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Fulfilment of the requirements for the  
Degree of Doctorate in Clinical  
Psychology  
Volume 1 of 2

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Samantha Lloyd

Doctorate in Clinical Psychology

University of Bath  
Department of Psychology

June 2018

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## **Declaration**

I declare that the work presented in this thesis is my own and has not been submitted for any other degrees in this or in any other university or institute of learning.

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# **Abstracts**

## Literature review

Background: Cognitive behavioural therapy (CBT) has been increasingly applied to the understanding and treatment of physical health problems, with it shown to be associated with improved quality of life and reduced distress. However, the outcomes for CBT for many physical health problems lag behind those associated with psychological disorders, particularly anxiety disorders. The concept of safety seeking behaviours is suggested to have significantly contributed to effective cognitive behaviour interventions across anxiety disorders. This construct has been increasingly applied to other disorders, including physical health disorders, with development of models to include this concept being suggested to have similar potential for improving outcomes. Aims: The aim of this systematic review was to examine the current evidence for SSB across physical health conditions and to synthesise what is currently known of the topology, perceived function and impact of such behaviours. Methods: 28 eligible papers were identified and included in the review. Given the wide variety of study designs, a qualitative synthesis of the findings only was carried out. Results: The construct of SSB was found to be relevant to a number of different physical health conditions including insomnia, chronic pain, diabetes, tinnitus, sexual dysfunction, irritable bowel syndrome and cardiac-related conditions. Conclusions: There is support for the relevance of SSB across a range of conditions. This has treatment implications for reducing distress and improving quality of life in medical conditions. However, further high-quality research is needed which takes into account the perceived function and impact and meaning attached to strategies in order to better inform interventions.

*Keywords:* systematic review; safety seeking behaviours; health; physical health; cognitive behavioural therapy

## **Main Research Project**

The aim of this study was to investigate the use of safety-seeking behaviours (SSB) in Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME) in response to physical exertion. An experimental design was used with N = 10 individuals with CFS/ME and N = 15 healthy controls (HCs) carrying out a physical task twice. Participants were recorded while completing the task and asked to identify from the recording strategies used during the task and the function of these. Significant differences on the number of strategies defined as SSB were found between groups, with the CFS/ME group using significantly more SSB during the Task 2. In addition, a significant correlation was found between the number of SSB and increased score on a measure of health anxiety. Overall the pilot study provides novel evidence for the use of SSB in CFS/ME and conceptualises topology and function of such strategies, with SSB representing an important potential target for cognitive behavioural interventions for this condition.

*Key words:* chronic fatigue; safety-seeking behaviours; cognitive behavioural therapy;

## **Service Improvement Project**

Despite an increasing evidence base for systemic therapy, the provision of such services does not measure up to this and a number of challenges to implementing family therapy have been discussed. The Family and Couple Therapy service (FaCT) in South Gloucestershire is representative of such challenges, with the service not having been used to full capacity. The aim of this project was to explore through mixed methodology, who is referred into the service and why. An audit of referrals data was conducted, along with qualitative interviews with five potential referrers. Referrals were received for individuals with a range of diagnoses and difficulties. Themes emerging from interviews demonstrated that whilst those interviewed appreciated the value of working systemically and regarded it relevant to the majority of their case load, there exist a number of service and service-user related barriers. The findings are discussed in relation to the wider literature and recommendations for addressing the emerging barriers are outlined.

*Keywords:* Family Therapy; systemic; interviews; referrals; service improvement

**Literature Review- Are safety-seeking behaviours relevant to medical conditions? A systematic review of topology, function and impact.**

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Internal supervisor: Dr Jo Daniels

Target Journal: Health Psychology Review

## **Abstract**

Background: Cognitive behavioural therapy (CBT) has been increasingly applied to the understanding and treatment of physical health problems, with it shown to be associated with improved quality of life and reduced distress. However, the outcomes for CBT for many physical health problems lag behind those associated with psychological disorders, particularly anxiety disorders. The concept of safety seeking behaviours is suggested to have significantly contributed to effective cognitive behaviour interventions across anxiety disorders. This construct has been increasingly applied to other disorders, including physical health disorders, with development of models to include this concept being suggested to have similar potential for improving outcomes. Aims: The aim of this systematic review was to examine the current evidence for Safety Seeking Behaviours (SSB) across physical health conditions and to synthesise what is currently known of the topology, perceived function and impact of such behaviours. Methods: 28 eligible papers were identified and included in the review. Given the wide variety of study designs, a qualitative synthesis of the findings only was carried out. Results: The construct of SSB was found to be relevant to a number of different physical health conditions including insomnia, chronic pain, diabetes, tinnitus, sexual dysfunction, irritable bowel syndrome and cardiac-related conditions. Conclusions: There is support for the relevance of SSB across a range of conditions. This has treatment implications for reducing distress and improving quality of life in medical conditions. However, further high-quality research is needed which takes into account the perceived function and impact and meaning attached to strategies in order to better inform interventions.

*Keywords:* systematic review; safety seeking behaviours; health; physical health; cognitive behavioural therapy

## **Introduction**

Around 15 million people in the UK – 24% of the population - have a long-term health condition, with this prevalence steadily rising over time (Naylor et al, 2012). Of those, one third also experience comorbid psychological difficulties - most commonly anxiety and depression (Department of Health, 2012) - with this contributing to poor health outcomes, quality of life and high levels of distress prevalent in health conditions (e.g. Wandell, 2005; Gralnek, Hays, Kilbourne, Naliboff & Mayer, 2000; Birtane, Uzunca, Tastekin & Tuna, 2007). Given the high prevalence, impairment and psychological impact of such conditions, there is a clear need for intervention.

As acknowledgment of the complex interplay between physical and psychological health grows, as do calls for interventions which target symptoms of both. This has prompted the development and application of cognitive behavioural models to a range of health conditions, with the aim of improving physical and psychological functioning and quality of life (Morley, Eccleston & Williams, 1999; Tyrer et al, 2014; Tyrer, Cooper, Crawford, et al., 2011; Osborn, Demoncada, & Feuerstein, 2006). For example, NICE guidelines for depression not only propose routine screening for depression in individuals with long-term health conditions, but also recommend cognitive behavioural therapy (CBT) as gold standard for those with comorbid depression in the context of physical health difficulties (NICE, 2009).

Whilst there is some evidence for the effectiveness of CBT in reducing symptoms and improving quality of life in medical conditions, effect sizes achieved are small to medium at best (Ismail, Winkley & Rabe-Hesketh, 2004; Castell, Kazantzis & Moss-Morris, 2011). This is in comparison to the field of mental health, where cognitive behavioural treatments of anxiety disorders are associated with large effect sizes (Olatunji, Cisler, & Deacon, 2010; Jamani & Clyde, 2008). It is suggested that this disparity may be due to cognitive behavioural models and treatment in physical health being overly behavioural with a focus on psycho-education, exposure and management of activity, at the expense of a more cognitive conceptualisation which incorporates the meaning of symptoms and experiences for the individual (Jamani & Clyde, 2008; Daniels & Loades, 2017; Sharp, 2001b).



There is support for the relevance of cognition and meaning of symptoms within physical health conditions, with the impact of fear experienced by those with physical health conditions often outweighing the burden of physical symptoms (Tyrrer et al, 2011). For example, pain-related beliefs are shown to be a more important determinant of disability and quality of life than pain intensity or duration (Dennison et al, 2005; Lamé, Peters, Kessels, Van Kleef & Patijn, 2008), and catastrophising associated with greater pain severity and illness behaviours across a range of conditions (Sullivan et al, 2001; Gracely et al, 2004). The example is given of someone with chronic lower back pain, who fears that lifting will result in reinjury and responds to this with avoidance and other strategies such as wearing a back brace (Tang et al, 2007; Jamani & Clyde, 2008). Despite not experiencing re-injury, the individual continues to hold this belief, consequently impacting on functioning and quality of life. So why in the face of contrary evidence does this belief remain?

The same question was posed in the anxiety disorders and addressed through application of the construct of safety-seeking behaviours (SSB). Introduced by Salkovskis (1996), safety-seeking behaviours are behaviours or strategies driven by anxiety, used in order to “prevent or minimize a feared catastrophe” (Clark, 1999, p. 7) and are proposed to represent a mechanism by which threat-related beliefs are maintained or increased. Commonly falling into one of three categories: avoidance of a feared situation, escape from a situation and more subtle behaviours which are employed to cope within the feared situation, SSB provided answer to the question of why, despite repeated exposure without the feared outcome occurring, threat-related beliefs and anxiety are maintained (Salkovskis, 1999). Salkovskis, Clark, & Gelder (1996) present the example of an individual who interprets the sensation of weakness in his legs as meaning that he is going to collapse. In response, a number of SSB are employed, including holding onto something, tensing his legs and sitting down, with the intention of preventing himself collapsing. Paradoxically these strategies maintain anxiety and prevent disconfirmation of fear-related beliefs, with the individual believing they have experienced a ‘near miss’ and the non-occurrence of collapse attributed to the use of these strategies (i.e. the belief that without these behaviours, they would have collapsed).

The development of cognitive behavioural models of anxiety disorders to include concepts such as safety seeking behaviours has been suggested to have led to significant advances in the theoretical understanding and treatment of such disorders (e.g., Salkovskis, Clark, Hackmann, Wells, & Gelder, 1999; Clark et al, 1995; Tang et al., 2007). Now established as a key concept in anxiety disorders, there is consistent evidence for the role of SSB in the development and maintenance of anxiety (Piccirillo, Dryman & Heimberg, 2016; Helbig-Lang & Peterman, 2010), and interference with treatment outcomes (Helbig-Lang & Peterman, 2010; Sloan & Telch, 2002). There is also evidence that reducing or eliminating SSB is associated with improved symptoms (Piccirillo et al, 2016), with behavioural experiments utilised as a means of testing out an individual's catastrophic beliefs and predictions (Bennett-Levy et al, 2004; Jamani & Clyde, 2008).

Given similar observations concerning the persistence of fear-related beliefs in health conditions such as chronic pain, it has been argued that a similar approach would be clinically useful within physical health, with emerging evidence that interventions incorporating the construct of SSB are associated with promising outcomes. Daniels & Loades (2017) reported on a case example of an individual with CFS/ME whose interpretation of physical sensations as signalling a CFS related ‘collapse’ was responded to with SSB, with the intention of avoiding such a collapse. These anxiety driven strategies were not only ineffective, but were proposed to maintain symptoms of CFS. An intervention using behavioural experiments to drop SSB and test out related predictions enabled anxiety-related beliefs to be challenged, providing disconfirming evidence of being able to cope with increased symptoms without a collapse and leading to a decrease in physical symptoms and increased social and work activity (Daniels & Loades, 2017).

The definition and conceptualisation of SSB is not without controversy, with an alternative view proposing that SSB are not necessarily deleterious and that such strategies may in fact be useful by making exposure therapy more acceptable (Rachman, Radomsky & Shafran, 2008). However, it is argued that much of this debate arises from conceptual issues in the way behaviours have been defined, with ‘safety seeking behaviour’ and ‘safety behaviour’ used interchangeably (Halldorsson, 2015; Helbig-Lang & Petermann (2010). As such, attempts have been made to

distinguish SSB from more adaptive coping strategies on the basis of the intention, perceived function of a behaviour to an individual in a given context, and the impact on cognitions (Thwaites & Freeston, 2005), with meaning seen as key to this distinction (Salkovskis, 1991; Halldorsson, 2015).

In summary, SSB have been extensively investigated in anxiety disorders, where they are linked to the development and maintenance of difficulties and where it has been demonstrated that cognitive behavioural interventions incorporating SSB are associated with superior outcomes relative to those within physical health. SSB appear to also have relevance to physical health conditions, where unidentified and unchallenged they may contribute not only to maintenance of both psychological and physical symptoms, but a restricted existence with poor quality of life. Given the below par outcomes associated with existing cognitive behavioural interventions in physical health, there is a clear need for the improvement of interventions. SSB represent a key candidate for improving outcomes, offering clear implications for intervention – in the form of behavioural experiments – which have the potential to affect not only behavioural but also cognitive change through the testing out of illness related beliefs (Sharp, 2001a; Jamani & Clyde, 2008). As such this begins to address the comparative lack of meaning that current cognitive behavioural models of physical health conditions are charged with. This is an extremely promising area given the poor outcomes presently and growing relevance of chronic and life limiting health conditions within the population.

This study will critically review the hypothesised importance and clinical utility of SSB in physical health conditions, by collating data on the topology, perceived function and impact of strategies. In addition to promising treatment implications, this review also contributes to better operationalisation of SSB within such conditions, therefore improving understanding and aiding further empirical work.

### **Aims and objectives**

The aim of this review was to synthesise the current evidence for SSB in medical conditions, according to the following research questions:

- 1) What is the current evidence for the presence of SSB within medical conditions?
- 2) What is the topology of these behaviours?
- 3) What is known about the perceived function and intention behind such behaviours?
- 4) What is known about the impact of these behaviours on cognitions and on psychological and / or physical symptoms.

## **Method**

This review was carried out and reported according to the PRISMA statement (Moher, Liberati, Tetzlaff, & Altman, 2009) and was registered on Prospero (CRD42018085573).

### **Search strategy**

Electronic databases of Scopus, EMBASE, Medline and PubMed were searched. Search terms were deliberately broad based on the aims and novelty of the review and the advice of an information specialist: ('safety behavio(u)r', safety seeking behavio(u)r). Reference lists of included papers were also checked.

### **Selection criteria**

Eligibility criteria were papers on safety seeking behaviours written in English, in peer reviewed journals or grey literature. Due to conceptual issues outlined, and so as not to exclude relevant papers, studies reporting on 'safety seeking behaviours' or 'safety behaviours' were eligible for inclusion. Studies were eligible if they involved individuals with physical health or medical conditions, including those with comorbid psychological conditions. Due to developmental differences, studies relating to children or adolescents were not eligible. As this was a novel area of review with the aim of capturing the current state of the literature, papers involving a range of study designs were eligible, including conceptual papers but excluding reviews.

## **Data extraction**

Titles and abstracts of studies generated by the initial search were screened by two researchers to assess eligibility (S.L.: 100%, M.H.: 20%). In addition to those deemed to be eligible, where it was unclear based on title and abstract, studies were included for review at the full text stage. Disagreements were resolved through discussion until consensus was reached. Full texts of potentially relevant articles were then screened (S.L.: 100%, M.H.: 20%), with discrepancies discussed and resolved through discussion. Data extraction and risk of bias assessment was completed by SL using an extraction spreadsheet.

Risk of bias in individual studies was assessed using the Cochrane risk of bias assessment tool based on the following domains: random sequence generation, allocation concealment, blinding of participants and personnel, blinding of outcome assessment, incomplete outcome data, selective reporting, and other sources of bias. Eligible studies were rated as high, low or unclear according to risk of bias in these domains, in line with the Cochrane guidelines. A copy of the risk of bias tool can be found in the appendices.

## **Data synthesis and analysis**

Due to the anticipated heterogeneity of available data, a narrative analysis of primary and secondary outcomes was planned and carried out to include: 1) SSB topology; 2) SSB perceived function (as measured by self-report, quantitative, qualitative or observational methods, or in the case of conceptual papers, expert opinion, extrapolation from findings of other research studies and principle driven theory; (Phillips et al, 2011); 3) Physical or psychological symptoms of medical health problems (as measured by self-report or objective measures) where the association between SSB and these outcomes was reported.

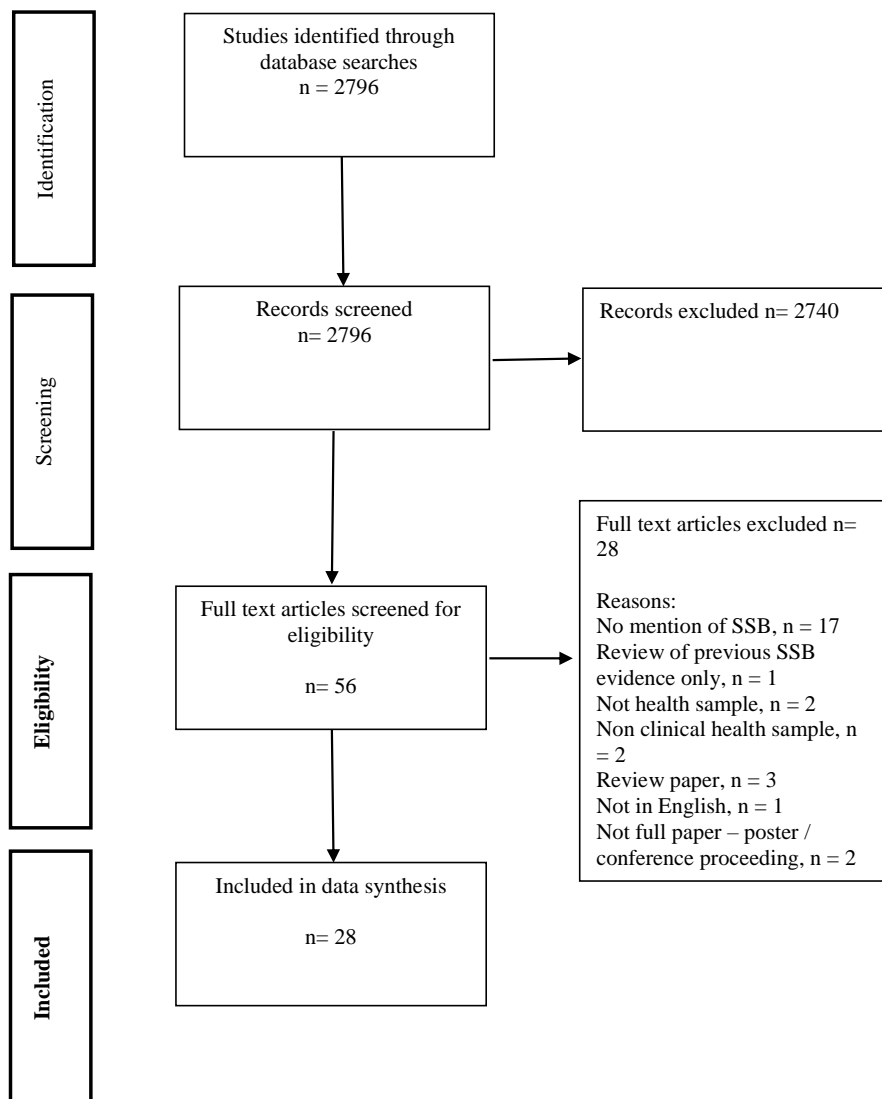
Effect sizes for main findings of included studies were calculated, where possible, using Cohen's *d* or Pearson's *r*.

## Results

### Selection and inclusion of studies

The search identified 2796 studies, with 56 studies identified as potentially relevant based upon title and abstract and the full papers reviewed by the main author. Review of full papers found 28 to meet eligibility to be included in the review. **Figure 1** shows a study flow diagram in line with PRISMA.

Inter-rater reliability was very good at both title and abstract ( $k = 0.82$ , 91.67% agreement) and full text stage ( $k = 0.96$ , 99.6% agreement).



**Figure 1: Flow-chart of systematic review process**

## **Study characteristics**

Key study characteristics and associated outcome data are shown in *Table 1*. Identified articles included both conceptual papers (N = 7), and empirical studies (N = 21). Empirical studies included a number of study designs: RCTS (N = 5), non randomised intervention studies (N = 1), experimental studies (N = 2), case control studies (N = 6), cross-sectional studies (N = 1), and case studies (N = 6). Papers were published between 2000 and 2017.

Studies reported on a range of health conditions: insomnia (N = 11), chronic pain (N = 4), comorbid pain and insomnia (N = 1), Irritable Bowel Syndrome (IBS, N = 1), persistent dizziness (N=3), incontinence (N = 1), sexual dysfunction, (N = 1), heart problems (N=2), non-cardiac chest pain (N = 1), tinnitus (N = 1), diabetes (N = 2).

Empirical studies ranged from a sample size of 1 to 2028, with a total sample size of N = 6350. Of the total sample, 3959 were in comparison groups of individuals without the physical health condition of interest, 127 were individuals with a physical health condition in the comparator condition of an intervention study (total comparator = 4086). All but two empirical studies reported mean age, ranging from 21.50 to 62.35, with a median age of 45.1 calculated. The overall sample included more females (64%).

## **Study outcome measures**

All studies included SSB, with measurement of this construct varying between studies. A range of tools were used to measure SSB and are outlined below. The psychological and physical symptoms of medical disorders were also a target outcome and are shown in *Table 1*. Due to significant heterogeneity between studies, measures of psychological and physical symptoms will not be outlined here.

### ***Questionnaire measures***

**The Safety Behaviour Index (SBI; Edelman, Mahoney & Cremer, 2012)** is an 18-item questionnaire to assess the frequency of strategies used in response to

experiencing or fearing experiencing chronic dizziness. The measure has been shown to have good internal consistency (Edelman et al, 2012), but is yet to be validated.

**The Sleep Related Behaviour Questionnaire (SRBQ; Harvey et al, 2002)** was developed from a selection of questions from the Dysfunctional Beliefs and Attitudes about Sleep Scale (DBAS, Morin, Stone, Trinkle, Mercer & Rems, 1993) and assesses any strategies used in response to sleep-related beliefs.

**The Safety Behaviours and Catastrophising Scale (SBCS; Macdonald, Linton & Jansson-Frojmark, 2008)** assesses symptoms of stress, pain and sleep difficulties. It has been shown to have acceptable internal consistency but is yet to be validated.

**The Cardiac Anxiety Questionnaire (CAQ; Eifert et al, 2000)** is an 18-item measure, which has been identified as having four subscales: fear, attention, avoidance and safety-seeking behavior. It is well validated and shown to have good internal consistency.

**The Questionnaire on Behaviours during Sexual Activities (Frank, Noyon, Hoyer, & Heidenreich, in preparation)**, has male and female versions (32 and 30 items respectively) and was developed based on typical behaviours of patients attending sex therapy. Participants are asked to rate to what extent they display typical SSB in sexual situations on a four-point Likert scale.

### *Diary method*

**The frequency of SSB** was measured using a daily diary method in a number of studies.

### *Experimental tasks*

Bag carrying task to elicit SSB (Tang et al, 2007): Participants completed a bag carrying task (designed to be mildly pain provoking), and watched back a recording, rating SSB using the Safety-behaviour Record Sheet (developed by authors). Participants were asked to identify anything they did because of



experiencing or expecting to experience pain and ratings of anxiety had they not used this strategy.

### *Semi-structured interview*

SSB: mean number of SSB associated with monitoring rated based on response to question in a semi-structured interview – ‘‘anything you typically do to avoid / prevent the feared consequence’’ (Semler & Harvey, 2004).

### **Risk of bias and quality**

*Table 2* shows the results of the risk of bias assessment. Overall this demonstrated a high risk of bias across studies, particularly for non-randomised or non-controlled trials.

### **Findings relating to study objectives**

#### **Objective 1: What is the current evidence for the relevance of SSB to physical health problems?**

SSB were found to be relevant across a number of physical health problems. The greatest proportion of studies reported on SSB in insomnia (N=10), where the role of SSB is well established, central to the cognitive behavioural model of insomnia (Harvey, 2002a) and supported by empirical studies.

SSB were also found to be relevant to pain-related conditions, including chronic pain and non-cardiac chest pain. The relevance of SSB to non-cardiac chest pain has been theoretically outlined (Eifert et al, 2000), although to date there has not been any empirical testing of this claim. A number of conceptual papers (Sharp, 2001a, 2001b; Jamani & Clyde, 2008) outline the relevance of SSB to chronic pain, with it proposed that the updating of the cognitive model of chronic pain, to include elements such as SSB, has the potential to further improve treatment outcomes. Furthermore, experimental evidence (Tang et al, 2007) has been found for SSB in

chronic pain, with individuals with chronic pain using a significantly higher number of SSB compared to those without chronic pain, in response to an exerting physical task. Significant differences were also found between those with high and low levels of health anxiety.

This review also found evidence for SSB in chronic dizziness within two RCTs of cognitive behavioural therapy for chronic dizziness (Edelman et al, 2012; Mahoney, Edelman & Cremer, 2012), along with case level description of SSB employed by an individual with Persistent Postural-Perceptual Dizziness (Whalley & Cane, 2017).

Case studies outlining the role of SSB were also identified in diabetes (Boyle, Allan & Millar, 2004; Kurt, Karabas, Wurz & Topçuoglu, 2016), Irritable Bowel Syndrome (IBS; Hunt, Moshier & Milonova, 2009), sexual dysfunction (Frank, Noyon, Höfling, & Heidenreich, 2010) and tinnitus (McKenna, Handscomb, Hoare & Hall, 2014). Studies of heart-related conditions also support the relevance of SSB to myocardial infarction and acute coronary syndrome (Van Beek et al, 2012, 2016), with SSB identified as a factor on the Cardiac Anxiety Questionnaire. Finally, SSB have been implicated in urinary incontinence within a conceptual paper by Molinuevo & Batista-Miranda (2012), although this is currently not supported by empirical evidence.

## **Objective 2: What is the nature / topology of these behaviours?**

Whilst there was significant variation in the topology of SSB across conditions, similarities were observed. Avoidance was common to all conditions, with this typically related to avoidance of certain situations or stimuli believed to be associated with greater risk of a feared outcome occurring. Avoidance of physical activity was common to urinary incontinence, sexual dysfunction and IBS, whilst avoidance of walking and activities believed to bring on physical symptoms were found in non-cardiac chest pain and conditions characterized by dizziness. Avoidance of certain activities such as driving, shopping, exercise and social activities were described in chronic pain, non-cardiac chest pain and dizziness, whilst avoidance of silence and certain situations was unique to tinnitus. In insomnia

avoidance was also identified in the form of cancelling activities or taking the day off work after a poor night's sleep, whilst avoidance of sexual activity was reported in sexual dysfunction.

However, across conditions, avoidance was only one of a number of strategies described. A range of more subtle strategies were also evident across conditions, for example in chronic pain, where when faced with a physically exerting task involving carrying a heavy bag, participants used a range of subtle SSB, for example, lifting and loading the bag cautiously, rocking and shifting weight and tensing stomach muscles, identified through watching back a recording of themselves (Tang, et al, 2007).

Cognitive strategies were less commonly described, although suppression of thoughts relating to the condition or symptoms of the condition was found in insomnia, chronic pain and sexual dysfunction, as well as suppression of images of falling in chronic pain, and attempts to try to control bodily sensations by focusing on them in sexual dysfunction. Reassurance seeking and requests for medical tests were common to both cardiac related conditions and non-cardiac related chest pain, whilst body checking and focusing on symptoms was found to be a feature of urinary incontinence, cardiac-related conditions, non-cardiac chest pain and sexual dysfunction. The use of medication was reported as an SSB in both IBS and insomnia.

SSB related to escape were identified in both IBS and urinary incontinence, with individuals sitting in easily exited areas (Hunt et al, 2009; Molineuvo & Batista-Miranda, 2012). Mapping of toilets and carrying of spare clothes were also common but specific to these two conditions.

Other SSB reported were idiosyncratic to specific disorders, with the use of environmental sound described in tinnitus and evidence of a range of sleep-related SSB in insomnia, including using alcohol to get to sleep, napping and trying to catch up on sleep at the weekend. In diabetes, case studies described inappropriate and excessive consumption of food and drink as an SSB used in response to physical symptoms. In conditions featuring dizziness, use of objects or another person for

balance was identified in response to fears of falling, with the use of back braces appearing specific to chronic pain.

**Objective 3: What is known of the intended function of these behaviours?**

Whilst all studies agreed on the function being to prevent a feared catastrophe, this was described varying amounts of detail by papers. For example, papers on tinnitus, urinary incontinence and heart-related conditions defined the function simply as being to prevent a perceived threat or catastrophe. In some studies this catastrophe was specified, for example prevention of hypoglycaemia in diabetes and prevention of fecal incontinence in IBS. In insomnia and pain, the function of behaviours has been described in more detail. In insomnia SSB are described as a response to the fear of not getting to sleep and the consequences and implications of these, for example not being able to cope and losing one's job because of this. In chronic pain, SSB are reported as being employed to protect oneself and prevent further damage, with this being paralysis at the most extreme. Few studies described or investigated the function and meaning of SSB in more depth.

The exception to this was case studies, which generally presented detailed idiosyncratic descriptions of perceived function at a deeper level relating to feared outcomes. For example, a case study of persistent post-perceptual dizziness (Whalley & Cane, 2017), described the specific meaning driving an individual's SSB to prevent dizziness, with her believing that dizziness would lead to falling, which would scare her children, confirming her deeply held beliefs of being a bad mother.

**Objective 4: What is known about the potential impact of these behaviours on cognitions and on psychological and / or physical symptoms?**

The majority of identified studies proposed that SSB prevent disconfirmation of catastrophic beliefs, therefore maintaining fear, anxiety and fear-based beliefs. However overall there was a lack of empirical testing of this hypothesized impact.

Some studies outlined the mechanism relating to this maintenance. For example, in non-cardiac chest pain Eifert et al (2000) proposed that avoidance of activity prevents an individual learning that cardiac activity due to physical activity is not synonymous with cardiac danger.

A number of other effects of SSB were reported across studies, including that certain strategies may in fact increase the risk of the feared outcome they are employed to prevent. In insomnia, attempts have been made to theoretically categorise the impact of SSB on symptoms (Harvey, 2002b), with this including interfering with the regularity of the sleep cycle, interfering with getting to sleep, paradoxical fueling of thoughts, increasing daytime sleepiness, causing the day to be unpleasant or boring and increasing pre-occupation with sleep. There is also some evidence, albeit correlational, for the impact of SSB on sleep symptoms, with consistent evidence that those with poor sleep have significantly greater use of SSB compared with those with good sleep (Harvey, 2002b; Jansson-Fröjmark, Harvey, Norell-Clarke & Linton, 2012; Semler & Harvey, 2004), along with evidence for differences between those with persistent insomnia and those with poor sleep in terms of the number of SSB used (Norell-Clarke et al, 2017). Longitudinal research has demonstrated that SSB are predictive of persistent insomnia or remission at long-term follow-up (Norell-Clarke et al, 2014).

In diabetes, it is proposed that overconsumption may contribute to physiological factors which confer risk for medical complications and poor control of diabetes. In line with this there is some evidence that elimination of SSB is associated with better illness control, along with reduced fear of hypoglycaemia, anxiety and depression (Kurt et al, 2015). In chronic pain, SSB in the form of avoidance has been linked to a worsening of the condition through deconditioning (Sharp, 2001), though this is yet to be empirically testing. Similarly, in non-cardiac chest pain (Eifert et al, 2000), the use of avoidance is proposed to lead to a loss in strength as a result of reduced cardiac activity, with this potentially leading to increased chest pain.

Another theorized mechanism by which SSB may play a role in maintenance of physical or psychological symptoms of health conditions was via the impact of

selective attention and hypervigilance. In sexual dysfunction, tinnitus and urinary incontinence it is proposed that the use of SSB, such as symptom focusing and self-focused attention, can reduce the threshold for detecting symptoms, thus leading to the perception that symptoms are more severe than may be the case. It was also apparent across all conditions that the use of SSB was associated with a narrowed existence in terms of activities, with avoidance of various activities or situations common across conditions.

**Table 1: Summary of included studies**

Condition	Authors	Design	N	Outcome measures	Comparison	Intervention	Main finding	Topology of SSB	Perceived function	Impact on symptoms
Diabetes	Boyle, Allan & Millar (2003)	Case study, experimental design	1	SSB: frequency, using diary method.  Frequency and severity of daily panic attacks (diary); Anxiety (BAI); Depression (BDI); Beck Depression Index (BDI); Beck Anxiety Inventory (BAI); fear of hypoglycaemia (HFS); treatment compliance (mean glucose level).	N/A	CBT (7 sessions), including in-vivo exposure, involving elimination of SSB.	Elimination of SSB associated with improved psychological and physical outcomes.	Eating food inappropriately in response to all physical symptoms.	Prevent hypoglycaemia, physical symptoms and loss of behavioural control	Stopping of SSB associated with reduction of panic frequency and severity. Large reductions in anxiety, depression, fear of hypoglycaemia, blood glucose stabilised, reduction in HbA <sub>1c</sub> - indicating good control of diabetes.
Polydipsia, diabetes mellitus type 2	Kurt, Karabas, Yorguner, Wurz & Topcuoglu (2015)	Case study	1	Description of SSB	N/A	N/A	Conceptualisation of SSB only	Avoiding being hungry and thirsty through excessive food and water consumption; always travelling with supplies; avoiding travel by public transport.	Aimed to prevent fear in relation to diabetes	SSB lead to psychogenic polydipsia which is a risk factor for diabetes mellitus type 2.
Chronic subjective dizziness	Edelman, Mahoney & Cremer (2012)	RCT	41: (CBT, n = 20; WLC n = 21)	SSB frequency/(SBI questionnaire)  Anxiety and depression	WLC	CBT model of panic adapted for dizziness	CBT including reducing SSB associated with significant	Walking close to walls, relying on another person to accompany, avoiding driving, shopping, exercise and social activity.	To manage dizziness.	Intervention associated with reductions in disability (DHI), reduced dizziness and related physical symptoms (DSI). However, effect of change

				(DASS); Dizziness symptoms (DSI); Impact of symptoms (DHI).			reductions in use of SSB (d = 1.58) and in disability, dizziness and physical symptoms.			in SSB on outcomes not measured.
Chronic subjective dizziness	Mahoney, Edelman & Cremer (2013)	RCT	44, (CBT, n = 23, WLC, n=21	SSB: Safety Behaviour Index  Anxiety and Depression (DASS-21); impact of symptoms (DHI).	WLC	CBT (3 sessions), including exposure aimed at reducing avoidance and SSB and developing alternative strategies for responding to dizziness.	CBT associated with significant reduction in SSB at end of treatment (d= 1.51) and 6-month follow-up (d = 1.39).	Walking close to a support, only going somewhere with another person, avoiding certain activities (driving, exercising, socialising).	To help manage dizziness	SSB (SBI score) not significantly associated with Dizziness Handicap Index at 6-month post treatment (r = 0.13).
Persistent Postural- Perceptual Dizziness	Whalley & Cane (2017)	Case study	1	N/A	N/A	N/A	Conceptualisation of SSB only	Sitting down; avoiding busy locations; checking balance regularly; reducing amount of physical activity, especially when on own / with children; minimising movement; climbing stairs carefully; trying to reduce trip hazards at home; avoiding physical activity if feeling unwell; using objects for balance, avoiding certain situations and locations – e.g. busy or uneven roads.	Ensure physical safety, prevent falls which would scare children.	Left with fewer opportunities to disconfirm anxious predictions about likelihood of catastrophe, reinforce idea of being a bad mother, greater perception of balance symptoms.
Insomnia	Harvey (2002a)	Conceptual	N/A	N/A	N/A	N/A	Conceptualisation of SSB only	Overt and covert coping strategies: thought control, imagery control, drinking	Attempt to avoid a feared outcome,	Prevents disconfirmation of fear-related beliefs and increases daytime



								alcohol, having an easy day, cancelling appointments and napping after a poor night's sleep.	namely not getting enough sleep or consequences of this, e.g. not coping.	sleepiness, anxiety and worry; interferes with sleep cycle.
Insomnia	Harvey (2002b)	Cross sectional	66 (Insomnia, n = 33, HC, n = 33)	SSB: Dysfunctional Beliefs and Attitudes about Sleep (DBAS), plus additional question to elicit SSB for each question (SRBQ, developed by authors); Detrimental effect of SSB also rated.  Insomnia symptoms (IDI)	HC	N/A	Greater number of SSB in the insomnia group compared with good sleepers (r = 0.61).	Napping during the day, getting as much sleep as possible during the day and at weekends; slowing down pace of day; reducing self-expectations; avoidance - cancelling appointments, taking the day off work; basing plans on amount of sleep; using caffeine to stay awake;	Prevent feared (sleep-related) outcomes from occurring.	Number of categories of effects defined: 1) Impact on regularity of sleep cycle (e.g. napping); 2) Impact on getting to sleep (e.g. caffeine intake); 3) Increasing negative and fear-related thinking (e.g. trying to stop worrying about sleep); 4) Contributing to daytime sleepiness (e.g. have an easy day); 5) Leading to the day being boring (e.g. avoidance of activities) 6) Increasing preoccupation with sleep (e.g. developing plans to catch up on sleep).  N.B. Consequences categorised by raters but not empirically tested.
Insomnia	Harvey (2007)	Non randomised trial of CBT for insomnia	19	SSB: SRBQ questionnaire  Insomnia symptoms (sleep diary); Insomnia Severity (ISI),	N/A	CBT (average 14 sessions), involving guided discovery and behavioural	The intervention was found to improve sleep and daytime functioning.	As measured by the SRBQ	Attempt to avoid a feared outcome - fear of not getting to sleep or impact of not getting	CBT including focus on SSB associated with significant reductions in SSB and improvements in sleep and daytime functioning. However, this was not the only focus of the intervention.

beliefs about sleep (DBAS), Depression (BDI); Index (ISI); Functioning (WSAS) pre-sleep arousal (PSAS), sleep monitoring (SAMI).

experiments used to identify the advantages and disadvantages of using SSB and dropping these.

CBT associated with reductions in SSB by the end of treatment (d = 2.57) and 12-month follow-up (d = 2.52).

sufficient sleep.

Insomnia	Jansson-Fröjmark et al (2012)	Case control study	1720 (Insomnia, n = 393; poor sleep, no sleep problems, n=1327)	SSB: SRBQ-16	Poor sleep, no sleep problems	N/A	Significant difference between insomnia group and poor sleepers on SRBQ-16 (d = 1.00) and those with no sleep problems (d = 2.27).	As measured by the SRBQ	To prevent not getting to sleep or feared consequences of this.	SRBQ-16 score associated with total awake time and sleep quality. SSB not significantly associated with sleep restoration or daytime symptoms.
Insomnia	Lancee, Eisma, van Straten & Kamphuis (2015)	RCT	63 (n=36 CBT n=27 WLC)	SSB: Dutch translation of the SRBQ; (Lancee and Kamphuis, in preparation).	WLC	Online CBT for insomnia (6 sessions)	SSB mediated effects of intervention on some insomnia related variables.  CBT for insomnia associated with changes in SSB.	As measured by SRBQ	Attempt to avoid a feared outcome, namely fear of not getting to sleep or perceived consequences of this	SSB mediated the effects of treatment on insomnia severity and sleep efficiency but not sleep quality.  Within group difference by end of treatment on SRBQ: (d = 0.61); difference between groups at end of intervention (d = 0.97).

Insomnia	Norell-Clarke (2017)	RCT	64 (CBT, n = 32, WLC, n= 32)	SSB: SBRQ Insomnia symptoms (ISI; time in bed); beliefs about sleep (DBAS-10); Depression (BDI); pre-sleep arousal (PSAS); anxiety about sleep (APSQ), automatic thoughts (ATQ-30); sleep monitoring (SAMI).	WLC	CBT for insomnia (4 sessions)	CBT associated with significant change in SSB, dysfunctional beliefs and sleep-related outcomes.	Using alcohol to fall asleep, cancelling activities after a poor night's sleep; taking sleep medication without attempting to sleep without; trying to suppress thoughts about sleep.	Attempt to avoid a feared outcome, typically fear of not getting to sleep or consequences of this, e.g. not coping.	Significant difference between groups at end of treatment on SRBQ (d = 0.53), significant within group change (d = 1.06).  Didn't find SSB to be a mediator of sleep outcomes.
Insomnia	Norell-Clarke et al (2014)	Case control	2028(Normal sleep n =1706; insomnia n = 322)	SSB: SRBQ-16 questionnaire Anxiety and depression (HADS); Insomnia severity (ISI).	Normal sleepers	N/A	Significant difference between normal sleepers and those with insomnia. SSB at baseline predictive of persistent insomnia / remission at 6-month and 18-month follow-up.	As measured by SRBQ	To prevent not getting to sleep or feared consequences of this.	Significant difference at baseline on SRBQ between normal sleepers and those with insomnia (d = 1.33). Significant difference on SRBQ at baseline between those with persistent insomnia at 6 months and those with remission at 6 months (d = 2.06). Difference at baseline between those with persistent insomnia at 18-months and those with remission (d = 0.49).
Insomnia	Semler & Harvey (2007)	Experimental	94 (n = 47, monitoring group, n = 16,	SSB: Number of Safety Behaviours (measure developed by authors).	N/A	N/A	The monitoring group reported more negative	As measured by SRBQ	To prevent not getting to sleep or feared consequences of this	Monitoring associated with more negative thinking and use of SSB. However the impact of monitoring rather than

no-monitoring group, n = 16, no instruction group, n = 15).  
 Insomnia severity (IDI; PSQI); Sleepiness: SSS); Depression (BDI); Anxiety (STAI); Worry (PSWQ)  
 Negative thoughts, Functioning Score, Subjective Sleep Quality Score (measures developed by authors)

thoughts, the use of more SSB (d = 1.19) and more sleepiness during the day compared with the no-instruction group.

SSB was the variable which was manipulated.

Insomnia	Semler & Harvey (2004)	Case control	70 (Insomnia, n = 32, normal sleep, n = 38)	SSB: mean number associated with monitoring response to question in a semi-structured interview – “anything you typically do to avoid / prevent the feared consequence.”  Insomnia symptoms (IDI; PSQI).	Normal sleepers	N/A	Monitoring for sleep related threat triggers negative thoughts which leads to Employment of SSB	Napping during the day, , getting as much sleep as possible during the day and at weekends; slowing down pace of day; reducing self-expectations; avoidance - cancelling appointments, taking the day off work; basing plans on amount of sleep; using caffeine to stay awake;	To prevent not getting to sleep or feared consequences of this	Significant differences between insomnia and normal sleep groups on Night-time number of SSB (d = 1.29). Number Of daytime SSB not significant. Total negative thoughts related to total SSB (r =0.54) Mean N of SSB associated with daytime and night-time monitoring. (r = 0.46-0.52).
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Insomnia	Ree & Harvey (2004)	Case control,	132 (Insomnia, n = 79; normal sleep, n = 53)	SSB: SRBQ questionnaire Insomnia Diagnostic Interview (IDI; PSQI; ISI)	Normal sleepers	N/A	Significant difference between those with insomnia and normal sleepers on SSB (d = 0.82).	As measured by SRBQ	Prevent feared sleep-related outcomes from occurring.	SSB significantly associated with day-time and night-time impairment.  Total SRBQ score associated with insomnia severity (r = 0.72), sleep difficulty (r = 0.63), daytime difficulty (r = 0.66) and distress (r = 0.66).
Insomnia	Yang, Lin & Cheng (2013)	Case control	152 (Chronic insomnia, n = 50; normal sleep, n = 102)	SSB: SRBQ questionnaire Insomnia severity (ISI, PSQI); Vulnerability to stress-related transient sleep disturbance (FIRST); beliefs about sleep (DBAS-16), pre-sleep arousal (PSAS).	Normal sleepers	N/A	SSB associated with insomnia symptom severity.	Clock watching during the night; monitoring of the expected consequences of lack of sleep; thought suppression; napping to catch up on sleep;	Compensate for sleep loss and avoid the consequences of sleeplessness.	Frequency of SSB significantly correlated with insomnia symptoms in both groups.  Insomnia group: significant correlation between SRBQ and insomnia severity (r = 0.30).
Pain and insomnia	MacDonald, Linton & Jansson-Frojmark (2008)	Case control	1159 (Moderate sleep difficulties, n = 133, pain problems, n = 447, insomnia, n =	SSB: Safety Behaviors and Catastrophizing Scale (developed by the authors).  Frequency of pain and insomnia symptoms over past week,	See groups	N/A	Elevated SSB and catastrophizing scores distinguished between persistent pain and moderate pain.  Participants with persistent	Behavioural SSB: avoiding activities  Cognitive SSB: avoiding emotionally charged situations; avoiding cognitively demanding activities.	Not captured by measure	Behavioural SSB associated with anxiety and depression (r = < .20). Cognitive SSB associated with anxiety and depression (r = 0.42 – 0.51).

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Chronic pain	Sharp (2001a)	Conceptual	N/A	N/A	N/A	N/A	Conceptualisation of SSB	Avoid lifting; wearing back brace	Attempt to avoid a feared outcome	Maintains anxiety / fear; influences fear and pain-related cognitions and beliefs by preventing disconfirmation.
Chronic pain	Sharp (2001b)	Conceptual	N/A	N/A	N/A	N/A	Conceptualisation of the role of SSB in chronic pain	Avoiding activities and actions such as lifting; wearing a back brace	Prevent further damage	Prevents disconfirmation of beliefs and maintains fear-related cognitions, e.g. lifting is dangerous, and I would have caused damaged had I not used a back brace.
Chronic pain	Tang et al (2007)	Empirical, experimental, observational	60 (n = 40 chronic pain; 20 high health anxiety, 20 low; n = 20 HCs)	SSB: Safety-behaviour Record Sheet (developed by authors) completed while watching recording of self-completing a mildly exerting experimental task. Pain, mood, thoughts during task (Pain, Mood and Thoughts Record Sheet (designed by authors).  Pain (SF-MPQ); Health anxiety (SHAI); anxiety and depression (HADS);	HCs	N/A	Significant differences between groups in use of SSB. Those with high levels of health anxiety used most SSB	Wide range of SSB, particularly in patients with high health anxiety, including lifting and loading bag cautiously with straight back; standing with weight on one side; constantly rocking and shifting weight; continually tensing stomach muscles; concentrating hard on the task.	Function varied according to behaviour, but overall goal was to protect from further pain, injury or danger / Something drastic happening.	Use of SSB significantly associated with catastrophizing (r = 0.42 – 0.46).

				catastrophising (CIPS).						
Chronic pain	Jamani & Clyde (2008)	Conceptual and case study	1	Depression (BDI); Pain-catastrophising (PCS); Pain-related fear (TSK).	N/A	CBT including behavioural experiments focusing on reducing SSBs.	Reduction in pain related fear and pain catastrophising, fear related beliefs and depression by end of treatment.	Not walking unaided; using a stick – for balance and protection from other people walking into her; avoiding walking and using stairs; image suppression (images of damage to body).	Protect self from serious injury and further damage; prevent paralysis from fall.	Prevent disconfirmation of catastrophic belief, maintaining and strengthening belief.
Non-cardiac chest pain	Eifert, Smolinsky, & Lejuez (2000)	Conceptual	N/A	N/A	N/A	N/A	N/A	Repeated requests for medical examination and tests; body checking; seeking reassurance, escape / avoid situations where symptoms occur, avoidance of activities believe bring on physical symptoms.	To protect the heart, reduce worry and anxiety over heart focused physical illness and physical symptoms.	Decreased levels of cardiac related activity lead to deconditioning and reduced strength, increasing physical symptoms and anxiety. Also prevents learning that cardiac activity due to physical exertion does not signify danger.
Acute coronary syndrome	Van Beek et al (2012)	Factor analysis, case control	286 (ACS, n = 237; RA, n = 49).	SSB: identification of factor on Cardiac Anxiety Questionnaire (CAQ)  Anxiety (BAI; STAI); depression	Rheumatoid arthritis	N/A	SSB identified on measure which distinguished between groups.	Identification of factor SSB	Behaviours aimed at preventing possible catastrophes.	Group difference (d = 0.83) on SSB cardiac related SSB.



				(BDI); mobility (MI)						
Myocardial infarction	Van Beek et al (2016)	Longitudinal	193	Cardiac anxiety questionnaire, Major Advance Cardiac Event (MACE), depression (BDI)	N/A	N/A	SSB not predictive of MACE	Having medical examinations; symptom focusing (heart rate); avoiding physical activity.	Behaviours aimed at preventing possible catastrophes (theoretical, not captured by measure).	SSB not predictive of MACE 4 months after discharge.
Irritable bowel syndrome (IBS)	Hunt, Moshier & Milonova (2009)	RCT	54 (n=28 CBT, n=26 WLC)	SSB: description only Gastrointestinal Symptom Rating Scale–IBS (GSRS–IBS); Anxiety Sensitivity Index (ASI); Visceral anxiety sensitivity; IBS quality of life (IBS–QOL); The Consequences of Physical Sensations Questionnaire (CPSQ)	WLC	CBT including identification of SSB and dropping of these in conjunction with exposure.	Description of SSB only. CBT associated with significant decrease in IBS symptoms and improvements in quality of life, which was maintained at follow-up.	Mapping location of public toilets; using anti-diarrheal medications; avoiding or limiting activities; only sitting in easily exited places in public, e.g. aisle seat.	Prevent fecal incontinence	Treatment efficacy was partially mediated by reductions in the catastrophising and implications of symptoms.  Effect of SSB not measured.
Tinnitus	McKenna, Handscombe, Hoare & Hall (2014)	Case study	N/A	N/A	N/A	N/A	Conceptualisation of SSB only	Avoiding silence, avoidance of specific situations and sound; use of environmental sound.	Prevent the perceived threat	Maintain or exacerbate existing worry; affect detection of tinnitus, leading to individuals overestimating intensity

and complexity of their condition.

Sexual dysfunction	Frank, Noyon, Höfling & Heidenreich (2010)	Conceptual paper and preliminary case control	102 (Sexual dysfunction, women, n = 30, men, n = 21. Healthy controls, women, n = 30, men n = 21).	SSB: Questionnaire on Behaviours during Sexual Activities (Frank, Noyon, Hoyer, & Heidenreich, in preparation), based on typical behaviours of patients attending sex therapy.	HCs without sexual dysfunction	N/A	Significant difference in SSB score between women with and without sexual dysfunction (d = 2.32), and men with and without sexual dysfunction (d = 1.55).	Range of overt and covert SSB: Dissociation from experiences; avoiding physical contact; avoiding talking about sex; attempting to control bodily function through body focusing; thought suppression.	Avoid feared outcomes of a sexual situation	Enhances self-focused selective attention, increases negative thinking and emotions, prevents challenging or beliefs, therefore maintaining. This was conceptualised only.
Urinary incontinence	Molineuvo & Batista-Miranda (2012)	Conceptual	N/A	N/A	N/A	N/A	Conceptualisation only	Mapping the location of toilets; limiting or avoiding physical activity; avoiding activities outside of the house, avoiding contact with others and sexual intimacy; only sitting in easily exited places in public, e.g. aisle seat.; wearing dark clothing; carrying spare clothes; self-medication;	Prevent or minimise feared catastrophe	Maintains increased vigilance and increases symptom detection.  Prevents disconfirmation of dysfunctional beliefs.

APSQ: Anxiety and Pre-occupation about Sleep Questionnaire; ASI: Anxiety Sensitivity Index; ATQ-30: Automatic Thoughts Questionnaire; BAI: Beck Anxiety Inventory; BDI: Beck Depression Inventory; CAQ: Cardiac Anxiety Questionnaire; CIPS: Catastrophising in Pain Scale; DASS: Depression Anxiety Stress Scale; CPSQ: ; DBAS: Dysfunctional Beliefs and Attitudes about Sleep; DHI: Dizziness Handicap Inventory; DSI: Dizziness Symptoms Inventory; ES: Effect Size (typically Cohen's d or Pearson's r); FABQ: Fear Avoidance Beliefs Questionnaire; FIRST: Ford Insomnia Response to Stress Test (FIRST); GRS-IBS: Gastrointestinal Symptom Rating Scale-IBS; HADS: Hospital Anxiety and Depression Scale; HFS: Hypoglycaemia Fear Survey; IBS-QOL: Irritable Bowel Syndrome Quality of Life; IDI: Insomnia Diagnostic Interview; ISI: Insomnia Severity Index; MI: Mobility Inventory; PANAS: Positive and Negative Affect Scale; PCS: Pain Catastrophising Scale; PSAS: Pre-Sleep Arousal Scale; PSQI: Pittsburgh Sleep Quality Index; PSWQ: Penn State Worry Questionnaire; RCT: Randomised Controlled Trial; SAMI: Sleep Associated Monitoring Index; SBI: Safety Behaviours Inventory; SF-MPQ: Short Form McGill Pain Questionnaire; SHAI: Health Anxiety Inventory Short Form; SRBQ: Sleep Related Behaviours Questionnaire; SSB: Safety Seeking Behaviours; SSS: Stanford Sleepiness Scale; STAI: Spielberger State Trait Anxiety Inventory; TSK: Tampa Scale for Kinesiophobia; WLC: Waiting List Control; WSAS: Work and Social Adjustment Scale;

## Discussion

The aim of this systematic review was to synthesise the current literature on SSB in medical conditions in order to describe SSB and to identify their perceived function and impact in the context of medical conditions and their presenting symptoms. Research into maintaining mechanisms with clear implications for intervention is much needed, given the high levels of distress and impairment often associated with physical health conditions (Wandell, 2005; Gralnek, Hays, Kilbourne, Naliboff & Mayer, 2000; Birtane, Uzunca, Tastekin & Tuna, 2007) and outcomes for cognitive behavioural interventions currently moderate at best (Ismail, Winkley & Rabe-Hesketh, 2004; Castell, Kazantzis & Moss-Morris, 2011).

This review found SSB to be reported across a range of physical health conditions, including diabetes, chronic subjective dizziness, insomnia, chronic pain, cardiac related conditions, IBS, sexual dysfunction and urinary incontinence. The inclusion of the SSB construct within models of a range of health conditions, suggests it to be a relevant, methodologically plausible and useful construct in understanding and treating psychological and physical health symptoms. Furthermore, there is also empirical evidence for the presence of SSB in a range of health conditions, providing support for the relevance of the construct beyond psychological conditions to physical health conditions.

It has been proposed that SSB can be distinguished from more adaptive coping strategies based on topology, perceived function and impact (Thwaites & Freeston, 2005), with the research questions posed by this review shaped by this. In terms of topology, this review found some commonality across disorders, with avoidance featuring as a strategy across a range of disorders. Avoidance included avoidance of a range of situations and activities, depending upon the condition. Whilst avoidance was common across conditions, this was only one of a large range of SSB identified. This is an important finding, given the criticism of cognitive behavioural interventions for conditions such as chronic pain and CFS/ME being based on a fear-avoidance model (Sharp, 2001a, 2001b, Jamani & Clyde, 2008; Daniels & Loades, 2017). It is also in

line with proposals of avoidance being only one of three common types of SSB (Salkovskis, 1999), along with escape and subtle avoidance or within situation SSB, with the review identifying behaviours relating to all three proposed categories in physical health conditions.

This review identified a range of subtle or covert in-situation behaviours identified, which may either be difficult to notice or may not be obviously identified as SSB without knowledge of perceived function and impact. This supports a need to assess what the unintended effects of subtle behaviours might be. Furthermore, whilst there was some overlap found between different conditions in terms of the nature of SSB, other SSB were idiosyncratic to specific disorders. This suggests that the development of specific, disorder related knowledge and the development of inventories of common SSB may be useful in guiding exploration of potential SSB.

In terms of function, whilst the specific function varied according to specific fear-driven beliefs in different conditions, the overall reported function of strategies was to prevent or reduce the likelihood of a feared catastrophe. This was not however consistently measured across studies and the majority of studies simply described the overarching function of strategies to be an attempt to prevent a feared outcome, with studies varying in the level of detail given regarding the feared outcome itself. There was a trend across studies for the description of the function at a rather superficial level, without capturing the meaning associated with the behaviour for the individual.

The hypothesized impact of SSB on beliefs was common to all studies, with it proposed that this prevented a disconfirmation of catastrophic or fear related beliefs. This is important given that illness beliefs and catastrophizing have been found to be associated with increased symptomology, distress and poorer quality of life across a range of conditions (Sullivan et al, 2001; Gracely et al, 2004). However, despite a theoretical focus on the consequences of SSB (i.e. prevention of disconfirmation of belief) many studies did not examine the effect of identified strategies on symptoms, beliefs and emotions. Few studies reported on the potential impact of SSB on cognitions

and psychological and / or physical symptoms. Much of the evidence presented was correlational in nature, and it was not possible to infer causality relating to the impact of SSB. The exception to this was where SSB were measured and manipulated experimentally and further studies of this kind are warranted, akin to those in anxiety disorders.

There are exceptions to this, for example in insomnia where the role of SSB in the development and maintenance of insomnia has been well defined and tested both empirically and experimentally. This has led to the development of tested and validated outcome measures to capture SSB and the wide study of SSB in this condition. It is perhaps not coincidental that insomnia is one of the areas of health where medium to large effect sizes have been reported for interventions, with this more akin to those in mental health and maintained at long-term follow-up (Okajima et al, 2010). This supports the utility of well-developed and validated measures of SSB, which essentially incorporate a level of meaning through perceived function and link to dysfunctional beliefs.

This review including studies of a number of designs – ranging from conceptual to experimental, and supports the unique contribution of a range of study designs to our knowledge. Randomised controlled trials (RCTs) provided rigorous evidence of group differences in SSB and associations between SSB and treatment outcomes, often utilizing well developed and validated measures of SSB, as exemplified in the field of insomnia. However it was apparent that RCTs encompassed less meaning and idiosyncrasy in relation to SSBs compared to other study designs. Smaller scale studies, including case studies, instead provided description of a wider range of potential strategies and detailed exploration of idiosyncratic strategies for individuals. Case control studies contributed strong evidence for the presence of SSB in a number of conditions in comparison to HCs, supporting the relevance of SSB to health conditions. Longitudinal and experimental studies, including experimental N = 1 studies, demonstrated causal and temporal evidence for the impact of SSB on symptoms and interaction with other outcomes. Further studies of this nature are needed, particularly to

test out the overarching assertion concerning the impact of SSB on catastrophizing and fear-related beliefs. Meanwhile, this review also supports the importance of plausible theoretical frameworks, in the form of conceptual papers, in informing empirical research and driving conceptual developments.

The importance of a complementary range of study designs to the development of research evidence is supported by the Medical Research Council's framework (MRC, 2000; 2006) for the development of complex interventions. Whilst RCTs are considered gold standard in terms of evidence for interventions, the value of smaller scale research is highlighted as being essential in the initial stages of development and theory and evidence and where current understanding is underdeveloped (MRC 2000,2006; Richards & Hallberg, 2015). Furthermore, small scale studies have been instrumental in demonstrating proof of concept of SSB in mental health, including anxiety disorders (e.g. Salkovskis et al, 1999).

### **Methodological considerations**

This is the first systematic review of SSB across physical health conditions and as such has important implications for both clinical practice and future research. As evidenced by the recency of the studies reviewed, this represents a novel but growing area. However the findings must be considered in the context of limitations of the review.

The risk of bias assessment demonstrated an overall high risk of bias. Study quality also varied greatly in terms of the extent to which studies reported on all aspects of SSB (Thwaites & Freeston, 2005) and included studies were heterogeneous in terms of design. As such the findings should be interpreted with caution and there is a significant need for high quality empirical research to build upon conceptual and small sample studies described. Whilst it is essential to consider risk of bias and quality issues in included studies, the Cochrane risk of bias tool used within the review is most relevant to randomised controlled trials and did not allow the quality of non controlled studies to be adequately addressed. Given the varying study designs included within the

review, there may be more appropriate assessment tools which could be utilized, for example, the CASP (Critical Appraisal Skills Programme, 2018) critical appraisal tools which cover a range of study designs in addition to RCTs and incorporate issues of both risk of bias and study quality. This is pertinent given that RCTs, although considered gold standard in intervention studies, represent only one relevant study design when investigating evidence for constructs such as SSB as outlined above. Indeed small-scale studies, including N = 1 studies may be conducted rigorously, and a tool which captures quality and issues of bias across study designs is needed.

As outlined, there are also challenges concerning terminology around SSB. Whilst this review purposively included terms relating to both safety seeking behaviours and safety behaviours – based on the terms often being used interchangeably, the search terms were limited. It is possible that the omission of related search terms, for example, ‘‘avoidance; fear-avoidance; coping; behavioural experiment’’ may have resulted in some relevant literature in which SSB were referred to in alternative terminology being omitted. However, it is hoped that this review highlights the need for an operationally defined and testable SSB construct, as well as taking steps towards the establishment of this.

### **Clinical implications**

The findings of this systematic review have important implications for clinical practice. SSB are central to models and associated treatment of psychological disorders including anxiety disorders, where effect sizes by far outweigh those associated with cognitive behavioural interventions in physical health conditions. As such the finding that they are relevant to health conditions has implications in terms of identifying and targeting SSB, with the hope of improving outcomes. As outlined, the use of behavioural experiments allows testing out of beliefs and underlying meaning alongside the dropping of SSB, giving the individual the opportunity to learn what really happens when they do not utilize these strategies, with the potential to lead not only to behavioural but also cognitive and therefore emotional change (Bennett-Levy et al, 2004; Jamani & Clyde, 2008). Given that the review identified a range of SSB in

addition to avoidance and including subtle or covert strategies, it also highlights a need for careful questioning around coping strategies and their perceived function in order to be able to identify those which may not be immediately obvious to either client or therapist and which need to be distinguished from more helpful coping strategies.

A more thorough understanding of SSB, including more subtle behaviours, and the distinction between these and more adaptive coping strategies, is essential in health professionals where there is risk of iatrogenic factors such as advice and use of medication contributing to maintenance of the disorder depending upon the intention, perceived function and impact of these strategies. This was highlighted in the context of sleep (e.g. Ree & Harvey, 2004), where there may be some overlap between SSB and strategies associated with sleep hygiene. The issue of iatrogenic factors such as information giving in fact appears to add an additional layer of complexity relating to SSB in physical health compared with mental health. This gives further support to the need for specific conceptualization and investigation of this construct in physical health.

### **Future directions for research**

Overall this review highlights a need for further high-quality research which reports on and investigates not only the topology of potential SSB but also perceived function and impact in order to distinguish these from more adaptive coping strategies. There is a need for experimental research involving manipulation of SSB and investigation of impact in order to provide further empirical evidence for SSB in physical health conditions.

### **Conclusion**

This systematic review provides evidence for safety seeking behaviours across a range of physical health conditions, with evidence of both commonalities and idiosyncratic differences between both conditions and individuals, all with the shared function of attempting to prevent a feared catastrophe, but in fact impacting upon both psychological and physical symptoms and preventing disconfirmation of beliefs. As



such this represents an important areas for further research, with the potential to inform and improve cognitive behavioural treatment outcomes for physical health conditions.

**Table 2: Assessment of risk of bias**

	Random sequence generation	Allocation concealment	Blinding of participants and personnel	Blinding of outcome assessors	Incomplete outcome data	Selective reporting	Other sources of bias
Boyle et al (2003)	-	-	-	-	+	?	-
Kurt et al (2015)	-	-	-	-	+	?	-
Edelman et al (2012)	+	-	-	-	?	?	-
Mahoney et al (2013)	?	-	-	?	-	?	-
Harvey (2002b)	-	-	-	+	?	+	-
Harvey et al (2007)	-	-	-	-	?	?	-
Jansson Fröjmark et al (2012)	-	-	-	?	+	?	-
Lancee et al (2015)	?	-	-	?	+	?	-
Norell-Clarke et al (2017)	+	?	-	?	+	+	-
Norell-Clarke et al (2014)	-	-	-	-	+	?	-
Semler and Harvey (2007)	?	+	-	-	-	?	-
Semler & Harvey (2004)	-	-	-	+	?	?	-
Ree & Harvey (2004)	-	-	-	-	-	?	-
Yang et al (2013)	-	-	-	-	?	-	-

<b>Macdonald et al (2008)</b>	-	-	-	-	-	?	-
<b>Tang et al (2007)</b>	-	-	-	+	?	?	-
<b>Jamani &amp; Clyde (2008)</b>	-	-	-	-	?	?	-
<b>Van Beek et al (2012)</b>	-	-	-	-	?	?	-
<b>Van Beek et al (2016)</b>	-	-	-	-	-	?	-
<b>Hunt et al (2009)</b>	?	?	?	+	+	?	-
<b>Frank et al (2010)</b>	-	-	-	?	?	?	?

- High risk of bias; + Low risk of bias; ? Unclear risk of bias

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**Main Research Project- Safety-seeking behaviours in Chronic Fatigue Syndrome /  
Myalgic Encephalomyelitis: a pilot experimental investigation of topology and  
function.**

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## **Abstract**

The aim of this study was to investigate the use of safety-seeking behaviours (SSB) in Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME) in response to physical exertion. An experimental design was used with N = 10 individuals with CFS/ME and N = 15 healthy controls (HCs) carrying out a physical task twice. Participants were recorded while completing the task and asked to identify from the recording strategies used during the task and the function of these. Significant differences on the number of strategies defined as SSB were found between groups, with the CFS/ME group using significantly more SSB during the Task 2. In addition, a significant correlation was found between the number of SSB and increased score on a measure of health anxiety. Overall the pilot study provides novel evidence for the use of SSB in CFS/ME and conceptualises topology and function of such strategies, with SSB representing an important potential target for cognitive behavioural interventions for this condition.

Key words: chronic fatigue syndrome; safety-seeking behaviours; physical exertion; experimental

## **Introduction**

Chronic fatigue syndrome / Myalgic Encephalomyelitis (CFS/ME) is characterised by unexplained, severe disabling fatigue which is not alleviated by rest. Joint pain, sleep disturbances and cognitive difficulties are also commonly experienced (NICE, 2007). Despite considerable research, the aetiology of CFS/ME remains poorly understood (Browne & Chalder, 2006). Although a recent meta-analysis (Castell, Kazantzis, & Moss-Morris, 2011) and a large scale multi-centre treatment trial (N = 641; White et al., 2011) found cognitive behavioural therapy (CBT) and graded exposure therapy (GET) were associated with reduced fatigue and improved physical functioning compared with adaptive pacing therapy (APT), such interventions are associated with only moderate sized outcomes. Treatment outcomes are significantly smaller than those achieved by cognitive behavioural therapies in mental health (Olantunji, Olatunji, Etzel, Tomarken, Ciesielski & Deacon, 2010) and some physical health conditions such as insomnia (Okajima, Komada & Inoue, 2010).

It has been suggested that there is a lack of clarity concerning the therapeutic aim and strategies of CFS/ME treatment, along with the mediating and moderating processes underlying mechanisms of change (Knoop, Bleijenberg, Gielissen, van der Meer, & White, 2007; Van Houdenhove, 2006). It is also proposed that increased focus on maintaining factors in an individualised, patient centred way is necessary in order to improve quality of life and likelihood of recovery in CFS/ME (Van Houdenhove & Luyten, 2008).

Current CFS/ME treatment is based on an original model by Wessely (1991) with associated treatment, including CBT and GET primarily behavioural, focusing on physical symptoms and behavioural change centred on activity management (Daniels & Loades, 2017). Whilst current theory takes into account how cognitive responses, for example, fear of activity, and behavioural responses such as avoidance of activity, maintain fatigue (e.g. Surawy, Hackmann, Hawton & Sharpe, 1995), there is comparatively little focus on the meaning given by individuals with CFS/ME to their symptoms, which lies at the heart of cognitive behavioural models of psychological

difficulties. Illness representations have been defined as an individual's "own implicit, common-sense beliefs about their illness" (Leventhal, Meyer & Nerenz, 1980, p. 10). In CFS it has been proposed that through such representations, individuals ascribe meaning to their symptoms, with this influencing responses to symptoms and found to be associated with both functioning and adjustment in CFS (Moss-Morris, Petrie & Weinman, 1996). For example, an individual who believes that they have some control over their symptoms is more likely to respond in helpful or adaptive ways, compared to someone who perceives CFS to have extreme consequences (Moss-Morris et al, 1996).

In the overlapping conditions of chronic pain, similarly modest outcomes give rise to questions relating to the mechanisms of the intervention, with it suggested that this may be related to an overly behavioural focus on psycho-education and exposure, at the expense of a more cognitive focus incorporating meaning (Jamani & Clyde, 2008; Sharp, 2001).

The development of cognitive behavioural models of anxiety disorders to include concepts such as safety seeking behaviours (SSB) has been suggested to have led to significant advances in the theoretical understanding and treatment of such disorders (e.g., Salkovskis, Clark, Hackmann, Wells, & Gelder, 1999; Wells, Clark, Salkovskis, & Ludgate, 1995, Tang et al., 2007). Driven by anxiety, SSBs are behaviours which are employed to "prevent or minimize a feared catastrophe" (Clark, 1999). For example, an individual with panic disorder may interpret a sensation of weakness in his body as signalling an imminent collapse and therefore employs a number of strategies – holding onto something, sitting down, tensing muscles - in an attempt to prevent a collapse (Salkovskis, Clark, & Gelder, 1996). However these strategies in fact maintain anxiety and prevent disconfirmation of fear-related beliefs, with the individual believing they have experienced a "near miss" and the non-occurrence of collapse attributed to the use of these strategies (i.e. the belief that without these behaviours, they would have collapsed). This maintains beliefs and increases fear related cognitions and can account for why, despite repeated exposure to a feared situation without the feared outcome occurring, threat-related beliefs and anxiety are maintained (Salkovskis, 1991).

SSB are now established as a key concept in anxiety disorders, with consistent evidence of their role in development and maintenance of anxiety (Piccirillo, Dryman & Heimberg, 2016; Helbig-Lang et al, 2010), interference with treatment outcomes (Helbig-Lang & Peterman, 2010; Sloan & Telch, 2002) and targeting being associated with improved symptoms (Piccirillo et al, 2016). Three types of SSB have been outlined - avoidance of a feared situation, escape from a situation and more subtle behaviours within situations SSB (Salkovskis, Clark & Gelder, 1996; Harvey et al, 2007), which can be distinguished from more adaptive coping on the basis of intention, perceived function of a behaviour to an individual in a given context and the impact on cognitions (Thwaites & Freeston, 2005).

Research supports the notion that anxiety disorders and CFS have overlapping cognitive behavioural maintaining factors (Surawy et al, 1995; Tyrer et al, 2011). Based upon this and given the much more impressive treatment outcomes associated with CBT for anxiety disorders, there is potential to learn from this with a view to improving treatment outcomes in CFS/ME. There is emerging evidence for the relevance of SSB in a range of physical health conditions as demonstrated by the recent systematic review presented in this thesis (Lloyd & Daniels, in preparation) and reporting of high rates of health anxiety and SSB found across medical conditions (Tyrer et al, 2011). Although the quality of current evidence is variable across conditions, SSB are central to current cognitive behavioural models of insomnia, where they have been well defined and their effect on the development and maintenance of insomnia tested both empirically and experimentally. It is of note that CBT for insomnia interventions, informed by a model which incorporates both SSB and the meaning driving such strategies, are associated with higher effect sizes than those for other physical health conditions (Okajima et al, 2011). This is in line with suggestions that a more cognitive approach which puts more emphasis both upon meaning and also incorporates SSB is likely to be associated with improved outcomes in health conditions including CFS/ME and the overlapping condition of chronic pain (Jamani & Clyde, 2008; Daniels & Loades, 2017; Sharp, 2001b).

There is preliminary support for the effectiveness of a cognitive behavioural approach emphasising the interpretation and meaning of symptoms in CFS/ME (Daniels & Loades, 2017), with a case study describing an individual's SSB – including an extremely rigid daily routine - as having the perceived function of preventing a CFS-related collapse but paradoxically being implicated in the maintenance of symptoms. An intervention with a strong focus on dropping SSB through behavioural experiments was found to challenge anxiety-related beliefs, improve symptoms and allow increased engagement with life. Whilst the surface perceived function was to prevent a worsening of symptoms, beneath this lay the meaning attributed to symptoms and the condition, with a worsening of symptoms predicted to lead to being unable to take care of her family, ultimately meaning that she was a ‘horrible’ person.

A larger replication case-series has been carried out with preliminary results showing that a cognitive behavioural intervention for CFS, with a significant proportion of treatment focusing on SSB, demonstrated reliable and clinically significant change for eight out of ten patients on at least one primary outcome (SF36/chalder fatigue scale), with 50% reporting non-case level symptoms of CFS at the end of treatment (Daniels & Salkovskis, in preparation). These findings are also supported by research which found that improvements in fatigue were explained by a decrease in the limiting of activities and catastrophic beliefs about symptoms (Wearden & Emsley, 2013) and that fear of movement and avoidance of physical activity is associated with symptom severity, quality of life and disability in a range of conditions including CFS/ME (Helbig-Lang & Petermann, 2010). Although there is some overlap between SSB and the fear avoidance which features in existing explanations of physical health conditions, fear avoidance has been criticised for being too behavioural without incorporating meaning of symptoms and the function of associated behavioural strategies (Sharp, 2001a, 2001b). It is evident that increased focus upon SSB is a promising avenue for treatment and may be instrumental in improving outcomes. However SSB are yet to be empirically investigated in CFS/ME, as has been the case in other conditions such as chronic pain. This is important given the unimpressive treatment outcomes for CFS/ME



at present. Further research is needed in order to test and better conceptualise this concept, with attention not only to the nature of the behaviours, but also meaning and function. This is essential as better identification of SSB would enable interventions to be adapted in order to crucially target SSB through behavioural experiments, enabling an individual's underpinning fears to be more fully challenged and evidence provided to disconfirm fear related cognitions. Unidentified and unchallenged, SSB will continue to limit the effectiveness of interventions.

Experimental research has demonstrated empirical evidence for a range of SSB in individuals with chronic pain (Tang et al, 2007) in response to a mildly exerting task, with those with high health anxiety using significantly more SSB than those with low health anxiety and pain free controls. Participants were required to carry out a circuit task involving carrying a heavy shopping bag and were filmed whilst doing so. They were then asked to watch back the recording and identify any behaviours which were carried out with the intention of preventing pain. This study supported the relevance of a range of SSB in addition to avoidance, including more subtle forms of behaviour, but all with the shared intended function of preventing a worsening of pain or further damage, danger and the occurrence of something catastrophic. It also provided the first empirical support for SSB in chronic pain, building upon case study and conceptual studies and using an ecological valid and rigorous experimental design.

Idiosyncratic beliefs and attributions lie at the heart of the construct of SSB, with a focus upon how the meaning an individual gives to symptoms of their condition drives such strategies (Salkovskis et al, 1996). If found to be relevant, the inclusion of SSB in explanations of CFS/ME would enable more accurate formulation of clients' difficulties, with the potential to inform more individualised care and improve treatment outcomes through allowing cognitive beliefs to be addressed and tested through the elimination of SSB (Sharp, 2001; Jamani & Clyde, 2008).

## **Aims and objectives**

The aim of this project is to experimentally investigate the topology and function of CFS/ME in the context of physical exertion by replicating the study design used by Tang et al (2007) in chronic pain. Despite considerable overlap between chronic pain and CFS/ME they represent distinct conditions with key differences in hallmark features of fatigue and pain (Jason et al, 1999; Nijs et al, 2013). In line with this, given the idiosyncratic nature of SSB found in chronic pain by Tang et al (2007) and in other physical health conditions (Lloyd et al, in preparation), it is necessary to investigate SSB specifically in this condition.

## **Methodology**

### **Design**

An experimental design was adopted to investigate what strategies are used by people with CFS/ME in response to a physical exertion task and why. Participants carried out a bag carrying task, which was designed to be mildly fatigue and provoking and replicated the design used by Tang et al (2007) in a study of SSB in chronic pain. All participants gave informed consent prior to taking part. The study received full ethical approval from the local Research Ethics Committee and the University ethics committee.

### **Participants**

Participants with a diagnosis of CFS/ME (N = 10) and healthy controls without a diagnosis of CFS/ME (N = 15) took part in the study. Participants with CFS/ME were recruited through specialist services, public advertisements, social media and University recruitment systems and through online advertisement of the study. Healthy controls were recruited through public advertisements, the university and social media.

Inclusion criteria for both groups were being aged over 18, fluent in English and not using a mobility aid. Additional inclusion criteria for HCs were low level and non-

consistent self-reported fatigue or no fatigue experienced over the past week and no pain experienced over the past week.

## **Measures**

A number of validated measures were used to assess clinical characteristics at baseline:

Fatigue was measured using the *Chalder Fatigue Scale* (Chalder et al., 1993), which assesses both physical and mental fatigue. It has been shown to be reliable and valid (Cella & Chalder, 2010), with internal reliability in this sample excellent (Cronbach's  $\alpha = 0.96$ ).

*The Short Health Anxiety Inventory* (SHAI; Salkovskis, Rimes, Warwick, & Clark, 2002) is a measure of health anxiety, developed for use in medical conditions, shown to be valid and reliable (Alberts et al, 2013). Internal reliability in this sample was excellent ( $\alpha = 0.89$ ).

Anxiety and depression were assessed using the *Hospital Anxiety and Depression Scale* (Zigmond & Snaith, 1983), with demonstrated reliability and validity and excellent sensitivity and specificity (Bjelland, Dahl, Haug, & Neckelmann, 2002; Zigmond & Snaith, 1983a). Internal reliability in this sample was adequate ( $\alpha = 0.69$ ).

*The Work and Social Adjustment Scale* (WSAS; Mundt, Marks, Shear, & Greist, 2002) was used as a measure of impairment in daily functioning across a number of domains, which has been reported to have adequate to excellent internal consistency and both adequate retest reliability and concurrent validity. Higher scores indicate increased impairment in functioning. Internal reliability in this sample was excellent ( $\alpha = 0.97$ ).

The *SF-36 Physical Functioning Scale* (Stewart, Hayes & Ware, 1988) which has been shown to be reliable and valid (Ware, Kosinski, Dewey, & Gandek, 2000), was used as a measure of functional impairment. Scores range between zero and 100, higher

scores being indicative of better health. Internal reliability in this sample was excellent ( $\alpha = 0.95$ ).

Catastrophising was measured using the relevant subscale of the *Cognitive Behavioural Response to Symptoms Questionnaire* (Skerrett & Moss-Morris, 2006) which has been developed and validated in CFS. Internal reliability for this sample was very good ( $\alpha = 0.85$ ).

In addition, current pain was assessed using a *visual analogue scale* between zero and 100, with increased scores indicative of higher pain.

### **Procedure**

Participants completed baseline questionnaires online prior to attending the experimental session. There were three parts to the experimental procedure.

#### ***Part 1: Bag carrying task***

Participants were asked to complete a bag carrying task replicating that used by Tang et al (2007) which was designed to be mildly fatigue provoking in order to elicit any potential SSB. This was circuit training exercise made up of a number of cycles. Each cycle involved 1) Each cycle involved: Walking from A to B (distance = 3m); 2) Lifting a moderately heavy shopping bag for one minute at B; 3) Carrying the bag from B to A then back from A to B; 4) Unloading the bag to the floor at B and 5) Walking back from B to A, the starting point. The weight of the bag was 5kg for female participants with CFS/ME and 6kg for males with CFS/ME, 10kg for females without CFS/ME and 12kg for males without CFS / ME. The weights were varied so as to adjust for general differences relating to gender and patient status, in line with Tang et al (2007). Participants were asked to do the bag carrying task twice in succession. For each task, they were asked to do as many cycles as they felt safe and comfortable to do. Participants were asked whether they wanted to attempt task 2. This task has been used previously to investigate SSB in pain patients and was considered appropriate for this

study as it is considered to be mildly pain and fatigue inducing, with these being the two main symptoms of CFS/ME. Participants were recorded whilst carrying out the task,

### ***Part 2: Completion of Fatigue, Pain, Mood and Thoughts Record Sheet***

Immediately after each bag carrying task, participants completed the Fatigue, Mood and Thoughts Record Sheet, giving ratings between 1 and 10 on levels of fatigue and general anxiety experienced during the performance of the task.

Participants were also asked to write down any thoughts they had whilst performing the task. These responses were analysed blindly for level of catastrophising (0 = not at all catastrophising, 5 = extremely catastrophising).

### ***Part 3: Viewing of recording and Behaviour Record Sheet***

Participants were asked to watch the recording of their session and note down any strategies or behaviours that they used because they were experiencing or expecting fatigue using the Behaviour Record Sheet. This measure was modified from that used by Tang et al (2007) in a chronic pain sample, in order to include measurement of perceived fatigue during the task, in addition to pain. Participants were shown a recording of their session and asked to write down any actions or behaviours which they carried out because they were experiencing or expecting fatigue or pain. The measure also included the following questions about each behaviour: 1) Why did you do this? 2) What do you think would have happened if you had not performed this action / behaviour? 3) How anxious would you have been if you had not done this? The purpose of these questions was to determine whether any strategies used could be classed as SSB. Copies of the information sheets, consent forms and measures can be found in the appendices.

### **Analysis**

To achieve 80% power, with a p-value of 0.05, 18 participants per group would be needed to detect a difference between groups of medium effect size, based upon the findings of Tang et al (2007). In line with this previous study, planned procedure and

analysis included comparison of three groups: 1) CFS/ME – high health anxiety; 2) CFS/ME – low health anxiety; 3) HCs, in order to investigate group differences according to level of health anxiety. Planned analysis included comparison of three groups to compare outcomes according to levels of health anxiety. Amendments were made to analysis due to difficulties in recruitment and resulting small sample size as outlined below.

Data for tasks one and two were analysed separately as not all participants took part in task 2, with identical analyses carried out for each task. A number series of one-way ANOVAs were planned to check for group differences in fatigue, pain, mood and catastrophising during the task. A univariate ANCOVA was then planned, controlling for level of fatigue, anxiety and depression, to test for significant between group differences in the use of SSB during the task. Due to small sample size, analyses were conducted between two groups (CFS/ME, HC), using independent t-tests and Mann Whitney U depending on the normality of the data.

Data were checked for normality using visual inspection of histograms. Data for task ratings of anxiety, low mood, fatigue, pain, N SSB, health-anxiety, work and social adjustment, physical functioning, catastrophising and all or nothing coping were found to be negatively skewed. Attempts were made to transform the data using square root and logarithmic transformations. However, this did not improve normality and therefore non-parametric tests (Mann-Whitney U) were used to investigate group differences. Group differences in baseline fatigue, anxiety and depression were analysed using a series of t-tests.

As planned, Task 1 and Task 2 were analysed separately, given that participants were given the option to not complete Task 2. The proportion of participants totally avoiding task 2 was compared using a chi-squared test, in line with the planned analysis. Spearman's rho correlation was used to explore the relationship between number of SSB utilised and the following measures: health anxiety, catastrophising, fatigue, pain, anxiety.

The Total number of SSBs was calculated based on the definition that SSBs were employed to (1) pre-emptively reduce or prevent fatigue or pain, and (2) to reduce anxiety (based on a 'Would have anxiety rating' of > 4). This was based on ratings by two blind raters according to these criteria. Agreement between raters was high for both Task 1 ( $k = 0.87$ , 93.94%) and Task 2 ( $k = 1$ , 100%) and subsequent analyses were therefore based on the average between raters. Agreement was also high for ratings of catastrophising in Task 1 (intra-class correlation = 0.97,  $p = <0.01$ ) and Task 2 (intraclass-correlation = 1.00  $p = <0.01$ ).

## Results

*Table 3* shows the results of analyses for group differences on demographic and baseline clinical variables. The overall sample was 100% white British, with a mean age of 37.8 (SD 14.8). No significant group differences were found for age or gender, with 60% and 66% of the CFS/ME and HC participants female (Chi-square = 17.60,  $p = 0.48$ ). 60% of the CFS/ME group were currently working reduced hours due health, and 10% not working due to health.

The CFS/ME group were found to have significantly higher scores on fatigue, pain, health anxiety, impairment and physical functioning, with scores for health anxiety, impairment and physical functioning above established clinical cut-offs for those measures. Anxiety and depression were not found to be above established clinical cut-offs. Mean fatigue for the CFS/ME group was similar to the mean obtained in a large sample of individuals with CFS/ME (Cella & Chalder, 2010:  $\bar{x} = 24.4$ , SD 5.8). Whilst not statistically significant, the HC group scored higher on baseline anxiety compared with the CFS/ME group, indicative of a 'moderate' level of anxiety. All other anxiety and depression scores for both groups were sub-clinical, with no differences between groups.

A range of SSB were observed and are outlined in *Table 4*, along with perceived function and ‘would have’ anxiety rating. As shown in *Table 5* and *Table 6*, whilst group differences in the number of SSB used in task 1 were not found to be significantly different, on task 2 significant differences were found between groups on task 2, with the CFS/ME group using significantly more SSB than HCs. Three participants (30%) in the CFS/ME group compared to one participant (7%) in the HC group opted out of task two. However this difference was not statistically significant (Chi-square = 2.43,  $p = 0.12$ ). Thoughts during the tasks rated as catastrophising were not found to differ significantly between groups.

Group differences were not observed for ratings of anxiety or low mood following either Task 1 or Task 2. However the CFS/ME group had significantly higher ratings of pain and fatigue. Ratings of pain and fatigue in Task 2 were significantly associated with the number of SSB used ( $\rho = 0.48$ ,  $p = 0.03$ ,  $p = 0.47$ ,  $p = 0.03$ ). This was not found for Task 1.

Across group analyses showed the number of SSB in task 1 to be associated with baseline health anxiety (Spearman’s  $\rho = 0.58$ ,  $p < 0.01$ ) and within task mood ( $\rho = 0.42$ ,  $p = 0.04$ ). N SSB within task 2 ( $\rho = 0.61$ ,  $p < 0.01$ ) was also associated with within task mood ( $\rho = 0.42$ ,  $p = 0.05$ ), fatigue ( $\rho = 0.47$ ,  $p = 0.03$ ) and pain ( $\rho = 0.48$ ,  $p = 0.03$ ). When analysing groups separately these associations failed to reach significance, with the only significant correlation being between N SSB at time 2 and fatigue experienced at time 1 within the CFS/ME group ( $\rho = 0.83$ ,  $p = 0.02$ ). Number of SSB was not associated with baseline catastrophising in either group.

Given the smaller than planned sample size, a post-hoc power analysis was carried out. Based on the effect size for the group difference on N SSB on task 1 ( $d = 0.75$ ) and the total achieved sample size ( $N = 25$ ), with a p-value of 0.05, the study had 55% power to detect a difference of this size.



**Table 3: Demographic and clinical characteristics**

	<b>CFS/ME (N = 10)</b>	<b>HC (N = 15)</b>	<b>t</b>	<b>p</b>	<b>ES (d)</b>
<b>Age</b>	40.22 (13.51)	36.33 (15.73)	-0.62	0.54	0.27
<b>Fatigue (CFQ)</b>	25.0 (4.81)	12.4 (4.80)	-6.42	<0.01	1.04
<b>Anxiety (HADS)</b>	9.90 (2.18)	11.20 (1.93) <sup>a</sup>	1.56	0.13	0.34
<b>Depression (HADS)</b>	8.30 (1.77)	9.27 (1.94)	1.29	0.21	0.54
			<b>z</b>	<b>p</b>	<b>ES (r)</b>
<b>Pain (Likert scale / 100)</b>	40.00 (23.00, 60.75)	3.00 (0.00, 11.00)	-2.93	<0.01	0.59
<b>Health anxiety (SHAI)</b>	22.50 (11.00, 26.00) <sup>b</sup>	11.00 (5.00, 15.00)	-2.53	<0.01	0.51
<b>Physical functioning (SF-36)</b>	52.50 (33.75, 80.00)	100.00 (95.00, 100.00)	-4.07	<0.01	0.81
<b>Impairment (WSAS)<sup>c</sup></b>	26.00 (22.00, 37.25)	6.00 (5.00, 17.00)	-3.6	<0.01	0.72
<b>Catastrophising (BAS)</b>	10.00 (6.75, 11.25)	7.00 (1.00, 8.00)	-2.86	<0.01	0.57

<sup>+</sup> Effect size for normally distributed outcomes reported as Cohen's d; effect size for non-normally distributed outcomes reported as Cohen's r

<sup>a</sup> Indicative of moderate anxiety

<sup>b</sup> Indicative of clinical levels of health anxiety

<sup>c</sup> Indicative of severe impairment.

CFQ: Chalder Fatigue Questionnaire; ES: Effect Size; HADS: HADS: Hospital Anxiety and Depression Scale; SF-36: Short Form Survey Instrument; SHAI: Health Anxiety Inventory Short Form; WSAS: Work and Social Adjustment Scale.

**Table 4: Examples of SSB**

<b>Behaviour</b>	<b>Self-reported function of behaviour</b>	<b>Anxiety (if behaviour not carried out) out of 10</b>
Standing taller to stretch out my spine	The pain in my lower back would have increased, to enable me to continue	6
Stand with feet apart more and tightened stomach	To protect my back, feel more in control of the effects of the task and keep going	5

muscles to improve core strength			
Stopped task	I would have been in too much pain, I would have had an overload of symptoms	10	
	To feel less fatigued and to not crash		
Switched hands	To complete task, continue for longer	10	
Shifting body weight to compensate for load	To stop muscle ache and pain from getting worse and recovery taking longer	9	
Holding bag closer to the floor	To retain energy	5	
Distraction looking out of the window during hold	To avoid thinking about the fatigue	6	
Slow pace of walking	To feel more in control of the effects of the task	5	

**Table 5: Group differences on task 1**

	<b>CFS/ME N=10</b>	<b>HC N=15</b>	<b>Z</b>	<b>Sig</b>	<b>Effect Size (r)</b>
<b>N SSB</b>	0.00 (0.00, 3.00)	0.00 (0.00, 0.00)	-1.23	0.40	0.25
<b>Anxiety<sup>a</sup></b>	2.50 (7.00, 4.00)	1.00 (1.00, 2.00)	-1.54	0.16	0.31
<b>Low mood<sup>b</sup></b>	1.00 (1.00, 2.00)	1.00 (1.00, 1.00)	-0.56	0.68	0.11
<b>Pain<sup>c</sup></b>	4.00 (1.00, 5.25)	2.00 (1.00, 3.00)	-2.24	0.04	0.45
<b>Fatigue<sup>c</sup></b>	4.00 (2.00, 4.50)	2.00 (1.00, 3.00)	-1.85	0.07	0.37
<b>Catstrophising<sup>d</sup></b>	0.00 (0.00, 0.75)	0.00 (0.00, 0.00)	-2.21	0.22	0.44

Data for all variables shown as Median (IQR)

<sup>a</sup> Likert scale 0-10, increased score indicates increased anxiety

<sup>b</sup> Likert scale 0-10, increased score indicates lower mood

<sup>c</sup> Likert scale 0-10, increased scale indicative or increased pain / fatigue

<sup>d</sup> Likert scale 0-5, ranging from no evidence of catastrophising to extremely catastrophising.

N SSB: Number of Safety Seeking Behaviours

Effect size:

**Table 6: Group differences on Task 2**

	CFS/ME (N = 7)	HC (N = 15)	Z	Sig.	ES (r)
<b>N SSB</b>	2.00 (0.00, 4.00)	0.00 (0.00, 0.00)	-2.78	0.02	0.59
<b>Anxiety<sup>a</sup></b>	1.00 (1.00, 3.00)	1.00 (1.00, 1.00)	-1.22	0.39	0.26
<b>Low mood<sup>b</sup></b>	1.00 (1.00, 1.00)	1.00 (1.00, 1.00)	-0.56	0.68	0.12
<b>Pain<sup>c</sup></b>	6.00 (1.00, 7.00)	2.00 (1.00, 3.00)	-2.07	0.05	0.44
<b>Fatigue<sup>c</sup></b>	5.00 (4.00, 8.00)	2.00 (1.00, 3.00)	-3.26	<0.01	0.70
<b>Catastrophising</b>	0.00 (0.00, 1.00)	0.00 (0.00, 0.00)	-2.25	0.18	0.48

Data for all variables shown as Median (IQR)

<sup>a</sup> Likert scale 0-10, increased score indicates increased anxiety

<sup>b</sup> Likert scale 0-10, increased score indicates lower mood

<sup>c</sup> Likert scale 0-10, increased scale indicative or increased pain / fatigue

<sup>d</sup> Likert scale 0-5, ranging from no evidence of catastrophising to extremely catastrophising.

N SSB: Number of Safety Seeking Behaviours

## Discussion

The aim of this pilot study was to experimentally investigate SSB in CFS/ME in response to a mildly exerting physical task. The study found evidence of SSB, with these strategies having the perceived intention of preventing worsening pain or fatigue and being driven by anxiety (as measured by a ‘‘would-have’’ anxiety rating, i.e. had the strategy not been used). Group differences on SSB were found to be statistically significant on Task 2, whilst differences on Task 1 failed to reach significance. More participants in the CFS/ME group also opted not to take part in the second task compared with HCs, although this difference was not found to reach significance. Whilst the small sample size precluded analyses of group difference on SSB according

to level of health anxiety, a significant association was found between health anxiety score and number of SSB used, in line with the hypothesis that increased health anxiety would be associated with increased use of SSB. Number of SSB was not associated with baseline catastrophising as was hypothesised would be the case. In the CFS/ME group N SSB used in task 2 was significantly associated with fatigue experienced during the first task, with the strategies used in the second task therefore appearing to be a response to fatigue experienced during the first task. This is also in line with the greater number of SSB used in task 2. Whilst some significant associations were found between SSB and within task mood and fatigue ratings across groups, this was not evident when analysing groups separately.

This study provides novel experimental evidence for the use of SSB in CFS/ME, in line with intervention research which has demonstrated a novel CBT intervention centred on the challenging of SSB to be associated with promising outcomes in CFS/ME (Daniels & Loades, 2017; Daniels & Salkovskis, in preparation). Both overt observable (e.g. stopping task, switching hands) and more subtle or covert strategies (tightening stomach muscles, distracting self) used within-situation were identified. Stopping the task prematurely was identified as an SSB. In addition, whilst reasons for not attempting Task 2 were not explicitly measured, verbal feedback in testing sessions from some participants indicated that this was in some cases due to fatigue and / or pain and concern as to the consequences if they were to continue with the task, and may therefore be evidence of avoidance as a SSB. However avoidance SSBs, were only one of a range of those identified and interestingly several participants explicitly outlined that the goal of a SSB as being ‘to enable me to continue’ with the task. This finding is extremely important given that existing models of CFS – and associated treatment – focus predominantly upon fear-avoidance. The findings also demonstrate that a model which does not account for meaning, including the meaning driving such behaviours, is insufficient in informing more effective intervention (Jamani & Clyde, 2008). All SSB had the intended function of preventing fatigue or pain or protecting the body. However, it is possible, given the nature of the described function or consequence of not using the strategy, e.g. ‘The pain in my lower back would have increased; to protect my

back and feel more in control of the effects of the task” that the SSB described may have the effect of preventing a disconfirmation of beliefs and the participant experiencing the reality of the task without the strategy.

The use of within-situation SSBs has been found to be common in a range of mental health problems, including panic, agoraphobia (Salkovkis et al, 1999), social anxiety (Wells et al, 1995; Clark, 1996); obsessive compulsive disorder (Salkovskis & Kirk, 1997) and panic (Salkovskis & Clark, 1991). Similarly within-situation SSBs have been identified in a range of physical health conditions including chronic dizziness (Mahoney et al, 2013, Edelman et al., 2012; Whalley & Kane, 2017), chronic pain (Tang et al, 2007; Jamani & Clyde, 2008) and sexual dysfunction (Frank et al, 2010).

In terms of the topology of the strategies identified, significant overlap was found between participants with CFS/ME in this study and those with chronic pain who carried out the same task in a previous study (Tang et al, 2007). The bodily focus evident in the SSB identified is also in line with findings in other varied health conditions such as persistent dizziness (e.g. Whalley & Kane, 2017), chronic pain (Tang et al, 2007; Jamani & Clyde, 2008) sexual dysfunction (Frank et al, 2010), IBS (Hunt et al, 2009) and urinary incontinence (Molinuevo & Batista-Miranda, 2012).

The presence of more subtle or covert SSB is also in line with the findings across physical health studies, as demonstrated by the systematic review. Covert cognitive strategies such as distraction are similar to SSB identified in other physical health conditions including concentrating hard on the task (Tang et al, 2007) and image suppression in chronic pain (Jamani & Clyde, 2008), body focusing and thought suppression in sexual dysfunction (Frank et al, 2010) and imagery and thought control in insomnia (Harvey et al, 2002a, Semler & Harvey, 2004). The fewer examples of cognitive SSB elicited in this study is also in line with cognitive SSB being less widely documented in health conditions, compared with more overt behavioural strategies (Lloyd et al, in preparation).

There are a number of potential explanations for the lack of group difference on SSB observed at Time 1. It is possible that the SSB construct is less relevant to CFS/ME than might be the case with other physical health conditions (see findings of systematic review). However, significant differences were observed on Task 2. Alternative explanations may relate to participant characteristics, with CFS/ME and HC samples within this study not differing on self-reported measures of anxiety or depression. This is contradictory to what might be expected, with a recent systematic review demonstrating consistent evidence of elevated levels of anxiety and depression in CFS/ME (Caswell, Daniels et al., in preparation). The lack of group differences on these measures may be reflective of the CFS/ME sample representing a less impaired group in terms of mood. Similarly, the sample included in this study was relatively less impaired than that used in the previous study by Tang et al (2007) in terms of employment and functioning. Although speculative, this may have resulted in smaller group differences on the tasks.

It is also possible that Task 1 may have represented an activating task, with the use of SSB associated with ongoing exertion and supported by observed trends on a number of variables between Task 1 and Task 2. A reduction in anxiety was observed between Task 1 and Task 2. Alongside this, an increase in pain and fatigue was observed in the patient group, whilst no change in mood and catastrophising was found. One interpretation of these findings and the observation of significant differences between groups on number of SSB at time 2 only is that task one may have been an activating process, with increases in pain and fatigue responded to with SSB. The lack of change in mood and catastrophising being a result of SSB, with the intention of reducing anxiety and the likelihood of a feared outcome. Power is also a consideration, given the small sample size. A post-hoc power calculation confirmed that the study was underpowered to detect a difference on task 1, which although medium to large, was smaller than that observed at time 2.

There are a number of limitations to this study. The small sample size is a significant limitation and the result of difficulties in recruiting to the study. Recruitment to this study was challenging, with a low take-up rate and negative responses to advertisement of the study from CFS/ME patient groups as seen in response to PACE trial (White et al, 2011). Despite additional recruitment strategies using a number of methods (social media, direct recruitment, attending psycho-educational groups). Despite there being additional time available to focus on recruitment, the research team advised cessation of recruitment due to a negative “Twitter storm” which generated hostile responses, with it deemed no longer safe or reliable to continue recruitment.

This is not uncommon in research in this area, with contention around the acceptance of a psychologically based model as a basis for intervention. This rejection of psychologically based treatments and associated treatment rationale have been discussed as barriers to treatment (Chew-Graham et al, 2011; Wearden et al, 2008) and is in this context of feelings of deligitimisation often found in this patient group (Moss-Morris, 2005). Furthermore, discussions with potential participants revealed a number of barriers to taking part, including travel and work commitments and the energy used by travelling and taking part in the study. As such the generalisability of the findings must be considered, as it is likely that those taking part represent a more able sample of individuals with CFS/ME. This study should be taken as a preliminary/pilot study with promising results for these reasons.

Additionally, analyses did not control for baseline demographic and clinical differences. Possible covariates include fatigue, pain, physical functioning, anxiety, depression and health anxiety in order to investigate the impact of these variables on findings. As a result it is possible that observed differences in SSB may be a function of health status, with this being a potential confounding factor. However, given that fatigue and pain represent core symptoms of CFS/ME it may be argued that it is not appropriate to attempt to control for the effects of these symptoms (Miller & Chapman, 2001). An additional limitation is that baseline measures were not taken immediately prior to the

tasks being carried out and therefore it is not possible to investigate any changes in mood, pain and fatigue which may have occurred between pre- and post-task.

This study used a bag carrying task in order to have high ecological validity. However, participants were tested in a laboratory setting and using standardised instructions and procedure. Furthermore, whilst the study aimed to increase the reliability of the self-report data through the use of videos which the participants rated, it is possible that not all behaviours may be obvious to the participant due to being subtle or covert (Harvey et al, 2007). The prevalence of subtle SSB in physical health conditions is supported by systematic review which forms as part of this portfolio.

Distinctions have been made in the wider literature between overt and observable SSB (e.g. direct avoidance) and covert SSB including internal processes and cognitive strategies (Helbig-Lang & Peterman, 2010; Salkovskis, Clark & Gelder, 1996), with both having been identified across physical health conditions (Lloyd et al, in preparation). Whilst this study captured examples of both overt – and covert strategies – e.g. distraction, fewer were noted, particularly cognitive in nature. This is in line with the findings across health disorders, where cognitive strategies less commonly identified, with this likely due to it being increasingly challenging to recognise and capture such strategies. One limitation of this study is that overt and covert strategies were not investigated separately. It is also possible that the study design, including reviewing of video recordings, may have biased the findings towards more overt observable strategies. Although instructions were given to record any strategies which were could be recalled or observed, viewing of recordings may have prompted increased focus on overt behavioural responses rather than cognitive strategies.

This has important implications given that if relevant / present in CFS/ME more covert strategies will be important to document, in order to inform careful questioning of potential strategies. This is also key given that differential effects of different SSB have been identified in the wider mental health literature (Plasencia, Alden & Taylor, 2011), whilst there is at present a lack of data concerning whether covert and overt strategies



have a differential impact on symptoms and severity (Goetz, Davine, Siwiec & Lee, 2016).

In social anxiety and panic disorder, it has been suggested that whilst all SSB have the function of preventing a perceived catastrophe, this function may be related to a number of levels or stages in this process, from avoidance of the feared stimuli, physical response to the stimuli or perceived consequences of the physical response (Thwaites & Freeston, 2005; Clark, 2001). Within this study the perceived function captured was largely at the level of the impact of physical exertion. It has been proposed that using ‘‘surface motivation’’ alone can be problematic in distinguishing between SSB and coping strategies (Thwaites & Freeston, 2005) and this may be particularly pertinent in physical health conditions, where detection of SSB may be further complicated by iatrogenic factors and advice giving (Ree & Harvey, 2002).

Whilst SSB were defined in this study on the basis of the function of a strategy being to prevent a feared outcome and the strategy being fuelled by anxiety, in line with the Tang et al (2007) study, study design modifications may enable more in depth exploration of SSB in this population. Questionnaire measures were used to elicit the function and reasons for using strategies. In future, use of more qualitative interview methods may be beneficial in elaborating on perceived function and related cognitions and meaning for the individual. This would enable techniques utilised in therapeutic settings, such as Socratic questioning and downward arrowing (Beck, Rush, Shaw & Emery, 1979; Burns, 1980) to be used to further elicit cognitions and meaning. This would also allow for further exploration of the presence of catastrophising. Indeed the scope of smaller scale studies to explore idiosyncratic and a deeper level of meaning for individuals was demonstrated as a strength of such studies in the systematic review conducted as part of this thesis. More frequent measurement of outcomes such as anxiety, mood, pain, fatigue and catastrophising – including measurement both immediately pre- and post-tasks would also aid investigation of temporality and further evidence concerning both the function and impact of strategies employed.

Although the small sample size did not allow meaningful comparisons between those in the CFS/ME group with high and low levels of health-related anxiety, group differences show the construct to be relevant to CFS/ME. Further research is needed but the findings suggest that refinement of the CBT model of CFS/ME may be needed, which focuses not only upon behavioural factors such as avoidance and SSB, but a focus on cognition and the function and associated meaning of these. This would lead to change at a more cognitive level and may contribute to larger effect sizes for CBT, akin to those achieved in psychological problems such as anxiety.

These findings have important implications for both clinical practice and further research. The meaning of symptoms and related perceived function of SSB used by individuals with CFS/ME, supported by this research, is not accounted for by current models of CFS/ME and their associated treatments apart from experimental N of 1 studies (Daniels & Loades, 2017). The findings support an increased cognitive conceptualisation of difficulties enhanced by SSB, as well as the importance of SSB as a maintaining factor which should be carefully assessed and targeted in treatment. Behavioural experiments have been established as an important treatment component in CBT, enabling testing out of an individual's catastrophic beliefs and predictions of what will happen if they do not use their SSB versus what happens in reality (Bennett-Levy et al, 2004; Jamani & Clyde, 2008). In line with Tang et al (2007), this study also highlights the presence of subtle SSB, where there was previously no inventory of SSB. This suggests that there is a need for careful assessment and case conceptualisation, particularly concerning subtle SSB, which may not be immediately obvious to the client (or the therapist) but which may have a considerable impact on both treatment outcomes and quality of life if not identified and addressed.

Further research, akin to that in anxiety disorders, is now needed to experimentally explore the impact of manipulation of SSB such as those in anxiety disorders and other physical health conditions such as insomnia. Future research may also focus on the development of an SSB inventory for use in clinical settings, outlining both overt and covert SSB as a prompt to those less aware of subtle SSB.

In conclusion, this study provides novel experimental evidence for SSB in CFS/ME in response to physical exertion, as well as providing an account of the nature and perceived function of these strategies. Further research of this kind would enable development of a more empirically grounded model of CFS/ME, and provide future targets for treatment, which are much needed given the currently substandard outcomes for cognitive behavioural interventions in this condition and significant distress, impairment and impact on quality of life.

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**Service Improvement Project - Improving appropriate referrals to the Family and  
Couples Therapy (FaCT) Service through exploring who is referred and why.**

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## **Abstract**

Despite an increasing evidence base for systemic therapy, the provision of such services does not measure up to this and a number of challenges to implementing family therapy have been discussed. The Family and Couple Therapy service (FaCT) in South Gloucestershire is representative of such challenges, with the service not having been used to full capacity. The aim of this project was to explore through mixed methodology, who is referred into the service and why. An audit of referrals data was conducted, along with qualitative interviews with five potential referrers. Referrals were received for individuals with a range of diagnoses and difficulties. Themes emerging from interviews demonstrated that whilst those interviewed appreciated the value of working systemically and regarded it relevant to the majority of their case load, there exist a number of service and service-user related barriers. The findings are discussed in relation to the wider literature and recommendations for addressing the emerging barriers are outlined.

*Keywords: Family Therapy; systemic; interviews; referrals; service improvement*

## **Background**

Family, couple and systemic therapies and / or the involvement of families and carers are recommended by NICE guidelines for a number of mental health problems in adults (Association for Family Therapy and Systemic Practice, 2016). There is increasing evidence for the efficacy and effectiveness of systemic approaches across a range of conditions, including affective disorders, depression, anxiety disorders, schizophrenia and substance use, adjustment to chronic illness, as well as more relational difficulties such as couple discord, relationship distress and autonomy (Stratton, 2016; Carr, 2014).

For depression, NICE guidelines (NICE, 2009) recommend couples therapy as part of a stepped care approach for individuals with mild to moderate depression requiring further treatment following a low intensity intervention. Behavioural couples therapy is also recommended as a high intensity option for those "who have a regular partner and where the relationship may be contribute to the development or maintenance of depression, or where involving the partner is considered to be of potential therapeutic benefit." (NICE, 2009, p. 22). For moderate or severe depression, a combination of antidepressant medication and a high-intensity psychological intervention – including couples therapy - is recommended. Narrative and systematic reviews demonstrate that systemic couple and family based interventions are as effective as individual approaches in reducing symptoms of depression in adults, and are associated with bigger improvements in relationship satisfaction (Carr, 2014; Whisman, Johnson, Be, & Li, 2012). The London Depression trial (Leff et al., 2000) found couple therapy to be more effective in reducing depression than antidepressants, with gains maintained at follow-up. This study also found couple therapy to be more acceptable – as demonstrated by lower drop-out – and cost-effective.

The importance of relationships is highlighted more widely in mental health policy, with it purported that a feature of good mental health services is that they recognise the importance of strong relationships in an individual's life - both in relation to the promotion of wellbeing (NHS England, 2016) and the management of risk

(Simon, 2010). The Think Family approach (Social Exclusion Task Force, 2008) also proposes that better outcomes for children, young people and families can only be achieved through considering how difficulties relate to and impact upon all the whole family.

However despite an increasing evidence base, mental health services continue to be focused on the individual, with systemic interventions not routinely available (Lebow, Chambers, Christensen, & Johnson, 2012; Stanbridge & Burbach 2007). Difficulties in the implementation of systemic interventions into routine clinical practice have been reported, including identifying and engaging appropriate families, the time-consuming nature of family work and managing this within a caseload (Kavanagh et al., 1993, Fadden 1997).

The importance of the referrals process in ensuring appropriate referrals has been highlighted more generally, with significant implications in terms of patient choice, outcome and satisfaction, delivering the most effective and cost-effective care, service provision and commissioning (Akbari et al, 2008; Imison & Naylor, 2010). Available evidence suggests that interventions targeting the referral process can influence appropriate referrals (Imison & Naylor, 2010), however there is a paucity of research relating to referrals to systemic services.

### **Local context**

The South Gloucestershire Psychological Therapies Service is a secondary care service offering a range of psychological interventions including systemic Family and Couple Therapy (FaCT). Referrals to FaCT are mainly received from the Recovery Teams but referrals can also be made by other practitioners within South Gloucestershire secondary mental health services. FaCT is permanently staffed by four clinical psychologists with systemic training, and a temporary rotation of multi-disciplinary students, including intermediate systemic therapy, clinical psychology, psychiatry and nursing. FaCT therefore provides an important service both for clients and professionals in training.

This project was commissioned by the service due to the FaCT service not being fully utilized in terms of capacity or potential to support service users and their wider system with a range of difficulties. The service was interested in exploring how best to encourage and support appropriate referrals from local teams.

### **Aims and objectives**

An initial aim was to establish the difficulties and diagnoses of those currently accessing FaCT and how this compares to the established evidence base. The project also aimed to explore the discourses held by the local teams around referring to FaCT. A further aim was to use this information to make recommendations for how best to encourage and support referrals.

### **Specific questions to be addressed**

- 1) What difficulties and / or diagnoses do clients referred to FaCT have?
- 2) What might be the reasons for a Care Coordinator to consider a referral for a systemic approach?
- 3) What are the discourses held about the FaCT service by those who might potentially refer into the service?

### **Methods**

#### **Quantitative referral data**

All referrals received by the FaCT service since its development were reviewed, with the following data captured: reason for referral, diagnosis, type of systemic therapy (e.g. family, couple). Individual interviews were carried out with five potential referrers, all of whom were care-coordinators and practitioners within teams able to refer into the FaCT service. Participants' professional backgrounds included social work (N = 2), mental health nursing (N = 2) and occupational therapy (N = 1).

### **Qualitative interviews**

Through carrying out interviews with individuals from referring teams, this project aimed to gather information about discourses held by those who might potentially refer into the service and their relationship to the consequent decision-making process. This is in line with White's (1997) proposal that discourses within healthcare are based upon interpretations of what is meaningful and useful in practice. Discourses have been defined as "systems of thoughts composed of ideas, attitudes, and courses of action, beliefs and practices that systematically construct the subject's and the world of which they speak" (Weedon, 1987, p. 108). Within this is reference to the social constructionist notion that that all knowledge is developed from and maintained by social interaction and is thus reality is socially constructed (Berger & Luckmann, 1966). This project is underpinned by a social constructionist epistemology in exploring the discourses held by staff teams and practitioners about who is appropriate to refer to FaCT and perceptions of the service. Within this project discourses are used to refer to the ideas, beliefs and practices held by participants.

A thematic analysis approach was considered the most appropriate methodology given the purpose of this project and the value of a more realist account of referrers' views other methodology such as discourse analysis, given that for the purpose of this service improvement project, a more realist account of what referrer's was felt to be more useful, rather than a discursive interpretation of their descriptions.

Interviews were based around a schedule developed in line with the aims of the project. Questions were broad and open-ended to elicit responses without being leading, with probes and further questions used where necessary. Interviews covered the following topics: experiences of referring into the service; decision making around potential referrals; what might encourage / facilitate referrals in; involvement with service users' wider networks within their role. Interviews were recorded and transcribed verbatim. Thematic analysis (Braun & Clarke, 2006), was used by S.L. to analyse transcripts and identify themes and subthemes. Themes were reviewed and refined with C.B. and S.B.

## Results

### Referral data

38 referrals were received between July 2013 and February 2018. Of these, 24 (63%) were for couple therapy, 12 (32%) family therapy, and two (5%) a combination of both. Those referred presented with a range of difficulties and diagnoses, as shown in Table 1. The majority had a psychiatric diagnosis, five (13.16%) had multiple diagnoses and only two individuals referred did not have a diagnosis (5.3%). For 14 (36.8%) individuals the reason for referral differed from their diagnosis. *Table 7* also shows reasons for referral where this differed from diagnosis.

### Qualitative interviews

Four main themes – each consisting of a number of subthemes – emerged from the data: the relevance of systemic work, carving out a space for family therapy, barriers to family therapy, and facilitators and solutions. The themes and subthemes are shown visually in *Figure 2* and are described below, with illustrative quotations.

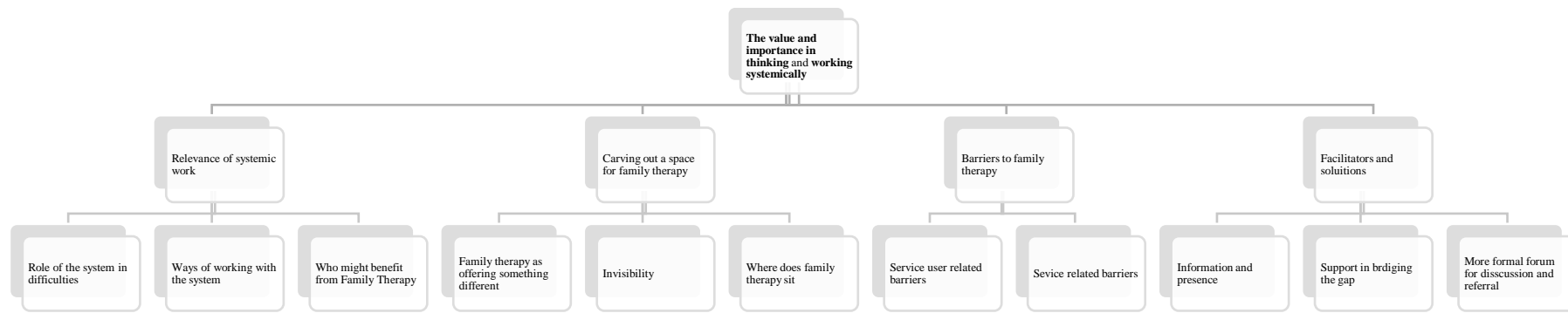
**Table 7: Reasons for referral to the FaCT service**

Diagnoses of those referred	N
Anxiety	6
Depression	3
Mixed anxiety and depression	7
Persistent mood disorder	1
Social anxiety	2
Aspergers	3
Bipolar disorder	2
Mania without psychotic features	1
Psychosis	3
Schizophrenia	2
Delusional disorder	2
Borderline personality disorder / Emotionally unstable personality disorder	5
Dependent personality disorder	1
Personality disorder not otherwise specified	3
Complex PTSD	1
Abnormal grief reaction	1



<b>Reason for referral (where different from diagnosis)</b>	<b>N</b>
Anxiety	1
OCD	1
Insecurity and self-confidence	2
Relational difficulties	3
Rigidity	1
Changes in personality following a brain injury	1
Perfectionism	1
Crisis	2
Overdose	2
Complex PTSD	3
Depression	1
Systemic work in the context of another intervention	1
Eating difficulties	1

OCD: Obsessive Compulsive Disorder; PTSD: Post-Traumatic Stress Disorder  
 Numbers do not add up to total number of referrals due to some referred service users having more than one psychiatric diagnosis / reason for referral.



**Figure 2: Visual representation of themes from qualitative interviews**

***Overarching theme: The value and importance in thinking and working systemically***

The overarching theme emerging from the interviews was the value and importance of thinking and working with the system around the individual. This theme extended beyond a focus on family therapy, with participants also discussing the wider system in the context of other work within the team.

*‘It’s really helpful meeting with other parts of the family because you get to hear other parts of the story, it gives it a much more global perspective.’ P1*

***Theme 1: The relevance of systemic work***

***1.1 Ways of involving the system***

Ways of involving the system outside of family therapy were discussed with all participants giving examples of working with the wider system, with this varying to the extent of involvement. Almost all participants said that they either involved, or were at least aware of the wider system around the clients they were care-coordinating.

*‘Where possible, as much as possible, I try to speak to all members of the family... going and meeting them and the family is there, and having some of those exploratory sort of conversations, I suppose, to test the water. To see how they might react to that and how they might be able to engage with that.’ P3*

*‘I suppose the other approach we have which is slightly different, is around carer support... we might see them with their partner or something like that. To an extent there’s some joint working, it’s not couples work or family work but it’s a degree of that. Some of the time we might do more family work in the way of information.’ P5*

Links were made between thinking systemically and professional background or training. For example, three participants spoke about Open Dialogue training giving them more of an awareness and practice in thinking and working

systemically. Two other participants spoke about their background in social work instilling a systemic perspective.

*“I do open dialogue... so I’m more open to the idea of having open conversations and I guess it fits quite well with my idea of Open Dialogue, the idea of couples and families having some of these open conversations.” P3*

*“You have to work with everyone. I’m a social worker so we have an awareness of family systems theory. We work with the whole family where we can but what we’re hampered by as care coordinators is our capacity to do that really.” P2*

### *1.2 Role of the system in difficulties*

A common subtheme concerned the role of the family in the development or maintenance of a service user’s difficulties. Specific examples were given of difficult dynamics that had been encountered:

*“Her and her husband were never apart basically and then two of their three adult children lived in the house. That was just chaos and really difficult to manage and at that time we were exploring all the options and just trying to open up some of the communication in the family, because it was very toxic.” P1*

Examples were also given of particular difficulties and the implication of system within these:

*“And I suppose a large proportion of my caseload is people with emotion dysregulation, personality disorder, attachment kind of stuff, and that is so much about the interpersonal world, that I think that they would really benefit from having some sort of family work alongside it... it feels like that’s what keeps people in those cycles or perpetuates behaviours and thought patterns and triggers.” P1*

### *1.3 Who might benefit from Family Therapy*

Related to the previous sub-theme, participants discussed reasons for potentially considering referrals to the FaCT service. Overall this centred on particular dynamics in the family which might be problematic.

*‘If there were particular dynamics in the family that made you think actually, this really needs some looking at.’ P2*

*‘And I guess where I take that decision, was with the couples where I can see its was the relationship that was having difficulties.’ P5*

Participants commonly expressed family therapy being relevant to the majority of service users, with there being few reasons that they wouldn't consider this approach for someone.

*‘I don't see who wouldn't benefit from it really, apart from people who maybe live in this area who have no local family so its impractical’. P1*

## ***Theme 2: Carving out a space for Family Therapy***

### *2.1 Family therapy as offering something unique but complementary*

The place of family therapy was discussed, with it seen as offering something distinct from other types of family involvement, such as family support and Open Dialogue. It was also suggested to offer something above that which could be offered within the care co-ordinator role, but which was complementary to this provision.

*‘It can offer families a good space to explore issues and feel held, in a way that a lone care coordinator can't do.... I've referred in a young woman and her family, into the therapy because I wasn't making any difference at all ... the lady I referred in couldn't actually go along to the sessions, she just found it too distressing. But what was helpful in having the option of the family therapy service, was that her parents and uncle could go there ... It was a really helpful space for them.’ P2*

*‘‘And I’ve got a case at the moment where the family team are working with a couple... So that been really helpful for them and they meet every couple of weeks which I think is necessary actually... Which is great cos it’s really taken the pressure of me because I’ve done what I can, managing his crises.’’ P1*

## *2.2 Invisibility*

Whilst Family Therapy was viewed as valuable, it was felt that it was not currently very visible and not at the forefront of peoples’ minds.

*‘‘So just to have a bit more awareness of it really and a bit more awareness of what the service offers, because it feels likes its gone off the radar. People don’t talk about it or mention.’’ P1*

*‘‘It’s a little bit invisible really and it’s a rare resource, it’s a rare resource and I’m not sure if its possibly even in secondary mental health services, how sort of valid colleagues feel it as an intervention you know. ...I think It’s just a bit of lack of information, lack of knowledge and just thinking about what sort of things indicate family therapy.’’ P3*

Related to this there were questions around the detail of family therapy. This ranged from practical questions, for example, the room where family therapy takes place and at what time, to more detailed questions regarding the nature of family therapy work.

*‘‘I think I’m right in saying, I don’t even know where here at Kingswood the Family Therapy room is, and when it runs, and I guess it would be X but I’m trying to think of his colleague. So I wasn’t quite sure about the team.’’ P5*

*‘‘Practical things about the service really, is it up and running, is it available.’’ P1*

### 2.3 Where does Family Therapy sit

Connected to the theme of carving out a place for family therapy, there were questions about where family therapy sits or is positioned and distinctions between this and other ways of working within the team. This was discussed both in relation to other therapies and also the evidence base for psychological therapies:

*“And the other thing is working in Open Dialogue... that is different from family therapy, which I think is another differentiation to make. And it’s quite difficult for some people to understand, well if you both work with families then how is that any different.” P4*

*“As a care-coordinator you generally would say NICE approved therapies if they’ve depression, CBT, if they’ve got a personality issue MBT, if they’ve got some sort of trauma then it would be trauma focused work. It’s kind of what we do and its where does family therapy sit within that... the diagnosis, formulation I guess and that, family therapy wouldn’t always necessarily be part of that treatment pathway.” P4*

Related to this, two participants also discussed family therapy being underused, with one feeling that it wasn’t positioned as being a first line treatment, instead being left as a last-resort for the most unwell. This was echoed by the experience of another participant who referred a service user to family therapy after a significant period of not seeing any change:

*“Often in the past it felt like family therapy was a last-ditch resort for really difficult people who are stuck and entrenched, but really it should be first line, rather than last” P1*

*“I’ve referred in a young woman, very traumatised by sexual abuse from childhood and her family, into the therapy because I wasn’t making any difference at all to this lady’s presentation, quality of life, anything, in my work with her. I was feeling quite stuck.” P2*

### ***Theme 3: Barriers to family therapy***

A number of barriers to referring to the service and / or service users accessing family therapy were discussed. Barriers divided into those relating to the service and those associated with service users and their families.

#### *3.1 Service related barriers*

Practical challenges around the provision of the service, availability and the impact on waiting lists were raised by participants:

*“I suppose sometimes just the practical bureaucratic thing, we have a waiting list, family therapy may not be like six sessions every fortnight or whatever. That could extend the role of the care-coordinator.” P1*

*“I think also it was a very small clinic, they had very limited availability, very limited slots available and people were just waiting too long. And obviously that was a provision issue, but that just makes it sort of inaccessible really. You think, by the time you get to the point that there’s an appointment, and then the family don’t turn up for one appointment.” P3*

A number of participants discussed valuing informal conversations with members of the FaCT team around referrals. This was suggested to be a facilitator in terms of the potential for the FaCT service to be more joined up with the teams.

*“I think if I had an idea about couple or family work, I would probably have a word with X about that because he’s the one person I know locally who is involved in that.” P5*

*“We’re lucky here... For it to be joined up rather than in a bubble somewhere.” P2*

However, one participant suggested that whilst he found this useful, he was not sure that other members of the team were having such conversations.



*“I’m not sure whether everyone else has those conversations, I have that link, so I maybe feel more able to.” P3*

### *3.2 Family related barriers*

#### *Timing and preparation*

There was a sense that whilst family therapy is considered relevant to most people, when to offer this can be an issue, along with the need for preparation work.

*“I guess I’m not always completely sort of clear, sometimes I might be a bit too pre-emptive in thinking about therapy, sometimes I might be a little bit too early referring people in without necessarily preparing the person for the idea of that more.” P3*

*“I think there might be some family situations where there might be in some sense a lot of strain already a lot of pressure already and maybe having quite fixed views about what the problem is...they may not see it as being a family issue. So they could be very inflexible about that, even with information or interest... that might be something about timing.” P5*

#### *Resistance from families*

Participants also spoke about there sometimes being resistance from families, with it suggested that family therapy may be something which service users and families can find difficult to understand.

*“I realised there was quite a lot of resistance from some people when you talk about the idea of someone coming in and having their family sit round and talk about them. There’s a real resistance... you’re trying to present something which is quite a foreign thing for them, for service users and their family as well.” P4*

*“And I think it’s difficult to explain to people what its about really, it can be very difficult to explain what the purpose and the aim might be, what might*

*be helpful. Because I think people find it hard to imagine what that is, without concrete examples.” P2*

#### *Care co-ordinator lack of knowledge*

It was suggested that this barrier was compounded by care-coordinators not having sufficient knowledge and confidence in the approach to discuss this with service users.

*“There is still a culture in the team of working with individuals and possibly sometimes a lack of awareness around families and family dynamics... a lack of knowledge about what that would mean for a family. That initial conversation so they know what it might involve, how it might come out and how it fits with what’s going on.” P1*

### ***Theme 4: Suggestions and solutions***

#### *4.1 Information and presence*

In line with themes of invisibility and carving out a place for family therapy, it was suggested that it would be helpful to establish more of a presence for family therapy, including information about the service and the types of difficulties and dynamics they work with in the FaCT service.

*“I guess it’s more raising the profile in the sense of making people aware that that’s a treatment option that’s available for people. Maybe including criteria, to say this is what we would definitely work with... Actually really breaking that down for people, because I think, like I say, because we’re completely pummeled NICE recommended, NICE recommended, then actually where’s the room for other stuff in that.” P4*

*“Yeah probably some information or some conversation or dare I say it, a training session, on understanding what goes on in family therapy.” P1*

There was suggestion that this would facilitate introducing the approach to families.

*‘Any local community services, they come and meet with us in our team meetings sometimes and then people go ‘oh yes, that’s in my mind now, I know that exists. They might have known about it but forgotten, it’s just having that current really, and just sort of refreshing really that these are the kind of people that we can really work with and this is what we would talk through.’ P1*

#### *4.2 Support in ‘bridging the gap’*

In line with this, other participants suggested ways of ‘bridging the gap’ between the FaCT team and recovery teams. One suggestion was around joint working and someone from the FaCT team meeting with the family in order to ‘dispel some of the myths’ around family work:

*‘So, I guess from a care co-ordinator point of view you would want them to come out with you, meet the family, talk through what the options are, talk through what the expectations are, ... Sometimes when people have got a real barrier about doing some therapy, it’s really helpful for them to meet the people that do it so that they can dispel some of the myths.’ P2*

Other participants suggested that being able to observe family therapy allowed them to gain a sense of what this involves, which encouraged them to hold the team in mind:

*‘I sat in on some of the FaCT assessments, that sort of reinforces, plans my thoughts about when to refer someone and how it might benefit them.’ P3*

*‘I’d quite like to observe some family therapy and I did a little bit when I was doing my nurse training, but it was quite limited really. It would be good to have it more in the forefront, because I think it should be.’ P1*

#### *4.3 More formal forum for discussion and referral*

Several participants suggested that having a regular supervision session, as a forum for discussion and hearing about cases would be helpful:

*‘The FaCT team are approachable. I don’t know whether there’s a monthly kind of supervision group where staff could go to discuss cases. We do that,*

*not necessarily for the FaCT, we do it generally for therapy, but I suppose something like that could be quite useful.” P4*

*“You’ve got so much going on your case load... But I suppose if there was a forum, where you can go to discuss how to refer in and what they might be able to offer, it might make people think, yes that’s what I need to do. Holding it in mind and also knowing if it’s the right thing to refer to.” P3*

## **Discussion**

This project aimed to explore referrals to the Family and Couples Therapy service using a mixed-methods approach, with a view to increasing referrals. Audit of referral data showed that referrals are received for service users who present with a range of difficulties and diagnoses. This is in line with guidelines and evidence for the effectiveness of systemic therapy across a range of difficulties (Carr; 2014; Stratton, 2016; NICE, 2009).

Qualitative interviews were used to further explore the views of potential referrers to the service (N = 5). As described above, an overarching theme was the importance and value in thinking and working systemically. It was apparent that those interviewed also used systemic thinking and family intervention within their work and that family therapy was felt to offer something unique, but complementary to the role of the care co-ordinator. The sub-theme of the role of the family in an individual’s difficulties is very much in line with systemic theory which proposes that in order to understand an individual and their behaviours and difficulties, we must understand the system around the individual (Bateson, 1972).

Family therapy was felt to be an underused resource, in line with the wider literature (Lebow, Chambers, Christensen & Johnson, 2012). However the findings of this project, particularly the qualitative element go beyond this observation, exploring why in this context this is the case. A number of challenges associated with referring to the FaCT service were discussed. Service user related challenges included service users and families not being on board with family therapy or understanding the rationale for it. This is supported by the wider literature which

presents this as a challenge in implementing systemic therapies and services (Burbach & Stanbridge, 2006).

This finding is in contrast to what has been found in previous research on the implementation of family therapy, where a lack of appropriate families has been reported, with this suggested to be related to perceptions of professionals as to who might be appropriate (Fadden, 1997; Spidel et al, 2006). In contrast, overall there was a sense that family therapy was relevant to the majority of care-coordinators caseloads. However, one of the subthemes emerging from the qualitative data was participants feeling they needed more information, knowledge and support around family therapy, in order to be able to discuss this with service users and refer appropriately. This echoes a need for information identified in family therapy literature (Berry & Haddock, 2008; Burbach & Stanbridge, 2006; Smith & Velleman, 2002). There were also queries as to whether family therapy would come under some service users' treatment pathways due to being unaware of it being recommended by NICE for some diagnoses. However, it was evident from both the qualitative and quantitative data, that reason for referral is often not related to an individual's diagnosis, but to family dynamic or other difficulties they are experiencing.

White (1997) proposes that the evidence base for psychological treatment itself is socially and culturally influenced, with the dominant discourse being based upon an interpretation of what is meaningful and useful in practice. Treatment guidelines such as NICE are one such discourse based upon an evidence-based approach. It is suggested its social and historical construction (Dopson, FitzGerald, Ferlie, Gabbay, & Locock, 2002; Wood, Ferlie, & Fitzgerald, 1998a, 1998b) influences both individual and group perception of evidence and, therefore, whether it is accepted or not (Rycroft-Malone et al., 2004). Whilst NICE guidelines were mentioned by a number of participants, there was more of a focus on the role of the family in an individual's difficulties and family dynamics and needs. However what did arise from the subtheme of where Family Therapy sits was a clear need for information about what the service provides, including distinctions between this and other approaches delivered by the service, e.g. Open Dialogue.

A number of solutions were discussed by participants, which mapped onto the perceived challenges and barriers to referring into the service. These included increased opportunities to learn about family therapy and what it involves, including through observation, training and discussion. The need for a more formal forum for discussion of possible cases and ways of working systemically also emerged. This is supported by evidence that team-based training and supervision is associated with changes in culture and practice for service development (Burbach et al, 2002; Stanbridge & Burbach, 2007; Berry & Haddock, 2008) and more efficacious than ‘passive dissemination of referral guidelines’ (Akbari et al, 2008, p. 40). The suggestion of group supervision is also in line with claims that staff support, and peer-support systems are important in the successful implementation of family work and encourage the valuing of this approach (Fadden, 2006).

The referrals data demonstrated that service users are referred for a range of different diagnoses and difficulties. This is in line with the qualitative sub-theme of ‘who might benefit from Family Therapy’, which suggested that interviewees regarded family therapy as relevant to the majority of their case load and talked more about dynamics that diagnoses. The qualitative themes build upon this data, enabling exploration of why, despite service users being referred for a range of difficulties, the service is not always used to capacity. This found that although there was sometimes a lack of awareness of where family therapy sits in terms of the evidence base and care pathways for service users, barriers were more service-related in terms of a need for information, education and a forum for discussion, rather than being based around team / practitioner discourses of who may be ‘appropriate’ for family therapy. As such, triangulation (Patton, 1990) between qualitative and quantitative methods was a strength of this study and enabled the specific challenges to be outlined and possible solutions explored. The findings of this project also highlight the need to remain open and curious when carrying out service development and research, akin to the approach taken in systemic therapy. The findings highlight a number of areas for development, which have the potential to improve the FaCT service and ensure that it is used to capacity through consistent appropriate referrals.

## **Limitations**

Although all members of the relevant teams were invited to take part in interviews, the sample ultimately consisted of those who were interested and / or willing to be interviewed. Interviews showed that participants had a range of experience of referring in, however it is possible that those willing to take part had more positive views of the FaCT team and / or systemic therapy which may have biased the findings. Indeed all of those interviewed saw a value in systemic therapy and this may not be the case for all members of the team. Similarly, links were made between particular professional backgrounds, e.g. social work, and training i.e. Open Dialogue and may not be representative to those with different professional backgrounds. Furthermore, the systemic clinic representative in the service is trained in both Open Dialogue and Systemic Therapy.

Whilst I was not known to the team, my association with the team and the commissioning of the project by the team, may have influenced the findings. Social desirability is problematic in qualitative research (Collins, Shattell & Thomas, 2005), and can introduce bias. Participants were aware that the findings would be fed back to the systemic clinic representative who was aware of who the participants were, having helped to recruit them. Members and staff may have been driven to present the project in a positive way therefore skewing the findings towards positive rather than negative experiences. However, a range of views were expressed in the interviews, with negative aspects and potential improvements also discussed.

Researcher bias is also a consideration, given my position as a Clinical Psychology trainee who values psychological intervention and a systemic approach, and may have impacted upon the findings of the study. In order to address this the findings were discussed with both C.B. and S.B, although both potentially biased towards valuing a systemic approach. The findings should be interpreted cautiously with the acknowledgement that they are a 'co-construction' (Hewitt, 2007) based upon context and characteristics of both myself and participants. This could have been addressed by having another researcher less invested in systemic therapy review the themes.

Steps were taken to ensure the rigour of the qualitative approach used within this project, in line with guidelines for conducting qualitative research. This included being explicit about the context and purpose of the study, with there being clear potential for contribution to knowledge, using appropriate methodology and outlining this, clarification of my position as the researcher and grounding the emerging themes in examples (Elliott, Fischer & Rennie, 1999). There are however a number of ways in which the rigour of work could have been enhanced. Whilst attempts were made to recruit a purposive sample, including varying experiences relating to the FaCT service, the sample size was small and appeared to be limited to those who saw value in systemic ways of working regardless of their experience of referring into the FaCT service. A larger sized sample including those who had varying opinions on a systemic approach and / or the service would have further allowed for data saturation. Furthermore, credibility checks of emergent themes and having data analysed independently by a number of researcher would have enhanced the rigour of the approach.

This evaluation is a case study of an individual service, the findings of which have important implications for service development. This design limits the extent to which the results can be generalised. However, given that the situation within the service is in many ways in line with the national picture, these findings are likely to be of interest to other services. The findings relating to challenges and solutions may also be relevant to the development of other projects and types of service in similar settings.

Based on the findings of this evaluation, recommendations were made and are shown in **Table 8**. It will be important in future to evaluate the impact of any implemented recommendations both from the perspective of members of the team and referral data.

**Table 8: Recommendations based on findings**

Recommendation	Rationale
A regular family / systemic therapy supervision slot	This would include the opportunity to discuss cases and potential referrals and address queries about the nature of family



	therapy. This would complement the existing informal discussions around referrals, in such a way that learning and knowledge can be shared with other members of the team. This will address some of the challenges around both visibility and knowledge.
Opportunities for observing family therapy or joint working	This would give care-coordinators a sense of what family therapy involves, which would enable more confident and productive conversations with service users and families around family therapy. This increased knowledge may lead to increased referral rates and uptake of the FaCT service.
Providing information and discussion around the evidence base for family therapy.	Information and training on family therapy and its evidence base would address the theme of carving out a place for family therapy.

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## **Executive Summary Main Research Project**

Chronic fatigue syndrome / Myalgic Encephalomyelitis (CFS/ME) is characterised by unexplained, severe disabling fatigue which is not alleviated by rest. Joint pain, sleep disturbances and cognitive difficulties are also commonly experienced (NICE, 2007). The cause and maintenance of CFS/ME continues to be poorly understood (Browne & Chalder, 2006). Although there is some evidence for the effectiveness of cognitive behavioural intervention in this population, outcomes are below par and lag behind those associated with cognitive behavioural treatment of psychological disorders such as anxiety (Olantunji et al, 2010). In line with this it is suggested that there is a need for research which focused on maintaining factors in a more individualised way. (Van Houdenhove & Luyten, 2008).

There is some overlap between anxiety disorders and CFS/ME and therefore looking to anxiety models with a view to trying to improve outcomes is appropriate.

The development of cognitive behavioural models of anxiety disorders to include concepts such as safety seeking behaviours (SSB) has led to significant advances in the theoretical understanding and treatment of such disorders (e.g., Salkovskis, Clark, Hackmann, Wells, & Gelder, 1999; Wells, Clark, Salkovskis, & Ludgate, 1995, Tang et al., 2007). Whilst there is some overlap between this concept and the fear avoidance model on which interventions for CFS/ME are currently based, to date SSB have not been empirically investigated in this condition.

With this in mind, the aim of this study was to investigate the use of safety-seeking behaviours (SSB) in CFS/ME in response to physical exertion. An experimental design was used with N = 10 individuals with CFS/ME and N = 15 healthy controls (HCs) carrying out a physical. A range of SSB were identified, with many of these subtle in nature. Significant differences on the number of strategies defined as SSB were found between groups, with the CFS/ME group using significantly more SSB. Although this study was limited by a small sample size, it provides novel evidence for the use of SSB in CFS/ME and conceptualises topology and function of such strategies, with SSB representing an important potential target for cognitive behavioural interventions for this condition.

# Connecting Narrative

The aim of this connecting narrative is to reflect on the process of developing and conducting the research aspect of training, as well as the implications for practice and key learning. Each of the key aspects of the research portfolio are discussed: case studies, main research project, literature review and service improvement project, as well as outlining my plans for research in the future.

## Case studies

I really valued the process of reflecting on the clinical work I have done. This also provided opportunity to engage more with the relevant literature, something which there has not always been sufficient time for. Planning and writing up my clinical work has also encouraged me to more carefully consider the use of outcome measures, having previously observed outcome measures often being used tokenistically or not at all within services. However, I have found measures to be more beneficial than anticipated, not only through measuring change but as a means of supporting conversations around symptoms and experiences. In addition, several service users I have worked with have also found the existence of a measure which assesses the symptoms they are experiencing extremely validating and reassuring.

One of the themes that has become most apparent to me throughout my clinical work, and which is highlighted by my case studies, is the importance of exploring the meaning of a service user's experience and capturing this within formulation and associated treatment. Related to this, it has also highlighted the importance of thorough assessment and formulation, and using the formulation to guide intervention, particularly where the evidence base may be limited. A good formulation has with most service users been a key part of intervention itself, as a means of making sense of and validating an individual's experiences.

I have come to appreciate the value of case studies, not only as a reflection of one's own work, but as an important way of contributing to the evidence base. I feel that this is extremely important, not only in driving developments where there is a lack of evidence, but also in providing an important level of detail which is often not

measured or reported by large scale trials. The themes of meaning and detail link my case studies with my main research project and systematic review.

### **Main Research Project**

I had originally wanted to carry out a project on predictors of Post Traumatic Growth (PTG) and Post Traumatic Stress due to my interest in this area. However, there were concerns from the research team in the Project Approval Session (PAS) over both the validity of the construct of PTG and the feasibility of recruiting a large number of participants with complex trauma making this project unrealistic.

I found out that Jo Daniels was interesting in supervising a project in Chronic Fatigue Syndrome (CFS), an area I had some familiarity and interest with due to having been a Research Assistant in a child and adolescent Chronic Fatigue Service. Following discussions with Jo, it was clear that there were several gaps in the CFS/ME literature, including the relevance of the Safety Seeking Behaviour (SSB) construct to this condition. The prospect of investigating this underdeveloped area was really exciting. I explored a number of methodologies for investigating this topic, before deciding to replicate an experimental study of SSB in a related condition, chronic pain. Having carried out experimental studies as part of my PhD I was keen to do further experimental research rather than a questionnaire study.

I ensured there was a lot of PPE involvement in the piloting and development of the study and materials, which was really valuable in refining both the task and information on the study. The task and equipment were piloted by members of the public at the University of Bath Anniversary event, whilst Meline Soukiassian, service user representative for the Bristol CFS/ME service helped me to develop the study information and other aspects.

Although I was familiar with the NRES system from prior applications, it took a significant period of time to develop a protocol and application approved by everyone involved. It was very useful to have the input and expertise of both supervisors, and managers within the CFS/ME service. However addressing



different viewpoints and priorities was a challenge and set me back considerably in terms of timescales.

I was hoping to gain ethical approval prior to the end of summer of second year, in order to be able to recruit and test over summer on study days. Due to this time pressure, I decided to submit my ethics application to a research ethics panel who had a reputation of being quite challenging. This turned out to be fine and the ethics meeting which I attended went well. However, despite there being few required amendments, the committee were slow to respond to these. More significantly in terms of set-backs was obtaining R&D approval from the NHS Trust following REC ethics approval. Despite repeated efforts to chase this up, via emails and phone calls, this took months to arrive and was extremely frustrating.

Whilst waiting for this approval, I gained university approval to begin to recruit healthy controls (HCs). This was extremely encouraging, as I got a good response from individuals who were interested in taking part. Recruitment of the CFS/ME group however turned out to be a rather different story. My main source of recruitment was the Bristol CFS/ME service, where I attended a number of Foundation Meetings, a psycho-educational group for patients who had been newly referred to the service. This was challenging in itself as the group took place on teaching days so most of my attendance here was restricted to annual leave, enabling me to attend the group five times to promote the study. Where I wasn't able to attend, my field supervisor Flora spoke about the study and the Bath CFS/ME service kindly agreed to advertise the study through posters in their waiting room. However, my personal presence at the meetings had a significant impact on encouraging more people to sign up. This procedure of attending the Foundation meetings was an effective but resource-intensive way to recruit, particularly as and many of those expressing interest did not end up taking part. It was also apparent from speaking to people that travel, time and energy spent coming along to take part in a study were significant barriers. I also had a number of last-minute cancellations.

Due to the unexpectedly slow recruitment rates, I broadened my recruitment strategy, and applied for a substantial amendment through the REC to recruit CFS/ME participants through social media and the university recruitment systems, something that had worked well with healthy controls. . The response to this was

huge, but unfortunately this caused significant and unforeseen difficulties. Over the course of three days I was inundated by emails from individuals with CFS/ME about the study, the details of which it seemed had been shared by patient groups, including internationally. Emails ranged from those politely asking for clarification around the aims and methods of the study, to those expressing anger and outrage at the study and misinterpretations of the study suggesting we believed CFS/ME to be a psychological and not physical condition. This resulted in involvement of the University Press Office, with a statement released and responses sent to clarify our position and the aims and rationale for the study. However, it also meant that the study advertisement had to be taken down. A decision was also made to cease recruitment to the study, given that it was not possible to tell whether any further requests to take part in the study were from individuals genuinely wanting to participate in the study.

In hindsight, carrying out an experimental study alongside the other aspects of the doctorate and in an area with a notoriously difficult to recruit population was somewhat ambitious. Originally I had planned to recruit 40 participants with CFS/ME and 20 HCs. However, it quickly became apparent that this was not feasible. Having to stop recruitment to the study early meant that I ended up with 10 participants with CFS/ME and 15 healthy controls. This has inevitably shaped the analyses I have been able to carry out. However, whilst the project did not go according to the original plan, this was despite considerable effort both on my part and my supervisors and despite this, I feel that the more in-depth consideration of a smaller number of participants still has meaningful and clinically-relevant implications.

Despite the trials and tribulations of this project, I have learned a lot from it. It has further highlighted for me the challenges of carrying out research with this particular client group, something which is well established. It has shown me the power of social media, something which in future I will both consider managing when advertising in this way in future as well as attempting to capitalize on positively if carrying out research with different populations. The negative backlash from the study has helped me to reflect on why CFS/ME is such an under-researched area. It was difficult to hear stories of so many people who have felt let-down and

left disillusioned and critical of research and treatment. I feel that this has much to do with how CFS/ME have been conceptualized in the past, but I find it frustrating that this is potentially holding back research into treatments that have been found to be beneficial but require further development. Whilst it has been difficult to carry out research in this area, I am glad that I have been able to make some small contribution and I am really grateful to the service users who have taken part and also shared their stories with me. Discussions with participants in the HC group have also demonstrated that there is increasing understanding and interest in this condition amongst the general public.

In common with reflections on my other projects, this project highlighted the reality of conducting research in clinical practice alongside competing demands and of carrying out research when not embedded in a team. What I have perhaps found most frustrating is the process of ethical approval, which at times felt slow and inefficient to the degree where it could be discouraging to individuals wishing to conduct research particularly alongside active clinical practice. Overall this project has been extremely testing but in addition to the learning points outlined, has taught me patience, adaptability and resilience.

### **Systematic Review**

I originally planned to carry out a systematic review on mindfulness in bipolar disorder. This was based on wanting to increase my knowledge of bipolar disorder, and a strong interest in mindfulness. However, having had my proposal approved, about to register this on Prospero and begin carrying out the review, another systematic review was published which was too similar to make my review meaningful. I used this as an opportunity to carry out a review on a topic related to my main research project: the relevance of Safety Seeking Behaviours across physical health conditions. From my reading for my main project, this appeared to be a relevant topic with potentially important implications for clinical practice in an area where intervention outcomes lag behind those in psychological health. I am grateful for having had the opportunity to gain a greater depth of knowledge in this area, through carrying out my main research and systematic review on similar topics.

Having carried out systematic reviews previously, I knew how arduous the process of can be but felt confident in the methodology. However, I found this review challenging at times, mainly due to vagueness in how the construct was described within different studies. This made it difficult to synthesise the studies in a meaningful way in order to develop a clear narrative. However it also highlighted the importance of this review in helping to conceptualize and operationalize SSB in physical health conditions, which has important implications for both further research and practice.

As many of the included studies were conceptual or case studies, this review again emphasised for me the importance of practice-based evidence and the value of case studies and clinical experience in driving new developments and the evidence base.

### **Service Improvement Project**

I initially developed a proposal around improving appropriate referrals in a secondary mental health team. This idea came about from an obvious service improvement need whilst on my first placement within a Psychological Therapies Team. This idea was supported and developed with my placement supervisor Chris Gillmore and university supervisor Ailsa Russell. However, when I presented the idea at the Project Approval Session, it was suggested that the project wasn't appropriate due to not having enough of a patient focus. It was proposed that the project was changed to focus more upon the patient experience of shared decision making around referrals. Having taken this back to my field supervisor and the team, they expressed that unfortunately they would not be able to support the project, given that it did not reflect what was needed in the service. This was extremely frustrating, particularly given that the idea had come from a real service improvement need within the service. But, once again, it was back to the drawing board.

I met with Catherine Butler as she had some ideas around systemic related service improvement projects. The Family and Couples' Therapy service which sits in a local PTS service, was having challenges relating to not being used to capacity

and was interesting in exploring how this could be addressed. Although quite similar to my previous proposal topic, this project was given the go-ahead. The project involved carrying out interviews with potential referrers into the service, in order to gain their views on who was appropriate to refer to the service and their experiences of referring. This was alongside an audit of referral data to investigate how this compared to the evidence base and guidelines for systemic therapy.

I tried a number of approaches to recruiting potential referrers to take part in interviews including attending several different team meetings to talk about the project and, on the suggestion of the service managers, spending time within the services and trying to catch people when they had some spare time. However, neither of these approaches were fruitful. My field supervisor, Stu Brooke, explained that that it was a very busy time for the services and therefore best to postpone data collection until things had settled down a bit. In the end, I managed to interview five potential referrers through Stu identifying and approaching relevant individuals and me contacting them to arrange specific times. This highlighted for me the challenges of carrying out research where the researcher is not embedded in the team and the importance of support from managers to gain “buy-in”, both of which I will consider in future research.

I really enjoyed the process interviewing and meeting with members of the teams to hear their views. I found it extremely interesting approaching this project from the position of a ‘scientist-practitioner’ when previously I had carried out qualitative interviews from a researcher perspective. I found that this influenced the way my thinking and what I was interested in / paid attention to, which has been really useful to reflect on and highlights the co-constructed nature of qualitative research. The project has felt very meaningful, in that there are clear and feasible recommendations which can be fed back to the service, which is extremely rewarding. The plan is to now present the findings to the service managers. This project enabled me to reflect on some of the barriers to implementing evidence-based interventions and how some of these might be addressed. This project also highlighted for me the importance of remaining curious and open in carrying out research, stances which are both emphasised by systemic theory and practice. Whilst there were prior conceptions – based on the perspectives of the FaCT team and the

existing literature – that barriers were likely to be related to potential referrers' views of who was appropriate to refer to family therapy, what became apparent was that service-related factors were more of a barrier. It is interesting that during the development of this project, the situation had changed, with the FaCT service developing a waiting list. However, I feel that the project continues to have important implications in terms of encouraging appropriate referrals and supporting the perceived value of systemic therapy in this setting.

### **Future Aspirations**

Having had a strong background in research prior to training, I am keen to continue to include research as part of my future career. I have been surprised by how difficult I have found this aspect of the course and this process has made me aware of the challenges of carrying out research alongside clinical practice and competing demands. As such it has given me an appreciation of the importance of using smaller scale research opportunities such as case studies and cases series to meaningful contribute to the evidence base. It has made me aware that in future it will be important to carefully agree, plan and protect time for research when I have the opportunity to. It has also emphasised the value of developing a culture in teams of supporting relevant research, which is something that I intend on taking forward as a qualified Clinical Psychologist.

## Acknowledgements

Firstly I would like to thank my academic supervisors Dr. Jo Daniels and Dr Catherine Butler for your thoughtful ideas and input into my projects, for your support, encouragement and not least, patience. Thank you especially to Jo for going above and beyond in your commitment and investment in my projects. Thank you for doing this with warmth and humour. Thanks also to my field supervisors Dr Flora Wilson and Dr Stu Brooke for your support in developing, setting up and running the projects. Special thanks also to my Clinical Tutor, Dr Liz Marks: your support, genuineness and compassion have helped me through the ups and downs of the course. Thank you to everyone who took part in my research and service improvement projects, particularly the service users. I hope that this makes some small contribution to improving treatments.

Thank you to all of my placement supervisors: Dr Chris Gillmore, Dr Suzanne Davis, Dr Anne Booth, Dr Kate Anslow, Dr Clive Weston, Dr Sadie Thomas-Unsworth, Dr Mary Griggs and Dr Lisa O’Leary. I have learned so much from each of you, your expertise, support and encouragement have enabled me to grow so much both professionally and personally. Thank you also to all of my colleagues, some of whom have become friends.

Thank you to all of the service-users I have worked with, from whom I have learned so much about life, strength and resilience and who have constantly reminded me of why I was doing this.

To my fellow trainees who have become great friends, thank you for your advice and support, but mostly for your friendship and for the fun and laughter over the past three years. It has been a pleasure training with you.

Thank you to my family, especially my parents Dawn and Vince, for giving me ‘my roots and my wings’, for not questioning my decision to do ‘another doctorate’ and for your constant support and encouragement.

Finally, thank you to Francesco: my editor, chef, counsellor, motivator, inspiration, adventure-buddy, biggest supporter and best friend. Thank you for believing in me even when I haven't believed in myself, for filling my life with so much joy and reminding me what is important. I couldn't have done this without you.



## **APPENDICES**

## **Literature review appendices**

## Appendix A – Author guidelines

Health Psychology Review – submission guidelines

### Preparing Your Paper

#### Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

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#### References

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An EndNote output style is also available to assist you.

#### Checklist: What to Include

1. Author details. All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors’ affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.
2. Should contain an unstructured abstract of 200 words.
3. You can opt to include a video abstract with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.
4. Between 3 and 6 keywords. Read making your article more discoverable, including information on choosing a title and search engine optimization.

5. Funding details. Please supply all details required by your funding and grant-awarding bodies as follows:

For single agency grants

This work was supported by the [Funding Agency] under Grant [number xxxx].

For multiple agency grants

This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].

6. Disclosure statement. This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. Further guidance on what is a conflict of interest and how to disclose it.

7. Data availability statement. If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s).

Templates are also available to support authors.

8. Data deposition. If you choose to share or make the data underlying the study open, please deposit your data in a recognized data repository prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.

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At the point of submission, you will be asked if there is a data set associated with the paper. If you reply yes, you will be asked to provide the DOI, pre-registered DOI, hyperlink, or other persistent identifier associated with the data set(s). If you have selected to provide a pre-registered DOI, please be prepared to share the reviewer URL associated with your data deposit, upon request by reviewers.

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The VoR is the article in its final, definitive and citable form (this may not be immediately paginated, but is the version that will appear in an issue of the journal). Both the AMO version and VoR can be cited using the same DOI (digital object identifier). To ensure rapid publication, we ask you to return your signed publishing agreement as quickly as possible, and return corrections within 48 hours of receiving your proofs.

## Appendix B – Copy of Cochrane Collaboration’s tool for assessing risk of bias

Domain	Support for judgement	Review authors’ judgement
<i>Selection bias.</i>		
<b>Random sequence generation.</b>	Describe the method used to generate the allocation sequence in sufficient detail to allow an assessment of whether it should produce comparable groups.	Selection bias (biased allocation to interventions) due to inadequate generation of a randomised sequence.
<b>Allocation concealment.</b>	Describe the method used to conceal the allocation sequence in sufficient detail to determine whether intervention allocations could have been foreseen in advance of, or during, enrolment.	Selection bias (biased allocation to interventions) due to inadequate concealment of allocations prior to assignment.
<i>Performance bias.</i>		
<b>Blinding of participants and personnel</b> <i>Assessments should be made for each main outcome (or class of outcomes).</i>	Describe all measures used, if any, to blind study participants and personnel from knowledge of which intervention a participant received. Provide any information relating to whether the intended blinding was effective.	Performance bias due to knowledge of the allocated interventions by participants and personnel during the study.
<i>Detection bias.</i>		
<b>Blinding of outcome assessment</b> <i>Assessments should be made for each main outcome (or class of outcomes).</i>	Describe all measures used, if any, to blind outcome assessors from knowledge of which intervention a participant received. Provide any information relating to whether the intended blinding was effective.	Detection bias due to knowledge of the allocated interventions by outcome assessors.
<i>Attrition bias.</i>		
<b>Incomplete outcome data</b> <i>Assessments should be made for each main outcome (or class of outcomes).</i>	Describe the completeness of outcome data for each main outcome, including attrition and exclusions from the analysis. State whether attrition and exclusions were reported, the numbers in each intervention group (compared with total randomized participants), reasons for attrition/exclusions where reported, and any re-inclusions in analyses performed by the review authors.	Attrition bias due to amount, nature or handling of incomplete outcome data.
<i>Reporting bias.</i>		
<b>Selective reporting.</b>	State how the possibility of selective outcome reporting was examined by the review authors, and what was found.	Reporting bias due to selective outcome reporting.
<i>Other bias.</i>		
<b>Other sources of bias.</b>	State any important concerns about bias not addressed in the other domains in the tool. If particular questions/entries were pre-specified in the review’s protocol, responses should be provided for each question/entry.	Bias due to problems not covered elsewhere in the table.

## **Main Research Project appendices**



## Appendix C – Author instructions

### Article structure

#### *Subdivision - unnumbered sections*

Divide your article into clearly defined sections. Each subsection is given a brief heading. Each heading should appear on its own separate line. Subsections should be used as much as possible when cross-referencing text: refer to the subsection by heading as opposed to simply 'the text'.

#### *Appendices*

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

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- **Corresponding author.** Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. This responsibility includes answering any future queries about Methodology and Materials. **Ensure that the e-mail address is given and that contact details are kept up to date by the corresponding author.**
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#### *Abstract*

A concise and factual abstract is required with a maximum length of 200 words. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself.

#### *Graphical abstract*

Although a graphical abstract is optional, its use is encouraged as it draws more attention to the online article. The graphical abstract should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide

readership. Graphical abstracts should be submitted as a separate file in the online submission system. Image size: Please provide an image with a minimum of 531 × 1328 pixels (h × w) or proportionally more. The image should be readable at a size of 5 × 13 cm using a regular screen resolution of 96 dpi. Preferred file types: TIFF, EPS, PDF or MS Office files. You can view Example Graphical Abstracts on our information site.

Authors can make use of Elsevier's Illustration Services to ensure the best presentation of their images and in accordance with all technical requirements.

### ***Highlights***

Highlights are mandatory for this journal. They consist of a short collection of bullet points that convey the core findings of the article and should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point). You can view example Highlights on our information site.

### ***Keywords***

Immediately after the abstract, provide a maximum of 6 keywords, to be chosen from the APA list of index descriptors. These keywords will be used for indexing purposes.

### ***Abbreviations***

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

### ***Acknowledgements***

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

### ***Formatting of funding sources***

List funding sources in this standard way to facilitate compliance to funder's requirements:

Funding: This work was supported by the National Institutes of Health [grant numbers xxxx, yyyy]; the Bill & Melinda Gates Foundation, Seattle, WA [grant number zzzz]; and the United States Institutes of Peace [grant number aaaa].

It is not necessary to include detailed descriptions on the program or type of grants and awards. When funding is from a block grant or other resources available to a university, college, or other research institution, submit the name of the institute or organization that provided the funding.

If no funding has been provided for the research, please include the following sentence:

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

### ***Shorter communications***

This option is designed to allow publication of research reports that are not suitable for publication as regular articles. Shorter Communications are appropriate for articles with a specialized focus or of particular didactic value. Manuscripts should be between 3000-5000 words, and must not exceed the upper word limit. This limit includes the abstract, text, and references, but not the title page, tables and figures.

## **Artwork**

## ***Electronic artwork***

### *General points*

- Make sure you use uniform lettering and sizing of your original artwork.
- Embed the used fonts if the application provides that option.
- Aim to use the following fonts in your illustrations: Arial, Courier, Times New Roman, Symbol, or use fonts that look similar.
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A detailed guide on electronic artwork is available.

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TIFF (or JPEG): Color or grayscale photographs (halftones), keep to a minimum of 300 dpi.

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- Supply files that are optimized for screen use (e.g., GIF, BMP, PICT, WPG); these typically have a low number of pixels and limited set of colors;
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- Submit graphics that are disproportionately large for the content.

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Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules and shading in table cells.

## **References**

### ***Citation in text***

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full.

Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results'

or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

### ***Web references***

As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

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This journal encourages you to cite underlying or relevant datasets in your manuscript by citing them in your text and including a data reference in your Reference List. Data references should include the following elements: author name(s), dataset title, data repository, version (where available), year, and global persistent identifier. Add [dataset] immediately before the reference so we can properly identify it as a data reference. The [dataset] identifier will not appear in your published article.

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Most Elsevier journals have their reference template available in many of the most popular reference management software products. These include all products that support Citation Style Language styles, such as Mendeley and Zotero, as well as EndNote. Using the word processor plug-ins from these products, authors only need to select the appropriate journal template when preparing their article, after which citations and bibliographies will be automatically formatted in the journal's style. If no template is yet available for this journal, please follow the format of the sample references and citations as shown in this Guide. If you use reference management software, please ensure that you remove all field codes before submitting the electronic manuscript. More information on how to remove field codes.

Users of Mendeley Desktop can easily install the reference style for this journal by clicking the following link:

<http://open.mendeley.com/use-citation-style/behaviour-research-and-therapy>

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### ***Reference style***

*Text:* Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Sixth Edition, ISBN 978-1-4338-0561-5, copies of which may be ordered online or APA Order Dept., P.O.B. 2710, Hyattsville, MD 20784, USA or APA, 3 Henrietta Street, London, WC3E 8LU, UK.

*List:* references should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters 'a', 'b', 'c', etc., placed after the year of publication.

*Examples:*

Reference to a journal publication:

Van der Geer, J., Hanraads, J. A. J., & Lupton, R. A. (2010). The art of writing a scientific article. *Journal of Scientific Communications*, 163, 51–59.

Reference to a book:

Strunk, W., Jr., & White, E. B. (2000). *The elements of style*. (4th ed.). New York: Longman, (Chapter 4).

Reference to a chapter in an edited book:

Mettam, G. R., & Adams, L. B. (2009). How to prepare an electronic version of your article. In B. S. Jones, & R. Z. Smith (Eds.), *Introduction to the electronic age* (pp. 281–304). New York: E-Publishing Inc.

Reference to a website:

Cancer Research UK. Cancer statistics reports for the UK. (2003).

<http://www.cancerresearchuk.org/aboutcancer/statistics/cancerstatsreport/> Accessed 13 March 2003.

Reference to a dataset:

[dataset] Oguro, M., Imahiro, S., Saito, S., Nakashizuka, T. (2015). *Mortality data for Japanese oak wilt disease and surrounding forest compositions*. Mendeley Data, v1. <https://doi.org/10.17632/xwj98nb39r.1>.

Reference to a conference paper or poster presentation:

Engle, E.K., Cash, T.F., & Jarry, J.L. (2009, November). The Body Image Behaviours Inventory-3: Development and validation of the Body Image Compulsive Actions and Body Image Avoidance Scales. Poster session presentation at the meeting of the Association for Behavioural and Cognitive Therapies, New York, NY.

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This journal encourages and enables you to share data that supports your research publication where appropriate, and enables you to interlink the data with your published articles. Research data refers to the results of observations or experimentation that validate research findings. To facilitate reproducibility and data reuse, this journal also encourages you to share your software, code, models, algorithms, protocols, methods and other useful materials related to the project. Below are a number of ways in which you can associate data with your article or make a statement about the availability of your data when submitting your manuscript. If you are sharing data in one of these ways, you are encouraged to cite the data in your manuscript and reference list. Please refer to the "References" section for more information about data citation. For more information on depositing, sharing and using research data and other relevant research materials, visit the research data page.

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If you have made your research data available in a data repository, you can link your article directly to the dataset. Elsevier collaborates with a number of repositories to link articles on ScienceDirect with relevant repositories, giving readers access to underlying data that gives them a better understanding of the research described. There are different ways to link your datasets to your article. When available, you can directly link your dataset to your article by providing the relevant information in the submission system. For more information, visit the database linking page. For supported data repositories a repository banner will automatically appear next to your published article on ScienceDirect.

In addition, you can link to relevant data or entities through identifiers within the text of your manuscript, using the following format: Database: xxxx (e.g., TAIR: AT1G01020; CCDC: 734053; PDB: 1XFN).

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This journal supports Mendeley Data, enabling you to deposit any research data (including raw and processed data, video, code, software, algorithms, protocols, and methods) associated with your manuscript in a free-to-use, open access repository.

Before submitting your article, you can deposit the relevant datasets to *Mendeley Data*. Please include the DOI of the deposited dataset(s) in your main manuscript file. The datasets will be listed and directly accessible to readers next to your published article online.

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To foster transparency, we encourage you to state the availability of your data in your submission. This may be a requirement of your funding body or institution. If your data is unavailable to access or unsuitable to post, you will have the opportunity to indicate why during the submission process, for example by stating that the research data is confidential. The statement will appear with your published article on ScienceDirect. For more information, visit the Data Statement page.

## Appendix D – University ethics approval

Ethics 17-242 Approved

 DELETE  REPLY  REPLY ALL  FORWARD 



Nathalia Gjersoe

Fri 13/10/2017 11:36

Mark as unread

To:  Samantha Lloyd;

Cc:  Jo Daniels;

 You replied on 05/02/2018 13:57.

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Dear Samantha,

**Ethics code 17-242 Cognitive and behavioural responses to physical exertion in Chronic Fatigue Syndrome/Myalgic Encephalomyelitis**

I am happy to confirm that you have received full ethical approval from the University of Bath Department of Psychology Ethics Committee for your application. In light of the fact that this project has previously received ethical approval from the NHS, this approval has been granted via Chair's Action. Please use the code 17-242 as proof of ethical approval on internal documentation.

Best of luck with your research,  
Dr. Nathalia Gjersoe  
Chair, Psychology Ethics Committee



## Appendix E – University ethics approval amendment

17-242 Amendment approved

← REPLY   ← REPLY ALL   → FORWARD   ⋮



psychology-ethics

Wed 28/03/2018 10:05

Inbox

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To:  Samantha Lloyd;

[Message Header Analyzer](#)

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Dear Samantha,

Thank you for letting us know about this amendment. I am happy to confirm that you have received full ethical **approval**, via Chair's Action. Your file will be updated to include these changes.

Best of luck with your research,  
Dr. Nathalia Gjersoe  
Chair, Psychology Ethics Committee

## Appendix F – REC Favourable opinion substantial amendment



### South West - Central Bristol Research Ethics Committee

Whitefriars  
Level 3, Block B  
Lewin's Mead  
Bristol BS1 2NT  
Email: nrescommittee.southwest-bristol@nhs.net

**Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.**

19 March 2018

Dr Samantha Lloyd  
Department of Clinical Psychology  
10 West University of Bath  
Bath  
BA27AY

Dear Dr Lloyd

<b>Study title:</b>	<b>Cognitive and behavioural responses to physical exertion in Chronic Fatigue Syndrome / Myalgic Encephalomyelitis</b>
<b>REC reference:</b>	<b>17/SW/0163</b>
<b>Protocol number:</b>	<b>N/A</b>
<b>Amendment number:</b>	<b>1.0,</b>
<b>Amendment date:</b>	<b>19 February 2018</b>
<b>IRAS project ID:</b>	<b>225160</b>

The above amendment was reviewed at the meeting of the Sub-Committee held in March 2018 by the Sub-Committee in correspondence.

#### **Ethical opinion**

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### **Approved documents**

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Social media advertisement script]		16 March 2018
Copies of advertisement materials for research participants [University recruitment study information]		16 March 2018
Notice of Substantial Amendment (non-CTIMP)	1.0,	19 February 2018
Other [Sponsor's letter ]		08 March 2018
Research protocol or project proposal [Protocol]	2.5	19 February 2018

### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

### Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

<b>17/SW/0163:</b>	<b>Please quote this number on all correspondence</b>
--------------------	---

Yours sincerely



**Dr Julie Woodley**  
**Chair**

E-mail: [nrescommittee.southwest-bristol@nhs.net](mailto:nrescommittee.southwest-bristol@nhs.net)

*Enclosures: List of names and professions of members who took part in the review*

*Copy to: Ms Helen Lewis-White, North Bristol NHS Trust  
Dr Samantha Lloyd*

### South West - Central Bristol Research Ethics Committee

#### Attendance at Sub-Committee of the REC meeting on in March 2018

#### Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mrs Liz McCullagh	Clinical Trials Pharmacist	Yes	
Dr Julie Woodley	Senior Lecturer/ Chair of Faculty Ethics Committee	Yes	

## Appendix G – R&D Access approval

Letter of Access 1

North Bristol   
NHS Trust

Employment Services  
Frenchay Beckspool Building  
Frenchay Park Road  
Bristol BS16 1LE

Tel: 0117 4145963

Email [jane.broughton@nbt.nhs.uk](mailto:jane.broughton@nbt.nhs.uk)  
Web: [www.nbt.nhs.uk](http://www.nbt.nhs.uk)

27 November 2017

Private and Confidential

Miss Samantha Lloyd  
Top Floor Flat  
18 Hampton Road  
Bristol  
BS6 6HL

Dear Miss Lloyd

**Letter of access for research**

**Title of Study: A pilot study investigating cognitive and behavioural responses to physical exertion in Chronic Fatigue Syndrome/Myalgic Encephalomyelitis**  
**Study Number: 4040**

This letter confirms your right of access to conduct research through North Bristol NHS Trust for the purpose and on the terms and conditions set out below. The right of access commences on 27 November 2017 and ends on 4 October 2018 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from North Bristol NHS Trust (R & D approval). Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from the Trust's R & D office giving permission to commence the project.

The information supplied about your role in research at North Bristol NHS Trust has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to North Bristol NHS Trust premises. You are not entitled to any form of payment or access to other benefits provided by us to employees and this letter does not give rise to any other relationship between you and North Bristol NHS Trust, in particular that of an employee.

While undertaking research through North Bristol NHS Trust, you will remain accountable to your employer but you are required to follow the reasonable instructions of your nominated research manager in the Trust or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.



Frank Collins  
Chair

A University of Bristol Teaching Trust  
A University of the West of England Teaching Trust



Andrea Young  
Chief Executive

You must act in accordance with North Bristol NHS Trust policies and procedures, which are available to you upon request, and the Research Governance Framework. You are required to co-operate with North Bristol NHS Trust in discharging its duties under the Health and Safety at Work Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on North Bristol NHS Trust premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged; I enclose a form in order that you can access an NBT Identity Badge. Please ask the appropriate NBT Manager/Research link person to sign this form and liaise with security as necessary. Please note that North Bristol NHS Trust accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

North Bristol NHS Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport/External Researcher Information Form (ERIF) changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in North Bristol NHS Trust.

**If you have any queries about the arrangements for research please contact Angelo Micciche, Research Infrastructure Manager (0117 3238601) in the first instance.**

Yours sincerely

  
 PP Emma Vallis  
 Team Leader

Copy: Angelo Micciche, Research Infrastructure Manager, Floor 3, Learning & Development, NBT,  
 Southmead  
 Alan Taylor, Taunton & Somerset NHS Foundation Trust

Enc



Frank Collins  
 Chair

A University of Bristol Teaching Trust  
 A University of the West of England Teaching Trust



Andrea Young  
 Chief Executive

## Appendix H – Participant information sheet: CFS

IRAS Ref: 225160  
Version number: 1.5  
08/09/17

### INFORMATION SHEET FOR PARTICIPANTS



**Title of study:** Responses to physical exertion in Chronic Fatigue Syndrome / Myalgic Encephalomyelitis

**Name of researcher:** Samantha Lloyd

We would like to invite you to participate in this postgraduate research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. We would really appreciate your involvement as this study will help to improve our understanding of chronic fatigue and may help us to modify or develop future treatments.

#### What is the purpose of the study?

- Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) is a condition defined by a marked loss of energy on physical or mental exertion. The cause of this illness is not yet fully understood.
- The purpose of this study is to look at how people with CFS/ME respond when asked to do a physically exerting task, and what thoughts and feelings they have while doing the task.
- Similar research has been done in chronic pain and has helped to improve treatment. We are therefore hoping to do the same in CFS/ME.

#### Why have I been invited?

You received a copy of this information sheet because you have recently attended the Bristol CFS /ME service and you have a diagnosis of CFS/ME. We would like to know how people with CFS/ME respond to a physically exerting task.

#### Who can take part?

We are recruiting adults with a diagnosis of Chronic Fatigue Syndrome / ME. To take part in the study you should meet the following criteria:

- Aged between 18 and 70
- Have a diagnosis of CFS/ME
- Currently attending a specialist service.
- Fluent in English language
- Do not use a mobility aid



IRAS Ref: 225160  
Version number: 1.5  
08/09/17

Unfortunately you will not be able to take part in the study if you:

- Have any OTHER long term medical condition or terminal illness.
- Have received previous extensive treatment for CFS/ME.

If you are unsure about whether you can take part please contact the researcher.

#### **What will participation involve?**

After signing the consent form, you will be asked to complete some questionnaires. These questionnaires ask about various things such as fatigue and mood, which we think could be important to understand responses to physical exertion in people with CFS/ME. Some of the questionnaires might seem relevant to you, but others might not.

If you are eligible to take part in the study, you will be asked to complete a number of questionnaires online or sent these by post. The questionnaires will ask you about various things, such as fatigue, emotional wellbeing, and thinking style, like worry and anxiety. Completing the questionnaires will take around 20 minutes. You will be given the choice to complete them online or have paper copies posted to you. Either way, you will be able to fill in the questionnaires in your own time and take breaks as you need to. You are welcome to ask a trusted friend or family member to help you with completing the questionnaires, as long as the answers are your own.

During your service assessment, you will have filled in questionnaires about your mood and fatigue. Some of these questionnaires are the same as ones we are using for the research, so accessing your records means you will not have to do them again. This is optional; if you would prefer to repeat the questionnaires rather than consent to us accessing your records, this is fine too.

You will also be asked to attend a one-off testing session which will last no longer than an hour and during which you will be asked to complete a practical task. The task will involve carrying a shopping bag. This will be video recorded and you will be asked to watch this back and answer some questions about it. This can take place in either Bath (University of Bath) or Bristol (Southmead Hospital or Cossham Hospital).

#### **What happens next?**

The researcher will contact you to answer any questions you may have and ask whether you would like to take part in the study. They will arrange for you to complete the study questionnaires and book a testing session for you to attend.

IRAS Ref: 225160  
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**What are the possible benefits of taking part?**

We hope to find out more about responses to physical exertion in those with and without Chronic Fatigue Syndrome. These results will improve our understanding and may contribute to the development of new treatments.

**What are the possible disadvantages or risks of taking part?**

The physical task is designed to be mildly exerting. This has been considered carefully by the research team. The same task has been used with individuals with chronic pain with no problems and has also been tried out with members of the public and an advisor with CFS. If you choose to take part, you are able to stop at any point. The questionnaires in this study are used routinely within a CFS service. However, if you find any of the questions upsetting, please talk to the researcher or your care team. We appreciate that some people may have to travel to take part in the study and that you are giving your time.

**Will I be paid for participating?**

Each participant will receive a £10 voucher for participating in the study. Alternatively this amount can be used towards travel costs.

**Will it possible to identify me from my results?**

Your participation in the study will be confidential. From the beginning of your involvement, you will be given an identification number and this will be used to match your completed measures rather than your name. Your data will be kept on a password protected computer and in locked storage. Your name will not appear anywhere in any publication or in any description of the findings. Only the researcher and supervisors will be allowed to see your files.

**Who is organising the research?**

The research is being carried out by Dr Samantha Lloyd, a Trainee Clinical Psychologist at the University of Bath. It is being supervised by Dr Jo Daniels and Dr Flora Wilson, Clinical Psychologists in the Bristol CFS Service.

**Who has approved this research?**

Before any research goes ahead it is looked at by an independent Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by the South West – Central Bristol Research Ethics Committee.

**What should I do if there is a problem?**

If you have any concerns or wish to complain about any aspect of the way you have been approached or treated as part of this study, you should initially contact the researchers, Dr Samantha Lloyd or Dr Jo Daniels, who will do their best to address your concerns. Their contact details are provided at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this through the North Bristol Trust Advice & Complaints Team (ACT) or you can contact the Sponsor of this study, the University of Bath.



IRAS Ref: 225160  
Version number: 1.5  
08/09/17

Every care will be taken to ensure your safety during the course of the study. The University of Bath, as Sponsor of the study has indemnity (insurance) arrangements in place for non-negligent harm, in the event that something does go wrong and you are harmed as a result of taking part in the research study. If you are harmed due to someone's negligence, then you may have grounds for legal action, but you may have to pay for it.

**What will happen to the results of the study?**

This study is intended to form part of a doctoral thesis and to be submitted for publication in a relevant academic journal. No individual participants will be identifiable in any written report resulting from this study.

If you would like us to retain your contact details in order to let you know the outcome of the research, there is an option on the Consent Form to indicate this.

**Who is organising and funding the research?**

The project is being organised and funded by the University of Bath, as part of the Doctorate in Clinical Psychology for Samantha Lloyd.

**What should I do if I want more information?**

For more information on any aspect of the study please contact me using the contact details below.

Dr Samantha Lloyd  
[s.lloyd@bath.ac.uk](mailto:s.lloyd@bath.ac.uk)

Dr Flora Wilson  
[Flora.Wilson@nbt.nhs.uk](mailto:Flora.Wilson@nbt.nhs.uk)

## Appendix I – Participant information sheet: HC

IRAS Ref: 225160  
University Ref: 17-242  
Version number: 1.5  
08/09/17



### INFORMATION SHEET FOR PARTICIPANTS

**Title of study:** Responses to physical exertion in Chronic Fatigue Syndrome / Myalgic Encephalomyelitis

**Name of researcher:** Samantha Lloyd

We would like to invite you to participate in this postgraduate research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. We would really appreciate your involvement as this study will help to improve our understanding of chronic fatigue and may help us to modify or develop future treatments.

#### What is the purpose of the study?

- Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) is a condition defined by a marked loss of energy on physical or mental exertion. The cause of this illness is not yet fully understood.
- The purpose of this study is to look at how people with CFS/ME respond when asked to do a physically exerting task, and what thoughts and feelings they have while they are doing the task. We would like to compare responses to people without CFS/ME.
- Similar research has been done in chronic pain and has helped to improve treatment. We are therefore hoping to do the same in CFS/ME.

#### Who can take part?

We are recruiting adults without a diagnosis of Chronic Fatigue Syndrome / ME.

To take part in the study you should meet the following criteria:

- Aged between 18 and 70
- Fluent in English language
- Do not use a mobility aid

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- Do not have CFS/ME, any other long term health condition or terminal illness
- Low level and non-consistent fatigue or no fatigue experienced over past week.
- No pain experienced over the past week.

If you are unsure about whether you can take part please contact the researcher.

#### **What will participation involve?**

After signing the consent form, you will be asked to complete some questionnaires. These questionnaires ask about various things such as fatigue and mood, which we think could be important to understand responses to physical exertion in people with CFS/ME. Some of the questionnaires might seem relevant to you, but others might not.

If you are eligible to take part in the study, you will be asked to complete a number of questionnaires online or sent these by post. The questionnaires will ask you about various things, such as fatigue, emotional wellbeing, and thinking style, like worry and anxiety. Completing the questionnaires will take around 20 minutes. You will be given the choice to complete them online or have paper copies posted to you. Either way, you will be able to fill in the questionnaires in your own time and take breaks as you need to. You are welcome to ask a trusted friend or family member to help you with completing the questionnaires, as long as the answers are your own.

During your service assessment, you will have filled in questionnaires about your mood and fatigue. Some of these questionnaires are the same as ones we are using for the research, so accessing your records means you will not have to do them again. This is optional; if you would prefer to repeat the questionnaires rather than consent to us accessing your records, this is fine too.

You will also be asked to attend a one-off testing session which will last no longer than an hour and during which you will be asked to complete a practical task. The task will involve carrying a shopping bag. This will be video recorded and you will be asked to watch this back and answer some questions about it. This will take place at the University of Bath.

#### **What happens next?**

The researcher will contact you to answer any questions you may have and ask whether you would like to take part in the study. They will arrange for you to complete the study questionnaires and book a testing session for you to attend.

#### **What are the possible benefits of taking part?**

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We hope to find out more about responses to physical exertion in those with and without Chronic Fatigue Syndrome. These results will improve our understanding and may contribute to the development of new treatments.

**What are the possible disadvantages or risks of taking part?**

The physical task is designed to be mildly exerting. This has been considered carefully by the research team. The same task has been used with individuals with chronic pain with no problems and has also been tried out with members of the public and an advisor with CFS. If you choose to take part, you are able to stop at any point. The questionnaires in this study are used routinely within a CFS service. However, if you find any of the questions upsetting, please talk to the researcher. We appreciate that some people may have to travel to take part in the study and that you are giving your time.

**Will I be paid for participating?**

Each participant will receive a £10 voucher for participating in the study. Alternatively, this amount can be used towards transport costs.

**Will it possible to identify me from my results?**

Your participation in the study will be confidential. From the beginning of your involvement, you will be given an identification number and this will be used to match your completed measures rather than your name. Your data will be kept on a password protected computer and in locked storage. Your name will not appear anywhere in any publication or in any description of the findings. Only the researcher and supervisors will be allowed to see your files.

**Who is organising the research?**

The research is being carried out by Samantha Lloyd, a Trainee Clinical Psychologist at the University of Bath. It is being supervised by Dr Jo Daniels and Dr Flora Wilson, Clinical Psychologists in the Bristol CFS Service.

**Who has approved this research?**

Before any research goes ahead it is looked at by an independent Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by the South West – Central Bristol Research Ethics Committee.

**What should I do if there is a problem?**

If you have any concerns or wish to complain about any aspect of the way you have been approached or treated as part of this study, you should initially contact the researchers, Dr Samantha Lloyd or Dr Jo Daniels, who will do their best to address your concerns. Their contact details are provided at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this through the Sponsor of this study, the University of Bath.

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Every care will be taken to ensure your safety during the course of the study. The University of Bath, as Sponsor of the study has indemnity (insurance) arrangements in place for non-negligent harm, in the event that something does go wrong and you are harmed as a result of taking part in the research study. If you are harmed due to someone's negligence, then you may have grounds for legal action, but you may have to pay for it.

**What should I do if I want more information?**

For more information on any aspect of the study please contact me using the contact details below.

Dr Samantha Lloyd  
[s.lloyd@bath.ac.uk](mailto:s.lloyd@bath.ac.uk)

Dr Jo Daniels  
[J.Daniels@bath.ac.uk](mailto:J.Daniels@bath.ac.uk)

The study questionnaires will be used for research rather than clinical purposes. If this study raises any difficult feelings for you, please seek professional help, for example from your GP. You may also find the following organisations helpful:

*Mind*

Information on mental health and sources of support

Website: [www.mind.org.uk](http://www.mind.org.uk)

Infoline: 0300 123 3393 (Monday to Friday 9.00am to 6.00pm)

Text: 86463

Email: [info@mind.org.uk](mailto:info@mind.org.uk)

*NHS*

Website: [www.nhs.uk/livewell/mentalhealth/Pages/Mentalhealthhome.aspx](http://www.nhs.uk/livewell/mentalhealth/Pages/Mentalhealthhome.aspx)

Information on mental health and sources of support



# Appendix J – Participant consent form: CFS

Version 1.2

08/09/17

IRAS Ref: 225160

Participant Identification Number:



## CONSENT FORM

**Title of Project: Responses to physical exertion in Chronic Fatigue Syndrome**

**Name of Researcher: Samantha Lloyd**

Please initial box

1. I confirm that I have read the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I agree to the video recording of my participation in this research. I understand that it will be used for research purposes only and not available to anyone outside the direct research team. I understand that it will be stored confidentially and anonymously and destroyed once the research has finished.
4. I agree to take part in the above study.
5. I would like to be emailed a summary of the findings of the study

If yes, please provide your email address .....

\_\_\_\_\_  
Name of Participant                      Date                      Signature

\_\_\_\_\_  
Name of Person                      Date                      Signature  
taking consent

## Appendix K – Participant consent form: HC

Version 1.2

08/09/17

IRAS Ref: 225160

Participant Identification Number:



### CONSENT FORM

**Title of Project: Responses to physical exertion in Chronic Fatigue Syndrome**

**Name of Researcher: Samantha Lloyd**

Please initial box

1. I confirm that I have read the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I agree to the video recording of my participation in this research. I understand that it will be used for research purposes only and not available to anyone outside the direct research team. I understand that it will be stored confidentially and anonymously and destroyed once the research has finished.
4. I agree to take part in the above study.
5. I would like to be emailed a summary of the findings of the study

If yes, please provide your email address .....

\_\_\_\_\_  
Name of Participant                      Date                      Signature

\_\_\_\_\_  
Name of Person                      Date                      Signature  
taking consent

## Appendix L – Validated measures

IRAS Ref: 225160, Version 1.3, 11/09/17

ID Code:

### Work & Social Adjustment Scale

Please circle one number in response to each question

<b>Because of my ill health, my ability to work is impaired</b>								
0	1	2	3	4	5	6	7	8
Not at all		Slightly		Definitely		Markedly		Very severely
<b>Because of my ill health, my home management (cleaning, tidying, shopping, cooking, looking after home or children, paying bills) is impaired.</b>								
0	1	2	3	4	5	6	7	8
Not at all		Slightly		Definitely		Markedly		Very severely
<b>Because of my ill health, my social leisure activities (with other people e.g. parties, bars, clubs, outings, visits, dating, home entertaining) are impaired.</b>								
0	1	2	3	4	5	6	7	8
Not at all		Slightly		Definitely		Markedly		Very severely
<b>Because of my ill health, my private leisure activities (done alone, such as reading, gardening, collecting, sewing, walking alone) are impaired.</b>								
0	1	2	3	4	5	6	7	8
Not at all		Slightly		Definitely		Markedly		Very severely
<b>Because of my ill health, my ability to form and maintain close relationships with others, including those I live with, is impaired.</b>								
0	1	2	3	4	5	6	7	8
Not at all		Slightly		Definitely		Markedly		Very severely

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ID Code: |

## Chalder Fatigue Scale

We would like to know more about any problems you have had with feeling tired, weak or lacking in energy in the past month. Please answer ALL the questions by crossing the answer that applies to you most closely. **If you have been feeling tired for a long while, then compare yourself to how you felt when you were last well.**

Please cross only one box in each line

		Less than usual	No more than usual	More than usual	Much more than usual
1.1	Do you have problems with tiredness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.2	Do you need to rest more?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.3	Do you feel sleepy or drowsy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.4	Do you have problems starting things?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.5	Do you lack energy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.6	Do you have less strength in your muscles?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.7	Do you feel weak?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.8	Do you have difficulty concentrating?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.9	Do you make slips of the tongue when speaking?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.10	Do you have problems thinking clearly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
		Better than usual	No worse than usual	Worse than usual	Much worse than usual
1.11	How is your memory?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

ID Code:

**SF-36**

The following questions are about ACTIVITIES you might do during a typical day.

**Does your health now limit you in these activities? If so, how much?**

**Please cross only one box in each line**

		Yes, limited a lot	Yes, limited a little	No, not limited at all
1.1	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.2	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.3	Lifting or carrying groceries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.4	Climbing several flights of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.5	Climbing one flight of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.6	Bending, kneeling, or stooping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.7	Walking more than a mile	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.8	Walking half a mile	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.9	Walking one hundred yards	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1.10	Bathing or dressing yourself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

ID Code:

## HADS

This questionnaire is designed to help describe how you feel. Please read each item and then place a cross in the box next to the reply that comes closest to how you have been feeling in the past week. Try to give your first reaction. This will probably be more accurate than spending a long time thinking about an answer.

**Please cross only one box for each question**

1.1 I feel tense or 'wound up':	1.8 I feel as if I am slowed down:
Most of the time <input type="checkbox"/>	Nearly all of the time <input type="checkbox"/>
A lot of the time <input type="checkbox"/>	Very often <input type="checkbox"/>
From time to time, occasionally <input type="checkbox"/>	Sometimes <input type="checkbox"/>
Not at all <input type="checkbox"/>	Not at all <input type="checkbox"/>
1.2 I still enjoy things the things I used to enjoy:	1.9 I get a frightened feeling, like 'butterflies' in the stomach:
Definitely as much <input type="checkbox"/>	Not at all <input type="checkbox"/>
Not quite so much <input type="checkbox"/>	Occasionally <input type="checkbox"/>
Only a little <input type="checkbox"/>	Quite often <input type="checkbox"/>
Hardly at all <input type="checkbox"/>	Very often <input type="checkbox"/>
1.3 I get a sort of frightened feeling, as if something awful is about to happen:	1.10 I have lost interest in my appearance:
Very definitely and quite badly <input type="checkbox"/>	Definitely <input type="checkbox"/>
Yes, but not too badly <input type="checkbox"/>	I don't take as much care as I should <input type="checkbox"/>
A little, but it doesn't worry me <input type="checkbox"/>	I may not take quite as much care <input type="checkbox"/>
Not at all <input type="checkbox"/>	I take just as much care as ever <input type="checkbox"/>
1.4 I can laugh and see the funny side of things:	1.11 I feel restless, as if I have to be on the move:
As much as I ever could <input type="checkbox"/>	Very much indeed <input type="checkbox"/>
Not quite so much now <input type="checkbox"/>	Quite a lot <input type="checkbox"/>
Definitely not so much now <input type="checkbox"/>	Not very much <input type="checkbox"/>
Not at all <input type="checkbox"/>	Not at all <input type="checkbox"/>
1.5 Worrying thoughts go through my mind:	1.12 I look forward with enjoyment to things:
A great deal of the time <input type="checkbox"/>	As much as I ever did <input type="checkbox"/>
A lot of the time <input type="checkbox"/>	Rather less than I used to <input type="checkbox"/>
From time to time, but not too often <input type="checkbox"/>	Definitely less than I used to <input type="checkbox"/>
Only occasionally <input type="checkbox"/>	Hardly at all <input type="checkbox"/>
1.6 I feel cheerful:	1.13 I get sudden feelings of panic:
Not at all <input type="checkbox"/>	Very often indeed <input type="checkbox"/>
Not often <input type="checkbox"/>	Quite often <input type="checkbox"/>
Sometimes <input type="checkbox"/>	Not very often <input type="checkbox"/>
Most of the time <input type="checkbox"/>	Not at all <input type="checkbox"/>
1.7 I can sit at ease and feel relaxed:	1.14 I can enjoy a good book, radio or TV programme:
Definitely <input type="checkbox"/>	Often <input type="checkbox"/>
Usually <input type="checkbox"/>	Sometimes <input type="checkbox"/>
Not often <input type="checkbox"/>	Not often <input type="checkbox"/>
Not at all <input type="checkbox"/>	Very seldom <input type="checkbox"/>

© GL assessment

ID Code:

### BELIEFS ABOUT SYMPTOMS

Thank you for agreeing to participate in this study. We are very interested in finding out more about the symptoms of your illness and the impact these symptoms have had on your life.

This booklet contains a number of questions about the nature of your symptoms, how you manage these symptoms and the impact these have had on your physical health and psychological well-being

There are no **right** or **wrong** answers to these questions. We are most interested in your **own** personal views rather than those of your family or the people who are treating you.

**Please indicate how much you agree or disagree with the following statements about your current symptoms by ticking the appropriate box.**

	<b>VIEWS ABOUT YOUR SYMPTOMS</b>	<b>STRONGLY DISAGREE</b>	<b>DISAGREE</b>	<b>NEITHER AGREE NOR DISAGREE</b>	<b>AGREE</b>	<b>STRONGLY AGREE</b>
FA1	I am afraid that I will make my symptoms worse if I exercise					
FA2	My symptoms would be relieved if I were to exercise					
FA3	Avoiding unnecessary activities is the safest thing I can do to prevent my symptoms from worsening					
FA4	The severity of my symptoms must mean there is something serious going on in my body					
FA9	Even though I experience symptoms, I don't think they are actually harming me					
FA10	When I experience symptoms, my body is telling me that there is something seriously wrong.					
FA12	Physical activity makes my symptoms worse					
FA14	Doing less helps symptoms					
FA15	Symptoms are a signal that I am damaging myself					
FA16	I am afraid I will have more symptoms if I am not careful					

FA17	I should avoid exercise when I have symptoms					
C1	I worry that I may become permanently bedridden because of my symptoms					
C2	I think that if my symptoms get too severe they may never decrease					
C4	My illness is awful and I feel that it overwhelms me					
C6	I will never feel right again					
SF1	When I experience symptoms, I think about them constantly					
SF2	I worry when I am experiencing symptoms					
SF3	When I am experiencing symptoms it is difficult for me to think of anything else					
	<b>VIEWS ABOUT YOUR SYMPTOMS</b>	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
SF5	I think a great deal about my symptoms					
SF9	My symptoms are always at the back of my mind					
SF12	I spend a lot of time thinking about my illness					
EA1	I am embarrassed about my symptoms					
EA2	I worry that people will think badly of me because of my symptoms					
EA3	The embarrassing nature of my symptoms prevents me from doing things					
EA4	I avoid social situations because I am scared my symptoms will get out of control					
EA5	I am ashamed of my symptoms					
EA6	My symptoms have the potential to make me look foolish in front of other people					

We are interested in how you respond to or manage your symptoms at the moment. Listed below are a number of different responses that people may have to their symptoms.

Please indicate how often you respond in the following ways by ticking the appropriate box. Choose the most accurate answer for YOU, not what you think "most people" would say or do.

	MANAGING SYMPTOMS	Never	Sometimes	Quite often	Very Often	All the time
L2	I stay in bed to control my symptoms					
L3	When I experience symptoms, I rest.					

L4	I tend to avoid activities that make my symptoms worse					
L7	I tend to nap during the day to control my symptoms					
AL1	I tend to overdo things when I feel energetic					
AL2	I find myself rushing to get things done before I crash					
AL3	I tend to overdo things and then rest up for a while					
AL4	I tend to do a lot on a good day and rest on a bad day					
L9	I sleep when I'm tired in order to control my symptoms					
	<b>MANAGING SYMPTOMS</b>	<b>Never</b>	<b>Sometimes</b>	<b>Quite often</b>	<b>Very Often</b>	<b>All the time</b>
L10	I avoid making social arrangements in case I'm not up to it.					
L11	I avoid exerting myself in order to control my symptoms					
AL5	I'm a bit all or nothing when it comes to doing things					
L13	I avoid stressful situations					

**EQ-5D**

<b>MOBILITY</b>	
I have no problem in walking about	<input type="checkbox"/>
I have slight problems in walking about	<input type="checkbox"/>
I have moderate problems in walking about	<input type="checkbox"/>
I have severe problems in walking about	<input type="checkbox"/>
I am unable to walk about	<input type="checkbox"/>
<b>SELF-CARE</b>	
I have no problems washing or dressing myself	<input type="checkbox"/>
I have slight problems washing or dressing myself	<input type="checkbox"/>
I have moderate problems washing or dressing myself	<input type="checkbox"/>
I have severe problems washing or dressing myself	<input type="checkbox"/>
I am unable to wash or dress myself	<input type="checkbox"/>
<b>USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)</b>	
I have no problems doing my usual activities	<input type="checkbox"/>
I have slight problems doing my usual activities	<input type="checkbox"/>
I have moderate problems doing my usual activities	<input type="checkbox"/>
I have severe problems doing my usual activities	<input type="checkbox"/>
I am unable to do my usual activities	<input type="checkbox"/>
<b>PAIN / DISCOMFORT</b>	
I have no pain or discomfort	<input type="checkbox"/>
I have slight pain or discomfort	<input type="checkbox"/>
I have moderate pain or discomfort	<input type="checkbox"/>
I have severe pain or discomfort	<input type="checkbox"/>
I have extreme pain or discomfort	<input type="checkbox"/>
<b>ANXIETY / DEPRESSION</b>	
I am not anxious or depressed	<input type="checkbox"/>
I am slightly anxious or depressed	<input type="checkbox"/>
I am moderately anxious or depressed	<input type="checkbox"/>
I am severely anxious or depressed	<input type="checkbox"/>
I am extremely anxious or depressed	<input type="checkbox"/>

Gusi, N., Olivares, P. R., & Rajendram, R. (2010).

ID Code:

**Visual Analogue Pain Rating Scale**

*Please mark the line to describe the severity of your pain*

**NO  
PAIN**



**PAIN AS BAD  
AS POSSIBLE**

<i>Instructions for scoring: Record distance from the LEFT end of the line in millimetres</i>	
---	--



ID Code:

**SHORT WEEK**

Ass / Wk / Sess: \_\_\_\_\_

**HAI**

Each question in this section consists of a group of four statements. Please read each group of statements carefully and then select the one which best describes your feelings, OVER THE PAST WEEK. Identify the statement by ringing the letter next to it ie. if you think that statement (a) is correct, ring statement (a); it may be that more than one statement applies, in which case, please ring any that are applicable.

1.
  - a. I do not worry about my health.
  - b. I occasionally worry about my health.
  - c. I spend much of my time worrying about my health.
  - d. I spend most of my time worrying about my health.
2.
  - a. I notice aches/pains less than most other people (of my age).
  - b. I notice aches/pains as much as most other people (of my age).
  - c. I notice aches/pains more than most other people (of my age).
  - d. I am aware of aches/pains in my body all the time.
3.
  - a. As a rule I am not aware of bodily sensations or changes.
  - b. Sometimes I am aware of bodily sensations or changes.
  - c. I am often aware of bodily sensations or changes.
  - d. I am constantly aware of bodily sensations or changes.
4.
  - a. Resisting thoughts of illness is never a problem.
  - b. Most of the time I can resist thoughts of illness.
  - c. I try to resist thoughts of illness but am often unable to do so.
  - d. Thoughts of illness are so strong that I no longer even try to resist them.
5.
  - a. As a rule I am not afraid that I have a serious illness.
  - b. I am sometimes afraid that I have a serious illness.
  - c. I am often afraid that I have a serious illness.
  - d. I am always afraid that I have a serious illness.
6.
  - a. I do not have images (mental pictures) of myself being ill.
  - b. I occasionally have images of myself being ill.
  - c. I frequently have images of myself being ill.
  - d. I constantly have images of myself being ill.
7.
  - a. I do not have any difficulty taking my mind off thoughts about my health.
  - b. I sometimes have difficulty taking my mind off thoughts about my health.
  - c. I often have difficulty in taking my mind off thoughts about my health.
  - d. Nothing can take my mind off thoughts about my health.
8.
  - a. I am lastingly relieved if my doctor tells me there is nothing wrong.
  - b. I am initially relieved but the worries sometimes return later.
  - c. I am initially relieved but the worries always return later.
  - d. I am not relieved if my doctor tells me there is nothing wrong.
9.
  - a. If I hear about an illness I never think I have it myself.
  - b. If I hear about an illness I sometimes think I have it myself.
  - c. If I hear about an illness I often think I have it myself.
  - d. If I hear about an illness I always think I have it myself.

10.
  - a. If I have a bodily sensation or change I rarely wonder what it means.
  - b. If I have a bodily sensation or change I often wonder what it means.
  - c. If I have a bodily sensation or change I always wonder what it means.
  - d. If I have a bodily sensation or change I must know what it means.
11.
  - a. I usually feel at very low risk of developing a serious illness.
  - b. I usually feel at fairly low risk of developing a serious illness.
  - c. I usually feel at moderate risk of developing a serious illness.
  - d. I usually feel at high risk of developing a serious illness.
12.
  - a. I never think I have a serious illness.
  - b. I sometimes think I have a serious illness.
  - c. I often think I have a serious illness.
  - d. I usually think that I am seriously ill.
13.
  - a. If I notice an unexplained bodily sensation I don't find it difficult to think about other things.
  - b. If I notice an unexplained bodily sensation I sometimes find it difficult to think about other things.
  - c. If I notice an unexplained bodily sensation I often find it difficult to think about other things.
  - d. If I notice an unexplained bodily sensation I always find it difficult to think about other things.
14.
  - a. My family/friends would say I do not worry enough about my health.
  - b. My family/friends would say I have a normal attitude to my health.
  - c. My family/friends would say I worry too much about my health.
  - d. My family/friends would say I am a hypochondriac.

For the following questions, please think about what it might be like if you had a serious illness of a type which particularly concerns you (such as heart disease, cancer, multiple sclerosis and so on). Obviously you cannot know for definite what it would be like; please give your best estimate of what you think might happen, basing your estimate on what you know about yourself and serious illness in general.

15.
  - a. If I had a serious illness I would still be able to enjoy things in my life quite a lot.
  - b. If I had a serious illness I would still be able to enjoy things in my life a little.
  - c. If I had a serious illness I would be almost completely unable to enjoy things in my life.
  - d. If I had a serious illness I would be completely unable to enjoy life at all.
16.
  - a. If I developed a serious illness there is a good chance that modern medicine would be able to cure me.
  - b. If I developed a serious illness there is a moderate chance that modern medicine would be able to cure me.
  - c. If I developed a serious illness there is a very small chance that modern medicine would be able to cure me.
  - d. If I developed a serious illness there is no chance that modern medicine would be able to cure me.
17.
  - a. A serious illness would ruin some aspects of my life.
  - b. A serious illness would ruin many aspects of my life.
  - c. A serious illness would ruin almost every aspect of my life.
  - d. A serious illness would ruin every aspect of my life.
18.
  - a. If I had a serious illness I would not feel that I had lost my dignity.
  - b. If I had a serious illness I would feel that I had lost a little of my dignity.
  - c. If I had a serious illness I would feel that I had lost quite a lot of my dignity.
  - d. If I had a serious illness I would feel that I had totally lost my dignity.



## Appendix N – Behaviour record sheet

### Behaviour Record Sheet

Please watch the recording and note down the following:

**Any behaviours that you did because you were experiencing fatigue / pain or expecting fatigue / pain.**

- 1)
- 2)
- 3)
- 4)
- 5)

For each of the above, please answer the following questions

a) What would have happened if you hadn't done this?

---

---

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---

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---

---

b) What was the purpose of this behaviour?

---

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---

---

c) How anxious would you have been if you had not done this?

**Not  
at all**

**Extremely**

1      2      3      4      5      6      7      8      9      10

## Appendix O – Demographic questionnaire

**Participant ID:**

### **DEMOGRAPHIC QUESTIONNAIRE**

The information that you give us on this sheet will be treated as strictly confidential. Your contact details on this sheet will be kept separate from the responses you provide in the following questionnaire. Only the lead researcher will have access to the file that links your identification details with the following questionnaire. Thank you for participating in this study.

**Name:** .....

**Contact number** .....

**Email:** .....

---

#### **YOUR DETAILS**

---

**Today's Date:** \_\_/\_\_/\_\_

**Date of birth:** \_\_/\_\_/\_\_      **Age:** \_\_

**Is English your first language?**    Yes / No

**What is your ethnicity?** .....

**Are you currently receiving treatment?**    Yes / No

**If yes, please give details below**

.....  
.....  
.....  
.....  
.....

**What is your current employment status?**

- |                                     |   |
|-------------------------------------|---|
| <input type="checkbox"/> Full time  | <input type="checkbox"/> Retired              |
| <input type="checkbox"/> Part time  | <input type="checkbox"/> Sick leave           |
| <input type="checkbox"/> Unemployed | <input type="checkbox"/> House wife / husband |
| <input type="checkbox"/> Student    | <input type="checkbox"/> Other                |

.....(please specify)

**Current hours of paid employment per typical week**

.....  
.....  
.....

**Effect of ill health on work or study:**

- Hours not reduced as a result of ill health
- Hours reduced as a result of ill health
- Currently on sick leave from existing job
- Unemployed because of ill health



## **Service Improvement Project appendices**

## **Appendix P – Author instructions**

### **Journal of Family Therapy submission – journal guidelines**

#### **Author Guidelines**

##### **Manuscript submission**

Papers submitted for publication should be original work not previously published in English and not currently submitted elsewhere for consideration. If accepted for publication, a paper cannot be published elsewhere in any language without the consent of both Editor and publisher. It is a condition of acceptance that the Association for Family Therapy and Systemic Practice automatically acquires the copyright throughout the world.

Manuscripts should be submitted to the following website:

<https://mc.manuscriptcentral.com/jft>. Full submission instructions can be found on this website.

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at <https://authorservices.wiley.com/statements/data-protection-policy.html>.

##### **Covering Letter**

A cover letter should be submitted with your manuscript and must include a statement that the data has not been published, and is not under consideration for publication elsewhere. It will be presumed that all listed authors of a manuscript have agreed to the listing and have seen and approved the manuscript. The cover letter should include a statement outlining what is new, impact making and original about the paper and why it should be considered for publication.

Please also include a paragraph detailing the Authorship contribution detailing the Author(s) responsible each of the following:

- designing the work
- acquiring the data
- interpreting the data
- drafting the work/ revising the work critically for intellectual content

A statement from the authors agreeing to be held accountable for all aspects of the

work and any questions relating to the accuracy or integrity of the work should also be included.

### **Manuscript Format**

1. Manuscripts should allow for 'blind/anonymised' refereeing and **must not** contain author names or any identifiable data.

2. Manuscripts **must** be typed in double spacing throughout, including quotation, notes and references in the following order:

- **Title Page**: to contain the title of the paper, word count, suggested running head (short title for your paper), key words, author names, affiliations and contact details for the corresponding author.
- **Abstract**: on a separate sheet, the title to be repeated followed by a summary of not more than 150 words. The suggested running head should also be present. *For tips on optimizing your abstract for search engines please click here.*
- **Practitioner Points**: two to six bullet points of no more than 180 characters each (including spaces), up to a total of 480 characters.
- **Organisation of the text**: see copy of Journal for the format currently in use.
- **Figures, tables, etc.**: All figures and tables should be numbered with consecutive arabic numerals, have descriptive captions and be mentioned in the text. They should be kept separate from the text but an approximate position for them should be indicated. These will need to be uploaded separately. Please supply figures in the format in which they were created, if possible.
- **References (in text)**: These should be indicated by the name and date e.g. 'Carr (2009)'. If more than two authors are listed, cite the reference as 'McHugh et al. (2010)'. Quotations should include page numbers. Websites should also be cited in this way, with a full reference appearing in the References section (see below). Please check all websites are live and the links are correct at time of submission.
- **References**: Should be listed at the end of the paper in alphabetical order according to the first author and be complete in all details following the APA style of referencing.
  - **Articles**: Altschuler, J. (2015). Whose illness is it anyway? On facing illness as a couple. *Journal of Family Therapy*, 37(1), 119-133.
  - **Chapters**: Burnham, J. (2012). Developments in the Social GRRRAAACCEEESSS: visible-invisible and voiced-unvoiced. In I.B. Krause (Ed.), *Culture and Reflexivity in Systemic Psychotherapy. Mutual Perspectives* (pp 139-163). London: Karnac.
  - **Books**: Burck, C., & Daneil, G. (2010). *Mirrors and Reflections. Process of Systemic Supervision*. London: Karnac.
  - **Web pages** (no author or date identified): Counting the cost: caring for people with dementia on hospital wards. (n.d.) Retrieved from [http://alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1199](http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1199). [Cite in text as (“Counting the costs”, n.d.)]

For further details, please see the APA Style website:

(<http://www.apastyle.org/learn/tutorials/basics-tutorial.aspx>)

3. The word limit, excluding abstract and practitioner points will vary depending on the type of paper you are submitting. Please refer to the ‘Advice to Authors’ section

below.

4. Style: Whilst Journal style is generally formal, originality in presentation does not necessarily preclude publication if clarity and readability is thereby enhanced. Sexist language forms are unacceptable.

Your manuscript will be returned to you if you fail to conform to these requirements.

### **Case material and Confidentiality**

*Journal of Family Therapy* readers particularly welcome papers which link theory and practice, and such papers are often enhanced by case material.

The Author takes responsibility for anonymising material in order to protect client confidentiality. All possible identifying information must be altered. Another way of protecting confidentiality is by presenting composite case material, made up of different aspects from a number of similar cases.

Do not identify any participants without consent or write about them in any way that identifies them to the public or other participants without consent.

### **Every paper that contains case material must be accompanied by:-**

- A statement in the letter to the Editor from the Author(s) specifying whether the material presented is disguised/generic/composite; or
- A statement in the letter to the Editor that the Author has gained signed consent from patients/clients or teachers/students authorizing publication of the material. Please note that upon signing the Author Agreement the Author becomes liable for any third party information collated and takes complete responsibility for preparing the work and gaining the relevant permissions and consent.

### **Pre-submission English-language editing**

It is often helpful to Authors for whom English is a second language to choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found [here](#).

All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

### **Evaluation of Manuscripts**

The Editorial office will acknowledge receipt of manuscripts. The Editor will arrange for evaluation by at least two assessors. Following receipt of the assessors comments the Editor will advise the authors about the decision concerning the manuscript. This will be done as rapidly as possible with the aim being 12 weeks for a first decision. Revised manuscripts may take longer to reach a final decision).

If your paper is accepted, the author identified as the formal corresponding author for

the paper will receive an email prompting them to login into Author Services; where via the Wiley Author Licensing Service (WALS) they will be able to complete the license agreement on behalf of all authors of the paper.

### **For authors signing the copyright transfer agreement**

If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the Copyright FAQs below:

CTA Terms and Conditions

### **For authors choosing OnlineOpen**

If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons License Open Access Agreements (OAA):

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Creative Commons Attribution Non-Commercial -NoDerivs License OAA

To preview the terms and conditions of these open access agreements please visit the Copyright FAQs hosted on Wiley Author Services and visit [this website](#).

If you select the OnlineOpen option and your research is funded by The Wellcome Trust and members of the Research Councils UK (RCUK) or the Austrian Science Fund (FWF) you will be given the opportunity to publish your article under a CC-BY license supporting you in complying with your Funder requirements. For more information on this policy and the Journal's compliant self-archiving policy please click [here](#).

All papers published in the *Journal of Family Therapy* are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

### **Copy Editing**

Following acceptance for publication an article is copy edited for conformity to the style of publication, clarity of presentation, punctuation, standard usage of terms, etc.

### **Proofs**

Corresponding authors will receive proofs for correction which must be returned within 48 hours of receipt. The corresponding author will receive an email alert containing a link to a web site. A working e-mail address must therefore be provided for the corresponding author. Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from this [website](#). Further instructions will be sent with the proof.

### **Early View**

The *Journal of Family Therapy* is part of the Wiley Online Library Early View service. Articles accepted for publication (excluding book reviews) can be accessed

on a regular basis online in advance of their appearance in a print issue.

These articles are fully peer reviewed, edited and complete and are considered fully published from the date they first appear online. This date is shown with the article in the online table of contents. The articles are available as full text HTML or PDF and can be cited as references by using their Digital Object Identifier (DOI) numbers. All of the articles currently available can be viewed [here](#). On print publication, the article will be removed from the Early View area and will appear instead in the relevant online issue, complete with page numbers and volume/issue details. No other changes will be made.

### **ADVICE TO AUTHORS**

Writing is a very enjoyable and satisfying way of being involved in the world of family therapy. The exchange of ideas and experience is important both for the development of our chosen field and for the development of the individual practitioner. We intellectually sustain ourselves by creating a healthy and vibrant literature. Family therapy needs to develop authors and *The Journal of Family Therapy* wants to hear from you.

These are the types of papers that are regularly submitted to the *Journal of Family Therapy*:

(The word count for all these papers does not include tables and figures.)

#### **Research Presentation** (3,000-6,000 words)

A research paper should include:

- An introduction to the principal concepts and theoretical issues relevant to the study
- Previous work
- Description of methodology including participants
- Results/Findings
- Discussion of results, including implications for future research and practice

#### **Systematic reviews** (up to 6000 words).

Systematic reviews are welcomed. For systematic reviews and meta-analyses please ensure that you have used the PRISMA checklist and include a flowchart as part of your submission. Please complete and supply AMSTAR for systematic reviews which are narrative reviews not meta-analyses.

Suggested headings for systematic reviews are:

- background or context;
- objective;
- search strategy;
- inclusion criteria;
- data extraction and synthesis;
- main results; discussion and conclusions.

Please ensure that you include the standard points for practice.

You should provide the PROSPERO number in the methods section of the paper, or explain in your covering letter if you have not registered your review with PROSPERO.

### **Case Study** (up to 2,000 words\*)

\*Longer papers may be considered at the discretion of the Editor if it is felt the manuscript fulfils the role of a full paper.

The *Journal of Family Therapy* welcomes case studies. A case study paper should include the following:

- Theoretical/Research Basis
- Introduction of the case including presenting issues
- Relevant background information
- Systemic case conceptualisation
- Self-reflexivity
- Description of intervention/ treatment
- Outcomes and follow up
- Implications/contributions to the field

For anonymised case studies informed consent to publish must be obtained from all participants in the treatment and/or all family members before submission.

### **CONSENT TO PUBLISH MUST ALWAYS BE OBTAINED FROM CLIENTS/FAMILIES BEFORE SUBMISSION**

### **Theoretical Discussions or Controversial Theoretical Papers** (4,000-6,000 words)

We welcome the submission of articles of this nature. A paper of this type would include:

- A brief general introduction
- A review of previous statements of the issues
- A definition of problems and solutions
- A development of an argument (Research based work which was undertaken for a thesis may be referenced)
- Relation of theory to practice
- Issues to be resolved

Often we will ask one of the reviewers to write a commentary on the paper to stimulate debate through the Journal pages.

### **Literature Review** (3,000–5,000 words)

These are much sought after by the readership. Such a paper would have:

- A brief general introduction
- A description of the way in which the themes in the literature are organised by the author for review. This may include conceptual and definition problems.
- The review
- An overview of the review process including gaps in existing knowledge
- Future directions

### **Teaching and Learning** (up to 2,000 words\*)

\*Longer papers may be considered at the discretion of the Editor if it is felt the manuscript fulfils the role of a full paper.

These should include:

- Practitioners Points – key ideas for trainers from paper
- Description of context – situation in which teaching event occurred, experience and constitution of participants and trainers, pre and post learning required for this session
- Aims of teaching event – aims and learning outcomes
- Theoretical Description which includes systemic theory / practice and education / learning/ pedagogical theory
- Description of event – pre reading, structure of session, length, didactic, experiential
- Feedback from participants – formal and informal
- Learning as a result of experience – trainers own evaluation, any suggested changes as a result of feedback or experience, suggestions for application in other settings

### **Additional Notes to Authors:**

- JFT has an international readership, so spell out details that might be unfamiliar to the non UK field.
- JFT welcomes the linking of previous literature in a substantive, explanatory sense and therefore advises authors to reference other papers where possible.


**PAPERS EXCEEDING THE SPECIFIED WORD LIMITS (including references) WILL BE RETURNED TO THE AUTHOR**



## Appendix Q – University approval

RE: Ethics 17-185: Exploring who is referred to the Family and Couples Therapy (FaCT) Service and why

X DELETE   ← REPLY   ← REPLY ALL   → FORWARD   ...

 **Nathalia Gjersoe**  
Wed 09/08/2017 09:13 Mark as unread

To:  Samantha Lloyd;  
Cc:  Catherine Butler;

[Message Header Analyzer](#)   [Action Items](#)   [+ Get more apps](#)

Dear Samantha,

Thank you for taking the time to make these amendments and clarifications. I am happy to confirm that you have full ethical approval for this amended application. Please use the code 17-185 as proof of ethical approval on all internal documentation.

Best of luck with your research,

Dr. Nathalia Gjersoe  
Chair, Psychology Ethics Committee

## Appendix R – Trust approval

### Avon and Wiltshire Mental Health Partnership AWP Trust

AWP Quality Academy

Fromeside- East Wing  
Manor Road  
Fishponds  
BS16 2EW

0117 378 4217

Date: 7<sup>th</sup> August 2017

Dear Samantha,

#### **Improving appropriate referrals to the Family and Couples Therapy (FaCT) service through exploring who is referred and why**

#### **AWP Reference: E2017.015**

This letter is to confirm that your evaluation is now approved and also provides you with our reference number.

If you do need any further support or information, please contact us using the contact details above, quoting our reference number for your study.

The importance of disseminating all evaluation work cannot be over emphasised. It is only by sharing our learning that we can improve services across AWP. For this reason, the findings of all evaluation work should be reported to the Evaluation team via email. The team will champion the results of service evaluations, and work with evaluators to ensure those results are disseminated and acted upon, and that the results of evaluations are reflected in future service delivery. The team will also work with evaluators to produce publications for the public domain.

I very much look forward to receiving the results of your evaluation in due course.

Yours sincerely,

Bryony McCann



## INFORMATION SHEET

### **Project: Exploring who is referred to the Family and Couples Therapy (FaCT) Service and why.**

We would like to invite you to participate in this postgraduate service improvement project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, there is information below on what is being done and what your participation will involve.

#### **What is the project about?**

Family, couple and systemic therapies are recommended for a number of mental health problems in adults (e.g. Carr, 2014). However, as is the case elsewhere, the South Gloucestershire Psychological Therapies Service systemic Family and Couple Therapy (FaCT) is not used to the full capacity. It has the potential to support more service users and their partners and / or families with a range of difficulties.

We would like to find out the views of referrers as to when they would be likely to refer to FaCT and what might prevent them from referring in.

#### **What are the aims of the project?**

- 1) To find out about the kinds of difficulties people who are currently accessing the services are experiencing.
- 2) To explore who, when and why local teams would consider referring to FaCT.

#### **What does taking part involve?**

We are looking to carry out short interviews with potential referrers to gain their views. Alternatively, if you prefer there is also a questionnaire which asks about similar topics.

#### **What will happen to this information?**

Interviews will be recorded and transcribed. They will be analysed to identify key themes. All identifying information will be removed from transcripts before analysis, and interviewees identified by a participant number. Questionnaires will also be anonymised. The findings of this project will be written up for the requirements of the Clinical Psychology doctorate. They may be submitted to

relevant academic journals if appropriate. It is proposed that the findings of this project will be fed back in team meetings.

**Who is carrying out this project?**

This service improvement project is being carried out by Sam Lloyd, Trainee Clinical Psychologist from the University of Bath, supervised by Catherine Butler and Stu Brooke.

**Will it possible to identify me from my results?**

Your participation in the study will be confidential. Transcriptions of interviews and questionnaires will be anonymised and assigned a participant number.

**Who has approved this research?**

This project has been registered as a service evaluation project with the Avon and Wiltshire NHS Foundation Research and Development. It has also been reviewed and given a favourable opinion by the University of Bath ethics panel.

**What should I do if there is a problem?**

If you have any concerns or wish to complain about any aspect of the way you have been approached or treated as part of this study, you should initially contact the researchers, Dr Samantha Lloyd or Dr Catherine Butler, who will do their best to address your concerns. Their contact details are provided at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this through the University of Bath.

**What should I do if I want more information?**

For more information on any aspect of the study please contact me using the contact details below.

Dr Samantha Lloyd  
Trainee Clinical Psychologist  
[s.lloyd@bath.ac.uk](mailto:s.lloyd@bath.ac.uk)

Dr Catherine Butler  
[c.a.butler@bath.ac.uk](mailto:c.a.butler@bath.ac.uk)

# Appendix T – Consent form

Participant Identification Number:



## CONSENT FORM

**Title of Service Improvement Project: Exploring who is referred to the Family and Couples Therapy (FaCT) Service and why**

**Name of Researcher: Samantha Lloyd**

Please initial box

1. I confirm that I have read the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I agree to the audio recording of my participation in this research. I understand that it will be used  for research purposes only and not available to anyone outside the direct research team. I understand that it will be stored confidentially and anonymously and destroyed once the research has finished.
4. I agree to take part in the above study.

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

## **Appendix U – Lay summary and interview schedule**

**Improving appropriate referrals to the Family and Couples Therapy (FaCT) Service through exploring who is referred and why.**

**What is this project about and why is it needed?**

Family, couple and systemic therapies are recommended for a number of mental health problems in adults. Studies have also shown that couple and family based interventions are as effective as individual treatments and medication for difficulties such as depression (e.g. Carr, 2014). Although it is suggested that this type of approach is offered where appropriate, this is not always the case (Lebow et al, 2012).

The South Gloucestershire Psychological Therapies Service offers a range of psychological interventions including systemic Family and Couple Therapy. At present this is not used to the full capacity and there is the possibility of supporting more service users and their partners and / or families with a range of difficulties.

We know that staff teams who can refer into the service will have ideas about who is suitable to refer to the service, which may or may not fit with guidelines on who might benefit from this type of therapy.

**What are the aims of the project?**

- 1) To find out about the kinds of difficulties people who are currently accessing the services are experiencing.
- 2) To explore who, when and why local teams would consider referring to FaCT.
- 3) To use this information to develop ways of encouraging and supporting local referrals from these teams, e.g. through circulating information about the service.

**What does the project involve?**

There are three main parts to this project:

- 1) Use referral information to establish the types of difficulties and diagnoses that people are currently referred into the service for.
- 2) Gain the views of potential referrers through:
  - a) Interviews with 8 referrers (please see possible interview questions below)
  - b) A short questionnaire to other referrers who may not want to be interviewed
- 3) Use this information to develop ways of influencing potential referrers' ideas about the FaCT service to improve appropriate referrals.

**Who is carrying out this project?**

This service improvement project is being carried out by Sam Lloyd, Trainee Clinical Psychologist from the University of Bath, supervised by Catherine Butler and Stu Brooke.

**Interview question areas:**

***Experience of referring into FaCT***

- What is your experience of referring into FaCT?
- How often do you make referrals to the service?

***Factors influencing decisions***

- How are decisions considering the most appropriate therapy made?
- What are the factors that would influence your decision to refer / consider referring an individual to FaCT?
- Are there particular difficulties / diagnoses you would refer for?
- What are the factors that would mean you would be less likely to consider someone for FaCT?
- Is there anything that would make you more likely to refer to FaCT in future?

***Focus on systemic factors***

- Do you ever see other members of a client's system?
- How much information do you generally have available on a client's family / system around them?
- Are systemic factors considered when thinking about the most appropriate therapy?
- If you were aware of relationship difficulties, how might this affect your thinking?