The Role of the Internet in the Secondary Prevention of Eating Disorders

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Submitted in Requirement for the Degree:

Master of Science by Research in Psychiatry

Trinity Term 2014

Word Count: 29,229

GENERAL ABSTRACT

Title: The Role of the Internet in the Secondary Prevention of Eating Disorders.

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Degree: Master of Science by Research in Psychiatry.

Term: Trinity Term, 2014.

Abstract: Eating disorders are a collection of serious mental illnesses. They are common causes of psychiatric morbidity amongst adolescent and young adult women and result in substantial costs to individuals, carers, communities, and health care services. Although evidence-based treatments are available, they fail to reach the majority of sufferers. Individuals often delay seeking help as a result of: shame, embarrassment, fear of stigma, an attendant desire to conceal the disorder, and low mental health literacy. Failure to recognise eating disorders in primary care settings, a shortage of therapists trained to provide individual face-to-face psychotherapy, and long waiting-lists may further delay the receipt of care. The present thesis set out to determine whether internet-delivered self-help might have the potential reduce this delay and to provide information to guide search engine optimisation for such interventions. It was comprised of two studies. Both involved the completion of a self-administered online questionnaire followed by a telephone discussion. The first recruited participants with a past or present eating disorder diagnosis who had previously taken part in a treatment trial. The second recruited participants through the website of a UK-based eating disorder's charity. The studies indicated that, in the majority of cases, there was a substantial delay between the onset of an eating disorder and help-seeking. During this time, most individuals went online to seek help or information and would have considered using online self-help. Frequently used search terms were: 'eating disorders', 'anorexia', 'bulimia', and 'weight'. Those who experienced binge eating also often searched for 'binge eat'. The results suggest that the provision of an online secondary prevention self-help resource would be likely to bring forward the receipt of care. Such programs require the results of research, including the present thesis, to ensure that they are encountered by sufferers of eating disorders in their online searches.

DISCLAIMER

The work included in this thesis is my own work except where indicated otherwise.

Signature: Emma. A. D. Clifton

Name: Emma A. D. Clifton

Date: 7th July 2014

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ABBREVIATION	**DEFINTION**
AN	Anorexia Nervosa
AN-BP	Anorexia Nervosa – binge eating/purging type
AN-R	Anorexia Nervosa – restricting type
APA	American Psychiatric Association
BDI	Beck Depression Inventory
BED	Binge-Eating Disorder
BMI	Body Mass Index
BN	Bulimia Nervosa
BWL	Behavioural Weight Loss
CBT	Cognitive Behaviour Therapy
CBT-BED	Cognitive Behaviour Therapy for Binge-Eating Disorder
CBT-BN	Cognitive Behaviour Therapy for Bulimia Nervosa
CBT-E	Enhanced Cognitive Behaviour Therapy
CBTgsh	guided self-help Cognitive Behaviour Therapy
CD-ROM	Compact Disk – Read Only Memory
CIA	Clinical Impairment Assessment
DALY	Disability Adjusted Life Year
DSM	Diagnostic and Statistical Manual of Mental Disorders
ED	Eating Disorder
EDE	Eating Disorder Examination
EDE-Q	Eating Disorder Examination Questionnaire
EDNOS	Eating Disorder Not Otherwise Specified
FBT	Family Based Therapy
GDP	Gross Domestic Product
GP	General Practitioner
gsh	guided self-help
HRQoL	Health-Related Quality of Life
ICD	International Classification of Diseases
IPT	Interpersonal Psychotherapy
ITT	Intent to Treat
kg	Kilogram
m	Meter
NCCMH	National Collaborating Centre for Mental Health
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
OCD	Obsessive Compulsive Disorder
Pro-ana	Pro-anorexia
QoL	Quality of life
RCT	Randomised Controlled Trial
SD	Standard deviation
SEO	Search Engine Optimisation
SIV	Self-Induced Vomiting
SMR	Standardised Mortality Ratio
SUD	Substance Use Disorder
TAU	Treatment as Usual
UK	United Kingdom
URL	Uniform Resource Locator
US	United States
WHO	World Health Organisation
WL	Waiting List

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ACKNOWLEDGEMENTS

Foremost, I would like to thank my supervisor, Professor Christopher Fairburn, for his invaluable help, advice, and patience throughout the preparation of this thesis.

I would also like to thank all the members of The Centre for Research on Eating Disorders at Oxford for their support. In particular, Professor Zafra Cooper and Mrs Marianne O'Connor, for giving their time to help with aspects of the studies, and Katy Sivyer for her advice regarding the analysis of the studies. Also Dr Katrina Witt, Dr Phil Burnet, and Sarah Collins for their encouragement. Finally, my family and OUWLRC for their support.

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CHAPTER 1:

INTRODUCTION

1.1 Introduction

The purpose of this chapter is two-fold. First, it will provide an overview of the classification, clinical features, epidemiology, burden, and treatments for eating disorders (EDs) in the twenty-first century. Second, the aims and forms of preventative medicine will be briefly outlined and the role of internet-delivered self-help in the secondary prevention of eating disorders will be discussed.

1.2 Eating Disorders and Their Classification

Eating disorders are a collection of mental illnesses characterised by persistent aberrations in eating behaviour in the absence of an obvious organic cause, and related abnormalities in beliefs concerning eating, shape, or weight. Alongside other mental illnesses, EDs are classified in both the American Psychiatric Association's (APA's) *Diagnostic and Statistical Manual of Mental Disorders 5* (DSM 5) and the World Health Organisation's (WHO's) *International Classification of Diseases-10* (ICD-10). The account given here will be based on that provided by the DSM 5, as it is both the most up-to-date and is most often used in research.

The DSM 5 recognises three distinct forms of ED, diagnosable on the basis of positive symptomatology: anorexia nervosa (AN), bulimia nervosa (BN) and binge-eating disorder (BED). A brief account of the diagnostic criteria follows. For a full account, see Appendix A.

1.2.1 Anorexia nervosa

Anorexia nervosa is characterised by three essential features:

1. Persistent restriction of energy intake.
2. Intense fear of gaining weight, fear of becoming fat, or enduring behaviour that interferes with weight gain.
3. A disturbance in self-perceived shape or weight.

Individuals must also be of significantly low weight (i.e. less than minimally or normally expected).

There are two subtypes:

1. **Restricting subtype (AN-R):** Weight loss is accomplished through dieting or fasting, possibly in combination with excessive exercise. The individual has not engaged in recurrent episodes of binge eating or purging in the last three months.
2. **Binge eating/purging subtype (AN-BP):** The individual has engaged in recurrent episodes of binge eating or purging in the last three months.

(APA, 2013)

1.2.2 Bulimia nervosa

Bulimia nervosa is characterised by:

1. Recurrent episodes of binge eating.

2. Recurrent inappropriate use of compensatory behaviours (purging) to prevent weight gain.
3. An undue emphasis of shape and/or weight on self-evaluation.

Both binge eating and purging must occur at a minimum frequency of once a week for three months. Binge eating is defined as the consumption of an abnormally large amount of food, given the circumstances, in a discrete time period. This is accompanied by a sense of loss of control.

(APA, 2013).

1.2.3 Binge-eating disorder

The essential feature of BED is recurrent episodes of binge eating (see above) that occur, on average, at a minimum of frequency of once a week for three months. Episodes of binge eating must be associated with marked distress and at least three of the following: eating much more rapidly than usual; eating until feeling uncomfortably full; eating large amounts of food when not feeling physically hungry; eating alone because of feeling embarrassed by how much one is eating; and feeling disgusted with oneself, depressed, or very guilty in the aftermath of the binge. (APA, 2013).

1.2.4 Residual categories

Two residual categories of ED are also recognised. These are applicable in instances where an individual's symptoms do not meet the full criteria of a specified diagnosis, yet still represent a clinically significant degree of distress or impairment.

1. Other specified feeding or eating disorder: This diagnosis applies to atypical forms of the three main diagnoses.

2. Unspecified feeding or eating disorder: This diagnosis applies to disorders of clinical severity that do not meet the criteria of the three main diagnoses.

(APA, 2013)

These classifications are subject to continual revision and are based on the clinical wisdom and the limited empirical evidence available at the time of publication. They represent suggestions and should not be reified to any great extent (Wilfley et al., 2007).

1.2.5 A note on binge-eating disorder and eating disorder not otherwise specified

Most research to date has been based on the DSM-IV classificatory scheme for EDs (in effect from 1994–2013) (APA, 1994). Two major differences exist between this scheme and the DSM 5.

1.2.5.1 Binge-eating disorder

Binge-eating disorder was listed in Appendix B of the DSM-IV as a research diagnosis for further study and was provisionally classified as a form of eating disorder not otherwise specified (EDNOS), pending further research (APA, 1994). Quality of life assessments lend support to significance of BED (Hay and Mond, 2005) and epidemiological data support its construct validity (Hudson et al., 2007). Further, BED aggregates in families in a manner speculatively indicating a possible genetic influence (Javaras et al., 2008). In light of these findings, BED has been included as a main ED diagnosis in the DSM 5.

1.2.5.2 Eating disorder not otherwise specified

Since the publication of the DSM III (APA, 1980) each broad diagnostic class of disorder has included an ‘atypical’ (DSM-III) or ‘not otherwise specified’ (DSM-III-TR and DSM-IV) category to denote disorders of clinical severity that do not meet the full criteria of a specified diagnosis and are, as such, residual to the specified categories within a class. In the case of EDs, this category was termed ‘eating disorder not otherwise specified’. Whilst being neglected in research, most ED cases in both clinical and community settings attracted a diagnosis of EDNOS (Fairburn et al., 2007).

1.3 The Epidemiology of Eating Disorders

Since the 1970s, interest in and research concerning EDs has grown, cumulating in their recognition as significant causes of psychiatric morbidity amongst adolescent and young adult women.

1.3.1 Anorexia nervosa

The term *‘anorexia nervosa’* was first introduced by Gull (1874). Despite its long medical history, epidemiological research was hampered by the absence of reliable case identification at least until the 1960s (Rosenvinge and Pettersen, 2014). Today, AN is the most commonly encountered ED in in-patient settings, accounting for 58% of all ED admissions (Patterson et al., 2013). However, it accounts for just 14.5% of out-patient ED diagnoses and is both the least prevalent and incident of the EDs amongst community-based groups (Fairburn and Bohn, 2005).

Estimates for the incidence rate of AN range between 1.2 per 100,000 person years for severe AN to 8.3 per 100,000 person years for the more broadly defined condition (Keel, 2010). Significant increases in apparent incidence occurred during the early to mid-twentieth century (Hoek and van Hoeken, 2003, Keel and Klump, 2003). Rates have remained relatively stable since the late twentieth century (Hoek and van Hoeken, 2003, Smink et al., 2012), save for increases amongst females aged 15–19 years (Smink et al., 2012).

The lifetime prevalence of AN falls between 0.3% and 1.0% amongst adolescent and young adult women (Hoek and van Hoeken, 2003, Keel, 2010) and its 12 month prevalence is 0.4% amongst young females (APA, 2013). Changes to the AN diagnostic criteria in the DSM 5 will result in an artificial increase in both prevalence and incidence (Smink et al., 2013).

The outcomes for sufferers of AN are reasonable (Zipfel et al., 2000); remission rates after 10 or more years are 50% (Keel and Brown, 2010). Diagnostic cross-over from initial AN to BN occurs in approximately a third of cases, typically within the first 5 years of onset (Eddy et al., 2008).

Anorexia nervosa has a clear demographic distribution. The disorder most often begins in adolescence or early adulthood, with 40% of all identified cases arising in those aged 15–19 years (Hoek and van Hoeken, 2003). The mean age of onset is 18.9 years (Hudson et al., 2007). Onset before puberty or after the age of 40 is rare (APA, 2013) and incidence rates are low for individuals over the age of 25. Approximately, one-in-10 cases in clinical settings occur in males (APA, 2013).

1.3.2 Bulimia nervosa

Bulimia nervosa was first described as an *'ominous variant'* of AN (Russell, 1979) and has since attained recognition as a distinct disorder (APA, 1980). Whilst BN accounts for a small proportion of inpatient ED diagnoses (e.g. Patterson et al., 2013), approximately one-third of cases in clinical practice attract a diagnosis of BN (Fairburn and Bohn, 2005). The 12 month prevalence amongst young women is 1.0%–1.5% (APA, 2013). However, due to low rates of detection, this figure is likely to be an underestimate.

There has been a clear increase in the incidence of BN since the 1970s. In tandem, prevalence estimates have increased over successive birth cohorts (Hudson et al., 2007). Whilst AN is not a culture bound syndrome (e.g. Bennett et al., 2004), there is evidence that BN is associated with exposure to modern Western ideals (Keel and Klump, 2003). Its emergence appears to be linked to a combination of access to large quantities of edible food, modern plumbing, and the idealisation of thinness (Keel and Klump, 2003). Some recent studies suggest that the incidence of BN may be declining, particularly amongst women aged 20–39 years, although other research indicates stability over the same time period (Keel, 2010).

The remission rates for BN are 75% after 10 or more years (Keel and Brown, 2010). The mean number of years with the disorder in one large, community sample was 8.3 years (Hudson et al., 2007). Diagnostic crossover from initial BN to AN occurs in a minority (10–15%) of cases (APA, 2013).

Bulimia nervosa has a clear demographic distribution. Onset typically occurs during late adolescence or early adulthood. Whilst there is overlap with the age-of-onset for AN, the mean age-of-onset for BN is slightly later (19.7 years) and the period of risk is more extended (Hudson et al., 2007). In clinical settings, approximately one-in-10 cases are diagnosed in men (APA, 2013).

1.3.3 Binge-eating disorder

Epidemiologically, BED is not typical of the EDs. Partly as a function of inconsistent definitions across studies, prevalence estimates vary. However, it appears that the condition is more prevalent than either AN or BN. The 12 month prevalence of the disorder is 1.6% amongst women and 0.8% amongst men (APA, 2013) and the lifetime prevalence is 3.5% and 2.0%, amongst women and men respectively (Hudson et al., 2007). One-in-3 cases arise in men, and prevalence does not appear to vary between ethnic groups (APA, 2013).

Binge-eating disorder has a higher mean age of onset than other EDs (25.4 years (Hudson et al., 2007)). Increases in BED across successive birth cohorts (Hudson et al., 2007) provide tentative evidence that the disorder has become more common in the United States (US) in recent decades (Keel, 2010). A dearth of follow-up studies limits inferences concerning outcomes. However, outcomes appear to be a more favourable in the short term than for either AN or BN, although this effect disappears if follow-up is extended over 5 years (Keel and Brown, 2010). The mean number of years with BED in one, large community-based study was 8.1 years (Hudson et al., 2007).

1.3.4 Sub-threshold disorders

Sub-threshold ED pathology is significant: first because it is associated with reductions in quality of life (Engel et al., 2009) and, second, because several of the associated practices, including self-reported dieting, body dissatisfaction, perceived pressure to be thin, and thin-ideal internalisation predict the onset of full syndrome disorders (Rohde et al., 2014). Sub-threshold disorders are more prevalent than their threshold variants. Lifetime prevalence rates by age 20 years amongst girls are 0.6%, 6.1% and 4.1% for sub-threshold AN, BN and BED respectively (Stice et al., 2009). Dieting and unhealthy weight control practices further affect between a third and half of adolescents, with significant minorities reporting serious disordered behaviour (Neumark-Sztainer et al., 2011). Significantly, both dieting and disordered eating track from adolescence to young adulthood (Neumark-Sztainer et al., 2011).

1.3.5 Caveats

Despite a growth in research and interest in EDs, their true incidence and prevalence remain unknown. The tendency for sufferers to lack insight, deny, or conceal their disorder, coupled with low levels of help-seeking and detection by health services means that present figures are likely to represent underestimates (Smink et al., 2012).

Inferences concerning changes in incidence and prevalence over time are also compromised. Apparent increases may, in part, be due to improved case detection and diagnosis, increased public awareness, greater help-seeking, and the wider availability of treatment services (Smink et al., 2012). Estimates are also confounded by the evolution of registration policy and, given high levels of chronicity and the relapsing course of many EDs (Berkman et al., 2007), the inclusion of readmissions as cases. Differences between populations may be confounded by demographic factors, service availability, and methods of detection (Hoek and van Hoeken, 2003).

1.3.6 Summary

Eating disorders are rare in the general population. However, they are common amongst adolescent and young adult women. Due to low rates of detection and the active avoidance of treatment (Hart et al., 2011), it is reasonable to assume that the true impact of EDs is underestimated.

1.4 The Burden of Eating Disorders

Despite some evidence of spontaneous remission (Vandereycken, 2012), for example during pregnancy (Madsen et al., 2009), it is not unusual for EDs to run a chronic course (Keel and Brown, 2010, Wonderlich et al., 2012). The potential costs and consequences are manifold and significant, encompassing costs to individuals, carers, families, communities, employers, society, and health care services.

1.4.1 Mortality

The most serious potential outcome of an ED is premature death. In this regard, AN is notable. It is the most morbid of the psychiatric disorders (Birmingham et al., 2005). The high all-cause mortality of AN, relative both to other mental disorders and to heavy smoking, was recognised in a recent meta-review (Chesney et al., 2014). However, other EDs also have potentially fatal consequences. A meta-analysis of articles published between 1st January 1966 and 30th September 2011 reported standardised mortality ratios (SMRs) of 5.86, 1.93 and 1.92 for the DSM-IV diagnoses of AN, BN, and

EDNOS, respectively (Arcelus et al., 2011). Many of the studies in this analysis are now dated with short follow-up periods and just 6 were based in the United Kingdom (UK).

A more recent investigation, based on a National Health Service (NHS) Hospital Episode Statistics dataset for the period 2001–2009 linked to data from death records, was conducted by Hoang and colleagues (2014). The researchers calculated all-cause mortality as an SMR within 365 days following hospital discharge. The SMR for individuals with an ED listed anywhere on their hospital record was 1.8. For individuals with a main diagnosis of an ED upon discharge, this figure was 1.5. The discrepancy is not statistically significant. The SMRs were further broken down by diagnosis. For individuals with a diagnosis of an ED anywhere on their hospital record, the SMRs for AN, BN, and EDNOS were 3.6, 3.2 and 1.3, respectively. For those with a main diagnosis of an ED upon discharge the corresponding figures were 3.4, 2.5 and 0.9. Age-specific analysis indicated a particularly elevated risk of death for ED sufferers aged 15–24 years. This group were 6 times more likely to die than the healthy age and sex-matched population, with those suffering from AN experiencing an 8.4 fold increase in risk of death (Hoang et al., 2014).

Mortality from EDs most often results from medical complications associated with the ED or from suicide (APA, 2013). The latter accounts for one-fifth of AN-related deaths (Deloitte Access Economics, 2012). Suicidality, ranging from suicidal ideation to completed suicide, is elevated amongst adolescents affected by any ED. The majority of adolescent BN sufferers report suicidal ideation (Swanson et al., 2011) and approximately one-third have attempted suicide (Franko and Keel, 2006). Between 3 and 20% of AN sufferers have attempted suicide (Franko and Keel, 2006). Rates of completed suicide are highest amongst sufferers of AN (Franko and Keel, 2006).

1.4.2 Medical complications

Eating disorders are associated with a litany of common, and not infrequently severe, medical complications. Disability-adjusted life years (DALYs) are a summary metric of population health, measuring the state of a population's health relative to the health that would be enjoyed if individual's lived a standard life-expectancy in full health. The measure combines years of life lost due to premature mortality and the years lived with disability as a result of illness (Murray et al., 2012). One lost DALY equates to one lost year of healthy life. In 2010, EDs cost 31 DALYs per 100,000 of the population across 21 global regions (Murray et al., 2012).

Medical complications are particularly common in AN where they are attendant to starvation and include: emaciation, hypotension, bradycardia, hypothermia, osteopenia and osteoporosis, loss of bone mineralisation, amenorrhea, cardiovascular and renal problems, skin problems, lanugo, gastro-intestinal complaints, and cognitive impairment (Katzman, 2005, Mitchell and Crow, 2006). Disorders of the reproductive hormones (low LH and FSH), suppressed thyroid stimulating hormone, growth hormone resistance, and raised cortisol levels have also been observed (NCCMH, 2004). Further, structural and functional changes to the brain may occur (Katzman, 2005, Katzman et al., 2001). Brain changes can persist following weight restoration (Katzman, 2005). Other complications depend on the timing of onset of the disorder and include delayed puberty and disruptions to linear growth in children. Preliminary evidence also suggests persistent disturbances to reproductive functioning in women following resolution of the ED (Freizinger et al., 2010).

Sufferers who engage purging behaviours may experience related complications. Self-induced vomiting (SIV), the abuse of laxatives, and the abuse of diuretics are all associated with electrolyte disturbance. The most common such disturbance, hypokalaemia, disposes patients to potentially dangerous cardiac arrhythmias and is present in approximately 5% of patients presenting with BN (Wolfe et al., 2001). The practice of SIV may further result in oral and gastrointestinal complications, pharyngeal soreness, dental problems amounting to destruction of the whole dentition in severe instances, gum disease, hypertrophy of the salivary glands (10–50% of BN patients), and oesophageal complications (Mehler, 2011). In addition, if the fingers are repeatedly used to instigate the gag reflex, Russell's sign, a scar or callous formation over the dorsal surface of the hand used to induce the reflex, may develop. Laxative misuse is associated with gastrointestinal complications, including functional impairment, and the misuse of diuretics is associated with fluid disturbance (Mehler, 2011). All EDs can result in irregular menses, which has the potential to interrupt bone mineralisation in adolescence and early adulthood (Myerson et al., 1992). Further, both BN and BED are associated with chronic back and neck pain, other chronic pain conditions, diabetes, and hypertension (Kessler et al., 2013).

In many instances EDs have a synergistic relationship with weight problems. In this regard, BED is notable. The disorder is associated with current severe obesity (BMI ≥40 kg/m^2) (Hudson et al., 2007). Lifetime BN and BED are both associated with high current BMI relative to control individuals without an ED history (Kessler et al., 2013). In addition, higher proportions of those with lifetime BN or BED are obese and lower proportions have a normal BMI when compared to individuals without an ED history (Kessler et al., 2013). Overweight and obese individuals are at risk of a number of adverse health outcomes (Dixon, 2010). Conversely, low BMI often persists in AN following resolution of the disorder (Hudson et al., 2007).

1.4.3 Psychiatric comorbidity

In addition to the physical corollaries EDs, ED sufferers experience high levels of psychiatric comorbidity. The majority meet the criteria for one or more other DSM-IV Axis I disorders. Comorbidity with mood and anxiety disorders is especially common. The lifetime prevalence rates of anxiety disorders amongst individuals presenting with BN or AN are 25%–75% and 23–75% respectively (Swinbourne and Touyz, 2007).

Obsessive Compulsive Disorder (OCD) is prevalent amongst the AN-R subtype, whilst substance use disorders (SUDs) are more often comorbid with the AN-BP subtype (APA, 2013). In addition to anxiety disorders, BN is associated with mood disorders (including major depression), borderline personality disorder, and SUDs (APA, 2013). Binge-eating disorder is associated with comparable levels of psychiatric comorbidity to AN and BN with the most common comorbidities being mood, anxiety, and, to a lesser degree, SUDs (APA, 2013).

1.4.4 Impairment

Eating disorders most often onset during adolescence or early adulthood (see Section 1.3). This is an important developmental period during which individuals form adult identities and transition to independence (Bulik, 2014b). Eating disorders may disrupt either or both of these processes leading to high levels of impairment across a range of life domains.

Amongst a large, community-based sample of adolescents aged 13–18 years from the US, 97.1% of those with AN, 78.0% of those with BN, and 62.6% of those with BED reported some measure of impairment in the preceding 12 months as a result of their disorder (Swanson et al., 2011). A significant minority (AN: 11.6%, BN: 14.4%, and BED: 9.8%) further reported being unable to carry out normal activities for an entire day. Reviews suggest that patients with AN experience less subjective impairment than those with other diagnoses (Hay and Mond, 2005). This may be attributable to the egosyntonic nature of the disorder but serves to highlight the significant levels of impairment experienced by other ED sufferers.

Amongst females, early-onset BED (defined as BED that onset whilst individuals were still students) is associated with reduced odds of currently being married (Kessler et al., 2014). Further highlighting the interpersonal difficulties experienced by this group of individuals, marital functioning is reported to be comparable or worse amongst female sufferers of BED than amongst women with major psychotic disorders (Whisman et al., 2012). Early-onset BED is associated with reduced odds of being currently employed amongst males (Kessler et al., 2014) and early-onset BN is associated with elevated odds of current work disability amongst females (Kessler et al., 2014).

1.4.5 Quality of life

Through consideration of the impact of symptoms and their corollaries on subjective well-being, quality of life (QoL) assessments provide a patient-centred method through which to appraise the impact of an illness on sufferers. The earliest QoL study to include EDs found reduced QoL amongst ED sufferers relative to healthy controls (Keilen et al., 1994). This finding has subsequently been replicated (Jenkins et al., 2014). It has also since been determined that any degree of ED pathology, including sub-clinical pathology, is associated with reductions in QoL (Jenkins et al., 2011). Health-related QoL (HRQoL), an assessment of an individual’s life specifically in relation to their health, is also impacted (Jenkins et al., 2014). Quality of life improves with treatment (de la Rie et al., 2005a, Hay and Mond, 2005), but does not return to the level of population norms (de la Rie et al., 2005a, Padierna et al., 2002).

Comparisons of QoL between the ED diagnoses have produced inconsistent findings. Some studies reveal no differences (Winkler et al., 2014), whilst others suggest that BED sufferers experience the highest levels of QoL impairment (Jenkins et al., 2011). This could be mediated by weight status, which has known QoL effects (Jenkins et al., 2011). However, BED in combination with obesity is associated with greater QoL impairment than obesity alone (Rieger et al., 2005). Additionally, AN patients may report higher QoL than expected due to the egosyntonic nature of the disorder.

Sufferers of EDs experience significant QoL impairment relative to those with other illnesses. In one study, ED sufferers reported lower QoL than both cystic fibrosis patients and male angina patients on domains related to social reactions, social isolation, and home relationships (Keilen et al., 1994). Eating disorder sufferers have also reported lower QoL than those with mood disorders (de la Rie et al., 2005a).

In summary, EDs have a significant impact on both QoL and HRQoL even in the absence of full-syndrome disorder (Jenkins et al., 2011). Quality of life improves with treatment but does not return to the level of population norms (de la Rie et al., 2005a).

1.4.6 Carers

As a result of recommendations that the EDs should be managed, wherever possible, on an outpatient basis (NCCMH, 2004), a large responsibility for care falls on families. Caring for someone with a mental illness can elicit strong emotional reactions including shame, guilt, despair, and anger (Zabala et al., 2009). Amongst carers of people with EDs, symptoms of anxiety and depression are markedly elevated relative to population norms (Martin et al., 2011, Zabala et al., 2009). Sufferers' mothers and partners are particularly vulnerable to experiencing an impact on their own mental health (Martin et al., 2011). Carers commonly report feelings of powerlessness, anxiety, sadness, and desperation (de la Rie et al., 2005b), as well as high levels of expressed emotion (Zabala et al., 2009). Carers for people with EDs also perceive a lack of information and support (Graap et al., 2005). The ramifications of EDs extend beyond the individual sufferer and significantly impact those close to them.

1.4.7 The economic cost

Mental ill-health is the largest single cause of disability in the UK, contributing almost 23% of the overall disease burden and accounting for 11% of England's annual secondary health care budget (HM Government, 2011). The aggregate economic and social costs of mental health problems for the financial year 2009/10 amounted to £105 billion (Centre for Mental Health, 2010).

Little data exists on the costs specific to EDs (Gustavsson et al., 2011) and there is reason to believe that current estimates represent the lower limits of the true cost. The reasons for this are two-fold. First, many studies are limited to AN and BN. Second, many of the costs are difficult to quantify including those associated with: lost productivity, informal care, private health care, and conditions caused or exacerbated by EDs. These are likely to be substantial. For example, those with BN and BED experience elevated outpatient, inpatient, and emergency department use days when compared to healthy controls (Striegel-Moore et al., 2008, Striegel-Moore et al., 2005) and there is a high private provision of treatment for EDs (e.g. Brown, 1997).

A review commissioned by the King’s Fund estimated that the total in and out-patient costs of EDs in England for the year 2007 amounted to £15.7 million and that the cost of lost employment amounted to £50.6 million (McCrone et al., 2008). Overall, the cost of lost employment accounted for 69% of the overall costs. The review acknowledged that the costs omitted from these estimations, including that of premature mortality, were likely to be substantial (McCrone et al., 2008).

Another separate report estimated that the total costs of EDs amount to a minimum of £1.26 billion/annum in England, comprising health care costs of £80–100 million, costs of reduced gross domestic product (GDP) of £0.23–2.9 billion, and costs of reduced length of life and compromised health of £0.95–6.6 billion (Pro Bono Economics, 2012). This estimate was limited to AN and BN and, further, acknowledged the probability of underestimating the true cost through lack of data (i.e. uncertainty surrounding the contribution of private health care), the omission of intangible costs, and the inability to calculate certain costs (including those arising from consultations for conditions caused or exacerbated by EDs and those incurred by informal carers).

In summary, EDs present a substantial economic burden. The broader social costs exceed the health care costs (McCrone et al., 2008, Pro Bono Economics, 2012).

1.4.8 Summary

Eating disorders are a collection of serious mental illnesses with amongst the highest mortality rates of any group of psychiatric disorders (Harris and Barraclough, 1998).

They are associated with both physical complications and psychiatric comorbidities. In addition to impacting the quality of life of sufferers and incurring substantial social, occupational, and economic costs, EDs present a serious burden to caregivers, health care services, and society.

1.5 Treatment

The National Institute for Health and Care Excellence (NICE) offers evidence-based guidelines concerning the identification, treatment, and management of illnesses. The guidelines pertaining to EDs are summarised as follows:

1. **Anorexia nervosa:** Adults should receive psychological treatment and physical monitoring on an outpatient basis wherever possible. Evidence-based treatment options are: cognitive analytic therapy, cognitive behaviour therapy (CBT), interpersonal psychotherapy (IPT), focal psychodynamic therapy, and family interventions focused explicitly on EDs. Patient and, if appropriate, carer preference should be taken into account when deciding upon which treatment to pursue. Adolescents and children should be offered family-based therapy (FBT). (NCCMH, 2004).

2. **Bulimia nervosa:** A possible first step in treatment is evidence-based self-help. Health care professionals can directly encourage and support these efforts. An additional or alternative first step is a trial of an anti-depressant drug. Sixty mg/day of fluoxetine can reduce core bulimic symptoms including binge eating, purging, and associated psychological features (Shapiro et al., 2007). However, the long-term effects are unknown. Adults should be offered cognitive

behaviour therapy for bulimia nervosa (CBT-BN). This treatment is also appropriate for adolescents provided that it is suitably adapted. Other psychological treatments should be considered where patients fail to respond to CBT-BN or do not want CBT. In these cases, IPT is a possible alternative. (NCCMH, 2004).

3. **Atypical eating disorders and binge-eating disorder:** In the absence of a rich evidence-base, clinicians should follow guidance for the ED to which the patient's symptoms most closely conform. More is known about how to treat BED. As a possible first-step, patients should be offered an evidence-based self-help program. Health care professionals can directly encourage and support these efforts. There is evidence that such support may improve outcomes. Alternatively or additionally, patients may try a trial of an anti-depressant drug. Adults should be offered CBT for binge-eating disorder (CBT-BED). Suitably adapted psychological treatments should be offered to adolescents. (NCCMH, 2004).

Overall, CBT is the most widely researched of the available treatment options and therapist-led enhanced CBT (CBT-E) is the best empirically supported therapy (Hay, 2013). Fairburn and colleagues (2009) found that approximately half of patients with an ED, excluding AN, will have a global eating disorder examination (EDE) score of <1.74 (i.e. less than 1 standard deviation above the community mean) after CBT treatment in intent to treat (ITT) analysis. Of those who complete treatment, the corresponding figure is two-thirds and 50% maintain this gain to 60 week follow-up (Fairburn et al., 2009). IPT provides an alternative to CBT-E. The treatment has equivalent effects but takes longer to induce symptomatic change (Hay, 2013). There is some evidence that FBT may provide an effective alternative for adolescents with BN (Couturier et al., 2013).

Anorexia nervosa is considered to be a difficult disorder to treat (Halmi et al., 2005). No pharmacological interventions are known to be effective (Bulik et al., 2007). FBT should be offered to younger patients, but is not known to be effective for adults (Bulik et al., 2007). There is growing evidence for the use of CBT amongst adult sufferers of AN (e.g. Byrne et al., 2011, Fairburn et al., 2013). One trial involving patients with AN from two sites, one in the UK (n = 50) and one in Italy (n = 49), found that those who completed CBT (two-thirds) experienced a mean weight gain of 7.47 kg and 62% achieved a BMI >18.5 kg/m². Eighty-eight percent of treatment completers experienced minimal ED psychopathology by the end of treatment, this proportion reduced to 78% at 60 week follow-up (Fairburn et al., 2013). Byrne and colleagues (2011) performed a trial of CBT-E for adults with EDs, excluding BED, referred to an out-patient clinic in Western Australia. Overall, the AN patients had lower rates of recovery in ITT analysis; 17.6% achieved full or partial remission compared to 45.0% of those with BN and 51.0% of those with EDNOS. However, this reflects higher rates of drop-out amongst the AN patients and was not true of treatment completers, except where recovery was defined as having a post-treatment global eating disorder examination questionnaire (EDE-Q) score of <2.46 in addition to a BMI ≥18.5 kg/m². There is some evidence that CBT-E may additionally be effective for adolescent AN sufferers where FBT is not desirable or possible (Dalle Grave et al., 2013). Tentative evidence exists that CBT reduces relapse risk amongst adults once weight gain is achieved (Bulik et al., 2007).

With regards to the treatment of EDNOS and BED, guidelines are less clear (Hay, 2013). The quality of the studies is generally poor when compared to those of AN and BN (Bulik et al., 2007, Hay, 2013). The only study to investigate treatment of the full range of EDNOS cases found CBT-E to be reasonably effective (Fairburn et al., 2009). CBT-E is generally advised as the treatment of choice for those who are not underweight (NCCMH, 2004). For BED patients, there is also good evidence supporting the use of CBT delivered in a guided self-help format (NCCMH, 2004, Wilson and Zandberg, 2012).

1.6 The Delay between the Onset of an Eating Disorder and the Receipt of Care

The National Institute for Health and Care Excellence recommends that:

> *People with eating disorders should be assessed and receive treatment at the earliest opportunity* (NCCMH, 2004, p. 62)

Despite these guidelines there is often a lengthy delay between the development of an ED and the receipt of care (e.g. Cachelin et al., 2001).

Amongst community-based groups, consistently less than half of those with EDs report ever having sought ED-specific treatment (e.g. Cachelin and Striegel-Moore, 2006, Hudson et al., 2007, Mond et al., 2007, Mond et al., 2010b). In one systematic review, the pooled proportion of individuals with EDs who reported having sought treatment was 23.2%, with a range of 0–52% for individual studies (Hart et al., 2011). Despite this, the majority of people who meet the criteria for an ED believe that they are in need of help (Hart et al., 2011).

Overall, it is estimated that 67–83% of ED cases have an unmet need for treatment (Hart et al., 2011). Cachelin and colleagues (2001) found that amongst a community group of 61 women with a DSM-IV diagnosable ED, 85% wanted help and 57% had made contact with health care services. However, just 8% had received treatment.

There are a number of barriers on the pathway to care explaining this short-fall in service provision. These comprise both psychosocial and institutional barriers.

1.6.1 Barriers to help-seeking

In order to seek help for an ED, an individual must first perceive that they have a problem. Denial, minimisation, and lack of insight leading to incomplete or absent problem recognition are common (Hepworth and Paxton, 2007, Schoen et al., 2012). In a study of 108 hospitalised AN patients, 63% denied their disorder (Abbate-Daga et al., 2013). Further, in one small qualitative study, individuals reported that they were only transiently aware of the severity of their ED and their need for help (Schoen et al., 2012). Denial may be lower amongst those who experience binge eating, as this behaviour is most often experienced as aversive (Stein et al., 2007).

In order to receive professional help, after an individual has identified the problem, they must choose to seek assistance. Mond and colleagues (2010b) found that whilst 66.7% of ED sufferers visiting primary care practices perceived that they may have an eating problem, less than 40% had sought advice or treatment.

Community-based studies indicate that a significant minority (14.8–44%) of sufferers do not want treatment (Hart et al., 2011). Partly, this results from denial and lack of insight. However, for some, a fear of change may stall or prevent help-seeking (Hepworth and Paxton, 2007). Positive feelings and pride in aspects of the ED have also been noted (e.g. Schoen et al., 2012), particularly in association with AN where ambivalence is common (Zeeck et al., 2005). Some sufferers indicate that EDs provide a means through which to communicate feelings of vulnerability and distress (Serpell et al., 1999) and to elicit care from others (Schmidt and Treasure, 2006). AN has been conceived of by sufferers as a *'guardian'*, affording feelings of safety and protection (Serpell et al., 1999), acting as an aid to the avoidance of negative emotions, giving sufferers confidence (Serpell et al., 1999), and leading to feelings of strength, separateness, and superiority (Abbate-Daga et al., 2013). Eating disorders may further satisfy a need for control and may be used to elevate boredom (Serpell and Treasure, 2002, Serpell et al., 1999). Sufferers of BN often report that their disorder allows them to stay slim whilst still being able to enjoy eating food (Serpell and Treasure, 2002).

Alongside positive ED experiences, other factors also prevent sufferers from seeking help. Sufferers may believe that their problem is not significant enough to warrant care (Hart et al., 2011) and may further experience: shame, hopelessness, fear of stigma, self-stigmatisation, fear of change, fear of compulsory treatment, guilt, concern regarding the financial costs of treatment, a belief that they should be able to cope independently, fear of health services, and low mental health literacy (e.g. Becker et al., 2004, Mond et al., 2010a). Over 50% of the participants in one study reported a personal experience of stigma or shame (Becker et al., 2010). *'Fear of stigma'* was the most commonly expressed barrier to help-seeking in another study, followed by low mental health literacy, low perception of need, and shame (Hepworth and Paxton, 2007).

Acting in orchestra these factors result in many cases of EDs remaining undetected or untreated.

1.6.2 Barriers to the receipt of care

After choosing to seek help, individuals often experience further barriers to the receipt of care. First, although general health service use is elevated amongst ED sufferers, EDs often go undetected in primary care (Becker et al., 2009). This may be particularly true of disorders that do not result in marked changes in weight. Patients raised concerns in one study that only those who are underweight can readily access care (Escobar-Koch et al., 2010). Corroborating this finding, 40% of participants in another study reported being told that their BMI was not low enough to access services (BEAT, 2013). This may result in a dangerous situation whereby individuals attempt to lose weight in order to receive help.

Health care providers may unintentionally delay the receipt of appropriate care for their patients. For example, inappropriate referrals, e.g. to weight loss services, are often provided (Cachelin et al., 2001). In one study, patients raised concerns about their general practitioner's (GP's) lack of knowledge and failure to provide a timely diagnosis, noting that these factors resulted in important delays to the receipt of care (Escobar-Koch et al., 2010). Further, less than 4% of GPs use national, evidence-based guidelines to inform the management of their ED patients (Currin et al., 2007).

If relevant referrals are given, long waiting list times pose a further important barrier to the receipt of care in the UK. Under the NHS Constitution, individuals with physical health problems benefit from an 18 week maximum waiting time target (Department of Health, 2013). No such target exists for mental health problems. A recent study (BEAT, 2013) revealed that 42% of those with a diagnosis of BN or EDNOS waited over 18 weeks to receive specialist treatment. For AN this figure was 20%. Overall, 26% of ED sufferers waited in excess of 6 months, 8% waited over a year, and some spent in excess of two years on a waiting list. A long time spent on a waiting list is a predictor of treatment drop-out (e.g. Byrne et al., 2011). Moreover, in a study conducted by BEAT (2013), 60% of participants agreed or strongly agreed that their motivation to change decreased due to the length of time they spent on a waiting list. The majority also agreed or strongly agreed that their self-esteem or self-worth was adversely affected (67%), their ED increased in severity (74%), they were made to feel that they were not *'sick enough'* (74%), other health problems developed (53%), their relationships were strained (69%), and their ability to succeed in their studies or career was affected (67%) by the length of time that they spent waiting for care.

One cause of long waiting list times is a pervasive shortage of appropriately trained clinicians. Issues of geography and uneven distribution of specialist services across the UK provide another important barrier to the receipt of care. In the recent BEAT (2013) study, 27% of the participants were told there was no appropriate treatment centre nearby and 30% had to travel in excess of 20 miles to access treatment; 7% travelled over 50 miles for this purpose. A significant minority of the participants (27%) did not have access to the transport required to get to the location of the nearest treatment service (BEAT, 2013).

Globally, high costs of private treatment in some countries (e.g. Australia (Banasiak et al., 1998)) are a further barrier to receiving help. In the US, those who are uninsured experience financial barriers and the care received by individuals with insurance may be dictated by what insurance companies are willing to pay for, as opposed to clinical need (Escobar-Koch et al., 2010). In the UK, problems accessing care on the NHS mean that, at substantial cost, 22% of patients pay for private treatment (BEAT, 2013).

The evidence-based medicine movement contends that the treatments offered to patients should be informed by the most robust research evidence available. However, once help is obtained, evidence-based treatment guidelines are not necessarily followed. Despite robust evidence to the contrary, many clinicians believe that CBT-E is not appropriate for their patients and is not effective in real-life settings (Waller, 2009). In one study, CBT was endorsed as the primary approach for the treatment of EDs by just one-third of psychologists (Mussell et al., 2000). Moreover, only a minority of those endorsing CBT as their primary treatment approach report having received specific training in its use (Mussell et al., 2000). This is likely to result in suboptimal care for patients.

Research plays only a minor role in informing therapist's choice of theoretical orientation and clinical decision-making (Gyani et al., 2014). Therapists are more likely to rely on *'intuition'*, *'personal experience'*, and *'clinical training'* (Gyani et al., 2014). Therapist drift, a phenomenon whereby clinicians diverge from evidence-based guidelines, has also been widely observed (Waller, 2009) and leads to the omission of central elements of CBT by therapists in practice (e.g. Stobie et al., 2007). The result is suboptimal care for patients and the possibility of an unnecessarily extended period of suffering.

1.6.3 Specific groups

Additional barriers to help-seeking and the receipt of care affect certain sub-groups. Eating disorders amongst males have been described as: '*overlooked, understudied and underreported'* (Greenberg and Schoen, 2008, p. 464). The adolescent supplement to the US-based National Comorbidity Survey highlighted that whilst few (12.8%) adolescents with a lifetime ED have been or are in contact with treatment services, for males the figure is particularly low (Merikangas et al., 2010). Just 1.8% of male sufferers reported having received treatment for a lifetime ED.

Across a range of illnesses, ethnic minority individuals are known to underuse health care services (Cachelin et al., 2001). Eating disorder sufferers from ethnic minority groups are less likely to seek help and, having sought it, are less likely to have received help or a diagnosis (Cachelin and Striegel-Moore, 2006). Unfamiliarity with health care services, cultural explanations, the expectation that therapists will be hostile, language barriers, the lack of ethnically representative professional staff, and faith in informal support networks are all significant barriers that may impact help-seeking amongst members of ethnic minority groups (Cachelin et al., 2001).

Ethnic minority individuals are also at risk of being overlooked in primary care settings. Symptomatic individuals are less likely to be queried by doctors about issues of eating and weight if they are from an ethnic minority group (Borowsky et al., 2000). When asked to read a passage concerning the eating patterns of a fictional patient, 'Mary', clinicians identified that 'Mary' had symptoms of an ED in over 40% of cases when 'Mary' was either Caucasian or Hispanic (Gordon et al., 2006). However, when 'Mary' was identified as African American, the corresponding figure was just 16.7% (Gordon et al., 2006). Undergraduate students evidence similar biases in their detection of disturbed eating patterns, more readily identifying the symptoms of an ED when a fictional character is described as Caucasian as compared to when she is described as Hispanic or African American (Gordon et al., 2002).

1.6.4 Summary

The time lapse between symptom onset and receipt of care for EDs is troubling for a number of reasons. First, it results in an extended period of suffering and creates the opportunity for secondary problems, including low self-esteem and relationship problems (Serpell et al., 1999), to arise which may result in the ED becoming more complex and difficult to treat. Second, EDs typically onset during adolescence or early adulthood; this is a period of continued physical, social and emotional development. Disruption to these processes has the potential to cause enduring educational, occupational, and social impairment. It may also influence the course and formation of relationships, adult identity, and an individual’s career. There is the additional possibility for long-term physical damage, particularly if health problems exist that may interact with the ED (e.g. diabetes mellitus (Pinhas-Hamiel and Levy-Shraga, 2013)). Otherwise healthy individuals are also at risk of adverse health consequences including fertility problems (Freizinger et al., 2010), stunted growth, and suboptimal bone mineralisation (Katzman, 2005). Third, there is evidence that early intervention improves treatment outcomes (Reas et al., 2000) and that disorders may become increasingly intractable with illness duration (Keel and Brown, 2010).

Immediate access to evidence-based care has the potential to improve outcomes and reduce suffering for people with EDs and may have the additional advantage of harnessing early enthusiasm for change (Fernandez-Aranda et al., 2009).

1.7 Preventative Psychiatry

Given the compelling case for early intervention and evidence that treatments are not promptly reaching those in need, the prevention of EDs requires renewed focus. Preventive interventions can be divided into three sub-groups.

1.7.1 Primary prevention

Primary prevention refers to interventions designed to reduce the incidence of a disease. It includes general health promotion, for example the provision of exercise and nutritional guidelines, as well as specific protection against disease, for example immunisation programs. Its purpose is to reduce the vulnerability of individuals or populations to disease (Edelman et al, 2014). This is achieved through intervening before disease onset to prevent the development of new cases and is relevant to diseases for which aetiology is at least partially understood and modifiable risk-factors exist.

1.7.2 Secondary prevention and early intervention

Secondary prevention refers to any intervention designed to reduce the prevalence of a disease through minimising the interval between the onset and the receipt of treatment. Such interventions take a number of forms (Edelman et al, 2014). Secondary prevention may refer to earlier case detection through the screening of non-symptomatic individuals. An example is the national breast cancer screening program in the UK. Alternatively, secondary prevention may refer to efforts designed to encourage early help-seeking through the promotion of symptom awareness, for example the ‘Be Clear on Cancer’ campaign. Finally, secondary prevention may refer to early intervention. Early intervention itself has a number of potential meanings. In the context of this thesis it refers to interventions responding as early as possible following the identification of illness. Emphasis on early intervention is relevant to the treatment of disorders, like EDs, for which there is a documented delay between onset and the receipt of care.

1.7.3 Tertiary prevention

Tertiary prevention refers to interventions designed to reduce the level of disability associated with a disease. It occurs when:

> *A defect of disability is permanent or irreversible. The process involves minimising the effects of disease and disability by surveillance and maintenance activities aimed at preventing complications and deterioration* (Edelman et al, 2014, p. 15)

Interventions aim to maximise quality of life and reverse or prevent, as far as possible, further medical, psychological, or social deterioration. Tertiary prevention is especially relevant to chronic diseases of long duration and slow progression where good long-term management is integral to maintaining quality of life and stalling or preventing the development of impairment.

This thesis is concerned with the potential role of the internet in the secondary prevention of eating disorders.

1.8 The Dissemination of Psychological Treatments for Eating Disorders

Across the spectrum of mental illnesses, services fail to reach all those in need of help. Given the manifold costs of EDs and evidence of increasing intractability with longer illness duration (Treasure and Russell, 2011), there is a compelling ethical and economic case for broadening the reach of current psychological therapies and for promoting primary and secondary prevention efforts. There has recently been a shift in focus from treatment development to an interest in the dissemination of existing evidence-based treatments (e.g. Fairburn and Wilson, 2013). Dissemination can be defined as:

> *An active approach of spreading evidence-based interventions to the target audience via determined channels using planned strategies* (Brownson et al, 2012, p. 26)

A complementary concept, implementation, can be defined as:

> *The process of putting to use or integrating evidence-based interventions within a setting* (Brownson et al, 2012, p. 26)

At present, in excess of 60 ED prevention programs have been developed and evaluated in published trials (Stice et al., 2013).

There are several potential approaches to dissemination. These are outlined by Fairburn and Patel (2014) and are summarised below:

1. ***Increase the number of therapists:*** This may take two forms. First, efforts could be made to train more therapists. Second, a ‘task-shifting’ approach, whereby less qualified individuals are trained to deliver a therapy (Fairburn and Patel, 2014), could be adopted.

2. ***Alter therapist training:*** Current methods of therapist training are not scalable. However, alternatives exist. One possibility is the adoption of a ‘train-the-trainer’ approach, whereby one staff member in a mental health organisation is educated to become a trainer for other staff members. This method needs to be evaluated in large controlled studies (Fairburn and Wilson, 2013) and is still limited in its scalability due to the time it takes to implement (Fairburn and Patel, 2014). An alternative approach is ‘internet-enhanced’ training whereby a website educates potential therapists in the use of a treatment. The website may be designed as a stand-alone educational resource or may be used in combination with limited guidance from a non-specialist. The Centre for Research on Eating Disorders at Oxford are currently developing and testing two such training websites for EDs and depression. This method of training is limited to settings in which internet access is pervasive. However, it may be well-placed to counter problems in the application of therapies, including ‘therapist drift’ (see Section 1.6.2), as therapists would be able to revisit the website (Waller, 2009).

Increasing the number of therapists would help to address the short fall in care for EDs. However, for mental health care in general, even doubling the existing numbers of therapists would have little overall impact (Kazdin and Blase, 2011). It is likely that there will always be limitations of the scalability of face-to-face therapy (Fairburn and Patel, 2014).

3. ***Address the mode of delivery for therapies*****:** Face-to-face therapy is labour intensive and it is likely that there will always be a shortage of appropriately trained therapists. Further, such therapies are only able to reach those patients who seek professional help. Alternatively, treatments may be modified such that they are solely or partly self-administered (i.e. pure or guided self-help). These interventions can be described as ‘program-led’ i.e. the intervention is delivered via a program as opposed to a therapist (Fairburn and Patel, 2014). In addition, technology-delivered treatments may be provided (Fairburn and Wilson, 2013) which are delivered, for example, over the internet.

A combination of approaches to dissemination is required. However, self-help programs are the most scalable of the options and, owing to their potential to maintain user anonymity, are uniquely placed to overcome certain barriers to treatment-seeking for individuals with stigmatised health conditions, including EDs (see Section 1.6.1).

1.9 The Role of Self-help

There are two forms of self-help:

1. Pure self-help: This form of self-help is entirely program-led and requires that an individual independently follows a treatment manual or protocol.

2. Guided self-help (gsh): This form of self-help uses self-help materials in conjunction with minimal guidance from either a health care professional or a trained lay person whose role it is to monitor progress, clarify procedures, answer questions, or provide general support and encouragement (Perkins et al., 2006).

In order to be an attractive method of disseminating treatments, self-help interventions must possess the ability to help, at least moderately, a significant proportion of ED sufferers. Factors affecting this capacity include: effectiveness, cost-effectiveness, clinical range, and acceptability to patients. These will be discussed in turn.

1.9.1 Effectiveness

There is good reason to believe that self-help may be of use to people with mental illnesses. The evidence is particularly compelling for anxiety and depression, where guided self-help has been shown be as effective as face-to-face therapies in some studies (Cuijpers et al., 2010).

The 1980s marked the beginning of interest in the use of self-help for binge-eating disorders. Initial reports of its utility were promising (e.g. Huon, 1985) although subsequent evidence has been mixed.

1.9.1.1 Guided self-help

Most of the research concerning guided self-help has been based on CBT-based programs (CBTgsh) (e.g. *'Overcoming Binge Eating'* (Fairburn, 1995)). The results have been mostly positive with the exception of one primary care-based study (Walsh et al., 2004). It is probable that the high drop-out rate and poor results from this particular study stemmed from the fact that the therapist ‘guides’ received no training or support. By contrast, the largest study to date (Mitchell et al., 2011) compared full CBT to CBTgsh as part of a stepped-care approach to the treatment of BN. At the 18 week post-treatment assessment, cessation from both bingeing and purging was 15% for full CBT and 11% for CBTgsh. Full CBT achieved remission rates (defined as no longer meeting the DSM-IV criteria) of 57% and CBTgsh achieved rates of 52%. The authors concluded that CBTgsh was an effective first step in treatment. Thus, whilst the evidence is mixed, there is reason for optimism concerning the effectiveness of CBTgsh.

Overall, there is *‘robust’* (Wilson and Zandberg, 2012) evidence for the effects of CBTgsh in the treatment of BED. It compares favourably to both face-to-face behavioural weight loss (BWL) (Wilson et al., 2010) and guided self-help based on BWL (Grilo and Masheb, 2005) and has a comparable performance to face-to-face IPT (Wilson et al., 2010). The initial findings of CBTgsh for the treatment of BN are also promising (e.g. Mitchell et al., 2011), although the evidence is less compelling (Beintner et al., 2014). It is worth noting that the trials to-date that used the self-help manual ‘*Overcoming Binge Eating’* (Fairburn, 1995) have been based on the first edition of the book. The treatment and, more recently, the book have since been updated to address the core psychopathology of EDs – the overvaluation of shape and weight (Fairburn, 2013). These elements are central to the treatment of BN and it is reasonable to assume that outcomes for patients with BN will improve with the updated treatment.

Most studies of guided self-help to date have addressed BN or BED. Studies of EDNOS are low in both number and quality. However, DeBar and colleagues (2011) found CBTgsh to be significantly more effective than treatment as usual (TAU) in producing remission from binge eating and reducing ED psychopathology. There is also a dearth of studies examining the impact of guided self-help in the treatment of AN. However, the evidence that does exist suggests guided self-help is preferable to a waiting list (WL) control prior to inpatient treatment for AN-BP (Fichter et al., 2008). The intervention decreased the duration of subsequent in-patient treatment and resulted in improvements in ED symptoms and general psychopathology. Further, guided self-help is associated with reductions in eating-related and general psychopathology when offered to patients following inpatient care (Fichter et al., 2012). Fewer studies have explored the use of guided self-help in out-patient AN care. However, evidence from one pilot study suggests that guided self-help is acceptable to patients with AN, is associated with good adherence, and results in improvements in BMI, mood, and ED-related knowledge and skills (Cardi et al., 2013). Although the study was small and lacked a control group, these initial findings are promising.

There is some evidence that CBTgsh is an effective treatment for adolescent ED patients. The effects may be comparable to that of FBT for BN and EDNOS. In one trial, CBTgsh initially achieved more rapid effects than FBT (Schmidt et al., 2007). In ITT analysis, 41.9% of the CBTgsh patients were abstinent from binge eating at the end of treatment, compared to 25.0% of FBT patients. The difference was no longer significant at 12 month follow-up.

Overall, it appears that CBTgsh may be as effective as more specialist therapies for EDs in some instances. The evidence is especially compelling for the treatment of BED (Perkins et al., 2006, Wilson and Zandberg, 2012). Evidence predicting who will benefit from guided self-help is lacking. However, there is some evidence to suggest that older individuals with higher BMI and lower EDE-Q Restraint scores are the most likely to derive benefit (Beintner et al., 2014). Further studies are needed, especially concerning the outpatient treatment of AN.

1.9.1.2 Pure self-help

Pure self-help is less well researched than guided self-help. Moreover, the research that has been conducted is less consistent. In general, pure self-help is thought to be less effective than guided self-help in the treatment of BED (Loeb et al., 2000, Sysko and Walsh, 2008, Wilson and Zandberg, 2012). However, there are studies that dispute this finding, suggesting no difference in binge eating abstinence rates between the two treatments (e.g. Ghaderi and Scott, 2003, Perkins et al., 2006, Stefano et al., 2006, Sysko and Walsh, 2008).

There is also speculation surrounding the relative efficacy of pure self-help compared to a WL control. Early studies, conducted in the 1990s (Carter and Fairburn, 1998, Peterson et al., 1998), suggest that pure self-help is more effective and later studies suggest that it may improve ED symptoms, excluding binge eating and vomiting, relative to WL control conditions (Perkins et al., 2006). However, a more recent study (Peterson et al., 2009) failed to replicate this finding. Another study found that although pure self-help did have an initial effect on vomiting frequency, this was not maintained and, at the end of treatment, there was no statistically significant difference between self-help and the placebo control condition (Mitchell et al., 2001). However, self-help had an additive positive effect on ED features when combined with fluoxetine (Mitchell et al., 2001).

In sum, the evidence concerning pure self-help is unclear. It may provide a useful first-step in treatment where other options are either unfeasible or unavailable. Better powered studies are required to compare pure and guided self-help.

1.9.2 Cost-effectiveness

Little is known about the cost-effectiveness of self-help interventions (Perkins et al., 2006). Although self-help is less labour intensive and has lower treatment costs than face-to-face therapy, it cannot be assumed to be more cost-effective on a societal level without investigation. If individuals continue to experience high levels of disability, resulting in losses in productivity and elevated health service use, self-help may not reduce costs substantially. For example, in one study, TAU was found to be less cost-effective than TAU in combination with CBTgsh, despite the higher treatment costs of the latter condition, primarily as a result of a reduction in the use of services amongst the TAU+CBTgsh participants (Lynch et al., 2010).

The limited available evidence does suggest that self-help is cost-effective. In a study comparing the direct medical costs of full CBT and a stepped care approach, beginning with self-help, Crow and colleagues (2013) found that in 81% of bootstrapped cases stepped care was both more effective and more cost-effective than full CBT. The costs per abstinent patient were $20,317 and $12,146 for full CBT and stepped care, respectively (Crow et al., 2013).

1.9.3 Clinical range

CBT-E (Fairburn, 2008) is a transdiagnostic intervention designed to address the core psychopathology of EDs (the overvaluation of shape and weight) with proven efficacy across diagnoses and in the treatment of both adolescent and adult ED patients (see Section 1.5). Thus, a self-help treatment based on CBT-E potentially has a broad clinical range. There are some limitations, however. Whilst evidence predicting who may benefit from self-help is lacking, self-help interventions are contraindicated for a small proportion of sufferers of AN who, as a result of being medically unstable, are unsafe to manage on an outpatient basis.

1.9.4 Acceptability, compliance, and drop-out

Regardless of effectiveness, cost-effectiveness, or clinical range, treatments are inappropriate for dissemination if uptake is likely to be poor and compliance low due to a lack of acceptability to patients. Few studies have addressed acceptability directly. However, drop-out rates from guided self-help trials are generally comparable to those of other psychological treatments (Beintner et al., 2014, Wilson and Zandberg, 2012), indicating that these interventions are acceptable to patients. Compliance is notably lower for pure self-help interventions (Newman et al., 2011) and, in research trials, a substantial proportion of the drop-out from the self-help arms occurs before treatment commencement (Waller and Gilbody, 2009), suggesting a lack of acceptability to some patients. Further, there are concerns surrounding compliance with guided online treatments. In one study, although 80% of participants completed the online guided intervention, just one-third completed all the components (Carrard et al, 2011).

In another study, participants reported the perception that self-help was less likely to be effective than face-to-face therapy (Musiat et al., 2014). However, these participants also acknowledged benefits of self-help including low costs, convenience of access, and short WL times (Musiat et al., 2014). In other studies patients report that they expect self-help to be highly effective prior to treatment commencement and adolescents rate guided self-help as more acceptable than family therapy (Schmidt et al., 2007). This is notable given the importance of this demographic for early intervention in EDs.

It is possible that self-help will be differentially acceptable in different cultural contexts and may be particularly well-suited to Western cultural values (Jorm, 2000). E-mental health in general has the potential to support cultural transformation and the movement towards a social model of health. In the West, there is an increasing shift away from the ‘paternalistic’ model of the doctor-patient relationship (Parsons, 1951) as the patient becomes an informed consumer of health care and health care itself becomes infused with an ideology of consumerism, personal responsibility, and personal autonomy (Newman and Vidler, 2006, Cabinet Office, 1991). Technology has contributed to this trend. The provision of thermometers and home pregnancy testing kits has de-mystified health care and given individuals a greater sense of control of, and responsibility for, their own health care (Shilling, 2003). In this cultural context, self-help may be particularly appropriate. Patients may self-refer and must take ultimate responsibility for their treatment. Patients themselves identify feelings of ‘self-achievement’ as amongst the potential benefits of self-help (Aardoom et al., 2013).

1.9.5 Other benefits of self-help

Aside from effectiveness, cost-effectiveness, clinical range, acceptability, and scalability, self-help may have other benefits for patients. These are noted by both Wilson and Zandberg (2012) and Perkins and colleagues (2009) and are summarised here.

By virtue of being able to maintain the anonymity of users, self-help interventions are well placed to overcome many of the barriers to help-seeking including embarrassment, shame, and fear of stigma. Furthermore, since self-help treatments may be self-referred, such interventions overcome the problems of poor detection, inappropriate referrals, and difficulties in accessing care experienced by sufferers who are not underweight or who experience distress but suffer from sub-threshold eating problems. The treatments may additionally be experienced as empowering. Individuals need not wait to receive a self-help intervention, thus treatment can be accessed with minimum delay. This is particularly important as self-help may reach people early in the development of their eating problem. Treatments are also not limited by geography and, even when delivered in guided formats, do not require highly trained clinical staff. Online treatments, in particular, may be interactive, engaging, and tailored to the type and intensity of the patient's needs whilst allowing patients to work at their own pace and at times that are convenient to them. Patients can revisit self-help treatments as required at no extra cost. This is particularly important in EDs given that setbacks are common. Finally, clinicians can also revisit treatments to update content as developments are made. (Perkins et al., 2006, Wilson and Zandberg, 2012).

1.9.6 Summary

Self-help may not be appropriate for all those with EDs. However, it may be effective as part of a stepped-care model whereby individuals are first offered the least intensive option for treatment and may 'step' up or down the pathway as appropriate. Cost-effectiveness analysis of the direct medical costs of 'stepped care' versus face-to-face CBT for BN revealed that stepped-care was both more effective and less expensive than full-CBT (Crow et al., 2013).

Of note, CBTgsh need not match the effectiveness of face-to-face therapies. If CBTgsh can reach large numbers of people and reliably help a significant number at low cost, it still has a valuable contribution to bridging the intervention gap. Further, such programs might reach people earlier in the course of their ED when they may be easier to treat than clinical patients (e.g. Lewinsohn et al., 2000).

1.10 The Use of the Internet in Self-help

Self-help interventions may be delivered through hard-copy manuals, CD-ROMs, online, or through a combination of these mediums. Whilst books potentially have a wider penetration, online programs have other advantages including the possibility of personalisation, the facility to update material, interactivity and the ability to mimic a face-to-face therapy experience. Globally, internet use has grown 556.4% between 2000 and 2012 (Internet World Stats, 2012a). Usage is particularly high in the Western world; 83% of people in the UK are now classed as ‘internet users’ (Internet World Stats, 2012b).

E-mental health aims to harness the growth in information and communication technology to improve care for mental health conditions. Over 10,000 sites related to health problems currently exist online including self-help programs addressing anxiety, depression, and EDs. The internet may be used to complement, replace, or partially replace face-to-face therapies, or to prevent relapse and provide on-going support. The highest level of integration between psychotherapies and technology is the development of program-led interventions (see Section 1.8), delivered with no therapist contact.

Pure, internet-delivered self-help may be of particular significance in the delivery of help and information to individuals suffering from EDs. In common with other forms of self-help, it overcomes many of the barriers to the receipt of care noted in Section 1.6. In addition, the internet can be accessed freely and anonymously from a person’s home at a time that is convenient to them. There is also a possibility that, if online interventions are well targeted using search engine optimisation (SEO) techniques (see Chapter 5), individuals may encounter them in their ED-related internet searches without the need for prior knowledge of their existence.

1.10.1 The internet as a vehicle for reaching people with eating disorders

The internet may be an effective way to reach people with EDs, particularly in resource-rich settings. Indirect evidence that people seeking information concerning EDs increasingly do so online, especially for binge eating problems, derives from the search terms used on the search engine *Google*. *Google Trends* tracks the use of search terms (keywords and phrases) on *Google* over time. Globally, from 2004–present, searches for *'binge eating definition'*, *'after a binge'*, *'binge eating symptoms'*, *'bulimia nervosa'*, *'anorexia nervosa'*, *'binged'*, and *'eating disorder treatment'* have all experienced a 'breakout rise' (>5000% increase) in use on *Google* (*Google Trends*, 2014). In the UK over the same time period, *'after a binge'*, *'binge eating disorder'*, *'binge eating symptoms'*, *'binge eating help'*, and *'what is bulimia'*, amongst others, have also experienced a 'breakout rise' in use (*Google Trends,* 2014).

More direct evidence exists that ED sufferers are already active online seeking help and information. A pilot study concerning usage and awareness of ED sites amongst adolescent ED sufferers identified that 41% of sufferers had visited pro-recovery sites (Wilson et al., 2006). Further, one small study reported that over one-third of participants used the internet as their primary source of information about EDs (Harrison-Yuill, 2013). Those not accessing treatment were the most likely to use the internet for this purpose (Harrison-Yuill, 2013).

Individuals who suffer from stigmatised illnesses are more likely to use the internet to seek health information than those with other chronic health conditions (Berger et al., 2005). This is especially true for individuals experiencing stigmatised psychiatric illnesses (Berger et al., 2005). The informality of internet use reduces the extent to which an individual must self-identify as having a disorder whilst seeking information (Berger et al., 2005). Online information can be casually perused, or stumbled upon, whilst going to a GP or purchasing a book requires a deeper level of identification with an illness.

The internet may have particular utility as a medium for reaching adolescents, the largest demographic of ED patients presenting to primary care services. In general, adolescent’s drive for autonomy and focus on the present make them difficult to reach and engage in health care. However, young people are particularly comfortable in an online space and seeking health information comprises a major use of their online time. Ninety-three percent of US 12–17 year olds report using the internet and 28% of their online time is spent seeking health information (Jones and Fox, 2009). Seventy-five percent of adolescent internet users seek health information online (Rideout, 2001). Of note, the top three health-related uses of the internet for adolescents are: seeking information about specific diseases, seeking sexual health information, and seeking weight loss or gain information (Rideout, 2001). This indicates that the internet might be a good medium through which to reach young people with body image or eating concerns. Additional age-related concerns including practical difficulties in seeking and accessing help without their parents’ knowledge and a lack of confidence in presenting their problem to adults may also make the internet an appealing medium through which to reach adolescents.

Many sufferers of EDs are active online through both ‘pro-eating disorder’ and ‘pro-recovery’ communities (Giles, 2006). Although pro-ED content was banned from *Tumblr* and *Pinterest* in 2012, communities continue to thrive online. Currently, over 400 sites exist (Giles, 2006). In one study, 96% of the users of these communities reported that they had learned new ED techniques through such sites (Wilson et al., 2006). Perhaps more troubling, 46% of users had acquired new ED techniques through pro-recovery communities (Wilson et al., 2006). This is in keeping with other findings (e.g. Harrison-Yuill, 2013) and reinforces studies (e.g. Rouleau and von Ranson, 2011) suggesting that many ED websites operate under the guise of support. Sufferers of EDs perceive social support to be lacking and seeking a substitute for this support constitutes a major reason for browsing online communities (Harrison-Yuill, 2013, Rodgers et al., 2012, Wesemann and Grunwald, 2008).

Pro-anorexia sites are better organized and more numerous than sites promoting recovery or professional services (Chesley et al., 2003), thus making them an appealing option for people driven to seek support online. There is a pressing need for a coherent alternative discourse.

1.10.2 Effectiveness

The effectiveness of internet-based self-help is not yet fully understood. However, the best studied internet-based prevention intervention to date, *Student Bodies* (Winzelberg et al., 2000), has significant effects on weight and shape concerns in college aged women at risk of developing an ED, although it is uncertain whether the program also prevents ED development (Bauer and Moessner, 2013). Promising effects of the program on ED symptoms have been shown amongst individuals with sub-threshold disorders (Jacobi et al., 2012).

In general, online prevention efforts based on guided self-help have yielded promising results relative to WL controls (Bauer and Moessner, 2013). Further, one systematic review (Aardoom et al., 2013) based primarily on studies of internet-delivered CBTgsh concluded that internet-based therapies significantly improve ED psychopathology and binge eating in both sub-threshold and full syndrome cases. Overall, internet-based treatments were found to be effective in reducing both binge eating and ED psychopathology, but of limited value in reducing purging. Further, such treatments were more effective for those with less comorbid psychopathology and for those with BED when compared to BN.

1.10.3 Acceptability

If treatments are not acceptable to patients their scalability and promise for dissemination is limited, regardless of their effectiveness. An indirect measure of acceptability derives from rates of treatment drop-out. In studies of internet-based self-help this ranges from 5.3–78.6% (Aardoom et al., 2013) and is generally considered to fall within the range of other psychological treatments, including that of individual face-to-face therapies. With regards to self-help therapies, internet-delivered programs have lower drop-out rates than either CD-ROM delivered therapies (Beintner et al., 2014) or treatments delivered through self-help manuals (Ruwaard et al., 2012) . The reasons for drop-out are not well researched but include: lack of motivation, energy, or time; loss of interest; lack of benefit; and technical computer problems (Leung et al., 2013).

Additionally, individuals must experience a certain level of impairment in order to ‘stick to’ self-help treatments (Pretorius et al., 2009).

More direct measures of acceptability have been gathered from research concerning the attitudes of patients recruited to trials examining self-help. Murray and colleagues (2003) were the first to investigate the attitudes of bulimic patients to a CD-ROM based self-help intervention. Whilst CD-ROM based interventions differ from internet-delivered therapy and generally experience higher drop-out rates (Beintner et al., 2014), indicating lower acceptability, many of the same issues pertain. Twenty-six percent of the participants did not commence the intervention, primarily due to concern surrounding the lack of therapist input. Participants also felt that lack of motivation and discipline might present a problem in the absence of therapist monitoring. However, advantages of self-help interventions were also identified. Such interventions were perceived to be less threatening than face-to-face therapy, were regarded as flexible, and participants predicted that their use may lead to feelings of personal achievement. In a later study, adolescents reported finding the accessibility, flexibility, sense of control, privacy, and anonymity of online programs appealing (Pretorius et al, 2010). However, technical difficulties frustrated the participants and some did not experience the online program as personal enough. Difficulties with motivation were also reported.

Overall, despite concerns regarding the impersonal nature of online self-help, studies suggest that ED sufferers find such interventions acceptable, useful, pleasant, convenient, flexible, and easy to use (Aardoom et al., 2013).

1.11 Summary and Conclusion

The internet is a potential vehicle for the secondary prevention of EDs. It provides an accessible, cost-effective, confidential platform through which sufferers may seek help. Sufferers of EDs are already active seeking help and information online and the online delivery of interventions may be particularly acceptable to adolescents, who comprise an important group for early intervention. However, there remain unanswered questions regarding how best to ensure that interventions are encountered and accessed by those who need them.

The two studies comprising this thesis address issues pertinent to the delivery of internet-based self-help programs for early intervention in EDs. This includes an investigation of: if and how sufferers use the internet to seek help or information in the early stages of their disorder; the search terms that they might use; the early features of EDs that lead people to go online; and whether sufferers would consider using an online intervention.

CHAPTER 2:

STUDY 1

THE USE OF THE INTERNET FOR HELP AND INFORMATION SEEKING PURPOSES IN THE EARLY STAGES OF AN EATING DISORDER

2.1 Study Aims

The primary aim of this study was to determine whether people in the early stages of an eating disorder would browse the internet to look for help or information and, if so, what search terms they would use. There were two subsidiary aims: first, to establish whether the provision of an online self-help secondary prevention intervention might diminish the documented gap between the onset of an eating disorder and the receipt of care and, second, to determine which features a developing eating disorder lead individuals to look for help or information online.

2.2 Methods

2.2.1 Design

This was a survey-based study involving the completion of a self-administered online questionnaire. Participants who had previously been involved in a randomised controlled trial (RCT) comparing treatments for eating disorders at the University of Oxford's

Department of Psychiatry were invited to take part and were contacted via email (see Appendix B) by the senior clinician who oversaw their care during the trial. The email contained a link to the questionnaire, preceded by an information sheet (see Appendix C) and consent section (see Table 2.1).

Upon completing the questionnaire, the participants were invited to take part in a one-on-one telephone discussion to elaborate upon their responses and to raise any other matters of relevance. In order to arrange these discussions, the participants were asked to provide their email address. They were then sent an email (see Appendix D). The calls were not recorded. However, after requesting permission, notes were taken.

2.2.2 Participants

The participants were drawn from an existing participant group (n =130) recruited by consecutive referrals from family doctors and other clinicians to an eating disorder clinic serving the central Oxfordshire area. These individuals participated in a transdiagnostic RCT comparing enhanced cognitive behaviour therapy (CBT-E) and interpersonal psychotherapy (IPT) as treatments for eating disorders. The inclusion criteria were as follows. Potential participants must:

1. Have an eating disorder of clinical severity, as judged by both the referring clinician and the senior eating disorder specialist to whom the patient was referred.

2. Be aged 18–65 years at the time of referral.

3. Have a body mass index >17.5 kg/m^2.

4. Provide written informed consent.

Criterion 3 precluded the inclusion of individuals suffering from AN. The participants thus comprised individuals with the DSM-IV diagnoses of BN and EDNOS (including BED).

If the patient had previously received treatment closely resembling either CBT-E, IPT, or another evidence-based treatment for the same eating disorder; had a co-existing Axis I psychiatric disorder that precluded eating disorder-focussed treatment; was medically unstable or pregnant at the time of recruitment; or was not available for the duration of treatment, they were not eligible for inclusion.

The intervention stage of the RCT was completed in 2011. The participants are involved in an ongoing follow-up study.

2.3 Measures

2.3.1 The online self-report questionnaire (Table 2.1)

The questionnaire, developed by EC, was designed to investigate the aims outlined in Section 2.1 and consisted of ten questions comprising both quantitative and free text items. It was hosted by '*Qualtrics*', a private research software company delivering web-based survey software, on an account providing anonymity to participants.

The questionnaire was piloted with 10 healthy volunteer adults to ascertain the length of time that the questionnaire took to complete, as well as to identify any necessary changes to ensure that it was functional and understandable.

Early Intervention in the Treatment of Eating Disorders

Thank you for agreeing to complete this questionnaire. Our goal is to create a web-based form of help for people who are developing an eating problem. We would like to get help to them as early as possible and are planning on using the internet in order to do this. To help us, we would be most grateful if you would answer this brief questionnaire.

The questionnaire is short - it should take no longer than 15 minutes to complete. Your responses will be anonymous and treated in confidence.

Thank you,
Emma Clifton and Christopher Fairburn

emma.clifton@psych.ox.ac.uk
01865-226479

Consent Section for EARLY INTERVENTION IN THE TREATMENT OF EATING DISORDERS study

Researchers: Ms Emma Clifton (MSc Student) and Professor Fairburn

☐ I have been provided with an Information Sheet, which I have read and understood
☐ I have had the opportunity to ask questions about the study and have received satisfactory answers to questions
☐ I have been provided with any additional details I have requested
☐ I understand that I may withdraw from the study at any time without penalty, by not completing the questionnaire
☐ I understand that the study has been reviewed by the Oxford Central University Research Ethics Committee
☐ I understand who will have access to data provided, how the data will be stored; and what will happen to the data at the end of the project
☐ I understand that the results of the study will be written up in a student's thesis and may also be written up in an academic journal. All my responses will remain completely anonymous
☐ I understand how to raise a concern or make a complaint
☐ I agree to take part in this study by completing the following questionnaire

All the following questions refer to the early stages of your eating problem.

When answering the questions please imagine that the internet existed then as it does today.

1. When your eating problem first began would you have considered going on the internet to look for help or information?

☐ Yes
☐ No

2. From the list below please tick ALL the features that you experienced in the early stages of your eating problem. If you experienced any additional features, please tick ‘Other’ and enter the feature/s in the box provided.

☐ Trying to eat very little or avoid certain types of food
☐ Having episodes of uncontrolled eating (binges)
☐ Making yourself sick
☐ Taking laxatives, diuretics or diet pills
☐ Exercising in a driven way
☐ Thinking too much about your eating
☐ Feeling very concerned about your shape
☐ Feeling very concerned about your weight
☐ Other (please specify) ______________________

3. Would any of the early features of your eating problem have led you to consider going on the internet to look for help or information?

☐ Yes
☐ No

4. From the list below, please tick ANY of the features of your eating problem that might have led you to go on the internet to look for help or information. Add any additional features by ticking 'Other' and entering them into the box provided.

☐ Trying to eat very little or avoid certain types of food
☐ Having episodes of uncontrolled eating (binges)
☐ Making yourself sick
☐ Taking laxatives, diuretics or diet pills
☐ Exercising in a driven way
☐ Thinking too much about your eating
☐ Feeling very concerned about your shape
☐ Feeling very concerned about your weight
☐ Other (please specify) ______________________

5. Please mark the feature that would have led you to go on the internet FIRST. If this feature is not in our list, please tick 'Other' and enter the details into the box.

- ☐ Trying to eat very little or avoid certain types of food
- ☐ Having episodes of uncontrolled eating (binges)
- ☐ Making yourself sick
- ☐ Taking laxatives, diuretics or diet pills
- ☐ Exercising in a driven way
- ☐ Thinking too much about your eating
- ☐ Feeling very concerned about your shape
- ☐ Feeling very concerned about your weight
- ☐ Other (please specify) ____________________

6. If you had gone on the internet to seek help or information, what phrases/words would you have entered into a search engine (e.g. *Google*)? Please enter each phrase/word on a new line in the box below:

7. Had you gone on the internet to seek help or information for your eating problem, how old would you have been?

8. How old were you when you first took steps to get professional help for your eating problem (e.g. going to visit your GP)?

9. How old were you when you first received professional help for your eating problem (e.g. saw a psychiatrist or psychologist)?

10. If you have any additional thoughts, comments or suggestions about this topic, we would be very pleased to hear from you. Please enter them below:

Finally, if you would be willing to speak to us on the phone about this topic, please enter your email address below. This will allow us to contact you to find a convenient time.

Thank you very much for taking the time to complete this questionnaire.
Emma Clifton and Christopher Fairburn
01865-226479
emma.clifton@psych.ox.ac.uk

TABLE 2.1 The online self-report questionnaire – Study 1

2.3.2 Assessment measures

The following measures were used to assess the participants during the treatment trial at baseline, treatment completion, and as part of the ongoing follow-up study.

2.3.2.1 Eating disorder psychopathology

Eating disorder psychopathology was measured using the 16th edition of the EDE interview (Fairburn, 2008). This was administered by a team of research assistants who were trained and supervised by Mrs M O'Connor, an expert on the use of the instrument. The EDE is a standardised, semi-structured, investigator-based interview focussing on an individual's behavioural and attitudinal eating disorder features over the past 28 days. Items are scored on a 7-point Likert scale from 0–6, reflecting the severity or frequency of each feature. Items are subsequently grouped into four subscales: Restraint, Shape Concern, Weight Concern, and Eating Concern. A global score, reflecting the overall severity of eating disorder psychopathology, is also generated.

2.3.2.2 Weight-for-height

The participants' height was measured at baseline and participants were weighed at regular intervals during the trial. This data was used to calculate body mass index (BMI) (kg/m^2).

2.3.2.3 Psychosocial impairment secondary to the eating disorder

Secondary psychosocial impairment was measured using the 22-item version of the Clinical Impairment Assessment (CIA) questionnaire (Bohn et al., 2008), a brief self-report measure of the severity of psychosocial impairment secondary to eating disorder features. The questionnaire focuses on the past 28 days and covers impairment in domains typically affected by eating disorder psychopathology. Each item is rated on 4-point Likert scale and a global score is calculated.

2.3.2.4 Depressive symptoms

The presence and severity of depressive symptoms was measured using the Beck Depression Inventory (BDI), version II (Beck et al., 1996), a 21-item self-report inventory. Items are scored on a scale ranging from 0–3 and a global score is calculated.

2.4 Data Analysis

2.4.1 Comparison of the overall sample and the participant subsample

Mann-Whitney or independent samples t-tests were used to determine the presence or absence of statistically significant differences between the study’s participant subsample and the remainder of the overall sample at baseline and most recent follow-up assessment. The analysis was performed using SPSS for Windows version 19.

2.4.2 Analysis of questionnaire responses

2.4.2.1 Quantitative responses

Questions 1–5, inclusive, asked participants to select responses from a list. For each question, the total number of participants who selected each of the responses was totalled and the percentage of participants who selected the option was calculated.

Questions 7–9, inclusive, asked participants to specify their age at significant points during the course of their eating disorder (i.e. when they first sought professional help). Means and standard deviations were calculated[1].

2.4.2.2 Qualitative responses

Question 10 asked participants to enter a free text response. Responses were analysed inductively by thematic analysis following the method outlined by Braun and Clarke (2006). The analysis aimed to provide a rich thematic description of the data set.

First, the data was read through twice in its entirety. The data was then read for a third time, making notes and marking ideas for coding. Next, the data was coded, noting the interesting features across the entire data set. This produced a list of 125 initial codes. The list was revised and reduced to a total of 14 codes (for an audit trail of this process see Appendix E).

The codes were collated into potential themes. Data relevant to each potential theme was gathered and candidate themes and subthemes with extracts of coded data were generated. The themes were then reviewed. Patton's (1990) dual criteria for judging

---

[1] Where age ranges were given, the midpoint was taken. Where participants reported that they went to see a specialist for another reason before receiving eating disorder-focussed treatment (e.g. were referred to a dietician and later to an eating disorder specialist), the date at which they first received help for their eating disorder was taken. Where participants reported that family members had taken them to their general practitioner and they had later acted independently, the younger age was taken.

categories were considered: the data must have internal validity and external heterogeneity i.e. the data should cohere together meaningfully and there should be identifiable distinctions between themes. Consideration was also given to the validity of individual themes in relation to the data set. The initial free text was re-read a number of times to check that the themes reflected the data accurately. Finally, a thematic map was created.

2.4.2.3 Search terms

Question 6 asked participants to enter potential 'search terms'. The number of participants listing particular words or phrases was calculated.

2.4.2.4 Telephone discussions

The calls were not recorded and their content was not written down verbatim. Analysis involved comparing the participants' responses with regards to the main areas discussed.

2.5 Ethical Approval

Ethical approval was obtained from the Medical Sciences Interdivisional Research Ethics Committee (ref: MSD-IDREC-C1-2013-090) (See Appendix F).

2.6 Results

2.6.1 The characteristics of the participants

Of the 130 RCT participants, 24 had requested not to be contacted for inclusion in future research and 27 could not be contacted because their contact details were not up-to-date. The remaining 79 participants were contacted. Of these, 50 (63.3%) responded to at least one of the online questionnaire questions. Thirty-three participants provided contact details to facilitate the scheduling of telephone discussions. Twenty-one discussions took place.

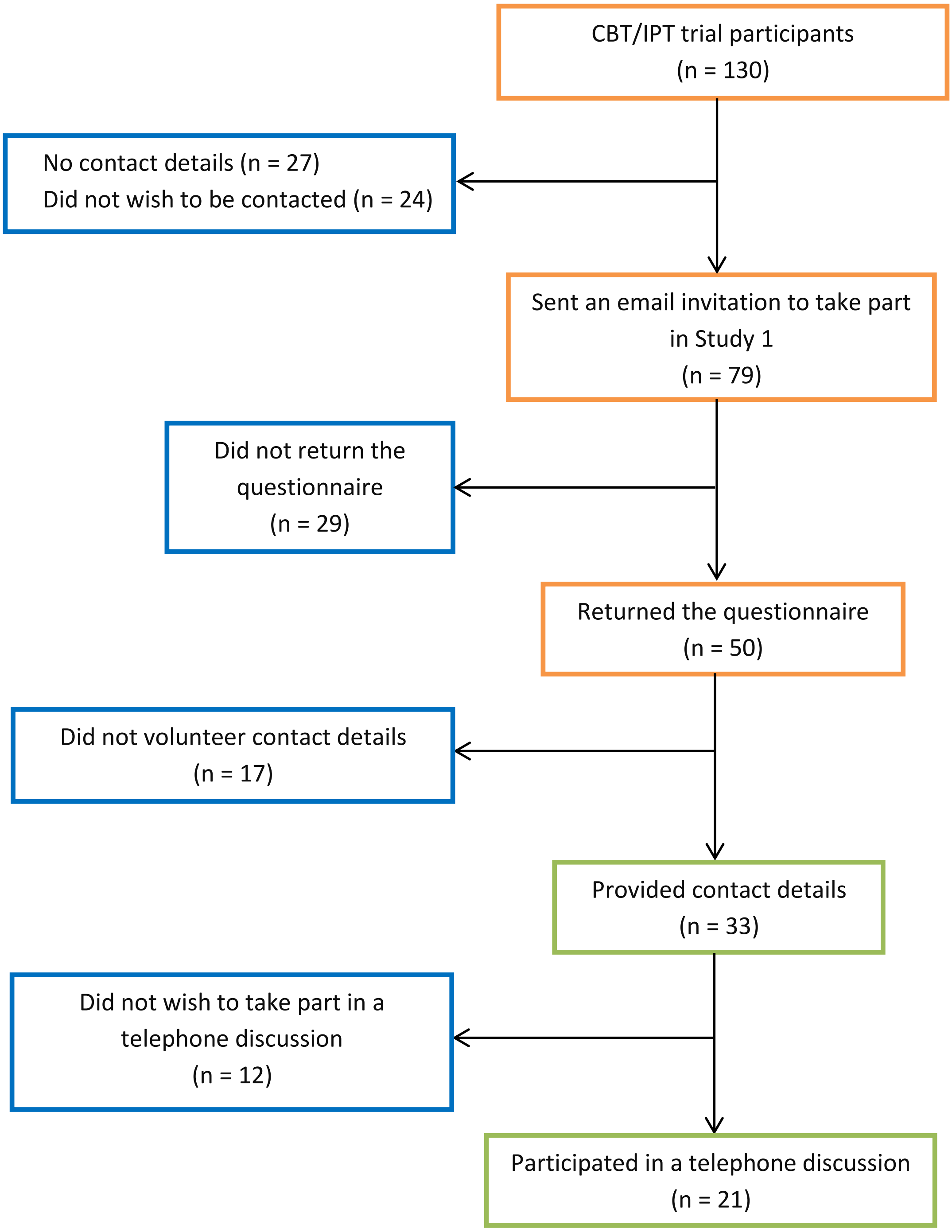

FIGURE 2.1 Flow diagram detailing the process of recruitment for Study 1

In order to ascertain whether those who responded to the questionnaire were representative of the overall sample recruited to the RCT, comparisons were performed to compare the participant subsample who provided contact details (and could thus be identified) (n = 33) and the remainder of the overall sample (n = 97) (see Table 2.2).

There were no statistically significant differences between the two groups with regard to: age, global EDE score, CIA score, BMI, or BDI score at baseline or at the most recent follow-up assessment. There were too few males (n = 3) in the original participant group to perform a comparison on the basis of sex.

Measures	Subsample (n = 33)			Remainder of the overall sample (n = 97)			Mann Whitney U (Z-score) or t-statistic	*p*	Effect size (*r*)	Mean difference	95% CI for mean difference	
	Mean	Median	SD	Mean	Median	SD					Lower	Upper
Age	27.27	25.00	8.30	25.40	23.00	7.49	-1.21	0.23	-0.11	1.87	-1.20	4.49
CIA	28.81	31.00	10.55	30.42	31.00	8.17	-0.24	0.81	-0.02	-1.61	-5.13	1.91
BMI	22.88	21.67	4.25	22.84	21.77	4.28	-0.15	0.88	-0.01	0.04	-1.66	1.75
BDI	20.25	19.89	10.41	22.27	20.00	10.82	-.077	0.44	-0.07	-2.02	-6.32	2.27
Global EDE	3.63	3.76	1.00	3.53	3.60	1.04	0.45	0.65	0.06	0.09	-0.32	0.51

TABLE 2.2 Comparison of the participant subsample and the remaining RCT participants before receiving treatment

Measures	Subsample (n = 33)			Remainder of the overall sample (n = 97)			Mann Whitney U (Z-score)	*p*	Effect size (*r*)	Mean difference	95% CI for mean difference	
	Mean	Median	SD	Mean	Median	SD					Lower	Upper
CIA	12.61	11.00	10.52	15.57	14.00	13.52	-0.84	0.40	-0.07	-2.96	-7.96	2.03
BMI	24.71	22.52	5.58	24.06	22.57	5.22	-0.34	0.74	-0.03	0.65	-1.60	2.90
BDI	12.49	9.00	11.79	14.28	11.00	13.23	-0.48	0.63	-0.04	-1.79	-7.34	3.77
Global EDE	1.77	1.74	1.36	1.82	1.53	1.51	-0.16	0.88	-0.01	-0.47	-0.63	-0.54

TABLE 2.3 Comparison of the participant subsample and the remaining RCT participants at the most recent post-treatment follow-up assessment

2.6.2 The findings of the questionnaire

1. **Would you have considered going online to look for help/information when your ED first began?** (n = 50)

Forty-two participants (84.0%) reported that they would have gone online to obtain help or information. The remaining 8 participants (16.0%) reported that they would not.

2. **Tick ALL the features that you experienced in the early stages of your eating problem?** (n = 50)

The features most commonly reported as being experienced early in the development of an eating problem were: food avoidance or restriction, thinking too much about eating, shape concern, weight concern, and binge eating.

Feature	Responses	Percentage
Food avoidance/restriction	48	96.0%
Binge eating	43	86.0%
Self-induced vomiting	29	58.0%
Laxative, diuretic or diet pill abuse	22	44.0%
Obsessive exercising	33	66.0%
Thinking too much about eating	48	96.0%
Shape concern	47	94.0%
Weight concern	44	88.0%
Other	7	14.0%

TABLE 2.4 Features experienced early in the development of an eating problem

3. **Would any of the early features have led you to consider going on the internet to look for help/information?** (n = 49)

Forty-three participants (87.8%) reported that the early features of their eating disorder would have led them to consider looking online for help or information. The remaining 6 (12.2%) reported that they would not have considered going online for this purpose.

4. **From the list below, please tick ANY of the features of your eating problem that might have led you to go on the internet to look for help/information.** (n = 46)

Thirty-three participants (71.7%) reported that binge eating might have led them to go online to search for help or information, making binge eating the most frequently cited reason. Over half of the participants reported that self-induced vomiting, food avoidance or restriction, shape concern, and thinking too much about eating would have led them to go online to look for help or information. Additionally, half of the participants reported that weight concern would have led them to go online for this purpose.

Feature	Responses	Percentage
Food avoidance/restriction	26	56.5%
Binge eating	33	71.7%
Self-induced vomiting	27	58.7%
Laxative, diuretic or diet pill abuse	16	34.8%
Obsessive exercising	16	34.8%
Thinking too much about eating	25	54.3%
Shape concern	26	56.5%
Weight concern	23	50.0%
Other	3	6.5%

TABLE 2.5 Features that might have led people to seek help or information online

5. **Please mark the feature that would have led you to go on the internet FIRST. If this feature is not in our list, please tick 'Other' and enter the details into the box.** (n = 45)

Binge eating followed by self-induced vomiting were the most common features leading people to go online for help or information first.

Feature	Responses	Percentage
Food avoidance/restriction	2	4.4%
Binge eating	15	33.3%
Self-induced vomiting	13	28.9%
Laxative, diuretic or diet pill abuse	2	4.4%
Obsessive exercising	1	2.2%
Thinking too much about eating	3	6.7%
Shape concern	1	2.2%
Weight concern	6	13.3%
Other	2	4.4%

TABLE 2.6 Features that would have led people to go online first

6. **If you had gone on the internet to seek help or information, what phrases or words would you have entered into a search engine (e.g. *Google*)?**

(n = 45)

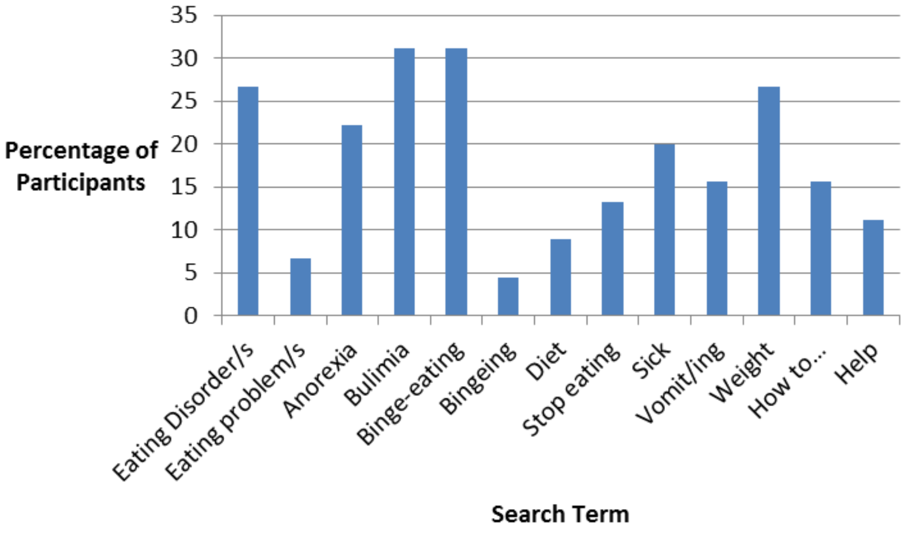

FIGURE 2.2 The use of search terms - Study 1

The most commonly used search terms were ‘bulimia’ and ‘binge eating’. Both were searched by 14 participants (31.1%). No participants used ‘bulimia’ in the context of ‘bulimia nervosa’ and no participants used ‘binge eating’ in the context of ‘binge-eating disorder’. The next most frequently used searched terms were ‘eating disorder/s’ and ‘weight’, both of which were searched by 12 participants (26.7%). Seven of the searches for ‘weight’ occurred in the context of ‘lose weight’ and two within the context of ‘weight loss’. ‘Anorexia’ was also commonly searched (10 participants, 22.2%). Many participants’ searches related to self-induced vomiting (22 participants, 48.9%). Half of these searches began with ‘making myself/yourself…’. ‘Sick’ was the most commonly searched word in this group (9 participants, 20.0%), followed by ‘vomit’ or ‘vomiting’ (7 participants, 15.6%). One participant searched for ‘purging’.

Many participants began their searches with ‘How to…’. For example: ‘How to have anorexia’ or ‘How to not eat’.

7. **Had you gone on the internet to seek help or information for your eating problem, how old would you have been?** (n = 43)

The mean age at which participants reported that they would have sought help or information on the internet was 19.2 years (SD = 5.4).

8. **How old were you when you first took steps to get professional help for your eating problem (e.g. going to visit your GP)?** (n = 45)

The mean age at which participants first took steps to seek professional help for their ED was 24.6 years (SD = 8.6).

9. **How old were you when you first received professional help for your eating problem (e.g. saw a psychiatrist or psychologist)?** (n = 45)

The mean age at which participants first received professional help for their ED was 25.6 years (SD = 8.8).

Mean differences:

The mean time lapse between first using the internet and first visiting a health care professional was 5.2 years.

The mean time lapse between first visiting a health care professional and first receiving professional help was 1.0 years.

Finally, the mean time lapse between first using the internet and first receiving professional help was 6.1 years.

10. **If you have any additional thoughts, comments or suggestions on this topic, we would be very pleased to hear from you. Please enter them below**.

    (n = 29)

Twenty-nine participants (58%) provided free text answers in response to the statement above. Five participants also left a total of six extended responses to other questions. All these participants also provided a free text response to Question 10. Their extended responses to other questions have been included in this analysis.

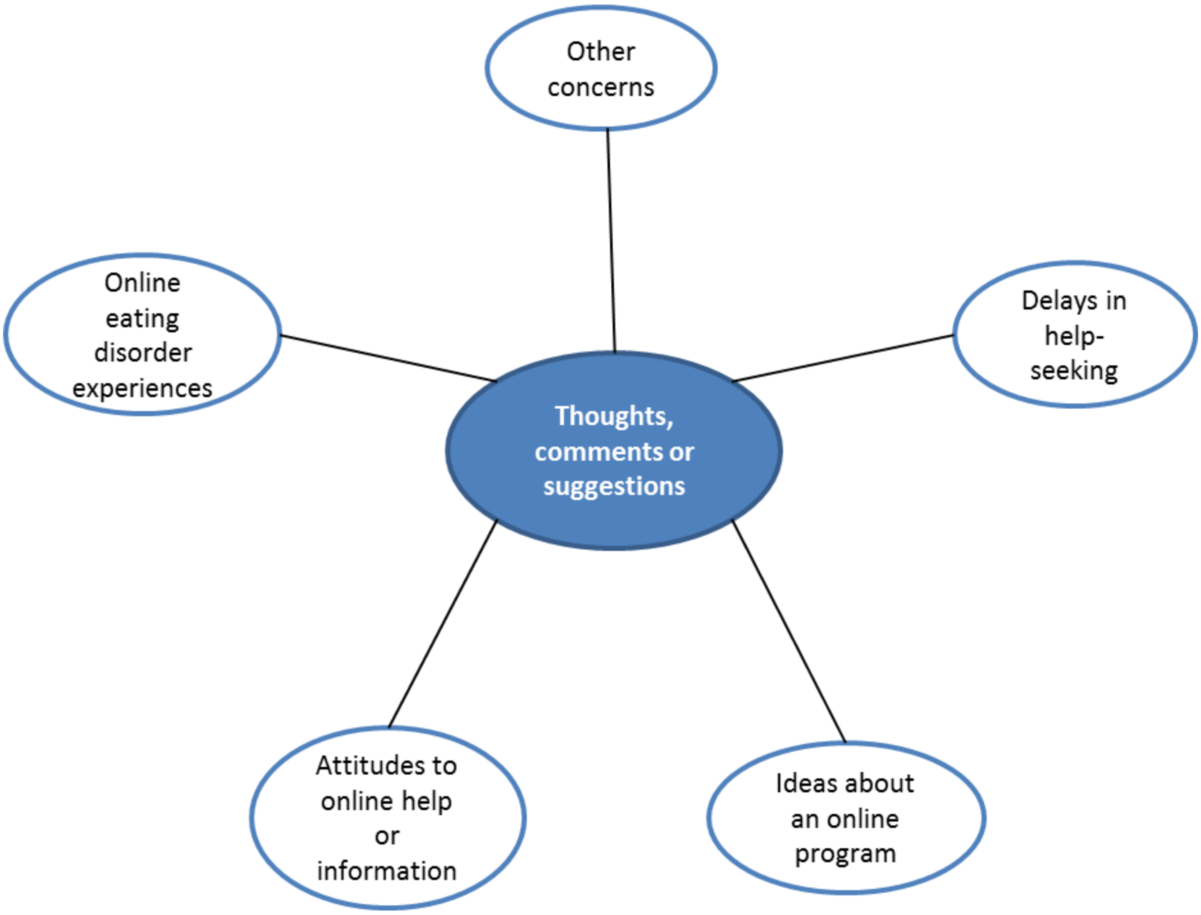

FIGURE 2.3 Thematic map - Study 1

1. Attitudes to online help or information

This theme refers to the attitudes of participants to the provision of online help or information. Fifteen participants (51.7%) gave explicit feedback related to this theme. This was primarily positive. For example:

> *I think it's an excellent idea to promote help on the net*
>
> *Think it's a great idea. Hope it comes to fruition*

Many participants voiced opinions on the specific benefits, two of which were particularly prevalent:

The facility to maintain anonymity:

> *I would have been much more likely to use something like the internet that can remain anonymous*
>
> *The anonymity of internet help would have helped me*

The need for an alternative discourse to pro-anorexia/thinspiration websites:

> *To have an alternative [to pro-anorexia/thinspiration] set of resources available would be a good thing*
>
> *Perhaps you may have some information [about] how harmful it is to get into these kinds of websites*

Other identified benefits included: overcoming isolation, secrecy and anxieties about contacting health care professionals, not needing time away from school or work, accessibility, and the idea that people would *'go there [online] first'.* Linked to these benefits, there was a sense that the internet may bring forward the receipt of care. One participant stated:

> *I would have got help a lot, lot sooner*

The responses of participants also speculatively suggest that online help or information would be acceptable. For example:

> *I would have found it useful*

There were, however, identified drawbacks to online information and help. One participant expressed strong feelings that an online treatment or information resource might be harmful:

> *I don't think it would be very helpful… it would be extremely triggering to read lots about eating disorders and not to be accountable to anyone to do something about it*

This was an isolated opinion. However, other problems and limitations of online help and information resources were identified. Most notably, the inability to overcome denial of the eating disorder and positive eating disorder experiences, particularly during periods of successful food restriction was cited. For example:

> *While it is mostly food restriction you don't want help*

It was also implicit that any contact between users of a website would have to be carefully monitored:

> *Some communities…which presented themselves as sharing/support groups… probably encouraged me to keep up some of my destructive behaviours*

2. Online eating disorder experiences

This theme refers to the online experiences of participants specifically in relation to their eating disorder. Eleven participants (31.4%) wrote about this theme. Two additional participants suggested ways in which the internet might have influenced the course of their eating disorder had it existed then as it does today. This gave a total of 13 responses (49% of the participants).

Many participants reported that they used or would have used the internet negatively to search for weight loss tips or fitness information, which served to *'aid'* their eating disorder:

> *Sometimes it was more in aid of the anorexia*
>
> *[I] have used tumblr and pinterest for weight loss tips/fitness inspiration*

Most of the negative internet use was linked to 'pro-anorexia' or 'thinspiration' websites, both of which participants reported using compulsively:

> *I looked on [them] and became obsessed*
>
> *Regretfully, I became addicted*

These sites, in addition to others, often provided unhealthy tips:

> *[They] gave me advice on how to keep my ED hidden…and also provided me with terribly unhealthy weight loss tips*

Although no participants expressed exclusively positive feelings about pro-eating disorder websites, one participant did express conflicting feelings, indicating that there were positive elements:

> *I gained a lot from the pro-anorexia sites, even though often encouraging negative behaviour, just in terms of support*

The desire for online support was shared by many participants who alleviated feelings of isolation and satisfied a need for reassurance and information through other online sources, forums and social media. A sense of community and support were the most prevalent positive online experiences:

> *The internet provided information and reassurance*
>
> *I found it much easier to tell people how I was/felt on msn or skype*
>
> *I did not feel so alone*

However, the participants suggested that some forums may have contributed to the perpetuation of their eating disorder:

> *They probably encouraged me to keep up some of my destructive behaviours*
>
> *Reading lots of stories about other people's experiences made me feel more like what I was doing was normal*

3. Ideas about an online program

This theme refers to the suggestions offered by participants regarding the content of an online program. Twelve participants (41.4%) commented on the theme; 8 provided explicit feedback and 4 provided implicit feedback, for example, by indicating what they had found helpful on other sites that they had visited.

Overall, there was a desire for some form of anonymous contact with health care professionals. Case studies were also desired and people felt that the internet could be used to overcome feelings of isolation. There was also an implicit desire for anonymity. Two participants noted that such programs were perhaps better targeted at those with binge eating problems:

> *I think the internet could help with the early stages of bingeing but sometimes it develops after another eating disorder*

4. Delays in help-seeking

Fourteen participants (48.3%) explicitly discussed the delay between the onset of their eating disorder and seeking help. Many went on to write about the causes of this delay. Prominent amongst these were: denial, lack of awareness, not wanting to get better, anxieties about revealing the problem or asking for help, a desire to conceal the disorder, and shame.

Lack of awareness

> *I remember…thinking that making myself sick wasn't a real eating disorder*
>
> *I was not really aware that I had an eating problem*

Denial

> *I was in denial that anything was wrong*
>
> *Denial was a big problem for me*

Not wanting to get better

> *In the early stages, while it is mostly food restriction you don't want help, you don't realise/you enjoy it*
>
> *In the very early stages…I did not want to get better*

Anxieties about disclosing the problem and asking for help

> *I couldn't approach my GP in person*
>
> *I wasn't ready to admit it*

Secrecy and shame

> *I hid it so well*
>
> *There is a lot of shame associated with having an eating disorder…it's very hard to admit to*

5. Other concerns

This theme refers to other concerns reported by the participants that initially seemed more pressing than their eating disorder. Many participants commented on this theme. Most commonly, their other concerns were associated with weight, but two participants also mentioned mood.

Weight

> *I acted independently at the age of 22… but the aim was weight loss*

Mood

> *I went to the GP initially… for depression…I don't think I'd have ever gone just for the eating problem*

2.6.3 The findings of the telephone discussions (n = 21)

Twenty-one participants (42.0%) took part in one-on-one telephone discussions. These ranged from 8–29 minutes in duration and lasted an average of 14 minutes. The conversations were semi-structured. Four broad areas were explored:

1. Eating disorder development
2. The help-seeking process and reasons for delays
3. Internet use during the early stages of an eating disorder
4. Ideas and attitudes towards online self-help

2.6.3.1 Eating disorder development

All but three of the participants (18 participants, 85.8%) reported that their eating problems began with shape or weight concern. For 15 of these participants (71.5%) this led to a period of dieting. The majority then went on to binge eat. Overall, just 8 participants (38.1%) did not experience binge eating. Four participants received a diagnosis of AN at some point during their eating disorder; two subsequently began to binge eat. Twelve participants (57.2%) reported self-induced vomiting (SIV). Half of these participants reported that their engagement in SIV was a direct response to binge eating.

Overall, the most common pattern of eating disorder development was as follows: weight or shape concern led to a period of dieting. Dieting was successful for a time, many participants reported being satisfied during this period. However, binge eating and SIV often subsequently developed.

2.6.3.2 The help-seeking process and reasons for delays

Fifteen participants (76.2%) reported that they were unaware that they were developing an eating disorder. Primarily, lack of awareness resulted from a lack of knowledge about eating disorders and the belief that dieting and shape or weight concern was normal. A lack of knowledge and information about eating disorders and their treatment affected 14 participants (66.7%), all of whom reported that if they had had access to better information they would have sought help earlier.

The participants endorsed different reasons for the eventual realisation of their eating disorder. Other people, including GPs, mothers, and partners, played a role in a significant minority of cases (7 participants, 33.3%). Extreme symptoms including radical weight loss, binge eating, vomiting, and laxative abuse were also significant (6 participants, 28.6%). Two participants (9.5%) indicated that searching online helped them to realise that they had an eating disorder. However, many more noted that people developing problems today would be likely to realise that they have a problem through looking online.

A significant minority of individuals (9 participants, 42.9%) stated that they were ambivalent about seeking help in the early stages of their disorder. For the most part, this was because they were happy losing weight and did not see dieting as a problem. Many of the participants reported that shame, embarrassment, and the desire to conceal their disorder prevented them from seeking help (9 participants, 42.9%). Not wanting to part with egosyntonic aspects of their eating disorder was also common (7 participants, 33.3%). Some participants also expressed that their help-seeking had been delayed as a result of concerns that their disorder was not severe enough to warrant help and would not be taken seriously by medical professionals (7 participants, 33.3%). Eight participants (38.1%) delayed seeking help because they were uncertain that their GP was the right person to contact (8 participants, 38.1%).

Despair, distress, and wanting to live a ‘normal’ life were prominent reasons for eventually seeking help (7 participants, 33.3%). Fifteen participants went to their GP as the first port-of-call. Three were taken by their mothers (all adolescents suffering from AN). A further 3 cases were picked up by GPs when participants sought help for depression or weight loss. Two individuals consulted their university counselling service and two rang treatment services directly.

2.6.3.3 Internet use during the early stages of an eating disorder

All of the participants reported that they either had (16 participants) or would have (5 participants) used the internet in the early stages of their eating disorder and the majority reported that, if their ED developed today, the first place they would look for information would be online. Reasons for not looking online at the time included having no private access to online resources and not owning a computer. The participants noted that this would most likely not be an issue today.

Fourteen participants (66.7%) reported that they used the internet to seek help, information, or support. Thirteen (61.9%) reported that they used the internet negatively, either to browse pro-anorexia or thinspiration websites (6 participants, 28.6%), or for dieting tips, weight loss advice, or advice concerning the use of laxatives, SIV, or diuretics (13 participants, 61.9%).

All but one participant (95.2%) reported believing that individuals developing eating disorders today would go online to seek help or information before consulting their GP.

2.6.3.4 Ideas and attitudes regarding online self-help

Five participants (23.8%) stated that they would not have used an online intervention. The desire for face-to-face contact and the need be accountable to someone due to concerns about self-motivation were the primary reasons for not using self-help. However, 16 participants (76.2%) reported that providing an online self-help intervention would be a good idea. A further 4 participants stated that they thought self-help was a good idea but email contact with a health care professional would be necessary. One participant thought that online self-help could be harmful.

Despite thinking that the provision of an online therapy would be a good idea, a quarter of the participants reported that they believed face-to-face therapy was necessary for them to get better, although an online program may work for others. The majority of the participants were sceptical about the ability of pure self-help to overcome ambivalence and keep people motivated through treatment.

The participants gave feedback on the desirable features of an online program, including:

1. The use of motivational, but not patronising statements to engage people
2. Make clear that EDs are treatable conditions and that engaging in the program was a chance for people to reclaim and change their lives
3. Stress the evidence-base
4. Offer hope
5. Provide case-studies of individuals with whom users will identify
6. Clarify who the program is designed for
7. Provide a diagnostic questionnaire
8. Make clear that you do not need to be underweight to have an ED

9. Maintain user anonymity
10. Provide email contact with a therapist
11. Provide links to other reputable websites and advice about further help-seeking
12. Provide a regulated forum
13. Make clear that it is not normal to feel *‘that way’*
14. Make clear that eating disorders are not rare and people are not alone
15. Make clear that eating disorders are taken seriously by medical professionals
16. Provide information alongside treatment
17. Provide ongoing support after treatment

2.7 Discussion

This study set out to determine whether people in the early stages of an eating disorder would look for help or information online and, if so, which search terms they would use. In addition, the study explored which features of an eating disorder lead people to search online and whether the provision of an online intervention might diminish the documented gap between the onset of an eating disorder and the receipt of care.

The participants were drawn from a group of patients with a past or present diagnosis of BN or EDNOS recruited to a RCT. Two-thirds of those contacted completed a self-administered online questionnaire and a significant minority also participated in a subsequent telephone discussion. The majority of the respondents to the questionnaire could be identified. This subsample was representative of the RCT participants with regard to age, eating disorder severity, secondary psychosocial impairment, BMI, and depressive symptoms at the time of their recruitment into the trial and at their most recent follow up assessment.

The majority of the participants reported that they would have considered looking online for help or information related to their eating disorder in its early stages - on average, 5.2 years before they presented to primary care services and 6.1 years before they received specialist treatment. The majority also reported that they would have used an online intervention in the early stages of their eating disorder. However, some participants believed that therapist contact via email, at minimum, would be necessary.

In the early stages of their illness, the majority of the participants experienced: food avoidance or restriction, thinking too much about eating, shape concern, weight concern, binge eating, obsessive exercising, and self-induced vomiting. The participants' eating disorders most often began with a period of dieting, preceded by shape or weight concern. The majority then went on to binge eat. The participants reported feeling satisfied whilst dieting was successful and there was a general consensus that an online program would struggle to engage people at this stage of an eating disorder.

Most commonly, the first feature that would have led the participants to seek help or information online was binge eating. Binge eating was also the most common reason for seeking help or information online, followed by self-induced vomiting.

'Bulimia' and 'binge eating' were the most frequently used search terms. The terms 'eating disorder' or 'eating disorders' and 'weight' (most often in the context of 'lose weight') were the next most commonly searched, followed by 'anorexia'. Participants were not euphemistic in their use of search terms. For example, they used 'eating disorder' more often than 'eating problem', and 'binge' more often than 'over eat'. However, they did not often use 'technical' terms or the full DSM names of the eating disorders. For example, they were unlikely to use 'purge', 'anorexia nervosa', 'binge-eating disorder', or 'bulimia nervosa'.

Thematic analysis of the free text responses revealed 5 key themes of which ‘attitudes to online help/information’ was the most dominant. In particular, many participants provided explicit feedback on the idea of developing a web-based self-help intervention. Most reported that they believed it to be a good idea, specifically citing the ability to maintain anonymity and the need for an alternative discourse to pro-anorexia websites. Thematic analysis also revealed that whilst an online intervention may not overcome denial and the egosyntonic nature of disorders limited to food restriction in their initial stages, such an intervention could overcome many of the important barriers to seeking help. These barriers included low mental health literacy, shame, secrecy, and anxieties about disclosing the problem. The telephone discussions corroborated these findings.

In sum, it is probable that the provision of online help would bring forward the receipt of care for people with eating disorders characterised by binge eating.

2.7.1 Strengths

This was the first study to explore the use of search terms amongst sufferers of eating disorders. The original 130 participants recruited to the trial from which this study’s participants were drawn can reasonably be assumed to be representative of the help-seeking community of eating disorder sufferers in the UK, excluding those with anorexia nervosa. The participant subsample (who could be identified) were found to be representative of these participants with regard to: age, ED-related psychopathology, psychosocial impairment secondary to ED features, depressive symptoms, and BMI. This indicates that the findings of the study may be generalised to the help-seeking community. In addition, having completed treatment for their ED, the participants were able to provide information concerning the process of seeking help, including the causes of delays.

The response rate was reasonable and participants were given the opportunity to expand upon the answers to the questionnaire and to raise any other matters of relevance through the telephone discussions.

2.7.2 Limitations

The study had certain limitations. The first pertains to how representative of those in the early stages of eating disorders in the community the study's participants can be considered to be. First, the findings of the study do not pertain to those suffering from anorexia nervosa. Further, as the participants were recruited from a trial involving participants with a threshold DSM recognised eating disorder, the results may not apply to those who have long-standing sub-threshold eating problems but do not develop an eating disorder. These individuals may be likely to seek help online. Second, the participants have a current mean age of 31.3 years making them substantially older than those at greatest risk for developing eating disorders (APA, 2013, Hudson et al., 2007). Given the known age-related differences in online behaviour (Jones and Fox, 2009), it is possible that the results of the study do not accurately reflect the online behaviour of those developing eating disorders at present. Finally, the participants who took part in this study are amongst the minority of those with eating disorders who both seek and receive professional help (Hart et al, 2011). Thus, the findings cannot be generalised to the majority of sufferers who do not seek help.

The time elapsed between the development of the participants' eating disorders and the present is a further limitation of which there are two significant consequences. First, it is possible that some participants may have struggled to accurately recall their internet use in the early stages of their disorder. However, the results of the telephone discussions corroborated the questionnaire findings. Therefore the participants were at least consistent in their recall. Second, many participants developed their ED before the internet existed as it does today and were forced to answer questions hypothetically. Socio-cultural changes including changing perceptions and greater public awareness of eating disorders may also influence help-seeking behaviour. It is conceivable that this could limit the applicability of the study's findings to the present.

To reduce the possibility of subjectivity or bias influencing the findings of the thematic analysis, it would have been beneficial for a second researcher to independently analyse the free text responses.

2.7.3 Implications

This study suggests that online self-help and information resources may be accessed by and appeal to individuals in the early stages of eating disorders characterised by binge eating. Individuals are most likely to use 'binge eating', 'bulimia', eating disorder/s', 'weight' or 'anorexia' as search terms. This information may be used for the purposes of search engine optimisation (SEO) (see Chapter 5). Online programs may help to address some of the barriers to seeking help.

The present study requires repetition with a different participant group in order to ascertain whether the findings can be replicated. Participants earlier in the evolution of their eating disorder, those who have not yet sought professional help, younger individuals, and those with anorexia nervosa should be included.

2.7.4 Conclusions

The findings of this study suggest that the majority of BN and EDNOS sufferers would consider looking online for help or information in the early stages of their eating disorder. Most commonly, the first feature to lead them online is binge eating and their searches are most likely to contain the terms ‘bulimia’, ‘binge eating’, ‘eating disorder’, or ‘weight’. The study corroborates past research suggesting a lag between the onset of an eating disorder and first contact with healthcare services (e.g. Hepworth and Paxton, 2007). The findings tentatively suggest that some of the barriers resulting in this delay could be overcome by the provision of an online self-help resource.

The study requires replication with an alternative group of participants.

CHAPTER 3:

STUDY 2

THE USE OF THE INTERNET FOR HELP AND INFORMATION SEEKING PURPOSES IN THE EARLY STAGES OF AN EATING DISORDER

3.1 Study Aims

This study was designed to repeat Study 1 with an alternative group of participants.

3.2 Methods

3.2.1. Design

This was a survey-based study involving the completion of a self-administered online questionnaire. The participants were recruited through a notice posted on the website of the UK-based eating disorder's charity, BEAT. The study was also advertised in the October and November 2013 issues of BEAT's monthly research update email.

Upon completing the questionnaire, the participants were invited to take part in a telephone discussion. In order to arrange these discussions, the participants were asked to provide their email address. They were then sent an email (see Appendix I). The discussions took the same form as those conducted in Study 1 (see Section 2.2.1).

3.2.2 Participants

The participants were primarily recruited through a notice posted on the '*Research*' page of BEAT's website. Visitors to the page were invited to take part in a study titled *'Accessing Early Help for Eating Problems'*. Clicking on the study's title took potential participants to a page containing a brief description of the study (see Appendix G) following which potential participants were invited to click on a link to the questionnaire and Information Sheet. The study was further advertised to BEAT's research contacts, a group of individuals who have indicated that they would like to receive updates concerning opportunities to take part in research related to eating disorders, in the October and November 2013 issues of BEAT's monthly research update email (to 490 and 498 contacts respectively).

Any individual who perceived that they may currently have, or previously have had, a problem with eating was eligible to take part. It was stated in the study's description (see Appendix G) that the researchers were particularly interested in hearing from individuals who *'think that they might have an eating problem but have not yet sought help'*.

3.3 Measures

3.3.1 The online self-report questionnaire (Table 3.1)

The online questionnaire, developed by EC, resembled that devised for Study 1 (see Table 2.1). It was amended to account for the fact that the participants may not have sought or received treatment. The questionnaire consisted of 14 questions comprising both quantitative and free text items and was hosted by *'Qualtrics'* (see Section 2.3.1).

Early Intervention in the Treatment of Eating Disorders

Before taking part in this study it is important that you read our 'Information Sheet'.

This provides information about the questionnaire and will help you decide whether or not to take part.

To download the 'Information Sheet' please click here: Information sheet

You can then proceed to the questionnaire.

Thank you for agreeing to complete this questionnaire.

Our goal is to create a web-based form of help for people who are developing an eating problem. We want to get help to them as early as possible and are planning on using the web in order to do this. To help us, we would be most grateful if you would answer a brief questionnaire.

The questionnaire is short - it should take no longer than 15 minutes to complete.

Your responses will be anonymous and treated in confidence.

Thank you,

Emma Clifton and Christopher Fairburn

emma.clifton@psych.ox.ac.uk
01865-226479

The following questions refer to the early stages of your eating problem.

If your eating problem began a while ago, please imagine that the internet was as it is today when answering the questions.

1. How long have you had your eating problem?

2. Have you ever looked online for help or information?

☐ Yes
☐ No

[DISPLAYED TO THE PARTICIPANT ONLY IF THEY ANSWERED 'YES' TO QUESTION 2]

3. How long after you realised you may have an eating problem did you go on the internet for the first time?

[DISPLAYED TO THE PARTICIPANT ONLY IF THEY ANSWERED ‘YES’ TO QUESTION 2]

4. How old were you when you looked on the internet for the first time for this purpose?

5. Have you ever spoke to a health care professional about your eating problem (e.g. visited your GP)?

☐ Yes
☐ No

[DISPLAYED TO THE PARTICIPANT ONLY IF THEY ANSWERED ‘YES’ TO QUESTION 5]

6. How old were you when you first went to see a health care professional (e.g. your GP) about your eating problem?

7. Have you ever received professional help for your eating problem (e.g. seen a psychiatrist, psychologist or mental health care professional)?

☐ Yes
☐ No

[DISPLAYED TO THE PARTICIPANT ONLY IF THEY ANSWERED ‘YES’ TO QUESTION 7]

8. How old were you when you first professional help for your eating problem (e.g. when you saw a psychiatrist, psychologist or mental health care professional)?

9. From the list below please tick ALL the features that you experienced in the early stages of your eating problem.
If you experienced any additional features, please mark ‘Other’ and enter the feature/s into the box provided.

☐ Trying to eat very little or avoid certain types of food
☐ Having episodes of uncontrolled eating (binges)
☐ Making yourself sick
☐ Taking laxatives, diuretics or diet pills
☐ Exercising in a driven way
☐ Thinking too much about your eating
☐ Feeling very concerned about your shape
☐ Feeling very concerned about your weight
☐ Other (please specify) ______________________

10. Would any of the early features of your eating problem have led you to consider going on the internet to look for help or information?

☐ Yes
☐ No

11. From the list below, please tick ANY of the features of your eating problem that might have led you to go on the internet to look for help or information. Add any additional features by ticking 'Other' and entering them into the box provided.

- ☐ Trying to eat very little or avoid certain types of food
- ☐ Having episodes of uncontrolled eating (binges)
- ☐ Making yourself sick
- ☐ Taking laxatives, diuretics or diet pills
- ☐ Exercising in a driven way
- ☐ Thinking too much about your eating
- ☐ Feeling very concerned about your shape
- ☐ Feeling very concerned about your weight
- ☐ Other (please specify) ____________________

12. Please mark the feature that would have led you to go on the internet FIRST. If this feature is not in our list, please tick 'Other' and enter the details into the box.

- ☐ Trying to eat very little or avoid certain types of food
- ☐ Having episodes of uncontrolled eating (binges)
- ☐ Making yourself sick
- ☐ Taking laxatives, diuretics or diet pills
- ☐ Exercising in a driven way
- ☐ Thinking too much about your eating
- ☐ Feeling very concerned about your shape
- ☐ Feeling very concerned about your weight
- ☐ Other (please specify) ____________________

13. If you had gone on the internet to seek help or information, what phrases/words would you have entered into the search engine (e.g. *Google*)? Please enter each phrase/word on a new line in the box below:

14. If you have any additional thoughts, comments or suggestions about this topic, we would be very pleased to hear from you. Please enter them below:

Finally, if you would be willing to speak to us on the phone about this topic please enter your email address below. This will allow us to contact you to find a convenient time.

Thank you very much for taking the time to complete this questionnaire.
Emma Clifton and Christopher Fairburn
01865-226479
emma.clifton@psych.ox.ac.uk

TABLE 3.1 The online self-report questionnaire – Study 2

3.4 Data Analysis

The data analysis followed the same strategy as that used in Study 1 (see Section 2.4).

For an audit trail of the coding process see Appendix H. Ninety-seven initial codes were generated. These were revised to a total of 15 final codes.

3.5 Ethical Approval

Ethical approval was obtained from the Medical Sciences Interdivisional Research Ethics Committee (ref: MSD-IDREC-C1-2013-090) (see Appendix F).

3.6 Results

3.6.1 The participants

Seventy-nine participants navigated to the questionnaire. Of these, 71 proceeded to answer at least one question. Thirty-five participants provided their email addresses to facilitate the organisation of a telephone discussion. Fifteen discussions took place.

3.6.2 The findings of the questionnaire

1. **How long have you had your eating problem?** (n = 70)

The participants had had their eating problem for a mean duration of 8.2 years (SD = 5.5 years).

2. **Have you ever looked online for help or information?** (n = 71)

Sixty-nine participants (97.2%) reported that they had been online to look for help or information. Two participants (2.8%) reported that they had not.

3. **How long after you realised you may have an eating problem did you go on the internet for the first time?** (n = 67)

The participants went online, on average, 1.8 years after their problem first developed (SD = 2.9 years)[2].

4. **How old were you when you looked on the internet for the first time for this purpose?** (n = 68)

The mean age at which participants first looked online for help or information was 17.0 years (SD = 4.7 years).

5. **Have you ever spoken to a health care professional about your eating problem (e.g. visited your GP)?** (n = 70)

Sixty-four participants (91.4%) reported that they had spoken to a health care professional. The remaining 6 participants (8.6%) reported that they had not.

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[2] *'A few months'* was taken to mean 2 months, <1 month was included as 0 months, those who stated they unsure were excluded, and those who stated that they used the internet immediately or concurrently were included as 0 months.

6. **How old were you when you first went to see a health care professional (e.g. your GP) about your eating problem?** (n = 62)

The mean age at which the participants went to see a health care professional was 17.2 years (SD = 3.5 years).

7. **Have you ever received professional help for your eating problem (e.g. seen a psychiatrist, psychologist or other mental health care professional)?**
   (n = 68)

Sixty participants (88.2%) reported that they had received professional help. The remaining 8 participants (11.8%) reported that they had not.

8. **How old were you when you first received professional help for your eating problem (e.g. saw a psychiatrist, psychologist or other mental health care professional)?** (n = 60)

The mean age at which participants received professional help was 17.7 years (SD = 4.0 years).

Mean differences:

The mean time lapse between first using the internet and first visiting a health care professional was 0.8 years (SD = 2.9 years) (n = 61).

The mean time lapse between first visiting a health care professional and first receiving professional help was 0.6 years (SD = 1.3 years) (n = 57).

Finally, the mean time lapse between first using the internet and first receiving professional help was 1.1 years (SD = 2.4 years) (n = 58).

9. **From the list below please tick ALL the features that you experienced in the early stages of your eating problem.** (n = 67).

The features most commonly experienced early in the development of an eating problem were: food avoidance or restriction, thinking too much about eating, shape concern, and weight concern. These were experienced by over 90% of the participants.

Feature	Responses	Percentage
Food avoidance/restriction	65	97.0%
Binge eating	32	47.8%
Self-induced vomiting	27	40.3%
Use of laxatives, diuretics or diet pills	18	26.9%
Obsessive exercising	44	65.7%
Thinking too much about eating	64	95.5%
Shape Concern	63	94.0%
Weight concern	61	91.0%
Other	8	11.9%

TABLE 3.2 Features experienced early in the development of an eating problem

10. **Would any of the early features of your eating problem have led you to consider going on the internet to look for help or information?** (n = 67)

Forty-three participants (64.2%) reported that the early features of their problem would have led them to consider going online for help or information. Twenty-four participants (35.8%) reported that the early features would not have led them to consider going online for this purpose.

11. **From the list below, please tick ANY of the features of your eating problem that led you to go on the internet to look for help or information.** (n = 65)

Over half of the participants cited thinking too much about eating, weight concern, and shape concern as reasons for seeking help or information online. Other significant features were food avoidance/restriction and self-induced vomiting.

Feature	Responses	Percentage
Food avoidance/restriction	31	47.7%
Binge eating	21	32.2%
Self-induced vomiting	31	47.7%
Use of laxatives, diuretics or diet pills	16	24.6%
Obsessive exercising	23	35.4%
Thinking too much about eating	38	58.5%
Shape Concern	34	52.3%
Weight concern	39	60.0%
Other	11	16.9%

TABLE 3.3 Features that led people to seek help or information online

12. **Please mark the feature that led you to go on the internet FIRST.** (n = 66)

The most frequent reason cited for going online first was food avoidance/restriction. This was followed by 'other' reasons. Self-induced vomiting was also a common reason for first seeking online help or information.

Feature	Responses	Percentage
Food avoidance/restriction	16	24.6%
Binge eating	4	6.1%
Self-induced vomiting	11	16.7%
Use of laxatives, diuretics or diet pills	2	3.0%
Obsessive exercising	2	3.0%
Thinking too much about eating	5	7.6%
Shape concern	3	4.6%
Weight concern	9	13.6%
Other	12	18.2%
None, I would not have looked on the internet	2	3.0%

TABLE 3.4 Features that led people to go online first

13. **If you had gone on the internet during your eating problem, what phrases or words would you have entered into the search engine (e.g. *Google*)?** (n = 61)

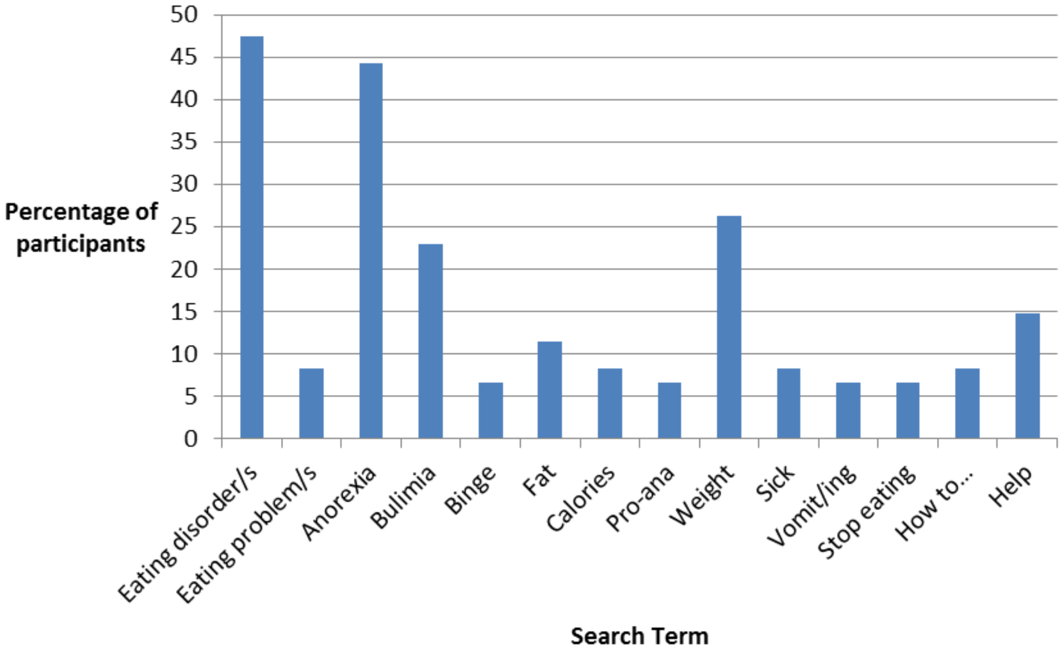

FIGURE 3.1 The use of search terms - Study 2

The most commonly used search term was ‘eating disorder’ or ‘eating disorders’. ‘Eating disorder/s’ was searched by 29 participants (47.5%). Five additional participants searched for ‘eating problem’. The second most commonly used search term, ‘anorexia’, was used by 27 participants (44.3%). No participants searched for ‘anorexia nervosa’.

Sixteen participants (26.2%) listed searches including the word ‘weight’. In 9 of these searches ‘weight’ was used in the context of ‘lose weight’, in 3 of the searches ‘weight loss’ was used.

Fourteen participants (23.0%) listed searches including the word ‘bulimia’. No participants searched for ‘bulimia nervosa’.

14. **If you have any additional thoughts, comments or suggestions on this topic, we would be very pleased to hear from you. Please enter them below.**

    (n = 26)

Twenty-six participants (36.6%) provided free text answers in response to the statement above.

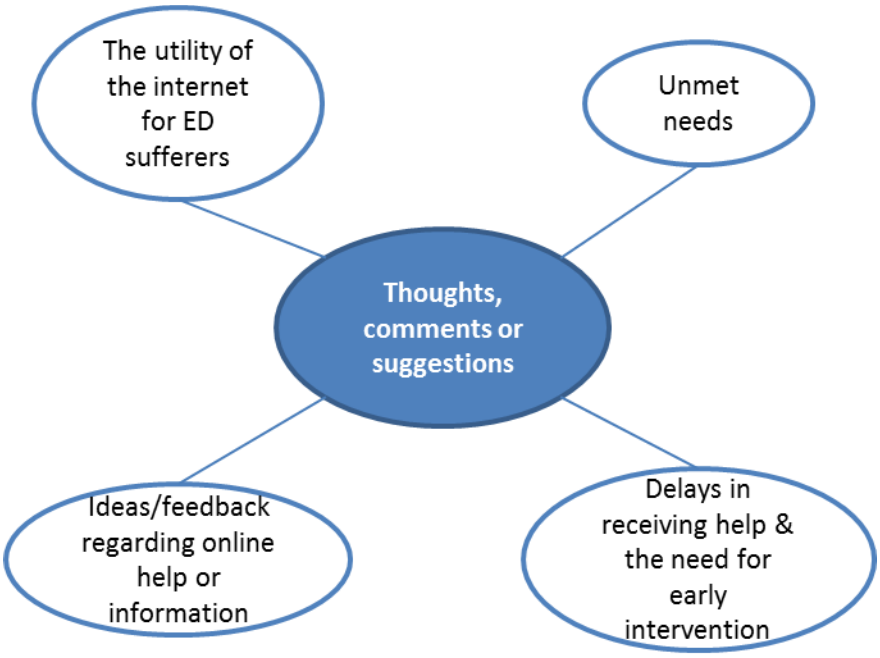

FIGURE 3.2 Thematic map - Study 2

1. The utility of the internet for sufferers of eating disorders

This theme refers to comments regarding how useful or unhelpful the internet was to the participants. The majority of the participants (16 participants, 61.5%) made reference to this theme. Overall, there was a balance between those who felt that the internet was helpful, those that felt it was unhelpful, and those that felt that its influence was mixed.

Mixed

Roughly one-third of participants who referenced this theme acknowledged that the internet was both useful and unhelpful to sufferers of eating disorders. For example:

> *The internet can be both helpful and extremely damaging*

A few participants noted that individuals should be vigilant online even when browsing neutral information about eating disorders or pro-recovery content:

> *Recovery websites can turn into pro-ED ones unconsciously*
>
> *Things can be too easily triggering*
>
> *YouTube is now more dangerous than pro-anorexia websites*

Helpful

Roughly one-third of the participants who commented on this theme regarded the internet as useful to sufferers. In particular, participants cited the ease of access to information as positive. For example:

> *It is easier to look for help online*
>
> *I found the online information essential…it made me recognise [that] I had a problem*
>
> *[Online information] motivated me to get help*

The internet was also seen as a vehicle through which to access support networks:

> *[I] have found a surprising amount of support by engaging in social media*

Unhelpful

One-third of the participants who referenced this theme suggested that the internet was unhelpful to eating disorder sufferers. Five participants referred to pro-anorexia websites. However, most viewed the internet as merely unhelpful, rather than dangerous. They reported that it did not provide enough information:

I struggled to find any useful information

I needed thorough, good quality information…this was not always easy to find

2. Unmet needs

This theme refers to the participants' perceptions that the internet failed to meet their needs. Ten participants (38.5%) discussed this theme. Approximately half discussed the need for more information or help online:

There was no help actually online

More information needs to be offered

Half of the participants discussed their feelings of isolation and stated that there was a need for more support:

There is very little support

Too many are left feeling that they are alone

3. Delays in receiving help and the need for early intervention

This theme refers to the delays participants described in receiving help for their eating disorder. Half of the participants made reference either to their personal experiences of delays in receiving appropriate care or to the delays experienced by sufferers of eating disorders more generally. There were two partially distinct sub-themes. A few participants commented on both.

Causes of delays in seeking help

Eight of the participants who commented on this theme (61.5%) discussed reasons for delays in help-seeking. The desire to conceal their disorder was prominent. For example:

You don’t want anyone to know

However, several participants also noted that they did not realise that they had an eating disorder in the early stages:

I was in denial…I didn’t think I had a problem

Several participants reported not wanting to consult a health care professional, either because of concerns that they would not be taken seriously, or because of negative past experiences in attempting to seek help for their disorder:

I thought I would be turned away again

I didn’t think I was good [or] ill enough

Problems accessing help

Eight of the participants who referenced this theme (61.5%) commented on the problems they encountered in accessing help. The most prominent difficulty was the failure of clinicians to take seriously the problems of individuals who were not of low weight:

[I] couldn’t access support because my BMI was too high

Because my BMI wasn’t dangerously low, I was told I didn’t have a problem

[I have] been told my BMI will need to be below 13 to receive help as services are limited

There was a pervasive feeling of having been *'turned away'* or *'let down'* by services:

> *I finally had the courage to go to the GP…and got turned away at the specialist appointment for not meeting all the criteria for an eating disorder*
>
> *I have been rejected/let down by services quite a lot*
>
> *Professionals knew but didn't help soon enough*

Some of the participants felt that their suffering could have been alleviated or prevented if early intervention had occurred:

> *[Hospitalisation] could have been avoided if a pro-active approach was taken straight away*
>
> *Early intervention would have prevented me from being in this position*

Two of the participants made reference to the impact of long waiting lists:

> *[I am] waiting to start CBT, but the waiting list is so long I don't know when…In the meantime I'm waiting on this list with no support*

4. Ideas or feedback regarding online help or information

This theme refers to the participants' feedback or ideas regarding the provision of an online help or information resource for sufferers of eating disorders. Seven participants (26.9%) gave direct feedback on this theme (three offered their ideas about how the internet could be incorporated into therapy and 4 gave feedback on the provision of online help or information). Despite the small number of responses, the theme has been included because of its salience to the study's aims. Some additional indirect feedback on this theme was provided by participants who described their unmet needs. These are discussed under the theme of *'Unmet needs'* and primarily comprise the need for more information and support online.

Three participants indicated that a self-help intervention would be likely to be accessed. For example:

> *It's easier to look for help online*

Only two participants commented on the potential utility of such an intervention. Both suggested that, by itself, it would be inadequate:

> *I cannot imagine an online intervention would be enough*
>
> *I also feel it's important to have feedback from another person face-to-face as well as using the internet*

Two of the participants offered their ideas about how the internet could be used as an adjunct to therapy. One participant suggested that GPs could be given a list of approved blogs. The other participant felt that:

> *Professionals could use the internet more to support their clients – for example, email contact*

3.6.3 The findings of the telephone discussions (n = 15)

Fifteen participants (21.1%) took part in the discussions which lasted between 5 and 16 minutes, with a mean duration of 10 minutes. The discussions were semi-structured and, as in Study 1, covered four broad areas:

1. Eating disorder development
2. The help-seeking process and reasons for delays
3. Internet use during the early stages of an eating disorder
4. Ideas and attitudes regarding online self-help

3.6.3.1 Eating disorder development

Two-thirds of the participants reported that they had developed AN at some point during the course of their eating disorder. One-third of the participants experienced BN at some point during their ED; no additional participants reported ever having experienced binge eating. For all but one participant (93.3%), participants' eating problems began with a period of dieting brought on by weight or shape concerns (12 participants, 80.0%). Four participants (26.7%) experienced self-induced vomiting.

The most common pattern of eating disorder development was as follows: weight or shape concerns caused individuals to diet. Most went on to develop AN; one-third developed BN.

3.6.3.2 The help-seeking process and reasons for delays

All of the participants reported that there was a delay between the development of their eating disorder and when they first sought help. The mean delay was 2.7 years, with a minimum delay of 7.5 months and a maximum delay of 7 years (2 participants).

The majority (11 participants, 73.3%) reported that they lacked insight in the early stages of their eating disorder. Over half of the participants reported that egosyntonic aspects of their disorder, including weight loss and a sense of control, prevented them from seeking help. One-third stated that denial played a role and one-third cited a desire to conceal their disorder. Three participants also reported that their symptoms were initially dismissed by their GP and one participant reported that a long waiting list resulted in her not commencing treatment.

For the majority of the participants, the severity of their symptoms triggered the realisation that they had a problem. Four participants (26.7%) indicated that other people helped them to realise. More than one-third of the participants indicated that they eventually sought help because of the impact that the eating disorder was having on their lives, particularly their social life. Four participants were *'forced'* into seeking help by their parents and three participants reported that self-induced vomiting led them to seek help.

Most of the participants (12 participants, 80.0%) initially sought help from their GP. A significant minority (5 participants, 41.7%) were taken by their mothers.

3.6.3.3 Internet use during the early stages of an eating disorder

Twelve participants (80.0%) reported that they used the internet during the early stages of their ED, one further participant reported that she would have done so had the internet existed then as it does today. Just two participants reported that they did not use the internet, one of whom was shown online material by concerned family members.

The most prominent online activities were: searching for information about eating disorders and their treatment; searching pro-anorexia websites (including pro-anorexia blogs, *Instagram* pages, *Facebook*, *Google Images*, and *Twitter*); and searching for pro-recovery websites. Other activities included the use of pro-recovery forums (these were used by almost one-third of participants). A small minority of individuals also sought dieting advice.

3.6.3.4 Ideas and attitudes regarding online self-help

Two-thirds of the participants reported that an online intervention would have minimised the delay between the onset of their disorder and when they first received help; one-third reported that it would not. Three participants (20.0%) reported that they would not have used an online program had they encountered one. Their reasons included a lack of motivation to change and a desire to hand over control of their eating disorder. The remaining 12 participants (80.0%) reported that they would have used an online intervention. Three participants (20.0%) actively sought online self-help programs.

Thirteen participants (86.7%) felt that providing an online self-help program would be a good idea. Two further participants reported that a guided self-help program would be beneficial. One participant felt strongly that online self-help would be a bad idea.

Four of the participants (26.7%) suggested that an online intervention would be improved by some form of therapist contact. Other suggested features were:

1. The provision of information alongside treatment
2. Clarification that eating disorders are serious illnesses
3. Information regarding the risks of eating disorders
4. Information regarding atypical eating disorders
5. Advice about how to speak to health care professionals, including how to approach a first consultation with a general practitioner
6. Links to professional help services
7. Make the program free of charge
8. Be motivating and encouraging
9. Provide case-studies
10. Stress the evidence-base
11. Link the intervention to apps

3.7 Discussion

This investigation set out to replicate Study 1 with an alternative group of participants. The participants were primarily recruited through a notice placed on the website of a UK-based eating disorder's charity. The study was also advertised to the charity's research contacts.

The participants had a mean age of 23.5 years and had had their eating problem for a mean duration of 8.2 years. During that time, almost all of the participants had looked online for help or information and the telephone discussions suggested that the majority would have used an online self-help intervention had they encountered one. On average, the participants were 17.0 years old when they first used the internet for help or information seeking purposes, one and three-quarter years after they first became aware of their eating problem. 'Eating disorder' was the most commonly used search term, followed closely by 'anorexia'. 'Weight', in the context of 'weight loss' or 'lose weight', and 'bulimia' were also frequently searched.

The participants viewed the internet as both useful and unhelpful to those with eating disorders. In particular, online information and support was valued. This corroborates the literature suggesting that seeking support constitutes a major reason for internet use amongst sufferers of eating disorders (e.g. Harrison-Yuill, 2013, Rodgers et al., 2012, Wesemann and Grunwald, 2008). A minority of the participants made reference to pro-eating disorder websites and the need for caution even when browsing seemingly innocuous content or pro-recovery material. However, the internet was discussed as falling short of meeting the information needs of sufferers more often than it was portrayed as dangerous. Many participants reported an unmet need for information and support.

Almost all of the participants had consulted a health care professional and most had also received professional help. Help or information was sought online an average of 0.8 years before the first consultation with a professional and 1.1 years before the receipt of specialist care.

The participants perceived that the receipt of care had been delayed in many instances. Prominent reasons for this delay were: secrecy, a lack of information resulting in low mental health literacy, denial, fear that the disorder would not be taken seriously, positive aspects of the eating disorder, and a lack of insight. Many participants also experienced barriers to accessing services following contact with their GP. Most notably, some participants reported having been unable to access care because their weight status was unremarkable. This corroborates the findings of a recent study (BEAT, 2013).

In the early stages of their eating problem, more than 60 of the participants (>90%) experienced: food avoidance/restriction, thinking too much about eating, shape concern, and/or weight concern. Approximately two-thirds reported that these early features led them to seek help or information online. Food avoidance or restriction, followed by ‘other’ reasons, were the first features of a developing eating problem to lead participants to seek help or information in this way. However, the most common reasons for seeking help or information online were: thinking too much about eating, weight concern, or shape concern.

Few participants provided direct feedback on the idea of developing an online help or information resource. However, those that did suggested ways in which the internet could be used as an adjunct to therapy or to fill an information gap. The two participants to give explicit feedback suggested that face-to-face contact with a therapist was more desirable than a program-led intervention. Despite reservations about the ability of online help to overcome the ambivalence of sufferers, the majority of participants reported that they would have used an online intervention had they encountered one. These responses suggest that people with eating disorders desire and see the utility of self-help. However, the limited evidence from the small number of participants who commented may indicate that sufferers see the internet more as an information source and potential adjunct to therapy than as a source of help in its own right.

3.7.1 Strengths

The aim of this investigation was to repeat Study 1 with a different group of participants. The present study's participants had a mean age of 23.5 years, making them substantially younger than those included in Study 1 (who had a mean age of 31.3 years). In contrast to Study 1, the majority of the present study's participants had an eating disorder characterised primarily by food restriction and many had suffered from AN. Further, having been recruited through a website, these participants comprise the target group for an online intervention (i.e. individuals with eating problems who seek help or information online), making their responses particularly pertinent.

Many participants had both sought and received help for their eating disorder, this enabled them to recount the help-seeking process and provide information concerning the delays and barriers they encountered at all stages. In addition, the response rate was relatively high.

3.7.2 Limitations

In common with Study 1, to reduce the possibility of subjectivity or bias influencing the results of the thematic analysis, it would have been beneficial for a second, independent researcher to analyse the free text responses.

The participants were not as distinct from those in Study 1 as the researchers had anticipated. The participants had had their eating disorder for a mean duration of over 8 years. It is thus possible that some participants may have struggled to accurately recall their internet use in the early stages of their disorder. However, the results of the telephone discussions corroborated the questionnaire findings. Thus the participants were at least consistent in their recall. The majority of the participants had been diagnosed with a threshold eating disorder and had both sought and received help. Therefore, the results cannot be generalised to individuals who suffer from long-term sub-threshold problems and may seek help online. Further, the findings cannot be generalised to the majority of eating disorder sufferers do not seek treatment (Hart et al., 2011). Individuals with impairing but sub-threshold problems and those who do not seek professional help are an important target groups for an online help or information resource.

The method of recruitment for the study may have influenced the findings. The participants were primarily recruited online through the website of an eating disorders charity. As a result, it is conceivable that the rates of online help and information seeking reported are inflated relative to the community of eating disorder sufferers. The study should be replicated with individuals recruited through notices in schools, colleges, universities, or magazines.

The proportion of participants who took part in the telephone discussions was low (15 participants, 21.1%). Amongst this sub-group, binge eating was less common than in the overall sample (47.8% versus 33.3%), this may limit the applicability of the findings of the telephone discussions to those suffering eating disorders characterised by binge eating.

3.7.3 Conclusions

The findings of the present study indicate that the majority of those in the early stages of an eating disorder looked online for help or information and would have used an online intervention if they had encountered one. Thinking too much about eating, shape concern, weight concern, food restriction/avoidance, and self-induced vomiting were likely to lead people to go online, with food restriction/avoidance being the earliest feature to lead people to seek help or information in this way. Common search terms were ‘eating disorder/s’, ‘anorexia’, ‘bulimia’, and ‘weight’ (particularly in the context of ‘lose weight’). The study corroborates both Study 1 and past research suggesting a lag between the onset of an eating disorder and first contact with health services. It supports the literature suggesting that the egosyntonic features of eating disorders, a desire to conceal the disorder, lack of insight, denial, and a lack of information prevent people from seeking help. The findings suggest that many of these barriers could be overcome and the receipt of care could be brought forward by the provision of an online self-help resource.

CHAPTER 4:

A COMPARISON OF THE FINDINGS FROM STUDY 1 AND STUDY 2

4.1 Introduction

Study 2 was designed to determine whether the results of Study 1 could be replicated with a different group of participants. Here follows a comparison of the two studies.

4.2 The Findings of the Questionnaire

4.2.1 Online eating disorder-related help or information seeking

	Study 1 (%)		Study 2 (%)	
	Yes	No	Yes	No
Looked/would have looked online	84.0	16.0	97.2	2.8
Early features did/would have led participants to look online	87.8	12.2	64.2	35.5

TABLE 4.1 Comparison of online help or information seeking between Study 1 and Study 2 participants

The majority of the participants in both studies did or would have searched online for help or information. This proportion was greater in Study 2.

The majority of participants did or would have gone online to search for help or information as a result of the early features of their eating disorder. This proportion was greater in Study 1.

4.2.2 The early features of eating disorders and online help or information seeking

Feature	Features experienced early in the development of the ED		Features that would have led participants to go online		First features that would have led participants to go online	
	Study 1 (%)	Study 2 (%)	Study 1 (%)	Study 2 (%)	Study 1 (%)	Study 2 (%)
Food avoidance/restriction	96.0	97.0	56.5	47.7	4.4**	24.6**
Binge eating	86.0**	47.8**	71.7**	32.2**	33.3**	6.1**
Self-induced vomiting	58.0	40.3	58.7	47.7	28.9	16.7
Use of laxatives, diuretics or diet pills	44.0	26.9	34.8	24.6	4.4	3.0
Obsessive exercising	66.0	65.7	34.8	35.4	2.2	3.0
Thinking too much about eating	96.0	95.5	54.3	58.5	6.7	7.6
Shape concern	94.0	94.0	56.5	52.3	2.2	4.6
Weight concern	88.0	91.0	50.0	60.0	13.3	13.6
Other	14.0	11.9	6.5	16.9	4.4**	18.2**

TABLE 4.2 Comparison of the early features of eating disorders and online help or information seeking of Study 1 and Study 2 participants

** = significant to the 0.05 level

A significantly higher proportion of Study 1’s participants: experienced binge eating in the early stages of their eating disorder; would have gone online as a result of binge eating; and would have gone online first because of binge eating. A significantly higher proportion of Study 2’s participants would have gone online first as a result of food avoidance/restriction or for ‘other’ reasons.

The experience of self-induced vomiting and the misuse of other purging methods in the early stages of an eating disorder were higher amongst the participants in Study 1. These results approached significance ($p = 0.058$ and $p = 0.053$, respectively).

4.2.3 The delay between first internet use for help or information seeking and seeking or receiving professional help

	Study 1 (years)	Study 2 (years)
Age at first internet use for help/information	19.2	17.0
Age at first consultation with a health care professional	24.6	17.2
Age at receipt of professional help	25.6	17.7

TABLE 4.3 Comparison of the age of Study 1 and Study 2 participants at significant time points

Study 1's participants were older than Study 2's at all time points. The discrepancy in age between the two groups grew across the three help-seeking time points. The gap was 2.2 years when the participants first sought help or information online, 7.4 years when they first consulted a health care professional, and 7.9 years when they first received professional help.

Years between:	Study 1 (years)	Study 2 (years)
First internet use and first consultation with a health care professional	5.2	0.8
First consultation with a health care professional and receiving help	1.0	0.6
First internet use and receiving help	6.1	1.1

TABLE 4.4 Comparison of the delay between first going online, seeking help and receiving care

Study 1's participants experienced greater delays in seeking and receiving help following their first internet use. The time elapsed between their first internet use and first visit to a health care professional was 4.4 years longer and the gap between their first internet use and the receipt of care was 5.0 years longer. In addition, after visiting a health care professional for the first time, Study 1's participants waited an average of 0.4 years longer before receiving help.

4.2.4 Search terms

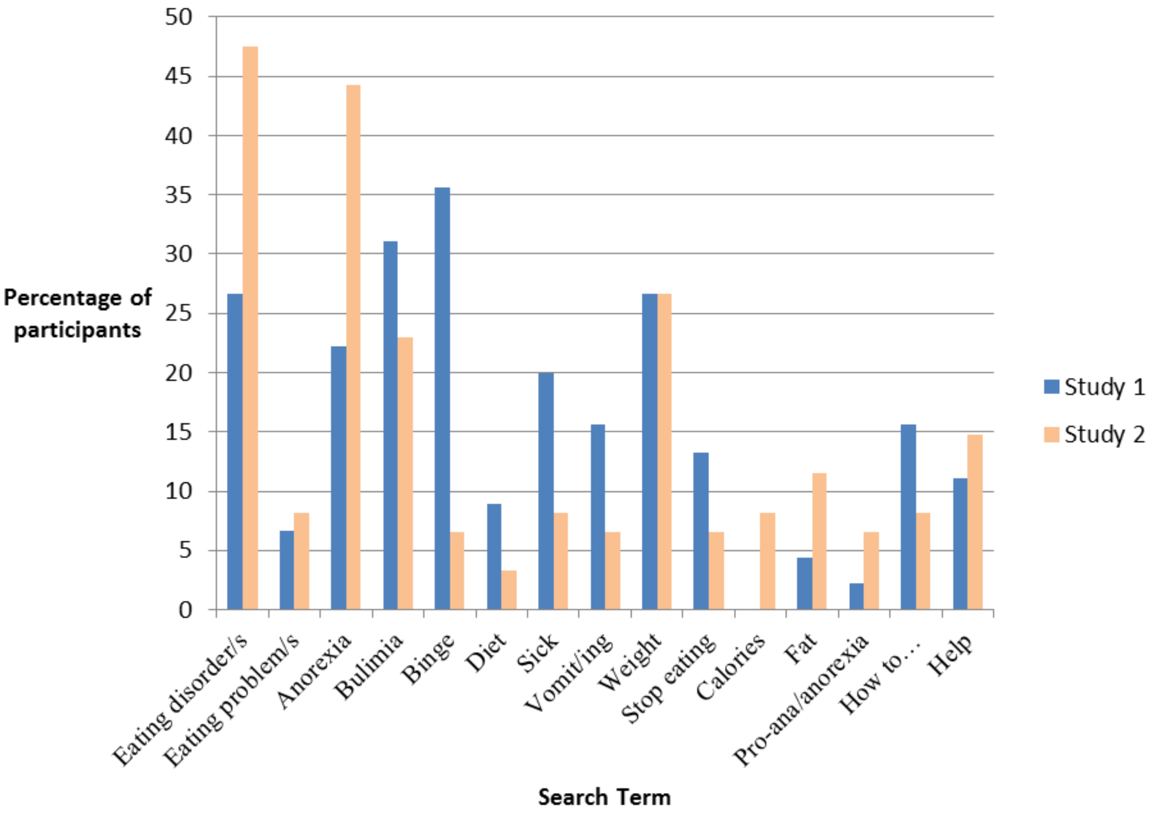

FIGURE 4.1 Comparison of the use of search terms

Study 1 - Top 5 search terms	Study 2 – Top 5 search terms
Binge†	Eating disorder/s
Bulimia†	Anorexia
Eating disorder/s	Weight
Weight	Bulimia
Anorexia	Help

TABLE 4.5 Comparison of the top 5 search terms used by participants in Study 1 and Study 2

= equal frequency

The overall pattern of the data is comparable between the two groups. Four of the 5 most prevalent search terms from each study are also present in the top 5 searches from the other study.

The most significant difference concerns the use of term ‘binge’. ‘Binge’, alongside ‘bulimia’, was the most frequently used search term in Study 1. By contrast, it was used by just 6% of Study 2’s participants. Study 1’s participants also searched for more information regarding self-induced vomiting, with over double the proportion searching for both ‘sick’ and ‘vomit’/‘vomiting’. Two other notable differences are evident. Almost double the proportion of the participants in Study 2 searched ‘eating disorder/s’ and double the proportion searched ‘anorexia’.

4.2.5 Free-text responses

Approximately half of the participants in both studies discussed delays in receiving care. A lack of insight, a lack of information, denial, and a desire to conceal the disorder were common causes of delays in seeking help amongst both groups of participants. In addition, Study 1’s participants more often noted shame, embarrassment, and ‘*not wanting to recover’* as barriers to help-seeking, although the latter sub-theme was also present in Study 2. Study 2's participants reported more barriers to receiving care having sought help. Prominent amongst these was the inability to access services whilst their weight status remained unremarkable. Both groups reported feelings of isolation and an unmet need for information and support.

Both groups of participants reported that the internet could be used both positively and negatively by sufferers of eating disorders. Many commented on the triggering nature of apparently innocuous and pro-recovery websites. Pro-anorexia websites were referred to more often by the participants in Study 1. Study 2's participants primarily focussed on the failure of online resources to meet their need for information. Both sets of participants noted that the internet is an important source of information, support, and reassurance.

Overall, the participants in Study 1 were more enthusiastic about the prospect of online self-help. No participants in Study 2 stated explicitly that they felt the provision of pure self-help would be a good idea – although many welcomed the provision of more online information and support.

4.3 The Findings of the Telephone Discussions

Most of the eating disorders amongst the participants in both studies began with shape or weight concern, resulting in a period of dieting. The two groups then diverge. Two-thirds of Study 2's participants went on to develop AN compared to approximately one-fifth of Study 1's. The majority of Study 1's participants engaged in binge eating. Binge eating was twice as prevalent amongst Study 1's participants and self-induced vomiting was also over twice as prevalent.

All of the participants in both studies noted a delay between the onset of their ED and when they first sought help. The reasons for this are comparable. In particular, similar proportions, 76% in Study 1 and 73% in Study 2, lacked insight. Ambivalence affected a significant number of the participants, as did a lack of information and the desire to conceal their disorder. Both groups cited the severity of their symptoms and concern about not being able to lead a full and normal life as reasons for eventually seeking help. The majority of the participants in both studies went to their GP as the first port-of-call. A greater proportion of those in Study 2 were taken by their mothers (42% versus 14%).

The primary uses of the internet were comparable between the two groups and included seeking information and browsing both pro-recovery and pro-eating disorder material. A small but comparable proportion of the participants in both studies would *not* have used an online self-help program had they encountered one (24% in Study 1 and 20% in Study 2). These individuals reported a desire for face-to-face contact and the need to be accountable to someone. The majority of the participants in both studies felt that the provision of online self-help would be a good idea (87% in Study 1 and 76% in Study 2). Many of their ideas about the desirable content of such a program concurred. For example, both groups wanted: information, links to services and other reputable websites, case-studies, motivational content, and clarification regarding the severity of eating disorders.

4.4 Discussion

4.4.1 Consistent findings

The majority of the participants in both studies would have looked online for help or information in the early stages of their eating disorder and would have used an online intervention had they encountered one. Both groups experienced delays in receiving help. High and equivalent proportions reported that: a lack of insight, denial, ambivalence, low mental health literacy, and a desire to conceal their disorder contributed to the delay. During this time, the majority went online with the primary intentions of seeking information, reassurance, and support. Individuals also went online to browse pro-eating disorder material. These findings are in keeping with other research regarding internet use amongst sufferers of eating disorders (e.g. Harrison-Yuill, 2013, Rodgers et al., 2012, Wesemann and Grunwald, 2008). 'Eating disorder/s', 'anorexia', 'bulimia', and 'weight' in the context of 'lose weight' were common search terms used by both groups of participants. High and equivalent proportions of participants in both studies experienced: food avoidance/restriction, obsessive exercising, thinking too much about eating, shape concerns, or weight concerns early in the development of their eating disorder.

4.4.2 Inconsistent findings and their likely explanations

There were notable differences in the nature of the eating disorders between the participants in the two studies. Study 1's participants were more likely to have engaged in binge eating and purging, whilst Study 2's were more likely to have suffered from eating disorders characterised by food restriction. These findings are corroborated by the telephone discussions and provide a possible explanation for the inconsistent findings.

A greater proportion of Study 1's participants reported that they would have looked online for help or information as a result of the early features of their eating disorder. Speculatively, this may result from the successful dieting of Study 2's participants being experienced positively (Bulik, 2014a), whilst the failure of dieting and engagement in binge eating experienced by Study 1's participants is likely to have resulted in distress (Goss and Allan, 2009). This is supported by the more frequent reports of shame and embarrassment amongst Study 1's participants.

Study 1's participants were more likely to seek online help or information for binge eating and were significantly more likely to use 'binge' as a search term. Conversely, the most common early feature to lead people to search online amongst the participants in Study 2 was food restriction or avoidance. Study 2's participants were also twice as likely to use 'anorexia' as a search term. These differences are most likely the result of the different nature of the eating disorders experienced by the two groups.

Study 1's participants waited almost 5 times as long as Study 2's between seeking help or information online and visiting a health care professional. This may partially be accounted for by the fact that binge eating is easier to conceal than AN as it does not result in extreme weight loss. Further, Study 2's participants were younger at all three time points (i.e. when they sought help online, first sought professional help, and first received professional help) than those in Study 1. It is possible that figures of authority, including parents and teachers, were able to take responsibility for help-seeking on their behalf. Some evidence for this is derived from the telephone discussions and the literature suggesting the role of parents in help-seeking for mental health problems amongst children and adolescents (Zwaanswijk et al., 2003). The age of Study 1's participants at seeking and receiving professional help might also be partly accounted for by the fact that the study's participants were recruited from a trial in which the minimum age of eligibility for inclusion was 18 years.

A greater proportion of Study 2's participants reported struggling to access care as a result of not being sufficiently underweight. Study 1's participants were recruited to a treatment trial and thus received relatively prompt care. This is a possible explanation for the discrepancy. It is possible that the help-seeking experiences of Study 2's participants who were not underweight when they first sought help better reflect the more general experiences of BN and EDNOS sufferers in the community (e.g. BEAT, 2013).

4.5 Conclusion

The key findings were consistent between the two studies. In particular, the majority of the participants reported that they would have gone online early in the development of their disorder, that there was a substantial delay between the onset of their symptoms and the receipt of professional help, and that they would have used an online intervention had they encountered one. 'Eating disorder', 'bulimia', 'weight', and 'anorexia' were commonly used search terms. Further, both groups reported similar barriers to seeking help.

The differences between the two groups appear to be attributable to the different nature of the eating disorders. Study 2's participants were more likely to be suffering from disorders characterised by food restriction, whilst Study 1's were more likely to have experienced binge eating. A greater proportion of Study 1's participants would have sought help or information online regarding binge eating, whilst Study 2’s participants were significantly more likely to first seek help or information online for food avoidance or restriction. The more frequent use of the term ‘binge’ amongst Study 1’s participants was the most notable difference with regards to the use of search terms.

Ultimately, Study 1’s participants were almost 8 years older when they first received help for their eating disorder. This discrepancy is largely accounted for by longer delays in help-seeking (see Tables 4.3 and 4.4), perhaps indicating that adults with binge eating problems are likely to delay seeking help for longer than adolescents with disorders characterised by food restriction.

CHAPTER 5:

FINAL DISCUSSION

5.1 Introduction

This final chapter reviews the aims of the research described in this thesis and assesses the findings in light of its limitations and strengths. The implications of the work are also considered.

5.2 Summary of the Aims

This thesis set out to determine whether people in the early stages of an eating disorder seek help or information online and, if so, which search terms they used. Secondarily, it explored which features of a developing eating disorder might lead people to seek help or information online and whether the provision of an online secondary prevention intervention has the potential to minimise the documented gap between the onset of an eating disorder and the receipt of care.

5.3 Design and Participants

This investigation was comprised of two studies. Both were survey-based and involved the completion of a self-administered online questionnaire, followed by a telephone discussion. The first study recruited participants with a past or present diagnosis of BN or EDNOS, who had previously been involved in a RCT comparing treatments for eating disorders at the University of Oxford’s Department of Psychiatry. Seventy-nine participants were contacted and 50 (63.3%) responded to at least one question on the questionnaire. Twenty one (42.0%) of the respondents subsequently took part in a telephone discussion. The majority of the respondents to the questionnaire provided their email address, enabling them to be identified. These participants did not differ from the other RCT participants with regard to age, eating disorder severity, secondary psychosocial impairment, BMI, or depressive symptoms at the time of recruitment or at their most recent follow-up assessment. The RCT participants had a mean current age of 31.3 years.

The second study recruited participants through a notice placed on the website of the UK-based eating disorder’s charity, BEAT (see Appendix G). In addition, BEAT sent the notice to its research contacts (individuals who had expressed an interest in participating in research related to eating disorders) in two editions of its monthly research update email. The mean age of the participants was 23.5 years.

5.4 Principal findings

5.4.1 Study 1

The study’s participants can reasonably be assumed to be representative of the help-seeking community of adult eating disorder sufferers, excluding those with anorexia nervosa. The study provides preliminary evidence that the majority of individuals in the early stages of eating disorders (excluding AN) would consider going online to seek help or information. The participants reported going online for this purpose over half a decade before they first made contact with primary care services. Prominent barriers contributing to the delay in seeking help included: shame, embarrassment, an attendant desire to conceal the disorder, anxieties concerning contacting health care professionals, and a lack of eating disorder-related information.

The majority of the participants would have tried an online intervention had they come across one. The perceived advantages of such a program were anonymity and the provision of an alternative discourse to pro-anorexia websites. The participants also noted that an online program would be well placed to overcome: shame, embarrassment, the desire to conceal the disorder, and anxieties about approaching health care professionals. Online help and information sources could not overcome positive experiences of the eating disorder as a reason for not seeking help. However, such resources may speculatively help to address lack of insight and denial by providing detailed information.

The participants reported that the earliest feature of their disorder that would have led them to seek help or information online was binge eating. Binge eating was also the most common reason for seeking help online. The most frequently used search terms were: ‘binge eat’, ‘bulimia’, and ‘eating disorders’.

5.4.2 Study 2

The study’s participants had a mean age of 23.5 years and had had their eating disorder for an average duration of 8.2 years. Most had both sought and received professional help. The findings provide further evidence that individuals in the early stages of an eating disorder would seek help or information online and would use an online self-help intervention. The earliest feature of an eating disorder to lead people to seek help or information online was food restriction or avoidance. However, the most common reasons were: thinking too much about eating, weight concern, and shape concern.

‘Eating disorder’ was the most commonly used search term, followed closely by ‘anorexia’. ‘Weight’ in the context of ‘lose weight’ and ‘bulimia’ were also searched frequently.

The mean delay between seeking help online and receiving professional help was approximately one year. Prominent barriers to help-seeking included: the desire to conceal the disorder, denial, lack of awareness, and anxiety about contacting health care professionals. Several participants experienced additional difficulties in accessing services owing to not being underweight. The participants expressed a need for more information and support.

5.4.3 Comparison of the findings from the two studies

Many of the key findings were consistent between the two studies. Most of the participants experienced a substantial delay between the onset of their disorder and when they first sought professional help. This delay resulted from: denial, lack of insight, lack of information, a desire to conceal the disorder, and anxieties about approaching health care professionals. Most of the participants went, or would have gone, online during this delay and would have used an online intervention. ‘Eating disorder’, ‘bulimia’, ‘weight’, and ‘anorexia’ were frequently used search terms.

The nature of the eating disorders experienced by the two groups of participants differed. Study 2’s participants were more likely to be suffering, or have suffered, from disorders characterised by food restriction, whilst Study 1’s were more likely to have experienced both binge eating and purging. This discrepancy provides a probable explanation for the inconsistencies between the studies. Study 1’s participants were more likely to have sought help or information online as a result of the early features of their eating disorder, speculatively because of the aversive nature of both binge eating and purging (Goss and Allan, 2009). Study 1's participants were also more likely to search for help or information regarding binge eating, and were more likely to use 'binge' as a search term. Study 2's participants were more likely to first go online to seek help or information concerning food restriction or avoidance and were more likely to use 'anorexia' as a search term.

Study 1's participants were older than Study 2's when they first sought help online, first sought professional help, and first received professional help. Additionally, Study 1's participants waited almost 5 times as long as Study 2's between seeking help or information online and approaching a health care professional. This suggests greater delays in help-seeking amongst adults who binge eat compared to adolescents with disorders characterised by food restriction. However, it is notable that 12% of the participants in Study 2 had not yet received help. In addition, the participants in Study 2 reported that having an unremarkable BMI often delayed the receipt of care once contact with primary care services had been made.

5.5 Strengths

This study was the first to explore the search terms used by people in the early stages of an eating disorder and adds to the indirect literature (including evidence of low drop-out rates) concerning the acceptability of online self-help. It corroborates research indicating delays in help-seeking amongst individuals with eating disorders and offers some explanations for this delay. Almost all of the participants in both studies had both sought and received professional help and could thus report the help-seeking process, including how it might have been altered by the provision of an online intervention. A particular strength of Study 2 was the online method of recruitment. Individuals who seek help or information online are an important target group for internet-delivered self-help interventions. Study 2's participants had sought help or information through the BEAT website, thus their responses are particularly pertinent.

5.6 Limitations

The main limitations of both studies pertain to the representativeness of the participant groups to eating disorder sufferers in the community, calling into question the generalizability of the findings. All of the participants in Study 1 and the majority of those in Study 2 had both sought and received help for their eating disorder. Whilst this enabled the participants to report the process of help-seeking, including the reasons for delays and eventual triggers to seeking help, the results cannot be generalised to the majority of sufferers in the community who do not seek help. Further, all of the participants in Study 1 and the majority in Study 2 have received an eating disorder diagnosis. As such, the findings cannot be generalised to individual's suffering from sub-clinical eating problems. These individuals, whose problems cause distress in their own right and may represent the early stages of an eating disorder, are an important target group for online interventions. Finally, the participants may have struggled to accurately recall their early online activity in some instances given the time elapsed since the first development of their problem. However, the results of the questionnaire were corroborated by the telephone discussions. Thus the participants were at least consistent in their recall.

The participants in Study 1 were significantly older than those at greatest risk for developing eating disorders (APA, 2013, Hudson et al., 2007). Given known differences in internet use amongst individuals of different ages (Jones and Fox, 2009), the findings from Study 2 may be more applicable to younger people.

To reduce the possibility of subjectivity or bias influencing the findings of the thematic analysis, it would have been beneficial for a second, additional researcher to independently analyse the free text responses. Ideally, this researcher would be blind both to the aims of the study and to the other questionnaire responses.

One final limitation, pertaining only to Study 2, is that the participants were recruited online via the website of an eating disorders charity. These participants are already seeking information online, thus they are an important target group for an online intervention. However, it is conceivable that this group of participants may report particularly high levels of online help-seeking. It would be beneficial to repeat the study with participants recruited through notices in schools, colleges, universities, or magazines.

5.7 Conclusions and Implications

Evidence-based treatments for eating disorders are available (NCCMH, 2004). However, the majority of sufferers experience substantial delays in both seeking (Hudson et al., 2007) and receiving (Hart et al., 2011) specialist care. This results in an extended period of suffering and is troubling given the substantial and potentially enduring costs of eating disorders. Efforts focussing on the implementation and dissemination of existing treatments attempt to address this gap. One important method of dissemination is the promotion of accessible program-led self-help interventions, including those delivered via the internet (Fairburn and Patel, 2014). The present study corroborates past research and contributes new findings relevant to the secondary prevention of eating disorders using the internet.

This study provides direct evidence that people in the early stages of eating disorders seek help or information online and that the majority of sufferers would use an online self-help intervention. The results support the literature suggesting that individuals suffering from stigmatised psychiatric conditions are likely to use the internet as an information source (Berger et al., 2005) and that seeking support and information comprise a major use of time spent online amongst people with eating disorders (Harrison-Yuill, 2013). In addition, the findings support research indicating that sufferers of eating disorders are active online browsing eating disorder-related content (Wilson et al., 2006) and that online self-help is both appealing (Pretorius et al., 2010) and acceptable (Aardoom et al., 2013).

The results of this study can be used to inform several aspects of secondary prevention. The findings may be built upon to encourage earlier contact with primary care services through the provision of pertinent information addressing some of the identified barriers to help-seeking. These include: lack of insight which may be aided by the provision of information about the symptoms of eating disorders, lack of knowledge about eating disorders (particularly those excluding anorexia nervosa) and their treatment, concerns that the GP is not the right person to contact, and anxieties that eating disorders are not taken seriously by health care professionals.

In combination with other research, the results of this study indicate that an online self-help program addressing eating disorders is likely to be used if it is encountered by sufferers and may be well-placed to promote early intervention. Programs will require the knowledge gained from research, such as this thesis, to ensure that they are detected. This information should be used for the purposes of search engine optimisation (SEO).

The participants reported having used ‘eating disorder/s’, ‘anorexia’, ‘bulimia’, and ‘weight’ as search terms. Those who experienced binge eating were also likely to have used ‘binge’ and those who experienced self-induced vomiting frequently used ‘sick’, often in the context of ‘making myself/yourself sick’. Depending on the users for whom a particular program is intended, it would be important to include some of these words towards the beginning of the title element (the title that appears on search engine results pages), in the uniform resource locator (URL), and in the meta-description tag (the concise description of a page appearing below the title on search engine results pages).

Meta-description tags play a significant role in influencing website selection after a site has appeared on a search engine results page. Research suggests that searchers spend time reading this tag before deciding whether to navigate to a page (Granka et al., 2004). It would be beneficial to ensure that the tag contains information pertinent to the user’s concerns. For example, in keeping with previous research (e.g. Perkins et al., 2006), the present study’s participants noted a desire to maintain anonymity. The program’s anonymity could thus be made explicit. Further, over half of the participants in both studies reported seeking help online for: thinking too much about eating, shape concerns, and weight concerns. It would be important for an online program to make clear that it addresses these features. If the program was to target those with binge eating problems, it would additionally be important to acknowledge binge eating.

The study corroborates previous findings that suggest a delay in help-seeking amongst sufferers of eating disorders (e.g. Hart et al., 2011, Hepworth and Paxton, 2007, Schoen et al., 2012). Many of the frequently cited causes of this delay in the present study also replicate previous findings, including: denial, lack of insight, positive aspects of the eating disorder, low mental health literacy, fear of contacting health services, shame, and embarrassment.

There are many potential advantages to the provision of online self-help. Foremost, it is likely to reach people earlier in the development of their eating disorder than face-to-face therapies through overcoming barriers to help-seeking and the receipt of care. Such interventions are also acceptable to sufferers (Aardoom et al., 2013, Pretorius et al., 2010, Schmidt et al., 2007) and have the potential to be anonymous, flexible, personalised, and foster a sense of empowerment (Williams, 2003).

There are also disadvantages. First, the efficacy of pure self-help is still not fully understood. Mirroring the concerns of a few individuals in the present study regarding the ability of an online program to overcome lapses in motivation during treatment, there are also questions of compliance (Newman et al., 2011) and drop-out. This may be partly mitigated by the provision of guided self-help (Wilson and Zandberg, 2012). Second, a minority of sufferers would not be willing to try self-help interventions and it is notable that disorders characterised by successful food restriction caused less initial distress amongst the participants than those characterised by binge eating. Self-help interventions in general may struggle to engage individuals who are dieting successfully. Third, the interventions themselves have limited penetration as a result of the requirement for both internet access and literacy. The latter concern is shared with other forms of self-help. Lack of internet access is not a pressing obstacle in resource-rich settings (Internet World Stats, 2012b), but will limit the use of online materials globally. Finally, it is possible that, in searching for information regarding eating disorders online, individuals may encounter pro-eating disorder websites. Such sites are attractive to individuals who perceive a lack of social support (Harrsion-Yuill, 2013) and have been shown to provide users with unhealthy tips (Wilson et al, 2006), as well as to decrease social self-esteem and effect body perception amongst healthy, young women (Bardone-Cone and Cass, 2007). Conversely, there is also the possibility that, if search engine optimisation techniques are well applied, people may encounter help and information resources in their pro-eating disorder searches. These resources may be able to offer an alternative form of support.

In summary, this study suggests that the internet is a potentially effective means through which to facilitate secondary prevention for eating disorders through the provision of an information and self-help resource. It is likely that the provision of such a resource would bring forward the receipt of care. The study further provides preliminary suggestions to inform search engine optimisation.

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APPENDICES

APPENDIX A

DSM 5 DIAGNOSTIC CRITERIA (APA, 2013):

ANOREXIA NERVOSA, BULIMIA NERVOSA, BINGE-EATING DISORDER AND ATYPICAL EATING DISORDERS

ANOREXIA NERVOSA

Diagnostic Criteria

A. Restriction of energy intake relative to requirements, leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health. *Significantly low weight* is defined as a weight that is less than minimally normal or, for children and adolescents, less than that minimally expected.

B. Intense fear of gaining weight or of becoming fat, or persistent behaviour that interferes with weight gain, even though at a significantly low weight.

C. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.

Coding note: The ICD-9-CM code for anorexia nervosa is **307.1**, which is assigned regardless of the subtype. The ICD-!)-CM code depends on the subtype (see below).

Specify whether:

(F50.01) Restricting type: During the last 3 months, the individual has not engaged in recurrent episodes of binge eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas). This subtype describes presentations in which weight loss is accomplished primarily through dieting, fasting, and/or excessive exercise.

(F50.02) Binge-eating/purging type: During the last 3 months, the individual has engaged in recurrent episodes of binge eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas).

Specify if:

In partial remission: After full criteria for anorexia nervosa were previously met, Criterion A (low body weight) has not been met for a sustained period, but either Criterion B (intense fear of gaining weight or becoming fat or behaviour that interferes with weight gain) or Criterion C (disturbances in self-perception of weight and shape) is still met.

In full remission: After full criteria for anorexia nervosa were previously met, none of the criteria have been met for a sustained period of time.

Specify current severity:

The minimum level of severity is based, for adults, on current body mass index (BMI) (see below) or, for children and adolescents, on BMI percentile. The ranges below are derived from World Health Organisation categories for thinness in adults; for children and adolescents, corresponding BMI percentiles should be used. The level of severity may be increased to reflect clinical symptoms, the degree of functional disability, and the need for supervision.

Mild: BMI ≥ 17 kg/m².
Moderate: BMI 16-16.99 kg/m².
Severe: BMI 15-15.99 kg/m².
Extreme: BMI < 15 kg/m².

BULIMIA NERVOSA

Diagnostic Criteria

A. Recurrent episodes of binge eating. An episode of binge eating is characterised by both of the following:
   1. Eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than what most individuals would eat in a similar period of time under similar circumstances.
   2. 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).

B. Recurrent inappropriate compensatory behaviours in order to prevent weight gain, such as self-induced vomiting; misuse of laxatives, diuretics, or other medications; fasting; or excessive exercise.

C. The binge eating and inappropriate compensatory behaviours both occur, on average, at least once a week for 3 months.

D. Self-evaluation is unduly influenced by body shape and weight.

E. The disturbance does not occur exclusively during episodes of anorexia.

Specify if:

In partial remission: After full criteria for bulimia nervosa were previously met, some, but not all, of the criteria have been met for a sustained period of time.
In full remission: After full criteria for bulimia nervosa were previously met, none of the criteria have been met for a sustained period of time.

Specify current severity:

The minimum level of severity is based on the frequency of inappropriate compensatory behaviours (see below). The level of severity may be increased to reflect other symptoms and the degree of functional disability.

Mild: An average of 1–3 episodes of inappropriate compensatory behaviours per week.
Moderate: An average of 4–7 episodes of inappropriate compensatory behaviours per week.
Severe: An average of 8–13 episodes of inappropriate compensatory behaviours per week.
Extreme: An average of 14 or more episodes of inappropriate compensatory behaviours per week.

BINGE-EATING DISORDER

Diagnostic Criteria

A. Recurrent episodes of binge eating. An episode of binge eating is characterised by both of the following:
   1. Eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than what most individuals would eat in a similar period of time under similar circumstances.
   2. 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).

B. The binge eating episodes are associated with 3 (or more) of the following:
   1. Eating much more rapidly than normal.
   2. Eating until feeling uncomfortably full.
   3. Eating large amounts of food when not physically hungry.
   4. Eating alone because of feeling embarrassed by how much one is eating.
   5. Feeling disgusted with oneself, depressed, or very guilty afterward.

C. Marked distress regarding binge eating is present.

D. The binge eating occurs, on average, at least once a week for 3 months.

E. The binge eating is not associated with recurrent use of inappropriate compensatory behaviour as in bulimia nervosa and does not occur exclusively during the course of bulimia nervosa and anorexia nervosa.

Specify if:

In partial remission: After full criteria for binge eating disorder were previously met, binge eating occurs at an average frequency of less than 1 episode per week for a sustained period of time.

In full remission: After full criteria for binge eating disorder were previously met, none of the criteria have been met for a sustained period of time.

Specify current severity:

The minimum level of severity is based on the frequency of binge eating (see below). The level of severity may be increased to reflect other symptoms and the degree of functional disability.

Mild: 1–3 binge eating episodes per week.
Moderate: 4–7 binge eating episodes per week.
Severe: 8–13 binge eating episodes per week.
Extreme: 14 or more binge eating episodes per week.

OTHER SPECIFIED FEEDING OR EATING DISORDER

This category applies to presentations in which symptoms characteristic of a feeding and eating disorder that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate but do not meet the full criteria for any of the disorders in the feeding and eating disorders diagnostic class. The other specified feeding or eating disorder category is used in situations in which the clinician chooses to communicate the specific reason that the presentation does not meet the criteria for any specific feeding or eating disorder. This is done by recording “other specified feeding or eating disorder” followed by the specific reason (e.g., “bulimia nervosa of low frequency”).

Examples of presentations that can be specified using the “other specific” designation include the following:

1. Atypical anorexia nervosa: All of the criteria for anorexia nervosa are met, except that despite significant weight loss, the individual’s weight is within or above the normal range
2. Bulimia nervosa (of low frequency and/or limited duration): All of the criteria for bulimia nervosa are met, except that binge-eating and inappropriate compensatory behaviours occur, on average, less than once a week and/or for less than 3 months.
3. Binge eating disorder (of low frequency and/or limited duration): All of the criteria for binge eating disorder are met, except that binge eating occurs, on average, less than once a week and/or for less than 3 months.
4. Purging disorder: Recurrent purging behaviour to influence weight or shape (e.g., self-induced vomiting; misuse of laxatives, diuretics, or other medications) in the absence of binge eating.
5. Night eating syndrome: Recurrent episodes of night eating, as manifested by eating after awakening from sleep or by excessive food consumption after the evening meal. There is awareness and recall of the eating. The night eating is not better explained by external influences such as the changes in the individual’s sleep-wake cycle or by local social norms. The night eating causes significant distress and/or impairment in functioning. The disordered pattern of eating is not better explained by binge eating disorder or another mental disorder, including substance use, and is not attributable to another medical disorder or to an effect of medication.

UNSPECIFIED FEEDING OR EATING DISORDER

This category applies to presentations in which symptoms characteristic of feeding and eating disorder that cause clinically significant distress or impairment in social, occupational, or other important areas of functioning predominate but do not meet the full criteria for any of the disorders in feeding and eating disorders diagnostic class. The unspecified feeding and eating disorder category is used in situations in which the clinician chooses *not* to specify the reason that criteria are not met for a specific feeding or eating disorder, and includes presentations in which there is insufficient information to make a more specific diagnosis (e.g., in emergency room settings).

APPENDIX B

THE EMAIL SENT BY A SENIOR CLINICIAN (CF or ZC), INVITING POTENITAL PARTICIPANTS TO TAKE PART IN STUDY 1

Email subject line: **Request from Professor Christopher Fairburn/Professor Zafra Cooper**

Attachments: Information about the Study.docx (58 KB)[Open as Web Page]

Dear _____________,

I am writing to ask you a small favour. It involves filling in a very brief questionnaire (taking 15 minutes at most). I would really appreciate your help.

Many people with eating problems experience a long delay between developing the problem and receiving help. This can amount to many years. My colleague Emma Clifton and I would like to minimise this delay by making a free, evidence-based, treatment program available on the web. Our hope is that the program will successfully address many emerging eating problems without there being a need for further help. To achieve this aim, we need to know which features of a developing eating problem might lead people to seek information or help on the internet and, more specifically, what search terms people might enter into a search engine (e.g., *Google*).

If would like to take part, please click on this link which will take you to the questionnaire

https://qtrial.qualtrics.com/SE/?SID=SV_3aAEWu8kuixz7A9

Many thanks and best wishes,
Christopher Fairburn/Zafra Cooper

APPENDIX C

INFORMATION SHEET FOR PARTICIPANTS

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Information Sheet - Early Intervention in the Treatment of Eating Problems

Researchers: Professor Christopher Fairburn and Ms Emma Clifton

What is the purpose of the study?
The purpose is to learn how best to help people who are suffering from eating problems access online help.

Why have I been invited?
You have been invited to take part because you have participated in research conducted by the Centre for Research on Eating Disorders at Oxford (CREDO) in the past.

Do I have to take part?
No. It is completely up to you.

Can I withdraw from the study?
You may withdraw from the study at any time without having to give a reason by closing the questionnaire. There is no penalty associated with withdrawing.

What will the study involve?
We are inviting you to complete a short online questionnaire concerning the early stages of your eating problem and how you might have used the internet to seek help or information. The questionnaire should take no longer than 10 minutes to complete.

Are there any risks in taking part in the study?
No.

Are there any benefits from taking part in the study?
No. There will not be any direct benefits to you. However, it is hoped that the results of the study will help people suffering from the early stages of eating problems.

Who has reviewed the study?
This research has received ethical approval from the University of Oxford Central University Research Ethics Committee (ref. MSD-IDREC-C1-2013-090).

What will happen to the results of the research?
The results will be completely anonymous, so it will not be possible to trace your responses. The data will be stored securely for 6months after the study is completed. It will then be destroyed. The findings will be written up and published in a scientific journal and, in addition, will be included as part of a student thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives.

Who will know that I am taking part in this research?
If you choose to provide the researchers with your email address at the end of the study they will know that you have taken part. However, this information will go no further and your responses will still be anonymous. Your email address will be deleted after four months.

What if something goes wrong?
If you have a concern about any aspect of this project, please contact Ms Emma Clifton (emma.clifton@psych.ox.ac.uk or 01865-226479) who will do her best to answer your query. If

you remain unhappy and wish to make a formal complaint, please contact the Research Ethics Committee at the University of Oxford (ethics@medsci.ox.ac.uk; Medical Sciences Inter-Divisional Research Ethics Committee, Medical Sciences Divisional Office, Level 3 John Radcliffe Hospital, Oxford OX3 9DU, UK).

What if I have further questions?

Please contact Emma Clifton on 01865-226479 or via email (emma.clifton@psych.ox.ac.uk), who will be happy to answer any further questions you may have.

APPENDIX D

THE EMAIL SENT TO THE PARTICIPANTS IN STUDY 1 WHO PROVIDED THEIR EMAIL ADDRESS

Email subject line: Request from Professor Christopher Fairburn/Professor Zafra Cooper

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Dear _______________,

Thank you very much for completing our questionnaire and for providing your email address. If possible, I would like to discuss your responses with you over the phone.

I was wondering if you might be able to suggest a convenient time?

Thank you very much once again

Best wishes
Emma

Ms Emma Clifton (working with Professor Christopher Fairburn)
Department of Psychiatry, Oxford University, Warneford Hospital, Oxford, OX3 7JX
http://credo-oxford.com

APPENDIX E

AUDIT TRAIL SHOWING INITIAL, REVISED AND FINAL CODES FOR STUDY 1

Final Codes	**Revised Codes**	**Initial Codes**
Dangerous internet use	Dangerous	Quite dangerous Encourage/promote EDs People try to out-do each other
	Damaging	Damaging to people with eating disorders
	Obsessive	I became obsessed
	Weight loss/fitness inspiration	Weight loss tips Fitness inspiration Aid to anorexia
	Eating disorder advice	How to keep the disorder hidden Very unhealthy tips
The internet as unintentionally dangerous	Misleading	Presented themselves as sharing and support groups
	Normalising	I wasn't bad in comparison Made me feel what I was doing was normal
Thin-spiration/pro-ana	Thin-spiration/pro-ana	Pro-ana Thin-spo Pro-mia Obsessed/addictive Destroying My problems would have escalated…at a younger age Images of very thin girls

		Aspiring to a level of control
Positive internet use	Online community	Reassurance Community Easier to tell people how I felt I did not feel so alone Sharing my problem online was a relief
	Information	Information
	Support	Reassurance Help each other
Other reasons for seeking help	Weight	Tips/information on how to lose weight The aim was weight loss The solution…would be to be slim
	Mood	For how I was feeling Initially for depression
Opinions on an online program	Good idea	Excellent idea Great idea Brilliant idea
	Bad idea	I don’t think it would be very helpful Very triggering
Benefits of online help/information	Alternative to pro-ana	Alternative set of resources Stressing the issues with pro-ana Would have been useful if there were more constructive forums
	Anonymous	Remain incognito Remain anonymous The anonymity I could’ve emailed anonymously
	No time off	No time away from school/work
	Secrecy	Don’t have to tell parents
	Accessible	Accessible

		People need access to proper help
	Acceptable	I would have found it useful It’s nice that there will be a place for people to go I’m sure a similar program for EDs would be useful
	Early intervention	People would go there first I would have got help a lot, lot quicker Early stage of binge-eating
Problems with online information/help	Bad information	There’s a lot of bad information
	No accountability	No accountability
	No early intervention in AN	Don’t want to get better You don’t want help Denial You enjoy it I wasn’t…always looking for help
Causes of delays in seeking help	Did not want help	Did not want to get better You don’t help You enjoy it I wasn’t…always looking for help
	Positives of eating disorders	It’s quiet, calming You enjoy it Control
	Secrecy	I hid it so well Definite need to keep it a secret It’s hard to admit it
	Shame	There’s a lot of shame
	Not ready	Not ready to admit it all I overcame bulimia…when I was ready
	Not perceptible	I hid it so well Bulimia is less perceptible

	Don’t want to admit to it	It’s hard to admit to I wasn’t ready to admit it all It shows you can’t do it on your own
	Concerns about health care professionals	Intimidated I couldn’t approach my GP Not taken as seriously as AN
	Denial or a lack of awareness	Denial I was not really aware I did not really know Not a real eating disorder Did not consider myself to have a problem I wasn’t 100% convinced I needed help You don’t realise Seemed normal Way of life
Realisation of the ED	Reading about others	Reading about others made me see
	Hated it	It became something I hated
Triggers for help-seeking	AN evolved into binge-eating/SIV	It was only the vomiting I only sought help when I began binge-eating
	Other people	My mum took me I was pushed The concern of others Your parents will probably deal with it
Eating disorder experiences	Good	Control You enjoy it Happy It’s quiet, calming
	Bad	Isolated Hated it Obsessed

Ideas about what to include in an online self-help program	Content	Case-studies Diagnostic questionnaires Age appropriate Stress the reasons for persevering with it Educate GPs Parenting advice
	Advice/information	Help people to feel more confident about seeing a medical professional Information
Health care professionals	Intimidating	Most intimidating part of the entire process I could not approach my GP in person
	Bad experiences	I had a bad experience It was most unhelpful The focus was on what was ‘wrong with me’
	Good	I went to the GP initially for depression
	Need for education	Please, please, please educate GPs
	Negative expectations	Would not be taken seriously

APPENDIX F

MEDICAL SCIENCES INTERDIVISIONAL RESEARCH ETHICS COMMITTEE APPROVAL LETTER

MEDICAL SCIENCES INTER DIVISIONAL RESEARCH ETHICS COMMITTEE
Medical Sciences Divisional Office

University of Oxford, Level 3, John Radcliffe Hospital, Headington, Oxford, OX3 9DU
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ethics@medsci.ox.ac.uk   http://www.medsci.ox.ac.uk

CONFIDENTIAL Ref: **MSD-IDREC- C1-2013-090**

Professor Christopher Fairburn and Ms Emma Clifton
5th June 2013
University Department of Psychiatry
Warneford Hospital
Oxford
OX3 7JX

Dear Professor Fairburn and Ms Clifton

I am writing to acknowledge receipt of your CUREC/1 form for your project: **Early intervention in the Treatment of Eating Disorders**

On the basis of the information you have provided this has now been approved by the Medical Sciences IDREC **subject to:**

a) **your following the BPS guidelines for online research;**

b) **it is your responsibility to comply with the requirements for administering any tests or questionnaires and if in doubt to contact the publisher of those tests or questionnaires.**

The reference number for this project is **MSD-IDREC-C1-2013-090** and may I remind you that your project may be reviewed at some stage during an annual audit of projects.

Amendments

Should you at some stage alter some of the techniques or procedures then you should first undertake a checklist (CUREC/1) to see whether these changes alter the ethics of the research. If these remain the same then the committee will require notification of the changes to lodge with the project. If they do not remain the same then you may need to complete a CUREC/2 form and undergo further scrutiny by the committee.

Please do not hesitate to contact me if you have any queries about this.

Yours sincerely
Rosie Mortimer
Senior Assistant Registrar & Secretary to IDREC

APPENDIX G

THE NOTICE POSTED ON THE BEAT WEBSITE PROVIDING INFORMATION ABOUT STUDY 2

Accessing Early Help for Eating Problems

Professor Christopher Fairburn & Ms Emma Clifton, Centre for Research on Eating Disorders (CREDO), University of Oxford

Purpose of this Study: Eating problems are common and can significantly affect quality of life and physical health. Although effective treatments are available, there is often a long delay, sometimes amounting to many years, between developing an eating problem and receiving help. We would like to minimise this delay by ensuring people have early access to sound information and advice and, if needed, free evidence-based online treatment. To achieve this, we need to know which features of an emerging eating problem lead people to seek information or advice online and what search terms they might enter into a search engine (e.g. *Google*).

Am I eligible to take part? Anyone with a past or present eating problem, whether or not it has been formally diagnosed, may take part. We are particularly interested in hearing from people who think they might have an eating problem but have not yet sought help.

What does the study involve? The study involves completing a short, anonymous online questionnaire. The questionnaire is concerned with the early stages of your eating problem and the ways that you might use (or have used) the internet to obtain information or advice. It should take no more than 15 minutes to complete.

How do I take part? The study is an online study. To take part, please click, or copy and paste, the link below. This will take you to an information sheet that provides further details about the study, followed by the questionnaire itself.

Thank you.

https://qtrial.qualtrics.com/SE/?SID=SV_bDRBvJD27QxY6LH

If you would like to discuss the study, or if you have any questions that are not answered by clicking on the link above, please feel free to contact us by telephone (01865-226479) or email (emma.clifton@psych.ox.ac.uk).

APPENDIX H

AUDIT TRAIL SHOWING INITIAL, REVISED AND FINAL CODES FOR STUDY 2

Final Codes	**Revised Codes**	**Initial Codes**
The internet as positive	Internet as positive	Exceptionally good blogs Fantastic sources of help Research evidence, advice, well-regulated forums
	Online information/advice	I found online information essential I read it on the internet Lots of information on recovery Spent time searching for answers online People seek advice
	Online support	Support from social media Online message boards very supportive Going through the same thing People seek advice or support
	Online help with realisation	I read it on the internet Made me realise I had a problem Motivated me to get help asap
Internet as mixed	Internet as mixed	Rise of pro-anorexia and pro-recovery websites Both helpful and extremely damaging
The internet as negative	Pro-anorexia	Glamorise it Youtube is more dangerous than pro-anorexia Rise of pro-ana and pro-recovery blogs

		Large communities
	Bad sites	The app calorie counter Online material encouraging EDs Things can be easily triggering Reinforced idea that treatment is only offered to a small number Recovery websites can turn into pro-ED
Online needs	Gaps in what is provided online	More information Little support Struggled to find useful information There was no help Not easy to find
	Online needs	Online information essential Support Advice
Problems with online help	Age	Is for young teenagers
	Don’t understand	We don’t understand it well enough yet
	Problems with online help	The most important ingredient is the therapeutic alliance Need for face-to-face therapy
Benefits of online help	Easy	Easier to look for help online
	Anonymous	Best way to seek help anonymously
	More likely to use it	More likely to talk over a computer
Ideas concerning online help	Ideas	GPs should have a list of approved blogs Could use the internet to help their clients Direct people from pro-ana to help and information
Early intervention	Early access	Pro-active approach needed right away Improve early access Didn’t help soon enough

	Waiting lists	Lengthy waiting lists On this list with no support The waiting list is so long
Isolation	Isolation	Very isolating They are alone
Help-seeking experience	Few services	Services are limited Access to help has always been a problem I have been rejected/let down
	Ignored	They knew…but I received no help Turned away again Let down Told I didn’t have a problem I got turned away
Not underweight, no problem	Not underweight, no problem	People are left until they are so ill Have to be a certain weight to receive treatment Emphasis on BMI Better access regardless of BMI My BMI was too high My BMI will need to be below 13 Really, really ill and underweight My BMI wasn’t dangerously low
Atypical EDs	Atypical EDs	I found this confusing
Help-seeking delays	Didn’t want to reveal it	Not in a position to admit it Didn’t want to talk to anyone Secrecy Shame Courage Anonymously Afraid of my parents finding out Didn’t want help

	Normalised	It was almost normal
	Denial	Denial
	Problem recognition	Didn’t think I had a problem I didn’t equate my behaviour Unaware Not a medical problem
	Worried about seeing a professional	Worried about seeing a professional Not ill/good enough Question if I did have a problem Turned away again
Other reasons for seeking help	Other reasons for seeking help	Depression Anxiety and confidence
Role of other people	Parents	My parents putting me in private treatment Didn’t want my parents to know
	Professionals	Greater awareness needed
	Others	Took other people pushing me

APPENDIX I

THE EMAIL SENT TO THE PARTICIPANTS IN STUDY 2 WHO PROVIDED THEIR EMAIL ADDRESS

Email subject line: BEAT survey response

Dear Participant,

I am contacting you because you recently completed an online questionnaire advertised on the BEAT website. Thank you very much for providing your email address. If possible, I would like to discuss your responses with you over the phone.

I was wondering if you might be able to suggest a convenient time?

Thank you very much once again

Best wishes
Emma

Emma Clifton (working with Professor Fairburn)

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