Phenomenology of bowel/bladder-control anxiety

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Thesis declaration form

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

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Overview

Volume 1 of this thesis is presented in three parts. Part 1 is a systematic review of Internet-based cognitive behavioural therapy for social anxiety disorder, which includes an objective assessment of study quality. Part 2 describes two studies exploring bowel/bladder-control anxiety (BBCA). Study 1 is an Internet-based survey to obtain initial clinical and demographic details about BBCA and study 2 uses postal questionnaires to explore the relationship of BBCA with panic attacks. This is a joint thesis as it forms part of a larger project and was conducted alongside that of another Trainee Clinical Psychologist. Part 3 is a critical appraisal of the research process, which considers implications of the conceptualisation of BBCA for the research project as well as multiple testing and advertising. It further discusses issues of conducting research and delivering psychological therapy via the Internet.

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Part 1: Literature Review

A systematic review of Internet-based cognitive behavioural therapy for the treatment of social anxiety disorder

Abstract

Background: Internet-based cognitive behavioural therapy (ICBT) for social anxiety disorder (SAD) has been proposed to be effective both in terms of outcomes and cost. The need to develop this form of treatment has arisen from the fact that among those with anxiety disorders, SAD patients continue to have the lowest rates of treatment-seeking despite the availability of effective face-to-face therapies such as CBT.

Aims: To summarise and evaluate evidence for the effectiveness of both guided and unguided ICBT for SAD.

Method: Extensive literature searches of literature published before 2013 identified randomised controlled trials (RCTs) of ICBT interventions for SAD. Treatment studies are examined by comparison group (waitlist or active) as well as by the level of guidance provided (guided or unguided).

Results: Nineteen studies were identified which reported a total of twenty RCTs, with five reporting more than one comparison group. Sixteen trials reported outcomes of guided ICBT and seven that of unguided ICBT. Twelve trials included a waitlist control group. The majority of ICBT for SAD showed statistically significant improvements relative to waitlist and equivalent outcomes relative to active control interventions. The overall effect size across studies was large. Guided and unguided ICBT had similar outcomes. The quality of the studies was generally good but detection bias was a consistent problem.

Conclusions: ICBT for SAD appears to be superior to waitlist and equivalent to active control interventions. Guided and unguided ICBT have similar outcomes but the evidence base for unguided ICBT remains limited. In future research,

independent assessment of outcomes should be conducted as well as longer-term follow-ups and trials in clinical settings to establish effectiveness.

Introduction

Social anxiety disorder (SAD), also known as social phobia (SP), was officially recognised in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) in 1980 (APA, 1980). Since then it has become clear that SAD is associated with high levels of social and occupational impairment (Bruch, Fallon & Heimberg, 2003) and finding effective treatments has become imperative. SAD is the most common anxiety disorder in the general population (e.g. Wittchen & Fehm, 2001), with lifetime prevalence rates in western countries of up to 13% (Kessler *et al*., 2005) and a twelve month rate of up to 7.4% (Kessler, Petukhova, Sampson, Zaslavsky & Wittchen, 2012).

Beidel and Wong (2010) described SAD as being characterised by high levels of social reticence, isolation, avoidance, and difficulty in social interaction. The diagnostic criteria for SAD specify a generalized subtype of patients who experience distress in a range of social settings (Turner, Beidel, Dancu & Keys, 1986) and they account for the majority of those seeking treatment (Turner, Beidel & Townsley, 1992). Patients whose SAD is defined by a more restricted pattern of social fear, often limited to one (or a few) situation(s) such as speaking, eating or drinking in public are often referred to as non-generalized subtype (Beidel, Rao, Scharfstein, Wong & Alfano, 2010).

There is evidence that SAD is a pervasive, chronic and debilitating condition (Beidel, Rao *et al.*, 2010; Stein & Kean, 2000) which is associated with considerable functional impairment (Antony, Roth, Swinson, Huta & Devins, 1998; Schneier *et al*., 1994) and reduced quality of life (Lochner *et al*., 2003; Safren, Heimberg, Brown & Holle, 1996/1997; Wong, Sarver & Beidel, 2012). It impacts on occupational, social and academic functioning and is linked to lower occupational achievement,

restricted social relationships and substance misuse (Bruch *et al*., 2003; Davidson, Hughes, George & Blazer, 1993; Katzelnick & Greist, 2001; Keller, 2003; Kessler, 2003). SAD can be highly disabling and should be recognised as a major public health problem (Kessler, 2003) which is associated with considerable economic costs (Patel, Knapp, Henderson & Baldwin, 2002; Smit *et al*., 2006) and high levels of service use (Magee, Eaton, Wittchen, McGonagle & Kessler, 1996; Stein & Kean, 2000).

Despite this SAD continues to have one of the lowest rates of treatment (Lampe, 2009; Veale, 2003). Several psychological treatments have been developed for the treatment of SAD (Roth & Fonagy, 2005) including behavioural therapy (Newman, Hofmann, Trabert, Roth & Taylor, 1994), exposure therapy (Acaturk, Cuijpers, van Straten & de Graaf,2009; Feske & Chambless, 1995; Hofmann *et al*., 2004), cognitive behaviour therapy (CBT; Clark *et al*., 2006; Herbert, Rheingol, Gaudiano & Myers, 2004), social skills training (Stravynski, Marks & Yule, 1982; Stravynski *et al*., 2000), applied relaxation (Öst, 1987), interpersonal psychotherapy (Lipsitz, Markowitz, Cherry & Fyer, 1999), attention bias modification (Amir *et al*., 2009; Schmidt, Richey, Buckner & Timpano, 2009), mindfulness (Bögels, Sijbers & Voncken, 2006; Goldin & Gross, 2010) as well as acceptance based approaches (Dalrymple & Herbert, 2007; Forman, Herbert, Moirta, Yeomans & Geller, 2007). Overall, the largest evidence base exists for the effectiveness of CBT in the treatment of SAD (Clark *et al*., 2006; Gould, Buckminster, Pollack, Otto & Yap, 1997; Ougrin, 2011) and Ponniah and Hollon (2008) argued that CBT is the psychological intervention of choice for SAD.

CBT for treatment of SAD

The two main cognitive models of SAD (Clark & Wells, 1995; Rapee & Heimberg, 1997) are relatively similar in their emphasis on the role of the socially anxious individual's internal representations during social situations and their perception of these as dangerous. Both suggest that the perception of potential evaluation by others triggers a cognitive routine which maintains the experience of anxiety (Pontoski, Heimberg, Turk & Coles, 2008). CBT for SAD generally includes psychoeducation, exposure strategies, cognitive restructuring, relaxation training, and social skills training (Heimberg, 2002).

CBT has been shown to be an effective treatment for SAD by a number of meta-analyses (Acarturk *et al*., 2009; Jørstad-Stein & Heimberg, 2009; Olatunji, Cisler& Deacon, 2010; Powers, Sigmarsson & Emmelkamp, 2008). Both CBT delivered individually or in groups has proven effective within research and 'real world', clinical settings (Clark *et al*., 2006; McEvoy, 2007). Estimates of the proportion of patients recovering during face-to-face CBT treatments are around 65-75% (Rodebaugh, Holaway, & Heimberg, 2004; Heimberg & Juster, 1995) and that treatment gains made during CBT endure after treatment is discontinued (Heimberg & Juster, 1995).

Alternative approaches: Computerised CBT or Internet-based CBT

Despite the availability of effective treatments such as CBT, many individuals with SAD do not seek treatment, and of those who do, many do not receive an evidence-based treatment (Issakidis & Andrews, 2002; Veale, 2003). Those who do not seek treatment often list fear of negative evaluation by the therapist as a significant barrier to treatment seeking (Olfson *et al*., 2000). Therefore, patients' accessibility to CBT is a continuing concern and alternative ways of

providing CBT have been explored. It has been shown that there is a population of individuals with SAD who use the Internet as a resource whose social anxiety symptoms are more severe than those of treatment seeking individuals (Erwin, Turk, Heimberg, Fresco & Hantula, 2004). Therefore computer-based treatments that can be disseminated via the web have become a priority for research.

Direct therapeutic contact in individual or group CBT has obvious advantages of on-going and direct monitoring of treatment adherence and symptoms, as well as ongoing *in vivo* opportunities for cognitive restructuring. However, it is also linked with significant healthcare costs and requires the availability of sufficient numbers of suitably qualified therapists (Ljotsson *et al*., 2011). Thus effective computerised CBT (CCBT) or Internet-based CBT (ICBT) might be seen as reaching a larger number of potential patients whilst also providing a cost-effective alternative to face-to-face CBT. Originally CCBTs were self-help CBT programmes which were largely text-based, similar to bibliotherapy but presented via the computer or on a website. CCBT has often been delivered in settings such as GP surgeries, psychiatric clinics, walk-in clinics and libraries or purchased by individuals for use on home computers. So *et al.* (2013) have argued that expectations of CCBT have increased due to technological progress in terms of interactivity, multimedia functions and flexibility and now more and more programmes are delivered via the Internet. For the purpose of this review CBT treatments delivered via the computer and not involving the Internet will be referred to as CCBT and those delivered via the Internet will be referred to as ICBT. Both CCBT and ICBT can be self-guided, supported by automated or therapist reminders or guided by a clinician via the telephone or emails.

A major advantage of ICBT is in accessibility and convenience for both patients and therapists. Treatment via the Internet circumvents long waiting list and

facilitates access to treatment for example by being accessible outside of normal business hours. This also reduces barriers relating to both therapist resources and geography i.e. where populations are spread out access to therapists can be more difficult (e.g. Australia). ICBT treatment protocols are increasingly making use of interactive features such as individual pacing and individualised behavioural experiments instead of requiring participants to mainly read text or follow audio/video instructions. Moreover, ICBT frequently uses moderated online discussion forums for clients which may have additional benefits in terms of adherence and symptom reduction (Houston, Cooper & Ford, 2002). In ICBT outcome measures can be completed via the internet and thus monitoring of clients is enhanced. Treatments are combined with homework tasks and have varying amounts of therapist input which ranges from minimal contact to ICBT being used as an adjunct to standard face-to-face CBT. Treatment protocols are usually developed for specific patient groups but there are also transdiagnostic protocols.

There is conflicting evidence from meta-analyses and systematic reviews of the literature on CCBT and ICBT for anxiety disorders in general. Several reviews have shown that CCBT was as effective as face-to-face CBT in phobia and panic disorders, and there is some evidence that CCBT was more effective than treatment as usual in depression and anxiety (Kaltenthaler *et al*., 2006). However, Battacharya, Kelley and Bhattacharjee (2012) reported that evidence regarding the long term benefits of CCBT for reducing depression and anxiety in adults is weak. It has also been argued that the computer cannot completely replace human contact but only minimise it in order to generate good outcomes (Palmqvist, Carlbring & Andersson, 2007; Spek *et al*., 2007). Despite the conflicting evidence, stepped care models such as Improving Access to Psychological Therapies, now routinely offer CCBT to

appropriately screened patients with a variety of different conditions. The National Institute for Clinical Excellence (2006) has recommended the use of Beating the Blues for people with mild and moderate depression, and FearFighter for people with panic and phobia.

Given these developments in computerised treatments and specifically the advances in delivering CBT via the Internet it is unsurprising that several ICBT programmes have been developed to treat SAD as it is more likely to overcome specific barriers to treatment that patients with SAD present with. This is particularly important given the finding that there is a large non-treatment seeking population of individuals with severe social anxiety symptoms who use the Internet as a resource (Erwin *et al*., 2004). A description of these recent developments in ICBT for SAD will form the remainder of this paper. In particular, we will systematically review randomly controlled trials (RCTs) of ICBT treatments for SAD. Only ICBT treatments for SAD which can be defined as minimal-contact psychological treatments will be included.

Our definition of "minimal contact" is based on Glasgow and Rosen (1978) and Newman, Szkodny, Llera and Przeworski (2011) and we included studies involving: *pure* or *predominant self help* (with therapist contact for assessment at most) or *guided self help*, in which limited and/or brief therapist contact occurred for the purposes of clarification of self-management strategies or homework assignments. The former will be referred to as unguided ICBT and the latter as guided ICBT for the purposes of this review.

This is the first review of its kind to specifically focus on ICBT interventions for SAD. Previous reviews, which included between five and sixteen randomly controlled trials of ICBT for SAD, have highlighted positive effects but none have

systematically investigated and focussed on this intervention. Andrews, Cuijpers, Craske, McEvoy & Titov (2010) conducted a review of 'computer therapy' for anxiety and depression which also included ICBT interventions for SAD and they reported superiority of outcomes of ICBT over controls for SAD with a large effect size of g=0.92 (95%CI, 0.74-1.09). A review of technology-assisted self-help and minimal contact therapy (Newman *et al.*, 2011) found that guided ICBT led to significant improvements compared to waitlist controls and proposed the critical factor in improvement to be contact with others. Hedman, Ljotsson & Lindefors (2012) conducted a review of the applications of ICBT and reported large within group effect sizes in all of the sixteen trials of ICBT for SAD. They noted that according to American Psychologist Association criteria for evaluating evidence (Chambless *et al*., 1998) it can be classified as a 'well-established treatment'.

Despite existing evidence of the merits of both technology-based treatments for anxiety disorders, to the best of the author's knowledge, no systematic review has been published so far that reports a detailed analysis of the research on ICBT for SAD. Therefore, this paper provides a literature review which is aimed at presenting an evaluation of research into ICBT for SAD, specifically highlighting trials which have used unguided or guided ICBT. Moreover, it aims to highlight implications for practice as well as to identify possible gaps in the research literature and to suggest scope and directions for further research.

Method

Search Methods for Identification of Studies

The following electronic databases were searched systematically: Medline, Embase and PsychInfo (all years). The search was restricted to studies published in

English and no filters or limits were used. The bibliographies of relevant publications were studied to locate further literature.

Title/abstract search: "social anxiety disorder" OR "social anxiety" OR "social phobia" OR "SAD" OR "performance anxiety" OR "shyness"

AND

Title/abstract search: "CBT" OR "cognitive behavio(u)ral therapy" OR "cognitive behavio(u)r therapy" OR "cognitive therapy" OR "psychologic$ therapy" OR "psychotherapy$" OR "counsel(l)ing" OR "psychology$ intervention" OR "mental health intervention" OR "cognitive intervention"

AND

Title/abstract search: "computer" OR "computer aided" OR "computerised CBT" OR "CCBT" OR "internet" OR "internet delivered" OR "ICBT" OR "website" OR "online" OR "internet therapy" OR "technology assisted" OR "self administered" OR "self help" OR "guided self help" OR "self management" OR "psychoeducation" OR "stepped care" OR "low intensity" OR "minimal contact therapy"

These database searches yielded a total of 1443 hits, which included the following number of results from each database: Medline (289), Embase (744) and PsycInfo (410). An initial assessment against inclusion criteria was made by scanning all titles and abstracts. The abstract screening subsequently led to retrieval of 113 full-text articles for assessment. 61 of these papers were duplicates, leaving 52 papers for assessment. The references of the selected studies were then examined to identify any overlooked studies. No additional studies were identified from this procedure that had not been identified by the database review. All potentially relevant papers were assessed against inclusion and exclusion criteria.

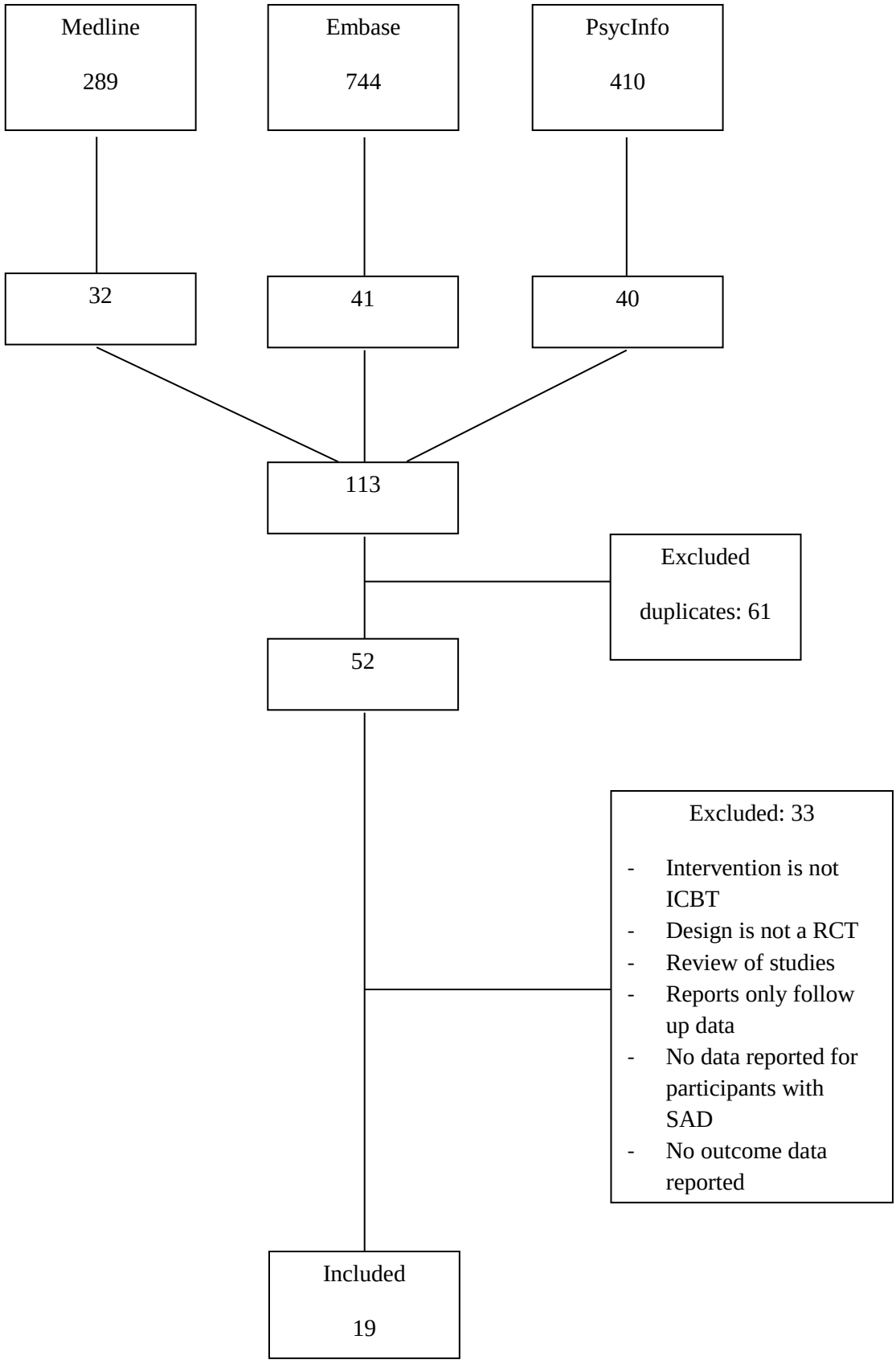
Criteria for Inclusion of Studies for this Review

The review includes efficacy studies i.e. randomised controlled trials. Studies were included if they (1) primarily aimed to test treatment effects of an intervention based on CBT principles; (2) presented quantitative data; (3) involved treatment using the Internet with minimal contact with a clinician as outlined above (Glasgow & Rosen, 1978); (4) involved adults (≥18 years old); and (5) were published in English.

Case studies or papers presenting only anecdotal evidence were excluded. Those studies whose treatment was not based on CBT were also excluded, as were those involving samples of children and adolescents (<18 years old).

Screening of the 1443 studies identified through database searches identified 52 papers potentially meeting inclusion criteria after duplicates were excluded. After reviewing and applying the exclusion criteria to the full manuscripts of these 52 studies, 33 were removed. Seven studies were excluded as they were not reports of ICBT interventions, six were not randomised controlled trials, five only provided follow up data, two transdiagnostic trials did not report separate data for SAD, three papers were reviews and nine papers did not report outcome data. This left 19 studies for inclusion in this review (see Figure 1 below).

Figure 1 - Flowchart of Literature Search Process.



Quality Assessment

The methodological quality of the included studies was assessed by CL using Cochrane Handbook criteria (Higgins & Green, 2011). These criteria were chosen as Higgins & Green reported a review of more than twenty-five scales to assess methodological quality and they found evidence of their reliability and validity lacking. Moreover, Cochrane Handbook criteria have been used in reviews of CCBT for other anxiety disorders (Cuijpers *et al*., 2009), CCBT for anxiety and depression (Andrews *et al*., 2010) and psychological treatments of SAD (Acaturk *et al*., 2009). The Cochrane Handbook criteria reflect six primary dimensions of study design that are deemed important when assessing quality: sequence generation and allocation concealment (selection bias); blinding of participants (performance bias); blinding of outcome assessment (detection bias); completeness of outcome data (attrition bias) and selective reporting (reporting bias). We only adopted five of the six Cochrane Handbook criteria to assess study validity, since it is not feasible to blind patients to an active intervention, thus this criterion was not relevant to the present review. The Cochrane Handbook criteria assessment tool states criteria for assessing risk of bias. Each study is assessed using the four criteria and each criterion is rated as either 'Low risk', 'High risk' or 'Unclear risk' of bias. These criteria were developed to evaluate face-to-face interventions but the quality indicators were generally applicable to therapy delivered using computers or the Internet. As per a review by Andrews *et al*. (2010) each study was then given a score out of five to indicate the adequacy of bias minimisation with 0= complete minimization and 5 = no minimization.

Data extraction and synthesis

After selecting the studies that were included in the present systematic review details of each paper were recorded in Table 1. The following variables were coded: authors and publication year, country, participant mean age, percentage of participants who were female, sample source, diagnosis (inclusion criteria and diagnostic tools used) and exclusion criteria, comparison conditions, sample size, type of ICBT (guided or unguided), compliance, follow up and main findings relative to control. This systematic review adopted a narrative analysis involving comparison of tabulated data and appraisal of methodological quality according to specified criteria. Moreover, the narrative analysis included a synthesis of findings by common themes thus presenting a broad picture of the available evidence.

Results

Descriptions of Studies

A summary of the key characteristics of the nineteen included studies is presented in Table 1.

Table 1

Characteristics of the 19 Included Studies

Author (year)	Country	Mean Age (S.D.)	Female (%)	Recruitment	Diagnosis Inclusion Criteria Exclusion Criteria	Comparison Conditions (n)	Type of ICBT	Compliance (%)	Follow Up (Months)	Main Findings (relative to control)
Andersson *et al.* (2006)	Sweden	37.3 (10.2)	60.3	Community adverts & Research webpage	DSM-IV+SCID (SAD-primary dx)+SPSQ+MADRS-S<31 on depression and<4 on suicide items Depression, Suicidality, Current psychological treatment, Psychosis, Substance Misuse, Not stable on medication	1. ICBT: 9 modules, therapist emails, online discussion forum + 2 live exposure sessions (n=32) 2. Waitlist (n=32)	Guided (email)	62% did all modules	12	Compared to Waitlist **SAD measures:** LSAS-SR ↓,SPS ↓, SIAS ↓, SPSQ ↓, PRCS ↓ **Secondary:** Anxiety (BAI) ↓, Depression (MADRS-S) ↔, quality of life (QOLI) ↓
Andersson *et al.* (2012)	Sweden	38.3	51.6	Research webpage advert	DSM-IV+SCID (SP-primary)+SPSQ+MADRS-S< 31 on depression and<4 on suicide items Depression, Suicidality, Current psychological treatment, Psychosis, Substance Misuse, Not stable on medication	1. ICBT: 9 modules, therapist emails, online discussion forum (n=102) 2. Waitlist (n=102)	Guided (email)	55% did all modules	12	Compared to Waitlist **SAD measures:** LSAS-SR ↓,SPS ↓, SIAS ↓, SPSQ ↓ **Secondary:** Anxiety (BAI) ↓, Depression (MADRS-S) ↓, quality of life (QOLI) ↓
Andrews *et al.* (2011)	Australia	31.9 (7.8)	40.5	Mental Health Clinic	DSM-IV+MINI+ SIAS+SPS+PHQ-9 Depression, Suicidality, Current psychological treatment, Psychosis, Substance Misuse, Not stable on medication	1. ICBT: 6 modules, therapist emails & phone calls, online discussion forum (n=17) 2. Group CBT:7 face-to-face group sessions (n=14)	Guided (phone & email)	82% completed all modules 100% attended all group CBT sessions	none	Compared to Active Control **SAD measures:** SPS ↔, SIAS ↔

Author (year)	Country	Mean Age (S.D.)	Female (%)	Recruitment	Diagnosis Inclusion Criteria Exclusion Criteria	Comparison Conditions (n)	Type of ICBT	Compliance (%)	Follow Up (Months)	Main Findings (relative to control)
Berger *et al.* (2009)	Switzerland	28.9 (5.3)	46.9	Community adverts & Research webpage	DSM-IV+SCID (SP-primary)+ >22 on SPS+ >33 on SIAS+ <1 on suicide item of BDI Depression, Suicidality, Current psychological treatment, Not stable on medication	1. ICBT: 5 modules, therapist emails, online discussion forum (n=31) 2. Waitlist (n=21)	Guided (email)	57% completed all modules	none	Compared to Waitlist **SAD measures:** LSAS-SR ↓,SPS ↓, SIAS ↓, **Secondary:** Depression (BDI) ↔
Berger *et al.* (2011)	Switzerland	37.2 (11.2)	55.8	Community adverts & Research webpage	DSM-IV+SCID (SP-primary)+ >22 on SPS+ >33 on SIAS+ <2 on suicide item of BDI Depression, Suicidality, Current psychological treatment, Borderline Personality Disorder, Psychosis, Older than 45 years old	1. ICBT: 5 modules, online discussion forum (n=27) 2. ICBT: 5 modules, therapist emails, online discussion forum (n=27) 3. ICBT: 5 modules, step up method: either unguided or therapist emails & phone calls, online discussion forum (n=27)	Unguided Guided (email) Guided (email & phone)	72% completed all modules	6	Compared to Active Controls **SAD measures:** LSAS-SR ↔,SPS ↔, SIAS ↔, SPSQ ↔ **Secondary:** Depression (BDI) ↔
Botella *et al.* (2010)	Spain	24.4 (5.8)	79.2	Community adverts (University only)	DSM-IV-TR+ADIS-IV(SP-primary +fear of public speaking) Depression, Current psychological treatment, Psychosis, Substance Misuse, Intellectual Disability	1. ICBT: 5 modules (n=62) 2. Face-to-face CBT: 5 sessions (n=36) 3. Waitlist (n=29)	Unguided	49% completed treatment	12	Compared to Waitlist **SAD measures:** Target Behaviours (fear) ↓, Target Behaviours (avoidance) ↓, Target Behaviours (beliefs) ↓, BFNE ↔, SAD ↓, FPSQ ↓, SSPS-N ↔, IST ↔, **Secondary:** Maladjustment Scale ↓, CGI ↓ Compared to Active Control **SAD measures:** Target Behaviours (fear) ↔, Target Behaviours (avoidance) ↔, Target Behaviours (beliefs) ↔, BFNE ↔, SAD ↔, FPSQ, SSPS ↔, IST ↔, **Secondary:** Maladjustment Scale↔, CGI ↔

Author (year)	Country	Mean Age (S.D.)	Female (%)	Recruitment	Diagnosis Inclusion Criteria Exclusion Criteria	Comparison Conditions (n)	Type of ICBT	Compliance (%)	Follow Up (Months)	Main Findings (relative to control)
Carlbring *et al.* (2007)	Sweden	32.7	65.0	Research webpage advert	DSM-IV+SCID (SP-primary)+SPSQ+MADRS-S< 31 on depression and<4 on suicide items Depression, Suicidality, Current psychological treatment, No previous CBT, Psychosis, Substance Misuse, Not stable on medication	1. ICBT: 9 modules, therapist phone calls, online discussion forum (n= 29) 2. Waitlist (n=28)	Guided (phone)	97% completed treatment	12	<u>Compared to Waitlist</u> **SAD measures:** LSAS-SR ↓,SPS ↓, SIAS ↓, SPSQ ↓ **Secondary:** Anxiety (BAI) ↓, Depression (MADRS-S) ↓, quality of life (QOLI) ↔
Furmark *et al*. (2009)	Sweden	36.4	67.5	Community adverts & Research webpage	DSM-IV+SCID (SP-primary)+SPSQ+MADRS-S< 31 on depression and<4 on suicide items Depression, Suicidality, Current psychological treatment, Psychosis, Substance Misuse, Not stable on medication	<u>Trial 1</u> 1. ICBT: 9 modules, therapist emails, online discussion forum (n= 40) 2. Pure self-help bibliotherapy: 9 modules, treatment diary (n=40) 3. Waitlist (n=40)	Guided (email)	98% completed treatment	12	Trial 1: <u>Compared to Waitlist</u> **SAD measures:** LSAS-SR ↓,SPS ↓, SIAS ↓, SPSQ ↓ **Secondary:** Anxiety (BAI) ↓, Depression (MADRS-S) ↓, quality of life (QOLI) ↓ Trial 1: <u>Compared to Active Control</u> **SAD measures:** LSAS-SR ↔,SPS ↔, SIAS ↔, SPSQ ↔ **Secondary:** Anxiety (BAI) ↔, Depression (MADRS-S) ↔, quality of life (QOLI) ↔

Author (year)	Country	Mean Age (S.D.)	Female (%)	Recruitment	Diagnosis Inclusion Criteria Exclusion Criteria	Comparison Conditions (n)	Type of ICBT	Compliance (%)	Follow Up (Months)	Main Findings (relative to control)
Furmark *et al.* (2009) *Continued*	Sweden	36.4	67.8	Community adverts & Research webpage	DSM-IV+SCID (SP-primary)+SPSQ+MADRS-S< 31 on depression and<4 on suicide items Depression, Suicidality, Current psychological treatment, Psychosis, Substance Misuse, Not stable on medication	<u>Trial 2</u> 1. ICBT: 9 modules, therapist emails, online discussion forum (n= 29) 2. Pure self-help bibliotherapy: 9 modules, treatment diary (n=29) 3. Pure self-help bibliotherapy plus online discussion forum, 9 modules, treatment diary (n=28) 4. Internet applied relaxation , 9 modules, therapist emails, online discussion forum (n=29)	Guided (email)	100% completed treatment	12	Trial 2: <u>Compared to Active Control Groups</u> **SAD measures:** LSAS-SR ↔,SPS ↔, SIAS ↔, SPSQ ↔ **Secondary:** Anxiety (BAI) ↔, Depression (MADRS-S) ↔, quality of life (QOLI) ↔
Gallego *et al.* (2011)	Netherlands	39.3 (14.4)	68.3	Community adverts (University only), mental health clinic & undergraduate psychology students	DSM-IV-TR+ADIS-IV-L(SP+fear of public speaking) Current psychological treatment, Psychosis, Substance Misuse	1. ICBT: 5 modules (n=24) 2. Waitlist (n=17)	Unguided (with email reminder)	54% completed all modules	none	<u>Compared to Waitlist</u> **SAD measures:** Target Behaviours (fear) ↓, Target Behaviours (avoidance) ↓, Target Behaviours (beliefs) ↔, BFNE ↔, SAD ↔, PRCS-M ↑, PSSEQ ↔, SSPS ↔, IST ↔, **Secondary:** Maladjustment Scale↔, CGI ↔

Author (year)	Country	Mean Age (S.D.)	Female (%)	Recruitment	Diagnosis Inclusion Criteria Exclusion Criteria	Comparison Conditions (n)	Type of ICBT	Compliance (%)	Follow Up (Months)	Main Findings (relative to control)
Hedman *et al.* (2011)	Sweden	35.4	35.7	Mental Health Clinic	DSM-IV+SCID+MINI (SP-primary)+ SPSQ+MADRS-S< 20 on depression and <4 on suicide items Depression, Suicidality, Current psychological treatment, No CBT in past 4 years, Psychosis, Substance Misuse, Personality Disorder, Not stable on medication	1. ICBT: 15 modules, therapist emails, online discussion forum (n= 64) 2. Group CBT: 1 individual face-to-face session, 14 face-to-face sessions (n=62)	Guided (email)	ICBT 30% completed all module	6	<u>Compared to Active Control</u> **SAD measures:** LSAS ↔, LSAS-SR ↔,SPS ↔, SIAS ↔, **Secondary:** Anxiety (BAI) ↔, Depression (MADRS-S) ↔, quality of life (QOLI) ↔
Johnston *et al.* (2011)	Australia	41.6 (12.8)*	58.8*	Research website advert	DSM-IV+MINI+ SIAS-6/SPS-6+PHQ-9<22 on depression and <2 on suicide item Depression, Suicidality, Current CBT treatment, Psychosis, Substance Misuse, Not stable on medication, Taking Benzodiazepines	1. Transdiagnostic ICBT: 8 modules, therapist emails, vignettes (n= 14) 2. Transdiagnostic ICBT: 8 modules, coach emails, vignettes (n=16) 3. Waitlist (n=15)	Guided (email)	NR	3	<u>Compared to Waitlist</u> **SAD measures:** SIAS-6/SPS-6 ↓ incl. other dx, MINI ↓ **Secondary:** PHQ-9 ↓ incl. other diagnoses <u>Compared to Active Control</u> **SAD measures:** SIAS-6/SPS-6 ↔ incl. other dx, **Secondary:** PHQ-9 ↔ incl. other diagnoses

Author (year)	Country	Mean Age (S.D.)	Female (%)	Recruitment	Diagnosis Inclusion Criteria Exclusion Criteria	Comparison Conditions (n)	Type of ICBT	Compliance (%)	Follow Up (Months)	Main Findings (relative to control)
Tillfors *et al.* (2008)	Sweden	31.4	76.9	Community adverts (university only) & Research webpage	DSM-IV+SCID (SP-primary)+SPSQ+MADRS-S< 22 on depression and<4 on suicide items Depression, Suicidality, Current psychological treatment, Previous CBT treatment, Not stable on medication	1. ICBT: 9 modules, therapist emails, online discussion forum and 5 live group exposure sessions (n=18) 2. ICBT: 9 modules, therapist emails, online discussion forum and 5 live group exposure sessions (n=19)	Guided (email)	44% ICBT+exp & 53% ICBT Completed all	12	<u>Compared to Active Control</u> **SAD measures:** LSAS-SR ↔,SPS ↔, SIAS ↔, SPSQ ↔ **Secondary:** Anxiety (BAI) ↔, Depression (MADRS-S) ↔, quality of life (QOLI) ↔
Titov, Andrews, Schwencke *et al.* (2008)	Australia	38.1 (12.2)	58.6	Community adverts & Research webpage	DSM-IV-TR+CIDI+SIAS+SPS+PHQ-9 <19 on depression and 0 on suicide item Depression, Suicidality, Current CBT treatment, Psychosis, Substance Misuse, Not stable on medication	1. ICBT: 6 modules, therapist emails, online discussion forum (n=50) 2. Waitlist plus discussion forum (n=49)	Guided (email)	78% completed all modules	none	<u>Compared to Waitlist</u> **SAD measures:** SPS ↓, SIAS ↓ **Secondary:** Depression (PHQ-9) ↔
Titov, Andrews & Schwencke (2008)	Australia	36.8 (10.9)	63.0	Community adverts & Research webpage	DSM-IV-TR+CIDI+SIAS+SPS+PHQ-9 <20 on depression and 0 on suicide item Depression, Suicidality, Current CBT treatment, Psychosis, Substance Misuse, Not stable on medication	1. ICBT: 6 modules, therapist emails, online discussion forum (n=41) 2. Waitlist (n=40)	Guided (email)	80% completed all modules	none	<u>Compared to Waitlist</u> **SAD measures:** SPS ↓, SIAS ↓ **Secondary:** Depression (PHQ-9) ↔

Author (year)	Country	Mean Age (S.D.)	Female (%)	Recruitment	Diagnosis Inclusion Criteria Exclusion Criteria	Comparison Conditions (n)	Type of ICBT	Compliance (%)	Follow Up (Months)	Main Findings (relative to control)
Titov, Andrews, Choi *et al*. (2008)	Australia	38.0 (11.3)	61.1	Community adverts & Research webpage	DSM-IV+MINI+ SIAS+SPS+PHQ-9 <20 on depression and 0 on suicide item Depression, Suicidality, Current CBT treatment, Psychosis, Substance Misuse, Not stable on medication	1. ICBT: 6 modules, therapist emails, online discussion forum (n=31) 2. ICBT: 6 modules, online discussion forum (n=30) 3. Waitlist (n=35)	Guided (email) Unguided	77% Guided ICBT & 33% unguided ICBT completed all modules	none	<u>Compared to Waitlist</u> **SAD measures:** SPS ↓, SIAS ↓ **Secondary:** Depression (PHQ-9) ↔ <u>Compared to Active Control</u> **SAD measures:** SPS ↓, SIAS ↓ **Secondary:** Depression (PHQ-9) ↔
Titov, Andrews, Choi *et al*. (2009)	Australia	41.2 (NR)	52.0	Community adverts & Research webpage	DSM-IV+MINI+ SIAS+SPS+PHQ-9 <22 on depression and 0 on suicide item Depression, Suicidality, Current CBT, Psychosis, Substance Misuse, Not stable on medication	1. ICBT: 6 modules, online discussion forum, phone reminders (n=31) 2. ICBT: 6 modules, online discussion forum (n=30)	Unguided (phone reminder) Unguided (no reminder)	81% Unguided ICBT with reminders & 68% unguided ICBT completed all modules	none	<u>Compared to Active Control</u> **SAD measures:** SPS ↓, SIAS ↓ **Secondary:** Depression (PHQ-9) ↔
Titov, Andrews, Schwencke *et al.* (2009)	Australia	38.9 (12.1)	56.0	Community adverts & Research webpage	DSM-IV+MINI+ SIAS+SPS+PHQ-9 <22 on depression and 0 on suicide item Depression, Suicidality, Current CBT, Psychosis, Substance Misuse, Not stable on medication	1. ICBT: 6 modules, online discussion forum, phone reminders (n=31) 2. ICBT: 6 modules, clinician assisted online discussion forum (n=30)	Unguided (phone reminders) Guided (forum)	79% in both groups completed all modules	none	<u>Compared to Active Control</u> **SAD measures:** SPS ↔, SIAS ↔ **Secondary:** Depression (PHQ-9) ↔

Author (year)	Country	Mean Age (S.D.)	Female (%)	Recruitment	Diagnosis Inclusion Criteria Exclusion Criteria	Comparison Conditions (n)	Type of ICBT	Compliance (%)	Follow Up (Months)	Main Findings (relative to control)
Titov, Andrews, Schwencke *et al.* (2010)	Australia	43.6 (14.6)	47.0	Community adverts & Research webpage	DSM-IV+MINI+ SIAS+SPS+PHQ-9 <22 on depression and 0 on suicide item Depression, Suicidality, Current CBT, Psychosis, Substance Misuse, Not stable on medication	1. ICBT: 6 modules (n=55) 2. ICBT + motivational enhancement strategies (MS): 6 modules (n=53)	Unguided	56% ICBT & 75% ICBT+MS completed all modules	3	Compared to Active Control **SAD measures:** SPS ↔, SIAS ↔ **Secondary:** Depression (PHQ-9) ↔
Titov, Andrews, Johnston *et al.* (2010)	Australia	40.0 (13.0)*	68.0*	Community adverts & Research webpage	DSM-IV+MINI+ SIAS+SPS+PHQ-9 <23 on depression and <2 on suicide item Depression, Suicidality, Current CBT treatment, Psychosis, Substance Misuse, Not stable on medication	1. Transdiagnostic ICBT: 6 modules, therapist emails, online discussion forum (n=12) 2. Waitlist (n=11)	Guided (email)	NR	3	Compared to Waitlist **SAD measures:** SPSQ ↔ **Secondary:** PHQ-9 ↓ incl. other diagnoses

Note: * includes other diagnoses (GAD & panic disorder); ↓ = significantly more improvement at end of treatment i.e. lower scores; ↔ = no significant difference between groups at end of treatment, ↑ = significantly less improvement (at end or follow up) i.e. higher scores; SCID - Structured Clinical Interview for DSM-IV Axis I Disorders; MINI - *Mini*-International Neuropsychiatric Interview; CIDI - *Composite International Diagnostic* Interview; ADIS-IV -Anxiety Disorders Interview Schedule for DSM-IV;LSAS-SR –Liebowitz Social Anxiety Scale self-reported; SPS - Social Phobia Scale; SIAS - Social Interaction Anxiety Scale; SPSQ - Social Phobia Screening Questionnaire ; SIAS-6/SPS-6 - Social Interaction Anxiety Scale and Social Phobia Scale –Short form; PRCS – Report of Confidence as a Speaker; BAI – Beck Anxiety Inventory; MADRS-S – Montgomery Asberg Depression Rating Scale; PHQ-9 – Patient Health Questionnaire; QOLI – Quality of Life Inventory; BDI – Beck Depression Inventory; BFNE – Brief version of the Fear of Negative Evaluation Scale; SAD – Social Avoidance and Distress Scale; FPSQ – Fear of Public Speaking Questionnaire; IST – Impromptu Speech Task; PSSEQ – Public Speaking Self-Efficacy Questionnaire; SSPS – Self Statements during Public Speaking Scale.

Study Designs

All of the studies were randomised controlled trials (RCTs). Of these, fifteen indicated that they were registered with an appropriate oversight body such as the Australian New Zealand Clinical Trial Registry (ANZCTR) or University Hospital Medical Information Centre Clinical Trials Registry (UMIN-CTR). Most of the RCTs reviewed here effectively employed procedures for ensuring that treatment allocation codes were concealed from those involved in recruitment. However, all studies relied on participant self-report and therefore assessments were not blind.

The nineteen papers reported a total of twenty trials. The majority of trials had two conditions whilst five trials had three conditions (Berger *et al*., 2011; Botella *et al*., 2010; Furmark *et al*., 2009; Johnston *et al*., 2011; Titov, Andrews, Choi *et al*., 2008) and one had four conditions (Furmark *et al*., 2009). Sixteen trials reported guided ICBT treatments whilst seven reported unguided ICBT. 'Compliance' was reported in thirteen out of the nineteen studies as the percentage of participants who completed all ICBT modules. This ranged from 33% (Titov, Andrews, Choi et al., 2008) to 81% (Titov, Andrews, Choi *et al.*, 2009).

Sample Characteristics

Sample sizes ranged from 23 to 204. Participants' mean age across the 19 studies was 36.2 years old (range across studies: 24.4 (S.D. 5.78) - 43.6 (S.D. 14.6) and percentages of female participants ranged from 36% to 79%. Recruitment of participants was based on a variety of methods. Apart from one study which used recruiting via community adverts alongside referrals from a University Mental Health Service and undergraduate psychology students (Gallego *et al*., 2011) and two

studies which relied purely on referrals from mental health clinics (Andrews *et al.*, 2011; Hedman *et al*., 2011), the remaining studies recruited treatment-seeking individuals, who self-referred in response to media adverts and research websites.

As can be seen from Table 2, all of the studies used structured diagnostic interview schedules to determine SAD diagnosis of participants according to DSM-IV criteria and only participants who had a primary diagnosis of SAD were included. Five studies assessed participants in face-to-face interviews (Andersson *et al*., 2006; Andrews *et al.*, 2011; Botella *et al*., 2010; Gallego *et al*., 2011; Hedman *et al*., 2011) and one study allowed participants to choose between telephone and face-to-face interviews (Berger *et al*., 2009) whilst the remaining studies conducted diagnostic interviews only over the telephone. The majority of the studies specifically stated that participants were included if their diagnosis of SAD was primary as assessed by the clinician administered diagnostic interview. Four studies included only participants with SAD who also had public speaking anxiety (Andersson *et al*., 2006; Botella *et al*., 2010; Gallego *et al*., 2011; Tillfors *et al*., 2008) as their interventions focussed on this specific aspect of SAD. Only five studies reported the proportions of participants who were diagnosed with the generalised or nongeneralised subtype of SAD (Andersson *et al*., 2012; Andersson *et al*., 2006; Botella *et al*., 2010; Furmark *et al*., 2009). The percentages of participants diagnosed with the generalised subtype ranged from 22.1% to 86.5%. Lower percentages were reported by two of the studies which investigated treatments for people who have SAD with public speaking anxiety (Andersson *et al*., 2006; Botella *et al*., 2010).

In general, studies closely followed CONSORT (Altman *et al.*, 2001) guidelines for reporting of randomized controlled trials. With the exception of Andrews *et al.* (2011), who only reported their exclusion criteria in their trial

protocol (ANZCTR, 2009), all trial publications clearly reported their exclusion criteria. All of the studies clearly reported the number of participants excluded on the basis of the stated exclusion criteria. On the whole, sample demographics were well described across the included studies as was information regarding the comparability of their treatment and control samples. Only one study (Andrews *et al.*, 2011) did not provide adequate information on comparability of groups.

Interventions

The studies generally tested efficacy of established and previously described ICBT treatment programmes. Apart from those studies using the 'Shyness Programme' and the 'Anxiety Programme' (see below), there were additional components on learning to shift the attentional focus in social situations. All of the treatment programmes included homework tasks.

All of the treatment programmes included psychoeducation about SAD and a module on the cognitive model of SAD explaining links between thoughts, feelings, behaviours and cognitions. In addition modules on cognitive restructuring, exposure and behavioural experiments, as well as relapse prevention were included in all trials.

The majority were specifically tailored to treat SAD, whilst two trials used a programme designed to treat specific SAD (fear of public speaking; Botella *et al*., 2010; Gallego *et al*., 2011). Two trials used a transdiagnostic treatment programme because the trial included participants with three primary diagnoses (Generalised Anxiety Disorder, SAD or panic disorder (Johnston *et al*., 2011; Titov, Andrews, Johnston *et al.*, 2010) and targeted common processes. Five different standardized and well described ICBT programmes were used across the studies. Seven studies used the 'Shyness Programme' for SAD originally developed by Drobny and Einstein for the CLIMATEGP programme (Andrews, 2007) and then adapted by

Titov, Andrews and Schwencke (Andrews *et al.*, 2011; Titov, Andrews, Schwencke *et al*., 2008; Titov, Andrews & Schwencke, 2008; Titov, Andrews, Choi *et al*., 2008; Titov, Andrews, Choi *et al*., 2009; Titov, Andrews, Schwencke *et al*., 2009; Titov, Andrews, Schwencke *et al*., 2010). Six studies (Andersson *et al*., 2012; Andersson *et al*., 2006; Carlbring *et al*., 2007; Furmark *et al*., 2009; Hedman *et al*., 2011; Tillfors *et al*., 2008) were based on a self-help manual for SAD designed by Furmark *et al.* (2006). The two transdiagnostic trials (Johnston *et al*., 2011; Titov, Andrews, Johnston *et al.*, 2010) used the 'Anxiety Programme' which included disorder-specific modules for SAD from the 'Shyness Programme.' Two trials (Botella *et al*., 2010; Gallego *et al*., 2011) used the 'Talk to Me' programme and two studies (Berger *et al*., 2011; Berger *et al*., 2009) used novel treatments based on an established CBT model for SAD (Clark & Wells, 1995) which was adapted by Stangier, Heidenreich and Peitz (2003).

Fifteen trials included secure and confidential moderated online discussion forums to enable sharing of experiences and provision of support amongst participants (Andersson *et al*., 2012; Andersson *et al*., 2006; Andrews *et al.*, 2011; Berger *et al*., 2011; Berger *et al*., 2009; Carlbring *et al*., 2007; Furmark *et al*., 2009; Hedman *et al*., 2011; Tillfors *et al*., 2008; Titov, Andrews, Schwencke *et al*., 2008; Titov, Andrews & Schwencke, 2008; Titov, Andrews, Choi *et al*., 2008; Titov, Andrews, Choi *et al*., 2009; Titov, Andrews, Schwencke *et al*., 2009). The total time spent per patient (excluding diagnostic interviews) in guided ICBT treatments which did not include live exposure sessions ranged from 18 minutes (Andrews *et al.*, 2011) to 168 minutes (Titov, Andrews, Choi *et al*., 2008).

Table 2
Effect sizes for primary outcome measures

Primary Outcome Measure(s) / Author (year)	Groups / *Comparison Groups*	Before Treatment			After Treatment		Effect Sizes	
		n	M	SD	M	SD	Within Groups	Between Groups (Post)
LSAS/LSAS-SR								
Andersson *et al*. (2006)	Guided ICBT	32	68.5	22.5	45.6	25.1	0.96	
	WLC	32	66.7	20.9	62.8	21.7	0.18	
	Guided v WLC							-0.73
Andersson *et al*. (2012)	Guided ICBT	102	68.23	23.33	43.74	24.33	1.03	
	WLC	102	66.65	21.72	63.85	23.69	0.12	
	Guided v WLC							-0.84
Berger *et al*. (2009)	Guided ICBT	31	68.7	16.9	52.7	21.9	0.82	
	WLC	21	75.0	17.4	70.7	17.2	0.25	
	Guided v WLC							-0.91
Berger *et al*. (2011)	Unguided ICBT	27	83.2	19.2	52.8	21.7	1.48	
	Guided ICBT	27	80.2	20.6	44.15	26.2	1.53	
	Step-up ICBT	27	84.6	25.0	47.4	27.7	1.41	
	Unguided v Guided							0.36
	Unguided v Step up							0.22
	Guided v Step up							-0.12

Primary Outcome Measure(s) / Author (year)	Groups / *Comparison Groups*	Before Treatment			After Treatment		Effect Sizes	
		n	M	SD	M	SD	Within Groups	Between Groups (Post)
Furmark *et al*. (2009)	Trial 1							
	Guided ICBT	40	71.30	22.49	50.98	21.12	0.93	
	Bibliotherapy	40	68.68	23.87	48.50	27.46	0.78	
	WLC	40	71.28	24.93	70.25	27.25	0.04	
	Guided v BiB							0.10
	Guided v WLC							-0.79
	Bib v WLC							-0.80
Furmark *et al*. (2009)	Trial 2							
	Guided ICBT	29	74.14	22.81	44.41	21.35	1.35	
	Bibliotherapy	29	62.90	26.81	42.55	30.26	0.71	
	Bibliotherapy + Discussion	28	75.75	22.08	43.89	22.83	1.42	
	Internet Relaxation	29	78.93	25.36	53.03	26.97	1.00	
	Guided v BiB							0.07
	Guided v BiB/D							0.02
	Guided v IAR							-0.35
	BiB v BiB/D							-0.05
	BiB v IAR							-0.37
	BiB/D v IAR							-0.37
Hedman *et al*. (2011)	Guided ICBT	64	68.4	21.0	39.4	25.0	1.26	
	Group CBT	62	71.9	22.9	48.5	15.1	1.21	
	Guided v Group CBT							-0.44
Tillfors *et al*. (2008)	Guided ICBT + exp	18	57.4	25.7	38.1	21.6	0.81	
	Guided ICBT	19	59.8	19.0	41.4	17.3	1.01	
	Guided + exp v Guided							-0.17

Primary Outcome Measure(s) / Author (year)	Groups / *Comparison Groups*	Before Treatment			After Treatment		Effect Sizes	
		n	M	SD	M	SD	Within Groups	Between Groups (Post)
SPS								
Andersson *et al*. (2006)	Guided ICBT	32	35.8	16.7	20.7	14.8	0.96	
	WLC	32	32.5	13.1	31.0	15.9	0.10	
	Guided v WLC							-0.67
Andersson *et al*. (2012)	Guided ICBT	102	38.81	15.59	23.31	14.33	1.04	
	WLC	102	37.25	14.98	32.90	14.76	0.29	
	Guided v WLC							-0.66
Andrews *et al.* (2011)	Guided ICBT	17	43.81	20.7	31.05	23.3	0.58	
	Face-to-face CBT	14	40.93	15.4	26.86	18.9	0.82	0.20
	Guided v Face-to-Face CBT							
Berger *et al.* (2009)	Guided ICBT	31	35.6	14.2	23.5	13.2	0.88	
	WLC	21	35.1	10.8	30.3	10.8	0.44	
	Guided v WLC							-0.56
Berger *et al.* (2011)	Unguided ICBT	27	35.2	13.4	19.0	9.9	1.38	
	Guided ICBT	27	34.5	13.0	18.2	9.6	1.43	
	Step-up ICBT	27	36.2	14.6	18.3	10.6	1.40	
	Unguided v Guided							0.08
	Unguided v Step up							0.07
	Guided v Step up							-0.01
Carlbring *et al*. (2007)	Guided ICBT	29	36.2	15.2	20	15.0	1.07	
	WLC	28	37.8	16.5	37.7	16.4	0.01	
	Guided v WLC							-1.13

Primary Outcome Measure(s) / Author (year)	Groups / *Comparison Groups*	Before Treatment		After Treatment		Effect Sizes	
		n	M	SD	M	SD	Within Groups	Between Groups (Post)
Furmark *et al*. (2009)	Trial 1							
	Guided ICBT	40	39.15	15.35	25.60	12.22	0.98	
	Bibliotherapy	40	36.58	15.43	25.90	16.32	0.67	
	WLC	40	36.35	17.10	35.60	16.16	0.05	
	Guided v BiB							-0.02
	Guided v WLC							-0.70
	Bib v WLC							-0.60
Furmark *et al*. (2009)	Trial 2							
	Guided ICBT	29	35.34	17.04	22.00	16.07	0.81	
	Bibliotherapy	29	36.28	15.21	21.65	10.87	1.11	
	Bibliotherapy + Discussion	28	40.68	16.53	24.39	13.58	1.08	
	Internet Relaxation	29	43.72	18.61	28.17	16.51	0.88	
	Guided v BiB							0.03
	Guided v BiB/D							-0.16
	Guided v IAR							-0.38
	BiB v BiB/D							-0.22
	BiB v IAR							-0.47
	BiB/D v IAR							-0.25
Hedman *et al.* (2011)	Guided ICBT	64	32.8	14.6	21.6	13.5	0.80	
	Group CBT	62	33.5	14.0	22.1	14.3	0.81	
	Guided vs Group CBT							-0.04
Tillfors *et al.* (2008)	Guided ICBT + Exposure	18	31.9	15.9	17.2	10.6	1.09	
	Guided ICBT	19	31.7	12.0	17.3	12.6	1.17	
	Guided + Exp v Guided							-0.01

Primary Outcome Measure(s) / Author (year)	Groups / *Comparison Groups*	Before Treatment			After Treatment		Effect Sizes	
		n	M	SD	M	SD	Within Groups	Between Groups (Post)
Titov, Andrews, Schwencke *et al.* (2008)	Guided ICBT	50	34.02	14.42	20.64	10.46	1.06	
	WLC	49	36.08	16.63	33.92	14.70	0.14	
	Guided v WLC							-1.04
Titov, Andrews & Schwencke (2008)	Guided ICBT	41	34.15	15.55	18.12	12.46	1.38	
	WLC	40	36.68	14.62	32.78	14.23	0.27	
	Guided v WLC							-1.10
Titov, Andrews, Choi *et al.* (2008)	Guided ICBT	31	34.71	15.04	18.65	12.20	1.17	
	Unguided ICBT	30	32.87	17.02	28.27	16.27	-0.06	
	WLC	34	34.38	18.77	35.44	18.42	0.28	
	Guided v Unguided							-0.67
	Guided v WLC							-1.07
	Unguided v WLC							-0.41
Titov, Andrews, Choi *et al.* (2009)	Guided ICBT	81	53.88	11.58	37.51	11.68	1.41	
	Unguided ICBT	82	54.61	11.10	42.52	13.39	0.98	
	Guided v Unguided							-0.40
Titov, Andrews, Schwencke *et al.* (2009)	Guided (Tel) ICBT	43	54.26	12.21	35.26	13.57	1.47	
	Guided (Forum) ICBT	39	54.59	10.17	37.56	11.56	1.56	
	Guided (Tel) v Guided (For)							-0.18
Titov, Andrews, Schwencke *et al.* (2010)	Unguided ICBT	55	52.76	12.06	38.05	13.19	1.16	
	Unguided ICBT + MI	53	53.13	9.53	40.02	13.08	1.56	
	Unguided v Unguided + MI							-0.15

Primary Outcome Measure(s) / Author (year)	Groups / *Comparison Groups*	Before Treatment		After Treatment		Effect Sizes	
		n	M	SD	M	SD	Within Groups	Between Groups (Post)
SPSQ								
Andersson *et al*. (2006)	Guided ICBT	32	30.4	8.7	20.0	8.5	1.21	
	WLC	32	30.2	7.6	28.9	7.9	0.17	
	Guided v WLC							-1.08
Furmark *et al*. (2009)	Trial 1							
	Guided ICBT	40	32.18	7.16	22.10	8.47	1.29	
	Bibliotherapy	40	30.63	7.99	21.93	11.32	0.89	
	WLC	40	30.28	10.33	29.73	11.83	0.05	
	Guided v BiB							0.02
	Guided v WLC							-0.74
	Bib v WLC							-0.67
	Trial 2							
	Guided ICBT	29	31.41	7.79	18.52	8.51	1.58	
	Bibliotherapy	29	30.93	9.32	17.55	12.68	1.20	
	Bibliotherapy + Discussion	28	33.43	8.96	18.68	9.19	1.63	
	Internet Relaxation	29	33.83	9.76	23.24	11.45	1.00	
	Guided v BiB							0.09
	Guided v BiB/D							-0.02
	Guided v IAR							-0.47
	BiB v BiB/D							-0.10
	BiB v IAR							-0.47
	BiB/D v IAR							-0.44
Tillfors *et al.* (2008)	Guided ICBT + Exposure	18	26.1	8.5	15.1	8.2	1.32	
	Guided ICBT	19	24.9	7.1	16.9	7.9	1.07	
	Guided + Exp v Guided							-0.22
Titov, Andrews, Johnston *et al*. (2010)	Guided ICBT	12	20.00	9.49	13.25	10.69	0.67	
	WLC	11	18.45	9.34	18.36	11.91	0.01	
	Guided v WLC							-0.45

Primary Outcome Measure(s) / Author (year)	Groups / *Comparison Groups*	Before Treatment		After Treatment		Effect Sizes	
		n	M	SD	M	SD	Within Groups	Between Groups (Post)
SIAS-6/SPS-6								
Johnston *et al.* (2011)	Guided ICBT	30	25.10	10.29	15.97	8.52	0.98	
	WLC*	42	22.17	13.59	22.05	13.83	0.01	
	Guided v WLC							-0.53
PRCS								
Andersson *et al.* (2006)	Guided ICBT	32	25.5	4.2	22.7	5.4	0.58	
	WLC	32	25.9	3.5	25.5	4.8	0.10	
	Guided v WLC							-0.55
PRCS-M								
Gallego *et al.* (2011)**	Unguided ICBT	13	133.92	20.37	106.38	20.99	1.33	
	WLC	11	132.09	23.57	127.36	18.81	0.22	
	Unguided v WLC							-1.05
FPSQ								
Botella *et al.* (2010)**	Unguided ICBT	62	53.27	14.34	39.70	15.45	0.91	
	Face to Face CBT	36	50.45	11.86	39.32	12.97	0.90	
	WLC	29	56.64	14.48	56.80	13.72	-0.01	
	Unguided v Face to Face CBT							0.03
	Unguided v WLC							-1.17
	Face to Face v WLC							-1.31

*Note: WLC – Waitlist Control; Unguided – Unguided ICBT; Guided – Guided ICBT; Step up – Step up ICBT; Exp – Exposure; MI- Motivational Enhancement Strategies; BiB – Bibliotherapy; BiB/D – Bibliotherapy plus discussion forum; For – Forum; Tel – Telephone; * - Waitlist control includes participants with other diagnoses; ** - Sample measure selected from Botella et al. (2010) and Gallego et al. (2011) to show effect sizes for one measure of SAD/fear of public speaking as papers report more than six measures related to SAD*

Outcomes and Effect Sizes

All but one of the studies (Gallego *et al*., 2011) used an intention to treat (ITT) or endpoint analysis and all of the studies reported significant within group (pre/post) improvements on SAD measures for both guided and unguided ICBT (Table 2). Mean within groups effect sizes ranged from 0.67 to 1.58 for guided ICBT and 0.38 to 1.64 for unguided ICBT compared to 0.01 to 0.86 for waitlist controls. Between groups effect sizes ranged from 0.34 to -1.17 for unguided ICBT and 0.45 to -1.31 for guided ICBT compared to waitlist controls. Between group comparisons of ICBT with active control conditions yielded effect sizes of 0.01 to -0.35. Both unguided and guided interventions showed large average within-groups effect sizes of 1.01 and 1.09 respectively. Average between-groups effects sizes when treatments were compared to waitlist controls showed a medium effect for unguided (0.64) and a large effect for guided interventions (0.81). Secondary outcomes of clinically significant changes in SAD were reported by nine studies and these ranged from 35.3% (Andersson *et al*., 2012) to 77% (Furmark *et al*., 2009) in the active intervention groups. None of the studies reported adverse effects of the active treatment.

Waitlist comparisons Waitlist comparisons were made in twelve of the trials (Andersson *et al*., 2012; Andersson *et al*., 2006; Berger *et al*., 2009; Botella *et al*., 2010; Carlbring *et al*., 2007; Furmark *et al*., 2009; Gallego *et al*., 2011; Johnston *et al*., 2011; Titov, Andrews, Schwencke *et al*., 2008; Titov, Andrews & Schwencke, 2008; Titov, Andrews, Choi *et al*., 2008;Titov, Andrews, Johnston *et al.*, 2010). The active interventions (guided and unguided ICBT) showed benefit on SAD measures in all but one of the trials. In one of the transdiagnostic ICBT trials (Titov, Andrews,

Johnston *et al*., 2010) which included participants with GAD and panic disorder alongside those with SAD, no differences were found on the SPSQ in participants with a primary diagnosis of SAD compared to controls. ITT was used by all but one of the studies (Gallego *et al*., 2011). Improvements were maintained at follow-up in the two studies which reported findings at follow up for both active intervention and waitlist control (Botella *et al*., 2010; Carlbring *et al*., 2007). Other studies did not include follow up data for the control group because they had received treatment for SAD in the meantime.

Active interventions led to significantly greater reductions in anxiety than waitlist control in five studies (Andersson *et al*., 2012; Andersson *et al*., 2006; Berger *et al*., 2009; Carbring *et al*., 2007; Furmark *et al*., 2009) and these findings were maintained at twelve month follow-up in the two studies which reported follow-up (Carlbring *et al*., 2007; Furmark et al., 2009).

Five studies (Andersson *et al*., 2006; Berger *et al*., 2009; Titov, Andrews, Schwencke *et al*., 2008; Titov, Andrews & Schwencke, 2008; Titov, Andrews, Choi *et al*., 2008) reported no difference in reductions in depression between active intervention and control group(s) whilst three studies (Andersson *et al*., 2012; Carlbring *et al*., 2007; Furmark *et al*., 2009) reported significantly greater improvements in depression resulting from active interventions compared to waitlist control and these improvements were maintained in two studies at twelve month follow-up (Carlbring *et al*., 2007; Furmark *et al*., 2009).

Active control comparisons Comparisons to active control were made in twelve of the trials (Andrews *et al*., 2011; Berger *et al*., 2011; Botella *et al*., 2010; Furmark *et al*., 2009; Hedman *et al*., 2011; Johnston *et al*., 2011; Tillfors *et al*., 2008;

Titov, Andrews, Choi *et al*., 2008; Titov, Andrews, Choi *et al*., 2009; Titov, Andrews, Schwencke *et al*., 2009; Titov, Andrews, Schwencke *et al*., 2010) and four utilised more than one active control condition (Berger *et al*., 2011; Furmark *et al*., 2009; Johnston *et al*., 2011; Titov, Andrews, Choi *et al*., 2008). The majority of the trials reported that there was no statistically significant difference on measures of SAD in the active intervention (guided and unguided ICBT) compared to the active control condition. However, one study showed that guided CBT was more effective than unguided CBT (Titov, Andrews, Choi *et al*., 2008) and another trial reported that unguided ICBT was more effective if reminders were used (Titov, Andrews, Choi *et al*., 2009). Findings were maintained at follow-up in four studies which reported findings for both active intervention and waitlist control (Berger *et al*., 2011; Hedman *et al*., 2011; Tillfors *et al*., 2008; Titov, Andrews, Schwencke *et al*., 2010) and Furmark *et al*. (2009) reported that ICBT groups were significantly more improved on SAD measures at follow-up than the other active control groups.

There were no statistically significant differences between active intervention conditions and active control conditions on anxiety and depression scores as reported by four (Berger *et al*., 2011; Furmark *et al*., 2009; Hedman *et al*., 2011; Tillfors *et al*., 2008) and seven studies (Berger *et al*., 2011; Furmark *et al*., 2009; Hedman *et al*., 2011; Tillfors *et al*., 2008; Titov, Andrews, Choi *et al*., 2008; Titov, Andrews, Choi *et al*., 2009; Titov, Andrews, Schwencke *et al*., 2009; Titov, Andrews, Schwencke *et al*., 2010) respectively. These findings were maintained in four studies at follow-up (Berger *et al*., 2011; Furmark *et al*., 2009; Hedman *et al*., 2011; Titov, Andrews, Schwencke *et al*., 2010), whilst Tillfors *et al.* (2008) reported that improvements in anxiety were not maintained in the ICBT group at follow-up.

Guided ICBT Sixteen trials reported outcomes of guided ICBT (Andersson *et al*., 2012; Andersson *et al*., 2006; Andrews *et al.*, 2011; Berger *et al*., 2011; Berger *et al*., 2009; Carlbring *et al*., 2007; Furmark *et al*., 2009; Hedman *et al*., 2011; Johnston *et al*., 2011; Tillfors *et al*., 2008; Titov, Andrews, Schwencke *et al*., 2008; Titov, Andrews & Schwencke, 2008; Titov, Andrews, Choi *et al*., 2008; Titov, Andrews, Schwencke *et al*., 2009; Titov, Andrews, Johnston *et al.*, 2010) and four utilised more than one control condition (Berger *et al*., 2011; Furmark *et al*., 2009; Johnston *et al*., 2011; Titov, Andrews, Choi *et al*., 2008). Ten compared guided ICBT to a waitlist control group (Andersson *et al*., 2012; Andersson *et al*., 2006; Berger *et al*., 2009; Carlbring *et al*., 2007; Furmark *et al*., 2009; Johnston *et al*., 2011; Titov, Andrews, Schwencke *et al*., 2008; Titov, Andrews & Schwencke, 2008; Titov, Andrews, Choi *et al*., 2008; Titov, Andrews, Johnston *et al.*, 2010) and eight to an active control condition (Andrews *et al.*, 2011; Berger *et al*., 2011; Furmark *et al*., 2009; Hedman *et al*., 2011; Johnston *et al*., 2011; Tillfors *et al*., 2008; Titov, Andrews, Choi *et al*., 2008). All but one of the trials comparing guided ICBT to waitlist reported significant benefit on SAD measures (Titov, Andrews, Johnston *et al*., 2010). Most of the trials comparing guided, clinician-assisted ICBT to an active control condition reported benefits of guided ICBT that were equal to those of the control condition (face-to-face individual therapy, face-to-face group CBT, self-help bibliotherapy, Internet relaxation programme, ICBT plus live exposure sessions and coach-assisted ICBT). Titov, Andrews, Choi et al. (2008) showed that guided, clinician-assisted CBT was more effective than unguided CBT on SAD measures.

Unguided ICBT Seven trials reported outcomes of unguided ICBT (Berger *et al*., 2011; Botella *et al*., 2010; Gallego *et al*., 2011; Titov, Andrews, Choi *et al*., 2008; Titov, Andrews, Choi *et al*., 2009; Titov, Andrews, Schwencke *et al*., 2009;

Titov, Andrews, Schwencke *et al*., 2010) and two utilised more than one control condition (Berger *et al*., 2011; Botella *et al*., 2010). Three compared unguided ICBT to a waitlist control group (Botella *et al*., 2010; Gallego *et al*., 2011; Titov, Andrews, Choi *et al*., 2008) and six to an active control condition (Berger *et al*., 2011; Botella *et al*., 2010; Titov, Andrews, Choi *et al*., 2008; Titov, Andrews, Choi *et al*., 2009; Titov, Andrews, Schwencke *et al*., 2009; Titov, Andrews, Schwencke *et al*., 2010). All of the trials comparing unguided ICBT to waitlist reported significant benefit on SAD measures. Most of the trials comparing unguided ICBT to an active control condition reported benefits of unguided ICBT that were equal to those of the control condition (face-to-face individual CBT, guided ICBT, unguided plus discussion forum and unguided plus motivational statements). In one trial unguided ICBT was not as effective as guided ICBT (Titov, Andrews, Choi et al., 2008) and another trial reported that unguided ICBT was more effective if reminders were used (Titov, Andrews, Choi et al., 2009).

Follow-up data Eleven out of the nineteen studies included some form of extended follow up data, ranging from three to twelve months (Andersson *et al*., 2012; Andersson *et al*., 2006; Berger *et al*., 2011; Botella *et al*., 2010; Carlbring *et al*., 2007; Furmark *et al*., 2009; Hedman *et al*., 2011; Johnston *et al*., 2011; Tillfors *et al*., 2008; Titov, Andrews, Schwencke *et al*., 2010; Titov, Andrews, Johnston *et al.*, 2010). It was only possible to compare seven of the studies because Andersson *et al*. (2012) only followed up their intervention group, Andersson *et al*. (2006) used a cross-over design and included control group data with that of the intervention group at follow-up and the two transdiagnostic trials did not report data separately for participants with SAD (Johnston *et al*., 2011; Titov, Andrews, Johnston *et al.*, 2010). The majority of studies reporting follow-up data had a duration of twelve months,

whilst two studies reported follow up data at six months (Berger *et al*., 2011; Hedman *et al*., 2011) and three at three months (Johnston *et al*., 2011; Titov, Andrews, Schwencke *et al*., 2010; Titov, Andrews, Johnston *et al.*, 2010).

Quality Assessment

Table 3 presents quality scores from the five criteria selected from the Cochrane Handbook ratings. The first five columns contain the ratings for each study – either high or low risk. The final column indicates the overall adequacy of bias minimisation for each study with a higher score pertaining to higher risk of bias.

Table 3
Consensus Cochrane Handbook Ratings

Author (Date)	Random Sequence generation (Selection Bias)	Allocation Concealment (Selection Bias)	Blinding of Outcome Assessment (Detection Bias)	Incomplete Outcome Data (Attrition Bias)	Selective Reporting (Reporting Bias)	Bias Risk Score (0-5)*
Andersson *et al.* (2006)	+	+	-	+	+	1
Andersson *et al.* (2012)	+	+	+	+	+	0
Andrews *et al.* (2011)	+	+	-	+	+	1
Berger *et al.* (2009)	+	+	-	+	+	1
Berger *et al.* (2011)	+	+	-	+	+	1
Botella *et al.* (2010)	+	+	-	-	+	2
Carlbring *et al.* (2007)	+	+	-	+	+	1
Furmark *et al.* (2009)	+	+	-	+	+	1
Gallego *et al.* (2011)	+	+	-	-	+	2
Hedman *et al.* (2011)	+	+	+	+	+	0
Johnston *et al.* (2011)	+	+	+	+	+	0
Tillfors *et al.* (2008)	+	+	-	+	+	1
Titov, Andrews, Schwencke *et al.* (2008)	+	+	-	+	+	1
Titov, Andrews & Schwencke (2008)	+	+	-	+	+	1
Titov, Andrews, Choi *et al.* (2008)	+	+	-	+	+	1
Titov, Andrews, Choi *et al.* (2009)	+	+	-	+	+	1
Titov, Andrews, Schwencke *et al.* (2009)	+	+	-	+	+	1
Titov, Andrews, Schwencke *et al.* (2010)	+	+	-	+	+	1
Titov, Andrews, Johnston *et al.* (2010)	+	+	-	+	+	1

Note: + Low risk of bias; - High Risk of bias; * Bias risk (0 = no risk, 5 = high risk)

Discussion

This review outlines evidence to suggest that ICBT is an efficacious treatment which is convenient for clients, reduces therapist time and is therefore more cost-effective whilst also offering treatment to a potentially hard to reach client group (Erwin *et al*., 2004). This review also adds to the wider evidence base which already includes a large number of RCTs which have provided empirical support for the efficacy of ICBT for depression and anxiety disorders (e.g. Kaltenthaler *et al*., 2006).

Overall, the efficacy of ICBT for SAD when compared to waitlist controls as well as active controls has been demonstrated by the majority of the studies included in this review. However, although all trials included patients with SAD as well as interventions designed to ameliorate SAD symptoms, their modality (guided versus unguided) and 'disorder specificity' (SAD specific versus transdiagnostic) varied.

Guided versus unguided ICBT for SAD

The level of therapist involvement varied widely from none at all in the unguided trials to regular face-to-face sessions in the guided trials. The optimal level of therapist involvement was unclear. Benefits were reported for both guided ICBT and unguided ICBT interventions. However, the number of trials investigating unguided ICBT was small. When comparing the within groups effect sizes of guided versus unguided therapies, it is clear that there is no difference and both have large effect sizes. Compared to waitlist controls, the average effect size was large for guided ICBT and medium for unguided ICBT, although the latter is based on a very small number of trials. Additional *in vivo* exposure sessions which were tested by two studies did not augment the outcome of guided ICBT (Andersson *et al.*, 2006; Tillfors *et al*., 2008).

The impact of therapist involvement should be investigated not simply by looking at outcome but also the level of attrition, therapy acceptability and compliance. Compliance rates in the studies included varied greatly even in the guided ICBT conditions and some studies of unguided ICBT had equivalent levels of compliance. In ICBT for other disorders, the variance explained by therapist factors was small to non-existent (Almlöv, Carlbring, Berger, Cuijpers & Andersson, 2006; Almlöv *et al*., 2011) which may explain this equivalence. However, two studies have reported that guided interventions are generally associated with higher adherence than unguided ICBT (Nordgreen *et al*., 2012; Titov, Andrews, Choi *et al*., 2008). The level of experience required for therapists providing guidance for ICBT has been debated and several of the studies reviewed found that guidance did not appear to require much experience (Andersson *et al*., 2012) and that it could also be provided by more junior mental health professionals or research assistants (Johnston *et al*., 2011; Titov, Andrews, Schwencke *et al*., 2009).

The need for 'professional' support in ICBT has been argued to be essential in order to achieve good outcomes by Palmqvis *et al.* (2007) and Spek *et al*. (2007), and a previous review which included ICBT for SAD argued that the critical factor in improvement may be contact with others (Newman *et al*., 2010). However, the unguided ICBT trials included in this review show that outcomes are better than waitlist control and equivalent to a number of active control conditions including face-to-face individual CBT and guided ICBT. There was also no difference in the baseline severity of participants in trials of unguided compared to guided interventions. Thus unguided ICBT remains a promising, more cost-effective alternative to guided ICBT although the small number of studies of unguided

interventions means that further high quality outcome research is needed to before this can be recommended as a stand-alone treatment.

It is possible that the extensive screening and diagnostic procedures for recruitment could have led to the selection of participants who are very motivated for treatment (Poston & Hanson, 2010) and compliance with unguided ICBT may therefore be higher than in populations which have not undergone this level of screening. Nordgreen *et al.* (2012) have argued that unguided ICBT should be offered as a potentially effective treatment option to patients with SAD, who, for various reasons, prefer this type of intervention. A question remains if there are patients who are more suitable for unguided ICBT as a first line treatment other than those who have such a preference and also if this could be used as part of a step-up model if an unguided treatment is not effective.

Disorder-specific versus transdiagnostic ICBT for SAD

All of the studies of 'disorder-specific' ICBT for SAD showed either superior outcome compared with waitlist controls or comparable outcome compared to active controls. This is in line with previous reviews of trials of ICBT for SAD (Andrews *et al*., 2010; Hedman, Ljotsson & Lindefors *et al*., 2012; Newman *et al*., 2011).

Transdiagnostic treatments are those designed to target the common elements of several disorders in one protocol and this review included two studies which used a transdiagnostic ICBT protocol to treat participants with SAD as well as participants with GAD or panic disorder. No improvement in social anxiety symptoms was found in one of these trials which compared guided ICBT using the 'Anxiety programme' to waitlist (Titov, Andrews, Johnston *et al.*, 2010). However, Johnston *et al*. (2011) found such improvements in another transdiagnostic trial using the same treatment protocol. As this evidence is very limited and both trials included only a very small

number of patients with a primary diagnosis of SAD, the merits of using transdiagnostic treatment ICBT protocols for SAD patients remain in doubt. Currently, outcomes cannot be adequately compared to ICBT specifically developed to treat SAD. However, the evidence shows that disorder-specific guided ICBT is efficacious, not only compared to waitlist but also compared to group CBT (Andrews *et al.* 2011; Hedman *et al*., 2011), individual CBT (Botella *et al.*, 2010) and pure self-help bibliotherapy (Furmark *et al.*, 2009).

Mode of presentation in ICBT for SAD

The research groups used different ways of presenting the CBT materials, for example the Swedish studies (e.g. Andersson *et al*., 2012) used a primarily text-based programme whilst the Swiss programme (e.g. Berger *et al*., 2011) included many interactive and multimedia features. Text-based programmes are self-help materials in a written format and are comparable to bibliotherapy albeit presented using the Internet rather than in the form of a self-help book or publication. The Swiss programme on the other hand is responsive to what participants have entered in each module and it uses graphical animations which incorporate individual responses. Despite these differences in the actual ICBT programmes, the results were similar and the effectiveness therefore comparable. This means that the strong empirical support for CBT for SAD for both individuals and groups (Olatunji *et al.*, 2010) seems to be extending to Internet-based treatments.

Long-term benefits of ICBT for SAD

The few studies reporting longer-term follow up data indicate that benefits of treatment are maintained for up to 5 years (Hedman *et al*., 2011). However conclusions about long-term benefits need to be treated with caution given the limited number of studies reporting long-term follow up data. Moreover, Battacharya

et al. (2012) argued that in studies of CCBT the evidence for long-term effects on anxiety disorders and depression is weak, thus highlighting the need for long-term follow ups.

ICBT – a more accessible therapy?

It is notable that a large number of studies originate in Australia where a number of 'Internet clinics' (i.e. services which provide ICBT) have begun to operate (Titov, Andrews, Kemp & Robinson, 2010). ICBT interventions may be especially valued in healthcare systems serving remote communities where it may be difficult for patients to access services. ICBT is also likely to significantly reduce cost, particularly but not exclusively in such situations, as it has been shown to be cost-effective compared to face-to-face therapy with significant reductions in clinician time (Marks & Cavanagh, 2009). Moreover, accessibility of ICBT is likely to be an important factor for patients with SAD given the evidence that there are often significant barriers to face-to-face treatment, including fear of negative evaluation (Olfson *et al*., 2000) and stigma (Titov, 2007). Thus ICBT appears to be a valuable addition to a stepped-care treatment model of SAD in a variety of different healthcare systems.

Methodological strengths of the studies reviewed

Formal assessment of the methodological quality of the studies included in this review suggests common strengths, which are common to many computer-based interventions. These relate especially to consistency of diagnostic procedures including use of DSM-IV diagnosis of SAD across the studies, using structured diagnostic interview schedules to determine diagnoses either face-to-face or via the telephone, appropriate randomisation procedures, *a priori* reporting of objectives and outcomes as well as the inclusion of withdrawals in analysis (ITT or endpoint

analysis). Diagnoses were made using a variety of validated tools including the Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I; First,Spitzer, Gibbon & Williams, 1995) and the *Mini*-International Neuropsychiatric Interview *(*M.I.N.I.; Sheehan *et al.*, 1998*),* either via the telephone or face-to-face. There did not appear to be any difference in the severity of the problems between participants diagnosed face-to-face or over the telephone, although generally a self-selection bias could have been introduced in those studies which required face-to-face contact due to the aforementioned fear of negative evaluation which may be lowered in telephone contact. However, Crippa *et al.* (2008) have shown that there was no statistically significant difference between SAD diagnosis assessed over the telephone or in-person using the SCID. Thus diagnoses across the studies are likely to be comparable, particularly as all are based on DSM-IV criteria for SAD. Moreover, the severity of symptoms of the Internet samples was comparable with that of participants attending specialist outpatient clinics which is in line with an Australian study (Titov, Andrews, Kemp *et al.*, 2010) reporting that people seeking treatment online have substantial disorders who may have a long history of illness experience, are motivated to seek and participate in treatment, but have had difficulty accessing traditional outpatient clinics. This means that the samples are likely to be representative of the Internet population of patients with SAD and of treatment-seeking individuals in clinics.

Limitations of the studies reviewed and suggestions for future research

The majority of studies recruited participants as volunteers via media adverts and only a minority included patients referred by their clinician. Thus the question of generalizability of such self-selected samples is raised. It is unclear whether these patients are comparable to those who seek face-to-face treatments and thereby

effectiveness of ICBT in clinical practice is uncertain. Only one of the studies reviewed showed effectiveness under clinically representative conditions (Hedman *et al*., 2011) as it is the only study which sought to determine whether ICBT for SAD is effective when it is administered in a psychiatric setting. Additional support for the effectiveness of ICBT 'prescribed' in clinical settings comes from Aydos *et al.* (2009). Thus it will be important to establish if the findings from the present review will be transferable to regular clinical settings.

The sole reliance on self-report measures in the majority of the trials poses a further problem as the lack of independent assessment at post-test and follow-up introduces bias. It is possible that participants may rate themselves as more improved than they actually are due to feeling grateful that they received treatment or because of expectancy effects because blinding of participants cannot occur in these trials. Using blind assessors to confirm benefits from self-reports or credibility assessment as an indirect measure of expectancy effects would reduce bias in future trials. In order to establish which patients may benefit from ICBT, comparisons of completers and non-completers may be a useful indicator. However such comparisons were not routinely reported in the trials and this could further enhance the evidence base if included in future research.

Conclusion

To summarise, ICBT for SAD appears to be superior to waitlist and equivalent to active control interventions. Guided and unguided ICBT have similar outcomes but the evidence base for unguided ICBT remains limited. The quality of the research in this area is generally good but in particular detection bias needs to be reduced. In future research, independent assessment of outcomes should be routinely included as well as longer-term follow-ups and trials need to be conducted in clinical

settings to establish effectiveness. Overall, ICBT for SAD appears to be an efficacious and acceptable treatment which is convenient for clients, reduces therapist time and is therefore more cost-effective. It is a promising treatment for a client group which has significant barriers to face-to-face treatment and continues to have the lowest rates of treatment.

References

Acarturk C., Cuijpers P., Van Straten A., & De Graaf R. (2009). Psychological treatment of social anxiety disorder: A meta-analysis. *Psychological Medicine*, 241–254.

Almlöv, J., Carlbring, P., Berger, T., Cuijpers, P., & Andersson, G. (2009).Therapist factors in Internet-delivered cognitive behavioural therapy for major depressive disorder. *Cognitive Behaviour Therapy*, *38*(4), 247–254.

Almlöv, J., Carlbring, P., Källqvist, K., Paxling, B., Cuijpers, P., & Andersson, G. (2011).Therapist effects in guided internet-delivered CBT for anxiety disorders. *Behavioural and Cognitive Psychotherapy*, *39*(3), 311–322.

Altman, D.G., Schulz, K.F., Moher, D., Egger, M., Davidoff, F., & Elbourne D. (2001). The revised CONSORT statement for reporting randomized trials: explanation and elaboration. *Annals of Internal Medicine*, *134*, 663-694.

American Psychiatric Association.(1980). *Diagnostic and Statistical Manual of Mental Disorders* (Third Edition.). Washington, DC: American Psychiatric Association.

American Psychiatric Association.(1994). *Diagnostic and Statistical Manual of Mental Disorders* (Fourth Edition.). Washington, DC: American Psychiatric Association.

Amir, N., Beard, C., Taylor, C. T., Klumpp, H., Elias, J., Burns, M., & Chen, X. (2009). Attention Training in Individuals with Generalized Social Phobia: A Randomized Controlled Trial. *Journal of Consulting and Clinical Psychology*, *77*(5), 961–973.

Andersson, G., Carlbring, P., Furmark, T., & S. O. F. I. E. Research Group. (2012). Therapist experience and knowledge acquisition in internet-delivered CBT for social anxiety disorder: a randomized controlled trial. *PLoS ONE*, *7*(5).

Andersson G., Carlbring P., Holmstrom A., Sparthan E., Furmark T., Nilsson-Ihrfelt E., Ekselius L. (2006). Internet-based self-help with therapist feedback and in vivo

group exposure for social phobia: A randomized controlled trial. *Journal of Consulting and Clinical Psychology*, *74*(4), 677–686.

Andrews, G. (2007) ClimateGP – web based patient education. *Australian Family Physician*. *36*(5), 371-372.

Andrews, G, Davies, M., & Titov, N. (2011). Effectiveness randomized controlled trial of face to face versus Internet cognitive behaviour therapy for social phobia. *Journal of Psychiatry*, *45*(4), 337–40.

Andrews, G., Cuijpers, P., Craske, M. G., McEvoy, P., & Titov, N. (2010). Computer Therapy for the Anxiety and Depressive Disorders Is Effective, Acceptable and Practical Health Care: A Meta-Analysis. *PLoS ONE*, 5(10), e13196.

Antony, M. M., Roth, D., Swinson, R. P., Huta, V., & Devins, G. M. (1998).Illness intrusiveness in individuals with panic disorder, obsessive-compulsive disorder, or social phobia. *The Journal of Nervous and Mental Disease*, *186*(5), 311–315.

Australian New Zealand Clinical Trial Registry.(2009). Internet vs. face to face cognitive behavioural therapy for social phobia. *ANZCTR*. Retrieved February 3, 2013, from https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=83680

Aydos L., Titov N., & Andrews G. (2009). Shyness 5: The clinical effectiveness of Internet-based clinician-assisted treatment of social phobia. *Australasian Psychiatry*, *17*(6), 488–492.

Beidel, D. C., Rao, P. A., Scharfstein, L., Wong, N., & Alfano, C. A. (2010). Social skills and social phobia: an investigation of DSM-IV subtypes. *Behaviour Research and Therapy*, *48*(10), 992–1001.

Beidel, D. C., & Wong, N. (2010). Social Phobia. In *The Corsini Encyclopedia of Psychology*. John Wiley & Sons, Inc.

Berger, T., Caspar, F., Richardson, R., Kneubuhler, B., Sutter, D., & Andersson, G. (2011). Internet-based treatment of social phobia: a randomized controlled trial comparing unguided with two types of guided self-help. *Behaviour Research & Therapy*, *49*(3), 158–69.

Berger, T., Hohl, E., & Caspar, F. (2009). Internet-based treatment for social phobia: a randomized controlled trial. *Journal of Clinical Psychology*, *65*(10), 1021–35.

Bhattacharya, R., Kelley, G., & Bhattacharjee, S. (2012). PMH8 Long-Term Follow-Up Effects of Computerized or Internet-Based Cognitive Behavioral Therapy for Depression and Anxiety: A Meta-Analysis. *Value in Health*, *15*(4), A82.

Bögels, S. M., Sijbers, G. F. V. M., & Voncken, M. (2006). Mindfulness and Task Concentration Training for Social Phobia: A Pilot Study. *Journal of Cognitive Psychotherapy*, *20*(1), 33–44.

Botella, C., Gallego, M., Garcia-Palacios, A., Guillen, V., Banos, R., Quero, S., & Alcaniz, M. (2010). An Internet-based self-help treatment for fear of public speaking: A controlled trial. *Cyberpsychology, Behavior, and Social Networking*, *13*(4), 407–421.

Bruch, M. A., Fallon, M., & Heimberg, R. G. (2003).Social Phobia and Difficulties in Occupational Adjustment.*Journal of Counseling Psychology, 50*(1), 109–17.

Chambless, D.L., Baker, M.J. & Baucom, D.H.(1998) Update on empircally validated therapies, II. *The Clinical Psychologist*, 51(1), 3–16.

Carlbring, P., Gunnarsdottir, M., Hedensjo, L., Andersson, G., Ekselius, L., & Furmark, T. (2007). Treatment of social phobia: Randomised trial of internet-delivered cognitive-behavioural therapy with telephone support. *Australian and New Zealand Journal of Psychiatry*, *190*(2), 123-128.

Clark, D.M., & Wells, A. (1995).A cognitive model of social phobia. In Heimberg, R.G. (Ed.), *Social Phobia: Diagnosis, Assessment, and Treatment* (pp. 69–93).

Clark, David M, Ehlers, A., Hackmann, A., McManus, F., Fennell, M., Grey, N., & Wild, J. (2006). Cognitive therapy versus exposure and applied relaxation in social phobia: A randomized controlled trial. *Journal of Consulting and Clinical Psychology*, *74*(3), 568–578.

Crippa, J.A., de Lima Osorio, F., Del-Ben, C.M., Filho, A.S., da Silva Freitas M.C., & Loureiro, S.R. (2008) Comparability between telephone and face-to-face structured clinical interview for DSM-IV in assessing social anxiety disorder. *Perspectives in Psychiatric Care*, *44*(4), 241-247.

Cuijpers, P., Marks, I. M., Van Straten, A., Cavanagh, K., Gega, L., & Andersson, G. (2009). Computer-aided psychotherapy for anxiety disorders: a meta-analytic review. *Cognitive Behaviour Therapy*, *38*(2), 66–82.

Dalrymple, K. L., & Herbert, J. D. (2007). Acceptance and commitment therapy for generalized social anxiety disorder: a pilot study. *Behavior Modification*, *31*(5), 543–568.

Davidson, J. R., Hughes, D. L., George, L. K., & Blazer, D. G. (1993). The epidemiology of social phobia: findings from the Duke Epidemiological Catchment Area Study. *Psychological Medicine*, *23*(3), 709–718.

Erwin, B. A., Turk, C. L., Heimberg, R. G., Fresco, D. M., & Hantula, D. A. (2004). The Internet: home to a severe population of individuals with social anxiety disorder? *Journal of Anxiety Disorders*, *18*(5), 629–646.

Feske, U., & Chambless, D. L. (1995). Cognitive behavioral versus exposure only treatment for social phobia: A meta-analysis. *Behavior Therapy*, *26*(4), 695–720.

First, M., Spitzer, R. L., Gibbon, M., & Williams, J. B. (1995). Structured Clinical Interview for DSM-IV Axis I Disorders—Non-Patient Edition. Biometrics Research Department, NY: *New York State Psychiatric Institute.*

Forman, E. M., Herbert, J. D., Moitra, E., Yeomans, P. D., & Geller, P. A. (2007).A randomized controlled effectiveness trial of acceptance and commitment therapy and cognitive therapy for anxiety and depression. *Behavior Modification*, *31*(6), 772–799.

Furmark, T., Carlbring, P., Hedman, E., Sonnenstein, A., Clevberger, P., Bohman, B., & Andersson, G. (2009). Guided and unguided self-help for social anxiety disorder: Randomised controlled trial. *Australian and New Zealand Journal of Psychiatry*, *195*(5), 440–447.

Furmark, T., Holmström, A., Sparthan, E., Carlbring, P., & Andersson, G. (2006) *Social Fobi – Effektiv Hjälp med Kognitiv Beteendeterapi* [Social Phobia – Effective Help with CBT]. Liber.

Gallego, M., Gerardus Emmelkamp, P., Van der Kooij, M., & Mees, H. (2011). The effects of a Dutch version of an Internet-based treatment program for fear of public speaking: A controlled study. *Journal of Clinical and Health Psychology*, *11*(3), 459–472.

Glasgow, R. E., & Rosen, G. M. (1978). Behavioral bibliotherapy: a review of self-help behavior therapy manuals. *Psychological Bulletin*, *85*(1), 1–23.

Goldin, P. R., & Gross, J. J. (2010). Effects of mindfulness-based stress reduction (MBSR) on emotion regulation in social anxiety disorder. *Emotion*, *10*(1), 83–91.

Gould, R. A., Buckminster, S., Pollack, M. H., Otto, M. W., & Massachusetts, L. Y. (1997). Cognitive-Behavioral and Pharmacological Treatment for Social Phobia: A Meta-Analysis. *Clinical Psychology: Science and Practice*, *4*(4), 291–306.

Griffiths, K. M., Farrer, L., & Christensen, H. (2010). The efficacy of internet interventions for depression and anxiety disorders: a review of randomised controlled trials. *The Medical Journal of Australia*, *192*(11 Suppl), S4–11.

Hedman, E., Andersson, G., Ljotsson, B., Andersson, E., Ruck, C., Mortberg, E., & Lindefors, N. (2011). Internet-based cognitive behavior therapy vs. cognitive behavioral group therapy for social anxiety disorder: A randomized controlled non-inferiority trial. *PLoS ONE*, *6*(3).

Hedman, E., Furmark, T., Carlbring, P., Ljotsson, B., Ruck, C., Lindefors, N., & Andersson, G. (2011). A 5-year follow-up of internet-based cognitive behavior therapy for a social anxiety disorder. *Journal of Medical Internet Research*, *13*(2), 34–43.

Hedman, E., Ljotsson, B. & Lindefors, N. (2012) Cognitive behavior therapy via the Internet: a systematic review of applications, clinical efficacy and cost–effectiveness. *Expert Review of Pharmacoeconomics and Outcomes Research*, *12*(6), 745–764.

Heimberg, R.G., & Juster, M. R. (1995). Cognitive behavioral treatment: literature review. In *Social Phobia Diagnosis, Assessment and Treatment.*(pp. 261– 309). New York, NY: Guildford Press.

Heimberg, Richard G. (2002). Cognitive-behavioral therapy for social anxiety disorder: current status and future directions. *Biological psychiatry*, *51*(1), 101–108.

Herbert, J. D., Rheingold, A. A., Gaudiano, B. A., & Myers, V. H. (2004).Standard versus extended cognitive behaviour therapy for social anxiety disorder: a randomized-controlled trial. *Behavioural and Cognitive Psychotherapy*, *32*(02), 131–147.

Higgins, J. P. T., & Green, S. (2011). *Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.0*. The Cochrane Collaboration.

Hofmann, S. G., Meuret, A. E., Smits, J. A. J., Simon, N. M., Pollack, M. H., Eisenmenger, K., Otto, M. W. (2006). Augmentation of exposure therapy with D-cycloserine for social anxiety disorder. *Archives of General Psychiatry*, *63*(3), 298–304.

Issakidis, C., & Andrews, G. (2002).Service utilisation for anxiety in an Australian community sample. *Social Psychiatry and Psychiatric Epidemiology*, *37*(4), 153–163.

Johnston, L., Titov, N., Andrews, G., Spence, J., & Dear, B. (2011). A RCT of a transdiagnostic Internet-delivered treatment for three anxiety disorders: Examination of support roles and disorder-specific outcomes. *PLoS ONE*, *6*(11).

Jørstad-Stein, E. C., & Heimberg, R. G. (2009). Social phobia: an update on treatment. *The Psychiatric Clinics of North America*, *32*(3), 641–663.

Kaltenthaler, E., Brazier, J., De Nigris, E., Tumur, I., Ferriter, M., Beverley, C., & Sutcliffe, P. (2006).Computerised cognitive behaviour therapy for depression and anxiety update: a systematic review and economic evaluation. *Health Technology Assessment*, *10*(33), iii, xi–xiv, 1–168.

Katzelnick, D.J., & Greist, J.H. (2001). Social anxiety disorder: an unrecognized problem in primary care. *The Journal of Clinical Psychiatry*, *62 Suppl 1*, 11–15.

Keller, M.B. (2003). The lifelong course of social anxiety disorder: a clinical perspective. *Acta Psychiatrica Scandinavica*, *108*, 85–94.

Kessler, RC. (2003). The impairments caused by social phobia in the general population: implications for intervention. *Acta psychiatrica Scandinavica. Supplementum*, (417), 19–27.

Kessler, R.C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005).Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in

the National Comorbidity Survey Replication. *Archives of General Psychiatry*, *62*(6), 593–602.

Kessler, R.C., Petukhova, M., Sampson, N.A., Zaslavsky, A.M. & Wittchen, H.U. (2012) Twelve-month and lifetime prevalence and lifetime morbid risk of anxiety and mood disorders in the United States. *International Journal of Methods in Psychiatric Research*, *21*(3), 169-184.

Lampe, L. (2011). Social anxiety disorder: common, disabling and often untreated. *Medicine Today*, *10*(03), 54-65.

Lipsitz, J. D., Markowitz, J. C., Cherry, S., & Fyer, A. J. (1999). Open trial of interpersonal psychotherapy for the treatment of social phobia. *The American Journal of Psychiatry*, *156*(11), 1814–1816.

Ljótsson, B., Hedman, E., Andersson, E., Hesser, H., Lindfors, P., Hursti, T., &Andersson, G. (2011). Internet-delivered exposure-based treatment vs. stress management for irritable bowel syndrome: a randomized trial. *The American Journal of Gastroenterology*, *106*(8), 1481–1491.

Lochner, C., Mogotsi, M., Du Toit, P. L., Kaminer, D., Niehaus, D. J., & Stein, D. J. (2003). Quality of life in anxiety disorders: a comparison of obsessive-compulsive disorder, social anxiety disorder, and panic disorder. *Psychopathology*, *36*(5), 255–262.

Magee, W. J., Eaton, W. W., Wittchen, H. U., McGonagle, K. A., & Kessler, R. C. (1996). Agoraphobia, simple phobia, and social phobia in the National Comorbidity Survey. *Archives of General Psychiatry*, *53*(2), 159–168.

Marks, I. & Cavanagh, K. (2009) Computer-aided psychological treatments: evolving issues. *Annual Review of Clinical Psychology*, *5*, 121-141.

McEvoy, P. M. (2007). Effectiveness of cognitive behavioural group therapy for social phobia in a community clinic: a benchmarking study. *Behaviour Research and Therapy, 45*(12), 3030–3040.

National Institute for Health and Clinical Excellence.(2006). *Guidance on the Use of Computerised Cognitive Behavioural Therapy for Anxiety and Depression*. NICE.

Newman, M. G., Hofmann, S. G., Trabert, W., Roth, W. T., & Taylor, C. B. (1994). Does behavioral treatment of social phobia lead to cognitive changes? *Behavior Therapy, 25*(3), 503–517.

Newman, M. G., Szkodny, L. E., Llera, S. J., & Przeworski, A. (2011). A review of technology-assisted self-help and minimal contact therapies for anxiety and depression: is human contact necessary for therapeutic efficacy? *Clinical Psychology Review, 31*(1), 89–103.

Nordgreen T., Havik O.E., Ost L.G., Furmark T., Carlbring P., & Andersson G. (2012). Outcome predictors in guided and unguided self-help for social anxiety disorder. *Behaviour Research and Therapy, 50*(1), 13–21.

Olatunji, B. O., Cisler, J. M., & Deacon, B. J. (2010). Efficacy of cognitive behavioral therapy for anxiety disorders: a review of meta-analytic findings. *The Psychiatric Clinics of North America, 33*(3), 557–577.

Olfson, M., Guardino, M., Struening, E., Schneier, F. R., Hellman, F., & Klein, D. F. (2000).Barriers to the treatment of social anxiety. *The American Journal of Psychiatry, 157*(4), 521–527.

Ost, L. G. (1987). Applied relaxation: description of a coping technique and review of controlled studies. *Behaviour Research and Therapy, 25*(5), 397–409.

Ougrin, D. (2011). Efficacy of exposure versus cognitive therapy in anxiety disorders: systematic review and meta-analysis. *BMC Psychiatry, 11*(1), 200.

Palmqvist, B., Carlbring, P., & Andersson, G. (2007). Internet-delivered treatments with or without therapist input: does the therapist factor have implications for efficacy and cost? *Expert Review of Pharmacoeconomics & Outcomes Research*, *7*(3), 291–297.

Patel, A., Knapp, M., Henderson, J., & Baldwin, D. (2002).The economic consequences of social phobia. *Journal of Affective Disorders*, *68*(2-3), 221–233.

Ponniah, K., & Hollon, S. D. (2008).Empirically supported psychological interventions for social phobia in adults: a qualitative review of randomized controlled trials. *Psychological Medicine*, *38*(1), 3–14.

Pontoski, K., Heimberg, R. G., Turk, C. L., & Coles, M. E. (2010).Psychotherapy of social anxiety disorder. In *Textbook of Anxiety Disorders* (Second Edition., pp. 501–521). Washington, DC: American Psychiatric Press.

Poston, J.M., & Hanson, W.E. (2010) Meta-analysis of psychological assessment as a therapeutic intervention. *Psychological Assessment*, *22*(2), 203-212.

Powers, M. B., Sigmarsson, S. R., & Emmelkamp, P. M. G. (2008).A Meta–Analytic Review of Psychological Treatments for Social Anxiety Disorder. *International Journal of Cognitive Therapy*, *1*(2), 94–113.

Rapee, R. M., & Heimberg, R. G. (1997). A cognitive-behavioral model of anxiety in social phobia. *Behaviour Research and Therapy*, *35*(8), 741–756.

Rodebaugh, T. L., Holaway, R. M., & Heimberg, R. G. (2004).The treatment of social anxiety disorder. *Clinical Psychology Review*, *24*(7), 883–908.

Roth, A., & Fonagy, P. (2006).*What Works for Whom?: A Critical Review of Psychotherapy Research*. Guilford Press.

Safren, S. A., Heimberg, R. G., Brown, E. J., & Holle, C. (1996).Quality of life in social phobia. *Depression & Anxiety*, *4*(3), 126–133.

Schmidt, N. B., Richey, J. A., Buckner, J. D., & Timpano, K. R. (2009). Attention training for generalized social anxiety disorder. *Journal of Abnormal Psychology*, *118*(1), 5–14.

Schneier, F. R., Heckelman, L. R., Garfinkel, R., Campeas, R., Fallon, B. A., Gitow, A., Liebowitz, M. R. (1994). Functional impairment in social phobia. *The Journal of Clinical Psychiatry*, *55*(8), 322–331.

Sheehan, D.V., Lecrubier, Y., Sheehan, K.H., Amorim, P., Janavs, J., Weiller, E., Hergueta, T., Baker, R. & Dunbar, G.C. (1998).The Mini-International Neuropsychiatric Interview (M.I.N.I.): the development and validation of a structured diagnostic psychiatric interview for DSM-IV and ICD-10. *The Journal of Clinical Psychiatry*. *59*(Suppl 20), 22–33.

Smit, F., Cuijpers, P., Oostenbrink, J., Batelaan, N., De Graaf, R., & Beekman, A. (2006). Costs of nine common mental disorders: implications for curative and preventive psychiatry. *The Journal of Mental Health Policy and Economics*, *9*(4), 193–200.

So, M., Yamaguchi, S., Hashimoto, S., Sado, M., Furukawa, T.A. & McCrone, P. (2013) Is computerised CBT really helpful for adult depression? – A meta-analytic re-evaluation of CCBT for adult depression in terms of clinical implementation and methodological quality. *BMC Psychiatry*, 13 (1), 113.

Spek, V., Cuijpers, P., Nyklícek, I., Riper, H., Keyzer, J., & Pop, V. (2007). Internet-based cognitive behaviour therapy for symptoms of depression and anxiety: a meta-analysis. *Psychological Medicine*, *37*(3), 319–328.

Stangier, U., Heidenreich, T. & Peitz, M. (2003) *Soziale Phobien. Ein kognitiv-verhaltenstherapeutsches Behandlungsmanual*. Beltz Psychologie Verlags Union (PVU) (Weinheim).

Stein, M. B., & Kean, Y. M. (2000). Disability and Quality of Life in Social Phobia: Epidemiologic Findings. *American Journal of Psychiatry*, *157*(10), 1606–1613.

Stravynski, A., Arbel, N., Bounader, J., Gaudette, G., Lachance, L., Borgeat, F., Todorov, C. (2000). Social phobia treated as a problem in social functioning: a controlled comparison of two behavioural group approaches. *Acta Psychiatrica Scandinavica*, *102*(3), 188–198.

Stravynski, A., Marks, I., & Yule, W. (1982).Social skills problems in neurotic outpatients. Social skills training with and without cognitive modification. *Archives of General Psychiatry*, *39*(12), 1378–1385.

Tillfors, M., Carlbring, P., Furmark, T., Lewenhaupt, S., Spak, M., Eriksson, A., & Andersson, G. (2008). Treating university students with social phobia and public speaking fears: Internet delivered self-help with or without live group exposure sessions. *Depression & Anxiety*, *25*(8), 708–17.

Titov, N. (2007) Status of computerized cognitive behavioural therapy for adults. *Australian and New Zealand Journal of Psychiatry.*41, 95–114.

Titov, N., Andrews, G., Choi, I., Schwencke, G., & Johnston, L. (2009).Randomized controlled trial of web-based treatment of social phobia without clinician guidance. *Australian and New Zealand Journal of Psychiatry*, *43*(10), 913–919.

Titov, N., Andrews, G., Choi, I., Schwencke, G., & Mahoney, A. (2008). Shyness 3: Randomized controlled trial of guided versus unguided Internet-based CBT for social phobia. *Australian and New Zealand Journal of Psychiatry*, *42*(12), 1030–1040.

Titov, N., Andrews, G., Johnston, L., Robinson, E., & Spence, J. (2010). Transdiagnostic Internet treatment for anxiety disorders: A randomized controlled trial. *Behaviour Research and Therapy*, *48*(9), 890–899.

Titov, N., Andrews, G., Kemp, A.,& Robinson, E. (2010). Characteristics of Adults with Anxiety or Depression Treated at an Internet Clinic: Comparison with a National Survey and an Outpatient Clinic. *PLoS ONE,* 5(5): e10885.

Titov N., Andrews G., & Schwencke G. (2008). Shyness 2: Treating social phobia online: Replication and extension. *Australian and New Zealand Journal of Psychiatry*, *42*(7), 595–605.

Titov, N., Andrews, G., Schwencke, G., Drobny, J., & Einstein, D. (2008). Shyness 1: Distance treatment of social phobia over the internet. *Australian and New Zealand Journal of Psychiatry*, *42*(7), 585–594.

Titov, N., Andrews, G., Schwencke, G., Robinson, E., Peters, L., & Spence, J. (2010). Randomized controlled trial of internet cognitive behavioural treatment for social phobia with and without motivational enhancement strategies. *Australian and New Zealand Journal of Psychiatry*, *44*(10), 938–945.

Titov, N., Andrews, G., Schwencke, G., Solley, K., Johnston, L., & Robinson, E. (2009).An RCT comparing effect of two types of support on severity of symptoms for people completing internet-based cognitive behaviour therapy for social phobia. *Australian and New Zealand Journal of Psychiatry*, *43*(10), 920–926.

Turk, D. C., Rudy, T. E., & Sorkin, B. A. (1993). Neglected topics in chronic pain treatment outcome studies: determination of success. *Pain*, *53*(1), 3–16.

Turner, S. M., Beidel, D. C., Dancu, C. V., & Keys, D. J. (1986). Psychopathology of social phobia and comparison to avoidant personality disorder. *Journal of Abnormal Psychology*, *95*(4), 389–394.

Turner, S. M., Beidel, D. C., & Townsley, R. M. (1992). Social phobia: a comparison of specific and generalized subtypes and avoidant personality disorder. *Journal of Abnormal Psychology*, *101*(2), 326–331.

Veale, D. (2003). Treatment of social phobia. *Advances in Psychiatric Treatment*, *9*(4), 258–264.

Wittchen, H. U., & Fehm, L. (2001). Epidemiology, patterns of comorbidity, and associated disabilities of social phobia. *The Psychiatric Clinics of North America*, *24*(4), 617–641.

Wong, N., Sarver, D. E., & Beidel, D. C. (2012). Quality of life impairments among adults with social phobia: the impact of subtype. *Journal of Anxiety Disorders*, *26*(1), 50–57.

Part 2. Empirical Paper

Phenomenology of bowel/bladder-control anxiety

Abstract

Aims To obtain initial clinical and demographic details about bowel *and*/*or* bladder-control anxieties (BBCA) and to explore relationships with panic attacks.

Methods For study 1, Participants with BBCA (n=239) were recruited via an Internet survey and compared to a control group of participants with panic attacks (n=423). An initial evaluation of the psychometric properties of a measure of fear of incontinence (FOIS), which was developed in collaboration with the main thesis supervisor and several experts in cognitive-behaviour therapy, was conducted to allow identification of differences between participants with panic attacks with and without associated BBCA. For study 2 participants who had BBCA with panic attacks (n=63) and panic attacks not related to this fear (n=68) also completed paper-based questionnaires to allow comparison on several psychological constructs. In particular, proposed predictors of disgust, shame, body vigilance, anxiety control and fear of incontinence (FOIS) were examined.

Results The sample of participants with BBCA showed characteristics very similar to those described in the only other study of a group of patients with BBCA such as a high prevalence of panic, preponderance of women sufferers, significant levels of avoidance, distressing symptoms, and role impairment. A principal components analysis showed the FOIS to be reliable, internally consistent and construct valid and two factors emerged which measured different aspects of this fear. Both factors of the FOIS were elevated in BBCA compared to a control group with panic attacks. Constructs of shame and disgust also appear to be related to BBCA, however they are not predictors of these concerns and body vigilance and anxiety control do not differ compared to panic controls. Only one factor of the FOIS (avoidance/safety behaviours/QoL) emerged as a superior predictor of BBCA.

Conclusions People with BBCA have an intense fear of incontinence which is accompanied by an experience of panic attacks in the majority of cases. Those with BBCA accompanied by panic seem to be distinct from people with panic and other bodily concerns. Two factors on a novel measure of BBCA (the FOIS) were superior predictors of BBCA whilst other proposed predictors (disgust, shame, body vigilance and anxiety control) are not significant.

Introduction

People with anxiety disorders occasionally report fears about losing control of basic bodily functions in public. In psychological therapy services such as Improving Access to Psychological Therapies (IAPT), the phenomenon of a specific and overwhelming fear of being incontinent in a public place has long been recognised. Anxiety UK (formerly The National Phobics Society), a major charity in the UK that deals with anxiety and other mental health problems, has recognised that 'toilet-related phobias' are a major concern and has developed a booklet and DVD that deal with various toilet-related anxiety issues, including bowel- and bladder-control anxiety. In 2006, the BBC ran a story on their website outlining the prevalence and nature of toilet-related anxieties ("Millions hit by toilet phobia", 2006). A Google search for 'toilet anxiety' produces more than 8.5 million hits. The absence of systematic research on these anxieties is therefore striking.

Bowel/bladder-control anxiety (BBCA) often occurs in the absence of physical disorders and it has been considered as a symptom of a number of different psychological disorders including obsessive compulsive disorder (Hatch, 1997), health anxiety, specific phobia and panic disorder. The main symptoms of BBCA include an overwhelming fear of urinary or faecal incontinence; checking for bowel/bladder sensations; frequent and intense viscerally-focused urgency during periods of anxiety; behavioural urges to use the toilet and avoidance of situations where anxiety or urges might be experienced (Beidel & Bulik, 1990; Cosci, 2012; Elridge, Walker & Holborn, 1993; Epstein & Jenike, 1990; Hatch, 1997; Jenike, Vitagliano, Rabinowitz, Goff & Baer, 1987; Lytsekos, 1992; Porcelli & Leandro, 2007; Sharma, 1991). The repetitive nature of these urges and checking behaviours has led some researchers to conceptualise these symptoms as aspects of obsessive

compulsive disorder and the term ‘bowel obsession’ has commonly been used to describe bowel-control anxiety (e.g. Beidel & Bulik, 1990; Cosci, 2012; Hatch, 1997; Jenike *et al*., 1987; Lytsekos, 1992; Porcelli & Leandro, 2007; Sharma, 1991). Descriptions of bladder-control anxiety appear less frequently in the literature but clinical experience suggests that its prevalence is not trivial (Epstein & Jenike, 1990; Lelliot, McNamee & Marks, 1991). The clinical presentation of BBCA is complicated by the presence of intense somatic symptoms which have some features of functional disorders like irritable bowel syndrome (IBS; Lydiard, Laraia, Fossey, & Ballenger, 1988), urge incontinence (UI; Perry, McGrother & Turner, 2010) and overactive bladder syndrome (OAB; Nicolson, Kopp, Chapple & Kelleher, 2008). Interestingly, even in such functional disorders anxiety has been implicated as a significant risk factor for developing somatic symptoms including gastrointestinal (Jerndal *et al*., 2010) and urinary symptoms (Perry *et al*., 2010) and Nicolson *et al.* (2008) reported that OAB causes anxiety and fear of incontinence even in the absence of episodes of incontinence.

Panic symptoms have been reported in people with BBCA (e.g. Porcelli & de Carne, 2008), along with intense social concerns about the consequences of the feared catastrophe. However, a factor analytic study examining a mixed group of patients with anxiety disorders found that those with concerns about incontinence formed a distinct group with different demographic and clinical features compared to those with panic ± agoraphobia or social anxiety (Lelliot *et al*., 1991). It has been argued that the focus on gastrointestinal symptoms observed in bowel-control anxiety is similar to that in emetophobia (i.e. fear of vomiting) (Lelliot *et al*., 1991; van Hout & Bouman, 2012). Boschen’s (2007) cognitive model of emetophobia proposed a general vulnerability to anxiety with an emphasis on the perception of

gastrointestinal symptoms. In BBCA an over-sensitivity or misinterpretation of gastrointestinal symptoms leading to a catastrophic fear of incontinence has also previously been suggested (Hinton, 2007).

It has been suggested that emetophobia and BBCA seem to have some distinct characteristics from other anxiety disorders and may represent particular types of viscerally-focussed phobic syndromes. In both syndromes the 'phobic situation' is one in which the locus of sensations is in the gastrointestinal tract/visceral systems; the primary concern relates to bodily (dys)function resulting in the involuntary release of bodily products associated with disgust; both types of anxiety tend to be accompanied by situationally-bound panic attacks (e.g. when experiencing nausea or bowel/bladder distension; van Hout & Bouman, 2012) and concerns about the social consequences of loss of control. Finally both are associated with intrusive flash-forward and flashback imagery (Pajak, Langhoff, Watson & Kamboj, 2013; Price, Veale & Brewin, 2012). A common psychophysiological-cognitive vulnerability akin to 'interoceptive sensitivity' (i.e. a sensitivity for one's internal bodily signals) may underlie both emetophobia and bowel/bladder control anxieties, although the bodily locus of this sensitivity is the visceral/gastrointestinal- rather than the cardiovascular and respiratory systems with which interoceptive sensitivity is usually associated (*c.f.* Herbert, Muth, Pollatos & Herbert, 2012; Muotri, Nunes & Bernik, 2007). This is significant because the functioning of the brain-gut axis and brain-bladder interactions are increasingly recognised as pivotal in the regulation of the stress response as well as being implicated in anxiety disorders (Aziz & Thompson, 1998; Mayer & Tillisch, 2011).

There may also be links between BBCA and health anxiety. For example, in emetophobia clients' concerns are sometimes focused around illnesses that could

cause vomiting (Veale, 2009). People with BBCA may have disease phobia if they are primarily worried about illnesses or infections that can cause incontinence or they may have hypochondriacal beliefs attributing the cause of gastrointestinal and urinary symptoms to physical problems such as IBS.

Thus, overall the current literature does not provide a clear description of patients with BBCA who may not have a functional gastrointestinal or urinary disorder and it does not elucidate the links with other anxiety disorders.

The Current Studies

The aim of the present studies was to obtain initial clinical and demographic details about BBCA to support future development of a psychological model and theory-derived treatment for these syndromes. This is an initial descriptive project to provide an account of both the phenomenology of BBCA as well as its nosology.

Study 1 was an internet-based survey. The main aim was to determine whether some basic features observed in clinical practice and other small-scale studies are found in a larger sample of individuals with these anxieties, and to begin to describe these systematically. It was also aimed to obtain preliminary data on help-seeking and problem-disclosure. Furthermore, an influential treatment manual suggests that BBCA should be treated with reference to the cognitive model of panic (Clark & Salkovskis, *in press*). As such we were interested to examine the presence of cognitive and behavioural features that might be specific to BBCA (i.e. specific beliefs related to shame and disgust). Since there are no existing measures of BBCA, a measure which was developed in collaboration with the main thesis supervisor and several experts in cognitive-behaviour therapy, was evaluated and used to investigate these cognitive and behavioural features.

By using an internet survey complete anonymity was offered which aimed to overcome potential recruitment difficulties related to shame/concealment, factors common for example in IBS (Kennedy, Robinson & Rogers, 2003), paruresis (i.e. shy bladder syndrome; Vythilingum, Stein & Soifer, 2002) and social anxiety (Olfson *et al.*, 2000) . In addition, an internet survey had the advantage of potentially targeting a large population, which is especially useful given that the prevalence of BBCA is unknown. Internet-based research has previously been used to study rare disorders, for example emetophobia (Lipsitz, Fyer, Paterniti & Klein, 2001), skin picking (Flessner & Woods, 2006) and trichotillomania (Wetterneck, Woods, Norberg & Begotka, 2006).

Study 2 was a postal questionnaire which aimed to further describe the characteristics of people with BBCA in terms of a number of key psychological constructs using validated questionnaires (especially disgust sensitivity/propensity, shame, positive/negative affectivity, body vigilance, and perceived control over emotions and external threats), likely psychopathological covariates (social anxiety, panic and OCD-like concerns) and presence/absence of any gastrointestinal or urinary symptoms. In particular, disgust sensitivity/propensity, shame, body vigilance and perceived control over emotions and external threats were predicted to be strongly related to BBCA. Disgust sensitivity has been reported to be the best predictor of emetophobic complaints and both disgust sensitivity and propensity are elevated in such patients (van Overveld, de Jong, Peters, van Hout & Bouman, 2008). Given the suggested overlap between emetophobia and BBCA, it is therefore likely that disgust is an important predictor of the latter. Shame has also been reported as an important factor in emetophobia (Marks, 1987; Price, Veale & Brewin, 2012) where it tends to have a social component (van Hout & Bouman,

2012). A reduced level of perceived control over emotions and external threats has previously been reported in BBCA (Pajak *et al*., 2013) and it has also been implicated in social phobia (Hofmann, 2007) and emetophobia (Davidson, Boyle & Lauchlan, 2007). Body vigilance was hypothesised to be another predictor of BBCA because of its focus on gastrointestinal and urinary symptoms. There is also evidence that people with IBS have higher levels of body vigilance (Keough, Timpano, Zawilinski & Schmidt, 2011).

As part of study 2 we recruited a separate control group consisting of participants who experienced panic attacks via a similar initial internet-based questionnaire which was followed by a postal questionnaire including the same measures. The aim was to obtain a group of people who experienced panic attacks but did not predominantly experience BBCA. The extent to which bowel/bladder-control anxieties are associated with panic is of particular interest given the association of panic with viscerally-focused functional disorders like IBS (e.g. Noyes, Cook, Garvey & Summers, 1990) and the fact that intense periods of anxiety are likely to contribute to an exacerbation of visceral symptoms and to a vicious cycle of symptom escalation (Clark & Salkovskis, *in press*). It has been argued that body vigilance is elevated in people with panic disorder (Olantunji, Deacon, Abramowitz & Valentiner, 2007; Schmidt, Lerew & Trakowski, 1997) and they have argued that this fits with evidence by Bouton, Mineka and Barlow (2001) that people with panic disorder have exaggerated vigilance for potentially dangerous sensations suggesting they may expect bodily events to be threatening.

Given that a central assumption of cognitive models of anxiety disorders in general is that the experience of anxiety is based on an over-estimation of feared outcomes (their occurrence or their consequences) we wanted to examine the degree

to which bowel/bladder-control anxieties may have been based on past experiences of such outcomes (which might influence subjective estimates of occurrence of incontinence during periods of anxiety), especially in the context of panic. In other words, do people with BBCA have past experience of losing bowel/bladder control and has this occurred during a panic attack?

Aims

- To obtain initial clinical and demographic details about BBCA and to provide an account of both the phenomenology of BBCA as well as its nosology.
- To examine the presence of cognitive and behavioural features that might be specific to BBCA.
- To contribute to the ongoing development of the FOIS as a measure of cognitive and behavioural features of BBCA.
- To compare participants with BBCA and panic attacks to a group of participants with panic attacks not related to BBCA in terms of a number of key psychological constructs using validated questionnaires.

Hypotheses

- Participants with BBCA will display cognitive and behavioural features specific to BBCA, particularly cognitions linked with shame and disgust.
- A large proportion of participants with BBCA will be suffering from panic attacks.
- Participants with BBCA and panic attacks will score higher on shame, disgust sensitivity/propensity, body vigilance and have lower level of perceived control over emotions and external threats compared to those participants with panic attacks who do not have BBCA.

Method

Joint Theses

This D.Clin.Psy. thesis was conducted as part of a larger project at UCL, which aims to extend our understanding of people who experience BBCA. It was a joint theses project with another Trainee Clinical Psychologist, Rosanna Pajak. Rosanna Pajak's thesis, which was submitted in June 2012, is qualitative study involving a subset of participants (n=20) who were recruited from the initial internet-based questionnaire used for my project and the questionnaire data for the participants who completed the interview were included in Rosanna's thesis for descriptive purposes only. Rosanna's study involved semi-structured interviews exploring the characteristics and content of mental imagery experienced by people with BBCA.

Rosanna and I worked together to gain ethical approval for both our projects as a whole entity. We also worked together to construct the online screening questionnaire: it was important that this included several questions about imagery for Rosanna's project. Whilst I took responsibility for setting up the online questionnaire itself using Opinio, we both worked to process participants' responses and both of us regularly screened the responses in order to identify those who reported imagery until Rosanna's project was completed. I was entirely responsible for the recruitment of the panic sample as this was only started after Rosanna had completed her thesis.

I also set up the databases for collating the questionnaire data and was responsible for data extraction from the online questionnaires and entry of data from the paper-based questionnaires. Rosanna offered assistance with printing, collating and posting out questionnaires, and in terms of liaising with NHS IAPT services to support recruitment. In return, I provided assistance in conducting a small number of

the telephone interviews, although Rosanna was responsible for transcription. Naturally, the analysis and write-up of this thesis were completely independent.

Participants and Recruitment

The study was approved by University College London Ethics Committee. In a cross-sectional design, a self-selected community-sample was recruited through internet advertisements. Recruitment via the internet was chosen due to the prediction that shame and concealment in this population would be high which might potentially limit the proportion of sufferers who seek help. Participants responded to an online advertisement (Figure 1) which contained a link to the consent form (Appendix B) and an internet survey (Appendix C). The advertisement stated that participants were required who "suffered from a fear of incontinence and worried about losing control of their bowel or bladder". It further made reference the impact on activities of daily living and high levels of distress caused by this fear, thus encouraging responses from those who have experienced significant impairment as a result of BBCA.

Inclusion Criteria

- Participants for whom BBCA is predominantly an *anxiety*-related difficulty.
- Participants for whom fear of incontinence is a preoccupation and who *agree* with the statement "My worst fear is that I would be incontinent in public" (scoring 3 or 4 on a scale which ranged from 0 (strongly disagree) to 4 (strongly agree)).
- Absence of organic disorders leading to experiences of incontinence.
- Participants reporting functional disorders (e.g. IBS, overactive bladder), or physiological or anatomical dysfunctions which are not usually associated with

an inability to voluntarily control excretory function (e.g. having a 'small bladder').

Exclusion Criteria

- Recent (i.e. in the past two weeks) experiences of incontinence
- Organic conditions associated with a disorder of bowel/bladder physiology or anatomy and neurological disorders which can lead to incontinence
- Participants who *do not agree* with the statement "My worst fear is that I would be incontinent in public" (scoring 0, 1 or 2 on a scale which ranged from 0 (strongly disagree) to 4 (strongly agree)).

Advertisements did not refer to the above criteria given that respondents' health beliefs will vary and we did not want participants to exclude themselves on the basis of specific beliefs about bowel and bladder structure and function. Therefore, before consenting, participants were presented with the advert and consent form and exclusion criteria were only applied once they had completed the baseline measures (Appendix C). Study inclusion criteria were deliberately conservative to ensure that participants reflected, as far as possible, the characteristics of patients seen in clinical practice and those reported in previous studies of BBCA.

Adverts or 'tweets' were placed on sites for people with anxiety-related problems (e.g. Anxiety UK; No More Panic) although more general online advertisement resources (Gumtree and a university-based advertisement system) and social networking websites (Facebook) were also used. Figure 2 provides a detailed overview of the places where the study was advertised. The period of recruitment for the BBCA sample was April 2011-February 2013 and for the control group it was May 2012-February 2013. A total of 887 respondents gave informed consent and

Figure 1 Adverts used for Study

BBCA Sample Advert	Panic Sample Advert
Understanding Fear of Incontinence Participants Needed for Research at University College London *Do you suffer from a fear of being incontinent?* *Do you worry about losing control of your bladder or bowels?* Living with a fear of incontinence is particularly distressing and disabling. People with this fear often report that it causes them great distress, limiting their day-to-day activities and disrupting social relationships. This debilitating fear is currently poorly understood and those affected often suffer in silence without receiving help. Through this important research we hope to learn more about the concerns of people who fear being incontinent in public. We are looking for participants to complete an online questionnaire, as part of our study, which is being conducted at University College London. Your information will increase our knowledge of this particularly distressing disorder, helping us to develop new and effective treatments which can improve the quality of people's lives. If you experience this fear, please click on the link below to find out more about the study. https://opinio.ucl.ac.uk/s?s=13853 *The Ethics Committee for University College London has approved this research (reference number 2850/001)*	**Participants needed for online research on Anxiety - University College London** *Do you suffer from symptoms of anxiety?* *Do you experience panic attacks?* People who experience panic attacks often have fears about how their body works. For example, some people have a strong fear of losing control of their bladder or/and bowel; for others this is not a major concern. These fears can cause them great distress, limiting their day-to-day activities and disrupting social relationships. We are looking for participants to complete an online questionnaire, as part of our study, which is being conducted at University College London. Your information will increase our knowledge of difficulties with anxiety, helping us to develop new and effective treatments which can improve the quality of people's lives. If you experience symptoms of anxiety, please copy and paste the link below into your browser to find out more about the study. https://opinio.ucl.ac.uk/s?s=19304 *The Ethics Committee for University College London has approved this research (reference number 2850/001)*

Figure 2 Locations of Online Advertisements

Facebook Groups	Online Forums	Other
Understanding Fear of Incontinence – Research Project (Created Own Page)	Anxiety UK	Gumtree
Incontinent Friends	No More Panic	Twitter Account: RozPajak
Incontinence Support Group	OCD Action	Twitter Account: LanghoffC
Incontinence Support and Discussions	oFear – Anxiety and Phobia Forum	UCL Announce – UCL based advertisement system
Adult Incontinence Community	Shy Bowel	
Irritable Bowel Syndrome Self Help and Support Group	United Kingdom Paruresis Trust	
Discussions	Anxiety Care UK	
Agoraphobia	No Panic	
Anxiety UK	Anxiety Forum	
BEAT anxiety	Anxiety Zone	
Support for mental illness	Mental Health Forum	
Toilet Phobia		
Coprophobia…		
Social Anxiety and Social Phobia and Agoraphobia Support Group		
Shy Bladder Syndrome Support Group		
Being completely unable to pee when someone else is near (a.k.a Pee -shy)		

completed the internet questionnaire. Of these 434 completed the BBCA survey and 453 completed the panic survey.

Of participants who completed the BBCA survey, 82 were excluded based on survey responses indicating the presence of an underlying *organic* problem that might be associated with regular occurrences of incontinence (e.g. multiple sclerosis, stress and urge incontinence, adverse consequences of surgical procedures, inflammatory bowel diseases). Of these, 51 disclosed episodes of incontinence in the past two weeks. A further 73 participants were also excluded as they reported incontinence in the past two weeks. Of the resulting 279 respondents, further filtering according to their response to the "worst fear" question resulted in the final sample of 239 participants (55.1% of respondents). This group differed from the 195 respondents who were not included in terms of gender ($p=0.02$) but not in terms of age ($p=0.79$).There were more men (39.8%) in the excluded sample than in the included group (26.1%).

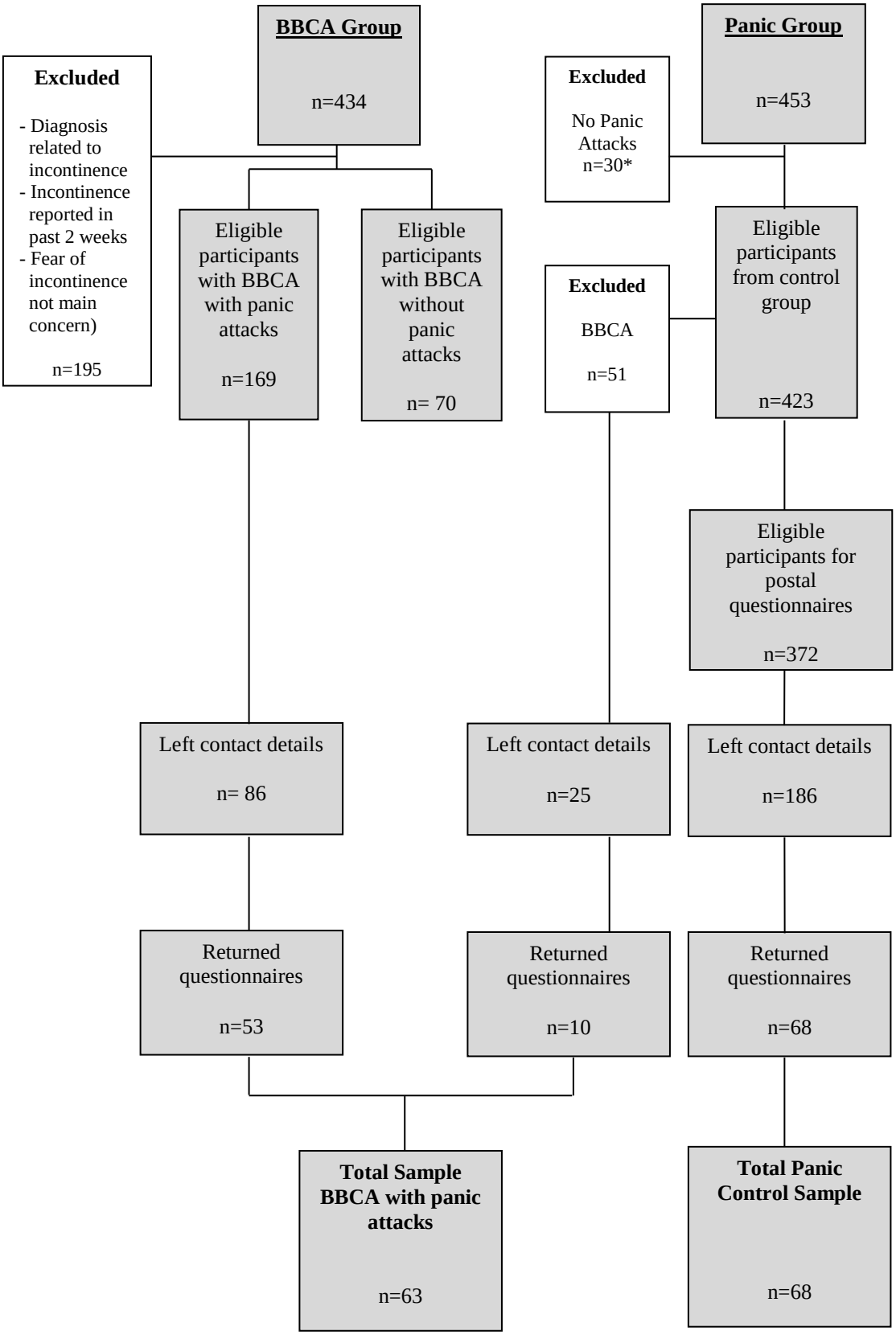
Thirty participants were excluded from the panic survey group as they reported that they did not experience panic attacks, leaving a sample of 423 participants whose responses to the internet questionnaire are reported. Of these, 51 participants in the control group indicated that their main (catastrophic) fear was of incontinence and these were excluded from the second part of the study, leaving a total of 372 panic controls who were eligible for the postal questionnaire.

For the second part of the study, a power calculation using the 'G*Power' computer program (Faul, Erdfelder, Lang & Buchner, 2007) assuming medium effect sizes ($d=0.5$-0.6) with an alpha level of $p=.005$ and power of 0.8, suggested a sample of n=156-218 participants required (n=76-109 per group). This figure accords with the study by van Overveld, de Jong, Peters, Cavanagh and Davey (2006; n=181)

which found large differences (effect size; η^2=0.51) in disgust sensitivity between emetophobics and a co-comparison group. The alpha level of p=.005 was adjusted downwards on the basis of using multiple comparisons (n=17). This was deemed a suitable alternative to using Bonferroni adjustments as Perneger (1998) showed that Bonferroni adjustments can be overly conservative, thereby increasing the likelihood of Type 2 errors and this can affect exploratory research. Using the Bonferroni method, the alpha level would have been set at p=.003 due to the multiple numbers of tests. By using a marginally higher p-value of p=.005 a balance between Type 1 and Type 2 errors in exploratory research is achieved. The actual numbers of participants were n=63 in the BBCA with panic group and n=68 in the panic group.

Participants who had left their contact details and met the inclusion criteria were invited to complete a postal questionnaire. Participants from the control group who had indicated a fear of incontinence and met the inclusion criteria were invited to complete the questionnaire related to BBCA and n=10 participated. These participants were similar to the overall sample of participants with BBCA. Figure 1 shows the participant flow through the study.

Figure 3 Participant Flow through the Study



Note: * n=4 of the participants who did not have panic attacks had BBCA

Materials

Study 1

BBCA Internet Survey

Since there are no specific assessment instruments relating to fear of losing bowel/bladder control, a set of questions was devised as part of the wider project at UCL which aimed to extend our understanding of people who experience BBCA. This was based on clinical experience of the trainee and her supervisors and consultation with Paul Salkovskis (an expert in cognitive behaviour therapy who took part in a seminar event on Toilet Phobia at the Royal Society of Medicine in October 2005; Salkovskis, 2005) who provided written feedback by E-mail.

The internet survey (Appendix C) contained items relating to demographics, chronicity of the problem, help-seeking specifically related to fear of losing bowel/bladder control, clinical symptoms (presence, severity and frequency of panic attacks; avoidance), beliefs about the 'cause' of their fear of incontinence and presence of panic attacks.

The phenomenological characteristics of catastrophic thinking were evaluated by asking participants whether they experienced intrusive mental images related to being incontinent. Participants responded 'yes'/'no' to this question. If they responded yes, they were asked to indicate frequency (number of times per week) and associated distress on a 0-8 scale (0 not distressing at all; 8=very severely distressing). At the end of the survey there was space for participants to add additional comments and to leave personal details if they wished to participate in future research.

The Work and Social Adjustment Scale (WASAS; Mundt, Marks, Shear, & Greist, 2002) was used to assess the degree to which bowel/bladder-control

anxiety impairs ability to perform work, home management, social leisure, private leisure and family/relationship activities (e.g. Responses are on a 0-8 scale (not at all-very severely) and the range of total scores is 0-40. Scores above 20 are associated with moderate-severe levels of distress; scores between 10 and 20 with mild-moderate and scores below 10 with sub-clinical levels of distress. The WASAS has been shown to be a valid, reliable and change-sensitive measure of work, social and other adjustment (Mataix-Cols *et al.*, 2005). Internal consistency as measured by Cronbach's α ranges from 0.70 to 0.94 and test-retest correlation was 0.73 (Mundt, Marks, Shear & Greist, 2002).

Following a detailed description of a panic attack (a sudden increase in anxiety accompanied by four or more symptoms (American Psychiatric Association, 2000; Wells, 1997), participants indicated the presence or absence of panic attacks. If present, participants rated the frequency of panic on a 0-4 scale (0=no panic attacks; 1=one panic attack per fortnight; 2= One or two panic attacks per week; 3=at least three panic attacks per week; 4=one or more panic attacks per day; Wells, 1997) and severity on a 0-8 scale (0=not at all disturbing/disabling; 8=very disturbing/disabling). They also indicated whether their main concern was that they would be incontinent during a panic attack and whether they have ever been incontinent during a panic attack.

Avoidance was assessed using the **Improving Access to Psychological Therapies (IAPT) phobia scale**, which is a condensed (three-item) version of the Fear Questionnaire (Marks & Mathews, 1979) assessing social, agoraphobic and specific-phobic domains on a 0 -8 scale (e.g. 0=would not avoid it; 4=definitely avoid it; 8=always avoid it). A score of four or greater is indicative of possible clinical disorder (IAPT data sourcebook, 2010).

Fear of Incontinence Scale (FOIS)

In addition, a questionnaire called the Fear of Incontinence Scale (FOIS) was designed to help distinguish between participants with fear of incontinence and those who do not have this concern. Items of the questionnaire were developed in collaboration with the main thesis supervisors and several experts in cognitive behaviour therapy: Chris Brewin, David Veale, Peter Scragg and Paul Salkovskis. The experts were all sent a copy of the questionnaire by E-mail and they provided written feedback on the items which informed the choice of the items included in the final version of the questionnaire.

The FOIS was made up of a series of questions inquiring about avoidance and safety behaviours (e.g. '*I limit the amount of food I eat and/or the amount of fluids I drink to reduce the chance of being incontinent*'), attentional symptoms and checking (e.g. '*I often check for sensations in my bladder or bowels*'), catastrophizing, shame and disgust (e.g. '*I often think about how awful it would be if I was actually incontinent in a public place;*' '*Being incontinent in public would mean I am a disgusting person'*) as well as catastrophizing about non-bowel/bladder-control concerns (e.g. '*I worry about having a heart attack or choking*'). The latter item was included to determine whether catastrophizing was general, or more specific to bowel and bladder-control related concerns. These statements were rated on a nominal rating scheme according to degree of agreement: 0=strongly disagree (very untrue of me), 1=mildly disagree (somewhat untrue of me); 2=neither agree nor disagree, 3=mildy agree (somewhat true of me), 4=strongly agree (very true of me).

Control Group Internet Survey

The control group of people with panic attacks completed a shorter version of the internet survey (Appendix D) which included the same demographic questions and

the WASAS, IAPT Phobia Scale and FOIS. Apart from the FOIS, the questionnaire excluded the questions related specifically to BBCA i.e. those asking about onset, help-seeking, disclosure related to BBCA. However, they were asked if they had ever been incontinent and if they had experienced incontinence in the last two weeks.

Presentation of Internet Surveys

Both of the surveys were set up using a platform called Opinio, an online system which allows creation, publication, analysis, and maintenance of surveys. A link to the survey was given in the adverts (Figure 1) and this took participants to the consent form for the study (Appendix B). If participants wanted to take part in the study, they could click on a button at the end of the consent form to confirm their participation. Subsequently, they were presented with the survey.

Consent for Postal Survey

At the end of the survey for both the BBCA as well as the panic sample, participants were asked to indicate if they would like to take part in a further study involving postal questionnaires. Those who agreed were sent a study information sheet, a consent form as well as the questionnaire for study 2 and were asked to return them in a pre-paid envelope.

Study 2

Postal Questionnaire measures

The postal questionnaire consisted of twelve validated measures which were completed by both participants with bladder/bowel-control anxiety and by panic controls.

Patient Health Questionnaire: PHQ-9. (Kroenke, Spitzer, & Williams, 2001) The PHQ-9 is a nine item self-report questionnaire in which respondents rate the presence of the nine core symptoms of a major depressive episode over the

preceding two weeks (e.g. ‘Feeling down, depressed, or hopeless’). The PHQ-9 score ranges from 0 to 27, since each of the 9 items is scored from 0 (not at all) to 3 (nearly every day). It has been shown to be a valid instrument to screen for depression with sensitivity=0.93 and specificity=0.85 (Wittkampf, Naeije, Schene, Huyser, & van Weert, 2007).

Generalised Anxiety Disorder Assessment: GAD-7. (Spitzer, Kroenke, Williams, & Lowe, 2006) The GAD-7 is a seven item, self-rated inventory developed to assess generalized anxiety disorder symptoms over the preceding two weeks (e.g. ‘Worrying too much about different things’). Each item is scored 0 (‘not at all’) to 3 (‘nearly every day’), providing a 0 to 21 severity score. The GAD-7 has been shown to be a reliable and valid measure of anxiety in the general population (Löwe *et al*., 2008) and has demonstrated adequate internal consistency (α = .79-.91) (Dear *et al*., 2011). It can also be used to screen for several anxiety disorders (Kroenke, Spitzer, Williams, Monahan, & Löwe, 2007).

Obsessive Compulsive Inventory-Short Version: OCI-SV. (Foa *et al*. 2002)

The OCI-SV is an 18-item self-report scale which measures concerns related to obsessive compulsive disorder (e.g. ‘I check things more often than necessary’). Each item is rated on a scale from 0 (‘not at all’) to 4 (‘extremely’) in terms of distress or how much it bothers respondents, yielding a score of 0 to 72. Foa *et al.* (2002) showed that the OCI-SV has excellent test-retest reliability and high internal consistency.

Social Phobia Inventory: SPIN. (Connor *et al*., 2000)

The SPIN is a 17-item measure of social phobia which evaluates fear, avoidance and physiological discomfort. Each item (e.g. ‘I avoid talking to people I

don't know') is rated on a scale from 0 ('not at all') to 4 ('extremely'), resulting in a total score which ranges from 0 to 68, with higher scores corresponding to greater distress. The SPIN has been shown to be a reliable and valid measure of social phobia severity (Antony, Coons, McCabe, Ashbaugh, & Swinson, 2006).

The Mobility Inventory for Agoraphobia: MI. (Chambless, Caputo, Jasin, Gracely & Williams , 1985)

The MI is a self-report measure of agoraphobic avoidance behaviours as well as panic attacks (frequency and intensity). Respondents rate 26 situations (e.g. 'Restaurants') on five-point Likert scales as to the degree they are avoid them 'when alone' and 'when accompanied'. The MI has good reliability and validity (Chambless *et al.,* 1985) and Craske, Rachman, and Tallman (1986) showed that it can discriminate agoraphobic patients from those with other anxiety disorders.

Body Vigilance Scale: BVS. (Schmidt, Lerew & Trakowski, 1997)

The BVS is a 4-item self-report measure of attentional focus on interoceptive activity. It assesses the degree of attentional focus, perceived sensitivity towards changes in bodily sensations (e.g. 'I am very sensitive to changes in my internal bodily sensations'), and the average amount of time spent scanning for bodily sensations. The final item involves separate sensitivity ratings on a 10-point scale (0-'not at all like me' to 10-'extremely like me') for attention to 15 sensations which are related to panic attacks following the statement 'I am very sensitive to changes in my internal bodily sensation' and an average score is yielded for these ratings. The BVS has acceptable internal consistency (α = .74 to .84), adequate test-retest reliability (r = .58 to .69) (Schmidt *et al.,* 1997) and good predictive utility (Olatunji, Deacon, Abramowitz & Valentiner, 2007).

Disgust Propensity and Sensitivity Scale-Revised: DPSS-R. (Olatunji, Cisler, Deacon, Connolly, & Lohr, 2007)

The 16-item DPSS-R measures disgust propensity (the extent to which disgust is experienced; e.g. 'I experience disgust') and sensitivity (how upsetting the disgust experience is considered to be; e.g. 'I think feeling disgust is bad for me'). Items are rated on a scale from 1 ('never') to 5 ('always') with total scores ranging from 16 to 80. The DPSS-R has demonstrated good reliability and validity (α=.90) (Olatunji, Cisler, *et al*., 2007).

Anxiety Control Questionnaire: ACQ. (Rapee, Craske, Brown & Barlow, 1996)

The ACQ is a 30-item self-report measure which assesses perceived control over external events and internal reactions which are relevant to emotional disorders (e.g. 'When I am frightened by something, there is generally nothing I can do'). Items are scored on a scale of 0 ('strongly disagree') to 5 ('strongly agree') and a total score is obtained by adding all of the scores. Eighteen of the items are reverse scored in order to avoid response bias. It has demonstrated good reliability, validity and sensitivity (Rapee *et al*., 1996, Zebb & Moore, 1999).

Bowel Symptom Severity Scale: BSSS. (Boyce, Gilchrist, Talley & Rose, 2000)

The BSSS is a self-report measure of frequency, disability and distress for eight gastrointestinal symptoms over the previous week (e.g. 'Over the past week how often have you had abdominal (tummy) pain?'). Symptoms are given a severity rating between 0 and 4 and they are summed to compute three subscales, with higher ratings for each subscale indicating greater severity. The BSSS has demonstrated higher internal consistency (α=.88) (Boyce *et al*., 2000).

Urgency Perception Score: UPS. (Blaivas, Panagopoulos, Weiss, Somaroo & Chaikin, 2007)

The UPS is a 5-item self-report measure which grades the urge to void and assesses the reason why individuals usually void (e.g. 'What is the reason that you usually urinate?'). The first three items are rated on a scale of 0 to 4 whilst the final item is rated on a scale of 0 ('perfect bladder control') to 10 ('no bladder control') with higher scores indicating higher levels of urinary urgency. It appears to be a valid and reliable means of grading urinary urgency (Blaivas *et al*., 2007).

Internalized Shame Scale: ISS. (Cook, 2001)

The ISS a 30-item self-report inventory designed to measure levels of internalised shame (e.g. 'When I compare myself to others I am just not as important.') Participants rate how they generally feel on a 5-point scale from 0 ('never') to 4 ('almost always'), yielding a total shame score with a range of 0 to 120 as well as two subscale scores for self-esteem and shame. The ISS has good internal consistency (α=.95 and .89) and test-retest reliability (del Rosario & White, 2006).

Statistical Analysis

Data were analysed in Statistical Package for Social Sciences version 21 using independent sample t-tests or one-way ANOVA for continuous data and chi-square for categorical data. In the event of violation of any statistical assumption, alternative analytic methods (e.g. non-parametric statistics) were used. Due to multiple testing (n=17), the alpha level for the main analyses for study 2 was set at p=.005, thereby balancing the risk of Type 1 and Type 2 errors.

An exploratory principal components analysis was used to determine the factor structure and the construct validity of the FOIS. Three items were excluded from the analysis. Items 11('I worry about having a heart attack or choking) and 19

('I worry about losing control or going crazy') had been deliberately designed to establish whether catastrophising was more general or specific to concerns relating to fear of incontinence. Item 5 ('My worst fear is that I would be incontinent in public') was excluded from the analysis as it had been used as an inclusion question and for the BBCA sample only those who scored either 3 or 4 on this item were included in the study. Sampling adequacy was tested for using the Kaiser-Meyer-Olkin test and Bartlett's statistic. Communalities were examined for all items and any items with inadequate communalties (<.4) were excluded. Varimax rotation was then used to rotate the factor structure and determine the number of factors of the FOIS. Then the amount of variance accounted for by these factors was established.

Finally, a step-wise binary logistic regression was run with the main predictors in the second part of the study.

Results

Study 1

Demographics: eligible sample

The eligible sample of respondents (Table 1) with BBCA (n=239) was divided into those who also suffered from panic attacks (n=169) and those who did not suffer from panic attacks (n=70). The mean age of the two groups (31.10 ± 11.11 and 30.96 ± 11.67 respectively) was not significantly different ($t(237)=-0.09$, $p=.93$), whilst the mean age of the panic control group (n=423; 27.89 ± 9.33) was significantly lower than the other two groups combined ($t(660)=3.87$, $p<.001$). There were significant between group differences in terms of gender and employment status ($p<.01$) but not in terms of marital status ($p>.05$). There was no significant difference between the gender ratios of the two groups who had panic ($\chi^2(1)=0.75$,

p=.39), but there were significantly more men in the group who did not have panic compared to those with BBCA with panic attacks ($\chi^2(1)=10.18$, df=1,p=.001) and the panic group ($\chi^2(1)=.75$, df=1, p=.39). The three groups were similar in terms of the marital status of respondents ($\chi^2(6)=5.45$, p=0.49), but the panic control group differed significantly on employment status compared to those with BBCA with panic ($\chi^2(1)=28.65$, df=6, p<.001) and BBCA without panic ($\chi^2(1)=22.64$, df=6, p=.001), with fewer people employed/self-employed and more students in this group.

Table 1
Demographics of the three groups of respondents

Variable	BBCA with panic (n=169) n (%)	BBCA without panic (n=70) n (%)	Panic Control Group (n=423) n (%)	Results of statistical tests
Gender				
Women	135 (79.9)	42 (60.0)	324 (76.6)	χ^2=11.16, df=2, p=.004
Men	34 (21.1)	28 (40.0)	99 (23.4)	
Age				
Mean Age (Standard Deviation)	31.10 (11.11)	30.96 (11.67)	27.89 (9.33)	F(2,661)=7.55, p=.001
Marital Status				
Single	96 (56.8)	38 (54.3)	272 (64.3)	χ^2=5.45, df=6, p=.49
Married or co-habiting	66 (39.1)	30 (42.9)	140 (33.1)	
Widowed	1 (0.6)	0 (0)	2 (0.5)	
Divorced	6 (3.6)	2 (2.9)	9 (2.1)	
Employment				
Employed or self-employed	81 (47.9)	36 (51.4)	122 (28.8)	χ^2=49.92, df=12, p<.001
Homemaker	7 (4.1)	0 (0)	12 (2.8)	
Unemployed	17 (10.1)	2 (2.9)	40 (9.5)	
Long-term sick leave	6 (3.6)	3 (4.3)	14 (3.3)	
Student	54 (32.0)	27 (38.6)	227 (53.7)	
Retired	3 (1.8)	2 (2.9)	2 (0.5)	
Other	1 (0.6)	0 (0)	6 (1.4)	

Problem History

Table 2 shows that the mean age of onset between the two groups with BBCA was similar ($t(237)=0.10$, $p=.92$) and that they were also similar ($\chi^2=3.02$, $df=2$, $p=.221$) in terms of their predominant concern (i.e. bladder-control, bowel-control or both bladder-and bowel-control). They were also similar ($\chi^2=-0.98$, $df=1$, $p=.33$) in terms of whether or not they had disclosed their BBCA to someone (including friends/family). However, help-seeking was similar amongst the groups who experienced panic attacks ($\chi^2=0.31$, $df=1$, $p=.58$), but it was significantly lower in the group who did not experience panic attacks compared to both BBCA with panic ($\chi^2=11.11$, $df=1$, $p=.001$) and the panic group ($\chi^2=10.63$, $df=1$, $p=.001$). In terms of beliefs about the 'cause' of their BBCA, compared to participants who did not have panic attacks more respondents who had panic attacks indicated that their fear was due to 'anxiety' ($\chi^2=18.54$, $df=1$, $p<.001$) or a 'near miss' ($\chi^2=5.12$, $df=1$, $p=.02$) and fewer indicated that it was due to 'stress' ($\chi^2=5.76$, $df=1$, $p=.02$) or 'urge incontinence' ($\chi^2=6.44$, $df=1$, $p=.01$).

In line with study goals, a relatively small proportion of participants in the two groups of respondents with BBCA (3.6% and 5.7%) had experienced incontinence ≥5 times and the majority (58.6% and 47.1%) had never been incontinent suggesting that symptoms and impairment outlined below are generally not a response to frequent experiences of incontinence. In comparison, of the 195 respondents who did not meet inclusion criteria 43.6% and 4.3% of the panic control group had experienced incontinence ≥5 times. Respondents in the panic control group reported a range of main concerns including fears relating to BBCA (12.1%) but the largest percentages were related to fear of acting foolishly (20.8%) and fear of suffocating / not being able to breathe (16.3%).

Table 2
Description of the problem history of the respondents

Variable	BBCA with panic (n=169) n (%)	BBCA without panic (n=70) n (%)	Panic Control Group (n=423) n(%)	Results of statistical tests
Incontinent				
Never	99 (58.6)	33 (47.1)	344 (81.3)	χ^2=479.69, df=8, p<.001
Once	33 (19.5)	18 (25.7)	25 (5.9)	
2-4 Times	31 (18.3)	15 (21.4)	36 (8.5)	
More than 5 times	6 (3.6)	4 (5.7)	18 (4.3)	
Main Concern				
Fear of faecal incontinence	65 (38.5)	19 (27.1)	16 (3.8)	
Fear of Urinary Incontinence	78 (46.2)	40 (57.1)	19 (4.5)	
Fear of both urinary and faecal incontinence	26 (15.4)	11 (15.7)	16 (3.8)	
Fear of acting foolishly			88 (20.8)	
Fear of suffocating / not being able to breathe			69 (16.3)	
Fear of fainting			50 (11.8)	
Fear of vomiting			41 (9.7)	
Fear of having a heart attack			45 (10.6)	
Fear of choking			5 (1.2)	
Other			74 (17.5)	
Mean Age of onset of BBCA (standard deviation)	20.86 (10.36)	21.01 (10.94)	-	t(237)=.10, p=.92
Panic Attacks				
Incontinence is main concern during panic attack	105 (62.1)	-	44 (10.4)	χ^2=171.56, df=1, p<.001
Ever been incontinent during panic attack	17 (10.1)	-	24 (5.7)	χ^2=3.60, df=1, p=.06
Help Seeking	83 (49.1)	18 (25.7)	197 (46.6)	F(2,659)=6.13, p=.002
Disclosure of BBCA	101 (59.8)	37 (52.9)	- -	χ^2=-.98, p=.33
Beliefs about cause				
Anxiety	100(59.2)	20 (28.6)	-	
Stress	49 (29.0)	10 (14.3)	-	
IBS	25 (14.8)	8 (11.6)	-	
Urge Incontinence	11 (6.5)	12 (17.1)	-	
Infection	7 (4.1)	6 (8.6)	-	
Experience of incontinence in public	54 (32.0)	26 (37.1)	-	
'Near miss' of being incontinent in public	67 (39.6)	17 (24.3)	-	
Don't Know	13 (7.7)	5 (7.1)	-	
Other	8 (4.7)	6 (8.6)	-	

Of those respondents with BBCA who had panic attacks, the majority (62.1%) reported that losing control of their bladder or bowel was their main concern during a panic attack and 17 (10.1%) reporting being incontinent during a panic attack which suggests that in some individuals, their catastrophic fear has a basis in reality. In comparison, the number of participants in the panic control group who had been incontinent during a panic attack was not significantly different (χ^2=3.60, df=1, p=.06) but significantly fewer respondents reported incontinence as their main concern during a panic attack (χ^2=171.56, df=1, p<.001).

Avoidance and impairment

Using the IAPT phobia scales, only the avoidance score for panic symptoms for people with BBCA who also have panic was above the proposed clinical cut-off (i.e. >4). This group was significantly more likely to avoid situations due to a fear of having a panic attack than those without panic (t(237)=-6.21, p<.001) and the panic group (t(590)=4.40, p<.001). Respondents with BBCA who do not have panic attacks had significantly lower avoidance (p<.001) and impairment (p<.001) scores than the other two groups. Both of the groups who experience panic attacks had impairment scores in the mild-moderate range and their scores were not significantly different from each other (t(590)=-0.43, p=.67) (Table 3).

Table 3
Avoidance and Impairment scores for the three groups of respondents

	BBCA group with panic (n=169)	BBCA group without panic (n=70)	Panic control group (n=423)	One-way ANOVA
	Mean (SD)	Mean (SD)	Mean (SD)	
Avoidance (IAPT Phobia Scale)				
Social Situations	3.72 (2.50)	2.50 (2.01)	3.33 (2.31)	F(2,661)=6.80, p=0.001
Panic Symptoms	4.21 (2.41)	2.19 (1.99)	3.26 (2.35)	F(2,661)=20.45, p<0.001
Objects/activities (specific phobia)	3.09 (2.40)	1.54 (1.88)	3.22 (2.50)	F(2,661)=14.60, p<0.001
Impairment (WASAS total)	13.72 (8.41)	8.84 (7.25)	14.06 (8.92)	F(2,661)=11.12, p<0.001

Beliefs and behaviours relating to loss of bowel/bladder-control - FOIS

Table 4 summarises the data for the three groups, which for brevity presents modal responses along with the percentage of modal responses for each item. There was a general tendency towards responding with strong agreement (or 'very true of me' responses) in the BBCA with panic attacks group and with strong disagreement (or 'very untrue of me') in the panic control group. The results for the BBCA without panic attacks presented a mixed picture, which generally reflected mild or strong agreement on the same items as the BBCA group with panic attacks. However, on three of the items (avoiding public transport, avoiding crowded places and worrying about losing control/going crazy), this groups' responses was the opposite of those with panic attacks (i.e. strong disagreement) and in line with responses of the panic control group.

BBCA participants with panic attacks expressed strong agreement to statements about attending to internal, viscerally-centred sensations as well as relevant external stimuli (location of toilets in unfamiliar places). There was no difference in the modal responses to using medications to stop incontinence and wearing extra underclothes or padding between the three groups. Other catastrophic concerns about losing (mental) control were only present in the BBCA group with panic attacks (mild agreement). All groups expressed strong disagreement on the item about more general somatic concerns (having a heart attack or choking).

Table 4

Bowel and bladder control specific questions (modal values) and percentage values of the proportion of participants in each group scoring the modal value.

Questionnaire Item	BBCA Group (with panic)	BBCA Group (without panic)	Panic Control Group
	Mode (%)	Mode (%)	Mode (%)
Attentional Symptoms and Checking			
I often notice sensations in my bladder/bowels, especially when I am anxious	5 (72.8)	5 (47.1)	1 (35.9)
If I go to an unfamiliar place, one of the first things I would do is look for the toilets	5 (68.6)	5 (38.6)	1 (51.5)
I notice other symptoms (e.g. heart racing, sweating, trembling) when I need to go to the toilet and cannot easily get to one	5 (70.4)	5(22.9)	1 (53.7)
I often check for sensations in my bladder or bowels	5 (47.3)	4 (37.1)	1 (55.6)
Avoidance and safety behaviours			
I limit the amount of food I eat and/or the amount of fluids I drink to reduce the chance of being incontinent	5 (45.6)	4 (38.6)	1 (68.3)
I avoid using public transport in case I am incontinent	5 (35.5)	1 (34.3)	1 (73.3)
I use medications to stop myself being incontinent	1 (48.5)	1 (62.9)	1 (85.1)
If I go out of the house I wear extra underclothes or I use padding in case I am incontinent	1 (37.9)	1 (54.3)	1 (83.0)
When I am out of the home, I make a mental note of where toilets are located in case I need to use one urgently	5 (66.3)	4 (34.3)	1 (60.0)
I avoid crowded places in case I am incontinent	5 (25.4)	1 (44.3)	1 (79.0)
I avoid certain work or social activities because of a fear of being incontinent	5 (42.0)	4 (32.9)	1 (73.8)
Catastrophizing, shame and disgust			
I often think about how awful it would be if I was actually incontinent in a public place	5 (53.8)	4 (40.0)	1 (62.2)
Being incontinent is the most shameful thing that could happen to a person	5 (30.8)	4 (31.4)	1 (59.1)
Being incontinent in public would mean I am a disgusting person	5 (39.1)	4 (35.7)	1 (44.9)
Other people would think I was a disgusting person if I was incontinent	5 (49.7)	4(44.3)	1 (38.8)
Other 'catastrophic' cognitions			
I worry about losing control or going crazy	5 (33.1)	1 (48.6)	4 (32.9)
I worry about having a heart attack or choking	1 (58.6)	1 (75.7)	1 (40.4)

Note: 5=Strongly agree, 4=mildly agree, 3=neither agree/disagree, 2=mildly disagree; 1=strongly disagree

Characteristics of the FOIS

In order to determine the extent to which concerns relating to incontinence were unique to the sample with BBCA, it was necessary to first examine whether the FOIS is a sufficiently robust measure. The results of the FOIS for all of the eligible participants (n=239 from the BBCA and n=423 from the panic group) were analysed to determine its characteristics.

Principal components analysis – FOIS

An exploratory principal components analysis was performed for the FOIS (n=662) to assess its factor structure. Items 11(‘I worry about having a heart attack or choking) and 19 (‘I worry about losing control or going crazy’) were not included in the factor analysis as they measured panic symptoms not related to BBCA. These items had been deliberately designed to establish whether catastrophising was more general or specific to concerns relating to BBCA. Item 5 (‘My worst fear is that I would be incontinent in public’) was also excluded from the analysis as it had been used as an inclusion question and for the BBCA sample only those who scored either 3 or 4 on this item had been included in the study.

Excellent sampling adequacy was found with the Kaiser-Meyer-Olkin test (KMO = 0.96) and Bartlett’s statistic (10076, df=136, $p < 0.001$) indicated that the sample was adequate for factor analysis. As communalities were inadequate (<0.4) for items 7 (‘If I go out of the house I wear extra underclothes or I use padding in case I am incontinent’) and 18 (‘I use medications to stop myself being incontinent’), these items were excluded from the questionnaire along with the excluded items mentioned above (5 & 11 & 19).

Varimax rotation was used to rotate the factor structure and two latent factors emerged (Table 5) which together accounted for 73% of the variance. The first factor

(avoidance/safety behaviours/QoL), which included twelve items of the FOIS, accounted for 51.8% of the variance in the model and the second factor (disgust and shame), which included three items, accounted for 20.9% of the variance. Table 5 shows the loading of the items on each of the two emergent factors as well as the communalities. Item 13 ('I often think about how awful it would be if I was actually incontinent in a public place') loaded more than 0.4 on both factors, but as its loading on the first factor was significantly higher, it was excluded from the second factor. Cronbach's alpha for the two factors were 0.96 and 0.86 respectively and the correlation was 0.57 ($p<.001$). If panic items 11 & 19 were included, the questionnaire has a three factor structure. These two excluded items form a third factor which confirms that they measure a separate construct.

Table 6 shows group differences on the FOIS total scores which were explored by excluding participants in the control group whose fears related to BBCA, leaving a control group of n=372. There were significant group differences ($p<0.001$) on total FOIS score FOIS Factor 1 and FOIS Factor 2.When combining the two groups of participants with BBCA (n=239), all of the FOIS scores were significantly higher compared to panic controls ($p<0.001$). Compared to those who did not have panic attacks, participants with BBCA with panic attacks had significantly higher scores on FOIS Total ($t(539)=28.07$, $p<0.001$), FOIS Factor 1 ($t(539)=29.13$, $p<0.001$) and FOIS Factor 2 ($t(539)=13.71$, $p<0.01$).

Table 5
Factor Loadings and communality of the FOIS

No.	Items	Factors		Communalities
		First Factor (avoidance/ safety behaviours/ QoL)	Second Factor (disgust and shame)	
1	I often notice sensations in my bladder/bowels, especially when I am anxious	**0.673**	0.293	0.539
2	I avoid using public transport in case I am incontinent	**0.844**		0.752
3	I limit the amount of food I eat and / or the amount of fluids I drink to reduce the chances of being incontinent	**0.795**	0.241	0.690
4	If I go to an unfamiliar place, one of the first things I would do is look for the toilets	**0.808**	0.289	0.736
6	Being incontinent in public would mean I am a disgusting person	0.231	**0.860**	0.793
8	I notice other symptoms (e.g. heart racing, sweating, trembling) when I need to go to the toilet and cannot easily get to one	**0.745**	0.365	0.688
9	I avoid certain work or social activities because of a fear of being incontinent	**0.873**	0.258	0.828
10	My relationships have been affected by a fear of being incontinent	**0.800**	0.252	0.703
12	I avoid crowded places in case I am incontinent	**0.765**	0.302	0.676
13	I often think about how awful it would be if I was actually incontinent in a public place	**0.721**	**0.463**	0.734
14	When I am out of the home, I make a mental note of where toilets are located in case I need to use one urgently	**0.828**	0.317	0.786
15	My ability to work, study or socialize has been affected by a fear of being incontinent	**0.869**	0.280	0.833
16	Being incontinent is the most shameful thing that could happen to a person	0.392	**0.744**	0.708
17	I often check for sensations in my bladder or bowels	**0.745**	0.302	0.646
20	Other people would think I was a disgusting person if I was incontinent	0.249	**0.862**	0.805

Note: Items 5, 7, 11, 18 and 19 were not included; Loadings of >0.4 are displayed in bold

Table 6
FOIS group differences

	Bladder/bowel control anxiety with panic (n=169)	Bladder/bowel control anxiety without panic (n=70)	Panic Control Group (n=372)	One-way ANOVA
FOIS Factor 1	48.12 (10.39)	37.79 (11.19)	20.32 (10.24)	$F(2,610)=437.65$, $p<0.001$
FOIS Factor 2	11.08 (3.45)	9.66 (3.18)	6.56 (3.60)	$F(2,610)=103.26$, $p<0.001$
FOIS Total	59.20 (12.28)	47.44 (12.44)	26.88 (12.47)	$F(2,610)=415.83$, $p<0.001$

Study 2: Comparison of participants who experience panic attacks with or without BBCA

Demographics and questionnaire scores

Table 7 shows that participants with BBCA and panic were similar in terms of gender, age, marital status and employment status.

Table 8 shows the mean scores and standard deviations obtained by the two groups on a variety of measures of impairment, depression, anxiety, OCD, social phobia and agoraphobia. As performing multiple statistical tests increases Type 1 error, a lower level of significance ($p<.005$) was chosen. The two groups were similar in terms of their scores on all of the measures.

Table 9 shows that the BBCA group scored significantly higher on the UPS (a measure of urinary urgency) than the panic group ($t(129)= 3.22$, $p=.002$). A trend can also be seen on the BSSS frequency score (a measure of bowel symptoms) with higher scores in the BBCA sample ($t(129)= 2.28$, $p=.02$).

Table 7
Demographics of participants with panic attacks

	Bladder/bowel-control anxiety group with panic (n=63)	Panic control group (n=68)	Results of statistical tests
	n (%)	n (%)	
Gender			
Women	55 (87.3)	56 (82.4)	χ^2 =0.62, df=1, p=.43
Men	8 (12.7)	12 (17.6)	
Age			
Mean Age (Standard Deviation)	31.03 (11.75)	30.76 (10.98)	t(129)= 0.13, p=.89
Marital Status			
Single	34 (54.0)	38 (55.9)	χ^2=3.31, df=1, p=.35
Married or co-habiting	24 (38.1)	29 (42.6)	
Widowed	1 (1.6)	0	
Divorced	4 (6.3)	1 (1.5)	
Employment			
Employed or self-employed	27 (42.9)	18 (26.5)	χ^2 = 9.09, df=1, p=.17
Homemaker	4 (6.3)	2 (2.9)	
Unemployed	5 (7.9)	8 (11.8)	
Long-term sick leave	3 (4.8)	4 (5.9)	
Student	22 (34.9)	35 (51.5)	
Retired	2 (3.2)	0	
Other	0	1 (1.5)	

Table 8

Mean Scores and Standard Deviations for Questionnaire Measures

	BBCA group with panic (n=63)	Panic group (n=68)	Results of independent samples t-test
	Mean (SD)	Mean (SD)	
Impairment (WASAS)	14.46 (9.31)	15.75 (9.63)	t(129)= -0.78, p=.44
Anxiety (GAD-7)	11.24 (5.93)	12.26 (5.72)	t(129)= -1.01, p=.32
Depression (PHQ-9)	9.56 (6.11)	11.25 (6.41)	t(129)= -1.55, p=.13
OCD (OCI-SV)	17.86 (12.67)	21.72 (13.70)	t(129)= -1.67, p=.10
Social Phobia (SPIN)	28.27 (16.84)	30.90 (17.61)	t(129)= -.87, p=.39
Agoraphobia – Alone (MIA)	57.84 (27.88)	60.00 (25.64)	t(129)= 1.97, p=.05
Agoraphobia – Accompanied (MIA)	65.40 (28.66)	48.96 (23.77)	t(129)= 1.14, p=.26
Panic Frequency (MIA)	1.76 (2.13)	2.29 (3.21)	t(129)= -1.11, p=.27

Table 9

Mean Scores and Standard Deviations for UPS and BSSS

	BBCA group with panic (n=63)	Panic group (n=68)	Results of independent samples t-test
	Mean (SD)	Mean (SD)	
Bowel Symptoms Frequency (BSSS)	10.68 (5.81)	8.29 (6.16)	t(129)= 2.28, p=.02
Urinary Urgency (UPS)	10.75 (5.12)	7.84 (5.22)	t(129)= 3.22, p=.002*

*Note: * Significant at the p<.005 level*

Results of the main questionnaire measures: disgust, shame, body vigilance, anxiety control and fear of incontinence

Table 10 shows the mean scores and standard deviations obtained by the two groups on the main measures: DPSS, ISS, BVS, ACQ and FOIS. The p values of independent samples t-tests conducted to compare the results for the two groups are also presented. Significant differences ($p<0.001$) were only found for FOIS Factors 1 and 2, whilst scores on DPSS-R for disgust propensity and on the ISS presented a notable trend ($p<.04$)

Logistic Regression of the proposed main predictors: shame, disgust, body vigilance, anxiety control and fear of incontinence

A step-wise binary logistic regression was run with predictors ISS Total, DPSS Propensity, DPSS Severity and BVS. The overall model fit was poor ($\chi^2(8)=3.67$, $p=.89$), Cox & Snell's R^2 revealed only 7% variance was explained by the model. Adding the ACQ total score did not improve the predictive value of the model or overall model fit and it was therefore excluded from the final analysis. However, if the FOIS Factor 1 and FOIS Factor 2 scores were added instead, the overall model fit improved ($\chi^2(8)=5.68$, $p=.68$) and Cox & Snell's R^2 revealed that 53% of the variance was explained by the model (See Table 11 for parameter estimates and significance tests).

However, as the test of the full model against a constant only model remained statistically non-significant, this indicates that the predictors as a set do not reliably distinguish between participants with BBCA in a sample of participants with panic attacks. The Wald criterion demonstrated that only FOIS Factor 1 made a significant contribution to prediction ($p<.001$).

Table 10

Scores and independent samples t-tests for disgust, shame, body vigilance, anxiety control and fear of incontinence

	BBCA group with panic (n=63)	Panic control group (n=68)	Results of independent samples t-tests
	Mean (SD)	Mean (SD)	
Disgust Propensity (DPSS-R)	12.35 (7.48)	15.07 (7.41)	t(129)= -2.09, p=.04
Disgust Sensitivity (DPSS-R)	11.56 (6.85)	13.59 (7.03)	t(129)= -1.67, p=.10
Shame (ISS)	63.76 (18.39)	70.21 (20.55)	t(129)= -1.89, p=.06
Body Vigilance (BVS)	33.40 (13.73)	30.68 (14.51)	t(129)= 1.10, p=.27
Anxiety Control (ACQ)	68.05 (18.61)	63.75 (22.38)	t(129)= 1.19, p=.24
Fear of Incontinence Scale (FOIS Factor 1)	47.11 (10.94)	22.65 (11.74)	t(129)= 12.31, p<.001*
Fear of Incontinence Scale (FOIS Factor 2)	10.48 (3.76)	7.78 (3.95)	t(129)= 4.00, p<.001*

*Note: * Significant at the p<.005 level*

Table 11
Outcome of the Logistic Regression Analysis for the main predictors.

	Measure	B	S.E.	Wald	df	P	Exp(B)	95% Confidence for Exp(B) (Lower-Upper)
Step 1	ISS Total	.03	.02	2.39	1	.12	1.03	.99-1.06
	DPSS Propensity	<.001	.05	<.001	1	1.00	1.00	.91-1.10
	DPSS Sensitivity	.09	.06	2.33	1	.13	1.09	.98-1.22
	BVS	-.01	.02	.17	1	.68	.99	.95-1.04
	FOIS Factor 1	-.16	.03	34.90	1	<.001*	.85	.81-.90
	FOIS Factor 2	.04	.09	.23	1	.63	1.04	.88-1.24
	Constant	2.58	1.13	5.29	1	.02	13.28	

*Note: * Significant at the p<.005 level*

Discussion

The study outlines for the first time some basic characteristics of BBCA. It further describes some basic psychometric properties of a measure which helped differentiate between participants with panic attacks with and without associated fear of incontinence. In study 2 a subset of people with BBCA and panic compared to a panic sample without this fear highlighted that while the groups were similar in many respects, the FOIS, as a measure that specifically inquires about fears of loss of control of bowel/bladder functioning, was the only predictor of group membership, in contrast to disgust, shame, body vigilance and anxiety control. The findings are discussed in detail below.

Key findings

The majority of participants with BBCA were female and the mean age of onset was in the early 20s. There was a high prevalence of panic attacks and help-seeking was higher in those suffering from panic attacks. Half of participants had experiences of being incontinent. There was a frequent strong endorsement of disgust- and shame-based cognitions in the overall sample of participants with BBCA.

The FOIS was shown to be reliable, internally consistent and construct valid measure of BBCA and two factors emerged which measured different aspects of this fear. The FOIS was highlighted as a superior predictor of BBCA in a comparison of participants with panic attacks and panic controls whilst other proposed predictors (disgust, shame, body vigilance and anxiety control) were not significant.

Characteristics of BBCA

Firstly, considering the sample of participants with BBCA alone, these participants showed characteristics very similar to those described in the only other study of a group of patients with BBCA such as a high prevalence of panic and preponderance of women sufferers (Lelliot *et al*., 1991). The mean age of onset of incontinence related fears was in the early 20s. The proportion of participants with bladder *versus* bowel *versus* bladder and bowel anxiety in the current sample was similar to that described by Lelliot *et al.* (1991). Despite comprising non-treatment-seekers, our sample exhibited significant levels of avoidance, distressing symptoms, and role impairment.

BBCA and panic attacks

As expected from previous findings (Lelliot *et al*., 1991), our study also showed that most participants had experienced panic attacks. For the majority of these, their main fear was that they would be incontinent during a panic attack. On the other hand a sizeable minority (~38%) indicated that this was not their main catastrophic fear. This may suggest that panic attacks associated with other catastrophic beliefs pre-date the development of BBCA in these individuals. Alternatively, since these participants were not more likely to agree with the statements relating to other catastrophic beliefs (i.e. losing control/'going crazy' or choking/having a heart attack) it may be that these participants were not yet aware of a connection between panic and specific catastrophic cognitions.

As might be expected, only those with BBCA and panic attacks met clinical cut-off for avoidance of situations for fear of panic symptoms. This may be related to their concern that they might be incontinent during a panic attack and thus this might explain why their avoidance of situations which induce panic symptoms is greater

than that of panic controls whose concerns during panic attacks do not relate to incontinence. Participants with BBCA and panic attacks were also more likely to avoid public transport and crowded places in case they are incontinent which may also be linked to their panic symptoms. Participants with BBCA reported more severe symptoms and higher levels of avoidance and impairment than those who did not have panic attacks. They were also more similar to the control group who also suffered from panic attacks.

Shame and disgust in BBCA

As expected there was frequent strong endorsement of disgust- and shame-based cognitions in our sample and this may further explain why avoidance is higher in this group. The literature shows that strong feelings of disgust (e.g. Davey, 2011) and shame (e.g. Schmader & Lickel, 2006) can lead to higher levels of avoidance. Disgust promotes both cognitive and behavioural avoidance of disgust-eliciting stimuli and importantly the anticipation of disgust, not its actual experience, is an important driver in avoidance (Cisler, Olatunji & Lohr, 2009).

Help-seeking in BBCA

Help-seeking showed a clear relationship with the presence of panic attacks which is consistent with previous studies on panic (Wittchen, Reed & Kessler, 1998) and is likely to be a function of their higher levels of distress. It had been predicted due to its strong links with shame that participants with BBCA would have lower levels of help-seeking, similar to people with social anxiety disorder who fear being judged (e.g. Olfson *et al*., 2000) and also to those with IBS (Kennedy *et al*., 2003). However, as those without panic attacks had lower rates of help-seeking, it appears that any potential experience of shame when seeking help may be overcome if symptoms are more severe.

BBCA and actual experiences of incontinence

Approximately half of the sample of people with BBCA had experienced their 'worst fear' i.e. they had been incontinent at least once and a smaller proportion had experienced incontinence during a panic attack. Porges (2007) has argued that in extreme anxiety some people may experience defecation because of the parasympathetic vagal pathway which may also lead to vomiting and fainting. This finding is also in line with evidence from people with emetophobia who are more likely to have had aversive experiences of nausea and vomiting (Boschen, 2007). In our study, people with BBCA were more likely to have experienced an episode of incontinence compared to the panic sample. This suggests that existing models for treating catastrophically interpreted bodily symptoms may need to be modified when treating people with BBCA (*c.f.* Clark and Salkovskis, *in press*).

Are panic attacks different for people with BBCA?

It was also found that, despite several similarities between participants with BBCA who have panic attacks and panic controls, there are also important differences. This fits with findings from a previous study showing that those with concerns about incontinence form a distinct group with different demographic and clinical features compared to those with panic ± agoraphobia without BBCA (Lelliott & Bass, 1990). Beliefs and behaviours related to BBCA as measured with the FOIS were rated more strongly in those who have BBCA with panic attacks compared to both panic controls and people who have BBCA without panic attacks. In particular these participants were more likely to strongly agree that they attend to internal, viscerally-centred sensations (e.g. noticing sensations in bladder or bowel especially when anxious) as well as to focussing on relevant external stimuli (e.g. locating toilets in unfamiliar places). Participants with BBCA and panic attacks had the

highest scores on both factors of the FOIS (i.e. avoidance/safety behaviours/QoL and shame/disgust), followed by those without panic attacks and the lowest scores were found in panic controls. This provides further evidence for severity of symptoms leading to higher levels of distress in those with BBCA and also highlights that there are important differences compared to people with panic attacks not related to BBCA.

Comparisons with previous research

With the exception of the Lelliot *et al.* study (1991), previously published studies have only provided case descriptions of treatment of these symptoms (e.g. Epstein & Jenike, 1990; Hatch, 1997). No study that we are aware of has outlined their phenomenology, associated impairment, nature of beliefs or safety behaviours in a systematic way. The present study has a significantly larger sample size compared to previous studies of both BBCA (n= 31; Lelliot *et al*., 1991) and of emetophobia (n=50; Lipsitz *et al*., 2001). The latter study recruited participants from an online forum for people with emetophobia, whilst the present study recruited participants through a wider variety of internet platforms as there was no specific forum catering for people with this fear. This can be explained by the considerable disagreement in terms of the classification of this concern, for example in terms of OCD, social phobia and due to overlaps with FGIDs and panic disorder as reported in the literature.

Moreover, BBCA is not currently a recognised diagnosis, unlike emetophobia which has been co-opted into the 'specific (situational) phobia' diagnosis (DSM-IV; APA, 2000). In outlining panic disorder ± agoraphobia and social anxiety, DSM-IV (APA, 2000) refers only to gastrointestinal / abdominal distress or diarrhoea as symptoms of anxiety, rather than the constellation of symptoms (i.e. the syndrome)

that is expressed in BBCA. Thus it is possible that our recruitment strategy may have been beneficial in targeting and recruiting participants who are currently self-classifying their fears under a variety of other disorders.

A Measure for assessing BBCA: the FOIS

Since there are no existing measures that allow an investigation of the presence and severity of distinctive behaviours and beliefs associated with BBCA, the FOIS was developed. The FOIS seems reliable, internally consistent and construct valid and it appears to have adequate properties as measure of BBCA after omitting two items relating to more general panic symptoms, an item which was used as an inclusion criteria and two further items with low factor loading. The factor structure of the FOIS was clear and the included items measuring two separate constructs: avoidance/safety behaviours/QoL and shame/disgust. The first factor does not appear to be very well separated out as it includes both behaviours related to BBCA such as avoidance and safety behaviours but also quality of life. However factor two is more clearly differentiated as it describes attributions which participants with BBCA might make in relation to the feared consequences.

It was not possible to check concurrent validity of the FOIS as there is no other known measure that related to the same construct. Further studies will be needed in the future to assess test-retest reliability and sensitivity to change. Moreover, the scale of the measure could be improved by changing it from agree/disagree to a scale which considers severity of symptoms. This would mean that more variability in symptoms could be explored.

BBCA: specific relationship to panic?

A comparison of a subset of participants with BBCA who also suffer from panic attacks and a control group of participants who suffer from panic attacks unrelated to BBCA highlighted Factor 1 of the FOIS as a superior predictor of BBCA. The two samples were similar with regards to the majority of constructs measured, including depression, generalised anxiety, OCD, social anxiety and agoraphobia. Thus there is no support that BBCA has direct overlaps with OCD as previously suggested (e.g. Hatch, 1997; Elliot & Jenike 1990). This also supports findings from Lelliott and Bass (1990) which showed that people with BBCA have distinct clinical characteristics from those with social anxiety. Predicted differences in body vigilance and anxiety control were not found. Differences in the groups in terms of shame and disgust propensity were not significant using a conservative alpha value of p=.005.

Disgust, shame, body vigilance and anxiety control had been proposed as likely predictors based on the available literature. In particular increased levels of disgust propensity and sensitivity were predicted to have strong associations with BBCA based on the finding that these are the best predictors of emetophobia (van Overveld *et al*., 2008). In the present study there was only a difference in disgust propensity at trend level and no difference in disgust sensitivity. Between-group differences on the shame/disgust factor of the FOIS were detected but it was not a predictor of BBCA.

Moreover, anxiety sensitivity has also been linked with body vigilance in people with panic disorder (Olatunji *et al.*, 2007; Schmidt *et al*., 1997). Importantly, alongside experiential avoidance, anxiety sensitivity has been shown to be particularly important in behavioural avoidance (Hayward & Wilson , 2006). Thus it

is possible that the predicted elevation in body vigilance was not found in participants with BBCA and panic attacks compared to panic controls because of their high levels of behavioural avoidance. It is also possible that elevated levels of body vigilance are a common risk factor for both panic attacks and BBCA and thus may explain that there is no difference between the groups in our study.

Finally, participants with BBCA did not have lower levels of perceived control over emotions and external threats and this could in turn be linked to behavioural and experiential avoidance as these might lead patients to feel that they have control over their emotions and external threats, simply by avoiding them. For example in a study by Eifert and Heffner (2003) participants who were asked to control their panic symptoms were more behaviourally avoidant than those who used acceptance strategies. Thus by being experientially and behaviourally avoidant, it is possible that people with BBCA gain a sense of predictability and controllability of their anxiety and external threats. As the FOIS factor which relates to avoidance and safety behaviours as well as QoL was the most significant predictor of BBCA, this further underlines the importance of avoidance of situations in which incontinence may occur and feelings related to incontinence.

Limitations

There are notable limitations to the breadth of the recruitment strategy which included a variety of internet platforms due to the lack of a specific forum catering for people with BBCA. In particular, this strategy may have led to large number of participants who had to be excluded as they had conditions which are associated with incontinence, had reported recent episodes of incontinence or did not endorse the statement that their main fear was a fear of incontinence. The actual advert for recruitment was phrased in such a way that it was also deliberately over inclusive as

to not exclude people who believe that their concerns are not related to anxiety. In combination with the wide-ranging study criteria which also deliberately did not exclude participants from the outset who had a history of incontinence or physical causes for their difficulties, this may have led to over inclusive recruitment of patients with BBCA, including many who actually suffer incontinence. The exclusion procedures according to three exclusion criteria may have helped to reduce the number of people who were included despite having underlying conditions which may lead to incontinence. Moreover, as no diagnostic assessment of panic disorder and panic attacks was included in the study, neither the BBCA sample with panic attacks nor the panic controls can be confirmed as having full symptom panic attacks or even whether or not they might qualify for a diagnosis of panic disorder.

This is further compounded as our study relied entirely on self-reports and there was no diagnostic interview to identify participants with such underlying conditions. Self-reports have well described disadvantages of inaccurate self-reporting caused by recall bias, social desirability bias and errors in self-observation (Paulhus, 1991). Moreover, as several of the measures were administered using the internet, it cannot be assumed that the psychometric properties described in the literature are identical to paper-and-pencil versions. However there is evidence from Hedman *et al.* (2010) that several measures of social anxiety uphold their psychometric properties if they are administered via the Internet.

In addition, given that the power calculations indicated that a sample of n=156-218 was required to give the study sufficient power, the lower total sample size of n=131 means that the present study is underpowered. This means that effects that were predicted may have been less easily detected i.e. the differences predicted between the panic samples with and without BBCA on shame, disgust, anxiety

control, fear of incontinence and body vigilance. Thus, it is possible that potential differences may not have been found. Where potential trends were highlighted, for example in shame and disgust, these may have been significant if the study had not been underpowered. However, they would have shown effects opposite to what had been predicted i.e. shame and disgust appeared elevated in the panic group who did not have BBCA compared to those with BBCA and panic.

Moreover, as the sample was recruited via the Internet, it is questionable whether they are truly representative of the wider population with BBCA and particularly of those who seek treatment. In IBS, differences have been noted between Internet and clinic samples for example on quality of life scores (Jones, Bratten, & Keefer, 2007) and age (Soetikno, Mrad, Pao, & Lenert, 1997). The present sample is relatively young given that there are potentially higher levels of concern about incontinence in older age groups and it is also predominantly female. However, such gender imbalance is also reflected within IBS and emetophobia samples, possibly reflecting noted gender differences in visceral sensitivity (Lee, Mayer, Schmulson, Chang, & Naliboff, 2001; van Overveld *et al.*, 2008).

Implications for future research

Future research into BBCA would benefit from the inclusion of a diagnostic interview to exclude participants with disorders likely to be associated with incontinence. This could also help identify participants who do not have formal diagnoses e.g. of IBS. A diagnostic interview would increase the certainty that the sample of participants is one in which anxiety plays a key part in the phenomenology rather than actual experiences of incontinence. A diagnostic interview of panic symptomatology should also be included in future research in order to confirm the relationship of BBCA and panic attacks. This should also include questions about the

sequence of symptoms and the focus of the fear as there appears to be a link between BBCA during panic attacks. Moreover, the use of diagnostic interviews would also address concerns of using only self-report measures.

Despite the FOIS having adequate reliability, internal consistency and construct validity, as a measure it has several disadvantages. For example, the scale of the measure could be improved by changing it from agree/disagree to a scale which considers severity of symptoms. The first factor i.e. avoidance/safety behaviours/QoL is not very well defined and thus poses difficulties in terms of its predictive value and its meaning. Moreover, as the overall model fit for the step-wise logistic regression was poor, the FOIS cannot be seen as a reliable predictor of BBCA.

As the present study is cross-sectional, no causal inferences can be made. Despite significant differences on the FOIS it cannot be concluded that higher levels of avoidance and safety behaviours related to incontinence as well as feelings of shame and disgust associated with incontinence are causally related to BBCA or whether they are a consequence of BBCA. However, as avoidance emerged as an important factor it is warranted that this is explored further in future research.

Moreover, given the relative success in recruitment of a large sample of people with BBCA using the internet and a much smaller subsample using postal questionnaires, there is a strong indication for any potential treatments to be made available via the internet. This would enable people who would otherwise not seek help (in this case people who do not have panic symptoms), possibly because of shame or disgust, to be able to access treatment. Internet-based cognitive-behavioural treatments have been developed to overcome barriers to treatment in social anxiety (e.g. Andersson *et al*., 2012) where levels of help-seeking are low (Issakidis &

Andrews, 2002). Thus future research to develop appropriate treatments for BBCA could explore both face-to-face as well as internet-based approaches.

Implications of Findings

The present study provides for the first time some basic characteristics of BBCA which has been lacking from the literature. Its specific focus on people who may not have a functional gastrointestinal or urinary disorder highlights that there may be a distinct subgroup of patients with BBCA and that this is accompanied by panic attacks in the majority of cases. Moreover, it also provides further evidence to elucidate the links with other anxiety disorders. The results of the survey provide evidence that this disorder is associated with significant levels of distress, avoidance and impairment which was also found by Lelliot *et al.* (1991). As incontinence related avoidance appears to be a particularly significant factor in BBCA, any potential treatment approaches should take this into consideration.

The results from the present study indicate that the FOIS distinguished participants with panic associated with BBCA-related beliefs from those with non-specific panic. As such this measure may help in identifying patients with BBCA in a clinical setting. This could be useful in primary care in order for clinicians to screen for BBCA if no actual incontinence is reported and to determine how much of an impact this anxiety disorder is having on the patient's life to help identify those who might benefit from a referral to psychological therapy. The FOIS could also be useful as an outcome measure as it considers safety and avoidance behaviours specifically related to BBCA which may be addressed during therapy.

Conclusion/summary

In conclusion, the present findings lend further support to the hypothesis that there may be a distinct subgroup of patients with BBCA and that this is accompanied by an experience of panic attacks in the majority of cases (e.g. Lelliot *et al.,* 1991). The FOIS was developed as a measure to help address the differences between participants with panic attacks with and without associated BBCA. It was shown to be reliable, internally consistent and construct valid and two factors emerged which measured different aspects of this fear. The FOIS was highlighted as a superior predictor of BBCA in a comparison of participants with panic attacks and panic controls whilst other proposed predictors (disgust, shame, body vigilance and anxiety control) were not significant. Future studies could benefit from using a thorough diagnostic procedure for participants to exclude those with functional disorders which may be related to incontinence and to confirm the relationship with panic attacks.

References

American Psychiatric Association. (2000). Diagnostic and Statistical Manual of Mental Disorders, (4th Edition), Washington, DC: American Psychiatric Association.

Andersson, G., Carlbring, P., Furmark, T., & S. O. F. I. E. Research Group. (2012). Therapist experience and knowledge acquisition in internet-delivered CBT for social anxiety disorder: a randomized controlled trial. *PloS one*, *7*(5), e37411.

Antony, M.M., Coons, M.J., McCabe, R E., Ashbaugh, A., & Swinson, R. P. (2006). Psychometric properties of the social phobia inventory: further evaluation. *Behaviour Research and Therapy*, *44*(8), 1177–1185.

Aziz, Q., & Thompson, D.G. (1998). Brain-gut axis in health and disease. *Gastroenterology*, *114*(3), 559–578.

Beidel, D.C., & Bulik, C.M. (1990). Flooding and response prevention as a treatment for bowel obsessions. *Journal of Anxiety Disorders*, *4*(3), 247–256.

Blaivas, J.G., Panagopoulos, G., Weiss, J.P., Somaroo, C., & Chaikin, D.C. (2007). The urgency perception score: validation and test-retest. *The Journal of Urology*, *177*(1), 199–202.

Boschen, M.J. (2007). Reconceptualizing emetophobia: a cognitive-behavioral formulation and research agenda. *Journal of Anxiety Disorders*, *21*(3), 407–419.

Bouton, M.E., Mineka, S., & Barlow, D.H. (2001). A modern learning theory perspective on the etiology of panic disorder. *Psychological Review*, *108*(1), 4–32.

Boyce, P., Gilchrist, J., Talley, N.J., & Rose, D. (2000). Cognitive-behaviour therapy as a treatment for irritable bowel syndrome: a pilot study. *The Australian and New Zealand Journal of Psychiatry, 34*(2), 300–309.

Chambless, D.L., Caputo, G.C., Jasin, S.E., Gracely, E.J., & Williams, C. (1985). The Mobility Inventory for Agoraphobia. *Behaviour Research and Therapy*, *23*(1), 35–44.

Cisler, J.M., Olatunji, B.O., Lohr, J.M., & Williams, N.L. (2009). Attentional Bias Differences between Fear and Disgust: Implications for the Role of Disgust in Disgust-Related Anxiety Disorders. *Cognition & Emotion*, *23*(4), 675–687.

Clark, D.M., & Salkovskis, P.M. (In Press). Panic Disorder. In Hawton, K., Salkovskis, P.M., Kirk, J. & Clark, D.M. (Eds.), C*ognitive Behaviour Therapy: A Practical Guide* (2nd Edition), Oxford: Oxford University Press.

Connor, K.M., Davidson, J.R., Churchill, L.E., Sherwood, A., Foa, E., & Weisler, R.H. (2000). Psychometric properties of the Social Phobia Inventory (SPIN). New self-rating scale. *The British Journal of Psychiatry: the Journal of Mental Science*, *176*, 379–386.

Cook, D.R. (2001). *Internalized Shame Scale: Technical Manual*. Toronto: Multi-Health Systems, Inc.

Cosci, F. (2012). "Bowel obsession syndrome" in a patient with chronic constipation. *General Hospital Psychiatry*. Retrieved from 14/06/2013 http://www.sciencedirect.com/science/article/pii/S0163834312001491

Craske, M.G., Rachman, S.J., & Tallman, K. (1986). Mobility, Cognitions, and panic. *Journal of Psychopathology and Behavioral Assessment*, *8*(3), 199–210.

Davey, G.C.L. (2011). Disgust: the disease-avoidance emotion and its dysfunctions. *Philosophical Transactions of the Royal Society B: Biological Sciences*, *366*(1583).

Davidson, A.L., Boyle, C., & Lauchlan, F. (2008). Scared to lose control? General and health locus of control in females with a phobia of vomiting. *Journal of Clinical Psychology*, *64*(1), 30–39.

Dear, B.F., Titov, N., Sunderland, M., McMillan, D., Anderson, T., Lorian, C., & Robinson, E. (2011). Psychometric comparison of the generalized anxiety disorder scale-7 and the Penn State Worry Questionnaire for measuring response during treatment of generalised anxiety disorder. *Cognitive Behaviour Therapy, 40*(3), 216–227.

Del Rosario, P.M., & White, R.M. (2006). The Internalized Shame Scale: Temporal stability, internal consistency, and principal components analysis. *Personality and Individual Differences*, *41*(1), 95–103.

Eifert, G.H., & Heffner, M. (2003). The effects of acceptance versus control contexts on avoidance of panic-related symptoms. *Journal of Behavior Therapy and Experimental Psychiatry*, *34*(3-4), 293–312.

Eldridge, G.D., Walker, J.R., & Holborn, S.W. (1993). Cognitive-behavioral treatment for panic disorder with gastrointestinal symptoms: a case study. *Journal of Behavior Therapy and Experimental Psychiatry*, *24*(4), 367–371.

Epstein, S., & Jenike, M.A. (1990). Disabling urinary obsessions: an uncommon variant of obsessive-compulsive disorder. *Psychosomatics*, *31*(4), 450–452.

Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G*Power 3: a flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, *39*(2), 175–191.

Flessner, C.A., & Woods, D.W. (2006). Phenomenological characteristics, social problems, and the economic impact associated with chronic skin picking. *Behavior Modification*, *30*(6), 944–963.

Foa, E.B., Huppert, J.D., Leiberg, S., Langner, R., Kichic, R., Hajcak, G., & Salkovskis, P.M. (2002). The Obsessive-Compulsive Inventory: development and validation of a short version. *Psychological Assessment*, *14*(4), 485–496.

Hatch, M.L. (1997). Conceptualization and treatment of bowel obsessions: two case reports. *Behaviour Research and Therapy*, *35*(3), 253–257.

Hayward, C., & Wilson, K.A. (2007). Anxiety sensitivity: a missing piece to the agoraphobia-without-panic puzzle. *Behavior Modification*, *31*(2), 162–173.

Hedman, E., Ljótsson, B., Rück, C., Furmark, T., Carlbring, P., Lindefors, N., & Andersson, G. (2010). Internet administration of self-report measures commonly used in research on social anxiety disorder: A psychometric evaluation. *Computers in Human Behavior*, *26*(4), 736–740.

Herbert, B.M., Muth, E.R., Pollatos, O., & Herbert, C. (2012). Interoception across modalities: on the relationship between cardiac awareness and the sensitivity for gastric functions. *PloS one*, *7*(5), e36646.

Hinton, D.E., Chhean, D., Fama, J.M., Pollack, M.H., & McNally, R.J. (2007). Gastrointestinal-focused panic attacks among Cambodian refugees: associated psychopathology, flashbacks, and catastrophic cognitions. *Journal of Anxiety Disorders*, *21*(1), 42–58.

Hofmann, S.G. (2007). Cognitive Factors that Maintain Social Anxiety Disorder: a Comprehensive Model and its Treatment Implications. *Cognitive Behaviour Therapy*, *36*(4), 193–209.

IAPT Data Handbook Retrieved June 14, 2013, from http://www.iapt.nhs.uk/silo/files/the-iapt-data-handbook.pdf

Issakidis, C., & Andrews, G. (2002). Service utilisation for anxiety in an Australian community sample. *Social Psychiatry and Psychiatric Epidemiology*, *37*(4), 153–163.

Jenike, M.A., Vitagliano, H.L., Rabinowitz, J., Goff, D.C., & Baer, L. (1987). Bowel obsessions responsive to tricyclic antidepressants in four patients. *The American Journal of Psychiatry*, *144*(10), 1347–1348.

Jerndal, P., Ringström, G., Agerforz, P., Karpefors, M., Akkermans, L.M., Bayati, A., & Simrén, M. (2010). Gastrointestinal-specific anxiety: an important factor for severity of GI symptoms and quality of life in IBS. *Neurogastroenterology and Motility: the Official Journal of the European Gastrointestinal Motility Society*, *22*(6), 646–e179.

Jones, M.P., Bratten, J., & Keefer, L. (2007). Quality of life in patients with inflammatory bowel disease and irritable bowel syndrome differs between subjects recruited from clinic or the internet. *American Journal of Gastroenterology*, *102*(10), 2232–2237.

Kennedy, A.P. (2003). Incorporating patients' views and experiences of life with IBS in the development of an evidence based self-help guidebook. *Patient Education & Counseling*, *50*(3):303-310.

Keough, M.E., Timpano, K.R., Zawilinski, L L., & Schmidt, N.B. (2011). The association between irritable bowel syndrome and the anxiety vulnerability factors: body vigilance and discomfort intolerance. *Journal of Health Psychology*, *16*(1), 91–98.

Kroenke, K, Spitzer, R.L., & Williams, J.B. (2001). The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal Medicine*, *16*(9), 606–613.

Kroenke, K., Spitzer, R.L., Williams, J.B.W., Monahan, P.O., & Löwe, B. (2007). Anxiety disorders in primary care: prevalence, impairment, comorbidity, and detection. *Annals of Internal Medicine*, *146*(5), 317–325.

Lee, O.Y., Mayer, E.A., Schmulson, M., Chang, L., & Naliboff, B. (2001). Gender-related differences in IBS symptoms. *The American Journal of Gastroenterology*, *96*(7), 2184–2193.

Lelliott, P, & Bass, C. (1990). Symptom specificity in patients with panic. *The British Journal of Psychiatry: the Journal of Mental Science*, *157*, 593–597.

Lelliott, P., McNamee, G., & Marks, I. (1991). Features of agora-, social, and related phobias and validation of the diagnoses. *Journal of Anxiety Disorders*, *5*(4), 313–322.

Lipsitz, J.D., Fyer, A. J., Paterniti, A., & Klein, D.F. (2001). Emetophobia: preliminary results of an internet survey. *Depression and Anxiety*, *14*(2), 149–152.

Löwe, B., Decker, O., Müller, S., Brähler, E., Schellberg, D., Herzog, W., & Herzberg, P. Y. (2008). Validation and standardization of the Generalized Anxiety Disorder Screener (GAD-7) in the general population. *Medical Care*, *46*(3), 266–274.

Lydiard, R.B., Laraia, M.T., Fossey, M., & Ballenger, J.C. (1988). Possible relationship of bowel obsessions to panic disorder with agoraphobia. *The American Journal of Psychiatry*, *145*(10), 1324–1325.

Lyketsos, C.G. (1992). Successful treatment of bowel obsessions with nortriptyline. *The American Journal of Psychiatry*, *149*(4), 573.

Marks, I.M. (1987). *Fears, Phobias and Rituals*. New York, NY: Oxford University Press.

Marks, I.M., & Mathews, A.M. (1979). Brief standard self-rating for phobic patients. *Behaviour Research and Therapy*, *17*(3), 263–267.

Mataix-Cols, D., Cowley, A. J., Hankins, M., Schneider, A., Bachofen, M., Kenwright, M., & Marks, I.M. (2005). Reliability and validity of the work and social adjustment scale in phobic disorders. *Comprehensive Psychiatry*, *46*(3), 223–228.

Mayer, E.A., & Tillisch, K. (2011). The Brain-Gut Axis in Abdominal Pain Syndromes. *Annual Review of Medicine*, *62*(1), 381–396.

Millions “hit by toilet phobia”. (2006, November 10). *BBC*. Retrieved from http://news.bbc.co.uk/1/hi/6128738.stm

Mundt, J.C., Marks, I.M., Shear, M.K., & Greist, J.H. (2002). The Work and Social Adjustment Scale: a simple measure of impairment in functioning. *The British Journal of Psychiatry: the Journal of Mental Science*, *180*, 461–464.

Muotri, R.W., Nunes, R.P., & Bernik, M.A. (2007). Aerobic exercise as exposure therapy to interoceptive cues in panic disorder. *Revista Brasileira de Medicina do Esporte*, *13*(5), 327–330.

Nicolson, P., Kopp, Z., Chapple, C.R., & Kelleher, C. (2008). It’s just the worry about not being able to control it! A qualitative study of living with overactive bladder. *British Journal of Health Psychology*, *13*(Pt 2), 343–359.

Noyes, R., Jr, Cook, B., Garvey, M., & Summers, R. (1990). Reduction of gastrointestinal symptoms following treatment for panic disorder. *Psychosomatics*, *31*(1), 75–79.

Olatunji, B.O., Cisler, J.M., Deacon, B.J., Connolly, K., & Lohr, J.M. (2007). The Disgust Propensity and Sensitivity Scale-Revised: psychometric properties and specificity in relation to anxiety disorder symptoms. *Journal of Anxiety Disorders*, *21*(7), 918–930.

Olatunji, B.O., Deacon, B.J., Abramowitz, J.S., & Valentiner, D.P. (2007). Body vigilance in nonclinical and anxiety disorder samples: structure, correlates, and prediction of health concerns. *Behavior Therapy*, *38*(4), 392–401.

Olfson, M., Guardino, M., Struening, E., Schneier, F. R., Hellman, F., & Klein, D. F. (2000). Barriers to the treatment of social anxiety. *The American Journal of Psychiatry*, *157*(4), 521–527.

Pajak, R., Langhoff, C., Watson, S., & Kamboj, S.K. (2013). Phenomenology and thematic content of intrusive imagery in bowel and bladder obsession. *Journal of Obsessive-Compulsive and Related Disorders*, *2*(3), 233–240.

Paulhus, D.L. (1991). Measurement and control of response bias. In J.P. Robinson, P.R. Shaver & L.S. Wrightsman (Eds.), Measures of Personality and Social Psychological Attitudes (pp. 17-59). San Diego, CA: Academic Press.

Perneger, T.V. (1998). What's wrong with Bonferroni adjustments. British Medical Journal, *316*, 1236-1238.

Perry, S., Shaw, C., Assassa, P., Dallosso, H., Williams, K., Brittain, K. R., & McGrother, C. (2000). An epidemiological study to establish the prevalence of urinary symptoms and felt need in the community: the Leicestershire MRC incontinence study. *Journal of Public Health*, *22*(3), 427–434.

Perry, S., McGrother, C.W., Turner, K., & Leicestershire MRC Incontinence Study Group. (2006). An investigation of the relationship between anxiety and depression and urge incontinence in women: development of a psychological model. *British Journal of Health Psychology*, *11*(P3), 463–482.

Porcelli, P., & De Carne, M. (2008). Non-fearful panic disorder in gastroenterology. *Psychosomatics*, *49*(6), 543–545.

Porcelli, P., & Leandro, G. (2007). Bowel obsession syndrome in a patient with ulcerative colitis. *Psychosomatics*, *48*(5), 448–450.

Porges, S.W. (2007). The polyvagal perspective. *Biological Psychology*, *74*(2), 116–143.

Price, K., Veale, D., & Brewin, C.R. (2012). Intrusive imagery in people with a specific phobia of vomiting. *Journal of Behavior Therapy and Experimental Psychiatry*, *43*(1), 672–678.

Rapee, R.M., Craske, M.G., Brown, T.A., & Barlow, D.H. (1996). Measurement of perceived control over anxiety-related events. *Behavior Therapy*, *27*(2), 279–293.

Salkovskis, P. (2005). What is toilet phobia? History, research and the present status of toilet phobia. Retrieved June 14, 2013, from

www.anxietyuk.org.uk/docs/TP_presentation_london1.ppt

Schmader, T., & Lickel, B. (2006) The approach and avoidance function of personal and vicarious shame and guilt. *Motivation and Emotion, 30,* 43-56.

Schmidt, N.B., Lerew, D.R., & Trakowski, J.H. (1997). Body vigilance in panic disorder: evaluating attention to bodily perturbations. *Journal of Consulting and Clinical Psychology*, *65*(2), 214–220.

Sharma, V. (1991). Bowel obsessions and clomipramine. *Canadian journal of psychiatry. Revue canadienne de psychiatrie*, *36*(3), 233–234.

Soetikno, R.M., Mrad, R., Pao, V., & Lenert, L.A. (1997). Quality-of-Life Research on the Internet. *Journal of the American Medical Informatics Association*, *4*(6), 426–435.

Spitzer, R.L., Kroenke, K., Williams, J.B.W., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of Internal Medicine*, *166*(10), 1092–1097.

Toilet Phobia. *Anxiety UK*. Retrieved June 14, 2013, from http://www.anxietyuk.org.uk/about-anxiety/anxiety-disorders/toilet-phobia/

Van Hout, W.J.P.J., & Bouman, T.K. (2012). Clinical features, prevalence and psychiatric complaints in subjects with fear of vomiting. *Clinical Psychology & Psychotherapy*, *19*(6), 531–539.

Van Overveld, M., De Jong, P.J., Peters, M.L., Van Hout, W.J.P.J., & Bouman, T.K. (2008). An internet-based study on the relation between disgust sensitivity and emetophobia. *Journal of Anxiety Disorders*, *22*(3), 524–531.

Van Overveld, W.J.M., De Jong, P.J., Peters, M.L., Cavanagh, K., & Davey, G.C.L. (2006). Disgust propensity and disgust sensitivity: Separate constructs that are

differentially related to specific fears. *Personality and Individual Differences*, *41*(7), 1241–1252.

Veale, D. (2009). Cognitive behaviour therapy for a specific phobia of vomiting. *the Cognitive Behaviour Therapist*, *2*(04), 272–288.

Vythilingum, B., Stein, D.J., & Soifer, S. (2002). Is "shy bladder syndrome" a subtype of social anxiety disorder? A survey of people with paruresis. *Depression and Anxiety*, *16*(2), 84–87.

Wells, A. (1997). *Cognitive Therapy of Anxiety Disorders: A Practice Manual and Conceptual Guide.* Chichester, UK: Wiley.

Wetterneck, C.T., Woods, D.W., Norberg, M.M., & Begotka, A.M. (2006). The social and economic impact of trichotillomania: results from two nonreferred samples. *Behavioral Interventions*, *21*(2), 97–109.

Wittchen, H.U., Reed, V., & Kessler, R.C. (1998). The relationship of agoraphobia and panic in a community sample of adolescents and young adults. *Archives of General Psychiatry*, *55*(11), 1017–1024.

Wittkampf, K.A., Naeije, L., Schene, A.H., Huyser, J., & Van Weert, H.C. (2007). Diagnostic accuracy of the mood module of the Patient Health Questionnaire: a systematic review. *General Hospital Psychiatry*, *29*(5), 388–395.

Zebb, B.J., & Moore, M.C. (1999). Another look at the psychometric properties of the Anxiety Control Questionnaire. *Behaviour Research and Therapy*, *37*(11), 1091–1103.

Part 3 - Critical Appraisal

Critical Appraisal

This critical appraisal will discuss several issues related to the research described in the previous chapter. The first part will address how the lack of agreement about the conceptualisation of bowel/bladder-control anxiety (BBCA) and the limited attention it has received in the literature influenced the research process, particularly recruitment. Secondly, issues relating to multiple statistical comparisons and advertising will be considered. Next, the usefulness of the Internet as a research tool will be discussed with a focus on recruitment of participants with conditions whose prevalence is unknown and who may not be treatment-seeking. Finally, the delivery of psychological therapy using the Internet will be explored in the light of the findings from both the literature review and the Internet research from the empirical paper.

Conceptualisation of BBCA

My interest in researching BBCA was sparked by my therapeutic work in an Improving Access to Psychological Therapies (IAPT) service during my first year of clinical psychology training. I saw two clients for brief cognitive behavioural therapy who suffered from BBCA. One had bowel-control anxiety and the other bladder-control anxiety and neither of my clients was suffering from incontinence but rather they were preoccupied with the possible loss of control of their bowel or bladder. BBCA had an enormous impact on their lives as they were engaging in a wide range of safety behaviours such as frequent visits to lavatories, planning journeys and avoiding public transport. At the time, I scoured the literature to find relevant reading to help with my therapeutic work and I noticed the relative absence of this difficulty from the scientific literature. However, from speaking to my supervisor and other colleagues it became clear to me that BBCA appeared to be an anxiety disorder

which was frequently encountered in IAPT. Thus, when the opportunity arose to take part in a larger project on BBCA, I was very excited to embrace the challenge of finding out more about this under-researched condition.

In order to plan the research, it was important to conceptualise BBCA and determine how it might differ from other difficulties or existing diagnoses. Even when I first searched the literature for relevant reading, I was unsure of the terminology for the difficulty I was looking for: 'fear of incontinence,' 'incontinence preoccupation' and 'bowel/urinary obsessions' were some of the search terms I used. I came across a variety of different ways in which BBCA had been conceptualised which also influenced the terminology which was used to describe it. For example, Beidel & Bulik (1990) described it as 'bowel obsessions' linking BBCA to obsessive compulsive disorder. Thus the initial stages of planning this research project were strongly influenced by the challenge of how to conceptualise BBCA in order to clarify the target population and how to recruit an adequate sample.

Defining BBCA. The more detailed searches of the literature to plan the research revealed that BBCA has been described under various diagnostic categories, including OCD (Hatch, 1997), and panic disorder (Hinton, Ba, Peou & Um, 2000). Moreover, it also has considerable overlap with functional disorders such as irritable bowel syndrome and overactive bladder. Given this lack of clarity in conceptualisation and the fact that clients might be identifying their concerns with a wide range of potential conditions and labels, it was decided to keep the definition of BBCA as broad as possible for the purpose of this initial recruitment. Despite the emphasis on bowel-control anxiety in the literature and the relatively few descriptions of bladder-control anxiety (Epstein & Jenike, 1990; Lelliot, McNamee

& Marks, 1991), it was decided to include both types of anxiety as our clinical observations had included clients with bladder-control anxiety.

We wanted to put as few constraints as possible for recruiting participants and instead decided to use careful filtering of participants who completed the Internet survey using a set of exclusion criteria. The aim of the exclusion criteria was to exclude participants for whom incontinence was a regular occurrence or who had a diagnosis of an organic disorder which could lead to incontinence. Thus those who had been incontinent in the past two weeks and those who had a diagnosis of such a disorder were excluded. Whilst it is likely that clients who have regular occurrences of incontinence are also likely to suffer from anxiety about being incontinent in public, this is a different population of participants for whom this frightening outcome actually happens on a relatively frequent basis. Finally, we decided to also exclude participants who did not agree at least 'mildly' with the statement that fear of incontinence is their main concern (i.e. their "worst fear"). Therefore the target population we hoped to recruit were those people for whom BBCA is an anxiety-related difficulty based on a relatively unrealistic belief that they will be incontinent in public, rather than a relatively frequent physical reality.

Internet recruitment of participants with BBCA. The online advertisements reflected the broad definition of BBCA used for the study. The question posed to potential participants was; '*Do you suffer from a fear of being incontinent? Do you worry about losing control of your bladder or bowels?'.* The advertisements made further reference to the distress BBCA often causes sufferers and the impact it has on day-to-day activities and social relationships. As potential participants were thought to associate their concerns with a variety of different conditions, the recruitment strategy was also very broad and we targeted a large

number of online forums, social networking sites (Facebook and Twitter) and online advertising sites (Gumtree). Selecting the most suitable online forums for advertising our study was a challenge and thus this is reflected in the variety of sites used, including forums for people with OCD, social anxiety, panic disorder, and those for people with IBS or toilet phobia.

Clearly this over-inclusive advertising and recruitment strategy is likely to have led to the large number of participants who were excluded due to regular occurrences of incontinence, presence of organic disorders related to incontinence or who did not regard fear of incontinence as their main fear. Moreover, it is possible that participants were included who in fact suffer from organic disorders which could lead to incontinence as our list of possible conditions was not comprehensive and we did not automatically exclude those who had indicated that they had 'other' diagnoses but had not given details. Moreover, even in the absence of incontinence in the past two weeks, it is still possible that participants did experience regular occurrences of incontinence. Thus more detailed screening questions about potential organic causes and actual incontinence could have improved the process of excluding participants who did not meet inclusion criteria.

NHS recruitment via IAPT services. In order to address concerns that the online sample did not accurately reflect the wider population of people with BBCA, it was decided to also recruit participants via a small number of London-based IAPT services. NHS ethics approval was obtained and participants were recruited over a period of approximately twelve months. However despite regular contacts with the services, less than ten participants completed paper-based questionnaires and this part of the study was abandoned. It is possible that given the fact that this is a disorder with unknown prevalence, the number of potentially eligible participants

with BBCA may have been low. Moreover, a variety of barriers to participation in mental health research, such as stigma, have been documented in the literature (Woodall, Morgan, Sloan & Howard, 2010) and these may have further reduced the pool of participants. In order to obtain a large enough sample, it would have been necessary to target a much larger number of IAPT services or extend the period for recruitment significantly. However this would not have been within the remit of a doctoral project.

Multiple Comparisons

The present study was an attempt to elucidate both the phenomenology and nosology of BBCA. Given the lack of clarity in previously published research and the number of different ways in which it had been defined, it was important to explore these different constructs (e.g. OCD, social anxiety, panic) alongside other constructs that were hypothesised to be linked to BBCA such as shame, disgust and body vigilance. This led to a large number of multiple tests (n=17) which had to be performed on the data collected. Tukey (1977) argued that when more than one statistical test is carried out, a more stringent criterion should be used for statistical significance than the conventional $p<0.05$. Bonferroni adjustments are frequently used to adjust the level of statistical significance in such cases. According to the Bonferroni method, the study would use a p value of $p<0.003$. Interestingly, even if this p-value had been adopted, the main findings which were statistically significant at $p<0.005$ would have also been significant at this more conservative level.

However, Perneger (1998) highlighted that the Bonferroni method is concerned with the general null hypothesis i.e. that all null hypotheses are true simultaneously. Bender and Lange (1998) also argued that the Bonferroni method ignores dependencies among the data and is therefore too conservative if the number

of tests is large. Clearly in the present study, which is exploratory, it is not predicted that the groups will differ on all 17 constructs. Instead it was hoped that we would be able to establish on *which* constructs they differ. Bender and Lange (1998) have argued that particularly in exploratory research, where the number of tests is frequently large and where the Bonferroni procedure has low power, a large number of true effects would be overlooked. They suggest that data of exploratory studies should be analysed without multiplicity adjustment. However, for the present study the p value was adjusted downward, albeit not to the very low level suggested by the Bonferroni method as there is disagreement in the literature on multiple testing (e.g. Tukey, 1977). If the study had adopted the conventional p value of $p<0.05$ as suggested by Bender and Lange (1998), in addition to the significant results reported above there would have been significant differences in bowel symptom severity and disgust propensity between the two panic samples. Moreover, shame and agoraphobic avoidance when alone would have shown trends with p-values of $p=0.06$ and $p=0.05$ respectively. Interestingly, the results for shame and disgust propensity would have been the opposite to what had been predicted, with higher levels of shame and disgust in the group without BBCA.

Advertising and potential sample bias

Both adverts used for recruitment (for the BBCA and the panic sample) contained reference to fear of incontinence. This was of course important in terms of recruiting the BBCA sample, however, including a reference to fear of incontinence in the advert recruiting people with panic attacks may have led to a biased sample. The advert stated that: ‘People who experience panic attacks often have fears about how their body works. For example, some people have a strong fear of losing control of their bladder or/and bowel; for others this is not a major concern. These fears can

cause them great distress, limiting their day-to-day activities and disrupting social relationships.' This may explain the relatively large number of participants (n=51) in the panic sample reporting fears related to incontinence. In order to reduce such bias, it would have been important either not to include any reference to incontinence in this advert or instead to also include references to other fears such as fear of fainting, having a heart attack, choking etc. This is particularly important as some people with panic attacks may not have participated in the study if they did not experience fear of losing control over their bladder or/and bowel as they may have thought that this was a criterion for inclusion in the study.

Moreover, neither advert clearly stated the exclusion criteria of the study. This may have had an impact particularly on the recruitment of the BBCA sample as large numbers of participants had to be excluded following completion of the internet survey as they either had recent experiences of incontinence, suffered from an organic condition which can lead to incontinence or did not agree that fear of incontinence was their main concern. It was thought that an over-inclusive recruitment strategy would mean that people who feel that their concerns may be related to physical causes, such as IBS or having a small bladder which in and of themselves do not lead to incontinence, would not have taken part if the advert had made reference to exclusion of people with organic causes for their incontinence. However, it may have been useful to state that people who have experienced incontinence in the past two weeks were not eligible to take part. This would have potentially excluded n=124 participants at the pre-screening stage who would not have had to complete the baseline questionnaires. This could be seen as having wasted both the participant's time (i.e. through filling in a survey for which they are ultimately not eligible) as well as the researcher's time (i.e. through screening results

once surveys have been completed and having to exclude large numbers of participants). In terms of the participant's time it may have been more ethical therefore to include an exclusion criterion in the advert for people who had experienced incontinence in the past two weeks.

Using the Internet for research

The use of the Internet for recruitment of participants was chosen to overcome predicted recruitment difficulties related to shame and concealment in the population of people with BBCA as it has been shown that online research can increase self-disclosure on sensitive matters (Bailey, Foote, & Throckmorton, 2000). It was also seen as a useful tool given that BBCA has received little research and the population can be seen as 'hidden'. In fact, the findings from our study showed that a significant number of participants had not sought help from health professionals. Wright *et al*. (2005) proposed that 'hidden' populations can be reached using the Internet, particularly if stigma forms a potential barrier to participation. Internet research has been used successfully to study low prevalence disorders such as emetophobia (Lipsitz, Fyer, Paterniti & Klein, 2001) and hidden populations, for example drug users (Miller & Sonderlund, 2010).

Internet research – the researcher's perspective. From my perspective as the researcher, I found the actual process of setting up online questionnaires, Internet recruitment as well as data extraction very user friendly and cost effective. Questionnaires were set up using a platform called Opinio, an online system which allows creation, publication, analysis, and maintenance of surveys. This was more labour-intensive than setting up similar questionnaires for distribution in a paper-based format as it involved understanding the system and how to format the questionnaire correctly. However, in terms of the actual cost involved, using online

surveys is very cost effective in particular given the limited funding which is available for doctoral projects in clinical psychology as costs of printing and postage are minimised. This is an important consideration in recruitment of participants especially if a large sample is required because costs of a postal survey could quickly spiral even if it was possible to reach large numbers of participants.

Being able to access and reach large numbers of potential participants is possibly the greatest benefit of Internet-based research. This seems particularly important in BBCA as it is a rare difficulty and thus traditional avenues of recruitment are likely to result in very few participants as shown by our attempt to recruit via NHS IAPT services. Thus Internet recruitment appears to be able to reach large numbers of participants, including those who are not attending services who might otherwise be a 'hidden' population, and it improves inclusivity.

Nonetheless, Internet-based research also presents concerns about the representativeness of the samples of participants recruited. It has previously been argued that samples recruited online are often male, better educated and younger than those recruited in other ways (Marks & Power, 2002). Those concerns were not reflected in our sample, for example, more women completed the survey than men who presented with BBCA. However, considering that the gender ratio and age of participants were similar to that in a study by Lelliot *et al.* (1991) which did not use Internet recruitment, this suggests that this is not likely to have had a major impact in this study. In terms of the representativeness of Internet samples, in drug research it has been shown that the majority of US drug users resemble online samples more than clinical populations of drug users.

Finally, using Internet questionnaires facilitates data collection not only through ease of recruitment, but also through ease of data entry. As Opinio offered

the option to extract data from the questionnaires into a variety of file formats, including SPSS and Excel, this greatly reduced the amount of time that it took to enter data. This process was very quick and involved ensuring that the data was labelled appropriately and was in a format which could be analysed statistically. Importantly, extracting data from questionnaires rather than entering them by hand avoids potential errors in data entry which have to be checked for.

Internet research – benefits for participants. Internet-based questionnaires can be seen as convenient not only for researchers, but also for participants. They are easy to complete and can be saved so that participants can complete them in their own time. However, the lack of interaction with the researcher might be problematic for some participants, particularly if they require further explanations of questions. We had therefore provided the researchers' contact details in case participants required assistance, however it is likely that participants would not complete the questionnaire if they have to email the researchers in order to understand questions. By emailing researchers another important benefit of Internet research is negated or compromised – anonymity. The complete anonymity of participants completing online questionnaires is an important aspect of Internet research (Joinson, 2001) and this was deemed particularly important in BBCA given the proposed links with shame – although these links were not actually supported by our findings.

Combining Internet and postal questionnaires. The study combined the initial Internet-based questionnaires with postal questionnaires for eligible participants who had left their contact details. In my opinion this represents a significant limitation of the overall study as it greatly reduced the numbers of participants who completed the second study from the initial very large sample and it also increased the costs of the project significantly. It was decided to split the study

into two parts as we wanted to obtain a large sample to describe the overall phenomenology of BBCA and completion of a large battery of questionnaires on the Internet was considered to be an unrealistic requirement of participants. If we had included all our questionnaires in one online study, this would most likely have reduced rates of completion as the survey would have taken more than an hour to complete.

However, it would have been possible to use an Internet-based format for the second part of the study instead of asking participants to provide their postal address and posting questionnaires to them. In this case it would have sufficed to ask participants to provide their E-mail address and then send them the link for the follow up questionnaire, maybe with a code to be able to link the questionnaire data from the two parts of the study. We had opted for paper-based questionnaires as we were using a number of measures which had only been validated as paper-based versions. However, there is evidence that there is strong correlation between face to face and online versions of the same questionnaires (Garb, 2007). A number of participants who had only provided their email address or phone number who we contacted replied that they would prefer to complete questionnaires online rather than being sent a questionnaire in the post. Thus it is likely that recruitment for the second part of the study could have been improved if this had also been conducted online.

The next step – Internet-based therapy?

Given the advances in technology and the large numbers of people using the Internet, it is not surprising that the Internet has not only been used as a research tool, but also for the delivery of psychological therapy. My review of the literature on Internet cognitive behavioural therapy (ICBT) for social anxiety disorder (SAD) highlights the use of the Internet for the delivery of CBT. Hedman *et al.* (2011) have

argued that ICBT has the potential to increase availability and facilitate dissemination of therapeutic services for SAD. Accessibility, convenience and cost-effectiveness of ICBT appear to be equally as important as they are for Internet-based research described above.

However, of utmost importance is the effectiveness of ICBT as a treatment and my review summarised the evidence for both guided and unguided ICBT for SAD, showing large effect sizes. This adds to the evidence base of the effectiveness of ICBT for other mental health problems such as other anxiety disorders, mood disorders and health conditions such as headache and insomnia as summarised by Andersson (2010). In terms of being an effective treatment for SAD, I feel that it is particularly exciting because the increased accessibility is likely to have a positive impact on improving treatment rates given the low numbers of people who are currently seeking help in traditional services (Issakidis & Andrews, 2002). Moreover evidence has shown that there are high numbers of people who are using the Internet who may have more severe SAD than treatment seeking individuals (Erwin, Turk, Heimberg, Fresco & Hantula, 2004) and thus enabling these individuals to use a medium which they are familiar with for therapy can only be seen as an advantage.

More generally, ICBT is not simply a useful resource in healthcare systems which encounter geographical challenges when it comes to accessibility of therapists such as in the Australian system, but it also reduces healthcare costs by reducing therapist time (e.g. Wright *et al.*, 2005). However, the studies I reviewed all used diagnostic interviews to diagnose SAD, either face-to-face or by telephone. In order to further increase the accessibility of ICBT, ways of obtaining reliable diagnoses of patients using the Internet may have to be developed in order to ensure suitability for particular treatment protocols. Importantly, ICBT might actually increase the overall

numbers of people who are able to benefit from psychological therapy with the help of these technological advances.

As a trainee clinical psychologist, trained in face-to-face therapy, I was struck by the findings that unguided ICBT for SAD yields medium to large effect sizes (e.g. Titov *et al*., 2009). This is a particularly potent finding given the extensive training which is required for therapists who deliver CBT and this will certainly be of interest in the current financial climate where cost savings in the NHS have become more and more important. For therapist-guided ICBT, I share Andersson's (2010) concerns that clinical skills developed through face-to-face practice may deteriorate if most therapists deliver therapy using the internet and that funding bodies may reduce funding of regular clinical services. I feel that this would be particularly detrimental for those patients who are not able to benefit from internet treatments. However, all in all I believe that as part of a package of care which is available to patients it is a very valuable addition, for example as part of a stepped care model (Bower & Gilbody, 2005), especially if patient choice continues to be at the forefront of healthcare in the NHS.

ICBT for BBCA? Given the large numbers of participants with BBCA we were able to recruit using the Internet in study one and also the lack of success in recruiting participants via IAPT services I think that ICBT also be useful for this presentation. However, as the prevalence of BBCA is largely unknown, it may not be viewed as cost effective to develop a disorder-specific ICBT treatment protocol for BBCA. Instead the development of transdiagnostic treatment protocols which target processes are common across disorders may be of interest for the treatment of such rare conditions.

Conclusion

This critical appraisal highlights the challenges of conducting research on a rare disorder like BBCA which has not yet been fully conceptualised. It was exciting to be able to be involved in a project which aimed to further advance our understanding of this condition. The use of the Internet as a research tool as well as a platform for therapeutic interventions is discussed. I was struck by the large numbers of participants we were able to recruit using the Internet and I strongly believe that it is both valuable for researchers and participants. I am excited by the developments in the field of Internet-based treatments and how they might shape the field of clinical psychology in the future.

References

Andersson, G. (2010). The promise and pitfalls of the internet for cognitive behavioral therapy. *BMC Medicine, 8*(1), 82.

Bailey, R.D., Foote, W.E., & Throckmorton, B. (2000). Human sexual behaviour. In M.H. Birnbaum (Ed.), *Psychological Experiments on the Internet*, San Diego: Academic Press.

Beidel, D. C., & Bulik, C. M. (1990). Flooding and response prevention as a treatment for bowel obsessions. *Journal of Anxiety Disorders*, *4*(3), 247–256.

Bender, R., & Lange, S. (1998). What's wrong with arguments against multiplicity adjustments? Letter to the editor concerning British Medical Journal, *316*, 1236-1238.

Bower, P., & Gilbody, S. (2005). Stepped care in psychological therapies: access, effectiveness and efficiency. Narrative literature review. *The British Journal of Psychiatry: The Journal of Mental Science*, *186*, 11–17.

Epstein, S., & Jenike, M. A. (1990). Disabling urinary obsessions: an uncommon variant of obsessive-compulsive disorder. *Psychosomatics*, *31*(4), 450–452.

Erwin, B. A., Turk, C. L., Heimberg, R. G., Fresco, D. M., & Hantula, D. A. (2004). The Internet: home to a severe population of individuals with social anxiety disorder? *Journal of anxiety disorders*, *18*(5), 629–646.

Garb, H. N. (2007). Computer-administered interviews and rating scales. *Psychological Assessment*, *19*(1), 4–13.

Hatch, M. L. (1997). Conceptualization and treatment of bowel obsessions: two case reports. *Behaviour Research and Therapy*, *35*(3), 253–257.

Hedman, E., Andersson, G., Ljotsson, B., Andersson, E., Ruck, C., Mortberg, E., & Lindefors, N. (2011). Internet-based cognitive behavior therapy vs. cognitive behavioral group therapy for social anxiety disorder: A randomized controlled non-inferiority trial. *PLoS ONE, 6*(3).

Hinton, D., Ba, P., Peou, S., & Um, K. (2000). Panic disorder among Cambodian refugees attending a psychiatric clinic. Prevalence and subtypes. *General Hospital Psychiatry, 22*(6), 437–444.

Issakidis, C., & Andrews, G. (2002).Service utilisation for anxiety in an Australian community sample. *Social Psychiatry and Psychiatric Epidemiology, 37*(4), 153–163.

Joinson, A. N. (2001). Self-disclosure in computer-mediated communication: The role of self-awareness and visual anonymity. *European Journal of Social Psychology*, *31*(2), 177–192.

Lelliott, P., McNamee, G., & Marks, I. (1991). Features of agora, social, and related phobias and validation of the diagnoses. *Journal of Anxiety Disorders*, *5*, 313-322.

Lipsitz, J. D., Fyer, A. J., Paterniti, A., & Klein, D. F. (2001). Emetophobia: preliminary results of an internet survey. *Depression and Anxiety*, *14*(2), 149–152.

Marks, L., & Power, E. (2002). Using technology to address recruitment issues in the clinical trial process. *Trends in Biotechnology*, *20*(3), 105–109.

Miller, P. G., & Sønderlund, A. L. (2010). Using the internet to research hidden populations of illicit drug users: a review. *Addiction*, *105*(9), 1557–1567.

Perneger, T.V. (1998). What's wrong with Bonferroni adjustments. British Medical Journal, *316*, 1236-1238.

Titov, N., Andrews, G., Schwencke, G., Solley, K., Johnston, L., & Robinson, E. (2009).An RCT comparing effect of two types of support on severity of symptoms

for people completing internet-based cognitive behaviour therapy for social phobia. *Australian and New Zealand Journal of Psychiatry, 43*(10), 920–926.

Tukey, J.W. (1977) Some thoughts on clinical trials, especially problems of multiplicity. *Science, 198,* 678-684.

Woodall, A., Morgan, C., Sloan, C., & Howard, L. (2010). Barriers to participation in mental health research: are there specific gender, ethnicity and age related barriers? *BMC psychiatry, 10,* 103.

Wright, J. H., Wright, A. S., Albano, A. M., Basco, M. R., Goldsmith, L. J., Raffield, T., & Otto, M. W. (2005). Computer-assisted cognitive therapy for depression: maintaining efficacy while reducing therapist time. *The American Journal of Psychiatry, 162*(6), 1158–1164.

Appendices

Appendix A: UCL Ethical Approval

UCL RESEARCH ETHICS COMMITTEE
GRADUATE SCHOOL OFFICE

Dr Sunjeev Kamboj
Research Department of Clinical, Educational and
Health Psychology
UCL

23 March 2011

Dear Dr Kamboj

Notification of Ethical Approval
Ethics Application: 2850/001: Incontinence pre-occupation in anxiety disorders

I am pleased to confirm that your study has been approved by the UCL Research Ethics Committee for the duration of the project (i.e. until December 2012).

Approval is subject to the following conditions:

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form'.

The form identified above can be accessed by logging on to the ethics website homepage: http://www.grad.ucl.ac.uk/ethics/ and clicking on the button marked 'Key Responsibilities of the Researcher Following Approval'.

2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. Both non-serious and serious adverse events must be reported.

   Reporting Non-Serious Adverse Events
   For non-serious adverse events you will need to inform Helen Dougal, Ethics Committee Administrator (ethics@ucl.ac.uk), within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair of the Ethics Committee will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

   Reporting Serious Adverse Events
   The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

On completion of the research you must submit a brief report (a maximum of two sides of A4) of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

With best wishes for the research.

Yours sincerely

Sir John Birch
Chair of the UCL Research Ethics Committee

Cc: Rosanna Pajak & Christine Langhoff, Research Department of Clinical, Educational and Health Psychology, UCL

Appendix B: Consent Form for Study 1

Information and Consent Form for Participants in Research Studies

Welcome to our research site on
"Fear of Incontinence in Anxiety Disorders"

We are interested in understanding the experiences of people who have a fear of incontinence and would like to invite you to participate in this research project. The study is being conducted by Rosanna Pajak and Christine Langhoff, (Trainee Clinical Psychologists) and supervised by Dr Sunjeev Kamboj (Lecturer in Clinical Health Psychology) and Dr Sue Watson (Clinical Director, DClinPsy) at UCL University.

Title of Project: Fear of Incontinence in Anxiety Disorders
This study has been approved by the UCL Research Ethics Committee [Project ID Number]: 2850/001
Name, Address and Contact Details of Investigators: Rosanna Pajak and Christine Langhoff, Research Department of Clinical, Educational and Health Psychology. University College London, Gower Street London, WC1E 6BT.
E-mail:

Before you decide whether you want to take part, it is important for you to read the following information carefully. Before taking part in this study, please read the information below. Please contact us if there is anything that is not clear or if you would like more information.

DETAILS OF THE STUDY

If you agree to take part in the study, you will be asked to answer a series of questions online, which typically takes 20 minutes. The questions are related to your fear of incontinence and are aimed to help us understand the thoughts and experiences of people who have this fear. It is unlikely that you will find completing these questions distressing, but if you do, please feel free to discontinue. You may also contact the investigators (using the details provided above) for information on accessing support.

After completing the questions, you will be asked whether you are happy to be contacted about participation in further parts of the study (for example, answering questionnaires by post or engaging in a short telephone interview).

We hope that gathering this information from people who suffer from a fear of incontinence will create a better understanding of this fear, an important step towards better treatment in the future. You can request a copy of the research results, which we will publish in a scientific or medical journal once our research is complete.

This study is strictly anonymous. All responses are treated as confidential, and in no case will responses from individual participants be identifiable. You will be given a unique participant number and will only be identifiable by this. If you have provided us with your contact details, this information will be kept separate from your data. All data will be collected and stored in accordance with the Data Protection Act 1998. Only researchers involved in the study will have access to the data and it will be securely stored at all times.
Participation is voluntary. It is up to you to decide to participate or not, and you are free to withdraw from the study at any time and without giving a reason.

If you:
- Are aged between 18 and 65 years of age
- Can proficiently read and write English
- Understand the statements above
- Freely consent to participate in the study

Please click on the "I Agree" button to complete the online questionnaire.

Appendix C: Study 1 BBCA Questionnaire

QUESTIONNAIRES – 1

You have been asked to complete this questionnaire because you indicated that you have a fear of being incontinent.
Please complete this questionnaire as best as you can to help us understand as much as possible about your concerns. Please note we use the term 'fear of incontinence' to mean a fear of losing control of your bladder or bowels (or both).

1. Age: _____

2. Gender (please circle): Male Female

3. Marital Status (please circle): Single Married or co-habiting Widowed Divorced

4. Employment Status (please circle):
   - Employed or self-employed
   - Homemaker
   - Unemployed
   - Long-term sick leave
   - Student
   - Retired
   - Other ……

5. What is your **main** concern (i.e. the one you worry about most)?:
   a) Fear of faecal incontinence
   b) Fear of urinary incontinence
   c) Fear of both urinary and faecal incontinence

6. How old were you when you first became aware of a fear of incontinence?

7. How old were you when a fear of incontinence began to significantly affect your life?

8. Has your fear of incontinence changed over time? If so how? Please circle the option below which best describes your problem?

   a) It has been continuous, but overall the problem has become worse
   b) It has been continuous, but overall the problem has stayed the same
   c) It has been continuous, but overall the problem has got better
   d) It has varied. Although it has never gone away, there have been times when the problem has been much worse and when it has been much better
   e) It has varied. At times it has not been a problem at all and at other times it has been worse

9. Have you ever sought help for your fear of incontinence? (please circle) Yes No

- **IF YES**, who have you sought help from? (please circle)

a) GP
b) Psychologist
c) Psychiatrist
d) Gastrointestinal Specialist
e) Other : …….

10. Have you received any diagnosis relating to incontinence? (Please circle all options that apply)

a) IBS
b) Anxiety
c) Urge incontinence
d) Infection
e) No diagnosis
f) Other (please specify)……..

11. What do *you* believe is the main cause of your fear of incontinence? (Please circle all options that apply)

a) IBS
b) Anxiety
c) 'Stress'
d) Urge incontinence
e) Infection
f) Anxiety due to an experience of being incontinent
g) Anxiety due to a near miss of being incontinent in public
h) Other (please specify)…….

12. Have you ever received any treatment for your fear of incontinence? (please circle) Yes No

- **IF YES**, specify the treatment you received. (please circle)
  a) Medical treatments (e.g. medication) - *Please specify* …….
  b) Psychological and psychiatric treatments (e.g. CBT, Hypnosis, Anxiety medication, Antidepressants) - *Please specify* …….
  c) Other (e.g. alternative medicine) – *Please specify* ……

13. Since school age or as an adult have you ever been incontinent in a public place (with other people around)? (please circle) Yes No

- **IF YES**, how many times did this happen (please circle):
  once 2-4 times more than 5 times

- **IF YES**, approximately how old were you (in years) when this first happened? _____

- **IF YES**, approximately how old were you (in years) when this last happened? (*If this only happened once, then please use the same age as entered in the preceding question)* _____

14. Please read all the options below and circle the letter that best describes your fear of incontinence, whether alone or in public?

    a) I fear being incontinent in public/social situations
    b) My main fear is of being incontinent in public, but I have some fear of being incontinent when alone
    c) I fear being incontinent whether I am in public/social situations and when I am alone
    d) My main fear is being incontinent alone, but I have some fear of being incontinent in public
    e) I only fear being incontinent when I am alone

15. Does your fear of incontinence depend on whether you are accompanied by someone you know and trust (e.g. a good friend or partner)? (please circle <u>one answer only</u>)

    a) My fear of being incontinent is less when I am with someone I know and trust.
    b) My fear of being incontinent is greater when I am with someone I know and trust.
    c) My fear of being incontinent does not depend on whether I am with someone I know and trust.

16. PRS

A **panic attack** means a **sudden** increase in anxiety during which four or more of the following sensations are experienced:

1. Feeling short of breath
2. Palpitations or heart racing
3. Choking
4. Chest feeling uncomfortable or painful
5. Sweating
6. Dizziness, unsteady feelings or faintness
7. Feeling unreal or depersonalisation
8. Nausea or discomfort in the stomach
9. Hot or cold flushes
10. Trembling or shaking
11. Numbness or tingling feelings (pins and needles)
12. Fear of dying
13. Fear of doing something uncontrolled or going crazy during an attack

- Do you experience panic attacks? (please circle) Yes No *(→ IF NO, please continue to 17)*

- **IF YES**, what was the **frequency of your panic attacks** during the last two weeks:

0	1	2	3	4
No panic attacks	One panic attack per fortnight	One or two panic attacks per week	At least three panic attacks per week but averaging less than one per day	One or more panic attacks per day

- **IF YES**, how **severe** a **problem** are **panic attacks** for you at present?

0	1	2	3	4	5	6	7	8
Not at all disturbing and/or disabling		Slightly disturbing and/or disabling		Definitely disturbing and/or disabling		Markedly disturbing and/or disabling		Very disturbing and/or disabling

- **IF YES**, in the past two weeks, how much have you **avoided situations** (or needed someone to accompany you) due to fear that you may panic/have symptoms? Examples are: being outside home alone, travelling, being in a crowd, supermarket or department store?

0	1	2	3	4	5	6	7	8
No avoidance or apprehension / distress		Occasional avoidance or escape/ mild apprehension /distress		Moderate avoidance, moderate apprehension / distress		Severe avoidance/ severe apprehension/distress		Always avoids, very severe apprehension / distress

- **IF YES**, have you ever been incontinent *during* a panic attack? (please circle)
  Yes No

- **If you do experience panic attacks**, is your main concern that you will be incontinent during a panic attack? (please circle) Yes No

17. In relation to avoiding situations or objects, choose a number from the scale below to show how much you would avoid each of the situations or objects listed below

0	1	2	3	4	5	6	7	8
Would not avoid it		Slightly avoid it		Definitely avoid it		Markedly avoid it		Always avoid it

- Social situations due to a fear of being embarrassed or making a fool of myself. ……

- Certain situations because of a fear of having a panic attack or other distressing symptoms
  (such as loss of bladder control, vomiting or dizziness). ……..

- Certain situations because of a fear of particular objects or activities (such as animals, heights, seeing blood, being in confined spaces, driving or flying)……..

18. How many times during the past week did you experience a fear of being incontinent? _____times

19. How many times during the past week have you actually been incontinent? _____times

20. Have you been able to discuss your fear of incontinence with anyone? (please circle)
    Yes No

- **IF YES**, with whom? (Please circle all that apply)
  a) Partner / Family
  b) Friend
  c) Health professional (e.g. doctor, psychologist, counsellor)
  d) Religious / spiritual advisor
  e) Other

21. The following is a questionnaire specifically designed to ask questions related to a person's fear of incontinence. Although you may have answered related questions in the sections above, please still answer the questions below.

Please indicate how much you agree with each of the following statements, or how true it is about you. Please select a number (0-4) to indicate your answer e.g. 0 - Strongly Disagree (very untrue about me) and 4 - Strongly Agree (very true about me):

		Strongly disagree (very untrue about me)	Mildly disagree (somew hat true about me)	Neither agree nor disagree	Mildly agree (some what true about me)	Strongly agree (very true about me)
1.	I often notice sensations in my bladder/bowels, especially when I am anxious	0	1	2	3	4
2.	I avoid using public transport in case I am incontinent	0	1	2	3	4
3.	I limit the amount of food I eat and / or the amount of fluids I drink to reduce the chances of being incontinent	0	1	2	3	4
4.	If I go to an unfamiliar place, one of the first things I would do is look for the toilets	0	1	2	3	4
5.	My worst fear is that I would be incontinent in public	0	1	2	3	4
6.	Being incontinent in public would mean I am a disgusting person	0	1	2	3	4
7.	If I go out of the house I wear extra underclothes or I use padding in case I am incontinent	0	1	2	3	4
8.	I notice other symptoms (e.g. heart racing, sweating, trembling) when I need to go to the toilet and cannot easily get to one	0	1	2	3	4
9.	I avoid certain work or social activities because of a fear of being incontinent	0	1	2	3	4
10.	My relationships have been affected by a fear of being incontinent	0	1	2	3	4
11.	I worry about having a heart attack or choking	0	1	2	3	4

	Strongly disagree (very untrue about me)	Mildly disagree (some what true about me)	Neither agree nor disagree	Mildly agree (some what true about me)	Strongly agree (very true about me)
12. I avoid crowded places in case I am incontinent	0	1	2	3	4
13. I often think about how awful it would be if I was actually incontinent in a public place	0	1	2	3	4
14. When I am out of the home, I make a mental note of where toilets are located in case I need to use one urgently	0	1	2	3	4
15. My ability to work, study or socialize has been affected by a fear of being incontinent	0	1	2	3	4
16. Being incontinent is the most shameful thing that could happen to a person	0	1	2	3	4
17. I often check for sensations in my bladder or bowels	0	1	2	3	4
18. I use medications to stop myself being incontinent	0	1	2	3	4
19. I worry about losing control or going crazy	0	1	2	3	4
20. Other people would think I was a disgusting person if I was incontinent	0	1	2	3	4

22. **W&SAS**

People's problems sometimes affect their ability to do certain day-to-day tasks in their lives. To rate your problems look at each section and determine on the scale provided how much your problem impairs your ability to carry out the activity.

a.) **work –** if you are retired or choose not to have a job for reasons unrelated to your problem, please tick here _____

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
not at all		slightly		definitely		markedly		very severely I cannot work

b.) **home management –** cleaning, tidying, shopping, cooking, looking after home/children, paying bills etc

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
not at all		slightly		definitely		markedly		very severely

c.) **social leisure activities –** with other people, e.g. parties, pubs, outings, entertaining etc

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
not at all		slightly		definitely		markedly		very Severely

d.) **private leisure activities –** done alone, e.g. reading, gardening, sewing, hobbies, walking etc

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
not at all		slightly		definitely		markedly		very severely

e.) **family and relationships –** form and maintain close relationships with others including the people that I live with

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
not at all		slightly		definitely		markedly		very severely

23. Sometimes when people think about their worst fear (e.g. being incontinent) they experience a mental picture (or pictures) in their minds eye. For example they might imagine or visualise themselves actually being incontinent or how other people would react to this. These mental pictures might be brief 'flashes' of your worst fear or they may be more like a 'movie' in your mind's eye.

    Do you ever have any mental pictures or images in your mind's eye associated with your fear of incontinence?

    Yes No *(→ IF NO, please proceed to question 24)*

    a. If yes, please try to picture these images in your mind, and write below what you see (Please provide as much detail as possible):

    b. How distressing do you find these mental pictures?

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
not at all distressing		slightly		definitely		markedly		very severely distressing

    c. How many times in the last week have you experienced these mental pictures?

    _____ times

24. Do you have any further comments about your fear of incontinence?

As fear of incontinence is poorly understood, we would like to invite you to take part in further research into the disorder. Your information will increase our knowledge of this particularly distressing disorder, helping us to develop new and effective treatments which can improve the quality of people's lives. If you wish to take part in further research, please provide us with your details below:

- Full Name:…….
- Address:…….
- Address:…….
- Postcode:……
- Telephone Number……
- E-mail:……..

Thank you very much for completing this questionnaire!

Appendix D: Study 1 Panic Online Questionnaire

QUESTIONNAIRES – 1

You have been asked to complete this questionnaire because you indicated that you experience panic attacks.
Please complete this questionnaire as best as you can to help us understand as much as possible about your concerns.

1. Age: _____

2. Gender (please circle): Male Female

3. Marital Status (please circle): Single Married or co-habiting Widowed Divorced

4. Employment Status (please circle):
   - Employed or self-employed
   - Homemaker
   - Unemployed
   - Long-term sick leave
   - Student
   - Retired
   - Other …….

5. What is your **main** concern (i.e. the one you worry about most)?:
   a) Fear of faecal incontinence
   b) Fear of urinary incontinence
   c) Fear of both urinary and faecal incontinence
   d) Fear of acting foolishly
   e) Fear of suffocating / not being able to breathe
   f) Fear of fainting
   g) Fear of vomiting
   h) Fear of having a heart attack
   i) Fear of choking
   a) Other

6. Have you ever sought help for your fear? (please circle) Yes No

   - **IF YES**, who have you sought help from? (please circle)

   f) GP
   g) Psychologist
   h) Psychiatrist
   i) Gastrointestinal Specialist
   j) Other : …….

7. Since school age or as an adult have you ever been incontinent in a public place (with other people around)? (please circle) Yes No

   - **IF YES**, how many times did this happen (please circle):
     once 2-4 times more than 5 times

8. PRS

A **panic attack** means a **sudden** increase in anxiety during which four or more of the following sensations are experienced:

1. Feeling short of breath
2. Palpitations or heart racing
3. Choking
4. Chest feeling uncomfortable or painful
5. Sweating
6. Dizziness, unsteady feelings or faintness
7. Feeling unreal or depersonalisation
8. Nausea or discomfort in the stomach
9. Hot or cold flushes
10. Trembling or shaking
11. Numbness or tingling feelings (pins and needles)
12. Fear of dying
13. Fear of doing something uncontrolled or going crazy during an attack

- Do you experience panic attacks? (please circle) Yes No *(→ IF NO, please continue to 17)*
- **IF YES**, what was the **frequency of your panic attacks** during the last two weeks:

0	1	2	3	4
No panic attacks	One panic attack per fortnight	One or two panic attacks per week	At least three panic attacks per week but averaging less than one per day	One or more panic attacks per day

- **IF YES**, how **severe** a **problem** are **panic attacks** for you at present?

0	1	2	3	4	5	6	7	8
Not at all disturbing and/or disabling		Slightly disturbing and/or disabling		Definitely disturbing and/or disabling		Markedly disturbing and/or disabling		Very disturbing and/or disabling

- **IF YES**, in the past two weeks, how much have you **avoided situations** (or needed someone to accompany you) due to fear that you may panic/have symptoms? Examples are: being outside home alone, travelling, being in a crowd, supermarket or department store?

0	1	2	3	4	5	6	7	8
No avoidance or apprehension / distress		Occasional avoidance or escape/ mild apprehension /distress		Moderate avoidance, moderate apprehension / distress		Severe avoidance/ severe apprehension/distress		Always avoids, very severe apprehension / distress

- **IF YES**, have you ever been incontinent *during* a panic attack? (please circle)
  Yes No

- **If you do experience panic attacks**, is your main concern that you will be incontinent during a panic attack? (please circle) Yes No

9. In relation to avoiding situations or objects, choose a number from the scale below to show how much you would avoid each of the situations or objects listed below

0	1	2	3	4	5	6	7	8
Would not avoid it		Slightly avoid it		Definitely avoid it		Markedly avoid it		Always avoid it

- Social situations due to a fear of being embarrassed or making a fool of myself. ……

- Certain situations because of a fear of having a panic attack or other distressing symptoms
  (such as loss of bladder control, vomiting or dizziness). ……..

- Certain situations because of a fear of particular objects or activities (such as animals, heights, seeing blood, being in confined spaces, driving or flying)……..

10. The following is a questionnaire specifically designed to ask questions related to a person's fear of incontinence. Although you may have answered related questions in the sections above, please still answer the questions below.

Please indicate how much you agree with each of the following statements, or how true it is about you. Please select a number (0-4) to indicate your answer e.g. 0 - Strongly Disagree (very untrue about me) and 4 - Strongly Agree (very true about me):

		Strongly disagree (very untrue about me)	Mildly disagree (somew hat true about me)	Neither agree nor disagree	Mildly agree (some what true about me)	Strongly agree (very true about me)
1.	I often notice sensations in my bladder/bowels, especially when I am anxious	0	1	2	3	4
2.	I avoid using public transport in case I am incontinent	0	1	2	3	4
3.	I limit the amount of food I eat and / or the amount of fluids I drink to reduce the chances of being incontinent	0	1	2	3	4
4.	If I go to an unfamiliar place, one of the first things I would do is look for the toilets	0	1	2	3	4
5.	My worst fear is that I would be incontinent in public	0	1	2	3	4
6.	Being incontinent in public would mean I am a disgusting person	0	1	2	3	4
7.	If I go out of the house I wear extra underclothes or I use padding in case I am incontinent	0	1	2	3	4
8.	I notice other symptoms (e.g. heart racing, sweating, trembling) when I need to go to the toilet and cannot easily get to one	0	1	2	3	4
9.	I avoid certain work or social activities because of a fear of being incontinent	0	1	2	3	4
10.	My relationships have been affected by a fear of being incontinent	0	1	2	3	4
11.	I worry about having a heart attack or choking	0	1	2	3	4

	Strongly disagree (very untrue about me)	Mildly disagree (some what true about me)	Neither agree nor disagree	Mildly agree (some what true about me)	Strongly agree (very true about me)
12. I avoid crowded places in case I am incontinent	0	1	2	3	4
13. I often think about how awful it would be if I was actually incontinent in a public place	0	1	2	3	4
14. When I am out of the home, I make a mental note of where toilets are located in case I need to use one urgently	0	1	2	3	4
15. My ability to work, study or socialize has been affected by a fear of being incontinent	0	1	2	3	4
16. Being incontinent is the most shameful thing that could happen to a person	0	1	2	3	4
17. I often check for sensations in my bladder or bowels	0	1	2	3	4
18. I use medications to stop myself being incontinent	0	1	2	3	4
19. I worry about losing control or going crazy	0	1	2	3	4
20. Other people would think I was a disgusting person if I was incontinent	0	1	2	3	4

11. **W&SAS**

People's problems sometimes affect their ability to do certain day-to-day tasks in their lives. To rate your problems look at each section and determine on the scale provided how much your problem impairs your ability to carry out the activity.

a.) **work –** if you are retired or choose not to have a job for reasons unrelated to your problem, please tick here _____

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
not at all		slightly		definitely		markedly		very severely I cannot work

b.) **home management –** cleaning, tidying, shopping, cooking, looking after home/children, paying bills etc

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
not at all		slightly		definitely		markedly		very severely

c.) **social leisure activities –** with other people, e.g. parties, pubs, outings, entertaining etc

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
not at all		slightly		definitely		markedly		very Severely

d.) **private leisure activities –** done alone, e.g. reading, gardening, sewing, hobbies, walking etc

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
not at all		slightly		definitely		markedly		very severely

e.) **family and relationships –** form and maintain close relationships with others including the people that I live with

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
not at all		slightly		definitely		markedly		very severely

12. Sometimes when people think about their worst fear (e.g. being incontinent) they experience a mental picture (or pictures) in their minds eye. For example they might imagine or visualise themselves actually being incontinent or how other people would react to this. These mental pictures might be brief 'flashes' of your worst fear or they may be more like a 'movie' in your mind's eye.

Do you ever have any mental pictures or images in your mind's eye associated with your fear of incontinence?

Yes No *(→ IF NO, please proceed to question 24)*

d. If yes, please try to picture these images in your mind, and write below what you see (Please provide as much detail as possible):

e. How distressing do you find these mental pictures?

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
not at all distressing		slightly		definitely		markedly		very severely distressing

f. How many times in the last week have you experienced these mental pictures?

_____ times

13. Do you have any further comments about your fear?

We would like to invite you to take part in further research into panic attacks. Your information will increase our knowledge, helping us to develop new and effective treatments which can improve the quality of people's lives. If you wish to take part in further research, please provide us with your details below:

- Full Name:…….
- Address:…….
- Address:…….
- Postcode:……
- Telephone Number……
- E-mail:……..

Thank you very much for completing this questionnaire

Appendix E: Study 2: Participant Information Sheet and Consent Form

Information Sheet for Participants in Research Studies (Form 2)

You will be given a copy of this information sheet.

Title of Project: Fear of Incontinence in Anxiety Disorders

This study has been approved by the UCL Research Ethics Committee [Project ID Number]: 2850/001

Name, Address and Contact Details of Investigators:

Christine Langhoff
Research Department of Clinical, Educational and Health Psychology
University College London, Gower Street,
London, WC1E 6BT

We would like to invite you to participate in this research project on fear of incontinence. You should only participate if you want to. Before you decide whether you want to take part, it is important for you to read the following information carefully. Contact us if there is anything that is not clear or if you would like more information.

Details of Study

We are interested in understanding the experiences of people who have a fear of incontinence. The study is being conducted by Christine Langhoff, (Trainee Clinical Psychologist) and supervised by Dr Sunjeev Kamboj (Lecturer in Clinical Health Psychology) and Dr Sue Watson (Clinical Director, D-Clin-Psy) at UCL University. It has been approved by the UCL Ethics Committee.

If you agree to take part in the study, you will be asked to fill out a number of questionnaires and return them to us by post, using the pre-paid envelope provided. Participation in this study typically takes 40 minutes. The questionnaires ask about a range of issues, including anxiety disorders, perception of bodily changes, control, disgust and quality of life. It is unlikely that you will find completing these questions distressing, but if you do, please feel free to discontinue. You may also contact the investigators (using the details provided above) for information on accessing support.

We hope that gathering this information from people who suffer from a fear of incontinence will create a better understanding of this fear, an important step towards better treatment in the future. You can request for a copy of the research results, which we will publish in a scientific or medical journal once our research is complete.

This study is **strictly anonymous**. All responses are treated as confidential, and in no case will responses from individual participants be identifiable. You will be given a unique 'participant number' and will only be identifiable by this. Your contact details will be kept separate from your data. All data will be collected and stored in accordance with the Data Protection Act 1998. Only researchers involved in the study will have access to the data and it will be securely stored at all times.

Participation is voluntary. It is up to you to decide to participate or not, and you are free to withdraw from the study at any time and without giving a reason.

If you have further questions about this study or if you wish to lodge a complaint or concern, you may contact the investigators, whose details are provided above.

If you are 18 years of age or older, understand the statements above, and freely consent to participate in the study, please sign the attached consent form and return it with your questionnaires. Please keep this information sheet for your own reference.

Informed Consent Form for Participants in Research Studies (Form 2)

(This form is to be completed independently by the participant after reading the Information Sheet and/or having listened to an explanation about the research.)

Title of Project: Fear of Incontinence in Anxiety Disorders

This study has been approved by the UCL Research Ethics Committee [Project ID Number]: 2850/001

Participant's Statement

I .....

Confirm that I am aged between 18 and 65 years and agree that I have:

- read the information sheet
- had the opportunity to ask questions and discuss the study;
- received satisfactory answers to all my questions or have been advised of an individual to contact for answers to pertinent questions about the research and my rights as a participant.

I understand that I am free to withdraw from the study without penalty if I so wish and I consent to the processing of my personal information for the purposes of this study only and that it will not be used for any other purpose. I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.

Signed: Date:

Investigator's Statement

I .....

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

Signed: Date:

Appendix F: Study 2 Questionnaires

PHASE 2 QUESTIONNAIRES

1. GAD-7

Over the **last 2 weeks**, how often have you been bothered by the following problems?		Not at all	Several days	More than half the days	Nearly every day
1	Feeling nervous, anxious or on edge	0	1	2	3
2	Not being able to stop or control worrying	0	1	2	3
3	Worrying too much about different things	0	1	2	3
4	Trouble relaxing	0	1	2	3
5	Being so restless that it is hard to sit still	0	1	2	3
6	Becoming easily annoyed or irritable	0	1	2	3
7	Feeling afraid as if something awful might happen	0	1	2	3

2. PHQ-9

Over the **last 2 weeks**, how often have you been bothered by the following problems?		Not at all	Several days	More than half the days	Nearly every day
1	Little interest or pleasure in doing things	0	1	2	3
2	Feeling down, depressed, or hopeless	0	1	2	3
3	Trouble falling asleep, staying asleep, or sleeping too much	0	1	2	3
4	Feeling tired or having little energy	0	1	2	3
5	Poor appetite or overeating	0	1	2	3
6	Feeling bad about yourself, feeling that you are a failure, or feeling that you have let yourself or your family down	0	1	2	3
7	Trouble concentrating on things such as reading the newspaper or watching television	0	1	2	3
8	Moving or speaking so slowly that other people could have noticed. Or being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9	Thinking that you would be better off dead or that you want to hurt yourself in some way	0	1	2	3

3. OCI-SV

The following statements refer to experiences that many people have in their everyday lives. Circle the number that best describes **HOW MUCH** that experience has **DISTRESSED or BOTHERED you during the PAST MONTH**.

	Not at all	A little	Moderately	A lot	Extremely
1. I have saved up so many things that they get in the way.	0	1	2	3	4
2. I check things more often than necessary.	0	1	2	3	4
3. I get upset if objects are not arranged properly.	0	1	2	3	4
4. I feel compelled to count while I am doing things.	0	1	2	3	4
5. I find it difficult to touch an object when I know it has been touched by strangers or certain people.	0	1	2	3	4
6. I find it difficult to control my own thoughts.	0	1	2	3	4
7. I collect things I don't need.	0	1	2	3	4
8. I repeatedly check doors, windows, drawers, etc.	0	1	2	3	4
9. I get upset if others change the way I have arranged things.	0	1	2	3	4
10. I feel I have to repeat certain numbers.	0	1	2	3	4
11. I sometimes have to wash or clean myself simply because I feel contaminated.	0	1	2	3	4
12. I am upset by unpleasant thoughts that come into my mind against my will.	0	1	2	3	4
13. I avoid throwing things away because I am afraid I might need them later.	0	1	2	3	4
14. I repeatedly check gas and water taps and light switches after turning them off.	0	1	2	3	4
15. I need things to be arranged in a particular order.	0	1	2	3	4
16. I feel that there are good and bad numbers.	0	1	2	3	4
17. I wash my hands more often and longer than necessary.	0	1	2	3	4
18. I frequently get nasty thoughts and have difficulty in getting rid of them.	0	1	2	3	4

4. SPIN

For the next questions, we'd like you to tell us if the following problems have bothered you during the past week. For these items, the response options are "not at all," "a little bit," "somewhat," "very much," and "extremely."

		not at all	*a little bit*	*somewhat*	*very much*	*extremely*
1	I am afraid of people in authority	0	1	2	3	4
2	I am bothered by blushing in front of people	0	1	2	3	4
3	Parties and social events scare me	0	1	2	3	4
4	I avoid talking to people I don't know	0	1	2	3	4
5	Being criticized scares me a lot	0	1	2	3	4
6	I avoid doing things or speaking to people for fear of embarrassment	0	1	2	3	4
7	Sweating in front of people causes me distress	0	1	2	3	4
8	I avoid going to parties	0	1	2	3	4
9	I avoid activities in which I am the centre of attention	0	1	2	3	4
10	Talking to strangers scares me	0	1	2	3	4
11	I avoid having to give speeches	0	1	2	3	4
12	I would do anything to avoid being criticized	0	1	2	3	4
13	heart palpitations bother me when I am around people	0	1	2	3	4
14	I am afraid of doing things when people might be watching	0	1	2	3	4
15	being embarrassed or looking stupid are among my worse fears	0	1	2	3	4
16	I avoid speaking to anyone in authority	0	1	2	3	4
17	trembling or shaking in front of others is distressing to me	0	1	2	3	4

5. MIA

1. Please indicate the degree to which you avoid the following places or situations because of discomfort or anxiety. Rate your amount of avoidance when you are with a trusted companion and when you are alone. Do this by using the following scale:

1	2	3	4	5
never avoid	rarely avoid	avoid about half of the time	avoid most of the time	always avoid

Circle the number for each situation or place under both conditions: when accompanied and when alone.

PLACES	**WHEN ACCOMPANIED**	**WHEN ALONE**
Theatres	1 2 3 4 5	1 2 3 4 5
Supermarkets	1 2 3 4 5	1 2 3 4 5
Shopping Malls	1 2 3 4 5	1 2 3 4 5
Classrooms	1 2 3 4 5	1 2 3 4 5
Department Stores	1 2 3 4 5	1 2 3 4 5
Restaurants	1 2 3 4 5	1 2 3 4 5
Museums	1 2 3 4 5	1 2 3 4 5
Elevators	1 2 3 4 5	1 2 3 4 5
Auditoriums/stadiums	1 2 3 4 5	1 2 3 4 5
Garages	1 2 3 4 5	1 2 3 4 5
High Places	1 2 3 4 5	1 2 3 4 5
Please tell how high		
Enclosed Spaces	1 2 3 4 5	1 2 3 4 5
OPEN SPACES	**WHEN ACCOMPANIED**	**WHEN ALONE**
Outside (for example: fields, wide streets, courtyards)	1 2 3 4 5	1 2 3 4 5
Inside (for example, large rooms, lobbies)	1 2 3 4 5	1 2 3 4 5
RIDING IN	**WHEN ACCOMPANIED**	**WHEN ALONE**
Buses	1 2 3 4 5	1 2 3 4 5
Trains	1 2 3 4 5	1 2 3 4 5
Subways	1 2 3 4 5	1 2 3 4 5
Airplanes	1 2 3 4 5	1 2 3 4 5
Boats	1 2 3 4 5	1 2 3 4 5
DRIVING OR RIDING IN A CAR	**WHEN ACCOMPANIED**	**WHEN ALONE**
At anytime	1 2 3 4 5	1 2 3 4 5
On expressways	1 2 3 4 5	1 2 3 4 5
SITUATIONS	**WHEN ACCOMPANIED**	**WHEN ALONE**
Standing in Lines	1 2 3 4 5	1 2 3 4 5
Crossing Bridges	1 2 3 4 5	1 2 3 4 5
Parties or Social Gatherings	1 2 3 4 5	1 2 3 4 5
Walking on the Street	1 2 3 4 5	1 2 3 4 5
Staying home alone	1 2 3 4 5	1 2 3 4 5
Being far away from home	1 2 3 4 5	1 2 3 4 5
Other(specify):	1 2 3 4 5	1 2 3 4 5

2. After completing the first step, circle the 5 items with which you are most concerned. Of the items listed, these are the five situations or places where avoidance/anxiety most affects your life in a negative way.

PANIC ATTACKS

3. We define a panic attack as:

- A high level of anxiety accompanied by……
- strong body reactions (heart palpitations, sweating, muscle tremors, dizziness, nausea) with…….
- the temporary loss of the ability to plan, think, or reason and…….
- the intense desire to escape or flee the situation (Note: this is different from high anxiety or fear alone).

Please indicate the number of panic attacks you have had in the past 7 days: _____

4. Many people are able to travel alone freely in the area (usually around their home) called their safety zone.

Do you have such a zone? If yes, please describe:

a. Its location:

b. Its size (e.g.radius from home):

6. BVS

Instructions: This measure is designed to index how sensitive you are to internal bodily sensations such as heart palpitations or dizziness. Fill it out according to how you have felt for the **past week**.

1. I am the kind of person who pays close attention to internal bodily sensations.

0 1 2 3 4 5 6 7 8 9 10
Not at all Like Me — Moderately Like Me — Extremely Like Me

2. I am very sensitive to changes in my internal bodily sensations.

0 1 2 3 4 5 6 7 8 9 10
Not at all Like Me — Moderately Like Me — Extremely Like Me

3. On average, **how much time** do you spend each day "scanning" your body for sensations (e.g., sweating, heart palpitations, dizziness)?

0 10 20 30 40 50 60 70 80 90 100
No Time — Half of the Time — All of the Time

4. Rate how much attention you pay to each of the following sensations using this scale:

0 1 2 3 4 5 6 7 8 9 10
None — Slight — Moderate — Substantial — Extreme

1. Heart Palpitations _____
2. Chest Pain/Discomfort _____
3. Numbness _____
4. Tingling _____
5. Short of Breath/Smothering _____
6. Faintness _____
7. Vision changes _____
8. Feelings of Unreality _____
9. Feeling detached from self _____
10. Dizziness _____
11. Hot flash _____
12. Sweating/clammy hands _____
13. Stomach upset _____
14. Nausea _____
15. Choking/Throat Closing _____

7. DPSS-R

Instructions: this questionnaire consists of 16 statements about disgust. Please read each statement and think how often it is true for you, then place a 'x' in the box that is closest to this.

	Never	Rarely	Some times	Often	Always
1. I avoid disgusting things.	0	1	2	3	4
2. When I feel disgusted, I worry that I might pass out.	0	1	2	3	4
3. It scares me when I feel nauseous.	0	1	2	3	4
4. I think disgusting items could cause me illness / infection.	0	1	2	3	4
5. I feel repulsed.	0	1	2	3	4
6. Disgusting things make my stomach churn.	0	1	2	3	4
7. I screw up my face in disgust.	0	1	2	3	4
8. When I notice that I feel nauseous, I worry about vomiting.	0	1	2	3	4
9. When I experience disgust, it is an intense feeling.	0	1	2	3	4
10. I experience disgust.	0	1	2	3	4
11. It scares me when I feel faint.	0	1	2	3	4
12. I become disgusted more easily than other people.	0	1	2	3	4
13. I worry that I might swallow a disgusting thing.	0	1	2	3	4
14. I find something disgusting.	0	1	2	3	4
15. It embarrasses me when I feel disgusted.	0	1	2	3	4
16. I think disgust is bad for me.	0	1	2	3	4

8. ACQ

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9. BSSS

Please indicate below, how often you have had each symptom of bowel disease over the past week. Do this by placing a cross neatly in the box. If you do not have the symptom place a cross in the 'not at all' box. Please ensure you answer all of the questions.

1a. Over the past week how often have you had loose or watery bowel motions?

Not at all	Every other day	Every day	1–3 times a day	More than 3 times a day

1b. How distressed were you by this?

Not at all	A little bit	Moderately	Quite a Bit	Extremely

1c. How much did this interfere with your everyday life?

Not at all	A little bit	Moderately	Quite a Bit	Extremely

2a. Over the past week on how many occasions did you have hard or lumpy stools when you had a bowel motion?

Not at all	Once or twice	3-5 times	Every day	More than once a day

2b. How distressed were you by this?

Not at all	A little bit	Moderately	Quite a Bit	Extremely

2c. How much did this interfere with your everyday life?

Not at all	A little bit	Moderately	Quite a Bit	Extremely

3a. Over the past week how often have you had abdominal (tummy) pain?

Not at all	Once or twice	3-5 times	Every day	More than once a day

3b. How distressed were you by this?

Not at all	A little bit	Moderately	Quite a Bit	Extremely

3c. How much did this interfere with your everyday life?

Not at all	A little bit	Moderately	Quite a Bit	Extremely

4a. Over the past week, on how many days have you had more than 3 bowel motions a day?

Not at all	1	2-3	4-5	6-7

4b. How distressed were you by this?

Not at all	A little bit	Moderately	Quite a Bit	Extremely

4c. How much did this interfere with your everyday life?

Not at all	A little bit	Moderately	Quite a Bit	Extremely

5a. Over the past week, how often have you felt bloated or had an uncomfortable fullness in your abdomen?

Not at all	Once or twice	3-5 times	Every day	More than once a day

5b. How distressed were you by this?

Not at all	A little bit	Moderately	Quite a Bit	Extremely

5c. How much did this interfere with your everyday life?

Not at all	A little bit	Moderately	Quite a Bit	Extremely

6a. Over the past week how often have you had an urgent need to have a bowel motion?

Not at all	Once or twice	3-5 times	Every day	More than once a day

6b. How distressed were you by this?

Not at all	A little bit	Moderately	Quite a Bit	Extremely

6c. How much did this interfere with your everyday life?

Not at all	A little bit	Moderately	Quite a Bit	Extremely

7a. Over the past week, how many days have there been when you were unable to have a bowel motion?

Not at all	1	2-3	4-5	6-7

7b. How distressed were you by this?

Not at all	A little bit	Moderately	Quite a Bit	Extremely

7c. How much did this interfere with your everyday life?

Not at all	A little bit	Moderately	Quite a Bit	Extremely

8a. Over the past week, how often have you had a general feeling of discomfort in your abdomen (tummy)?

Not at all	Once or twice	3-5 times	Every day	More than once a day

8b. How distressed were you by this?

Not at all	A little bit	Moderately	Quite a Bit	Extremely

8c. How much did this interfere with your everyday life?

Not at all	A little bit	Moderately	Quite a Bit	Extremely

10. UPS

1. What is the reason that you usually urinate?

— Out of convenience (no urge)
— Because I have a mild urge (but can delay urination for over an hour if I have to)
— Because I have a moderate urge (but can delay urination for more than 10 but less than 60 minutes if I have to)
— Because I have a severe urge (but can delay urination for less than 10 minutes)
— Because I have desperate urge (must stop what I am doing and go immediately)

2. Once you get the urge to urinate, how long can you usually postpone it comfortably?

— More than 60 minutes
— About 30–60 minutes
— About 10–30 minutes
— A few minutes (less than 10 minutes)
— Must go immediately

3. How often do you get a sudden urge to urinate that makes you want to stop what you are doing and rush to the bathroom?

— Never
— Rarely
— A few times a month
— A few times a week
— Daily

4. How often do you get a sudden urge to urinate that makes you want to stop what you are doing and rush to the bathroom but you don't get there in time (eg, you leak urine or wet pads)?

— Never
— Rarely
— A few times a month
— A few times a week
— Daily

5. In your opinion how good is your bladder control?

0 1 2 3 4 5 6 7 8 9 10
perfect control good control no control at all

11. ISS

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12. SUIS

Please read each of the following descriptions and indicate the degree to which each is appropriate for you. Do not spend a lot of time thinking about each one, but respond based on your thoughts about how you do or do not perform each activity. If a description is always completely appropriate, please write "5"; if it is never appropriate, write "1"; if it is appropriate about half of the time, write "3"; and use the other numbers (2 and 4) accordingly.

_____ 1. When going to a new place, I prefer directions that include detailed descriptions of landmarks (such as the size, shape and colour of a petrol station) in addition to their names.

_____ 2. If I catch a glance of a car that is partially hidden behind bushes, I automatically "complete it," seeing the entire car in my mind's eye.

_____ 3. If I am looking for new furniture in a store, I always visualize what the furniture would look like in particular places in my home.

_____ 4. I prefer to read novels that lead me easily to visualize where the characters are and what they are doing instead of novels that are difficult to visualize.

_____ 5. When I think about visiting a relative, I almost always have a clear mental picture of him or her.

_____ 6. When relatively easy technical material is described clearly in a text, I find illustrations distracting because they interfere with my ability to visualize the material.

_____ 7. If someone were to tell me two-digit numbers to add (e.g., 24 and 31), I would visualize them in order to add them.

_____ 8. Before I get dressed to go out, I first visualize what I will look like if I wear different combinations of clothes.

_____ 9. When I think about a series of errands I must do, I visualize the stores I will visit.

_____ 10. When I first hear a friend's voice, a visual image of him or her almost always springs to mind.

_____ 11. When I hear a radio announcer or DJ I've never actually seen, I usually find myself picturing what they might look like.

_____ 12. If I saw a car accident, I would visualize what had happened when later trying to recall the details.

Appendix G: Information on Joint Theses

Information on Joint Theses

This D.Clin.Psy thesis was conducted as part of a larger project at UCL, which aims to extend our understanding of people who experience bowel/bladder-control anxiety (BBCA). As such, this project can be considered to be a joint thesis, as it was conducted alongside that of another Trainee Clinical Psychologist, Rosanna Pajak.

Rosanna Pajak's thesis, which was submitted in June 2012, is qualitative study involving a subset of participants (n=20) who were recruited from the initial internet-based questionnaire used for my project and the questionnaire data for the participants who completed the interview were included in Rosanna's thesis for descriptive purposes only. Rosanna's study involved semi-structured interviews exploring the characteristics and content of mental imagery experienced by people with BBCA.

Rosanna and I worked together to gain ethical approval for both our projects as a whole entity. We also worked together to construct the online screening questionnaire: it was important that this included several questions about imagery for Rosanna's project. Whilst I took responsibility for setting up the online questionnaires itself, we both worked to process participants' responses and both of us regularly screened the responses in order to identify those who reported imagery until Rosanna's project was completed. I was entirely responsible for the recruitment of the panic sample as this was only started after Rosanna had completed her thesis.

I also set up the databases for collating the questionnaire data and was responsible for data extraction from the online questionnaires and entry of data from the paper-based questionnaires. Rosanna offered assistance with printing, collating and posting out questionnaires, and in terms of liaising with NHS IAPT services to

support recruitment. In return, I provided assistance in conducting a small number of the telephone interviews, although Rosanna was responsible for transcription. Naturally, the analysis and write-up of this thesis were completely independent.