therefore, it is important to conduct research in various social and ethnic contexts to provide meaningful input to develop universal treatments for eating disorders.

Further research into potential variables affecting disparities in website use may assist in understanding individualised experiences of pro-ED website use. For example, it would be useful to investigate social and psychological variables such as attachment style, which may be associated with disparities in ‘active’ and ‘passive’ use of websites, and differences in social comparisons made on the websites. This may allow interventions to be targeted accordingly, potentially enhancing the effectiveness and responsiveness of treatment.

Recommendations from the present research include supporting therapists to adopt a non-judgemental attitude towards pro-ED websites, in order to reduce a sense of stigma and enhance openness with service users. Therefore, research with therapists to explore clinicians’ perspectives of pro-ED websites would also be useful. This would assist in the development of appropriate training for therapists who facilitate interventions with individuals who use pro-ED websites.

## 4.6 CONCLUSIONS

Overall the research has provided unique opportunities to explore the use of pro-ED websites of individuals in treatment for eating disorders. Constructivist Grounded Theory was used to generate a model to explain the function and impact of pro-ED websites. Five themes emerged in the data: fear, cognitive dissonance, social comparisons, shame, and pro-ED website maintaining eating disordered behaviour. Similarities and divergences in perceptions of pro-ED websites were apparent amongst participants.

All individuals who took part in the research reported experiencing eating difficulties prior to using pro-ED websites. Websites were often used to reduce a sense of social isolation, fuelled by stigma and shame associated with the eating disorder and use of pro-ED websites. Cognitive dissonance was often experienced regarding the eating disorder and the use of pro-ED websites. Accordingly, pro-ED websites were often used to protect the individual from pressures to recover. Moreover, fear of recovery and losses associated with recovery led some individuals to use pro-ED websites to superficially engage in treatment attempts.

The pro-ED websites appeared to offer a sense of support, validation and reassurance, whilst simultaneously reinforcing and maintaining eating disordered behaviour. A sense of pride and achievement appeared to be earned through weight loss, an ethic reinforced on the websites. Subsequent comparisons with other users served to enhance competition and a drive to work harder at the eating disorder. Websites were often used to motivate food restriction, and were at times used as a method of punishment when individuals experienced self-criticism.

Only one participant reported actively engaging in pro-ED websites, with the remaining individuals reading website content. Some individuals appeared to anticipate rejection from the online community which led to participants passively observing the websites, feeling on the periphery of the pro-ED community. Ultimately, individuals appeared to view the websites as helpful when in the midst of their eating disorder. However, for those participants who were actively working towards recovery, many reflected on their beliefs that pro-ED websites are dangerous in influencing vulnerable individuals and maintaining eating disordered behaviour.



The study offers one perspective of the process through which individuals in treatment for eating disorders use and respond to pro-ED websites. It is hoped that both the systematic review and current research begin to address the paucity of research exploring the impact of pro-ED websites within clinical populations.

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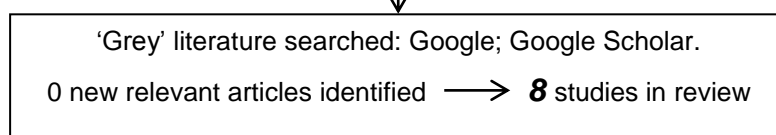
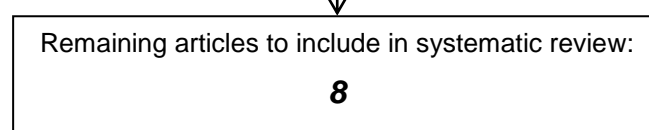
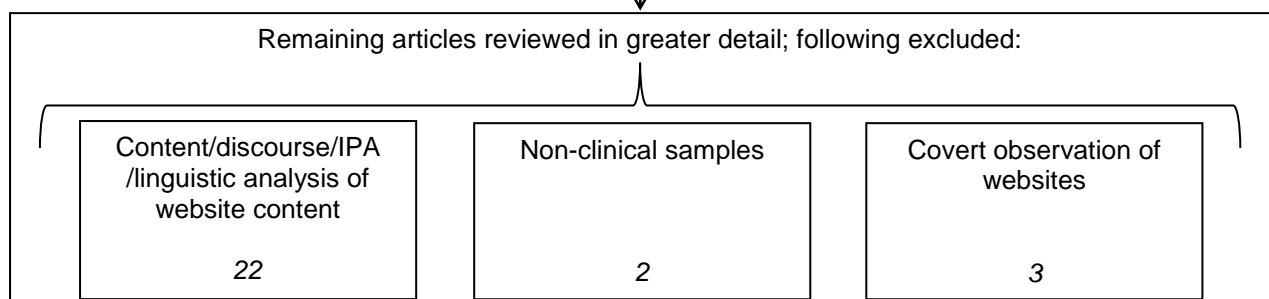
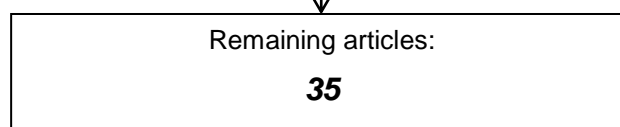
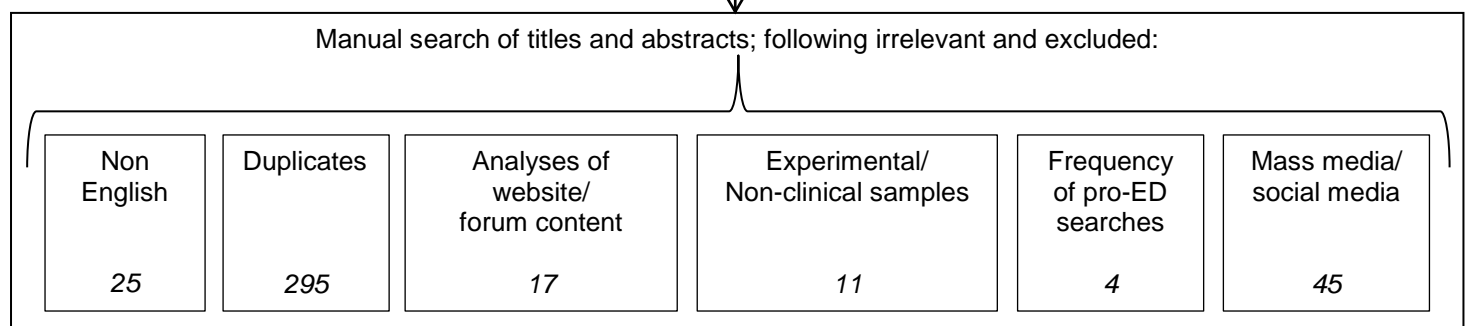
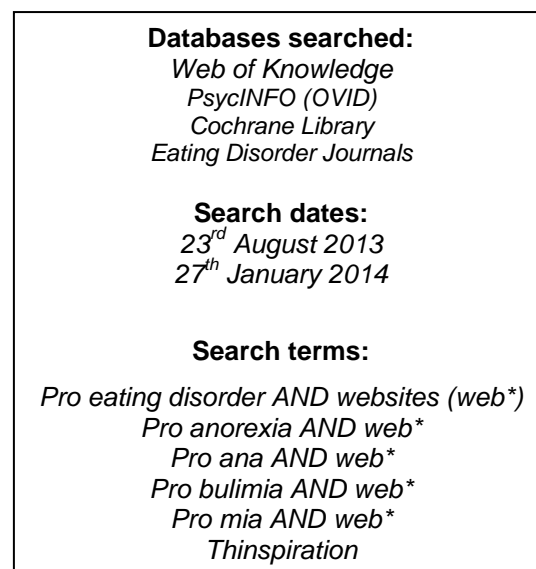
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## APPENDIX A, SYSTEMATIC REVIEW SEARCH PROCESS



APPENDIX E, CONSENT TO BE CONTACTED FORM



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Ysgol Seicoleg

South Wales Doctoral Programme in Clinical Psychology  
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Cymru Y Deyrnas Unedig*

---

**CONSENT TO BE CONTACTED FORM**

---

Title of Project: **Experiences of Pro Eating Disorder Websites**

Name of Researcher: **Leigh Collyer**

Please initial the  
box

I consent to be contacted by Leigh Collyer to discuss participation in the research titled "Service-users experience of using Pro-eating disorder websites: A qualitative study with service users and service providers in NHS eating disorders services."

☐

Preferred contact details (only fill in details that you wish to be contacted on)

Telephone number.....

Preferred day/time to receive telephone calls. ....

Email address.....

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person  
taking consent.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## APPENDIX F, INITIAL INTERVIEW SCHEDULE

### Interview Schedule

I'm going to be asking questions about your own use of pro eating disorder (pro-ED, pro Ana, pro Mia) websites.

1. How did you first hear about/find out about the websites?

*Prompt: friends, family, Internet cookies, hyperlinks, Facebook?*

2. How did you react when you first heard about/saw a link to a website?

*How did you decide whether to look at it or not? What were you thinking? How were you feeling? What were you hoping to get from using the websites?*

3. How do you/did you use the websites?

*How often do you use them? How long have you used them? How interactive are you on the websites? Do you look at pictures/read content, blog/write on forums, upload pictures? Which parts do you focus on? Which has the biggest impact on you and why? Do you have 'favourite' websites? What makes a 'good' versus not so good pro-ED website? Does anybody other than your therapist know that you use/did use pro-ED websites?*

4. When would you be most likely to use/view the websites?

*What thoughts, feelings, situations might make you more likely to use them?*

5. Tell me about your experience when you first saw or used a pro-ED website?

*How did you feel? What were your thoughts? What did you do during and after using the website? What makes you/made you return to websites? Did your experience match your expectations? What was helpful? What was not so helpful?*

6. How has this experience changed over time?

*How have your thoughts and feelings about pro-ED websites changed over time? How has your response to them changed?*

## APPENDIX F, INITIAL INTERVIEW SCHEDULE

7. How does using pro-ED websites impact on you?

*How do the websites impact on your thoughts and feelings regarding yourself and your eating disorder? How do they influence your behaviour? How do they impact on your relationships with friends and family? How do they affect your recovery?*

8. How do pro-ED websites compare to any other self-help websites that you know of?

*What websites do you find most helpful/least helpful?*

9. How do pro-ED ideas 'spill out' from the virtual world into the 'real world'?

*What influence do pro Ana/pro Mia ideas have on your relationships, what are your thoughts on the personification of anorexia as 'Ana' and bulimia as 'Mia'? How does this affect you? How does this make you feel?*

10. If you knew somebody with an eating disorder and they asked about pro-ED websites, what would you say to them?



## APPENDIX G, PARTICIPANT CONSENT FORM



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Ysgol Seicoleg

South Wales Doctoral Programme in Clinical Psychology  
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Plas y Parc  
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Cymru Y Deyrnas Unedig*

### CONSENT FORM (SERVICE USER)

Title of Project: **Experience of Using Pro Eating Disorder Websites**

Name of Researcher: **Leigh Collyer**

Please initial all  
boxes

1. I confirm that I have read and understand the information sheet (participant information sheet, service user, 18<sup>th</sup> July 2013, version 2) 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 participation will involve my interview being audio-taped, with use of anonymised verbatim quotation. ☐
4. I understand that my information will be stored securely in a filing cabinet, and the information I provide will be anonymised for use in the study. ☐
5. I agree to take part in the above study. ☐
6. I agree for my care co-ordinator to be informed of my participation in the study ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature



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Cymru Y Deyrnas Unedig

### Experiences of Using Pro Eating Disorder Websites

Date:

To whom it may concern,

I am writing to inform you that ..... has agreed to take part in the qualitative research titled Service-users experience of using Pro-eating disorder websites: a qualitative study with service users and service providers in NHS eating disorders services. Please refer to the clinician information sheet dated 17 April 2013 for further information related to the research.

If you have any questions please do not hesitate to contact me

Yours faithfully,

Leigh Collyer  
Trainee Clinical Psychologist

## APPENDIX M, SUMMARY OF THEMES

List of **THEMES**, **CORE CATEGORIES**, **categories** and *sub-categories*

### 1. **FEAR**

#### ➤ **FEAR OF RECOVERY**

- **fearing own pro-recovery related thoughts**
- **external pressure to recover**
- *fear of being pressured in to treatment*
- *feeling threatened or pressurised during treatment*

#### ➤ **LOSSES OF RECOVERY**

- **weight gain**
- *lack of control*
- *lost eating disorder identity*
- **using pro-ED websites to superficially engage in treatment**

#### ➤ **FEARING JUDGEMENT**

- **fear of criticism or judgement regarding pro-ED website use**

#### ➤ **FEAR OF PRO-ED WEBSITES**

- **fear of relapse**
- **apprehension at websites supporting high risk behaviour**

### 2. **COGNITIVE DISSONANCE**

#### ➤ **DESCRIBING DISSONANCE**

- **dissonance regarding ED and use of pro-ED websites**
- **minimised perception of risks to the self**
- *pressure to meet diagnostic criteria*

## APPENDIX M, SUMMARY OF THEMES

### ➤ USING PRO-ED WEBSITES TO REDUCE DISSONANCE

- **using pro-ED websites to protect ED**
- **illusion of ‘healthy’ looking images supporting ED**

### ➤ CHANGING VIEW OF WEBSITES THROUGH RECOVERY

- **readiness for change and wanting to help recover**
- **recognising the dangers of pro-ED websites**
- *vulnerability of people with ED*
- *pro-ED websites accountable for encouraging ED*
- **warning others against using pro-ED websites**

### ➤ PRO-ED WEBSITES AND RECOVERY

- **pro recovery websites not meeting needs**
- **ending the use of pro-ED websites to engage in treatment**

## 3. SOCIAL COMPARISONS

### ➤ EMOTIONAL IMPACT OF COMPARISONS WITH OTHERS ON PRO-ED WEBSITES

- **defining personal achievement through weight loss**
- **pressure to be thin is reinforced on pro-ED websites**
- *comparing self negatively to others leads to feeling jealous, inadequate and a failure*
- *comparing self favourably to others results in reinforcing ED/enhancing self-esteem and pride*

### ➤ COMPARISONS INCREASING ED BEHAVIOUR

- **websites fuel comparisons and competition**
- **admiring/idealising/aspiring to be like others on websites**
- **Self-efficacy**
- *identifying with extremely thin users and striving to achieve their body image*
- *believing thin images unattainable, not identifying with extremely thin images*
- **comparisons increase motivation to work harder at ED**

## APPENDIX M, SUMMARY OF THEMES

### ➤ IDENTIFICATION WITH USERS

- **observing versus interacting on websites**
- *feeling inferior to other users and anticipating rejection if they interacted on websites*
- *fearing lack of anonymity if posted online*

## 4. SHAME

### ➤ STIGMA OF USING WEBSITES

- **use of pro-ED websites is more shameful than having ED**
- *preconceptions of pro-ED websites*
- **using websites privately and secretly**

### ➤ WEBSITES NORMALISING ED: REDUCING SHAME

- **social isolation; feeling different from others**
- *reluctance to disclose ED to 'real' people*
- **websites normalising experiences**

## 5. WEBSITES MAINTAINING ED

### ➤ LEARNING/IMPLEMENTING TIPS TO INCREASE ED BEHAVIOUR

- **experiencing eating difficulties prior to using pro-ED websites**
- *websites encourage and glamorise high risk behaviour*

### ➤ SENSE OF SUPPORT AND VALIDATION

- **providing validation**
- *reinforcing an ED identity, reaffirming beliefs and attitudes about ED*
- **identifying with others' experiences**
- **feeling a sense of support and belonging**
- **externalisation of anorexia as Ana**

## APPENDIX M, SUMMARY OF THEMES

### ➤ USING PRO-ED WEBSITES FOR MOTIVATION TO RESTRICT/LOSE WEIGHT

- **using websites for motivation when hungry, weak or self-critical**
- **using pro-ED websites as punishment when eaten or binged**
- **support of the Transdiagnostic Model of eating disorders**

### **ADDITIONAL FINDINGS**

- **continuum of pro-ED websites**
- **positive experiences of treatment**
- *empathy and support through non-judgemental therapists*
- *implementing skills learned in treatment*
- *personification of ED can be helpful in treatment*