# Interpretation bias and anxiety in people with Parkinson's disease

Beigi, Mazda

*Awarding institution:*
King's College London

# Volume I

# Systematic Literature Review

# Empirical Project

**Mazda Beigi**

**Institute of Psychiatry, Psychology and Neuroscience**

**King's College London**

**Thesis submitted in partial fulfilment for the degree of**

**Doctorate in Clinical Psychology 2019**

**Acknowledgements**

My thanks go to Prof. Richard Brown for his guidance and invaluable expertise. Thank you for being a calming presence throughout the three years. Thanks also to Dr Lonneke van Tuijl whose experience and knowledge have been essential. Thank you for the time you have dedicated to the project. I would also like to thank Dr Janet Wingrove for her advice and suggestions.

I would like to thank my parents for their unconditional love and support. My achievements are entirely a reflection of what you have both enabled me to accomplish. Thank you to my wife Aidah for her love and encouragement. You have always been there to support me. Finally, I would like to thank my son Faris who is the most extraordinary source of joy and love. You will always be the most cherished part of my life.

**Overall Table of Contents**

**Systematic Literature Review**

# Interpretation bias in adults with physical health conditions: a systematic review of its presence, associated factors and modifiability.

**Supervisor: Richard Brown**

## Table of Contents

**List of Tables and Figures**

**Abstract**

**Background**: studies have demonstrated that interpretation bias (IB) occurs in a wide variety of people, particularly those with high levels of worry and affective disorders. Studies have also identified that interpretation bias may exists in people with physical health conditions although to date, no review has assessed this effect in general.

**Objectives**: this review aims to clarify, (i) the presence of IB in people with physical health conditions relative to healthy controls, (ii) the association between IB and anxiety, (iii) the association between IB and physical illness symptom (including controlling for affective symptoms), (iv) whether IB can be altered through cognitive bias modification, and (v) whether methodological approaches may inform our understanding of this process in physical health conditions.

**Method**: we specifically identified studies that assessed interpretation bias across a range physical health conditions published in print or on-line up to April 2019. The review conducted searches from a range of platforms (PubMed, Web of Science and OvidSP) to identify peer reviewed journal articles and applied a quality assessment method developed by a previous systematic review of interpretation bias. Only quantitative studies that involved assessment of interpretation bias in adults were selected. Studies that only assessed other forms of cognitive bias and child/adolescents were excluded from the study.

**Results**: twelve studies were identified that directly investigated interpretation bias, of which eleven found evidence of bias in patients when compared to controls. Anxiety was found to be associated with interpretation bias in only one study, indicating that bias did not simply reflect affective state. Six studies investigated whether physical Illness severity was associated with interpretation bias, of which four papers found a significant positive effect. Only one study applied bias modification to participants with physical health conditions. This study presented an improvement in interpretation bias for patients with fear of cancer recurrence. Methodological considerations revealed that a wide variety of bias detection paradigms were used, each with their own implications for how

interpretation bias was examined and the results interpreted in terms of psychological processes.

**Conclusion**: the sample of studies that have investigated interpretation bias are small in size and largely focused on chronic pain and CFS with few studies in patients with more common physical health conditions. However, the studies identified consistently demonstrate interpretation bias in people with specific physical health conditions assessed relative to controls, regardless of the paradigms used. Further research is still required with a broader range of common physical health conditions to establish the scale of interpretation bias. While we did not find consistent evidence for an association between anxiety and IB, illness severity did have an effect in four studies. The review discusses some methodological and theoretical principles that may be relevant to the direction of future research.

## Introduction

### Cognitive bias

In relation to mental health, cognitive biases are often explained through Becks schema theory (Beck, 1976; Beck & Emery, 1985), where maladaptive beliefs of oneself and the world around us, can negatively alter appraisals of often benign experiences. This process programmes individuals to become hyper-vigilant to ambiguous cues, through negative appraisals of some situations. Cognitive biases can occur through the formation of persistent attention to negative cues, inaccurate interpretations of what those cues mean and unhelpful memories that trigger recall of previous overestimations of threat. As a consequence, some people find it difficult not to attend to potential threats in their environment and automatically interpret them in negative ways (Mathews & Mackintosh, 1998). Hirsch and colleagues (2006) first described the combined cognitive biases hypothesis as the process through which cognitive biases interact and are maintained. This theory postulates that biases are not developed through entirely separate systems but rather; operate simultaneously or in succession (Hirsch, Clark, & Mathews, 2006). A common belief is that biases in both attention and interpretation are regulated by an attentional control system (Eysenck, Derakshan, Santos, & Calvo, 2007). Studies have demonstrated that people with poor control over where their attention can be drawn (in this case, uncontrollably being drawn towards ambiguous threats), demonstrate higher levels of both biased attention and interpretation (Heathcote et al., 2015; Salemink & Wiers, 2012).

### Interpretation bias (IB)

Interpretation in particular, has been described as a process through which ambiguity can be resolved (Hirsch, Meeten, Krahé, & Reeder, 2016). Again, these interpretations are largely dependent on the formulation of schemas that inform the way in which threat appraisals are understood. Studies have suggested that while IB is occurring, attentional resources are triggered that specifically focus on negative information while processing stimuli (Everaert, Jonas; Tierens, Marlies;

Uzieblo, Kasia; Koster, 2013). This process is connected to Mathews and Macintosh's (1998) threat evaluation system where both positive and negative interpretation systems are involved in the general interpretative process but later become dominated by threat evaluations in some people (Mathews & Mackintosh, 1998). It is argued that within this process, the positive evaluation system is generally stronger for most people (Taylor & Brown, 1988) indicating that we have an overriding tendency to assume positive interpretations. It is thought that the reason for negative evaluations becoming dominant in some people is a result of mood disturbances and/or developmental processes that adjust schemas. Therefore, biases in general can be positive or negative. It is negative biases of ambiguous situations that are considered to be indicative of mood related difficulties.

Although studies have shown a connection between higher levels of depression and more significant levels of IB in participants, these findings have been subject to methodological criticism such as the small number of studies and small effect sizes reported (Everaert, Podina, & Koster, 2017). It is noted that some studies have not demonstrated an association between IB and depression (Mogg, Bradbury, & Bradley, 2006; Moser, Huppert, Foa, & Simons, 2012), while others that have shown a relationship, have used anxiety relevant themes deemed to be more representative of worry than depression (Hirsch et al., 2016).

The link between IB and anxiety has been more widely explored in the literature than depression. Studies involving healthy participants and those with anxiety disorders have demonstrated an association between negative biased interpretations and high trait-anxiety scores (Eysenck, Macleod, & Mathews, 1987; Mathews, Mogg, May, & Eysenck, 1989). Studies have also demonstrated that participants who rate higher on anxiety measures apply threatening interpretations to ambiguous cue words (Mathews et al., 1989) and more complex sentence structures (Eysenck, Mogg, May, Richards, & Mathews, 1991). More recent studies have identified that anxious participants demonstrate IB of ambiguous scenarios (Hirsch & Mathews, 2012). Mathews and Mackintosh (1998) have hypothesised

that those with high levels of anxiety would once have been subject to the same internal bias for positive evaluations as others (Taylor & Brown, 1988) but that this mechanism would have shifted to a strengthening of the threat evaluation system in line with developments in negative schemas (Mathews & Mackintosh, 1998). As a consequence, those with higher levels of anxiety are likely to represent people with strengthened threat evaluation systems that make IB more prominent.

The effects of IB have been documented in various anxiety disorders. Studies in social anxiety have demonstrated that IB of ambiguous social interactions are more evident in client groups than healthy controls and high trait anxiety participants (Amir, Beard, & Bower, 2005). Hirsch and colleagues (2016) have argued that negative assumptions triggered in social anxiety interact with threat related interpretations, resulting in a cycle of worry where both processes encourage negative appraisals. This is consistent with findings from other experiments identifying IB in social anxiety (Constans, Penn, Ihen, & Hope, 1999; Huppert, Foa, Furr, Filip, & Mathews, 2003; Huppert, Pasupuleti, Foa, & Mathews, 2007). Participants with generalized anxiety disorder (Eysenck et al., 1991; Hayes, Sarra; Hirsch, 2007) and panic disorder also show negative IB, with one study even arguing that IB can predict onset of panic disorder (Woud, Zhang, Becker, McNally, & Margraf, 2014).

Methods for exploring interpretation bias

When exploring IB, studies have used a range of methods to determine its presence. Some studies have used homophones to detect preferences for certain words (Eysenck et al., 1987, 1991; MacLeod, 1990). Homophones consist of words that have distinct meanings and spellings (although sometimes spelling can be very similar) but sound the same when spoken. For example, pain/pane or night/knight. IB tasks have developed a range of experimental procedures to explore instinctive preferences for some words over others. For example, in physical health conditions, studies have developed a series of illness and non-illness related words. The rational is that participants with certain conditions will demonstrate a bias towards illness related interpretations of words due to heightened awareness and

worry for those consequences based on their experiences. Conversely, control participants who have different experiences and world views are not expected to demonstrate the same biases for the same homophones. This may be due to what has been describes as a frequency bias for different sets of participants (Pincus, Pearce, & Perrott, 1996). This refers to the frequency with which people are exposed to certain words.

Another method for exploring IB is to use homographs, which constitute words that are spelt the same but have different meanings (and in some cases different sounds, e.g. tear can refer to a rip or someone crying). Similar to homophones, homographs have been included in word generation tasks to explore biases that participants may have towards one particular negative variation of a word over another more positive/neutral interpretation.

As well as studies that have looked into homophonic and homographic cue associations, other studies have deployed different strategies to investigate IB. One such strategy is to develop scenarios consisting of generally ambiguous situation that participants read and form impressions of. These experiments typically ask participants to provide responses to each scenario to gauge their impression (interpretation) of what the statement represents. In these cases, participants are provided several interpretations to indicate whether the scenario represents something positive, negative or neutral/ambiguous (A. M. Hughes, Chalder, Hirsch, & Moss-Morris, 2017). Specific responses to these scenarios are said to demonstrate the degree to which participants negatively interpret ambiguous situations and therefore indicate whether an IB is present (A. M. Hughes et al., 2017).

Physical health conditions

Physical health conditions have been categorised as a range of disorders including arthritis, chronic fatigue syndrome (CFS) and chronic pain. A recent study in Australian populations placed the prevalence of physical health conditions at 32.2% (Teesson et al., 2011) of people in the general public. Rates in the UK have indicated consistent estimates, that 30% of people live with long term physical

health issues (Naylor et al., 2012). It is also reported that 46% of people in the UK living with a mental health disorder experience physical health difficulties (Naylor et al., 2012), indicating that the two are highly associated.

Physical health and anxiety

Comorbidity between physical health conditions and affective disorders are becoming increasingly recognised in disorder management. An assessment of physical conditions with comorbid disorders (anxiety and depression) reported that obesity, diabetes, asthma, hypertension, arthritis, heart disease, back pain and chronic headaches were all comorbid with mood difficulties, particularly anxiety (Scott et al., 2007). Scott and colleagues (2007) surveyed people from 17 different countries and found estimates ranging between 1.2% – 4.5% of people with physical health conditions experiencing comorbid anxiety and depression, which have been diagnosed. Another study investigating the prevalence of anxiety disorders in older adults with a diagnosis of a physical health disorder reported ratings of 9.6% (arthritis), 11.2% (back pain), 9% (heart disease), 8.1% (diabetes) and 13.3.% (lung disease) to name a few (El-Gabalawy, Mackenzie, Shooshtari, & Sareen, 2011). Other studies have reported direct comorbidity between anxiety and arthritis, migraine and respiratory disease (J Sareen et al., 2006). A more recent study reported that those with arthritis (6.8%) and cardiovascular disease (6.4%) also reported elevated comorbid levels of anxiety disorders (El-Gabalawy, Mackenzie, Pietrzak, & Sareen, 2014). Findings also revealed that anxiety was more prominent than depression in participants with arthritis (El-Gabalawy et al., 2014) relative to healthy populations. Further investigation by El-Gabalawy and colleagues (2011) revealed that this combination of arthritis and anxiety resulted in more severe scores on quality of life scales than those who only reported arthritis. This trend has also been noted in other studies (J Sareen et al., 2006). Finally, surveys have reported that 32.2% of those with physical health conditions reported affective or anxiety disorders, which was higher than rates in healthy populations (Teesson et al., 2011).

The nature of anxiety and illness severity in physical health conditions

Studies have suggested that elevated levels of anxiety disorders in people with physical health conditions are connected to worries regarding life altering physical impairments (J Sareen et al., 2006). For instance, there is a consistent trend towards identification of comorbid panic disorder with chronic pain (McWilliams, Cox, & Enns, 2003; P. J. Norton & Asmundson, 2004), thought to be a result of elevated worry sensitivity based on beliefs that something will go wrong (Jitender Sareen, Cox, Clara, & Asmundson, 2005). This presents a complex interaction between mood and physical symptoms contributing towards anxiety. There is however a shortage of direct investigations into the nature of anxiety in physical health difficulties and to what extent this is mediated by illness severity. It seems reasonable to assume that the same schemas that deviate towards threat appraisals are engaged in physical health conditions but in a more focused narrative dependent on the physical impairments in question. In this sense, one may expect anxiety in physical health conditions to present in subtly different ways to anxiety in others. For example, it is widely believed that those with chronic pain are subject to schema related distortions that contribute to their disorder's development and maintenance (Ingram, Miranda, & Zindel V, 1998). A common theory in those experiencing chronic pain is that psychological factors account for at least some degree of patients' experience of physical discomfort (Eccleston & Crombez, 1999). In light of this, the cognitive behavioural model has been applied to the treatment of chronic pain to address the link between attention and anxiety (Macleod, 1999; Williams, Mathews, & MacLeod, 1996). In a review of cognitive bias studies in chronic pain, Pincus and Morley (2001) propose a schema enmeshed model of pain consisting of three schemas representing pain, illness and the self (Pincus, Tamar; Moreley, 2001). This indicates that anxiety in chronic pain may uniquely focus on threat evaluations specific to pain related cues, suggesting that pain is as much symptom as it is illness focused. Although cognitive behavioural treatments have been developed for management of symptoms in chronic pain, more studies are needed to explore the efficacy of similar approaches for other physical health conditions.

Previous systematic reviews of interpretation bias in physical health conditions

IB studies including participants with physical health conditions offer a helpful insight into the relationship between these conditions and anxiety. To date, there have been three systematic reviews in this area, two addressing cognitive bias in chronic pain (Pincus, Tamar; Moreley, 2001; Schoth & Liossi, 2016) and one in CFS (Hughes et al., 2016). All three reviews reported reliable and consistent accounts of IB in studies they identified. However, they report more variable associations between bias and anxiety. Pincus and Morley (2001) reviewed all attention (9 studies), interpretation (4 studies) and recall bias (8 studies) articles involving participants with chronic pain. They report that their studies did not clearly differentiate between biases related to clients being in pain at the time of testing, illness related biases or mood. They argue that self-related stimuli are the most potent aspect of the schema enmeshment model of pain. This implies that bias largely depends on evaluations based on disorder specific experiences. Schoth and Liossi (2016) were the only review of the three to specifically focus on IB (6 studies). They conducted a systematic review and meta-analysis of studies involving chronic pain, reporting that although IB is consistently identified, the range of paradigms used to investigate this were limited. Again they point to a lack of clarity regarding the nature of IB in chronic pain and call for more research addressing the role of anxiety and illness severity in making responses. Furthermore, Schoth and Liossi (2016) discussed the merits of cognitive bias modification in chronic pain, given that it has been helpful in affective disorders. However, the authors again highlight the lack of investigation using varied paradigms to explore which specific modalities (scenarios, images, words etc.) are most effective. Finally, Hughes and colleagues (2016) performed a systematic review of IB (4 studies including a PhD article) in CFS. This study also included an investigation of attention bias (6 studies). The authors identified the presence of attention and IB in their sample of studies but argued that this did not seem to be correlated with anxiety or depression.

Cognitive bias modification

The process of modifying cognitive biases such as those used to address IB are modelled on those relevant to cognitive behavioural therapy. In particular, bias modification targets negative automatic thoughts and repetitive thinking to shift thinking patterns (Hirsch et al., 2016). Hirsch and colleagues (2016) argue that bias modification may be beneficial over CBT as it requires less effortful attentional resources in order to promote change. Studies have suggested that repeated exposure to stimuli when modifying bias for interpretations may alter state and trait anxiety which are long lasting (Beard, 2011). One important aspect of bias modification for interpretations is the active role that participants have to play in generating responses (Mathews & Mackintosh, 2000) making it a collaborative process.

Bias modification was first demonstrated by Grey and Mathews (2000) who used a cognitive bias modification for interpretation (CBM-I) paradigm to shift biases. This paradigm involves participants resolving sentence strings either positively or negatively. Their study involved two CBM-I groups, one designed to promote negative interpretations and another designed to promote positive interpretations. The study identified that those participants involved in the positive CBM-I group demonstrated less IB of ambiguous cues to others. Research has generally established that those with IB do benefit from bias modification, with those receiving intervention reporting less IB post treatment (Grey & Mathews, 2000; Mathews & Mackintosh, 2000).

One particular review has suggested that bias modification studies have a stronger effect on IB than attention bias (Hallion & Ruscio, 2011). The same review also identified that while cognitive bias modification did not have a reliable effect on improving depression, it did consistently improve anxiety (Hallion & Ruscio, 2011). This is thought to be consistent with models of anxiety stating that low level systematic processing biases for negative information are present in people with anxiety (MacLeod & Mathews, 2012). A separate study supported the effectiveness of CBM-I in participants but pointed to a shortage of studies in clinical settings

(Beard, 2011). Beard and colleagues (2011) did however report that a combined CBM-I and attention bias modification intervention did report improvements in social anxiety symptoms with most participants subjectively stating that they found CBM-I more helpful. A recent systematic review of twelve published meta-analyses of cognitive bias modification has explored the benefits of CBM-I (Jones & Sharpe, 2017). The review included studies that addressed both attention and interpretation bias, with three studies involving CBM-I (one study fully dedicated to interpretation bias). Of the three studies exploring CBM-I, Jones and Sharpe (2017) reported that the intervention improved biases with a medium to large effect size (ES = 0.52-0.81). These qualitative improvements are consistent with another meta-analysis assessing the effect of CBM-I (Menne-Lothmann et al., 2014). However, Menne-Lothmann and colleagues (2014) reported smaller effect sizes (.08). Both studies stress the need for more robust findings to support the evidence for CBMI-I benefits, given the moderate effect sizes published. These studies indicate that while CBM-I reports improvements in anxiety related disorders, there are slight reservations regarding the robustness of these findings given the small number of studies and effect sizes reported. It is also noted that many of these studies have applied combined interpretation and attention bias modification interventions, making it difficult to support an entirely CBM-I orientated intervention.

Objectives

This review aims to address several questions in light of the topics addressed above. To the best of our knowledge, no reviews have investigated the general prevalence of IB across the range of physical health conditions. One recommendation from the three existing reviews in chronic pain and CFS is that more research is required to strengthen arguments regarding the presence of IB in those conditions. Our review aims to address the concern regarding power, by broadening the scope for IB application to physical health conditions in general, in order to examine more studies. Furthermore, given the specific evidence for comorbid anxiety issues in people who have physical health conditions and the role

it may play in IB this review aims to investigate this further. Connected to this point, previous studies have questioned whether anxiety in physical health conditions is similar in nature to affective disorders or specific to symptoms related to physical impairments. This review therefore aims to examine the possible relationship and interactions between IB, anxiety and illness severity. It is also noted that to date, no reviews have addressed the modifiability of bias in physical health conditions. This is considered to be an important evolution of research in this area, given the beneficial clinical applications for improving anxiety in these populations. As mentioned above, treatments are being developed for anxious clients with affective disorders as a result of the role IB in anxiety. If research in physical health conditions reveals a similar process in these conditions, CBM-I could prove to be a beneficial intervention. This review aims to explore whether this has been demonstrated in existing research. Finally, given concerns raised regarding methodological differences, we seek to explore the prevalence of IB across different modalities to explore how robust its identification may be.

In order to address the above topics for consideration, the following questions have been identified for the purpose of this review:

1. Is there evidence for the existence of IB in people with physical health conditions?

2. Is there evidence for an association between IB and anxiety in this population?

3. Is there evidence for an association between IB and disorder severity?

4. Is there evidence for the modification of IB in this population and any associated changes in anxiety?

5. What are the methodological aspects of the assessment of IB and/or bias modification and their impact on Questions 1-4?

## Methods

### Procedure

In developing an approach to searching for and extracting data, the review modelled its methodology on the well-established, Preferred Reporting Items for Systematic Review and Meta-analysis protocols (PRISMA-P) (Shamseer et al., 2015) method.

### Inclusion criterion

1. All IB studies including studies referred to as 'cognitive bias' in order to capture broader terms.
2. Only studies that involved physical health conditions were included. This included reference to physical condition and long term conditions for a broader reference to how these terms may have been labelled.
3. We included CFS and pain as both conditions include perceived and/or physical impairments that are consistent with physical health issues.
4. Only quantitative studies were included in the final extraction of data. Only studies that quantitatively measured IB were therefore included.
5. Only adults were included in the study, therefore a cut-off of 18 was implemented with no maximum age. This was primarily in order to insure a final sample of studies that were comparable for age, given that physical health conditions are expected to involve older age populations.
6. No date restrictions were applied to the search.
7. All studies were peer reviewed papers published in journal articles.
8. Only studies published in English were included.

### Exclusion criterion

1. Studies that only assessed other cognitive biases (such as attention and/or recall bias) but not IB.

2. Studies presenting only qualitative evidence.
3. Studies in animals.
4. Studies that did not use groups of participants entirely consisting of physical health conditions.
5. Studies that investigated symptoms of physical health conditions on healthy participants.

Search Strategy

Three separate journal article search platforms were used to identify relevant studies: PubMed, Web of Science and OvidSP (including PsychINFO database). These searches were further supplemented by additional searches in light of relevant sounding articles found in some review studies identified. This involved reading articles and identifying studies that were not captured by the original search, through reference lists.

In light of different search parameters and rules in each of the platforms used, slightly different search scripts were developed for each platform.

For each search, a broader term for IB was used to ensure that all relevant papers would be captured. Broader terms for physical health conditions were also used to ensure that any papers that may have referred to these conditions in a slightly different way were included in search results.

**When using PubMed, the following search script was applied:**

("Interpretation bias*"[title/abstract] OR "cognitive bias*"[title/abstract] AND "anxiety") OR ("Interpretation bias*"[title/abstract] OR "cognitive bias*"[title/abstract] AND health* condition$) OR ("Interpretation bias*"[title/abstract] OR "cognitive bias*"[title/abstract] AND physical health* condition$) OR ("Interpretation bias*"[title/abstract] OR "cognitive bias*"[title/abstract] AND long?term condition$) OR ("Interpretation bias*"[title/abstract] OR "cognitive bias*"[title/abstract] AND long?term health condition$) OR ("Interpretation bias*"[title/abstract] OR "cognitive

bias*”[title/abstract] AND chronic condition$) OR (“Interpretation bias*”[title/abstract] OR “cognitive bias*”[title/abstract] AND chronic health* condition$) OR (“Interpretation bias*”[title/abstract] OR “cognitive bias*”[title/abstract] AND Chronic Disease*).

**When using Web of Science, the following search scripts was used:**

(“Interpretation bias*” OR “cognitive bias*” AND “anxiety”) OR (“Interpretation bias*” OR “cognitive bias*” AND health* condition$) OR (“Interpretation bias*” OR “cognitive bias*” AND physical health* condition$) OR (“Interpretation bias*” OR “cognitive bias*” AND long?term condition$) OR (“Interpretation bias*” OR “cognitive bias*” AND long?term health condition$) OR (“Interpretation bias*” OR “cognitive bias*” AND chronic condition$) OR (“Interpretation bias*” OR “cognitive bias*” AND chronic health* condition$) OR (“Interpretation bias*” OR “cognitive bias*” AND Chronic Disease*).

**Finally, when using OvidSP (including PsychINFO), the following search script was used:**

(Interpretation bias* OR cognitive bias* AND anxiety) OR (Interpretation bias* OR cognitive bias* AND health* condition$) OR (Interpretation bias* OR cognitive bias* AND physical health* condition$) OR (Interpretation bias* OR cognitive bias* AND long?term condition$) OR (Interpretation bias* OR cognitive bias* AND long?term health condition$) OR (Interpretation bias* OR cognitive bias* AND chronic condition$) OR (Interpretation bias* OR cognitive bias* AND chronic health* condition$) OR (Interpretation bias* OR cognitive bias* AND Chronic Disease*).

<u>Management of initial search results</u>

Results from all three platforms were exported into a single excel sheet where they were sorted alphabetically and conditional formatting applied to highlight all duplicates. Those papers whose relevance could not be determined through title alone were left in the list of accepted studies to ensure a conservative approach. However, those studies that clearly did not meet the inclusion criteria or did meet

the exclusion criteria were removed. For example, some papers were clearly labelled as child or animal studies. More detailed selection involved reading abstracts and methods sections to identify whether studies involved interpenetration bias and participants with physical health conditions.

Data extraction

When reporting information, existing guidance from Shamseer and colleagues (2015) was followed. In this article, the authors discuss best practice guidelines, specifically for how to report data collected from a systematic review. Attention was given to guidelines for search strategies to ensure comprehensiveness of terms and different search terms used across platforms (Shamseer et al., 2015). We also followed their guidelines on selection process regarding how studies are screened and reviewed by independent researchers.

Where reported, quantitative effect sizes of the magnitude of IB relative to controls was extracted. Where not reported, effect sizes were estimated from the group data using Cohen's *d* where possible.

Quality assessment

Quality assessment of all final studies identified was based on a separate systematic review on IB (Schoth & Liossi, 2016). Minor alterations were made to this assessment system to make it more inclusive of all physical health conditions (see Appendix A). This involved removing specific reference to pain symptoms and replacing them with terms inclusive of a broad range of physical health conditions. We also removed one question referring to depression, as this was not the main focus of this review. Scores ranged from 0-14, with higher scores indicating better quality. One assessment criteria regarding depression was removed from Schoth & Liossi's (2016) quality assessment tool as it was not relevant for the purposes of this review. One question was added to address bias modification. Ratings were conducted by a primary and secondary researcher. The primary researcher extracted relevant data and attributed an overall quality rating before the secondary researcher reviewed these decisions. Where differences were recorded,

a compromised score was agreed through discussion (71.4% agreement rate before discussion).

## Results

Searches were completed on 15/04/2019. Initially, search results returned 3620 studies, however, an additional four studies were later added through reading of other systematic reviews that had been identified in papers from the initial search. Duplicates were removed from the sample, leaving 2279 articles. The remaining article titles were screened to determine whether they were related to the desired topic. Where it was unclear from the title whether a study was relevant or not, the abstract was reviewed for further details. This process removed a further 2252 articles, leaving 28 for full text assessment. This whole process resulted in the identification of 13 eligible studies for data extraction and quality assessment (see figure 1).

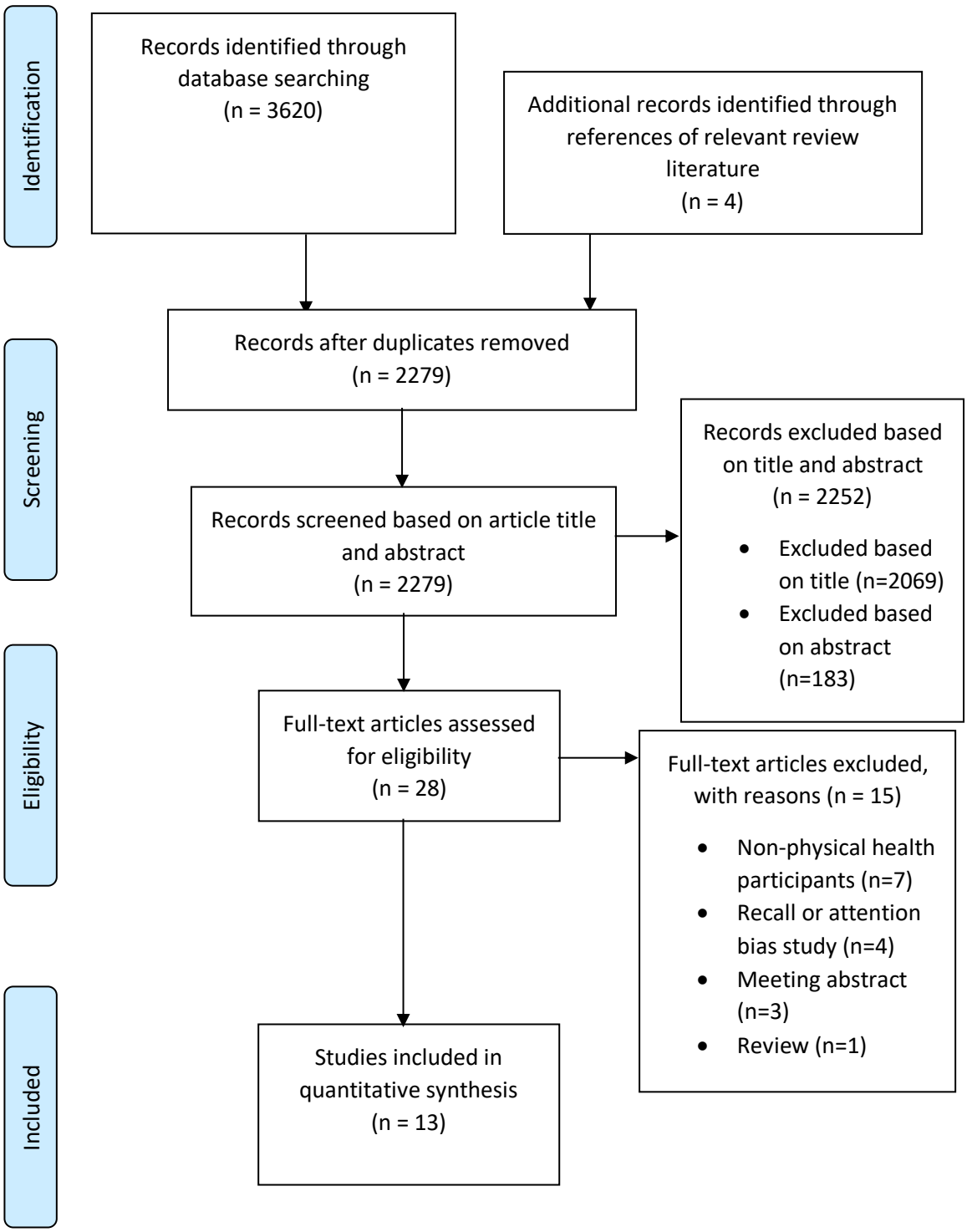


Figure 1. PRISMA Flow Diagram

General overview of studies

In general, the quality of the studies was high (see table 2, Mean=10.1/15, SD=1.7). Only one study could be found that applied a bias modification treatment for participants (Lichtenthal et al., 2017). The majority of studies involved participants with either chronic pain (N=5) or CFS (N=4). Other studies included chronic headache (N=2), congenital heart disease (N=1) and breast cancer survivors (N=1). Most studies 11/13) had a measure of anxiety and depression, often (7/13) the Hospital Anxiety and Depression Scale (HADS). All included studies included a healthy control group for comparison; however, these were not always age matched. It is notable that a range of methods have been used to assess IB across the physical health conditions investigated.

As mentioned above, to date, there are three systematic reviews assessing IB in chronic pain and CFS. The aim of this review is to address the objectives listed in the introduction above. This section will focus on extraction of data relevant to those five questions.

Table 1. Demographic details

| Author | Conditions assessed | Sample size | Gender | Mean age |
|---|---|---|---|---|
| **Lichtenthal et al 2017** | Breast Cancer Survivors | N=99 overall who completed pre-treatment measures. AIM-Neutral = 31, AIM-Meaning = 33 and Control Condition = 33 | 100% female | AIM-FBCR = 55.8, Control Condition = 53.9 |
| **Hughes et al 2017** | Chronic Fatigue Syndrome | CFS (n=52), Healthy Control (n=51) | CFS (32% female), Healthy Control (32% female) | CFS (37), Healthy Control (32) |
| **Schoth et al 2018** | Chronic Headache | Chronic Headache (n=28), Healthy Controls (n=34). | Chronic Headache (79% female), healthy Controls (71% female) | Chronic Headache (39.11), healthy Controls (37.44) |
| **Schoth et al 2016** | Chronic Headache | Chronic Headache (n=17), Healthy Controls (n=20). | 81% female | Chronic Headache (38.76), healthy Controls (35.55) |
| **Hughes et al 2018** | Chronic Fatigue Syndrome | CFS - Dutch (n=38), CFS - UK (n=52), Healthy Controls - UK (n=51) | CFS - Dutch (16% female), CFS - UK (32% female), Healthy Controls - UK (32% female) | CFS - Dutch (40), CFS - UK (39), Healthy Controls - UK (34) |
| **Karsdorp et al 2008** | Congenital Heart Disease | Congenital Heart Disease (n=66), Healthy Controls (n=50) | Congenital Heart Disease (55% female), Healthy Controls (54% female) | Congenital Heart Disease (33, SD=8.83), Healthy Controls (29.32, SD=8.96). |
| **Pincus et al 1994** | Chronic pain | Exp.1: Pain patients (n=107), Physiotherapists (n=67), Healthy controls (n=94). | Pain patients (76% female), Physiotherapists (78%), Healthy controls (53%). | Pain patients (53.2, SD=14.9), Osteopaths (30, SD=9.3), Healthy controls (38.4, SD=12.9). |

| | | | | |
|---|---|---|---|---|
| | | Exp. 2: Pain patients (n=47), Osteopaths (n=43), Healthy controls (n=25). | Pain patients (77% female), Osteopaths (67%), Healthy controls (64%). | Pain patients (41, SD=14), Osteopaths (30, SD=8), Healthy controls (23, SD=8). |
| **Pincus et al 1996** | Chronic pain | Pain patients (n=20), Healthy controls (n=20) | Pain patients (55% female), Healthy controls (unreported) | Pain patients (47.6, SD=11.12), Healthy controls (48.7, SD=10.26) |
| **Edwards and Pearce 1994** | Chronic pain (rheumatology) | Pain patients (n=38), Healthcare professionals (n=28), Healthy controls (n=38) | Pain patients (71% female), Healthcare professionals (100% female), Healthy controls (50% female) | Pain patients (46.8, SD=17.2), Healthcare professionals (31.3, SD=7.7), Healthy controls (29.6, SD=14.1). |
| **Moss-Morris and Petrie 2003** | Chronic Fatigue Syndrome | CFS patients (n=25), Healthy controls (n=24) | CFS patients (88% female), Healthy controls (87.5% female) | CFS patients (47.72, SD=11.79), Healthy controls (46.17, SD=11.60) |
| **Martin and Alexeeva 2010** | Chronic Fatigue Syndrome | CFS patients (n=33), Healthy controls (n=33) | CFS patients (52% female), Healthy controls (67% female) | CFS patients (38.1, SD=16.1), Healthy controls (32.3, SD=9.2) |
| **Khatibi et al 2015** | Chronic pain | Pain patients (n=50), Healthy controls (n=25) | Pain patients (62%% female), Healthy controls (56% female) | Pain patients (43.6, SD=9.8), Healthy controls (36.2, SD=6.2). |
| **McKellar et al 2003** | Chronic pain | Pain patients (n=80), Acute pain (n=50), Medical staff (healthy controls) (n=49) | 100% male | Pain patients (51.22, SD=13.10), Acute pain (60.92, SD=8.96), Medical staff (healthy controls) (41.21, SD=9.38) |

Table 2. Interpretation bias summary

| Author | Study design and aim | IB paradigm | CBM Intervention | Other measures assessed | Findings | Quality assessment |
|---|---|---|---|---|---|---|
| **Lichtenthal et al 2017** | Randomized trial with (i) Attention and Interpretation modification (AIM) for Fear of Breast Cancer Recurrence (AIM-FBCR) for neutral versions of AIM (AIM-Neutral), (ii) a meaning version of AIM (AIM-Meaning) and (iii) a Control Condition.<br>To examine the feasibility, acceptability and efficacy of AIM-FBCR. | Word Sentence Association Paradigm. Involved 118 trials of word sentence pairings. | Attention and Interpretation modification (AIM) for Fear of Breast Cancer Recurrence (AIM-FBCR). Joint intervention for attention and IB. | Concerns About Recurrence Scale (CARS). Assessments were measured pre, post and three month follow-up intervention. | AIM-FBCR significantly reduced health related worries in both groups compared to controls. CARS results revealed the overall rate of improvement was better for patients (p=.019, estimated ES = .05). There was no significant improvement in the AIM-FBCR group at pre (T1) vs. post (T2) intervention when compared to controls (p=.095, ES = .35) but there was a significant improvement at the post (T2) vs. 3 month post (T3) intervention comparison (p=.005, ES = .54). However, a reliable change index calculation of scores in the AIM-FBCR assessing improvements between patients and controls was not significant (p=.063). | 9 |

| Author | Study design and aim | IB paradigm | CBM Intervention | Other measures assessed | Findings | Quality assessment |
|---|---|---|---|---|---|---|
| **Hughes et al 2017** | Assessment of both attention and IB in participants with CFS, compared to that of healthy controls. | Scenario based Recognition Task | None | Chalder Fatigue Questionnaire, Work and Social Adjustment Scale, Cognitive Behavioural Responses Questionnaire, Clinical Interview Schedule Revised | CFS group made fewer positive (p<.001, Cohen's *d* ES = .71) and more negative interpretations than controls (p=.04, Cohen's *d* estimated ES = .43). No correlations were observed between IB and attentional control for either CFS (p=.41) or controls (p=.10). | 11 |
| **Schoth et al 2018** | Assessment of interpretation, attention and memory bias in chronic headache, compared to that of healthy controls. | Sentence Generation Task. Involved Homographs and pseudo-homographs. Similar design to previous study. | None | Hospital Anxiety and Depression Scale, State-Trait Anxiety Inventory, McGill Pain Questionnaire, Brief Pain Inventory-Short Form and Migraine Disability Assessment Questionnaire. | Chronic headache provided significantly more pain responses to pain words than controls (p=.001, ES=.58) but not neutral words (p=.775, ES=.08). No significant correlations were reported. The chronic headache participants reported significantly higher state (P=.005, ES=.76) and trait (p=.005, ES=.75) anxiety and depression (p.005, ES=.75) scores than controls. | 13 |
| **Schoth et al 2016** | Assessment of interpretation, attention and | Sentence Generation Task | None | Hospital Anxiety and Depression Scale, State–Trait Anxiety | Significantly greater trait anxiety in patients (p<.05). | 13 |

| Author | Study design and aim | IB paradigm | CBM Intervention | Other measures assessed | Findings | Quality assessment |
|---|---|---|---|---|---|---|
| | memory bias in chronic headache, compared to that of healthy controls. | using homographs and pseudo-homographs. | | Inventory, McGill Pain Questionnaire, Brief Pain Inventory–Short Form and MIDAS Questionnaire | Participants differed in their interpretation of stimuli between both groups (p<.001, ES=.01). Significantly more pain responses to sensory-pain words (p=.001, ES=1.19) and disability responses to disability words (p=.040, ES=.71) in the chronic headache group when compared to controls. | |
| **Hughes et al 2018** | Investigation into interpretation and attention bias in Dutch and UK nationals with CFS. Aimed to replicate previous findings in Dutch participants. | Scenario based Recognition Task. | None | Chalder Fatigue Questionnaire, Work and Social Adjustment Scale, Hospital Anxiety and Depression Scale HADS | Dutch and UK CFS participants did not significantly differ in their general CFQ scores (p=.06), WSAS (P=.90) or depression ratings (p=.53). Dutch CFS group endorsed positive interpretations significantly less than controls (p<.001, estimated ES = .89). Conversely, they endorsed somatic (negative) interpretations significantly more than controls (p<.001, | 10 |

| Author | Study design and aim | IB paradigm | CBM Intervention | Other measures assessed | Findings | Quality assessment |
|---|---|---|---|---|---|---|
| | | | | | estimated ES = .56). No significant differences between the two CFS groups for either positive or somatic interpretations. | |
| **Karsdorp et al 2008** | To examine if and how IB in congenital heart disease affects health related quality of life. | Implicit Models of Illness Questionnaire (IMIQ, based on Turk, Rudy, & Salovey, 1986), translated to Dutch. | none | State and trait anxiety inventory (translated to Dutch), Adult Quality of Life Questionnaire | No significant correlations between severity of heart disease, state anxiety, IB and daily functioning. Trait anxiety and IB was mediated by state anxiety ($p>.05$). IB significantly mediated the relationship between state anxiety ($p<.05$) and daily activities ($p<.05$) more strongly in the congenital heart disease group than controls. | 10 |
| **Pincus et al 1994** | Assessment of IB in patients with chronic pain, physiotherapists or osteopaths and healthy controls. Two studies: (i) investigating the relationship between ambiguous cues produced by the three groups of participants and | Study 1: Homographic Word cue generation task | None | Pain intensity scores taken at the end of the task. | No difference between physiotherapists and controls. Pain patients made significantly more pain related associations than physiotherapists (estimated ES=.63) and controls (estimated ES=.66) ($p<.001$ for both). | 6 |

| Author | Study design and aim | IB paradigm | CBM Intervention | Other measures assessed | Findings | Quality assessment |
|---|---|---|---|---|---|---|
| | (ii) investigating the same process and possibility that mood differences between groups affected interpretation of cues. | Study 2: Homographic Word cue generation task | | The Hospital Anxiety and Depression Scale. Pain intensity scores taken at the end of the task. | Pain patients made significantly more pain related associations than both controls ($p<.001$, estimated ES=1.03) and osteopaths ($p<.01$, estimated ES=.47). Significant difference in pain association scores between controls and osteopaths ($p<.05$, estimated, ES=.57). | 6 |
| **Pincus et al 1996** | Assessment of IB on ambiguous homophones in chronic pain and healthy controls using health related cues. | Homophone recognition task | None | The Hospital Anxiety and Depression Scale, Pain rating scale (based on Jensen et al., 1986). | The Pain group interpreted more homophones to be pain related than controls ($p<.0001$). Results were not correlated to differences in mood ($p<.0001$). Pain intensity and duration predicted the number of negative interpretations made ($p<.05$). Anxiety and Depression did not correlate with bias. *Data not provided for effect size calculation | 13 |

| Author | Study design and aim | IB paradigm | CBM Intervention | Other measures assessed | Findings | Quality assessment |
|---|---|---|---|---|---|---|
| **Edwards and Pearce 1994** | Assessment of IB in chronic pain patients, healthcare professionals (nurses and physiotherapists, approximately 1:1 ratio split). | Word stem completion task. | None | None | Chronic pain patients produced significantly more sensory pain words than healthcare professionals and controls ($p<.025$). *Data not provided for effect size calculation | 6 |
| **Moss-Morris and Petrie 2003** | An assessment of interpretive and attention bias in CFS using an ambiguous cues. | Ambiguous cue (homographs) and homophone (2 pairs) task (word cue generation) | None | National Adult Reading Test, Hospital Anxiety and Depression Scale, The two-dimensional Positive and Negative Affect Schedule, The Profile of Fatigue Related Symptoms, The Somatic Checklist (developed from Pennebaker 1982). | CFS participants made significantly more somatic interpretations than controls ($p<.001$, estimated ES=1.09). | 8 |
| **Martin and Alexeeva 2010** | An assessment of interpretation and attention bias in participants with CFS against that of healthy controls. To investigate whether participants with CFS demonstrate illness related IB. | Lexical decision task using homophones. Reaction times were measured. | None | Hospital Anxiety and Depression Scale, The Visual Analogue Scale. | No IB reported ($p>.05$). No significant differences in accuracy scores between CFS participants and controls. Responses to neutral words were significantly faster than responses to illness words ($p=.002$, ES = .19) and social threat words ($p=.020$, ES = .13) but estimated Cohen's *d* effect sizes were small. | 11 |

| Author | Study design and aim | IB paradigm | CBM Intervention | Other measures assessed | Findings | Quality assessment |
|---|---|---|---|---|---|---|
| **Khatibi et al 2015** | Assessment of IB in participants with chronic pain, using a visual, facial expression interpretation task. | Incidental learning, face expression interpretation task. | None | Persian version of the following measures were used: Visual Analogue Scale, Pain Catastrophizing Scale, Fear of Pain Questionnaire | Chronic pain patients demonstrated a bias towards painful faces (p=.03). Significant correlation between IB and pain intensity (p<.001, Cohen's *d* ES = .4). | 10 |
| **McKellar et al 2003** | Investigation of whether IB in chronic pain is a feature of that condition or of experiencing pain. | Homographic word cue generation task. | None | Beck Depression Inventory, State-Trait Anxiety Inventory, Pain Visual Analog Scale, Medical and demographic variable, Chronic pain screening | Results identified that chronic pain patients demonstrated a bias towards pain related words when compared to acute pain (p<.001, estimated ES=.84) and medical staff (p<.001, estimated ES=1.12). | 7 |

Did studies identify interpretation bias?

Of the thirteen studies identified, twelve investigated the effect of IB in physical health conditions. All but one (Martin & Alexeeva, 2010) of the studies identified significant evidence for IB in their patient conditions when compared to controls. In most studies, effect sizes were calculated based in data provided. In general, effect sizes were in the medium range, indicating that results were moderately reliable. However, the variation in effect sizes, even within studies, indicates that more research is required to consolidate the evidence for IB.

Were control groups appropriate?

All of the studies involved healthy control comparison groups to explore differences. Three studies provided a novel approach of including healthcare professions as part of a control comparison, consisting of physiotherapists/osteopaths (Pincus, Pearce, McClelland, Farley, & Vogel, 1994), physiotherapists/nurses (Edwards & Pearce, 1994) or medical staff (McKellar, Clark, & Shriner, 2003). One study included a sample of participants with acute pain as a separate control group (McKellar et al., 2003). Healthcare professionals and those with acute pain were included in these studies to control for language frequency biases. Sample sizes varied across studies from the lowest total n = 37 (Schoth & Liossi, 2016) to largest n = 264 (Pincus et al., 1994). Given the robust evidence for IB in these studies, results do not seem to have been limited by variations in sample and effect sizes.

What paradigms were used to measure interpretation bias?

Studies identified used a range of methodological approaches to investigating IB. Two studies used sentence generation paradigms (Schoth, Beaney, Broadbent, Zhang, & Liossi, 2018; Schoth & Liossi, 2016), two computerised scenario recognition tasks (A. M. Hughes et al., 2017, 2018), three word cue generation (McKellar et al., 2003; Moss-Morris & Petrie, 2003; Pincus et al., 1994), one word stem completion (Edwards & Pearce, 1994), one recognition (Pincus et al., 1996),

one Lexical decision task (Martin & Alexeeva, 2010), one face expression interpretation task (Khatibi, Sharpe, Jafari, Gholami, & Dehghani, 2015) and one using the implicit models of illness questionnaire (Karsdorp, Kindt, Rietveld, Everaerd, & Mulder, 2008). Studies were also differentiated in terms of stimuli used. Four studies used homographic stimuli (McKellar et al., 2003; Pincus et al., 1994; Schoth, Parry, & Liossi, 2016)(McKellar et al., 2003; Pincus et al., 1994; Schoth et al., 2018, 2016), two homophones (Martin & Alexeeva, 2010; Pincus et al., 1996), one used both homophones and homographs (Moss-Morris & Petrie 2003), one visual stimuli based on facial expressions, one incomplete word stems (Edward & Pearce 1994) and three scenario based stimuli (A. M. Hughes et al., 2017, 2018; Karsdorp et al., 2008). The results seem to indicate that a range of methods and stimuli can illicit IB in physical health conditions.

Was anxiety correlated to interpretation bias?

As well as studies employing a wide range of different paradigms to assess IB, the studies identified have also used a range of anxiety measures which may prove to be more problematic. Seven studies measured anxiety using the HADS total scores (A. M. Hughes et al., 2018; Martin & Alexeeva, 2010; Moss-Morris & Petrie, 2003; Pincus et al., 1994, 1996; Schoth et al., 2018, 2016). Three studies measured anxiety using the State-Trait Anxiety Inventory (McKellar et al., 2003; Schoth et al., 2018, 2016). One study used the CIS-R (A. M. Hughes et al., 2017). Two studies did not incorporate a direct measure of anxiety (Edwards & Pearce, 1994; Khatibi et al., 2015). It is notable that the HADS is not an entirely specialized measure of anxiety as it also includes a measure of depression. Studies have suggested that the HADS are a more appropriate measure of distress than anxiety and depression (S. Norton, Cosco, Doyle, Done, & Sacker, 2013). This variability across measures makes the assessment of anxiety and how it contributed to IB complicated as different measures may be reflective of subtly different processes. Furthermore, the time that these anxiety measures were provided varied across studies, with some providing measures the day before IB was measured while one study assessed anxiety after the paradigm (Martin & Alexeeva, 2010). This may be relevant if

performance of IB tasks have artificially modulated overall mood before completion of the HADS.

Seven studies reported that patients scored significantly higher on anxiety measures than controls. Three studies identified differences using the HADS ($p<.05$) (A. M. Hughes et al., 2018), ($p<.05$) (Moss-Morris & Petrie, 2003), ($p<.001$) (Pincus et al., 1996). Three reported differences using State-Trait Anxiety Inventory ($p<.05$) (McKellar et al., 2003), ($P<.05$) (Karsdorp et al., 2008) and ($p<.05$) (Schoth et al., 2016). One study reported differences using both State and Trait anxiety ($p<.001$) and HADS ($p=.02$) (Schoth et al., 2018). One study reported differences using the CIS-R ($p<.05$) (A. M. Hughes et al., 2018). One study used but did not report results for the HADS (Schoth et al., 2016). Two studies found no significant differences using anxiety measures, both involving the HADS, ($p=.828$) (Martin & Alexeeva, 2010) and ($p>.05$) (Pincus et al., 1994). Two studies did not use any specific measure of anxiety (Edwards & Pearce, 1994; Khatibi et al., 2015). Two studies that did not report differences in anxiety measures involved participants with different disorders (chronic pain and CFS). While one of the studies did demonstrated IB in their main analysis (Pincus et al., 1994), the other did not (Martin & Alexeeva, 2010). This may be indicative of the HADS being sensitive to mood fluctuations in participants (A. M. Hughes et al., 2018) or that participants in both cohorts were on the milder end of the symptom spectrum.

One study identified that IB mediated State anxiety and daily activities (Karsdorp et al., 2008). They also found that the relationship between IB and Trait anxiety was mediated by State anxiety. Five other studies did not find an association between IB and anxiety. Of these, one involved scores from State form of the State-Trait Anxiety Inventory ($p>.820$) (McKellar et al., 2003), three involved the HADS (A. M. Hughes et al., 2018; Moss-Morris & Petrie, 2003; Pincus et al., 1996) and one the CIS-R (A. M. Hughes et al., 2017). Two studies did not analyse their anxiety measures as covariates as they argued that it was not predictive of cognitive bias for sensory-pain words (Schoth et al., 2018, 2016). As mentioned above, two studies did not use a measure of anxiety (Edwards & Pearce, 1994; Khatibi et al.,

2015) and two did not find a difference in anxiety scores between patients and controls in the first place (Martin & Alexeeva, 2010; Pincus et al., 1994). It is interesting to note that both patients (8.25, SD=3.48) and controls (8.44, SD=3.41) in Martin and Alexeeva's study scored in the Mild range for anxiety. Again, this may have been influenced by the fact that they measured anxiety at the end of their study.

As reported above, Karsdorp and colleagues (2008) performed mediation analysis of IB and anxiety. No other studies reported significant correlations between anxiety and IB. Three studies reported that there were no significant correlations (McKeller et al., 2003 (p=.558, r value not reported); Pincus et al., 1996 (p and r values not reported); Moss-Morris and Petrie 2013 (p and r values not reported)). Nine studies did not investigate correlations between anxiety and IB (Edwards & Pearce, 1994; A. M. Hughes et al., 2017, 2018; Khatibi et al., 2015; Lichtenthal et al., 2017; Martin & Alexeeva, 2010; Pincus et al., 1994; Schoth et al., 2018, 2016).

Was illness severity associated with bias?

Eleven IB studies included a measure of illness severity. Three used the Pain Visual Analog Scale (PVAS) (Edwards & Pearce, 1994; Khatibi et al., 2015; McKellar et al., 2003), two used similar visual scales from (Pincus et al., 1994, 1996), two used the Chalder Fatigue Questionnaire (CFQ) (A. M. Hughes et al., 2017, 2018), two used a combination of McGill Pain Questionnaire, Brief Pain Inventory–Short Form and MIDAS Questionnaire (Schoth et al., 2018, 2016), one used the Profile of Fatigue-Related Symptoms (PFRS) and the Somatic Checklist (Moss-Morris & Petrie, 2003), and one used two subscales of the Adult Quality-of-Life Questionnaire for motor functioning and daily activities (Karsdorp et al., 2008). However, Martin and Alexeeva (2010) applied the CFS symptoms checklist taken from Fukuda and colleagues (1994), which is more of a diagnostic measure. Six studies ran analysis to investigate the association between symptom severity and IB. Four studies found a significant association. Moss-Morris and Petrie (2003) reported scores on the PFRS and Somatic Checklist were significantly correlated with somatic IB (r value not provided). Analysis of within groups factors for CFS participants revealed

a correlation between somatic bias and the Somatic Checklist (r=.41, p<.05). Khatibi and colleagues (2015) revealed a positive correlation between pain intensity and IB (r=.51, p<.001). Pincus and colleagues (1996) found that pain intensity and duration predicted the number of health related homophones generated (r=.48, p<.05). Furthermore, in a previous study, Pincus and colleagues (1994) revealed that pain accounted for 11% of the variance in scores for pain patients (p<.05). Two studies did not find significant associations between symptom severity and IB (McKellar et al., 2003, r value not provided, p>.558; Karsdorp et al., 2008, r=.66, p>.05). The remaining six studies did not assess the association between symptom severity and IB. These findings indicate that illness severity was moderately associated level of bias detected. While is it is not surprising that patient groups reported increased levels of illness severity, the impact of this impairment on bias may be more critical than anxiety. None of the studies reviewed commented on how or whether illness severity influenced patient's ability to complete the experiment and whether this influenced results and biases. It is surprising that six of the studies did not account for illness severity in their assessment of IB. These combined results indicate that this should be an important consideration for future results.

Did cognitive bias modification alter negative bias?

One study investigated the effect of CBM-I on a group of participants with fear of breast cancer recurrence (FBCR) (Lichtenthal et al., 2017). Lichtenthal and colleagues (2017) developed an attention and interpretation modification (AIM), intervention for FBCR. The aim of the study was to examine the feasibility of this particular bias modification paradigm.

To assess IB, the study applied a Word Sentence Association Paradigm taken from previous studies (Beard & Amir, 2009). This Involved 118 trials of word sentence pairings developed specifically for the population being assessed. Word sentence pairings were developed by taking those used in other studies and piloting them on ten women who experienced fear of cancer recurrence. The most emotionally effective word pairs were selected from this pilot.

Bias modification involved joint intervention for attention and IB, consisting of eight personalized treatment sessions, each lasting 30 minutes. The sessions were provided twice a week for four weeks. The first session was provided in a clinic, but the remaining sessions were completed at home. CBM-I involved 100 trials of a modified word sentence association paradigm with feedback. The control condition differed in that feedback was controlled so that it reinforced participants for making benign or threat interpretations 50% of the time.

Results indicated that AIM-FBCR significantly reduced health related worries in both groups compared to scores in the control condition. They also reported that IB decreased compared to the control condition ($p<.05$). Fear of cancer recurrence scale results (CARS) revealed a significant Time (pre vs. post vs. three month follow-up) x Condition (AIM-FBCR vs. Control Condition) interaction ($p=.019$). This means that the rate of improvement across the three measures differed for the AIM-FBCR and Control Conditions. Any improvement in the AIM-FBCR group at pre vs. post intervention when compared to that of the Control Condition were not significant ($p=.095$). There was however a significant improvement in CARS scores recorded for the AIM-FBCR group at the three month follow-up stage ($p=.005$). Reliable Change Index scores examining the degree to which participants improved from pre to three month post follow-up revealed a trend towards significance ($P=.063$) with 45% of AIM-FBCR participants demonstrating reliable improvements compared to 23% in the control condition. Regarding the Cognitive Bias scores. There was a significant interaction between Time x Condition for rate of Threat Endorsement ($P<.001$), meaning that clients made fewer negative interpretations across the pre, post and three month follow-up stages for the AIM-FBCR but not the control condition. AIM-FBCR participants produced greater reductions at the post intervention stage than those in the control condition ($P<.001$) for Threat Endorsement. The same interaction was also significant for Reaction Times to Threat Rejection ($p=.007$). They also demonstrated greater reductions at the post intervention stage ($P=.002$) to that of the Control Condition. The same series of analysis were also significant at the three month post intervention stage for both Threat Endorsement and Reaction Time to Threat Rejection.

Stage of disease was controlled for on further analysis but did not impact on the above findings (p=.380). The study states that mental health information was assessed but this information is not presented in the manuscript.

## Discussion

### Evidence of interpretation bias

The review has identified a robust finding regarding IB in physical health conditions. Despite the use of multiple paradigms and stimuli across a range of different conditions, only one study failed to identify IB in patient populations.

IB is thought to occur as a result of persistent negative experiences reinforcing potentially hyper-vigilant threat appraisals of what could over time extend to ambiguous situations (Mathews & Mackintosh, 1998). Studies have described the influence of schemas (Beck & Emery, 1985), combined cognitive biases (A. Hughes, Hirsch, Chalder, & Moss-Morris, 2016), attentional resources focusing on negative information (Everaert, Jonas; Tierens, Marlies; Uzieblo, Kasia; Koster, 2013), and threat evaluation systems (Mathews & Mackintosh, 1998). This may be consistent with Martin and Alexeeva's (2010) failure to detect IB in their lexical decision task. The authors argued that their paradigm did not facilitate higher order processing of material before interpretations were made, thus prohibiting biased schemas from being engaged by the time responses were made. This may be evidence of Taylor and Brown's (1998) theory that positive interpretations are more readily available at an implicit level, even in CFS participants. It may also indicate that Mathews and Macintosh's (1998) positive evaluation system is more immediately engaged before threat evaluations overcome it. Little evidence could be found amongst the studies identified or other literature to indicate that these multiple systems have been directly considered in IB studies in physical health conditions. It is interesting to consider how specific processes such as the schema enmeshment model of pain may or may not alter any potential preference for positive or negative automatic biases at an implicit level. Martin and Alexeeva (2010) argue that this may have

driven the effects in their findings, but direct investigations of this process are required to shed further light on the topic. Replication of its effect on other physical health conditions would also be helpful to investigate its relevance to other disorders. These findings also seem to challenge the view that more implicit measures present a more accurate account of IB while explicit tasks do not (A. Hughes et al., 2016; Pincus, Tamar; Moreley, 2001).

In light of the above, it is interesting to consider the primacy of IB for both chronic pain and fatigue participants. It is possible that those in the Pincus and colleagues (1996) paradigm that involved homophonic stimuli were subject to greater opportunity to consider and select a response that allowed their schemas to be engaged and applied. In contrast, those in the Martin and Alexeeva (2010) study were forced to make their responses more urgently, therefore denying cognitive access to internal biases. It would be interesting to replicate these studies by switching the paradigms used with the participants groups involved in order to investigate whether similar IB delays are noticeable in pain participants.

The role of anxiety in interpretation bias

A surprising finding from this review is that in all but one study, anxiety severity did not seem to correlate with IB. Karsdor and colleagues (2008) found that IB mediated the interaction between state anxieties. The authors found that those with congenital heart disease who had high state and trait anxiety produced elevated levels of IB, albeit with a weak affect. All other studies failed to demonstrate an association. Given the evidence regarding schemas in decision making and the role of anxiety in negative interpretations of ambiguous cues, one may conclude from these findings that the cognitive bias detected in participants with physical health conditions is illness as opposed to symptom specific. This means that those with physical health conditions are presenting with biases as a result of disorder specific schemas that are unique to their specific illness and catastrophic thinking patterns that may be a result of their physical impairments. These findings are consistent with those reported in other systematic reviews looking into IB in CFS (Hirsch et al., 2016) and chronic pain (Schoth & Liossi, 2016).

This study builds on their findings by developing the scope of this argument to all healthcare conditions. However, it may be of interest to note that the one study in the sample that did not identify IB did not find differences in anxiety ratings between patients and controls (Martin & Alexeeva, 2010). As reported above, the study reported anxiety scores in the Mild range for both patients and controls. Further investigation of IB using the Lexical decision task with less anxious participants may be helpful to establish whether this effected results.

The review also identified that bias modification intervention did seem to improve health related worries, although the robustness of this finding requires further validation (see Lichtenthal et al., 2017). One reason for the uncertainty regarding the role of IB in anxiety in these studies may be due to the studies reported being principally interested in cognitive bias and not specifically how it interacts with mood. This is evidenced by the fact that many studies did not use anxiety or any other mood measure as a covariate in their analysis. It is possible that existing studies have not developed procedures or analysis sensitive and specific enough to detect the relationship between mood (specifically anxiety/worry) and IB. Further research, specifically targeting this association may be critical to further explain this interaction. It is also interesting to consider that Lichtenthal and colleagues (2017) did not use a general measure of anxiety or depression in their assessment of breast cancer survivors. More detailed investigation into bias modification and its modulation of mood in general would be of clinical significance in this sense.

Another critical consideration is the distinction between purely mood (symptom) related and illness related worry and biases. There are relatively few studies specifically investigating this distinction, but those that have, reveal conflicting findings (Smith, Martin-herz, Womack, & Marsigan, 2003). One particular study has demonstrated that in cancer sufferers, a distinction exists between mood and illness presence or intensity (Teunissen, de Graeff, Voest, & de Haes, 2007). In this study, the authors found that not only did mood not interact with illness severity but that symptom severity did not seem to correlate with mood either (Teunissen et al., 2007). However a recent study looking at the role of anxiety in chronic

physical conditions reported that it was significantly associated with symptoms and cognitive functioning (Battalio, Jensen, & Molton, 2019). Battalio and colleagues (2019) found that the more anxious participants with physical conditions became, the more deterioration was evident in their physical functioning. However, Battalios and colleagues (2019) did not use a specific measure of anxiety, instead relying on the Patient Reported Outcomes Measurement System which is a broad measure of a variety of health related features. The use of non-specific mood related screening measures is considered to be one potential explanation for the uncertainty in this area (Teunissen et al., 2007). The same variability in anxiety measures has been noted in the sample of studies explored in this review. Further investigation is therefore required to determine whether symptom specific IB in physical health conditions are processing the same worries as with other populations consisting of anxious participants; or whether these findings are describing a subtly different system. Studies in clinically anxious populations have suggested that associations between IB and anxiety may be most sensitive to trait anxiety (Mathews et al., 1989). Further research may wish to focus on trait anxiety in the first instance.

### The role of disorder severity in interpretation bias

Results of the review indicate that disorder severity has a more prominent association with IB in people with physical health conditions than anxiety. This is consistent with the theory that IB in this sample of physical health conditions is illness specific while anxiety measures tend to be global. This suggests that studies should place greater emphasis on including disorder specific ratings of anxiety in their analysis. It is important to consider that Martin and Alexeeva (2010) did not provide a severity measure for their CFS participants but only that they met diagnostic criteria. It would have been interesting to identify whether their CFS participants were on the milder end of the syndrome scale. However, this information was not obtained.

Studies may also wish to consider the inclusion of control participants who are experiencing symptoms similar to that of patients in order to counteract the

influence of symptom discomfort on bias representation. To date, only one study has attempted to do this (McKellar et al., 2003). Findings from Pincus and colleagues (1994) and McKellar and colleagues (2003) support the understanding that people with chronic pain retain an IB for pain associated, homographic cues. However, the findings from McKellar and colleagues have enhanced this debate by exploring additional confounding variables such as specific categorisation of homographs being used (disability or pain cues) and the general familiarity of participants towards specific words (and their variations) involved. The results indicate that participants with chronic pain produced more pain related words than those in the acute pain or medical staff groups to homographs that were determined to be pain associated (McKellar et al., 2003). This can be said to be consistent with other studies. However, there were no significant differences across groups to disability responses to pain related homographs. Furthermore, when it came to disability associated homographs, the chronic pain group produced significantly more pain related responses to disability cues than medical staff but not acute pain participants. Results of disability responses to disability related homographs indicate that chronic pain patients provided significantly more disability words than acute pain participants but not medical staff. The findings that the chronic pain group experienced similar levels of pain than the acute pain groups was also considered to indicate that IB scores were reflective of specific bias in the chronic pain condition and not something that was modulated by how much pain participants were experiencing (McKellar et al., 2003). This supports the schema enmeshment model of pain, indicating that IB is a result of persistent, reinforced experiences that form a general association to meaningful words. In light of these findings, it is important to consider the biases being investigated and the relationship that participants may have with the specific homographs being used. It is also important to build on McKellar and colleague's exploration of whether participant's experience of pain at the time of testing is influencing interpretations or not. Although they report that this did not seem to influence results, this is the first study to develop such a novel approach to controlling for

this confound. It is recommended that other studies incorporate similar designs to attempt to replicate these findings to test its validity.

Interpretation bias modification

As mentioned above, one study investigating the effect of bias modification was identified in our search. Lichtenthal and colleagues (2017) reported significant improvements in their IB modification intervention groups, consistent with attention bias modification studies (Schoth, Georgallis, & Liossi, 2013; Sharpe et al., 2012). Lichtenthal and colleagues (2017) have demonstrated that marginal improvements are achievable over a period of time with the use of bias modification interventions. However, their results are tentative, and subject to interpretation as discussed below.

Results from Lichtenthal and colleagues (2017) bias modification intervention demonstrate that benefits to bias modification may not be gained in a relatively short period of time. The author's results indicate that there were no significant improvements in subjective ratings of fear of cancer reoccurrence immediately after initial intervention. The authors did however report a significant improvement after 3 months of IB training. These results indicate that bias modification requires a sustained period of practice before measurable improvements in mood are identified. Nevertheless, when this effect was further controlled for through reliable change index adjustments, the same comparison was marginally not significant. These findings challenge the reliability of Lichtenthal and colleagues (2017) overall results.

It is also noted that Lichtenthal and colleagues (2017) employed the CARS which is a specific measure of fear of cancer reoccurrence. They do not use any other measure of anxiety/worry. It is therefore difficult to relate their findings to whether bias modification improved general levels of anxiety in their participants. This also makes it difficult to use their findings as an indicator for similar improvements in other populations.

Furthermore, results indicating that those in the control condition benefited from small improvements in scores on the CARS indicate that some marginal gains may be subject to placebo effects. Lichtenthal and colleagues (2017) point to the fact that those in the control condition still received feedback and exposure to anxiety provoking situations that may have supported them to feel more empowered and habituated to their worries, thus improving their condition over time, due to intervention. Nevertheless, this effect requires further investigation. Improvements in this condition may be indicative of general variability in the author's participants and may offer clues as to why their reliable change index analysis did not reveal a significant difference.

Some important findings regarding the feasibility of Lichtenthal and colleagues (2017) AIM-FBCR intervention was that 74% of participants screened with the CARS did not agree to participate in the programme. The authors noted that the reliance on computer-based systems and technical difficulties seemed to contribute the most towards participant dissatisfaction (Lichtenthal et al., 2017). However, the authors also point to the low cost of AIM-FCBR and the fact that it can be largely delivered at people's homes without the need for clinicians to be directly involved. This suggests that the system can be implemented with minimal constraints on clinical resources. Further research using this intervention will be necessary to better develop an understanding of its feasibility and efficacy. It would also be interesting to apply this method to other physical healthcare conditions to assess its effects on a broader range of patients.

Given that pain clinics have for years focused on psychological implications of chronic pain and reported encouraging findings regarding cognitive modification of pain appraisals over time, it is important for more research to be carried out, investigating the feasibility and effectiveness of cognitive bias modification for interpretations. Lichtenthal and colleagues (2017) have contributed to the beginning of this broadening of the topic but more research is required to replicate and clarify its efficacy in physical health conditions. More immediately, the validity

of the changes noted in Lichtenthal and colleagues (2017) must be established before significant weight can be attributed to their findings.

Methodological considerations

A considerable proportion of studies investigating IB in physical health conditions have incorporated homophones and homographs into their designs to explore biases. One has even developed a paradigm comprising of both (Moss-Morris & Petrie, 2003). However, these methods are not without their complications. As discussed above, one limitation is the possibility for response bias due to language familiarity. This was directly controlled for in one study (Pincus et al., 1994), based on homographs. It was also controlled for by Edwards and Pearce (1994), using word stem completion. Both studies concluded that patient groups still demonstrated more bias than healthcare professionals. While Pincus and colleagues (1994) reported pain associations for their healthcare conditions participants, Edwards and Pearce's (1994) sample only included those who had no recent history of pain. More detailed investigation of healthcare professionals and their personal relationship with pain may be relevant to formulating a better understanding of these groups and their applied schemas when completing similar tasks. It is interesting to consider whether those with mood related disorders have a distorted threat appraisal whereas those with physical health conditions do not. Further research is required to elaborate on this.

More recently, IB studies have involved formulation of specific scenarios that participants can relate to in order to illicit IB. Again, these have consistently reported IB in physical health conditions but only two studies could be identified (A. M. Hughes et al., 2017, 2018). Scenarios have been used in many non-physical health condition studies such as social phobia (Stopa & Clark, 2000). One advantage of using scenarios instead of word cues, is that they are considered to be a better measure of specific biases as opposed to negative interpretations in general (Schoth & Liossi, 2016). As scenarios can be tailored and developed to the requirements of specific populations, they can be said to measure specific categories of biases, such as to social or financial situations (Hirsch et al., 2016).

This may provide more certainty regarding the nature of biases that is being observed and avoid the type of language frequency issues discussed above, regarding familiarity of specific terms and words. It also avoids written frequency issues (Schoth & Liossi, 2016). This refers to the fact that some words such as pain are known to have a higher written frequency than pane (Kucera & Francis, 1967).

Two studies by Schoth and Parry (2016) and Schoth and colleagues (2018) lend further support for the robustness of IB in physical health conditions and help to expand this evidence across other conditions (in this case chronic headaches) than chronic pain and CFS. The former study in particular develops an interesting trend towards differentiating between pain specific and disability specific homographic cues. Results indicating that pain related IB is strongest for pain specific homographs suggests that illness specific stimuli should be applied and/or developed when investigating IB in physical health conditions and in a broader sense for other populations. This may be more consistent with how scenarios are developed to be specific to conditions they are assessing.

To date, no studies have explored the strength of these biases between physical healthcare conditions. The use of scenarios and their specificity to patient groups suggests that biases are subjective to any given conditions' particular experiences. This could to some extent explain why people with physical health conditions demonstrate more IB for homographic word generation (Pincus et al., 1994) and word stem completions (Edwards & Pearce, 1994), when compared to healthcare professions. It is possible that healthcare professions may conceptualise their experience of illness related words and situations in a different way to patient groups. Using existing cues may, therefore, involve stimuli that more sensitivity engages schemas common for patient groups. Further studies investigating a range of biases for pain and mood related symptoms can help to better establish the nature of IB and perhaps aid design of interventions.

Finally, the review consists of studies that have investigated IB on its own, those that have involved interpretation and attention bias and some that were interested in IB, attention bias and recall bias. Of those studies looking at IB along with other

biases, primary emphasis seems to have been placed on the other process investigated. Given the complex considerations involved when discussing IB, more research focusing entirely on IB is required to provide more detailed methodological assessments.

Strengths and Limitations of the review

The findings of this review are limited by the small number of studies identified and the wide range of methodologies used. As mentioned above, there are no studies that have directly compared healthcare conditions to assess the generalizability of IB amongst people with physical health conditions. Furthermore, only one study has investigated the outcomes of IB modification. It is also noted that few studies have sought to replicate the findings of certain paradigms, either within the same or in different conditions.

As mentioned above, the majority of studies in this review were based on CFS and chronic pain participants. Although involving physical symptoms, such medically unexplained symptoms may not be generalizable to patients with physical health conditions with known pathology or etiology. More research is needed on such groups, as well as exploration of more complex psychosocial models in patients with medically unexplained symptoms.

Implications for further research and clinical practice

Suggestions for further research primarily revolve around the importance of illness severity and the type of anxiety measures used to explore mood. This review has identified that illness severity has so far indicated a stronger interaction with IB than mood. However, this has not been directly explored in the studies that fell into the scope of this review. Variations in anxiety measures have made it difficult to comment on whether anxiety plays a limited role in IB in physical health conditions, as this review seems to indicate. Future research may wish to focus on the specific measures of anxiety applied and how this manifests itself in the bias presented. Similarly, illness severity seems to present an important factor for IB.

Further research is needed to investigate what aspects of illness severity are influencing IB and whether this is consistent across conditions.

The failure to identify consistent correlations between IB and anxiety in physical health conditions supports the view that the narrative regarding specific types of biases in this population may be qualitatively different to that seen in others. Biases that are being detected may therefore correspond more accurately to illness severity over symptoms of anxiety that are measured in scales such as GAD-7. Clinicians may wish to consider whether illness related anxieties are therefore captured within these conventional measures of mood and if not, whether semi structured or entirely open dialogue assessments would be more helpful to identify anxiety. Another consideration is whether the IB paradigms in these scenarios are engaging anxiety at all. Most studies in this review have employed IB measures that are specific to their participant's specific experiences as physical health patients. It is possible that in doing so, these studies have circumvented anxiety related issues and engaged physical health related biases. This would suggest that frequency biases do not always relate to anxiety related material. Future research may wish to clarify this possibility by applying more conventional IB scenarios with physical health condition participants.

Only one study investigating bias modification in physical health conditions was identified in this review. More studies are required to investigate the clinical benefits of IB modification in this population. Evidence from illness severity indicates that people with physical health conditions are subject to biases towards threatening interpretations as a result of their conditions. Treating bias in these conditions may offer an interesting means of controlling some subjective representations of illness related distress in physical health conditions in the same way that pain clinics apply cognitive behavioural techniques to manage disorder specific difficulties. The results of this review support the presence of IB in physical health conditions and the potential for it modifiability. Clinicians may wish to therefore consider the presence of affective comorbidities in their patients when

offering treatments and their potential for disorder specific catastrophizing when considering treatments or providing subjective account of their illness.

## Conclusion

A review of studies investigating IB in physical health conditions has revealed a consistent pattern of bias in this population. Studies have largely investigated this effect in patients with chronic pain or CFS. Studies have also managed to replicate findings using different paradigms, whether they be word generation tasks using homographs, sentence generation studies or scenario based cues.

Surprisingly, there was only one study identified that has applied cognitive bias modification in the patients with physical health conditions. It may be of further surprise that this one study does not involve patients with chronic health conditions or CFS, considering that they have been the most widely researched. There is a distinct need to develop more bias modification studies to explore the efficacy of these treatments for people with physical health conditions.

An important consideration raised in this review is the impact of illness severity on IB. Only one study has directly challenged this with an acute pain control condition, but more studies are needed to investigate the effect of physical distress on IB and whether this is illness specific.

The paradigms discussed have explored a range of different techniques to explore IB in physical health conditions and many have sighted schema related theories to explain their results. However, studies have mainly failed to demonstrate any association between IB of illness related cues and anxiety. Further investigation is required to better understand the nature of these schemas in physical health conditions and whether they differ between different conditions. It may also be interesting to compare physical health participants with those who experience mood related disorders as a direct comparison of populations with well reinforced schemas based on physical or psychological disturbances.

## References


Amir, N., Beard, C., & Bower, E. (2005). Interpretation bias and social anxiety. *Cognitive Therapy and Research*, *29*(4), 433–443.

Battalio, S. L., Jensen, M. P., & Molton, I. R. (2019). Secondary health conditions and social role satisfaction in adults with long-term physical disability. *Health Psychology*, *38*(5), 445–454.

Beard, C. (2011). Cognitive bias modification for anxiety: Current evidence and future directions. *Expert Review of Neurotherapeutics*, *11*(2), 299–311.

Beard, C., & Amir, N. (2009). Interpretation in social anxiety: When meaning precedes ambiguity. *Cognitive Therapy and Research*, *33*(4), 406–415.

Beck, A. (1976). *Cognitive therapy and the emotional disorders*. New York: International Universities Press.

Beck, A., & Emery, G. (1985). *Anxiety and its disorders*. New York: Guildford Press.

Constans, J. I., Penn, D. L., Ihen, G. H., & Hope, D. A. (1999). Interpretive biases for ambiguous stimuli in social anxiety. *Behaviour Research and Therapy*, *37*, 643–651.

Eccleston, C., & Crombez, G. (1999). Pain Demands Attention: A Cognitive-Affective Model of the Interruptive Function of Pain. *Psychological Bulletin*, *125*(3), 356–366.

Edwards, L. C., & Pearce, S. A. (1994). Word Completion in Chronic Pain: Evidence for Schematic Representation of Pain? *Journal of Abnormal Psychology*, *103*(2), 379–382.

El-Gabalawy, R., Mackenzie, C. S., Pietrzak, R. H., & Sareen, J. (2014). A longitudinal examination of anxiety disorders and physical health conditions in a nationally representative sample of U.S. older adults. *Experimental Gerontology*, *60*, 46–56.

El-Gabalawy, R., Mackenzie, C. S., Shooshtari, S., & Sareen, J. (2011). Comorbid physical health conditions and anxiety disorders: A population-based exploration of prevalence and health outcomes among older adults. *General Hospital Psychiatry*, *33*(6), 556–564.

Everaert, Jonas; Tierens, Marlies; Uzieblo, Kasia; Koster, E. (2013). *Indirect Effect of Attention on Memory*. *27*, 1450–1459.

Everaert, J., Podina, I. R., & Koster, E. H. W. (2017). A comprehensive meta-analysis of interpretation biases in depression. *Clinical Psychology Review*, *58*, 33–48.

Eysenck, M. W., Derakshan, N., Santos, R., & Calvo, M. G. (2007, May). Anxiety and cognitive performance: Attentional control theory. *Emotion*, Vol. 7, pp. 336–353.

Eysenck, M. W., Macleod, C., & Mathews, A. (1987). Cognitive functioning and anxiety. *Psychol Res*, *49*, 189–195.

Eysenck, M. W., Mogg, K., May, J., Richards, A., & Mathews, A. (1991). Bias in Interpretation of Ambiguous Sentences Related to Threat in Anxiety. *Journal of Abnormal Psychology*, *100*(2), 144–150.

Grey, S., & Mathews, A. (2000). Effects of Training on Interpretation of Emotional Ambiguity. *The Quarterly Journal of Experimental Psychology Section A*, *53*(4), 1143–1162.

Hallion, L. S., & Ruscio, A. M. (2011). A Meta-Analysis of the Effect of Cognitive Bias Modification on Anxiety and Depression. *Psychological Bulletin*, *137*(6), 940–958.

Hayes, Sarra; Hirsch, C. (2007). Information processing biases in generalized anxiety disorder. *Psychiatry*, *6*(5), 176–182.

Heathcote, L. C., Vervoort, T., Eccleston, C., Fox, E., Jacobs, K., Van Ryckeghem, D. M. L., & Lau, J. Y. F. (2015). The relationship between adolescents' pain catastrophizing and attention bias to pain faces is moderated by attention control. *Pain*, *156*(7), 1334–1341.

Hirsch, C. R., Clark, D. M., & Mathews, A. (2006). Imagery and Interpretations in Social Phobia: Support for the Combined Cognitive Biases Hypothesis. *Behavior Therapy*, *37*, 223–236.

Hirsch, C. R., & Mathews, A. (2012). A cognitive model of pathological worry. *Behaviour Research and Therapy*, *50*(10), 636–646.

Hirsch, C. R., Meeten, F., Krahé, C., & Reeder, C. (2016). Resolving Ambiguity in Emotional Disorders: The Nature and Role of Interpretation Biases. *Annual Review of Clinical Psychology*, *12*(1), 281–305.

Hughes, A., Hirsch, C., Chalder, T., & Moss-Morris, R. (2016). Attentional and interpretive bias towards illness-related information in chronic fatigue syndrome: A systematic review. *British Journal of Health Psychology*, *21*(4), 741–763.

Hughes, A. M., Chalder, T., Hirsch, C. R., & Moss-Morris, R. (2017). An attention and interpretation bias for illness-specific information in chronic fatigue syndrome. *Psychological Medicine*, *47*(5), 853–865.

Hughes, A. M., Hirsch, C. R., Nikolaus, S., Chalder, T., Knoop, H., & Moss-Morris, R. (2018). Cross-Cultural Study of Information Processing Biases in Chronic Fatigue Syndrome: Comparison of Dutch and UK Chronic Fatigue Patients. *International Journal of Behavioral Medicine*, *25*(1), 49–54.

Huppert, J. D., Foa, E. B., Furr, J. M., Filip, J. C., & Mathews, A. (2003). Interpretation bias in social anxiety: A dimensional perspective. *Cognitive Therapy and Research*, *27*(5), 569–577.

Huppert, J. D., Pasupuleti, R. V., Foa, E. B., & Mathews, A. (2007). Interpretation biases in social anxiety: Response generation, response selection, and self-appraisals. *Behaviour Research and Therapy*, *45*, 1505–1515.

Ingram, R. E., Miranda, J. S., & Zindel V. (1998). *Cognitive vulnerability to depression*.

Jones, E. B., & Sharpe, L. (2017). Cognitive bias modification: A review of meta-analyses. *Journal of Affective Disorders*, *223*(July), 175–183.

Karsdorp, P. A., Kindt, M., Rietveld, S., Everaerd, W., & Mulder, B. J. M. (2008). Interpretation bias for heart sensations in congenital heart disease and its relation to quality of life. *International Journal of Behavioral Medicine*, *15*(3), 232–240.

Khatibi, A., Sharpe, L., Jafari, H., Gholami, S., & Dehghani, M. (2015). Interpretation biases in chronic pain patients: An incidental learning task. *European Journal of Pain (United Kingdom)*, *19*(8), 1139–1147.

Kucera, H., & Francis, W. N. (1967). *Computational analysis of present-day American*

*English*. Brown University Press.

Lichtenthal, W. G., Corner, G. W., Slivjak, E. T., Roberts, K. E., Li, Y., Breitbart, W., … Beard, C. (2017). A pilot randomized controlled trial of cognitive bias modification to reduce fear of breast cancer recurrence. *Cancer*, *123*(8), 1424–1433.

Macleod, C. (1999). Anxiety and Anxiety Disorders. In *Hanbook of Cognition and Emotion*.

MacLeod, C. (1990). Mood disorders and cognition. *Cognitive Psychology: An International Review*, 9–56.

MacLeod, C., & Mathews, A. (2012). Cognitive Bias Modification Approaches to Anxiety. *Annual Review of Clinical Psychology*, *8*(1), 189–217.

Martin, M., & Alexeeva, I. (2010). Mood volatility with rumination but neither attentional nor interpretation biases in chronic fatigue syndrome. *British Journal of Health Psychology*, *15*(4), 779–796.

Mathews, A., & Mackintosh, B. (1998). A Cogn itive Model of Selective Processin g in An xiety. *Cognitive Therapy and Research*, *22*(6), 539–560.

Mathews, A., & Mackintosh, B. (2000). Induced emotional interpretation bias and anxiety. *Journal of Abnormal Psychology*, *109*(4), 602–615.

Mathews, A., Mogg, K., May, J., & Eysenck, M. (1989). Implicit and explicit memory bias in anxiety. *Journal of Abnormal Psychology, 98*(3), 236–240.

McKellar, J. D., Clark, M. E., & Shriner, J. (2003). The cognitive specificity of associative responses in patients with chronic pain. *British Journal of Clinical Psychology*, *42*(1), 27–39.

McWilliams, L. A., Cox, B. J., & Enns, M. W. (2003). Mood and anxiety disorders associated with chronic pain: An examination in a nationally representative sample. *Pain*, 127–133.

Menne-Lothmann, C., Viechtbauer, W., Höhn, P., Kasanova, Z., Haller, S. P., Drukker, M., … Lau, J. Y. F. (2014). How to boost positive interpretations? A meta-analysis of the effectiveness of cognitive bias modification for interpretation. *PLoS ONE*, *9*(6), 1–26.

Mogg, K., Bradbury, K. E., & Bradley, B. P. (2006). Interpretation of ambiguous information in clinical depression. *Behaviour Research and Therapy*, *44*, 1411–1419.

Moser, J. S., Huppert, J. D., Foa, E. B., & Simons, R. F. (2012). Interpretation of ambiguous social scenarios in social phobia and depression: Evidence from event-related brain potentials. *Biological Psychology*, *89*(2), 387–397.

Moss-Morris, R., & Petrie, K. J. (2003). Experimental evidence for interpretive but not attention biases towards somatic information in patients with chronic fatigue syndrome. *British Journal of Health Psychology*, *8*(2), 195–208.

Naylor, C., Parsonage, M., McDaid, D., Knapp, M., Fossey, M., & Galea, A. (2012). Long-term conditions and mental health: the cost of co-morbidities. The King's Fund and the Centre for Mental Health. In *Long-term conditions and mental health*.

Norton, P. J., & Asmundson, G. J. G. (2004). Anxiety sensitivity, fear, and avoidance behavior in headache pain. *Pain*, 218–223.

Norton, S., Cosco, T., Doyle, S., Done, J., & Sacker, A. (2013). The Hospital Anxiety and

Depression Scale: A meta confirmatory factor analysis. *Journal of Psychosomatic Research*, *74*(1), 74–81.

Pincus, Tamar; Moreley, S. (2001). Cognitive-Processing Bias in Chronic Pain: A Review and Integration. *Psychological Bulletin*, *127*(5), 599–617.

Pincus, T., Pearce, S., McClelland, A., Farley, S., & Vogel, S. (1994). Interpretation bias in responses to ambiguous cues in pain patients. *Journal of Psychosomatic Research*, *38*(4), 347–353.

Pincus, T., Pearce, S., & Perrott, A. (1996). Pain patients' bias in the interpretation of ambiguous homophones. *British Journal of Medical Psychology*, *69*(3), 259–266.

Salemink, E., & Wiers, R. W. (2012). Adolescent threat-related interpretive bias and its modification: The moderating role of regulatory control. *Behaviour Research and Therapy*, *50*(1), 40–46.

Sareen, J, Jacobi, F., Cox, B. ., Belik, S. ., Clara, I., & Stein, M. . (2006). Disability and poor quality of life associated with comorbid anxiety disorders and physical conditions. *Archives of Internal Medicine*, *166*(19), 2109–2116.

Sareen, Jitender, Cox, B. J., Clara, I., & Asmundson, G. J. G. (2005). The relationship between anxiety disorders and physical disorders in the U.S. National Comorbidity Survey. *Depression and Anxiety*, *21*(4), 193–202.

Schoth, D. E., Beaney, R., Broadbent, P., Zhang, J., & Liossi, C. (2018). Attentional, interpretation and memory biases for sensory-pain words in individuals with chronic headache. *British Journal of Pain*, *13*(1), 22–31.

Schoth, D. E., Georgallis, T., & Liossi, C. (2013). Attentional Bias Modification in People with Chronic Pain: A Proof of Concept Study. *Cognitive Behaviour Therapy*, *42*(3), 233–243.

Schoth, D. E., & Liossi, C. (2016). Biased interpretation of ambiguous information in patients with chronic pain: A systematic review and meta-analysis of current studies. *Health Psychology*, *35*(9), 944–956.

Schoth, D. E., Parry, L., & Liossi, C. (2016). Combined cognitive biases for pain and disability information in individuals with chronic headache: A preliminary investigation. *Journal of Health Psychology*, *23*(12), 1610–1621.

Scott, K. M., Bruffaerts, R., Tsang, A., Ormel, J., Alonso, J., Angermeyer, M. C., … Von Korff, M. (2007). Depression-anxiety relationships with chronic physical conditions: Results from the World Mental Health surveys. *Journal of Affective Disorders*, *103*(1–3), 113–120.

Shamseer, L., Moher, D., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., … Whitlock, E. (2015). Preferred reporting items for systematic review and meta-analysis protocols (prisma-p) 2015: Elaboration and explanation. *BMJ (Online)*, *349*, 1–25.

Sharpe, L., Ianiello, M., Dear, B. F., Nicholson Perry, K., Refshauge, K., & Nicholas, M. K. (2012). Is there a potential role for attention bias modification in pain patients? Results of 2 randomised, controlled trials. *Pain*, *153*, 722–731.

Smith, M. S., Martin-herz, S. P., Womack, W. M., & Marsigan, J. L. (2003). Chronic Fatigue or Migraine. *Pediatrics*, *111*(4), 376–381.

Stopa, L., & Clark, D. M. (2000). Social phobia and interpretation of social events. *Behaviour*

*Research and Therapy*, *38*, 273–283.

Taylor, S. E., & Brown, J. (1988). Illusion and Well-Being: A Social Psychological Perspective on Mental Health. *Psychological Bulletin*, *103*(2), 193–210.

Teesson, M., Mitchell, P. B., Deady, M., Memedovic, S., Slade, T., & Baillie, A. (2011). Affective and anxiety disorders and their relationship with chronic physical conditions in Australia: Findings of the 2007 National Survey of Mental Health and Wellbeing. *Australian and New Zealand Journal of Psychiatry*, *45*(11), 939–946.

Teunissen, S. C. C. M., de Graeff, A., Voest, E. E., & de Haes, J. C. J. M. (2007). Are anxiety and depressed mood related to physical symptom burden? A study in hospitalized advanced cancer patients. *Palliative Medicine*, *21*(4), 341–346.

Williams, J. M. G., Mathews, A., & MacLeod, C. (1996). The emotional Stroop task and psychopathology. *Psychological Bulletin*, *120*(1), 3–24.

Woud, M. L., Zhang, X. C., Becker, E. S., McNally, R. J., & Margraf, J. (2014). Don't panic: Interpretation bias is predictive of new onsets of panic disorder. *Journal of Anxiety Disorders*, *28*(1), 83–87.

## Appendices

Appendix 1: Quality Assessment Table

| | Lichtenthal et al 2017 | Hughes et al., 2017 | Schoth et al., 2018 | Schoth et al 2016 | Hughes et al 2018 |
|---|---|---|---|---|---|
| 1. Were inclusion criteria specified? | 0 | 1 | 1 | 1 | 1 |
| 2. Were exclusion criteria specified? | 0 | 1 | 1 | 1 | 0 |
| 3. Was symptomology specified (e.g., 'low back pain')? | 1 | 1 | 1 | 1 | 1 |
| 4. Was information on illness duration provided? | 0 | 1 | 1 | 1 | 0 |
| 5. Was information on illness intensity/stage at time of testing provided? | 0 | 1 | 1 | 1 | 1 |
| 6. Were patient and control groups matched on age? | 1 | 0 | 1 | 1 | 0 |
| 7. Were patient and control groups matched on gender? | 1 | 1 | 1 | 1 | 1 |
| 8. Was the testing environment the same for all participants? | 1 | 1 | 1 | 1 | 1 |
| 9. Were appropriate stimuli used for the particular interpretation bias paradigm adopted? | 1 | 1 | 1 | 1 | 1 |
| 10. Were stimuli adequately described? | 1 | 1 | 1 | 1 | 1 |
| 11. Were levels of anxiety assessed and data reported? | 0 | 1 | 1 | 1 | 1 |
| 12. Were levels of illness-related fear assessed and data reported? | 0 | 0 | 0 | 0 | 0 |
| 13. Were response classification/scoring methods free from ambiguity or potential bias? | 1 | 1 | 1 | 1 | 1 |
| 14. Were statistical analyses appropriate? | 1 | 1 | 1 | 1 | 1 |
| **Total** | **9** | **11** | **13** | **13** | **10** |

Quality Assessment Table

| | Karsdorp et al., 2008 | Pincus et al., (1994, Exp.1) | Pincus et al., (1994, Exp.2) | Pincus et al., (1996) | Edwards & Pearce (1994) |
|---|---|---|---|---|---|
| 1. Were inclusion criteria specified? | 0 | 0 | 0 | 1 | 0 |
| 2. Were exclusion criteria specified? | 0 | 1 | 0 | 1 | 1 |
| 3. Was symptomology specified (e.g., 'low back pain')? | 1 | 0 | 0 | 1 | 0 |
| 4. Was information on illness duration provided? | 0 | 1 | 1 | 1 | 1 |
| 5. Was information on illness intensity at time of testing provided? | 1 | 1 | 1 | 1 | 1 |
| 6. Were patient and control groups matched on age? | 1 | 0 | 0 | 1 | 0 |
| 7. Were patient and control groups matched on gender? | 1 | 0 | 0 | 1 | 0 |
| 8. Was the testing environment the same for all participants? | 1 | 0 | 0 | 1 | 0 |
| 9. Were appropriate stimuli used for the particular interpretation bias paradigm adopted? | 1 | 1 | 1 | 1 | 1 |
| 10. Were stimuli adequately described? | 1 | 1 | 1 | 1 | 1 |
| 11. Were levels of anxiety assessed and data reported? | 1 | 0 | 1 | 1 | 0 |
| 12. Were levels of illness-related fear assessed and data reported? | 0 | 0 | 0 | 0 | 0 |
| 13. Were response classification/scoring methods free from ambiguity or potential bias? | 1 | 0 | 0 | 1 | 0 |
| 14. Were statistical analyses appropriate? | 1 | 1 | 1 | 1 | 1 |
| **Total** | **10** | **6** | **6** | **13** | **6** |

Quality Assessment Table

| | Moss-Morris & Petrie (2003) | Martin & Alexeeva (2010) | Khatibi et al., (2015) | McKellar et al., (2003) |
|---|---|---|---|---|
| 1. Were inclusion criteria specified? | 0 | 0 | 1 | 0 |
| 2. Were exclusion criteria specified? | 0 | 0 | 1 | 1 |
| 3. Was symptomology specified (e.g., 'low back pain')? | 0 | 1 | 1 | 0 |
| 4. Was information on illness duration provided? | 1 | 1 | 1 | 0 |
| 5. Was information on illness intensity at time of testing provided? | 0 | 1 | 0 | 1 |
| 6. Were patient and control groups matched on age? | 1 | 1 | 1 | 0 |
| 7. Were patient and control groups matched on gender? | 1 | 1 | 0 | 1 |
| 8. Was the testing environment the same for all participants? | 1 | 1 | 1 | 0 |
| 9. Were appropriate stimuli used for the particular interpretation bias paradigm adopted? | 1 | 1 | 1 | 1 |
| 10. Were stimuli adequately described? | 1 | 1 | 1 | 1 |
| 11. Were levels of anxiety assessed and data reported? | 1 | 1 | 0 | 1 |
| 12. Were levels of illness-related fear assessed and data reported? | 0 | 0 | 0 | 0 |
| 13. Were response classification/scoring methods free from ambiguity or potential bias? | 0 | 1 | 1 | 0 |
| 14. Were statistical analyses appropriate? | 1 | 1 | 1 | 1 |
| **Total** | **8** | **11** | **10** | **7** |

# Empirical Project

# Interpretation bias and anxiety in people with Parkinson's disease

## Supervisor: Richard Brown

## Table of contents

**List of Tables**

## Abstract

**Background**: there is growing evidence that people with Parkinson's disease can experience high levels of anxiety, although this has not been well researched. Interpretation bias is one form of processing difficulty that has been highly associated with anxiety. Although interpretation bias has been well investigated in other populations and now developed into interventions for these groups, it has not been explored in people with Parkinson's disease.

**Objectives**: this study aims to explore whether, (i) interpretation bias is present in people with Parkinson's disease, (ii) any such bias is associated with anxiety and (iii) that it is associated with illness severity.

**Method**: this study used an on-line survey delivered programme using Qualtrics. In total, 110 people with Parkinson's disease completed online surveys at home. The first part involved self-rated measures of anxiety (General Anxiety Disorder Questionnaire 7 (GAD 7)) mood (Patient Health Questionnaire 8 (PHQ 8)) and illness severity (Schwab and England Scale (S&E) and Hoehn and Yahr Scale (H&Y)). In addition, worry (Penn State Worry Questionnaire (PSWQ)), self-esteem (Rosenberg Self Esteem Scale (RSES)) and rumination (and Ruminative Response Scale (RRS)) were also assessed. The second part of the study involved two measures of interpretation bias, the Scrambled Sentences Test (SST) and Interpretation Questionnaire (IQ).

**Results**: several analyses were run to examine correlations between interpretation bias and variables of interest. Hierarchical regressions identified significant correlations between anxiety (GAD 7) and interpretation bias on the SST and for interpretation of positive and negative endorsements in the IQ. Stepwise analysis also revealed a significant correlation between anxiety and interpretation bias on negative endorsements on the SST. Analysis also revealed a significant correlation between rumination and interpretation bias for both the SST and negative interpretation endorsements on the IQ. Secondary analyses of high and low level anxiety and rumination confirmed a significant differences in interpretation bias on the SST and IQ.

**Conclusion**: the result of this study confirm the presence of interpretation bias in people with Parkinson's disease measured through the SST and IQ, associated with degree of anxiety and rumination with interpretation bias.

## Introduction

### Anxiety in the general public

Untreated mental health difficulties are considered to be among the most prominent health related concerns of the modern era (Bandelow & Michaelis, 2015). A recent systematic review of 48 articles reported that anxiety disorders occur in 3.8% to 25% of the general public (Remes, Brayne, van der Linde, & Lafortune, 2016). This rate does however vary more widely when applied specifically to people with long term conditions (1.7% to 70%). In light of this, anxiety disorders constitute a global concern that applies to a range of people with and without pre-existing conditions.

Anxiety disorders are characterised in range of multifaceted theories. One area of interested is the role of worry in anxiety. Borkovec and colleagues (2004) have devised an emotional avoidance model explaining that anxiety can be portrayed through avoidance of undesirable thoughts. Another key factor to anxiety is considered to be worry and its connection to fear appraisals (T. D. Borkovec, Robinson, Pruzinsky, & DePree, 1983). Although worry can be a helpful emotion, it can also result in hypervigilance to threat and excessive concern regarding potential dangers in the environment. This can also lead to unhelpful beliefs that worry is a positive process as experienced by people with Generalized Anxiety Disorder (Dugas, Gagnon, Ladouceur, & Freeston, 1998). The avoidance model of worry lends to the understanding of how worry is maintained by postulating that some people continue to experience anxiety as they are unable to access mental imagery (T. D. Borkovec, 1994; T. D. Borkovec & Inz, 1990) that is key to the habituation and extinction of anxiety (Foa & Kozak, 1986; Newman & Llera, 2011). Others have understood anxiety through emotional schema models indicating that a combination of awareness and interpretations contribute to anxiety (Khaleghi et al., 2017) and that one's experiences lead to learnt and reinforced beliefs that inform our behaviour (Beck, 1976). These schemas result in cognitive biases that are rife in anxiety (Hirsch, Meeten, Krahé, & Reeder, 2016; Andrew Mathews & Mackintosh, 1998). For example, attention bias refers to a tendency for some to

selectively attend to threatening stimuli in the environment, even when they are neutral (Beard, 2011). Treatment in anxiety related disorders therefore concentrate on correcting these biases and supporting clients to adjust their appraisals of anxiety provoking situations through a combination of cognitive and behavioural techniques.

Threat Appraisal

On a more general level, threat appraisal systems have been discussed as a means through which people demonstrate both innate (Ohman & Mineka, 2001) and conditioned (Britton, Lissek, Grillon, Maxine, & Pine, 2012) fears towards certain stimuli. For this reason, threat appraisal models have been largely developed by those exploring evolutionary and neurobiological systems that underpin our selective tendency to fear certain scenarios more than other (Ohman & Mineka, 2001). Studies that have utilised the threat appraisal system tend to argue that humans and other animals are innately programmed to fear specific situations (such as certain predators in the natural world) over other conditions that are not as consistently relevant and pervasive in our evolutionary history (Bolles, 1970; Seligman, 1970; Tooby & Cosmides, 1990). These models suggest that as a species we are specifically primed to be particularly fearful of certain situations that contain a context that is relevant to those our ancient ancestors would have faced. These systems argue that we are therefore more susceptible to fearful responses towards predators, heights and certain social situations over more recent inventions such as weapons and technologies (Ohman & Dimberg, 1978; Seligman, 1970). These concepts have been further developed by psychologist, not least of all in CBT for phobias, to better understand and treat fearful responses based on mechanisms that underpin such potentially innate but also learnt threat appraisals. Cognitive behavioural approaches to such threat appraisal systems have developed the argument by considering the nature of the selective narrative that reinforces fearful behaviours, such as avoidance models that maintain the state of anxiety (Britton et al., 2012). They have also developed an understanding of how such threat appraisals can develop more recently within individuals through Pavlovian

Conditioning (Britton et al., 2012; Ohman & Mineka, 2001; Razran, 1971). For example, cognitive reappraisal is based on a process through which participants are supported to attend to their negative emotional response to a stimuli before being trained to reappraise their reaction (Ochsner, Bunge, Gross, & Gabrieli, 2002). Similar studies have emphasises the role of internal biases that underpin negative appraisals towards relevant stimuli (Britton et al., 2012; Goldin, Manber, Hakimi, Canli, & Gross, 2009), including attention biases (Bar-Haim, Lamy, Pergamin, Bakermans-Kranenburg, & Van Ijvendoorn, 2007; Mogg & Bradley, 2018). In this sense. Attention and Interpretation bias models fall within threat appraisal systems but as specific processes through which biases are developed. It is assumed that this can refer to both innate but largely newly learnt biases.

Rumination

Rumination is a repetitive state of reflection where people become locked in a cycle of scrutinising concerns such as decisions they have made or symptoms that they are experiencing (Nolen-Hoeksema, 1991, 2000). In general, rumination has often been associated with depression but is also known to predict anxiety (see (Aldao, Nolen-Hoeksema, & Schweizer, 2010 for meta-analysis). For example, studies investigating social anxiety have found increased levels of rumination after social interactions (Brozovich & Heimberg, 2008), termed as “post-event processing” (Clark & McManus, 2002). This seems to implicate rumination in anxiety as well as depression. In general, rumination is perceived by people as fulfilling a helpful exercise that identifies threats and develops solutions (Brown & Fernie, 2015) but can ultimately result in a persistent cycle of negative thoughts that reinforce problem-thinking.

Interpretation bias

Cognitive biases in general are thought to constitute multiple systems involving attention, interpretation and recall (memory) (Hirsch, Clark, & Mathews, 2006; Andrew Mathews & Mackintosh, 1998). These systems are thought to operate in parallel but the role of interpretation is particularly thought to be associated with

anxiety and worry (Andrew Mathews & Mackintosh, 1998). Studies have argued that those with high levels of anxiety are particularly likely to misinterpret ambiguous cues to be threatening. This process, known as interpretation bias (IB), has been measured in a range of anxiety disorders and those with long term conditions. Studies have shown that when given ambiguous cues to respond too, some participants provide a more negative evaluation of the question than is warranted (Hirsch et al., 2016; Andrew Mathews & Mackintosh, 2000). An important mechanism behind these negative appraisals is thought to be worry. This is considered to be a critical component of anxiety in general (T. D. Borkovec et al., 1983) but is primarily engaged in relation to future events (Sibrava & Borkovec, 2006) and reinforced through avoidance (Thomas D Borkovec, Alcaine, & Behar, 2004), making it particularly relevant to the emotional avoidance model of anxiety and IB.

Interpretation biases have been investigated through a range of paradigms that consistently demonstrate its presence. More recently, the use of scenario based stimuli has been developed to explore how IB occurs in anxiety disorders and healthy populations. The key to using scenario based stimuli is thought to be their relatability for participants, meaning that in some cases, they have to be specifically designed for the target cohort being tested. In order to achieve this, studies have focused on designing scenarios that are appropriate for participants and their particular experiences. Other studies have explored IB by identifying participants with high and low level anxiety in their participants to differentially investigate its role in bias (Dugas et al., 2005). Others have employed participants with affective disorders in comparison to controls to establish increased levels of IB in patient cohorts (Amir, Beard, & Bower, 2005; Constans, Penn, Ihen, & Hope, 1999; Eysenck, Mogg, May, Richards, & Mathews, 1991; Huppert, Foa, Furr, Filip, & Mathews, 2003; Huppert, Pasupuleti, Foa, & Mathews, 2007). These studies have confirmed that those with high levels of anxiety are more likely to endorse ambiguous cues in a negative way than those with lower levels. Other studies have identified associations between IB and anxiety, reporting correlations between the two. Regression models have identified that measures such as the State-Trait Anxiety

Inventory (Eysenck, Macleod, & Mathews, 1987) and Penn State Worry Questionnaire (PSWQ) (Dugas et al., 2005) both predicted interpretation bias. Finally, studies have also reported a more general association between IB and anxiety (Eysenck & Calvo, 1992; Eysenck et al., 1991; Huppert et al., 2003).

Although many studies have developed a robust argument for negative IB, others have identified positive effects too. One such study examining IB of ambiguous scenarios has presented positive bias for cues in younger and older adults (Juang & Knight, 2016). This is an effect that has been reported in older adult populations before (Knight, Maines, & Robinson, 2002). In light of these studies, it should be acknowledged that IB does not exclusively effect in negative appraisals.

Introduction to Parkinson's disease

Rates of people being diagnosed with Parkinson's disease increases with age. Studies estimate that it has a prevalence of between 0.13%-1.6% of people under the age of 60, rising to approximately 9% of people between the ages of 80-84 (Nerius, Fink, & Doblhammer, 2017). People with Parkinson's disease have a depletion of dopamine producing receptors in an area of the basal ganglia called the substantia nigra pars compacta resulting in motor symptoms such as slowness and tremor. Given the physical impairments evident from Parkinson's disease, it is not surprising that these visibly apparent symptoms have been investigated by researchers for many decades in order to alleviate movement difficulties with a range of treatments. However, there have been more recent developments in our understating of Parkinson's disease that has encouraged a broader range of interests when considering its impact on patients. As well as motor related symptoms, research has widely explored cognitive deficits that are present as a result of the basal ganglia's role in memory and frontal executive functions. Research in this area has now developed a well-informed understanding that people with Parkinson's disease experience a range of cognitive difficulties as a result of their condition.

The cognitive behavioural model of anxiety and depression in Parkinson's disease

More recently, research has focused on a growing body of work indicating that mood related disorders (depression and anxiety) are also common in people with Parkinson's disease. A recent review has developed a bio-psychosocial model of anxiety and depression in people with Parkinson's disease, designed to help inform CBT interventions (Egan, Laidlaw, & Starkstein, 2015). Egan and colleagues (2015) model emphasizes the role of catastrophizing and hypervigilance in the development of anxiety whereas rumination and avoidance inform depression. The authors argue that that as well as standard CBT related processes, people with Parkinson's disease experience illness related beliefs that contribute to low mood and anxiety (Egan et al., 2015). This can include rumination regarding their symptoms in comparison to other people with Parkinson's disease as well as assessing their current abilities to how they were before their diagnosis, resulting in increased hopelessness (Egan et al., 2015).

Parkinson's disease related anxiety

Although depression has been studied in detail for several decades, anxiety has only recently become a focus of attention for research. A meta-analysis of 49 studies reported a prevalence of 31% of people with Parkinson's disease experiencing anxiety related symptoms synonymous with a range of anxiety related disorders (Pontone et al., 2011) with other studies reporting it to be as high as 49% (Dissanayaka et al., 2010). This figure is reported to be in excess of those identified in the general public (Remes et al., 2016) as noted above.

Understanding the role of anxiety in people with Parkinson's disease is particularly important as it is thought to contribute towards the exacerbation of existing motor and cognitive impairments in the condition (Dissanayaka et al., 2015). It is also thought that anxiety related symptoms are particularly prevalent in early and even pre-diagnostic stages of the illness, with some claiming that it can precede physical symptoms by as much as 20 years (Djamshidian & Friedman, 2014; Jacob, Gatto, Thompson, Bordelon, & Ritz, 2010) indicating that it may be independent of symptom severity and therefore unrelated to concerns regarding physical

disabilities. These recently explored perspectives regarding anxiety in people with Parkinson's disease is helping to develop compelling arguments for its consideration when treating clients and providing prognosis. This is supported by studies that report that anxiety in people with Parkinson's disease significantly impairs quality of life in general (Pontone et al., 2011).

The cause of anxiety in people with Parkinson's disease is commonly thought to be physiological, with decreased dopamine transporter availability thought to be a critical factor (Erro et al., 2012; Moriyama et al., 2011). Other contributing causes have been reported to be physiological changes to the amygdala (Vriend et al., 2016) and loss of serotonin cells (Kish, 2003). In light of this evidence, studies have largely investigated the role of anxiety in people with Parkinson's disease through animal models (Faivre, Joshi, Bezard, & Barrot, 2019), serotonin production in the brain (Joling, Van Den Heuvel, Berendse, Booij, & Vriend, 2018; Maillet et al., 2016), functional imaging (Thobois, Prange, Sgambato-Faure, Tremblay, & Broussolle, 2017), computational models (Broen et al., 2016), as well as studies looking at prevalence rates (Dissanayaka et al., 2016) and assessments of predictors for anxiety in Parkinson's disease (Landau et al., 2016). However, whether these are true causes or risk factors for the development or maintenance of anxiety remains unclear. Very few behavioral studies have been conducted to investigate the nature of anxiety and worry in people with Parkinson's disease. Recent studies have explored the effect of metacognitive therapy (Brown & Fernie, 2015) and CBT (Mulders et al., 2018) but more specific assessments of anxiety are required to gain a detailed understanding of how anxiety effects people with Parkinson's disease and whether it is qualitatively different to how it presents in others.

Interpretation bias implications for Parkinson's disease

Given the absence of behavioural studies, to comprehensively understand psychological processes of anxiety in people who have Parkinson's disease, parallels can be sought from research looking at IB in people with physical health conditions and older adults. Studies have consistently demonstrated that IB is evident in people with chronic pain (Pincus, Pearce, McClelland, Farley, & Vogel,

1994; Pincus, Pearce, & Perrott, 1996) and chronic fatigue (Hughes, Chalder, Hirsch, & Moss-Morris, 2017; Schoth, Beaney, Broadbent, Zhang, & Liossi, 2018). These studies have identified a consistent trend for IB using a range of paradigms including scenario-based measures. However, the correlations between IB and measures of anxiety have been less convincing. While some studies have reported associations (Karsdorp, Kindt, Rietveld, Everaerd, & Mulder, 2008), others have not (Martin & Alexeeva, 2010). More generally, studies in older adults have revealed less robust findings. While older adults demonstrate some IB, this is at a lesser extent to younger adults (Juang & Knight, 2016). This was also the case for older adults who demonstrated higher anxiety scores. Juang and Knight (2015) describe this to be a positivity bias consistent with studies in older adults in general (Zebrowitz, Boshyan, Ward, Gutchess, & Hadjikhani, 2017). However, the authors noted that older adults did endorse as many negative cues on health related items as younger adults (Juang & Knight, 2016), indicating a relative bias towards illness related symptoms. One may also consider Egan and colleagues (2015) cognitive behavioural model which emphasises the role of hypervigilance and avoidant behaviours that may promote excess tendencies to attend to and interpret events negatively.

Rumination in Parkinson's disease

In people with Parkinson's disease, rumination has been implicated in a range of psychological processes resulting in low mood and anxiety (Allott, Wells, Morrison, & Walker, 2005; Brown & Fernie, 2015; Julien, Rimes, & Brown, 2016). Rumination in people with Parkinson's disease can be additionally problematic as it is thought to be associated with attentional rigidity (Davis & Nolen Hoeksema, 2000). While this finding has implications for attention bias, it is not clear whether this would be expected to modulate interpretation of scenarios. It is also unclear as to whether rumination in interpretation bias would be a reflection of low mod and/or anxiety. One study involving socially anxious students investigating the role of rumination in interpretation bias found that it mediated negative interpretations (Badra et al., 2017). Another study involving healthy populations demonstrated that rumination

promotes bias but specifically as a result of depression (Mor, Hertel, Ngo, Shachar, & Redak, 2014).

Clinical implications

In light of the role of IB in anxiety and its prevalence in people with a range of difficulties, bias modification systems have been proposed as a potential treatment for anxiety. Modification of biases is achieved through altering maladaptive schemas that resolve ambiguous cues with a negative interpretation. CBM-I has been specifically designed to target IB by encouraging participants to habituate to ambiguous, non-threatening stimuli and cues (Hallion & Ruscio, 2011). Interventions have been designed to be applied over a single or multiple sessions with studies suggesting that both are equally helpful (Hakamata et al., 2010), while others have even suggested that there are benefits to single sessions (Cristea, Kok, & Cuijpers, 2016).

A recent meta-analysis of CBM-I involving 12 studies, five of which were focused on IB modification, concluded that there was robust evidence for its benefits in shifting bias (Jones & Sharpe, 2017). Jones and Sharpe's (2017) review included studies with mixed populations of participants ranging from children to adults and those with and without high levels of anxiety or depression. The study identified that 8/8 attention bias studies and 5/5 CBM-I studies modified bias. The authors also reported that while 8/10 studies reported improvement in anxiety, only 3/7 found the same for depression after bias modification (Jones & Sharpe, 2017).

However, it is noted that date on the effectiveness of CBM-I is limited. Jones & Sharpe (2017) point out themselves that the reliability of their findings are limited to small effect sizes in their samples. The authors also point out that their study sample does not specifically target the effect of CBM-I on anxiety as a specific goal but instead assess improvements in anxiety as a combined outcome of CBM-I and attention bias modification (Jones & Sharpe, 2017). In other words, it is difficult to identify whether improvements are the result of CBM-I or attention bias modification. Other studies have reported benefits of attention bias modification over CBMI-I (Cristea et al., 2016; Hallion & Ruscio, 2011) indicating that it is

potentially a less well developed or less effective intervention. A further systematic review of CBM-I argues that the intervention requires a large number of training sessions and should only be seen as an additional intervention to conventional psychotherapies (Menne-Lothmann et al., 2014). The authors also suggest that their finds only report a small improvement in mood measures post CBM-I (Menne-Lothmann et al., 2014).

Despite being at an early stage of development, CBM-I is suggested to be a potentially cost effective means of treating anxiety in client groups, given that it can be administered online and relatively quickly compared to standard CBT. In light of prevailing opinion regarding the role of anxiety in Parkinson's disease, CBM-I seems to offer an attractive solution to modifying cognitive biases that may be present. However, as no studies have been conducted to first demonstrate IB in people with Parkinson's disease and its association with anxiety/worry, any suggestions to trial this system would be premature.

As noted above, there are few studies investigating the treatment of anxiety in people with Parkinson's disease, even though this is thought to be an important consideration. Those that have, often focus on CBT as a means of treatment with an increased emphasis on home assessments (Reynolds, Saint-Hilaire, Thomas, Barlow, & Cronin-Golomb, 2019) or even fully home based interventions (Wuthrich & Rapee, 2019). Both studies reported positive benefits of CBT in people with Parkinson's disease with better effects for depression (Reynolds et al., 2019; Wuthrich & Rapee, 2019). Similar to these recent studies, CBM-I offers the potential for home based interventions thus removing accessibility issues that may hinder those with more advanced physical symptoms of Parkinson's disease. CBMI-I therefore presents the potential for a viable intervention in this population that may build on findings from the limited number of studies investigating the benefits of CBT.

Current study

To the best of our knowledge, no published studies have investigated IB in people with Parkinson's disease. Given strong indications for the fact that anxiety is highly

comorbid in Parkinson's disease, it is important to better understand its nature in this condition. Furthermore, as IB is thought to be associated with anxiety and worry, it is important to first identify whether this process exists in people with Parkinson's disease, so that more specific discussions regarding the prospect of treating it with CBM-I can be developed.

Although studies have developed well founded evidence of structural and neurochemical changes contributing to elevated levels of anxiety in Parkinson's disease, the behavioural components are not as well understood. Studies have commented on the possibility that affective disorders in people who have Parkinson's disease may have a unique underlying pathology, related to the combined physical and cognitive impairments they experience (Moriyama et al., 2011). In this case, Moriyama and colleagues (2011) argue that traits related to social anxiety in people with Parkinson's disease are specifically correlated with dopamine transporter binding potentials. However, no studies have directly investigated whether these neurochemical modulations have implications for detecting anxiety using conventional measures. The implication here being that social anxiety in people with Parkinson's disease may present itself differently to that seen in other populations. However, studies in people with physical health conditions and older adults have offered suggestions that bias may or may not present itself in a way that is familiar with healthy participants. Given that people with Parkinson's disease are likely to have their own specific experiences that are expected to be different to those of healthy individuals and people with different physical health conditions, it is important to investigate the effects of IB in this population independently to develop our understanding. It may be expected that if anxiety in Parkinson's disease were entirely a consequence of neurological impairments, the specific behavioural/developmental (schema based) components of IB may not correlate with anxiety measures that take a traditional account of what anxiety looks like but be more reflective of illness severity.

Objectives and hypothesis

This study aims to investigate the role of IB in people with Parkinson's disease to identify whether it is evident and whether it is correlated to general anxiety and worry. The study is also interested in whether IB in people with Parkinson's disease correlates with low mood and/or disease severity, the latter of which has been identified in physical health conditions. In light of current evidence, we set the following exploratory questions: (1) to identify whether IB will be detected in people with Parkinson's disease, (2) whether bias will be correlated with anxiety or any other mood related variables and (3) whether IB will be correlated with disease severity. In line with these objectives, we hypothesise that: (1) IB will be present in people with Parkinson's disease, (2) bias will be correlated with one or more measure of anxiety but not depression and (3) IB will correlate with disease severity.

## Methods

Participants

Participants were recruited for an initial pilot study and the subsequent main study. *Pilot stages*. Participants in the pilot stage of the study were contacted through a list of previous volunteers who had completed unrelated studies and consented to being contacted about participating in other projects. Participants in the pilot stage were sent £5 Amazon gift vouchers for their participation. *Main study*. Participants in the main study were recruited through Parkinson's UK, via their website and news-letters. These participants were not provided with vouchers due to restrictions on 'payment' for research placed on the study by Parkinson's UK.

The inclusion criteria for participants was for them to (i) be over 18 years of age (with no maximum age limit), (ii) have a diagnosis of Parkinson's Disease, (iii) have a level of English to be able to read and understand moderately complex material, and (iv) to have access to a computer or tablet with internet functionality to complete the surveys.

Taking anti-anxiety or anti-depressive medication was not an immediate exclusion criteria but participants were required to be on the same dosage of medication for the past six weeks.

Participants in the pilot study were required to complete the survey in one sitting, without taking breaks. Those who took over an hour and a half were excluded from the study, as this was taken to be an indication that they were taking breaks and/or finding it cognitively challenging to complete the task.

The main testing stage of the study involved 135 participants, of which 25 were excluded from the final analysis due to technical difficulties or failure to engage with all tasks (leaving 110 participants).

Piloting

Two rounds of piloting were completed to assess the feasibility of online IB testing of participants with Parkinson's disease and the acceptability of the online platform and materials. The first round of piloting involved 35 participants who completed all demographic measures and IB tests in a single on-line sitting. All participants were invited to provide their feedback at the end of testing to gauge an understanding of how they found the experience. We were particularly interested in participant's experience of using scenarios as well as their general experience of the online tasks. In light of their feedback, successful completion of this pilot seemed to depend on several factors, ranging from disease severity, general computer literacy and fatigue. Variability in participant proficiency, most likely as a result of their motor symptoms and familiarity with computers, resulted in some participants finding it difficult to complete the assessment in one sitting. Others commented on some scenarios being difficult to relate to while others specifically stated that they found the same scenarios interesting. In light of the feedback, two scenarios were altered in order to make them more appropriate for older adults. Given that some participants were commenting on the length of the study and finding it difficult to complete in one sitting, we made the decision to split the online tasks into two separate surveys, the first focusing on demographic information and mood related questionnaires and the second mainly containing IB

measures. Participants were asked to complete the second stage of the study within 24 hours of the first, although this was not always possible for some. In order to assess whether these adaptations had the desired effect on feasibility, we conducted a second pilot phase where 25 participants completed this revised method. Participants were issued with an initial link to access the first part of the study and informed that a second link would be automatically generated on completion of this first one. Feedback form participants was generally positive, with no further comments regarding the length of the study. There were some difficulties in participants completing the second stage of the study in a timely manner. Some participants did not complete the second link until a week later, resulting in the Qualtrics link expiring and a new one having to be generated which resulted in delays. However, the majority of participants were able to complete both links on the same day (18/25). Pilot stage two also included the addition of disease severity scales, Hoehn and Yahr (H&Y) (1967) and Schwab and England (S&E) (1969).

Measures

The study involved a range of questionnaires to measure mood and disease severity. The following questionnaires were used as a measure of anxiety: General Anxiety Disorder (GAD-7) Scale (K Kroenke, Spitzer, Williams, Monahan, & Lowe, 2007; Spitzer, Kroenke, Williams, & Löwe, 2006), Penn State Worry Questionnaire (PSWQ) (Meyer, Miller, Metzger, & Borkovec, 1990) and Rosenberg Self Esteem Scale (RSES) (Rosenberg, 1965). The following measures were used to assess depression: Personal Health Questionnaire (PHQ 8) Scale (Kurt Kroenke et al., 2009) and Ruminative Response Scale (RRS) (Treynor, Gonzalez, & Nolen-Hoeksema, 2003). We used the following measures to assess illness severity: Parkinson's disease Activities of Daily Living Scale (PADL) (Hobson, Edwards, & Meara, 2001), Wearing Off Scale (Antonini et al., 2011), Hoehn and Yahr scale (H&Y) (Hoehn & Yahr, 1967) and Schwab and England (S&E) scale (Schwab & England, 1969). Finally, we used the Modified Telephone Interview of Cognitive Status (TICS-M) (Brandt, Spencer, & Folstein, 1988) as a screen for cognitive impairment. Participants were

asked to complete the TICS-M assessment as a measure of cognitive impairment. This allowed for participants demonstrating high levels of cognitive impairments to be removed from analysis. Studies have previously considered scores of 30/31 (Welsh, Breitner, & Magruder-Habib, 1993) or 34 (Cook, Marsiske, & McCoy, 2009) out of 50 to be indicative of a possible cognitive impairment.

Experimental Paradigms

*Scrambled Sentence Test (SST)*. An online version of the SST (Wenzlaff & Bates, 1998) was based on previous studies and our two pilot stages (Lee, Mathews, Shergill, & Yiend, 2016; Rude, Valdez, Odom, & Ebrahimi, 2003). Participants were provided with 20 sentences to complete, using any five of six word options for each sentence (See Appendix 4). All sentences had two grammatically correct completions, one involving a word that was positive and one negative, although they were not informed of this. They were instructed to select the first sentence that came to mind and work as quickly as possible. Participants were instructed to use a mouse to select the order of the words they felt completed the sentence they wanted. Six possible word options were provided on the left side of the screen, with five empty grid options indicating the location of the word within their chosen sentence appearing horizontally to the right of each word. Before performing practice items, participants were shown two possible sentence completions from a possible example sentence. Participants were next guided through two practice sentences with feedback regarding when they had generated a correct sentence. After successful completion of the two practice items, participants were instructed to move onto the 20 test sentences. They were instructed that they would have ten minutes to complete as many sentences as possible. Before beginning the 20 test items, participants were asked to memories a six digit number which they would be asked to repeat at a later stage in testing. Participants were asked not to write this number down. They were asked to type this number immediately after they had completed the 20 sentences or their ten minutes had elapsed. This cognitive load exercise was provided to prevent reported strategies that participants may otherwise use to complete testing (Rude, Wenzlaff, Gibbs, Vane, & Whitney, 2002).

Participants were also asked to provide a stress rating at the end of the SST (0 to 100 with higher numbers indicating more stress).

As with previous studies that have used the SST, we calculated proportions between positive and negative cue selections to derive an overall score collapsed across all 20 SST sentences completed for each participant (Lee et al., 2016; Rude et al., 2003). This resulted in a score ranging between 0 – 1 for negative and/or positive cues with a higher score indicating more endorsements of that valence for either cue selections. Scores were calculated for each participant by dividing the number of negative or positive selections by the total number of sentences completed. Invalid sentences, or sentences that only involved four of the five words requested were excluded. Only scores for the negative endorsements on the SST were analyzed as positive endorsements represented proportional values in the opposite direction.

*Interpretation Questionnaire (IQ)*. The second IB measure was again based on previous studies (Amin, Foa, & Coles, 1998; Butler & Mathews, 1983) and was not adapted after our two pilot stages. The IQ involved ten scenarios that participants were asked to read (See Appendix 4). Again, participants were provided with instructions and guided through one practice example. On each of the ten questions, participants were presented with a scenario on one screen and asked to move onto a new page when they had read it. The scenarios were designed to involve a relatable situation based on social or personal circumstances. Each scenario was designed to end ambiguously, with participants being able to draw their own conclusions regarding whether the outcome was going to be negative, positive or neutral.

After reading the scenario, participants were next asked to complete a comprehension task where they were provided with two short statements, one of which related to the scenario they had read. This comprehension question was included to ensure that participants not reading the scenarios may be identified.

After the comprehension question, participants were asked to rank three possible explanations that could have been derived from the scenario in order of how

plausible they were. Of the three explanations provided, one was coded as a positive, one neutral and one negative response (See scenarios presented in Appendix 4). Participants ranked each of the outcomes from one to three with endorsements calculated as 1 for “most likely”, 2 for “neither likely or unlikely” and 3 for “least likely”. Responses were controlled so that participants had to choose a different rating for each suggested outcome (e.g. they could not select both positive and neutral outcome suggestions as being “most likely”). Ratings that were awarded for each scenario were calculated separately for IQ Negative (IQN), IQ Positive (IQP) and IQ Neutral (IQNu) resulting in scores for each. These separate scores were then averaged across all ten scenarios for each participant. This resulted in an overall score for each participant for Positive, Negative and Neutral scenario interpretations independently. Scores of one equated to participants agreeing the most with the statement (whether it be positive, neutral or negative) and scores of three meaning that they least agreed (whether it be positive, neutral or negative).

Finally, participants were asked to indicate how likely they felt each explanation were to apply to them if they were in a similar situation. This ranking ranged from zero (not at all likely) to eight (extremely likely). This particular IB measure was not timed. This section of the IQ was not analyzed, consistent with other studies.

Experimental Procedure

Ethical approval was obtained through the King’s College London Psychiatry, Nursing and Midwifery Research Ethics Committee (LRS-16/17-4729). All testing regarding the two experimental links were completed using the Qualtrics XM (https://www.qualtrics.com) electronic platform. Participants completing the main stage of testing were contacted by the research team via email, with a list of instructions regarding the study and an initial electronic link to the first part of the study. They were informed that this first link could only be opened once and would expire after a week. Link 1 contained questions regarding demographic details, illness related measures and medication history. The link also included mood related measures such as the GAD-7 and PHQ 8. Participants were automatically

emailed a second link to part two of the study immediately after completion of the first link. This second link began with the PSWQ and lead onto the two IB tasks. Participants were finally asked to indicate whether they had any feedback regarding the study and to state whether they had any help when completing the task.

On completion of the two experimental links, participants were asked to arrange a date for a telephone cognitive assessment (TICS-M) and to provide any further feedback. These telephone assessments were completed within three weeks of testing. On completion of the telephone assessment, participants were sent a debriefing email to thank them for their participation in the study.

Sample size calculation and statistical analysis plan

We aimed for 115 participants to complete the main study. This is based on a 95% calculation for power to detect a medium effect size for a bivariate correlation (0.30 for Pearson's *r* or 0.15 for Cohen's $f^2$) at .05 significance. To account for a 10% estimate for non-usable data, we expect a sample size of 130 may be required.

## Results

A total of 110 participants completed at least one of the two tests. There were 109 participants who completed the IQ and 101 that completed the SST. One participant was excluded from the IQ as they answered 40% of comprehension questions incorrectly. Nine participants were excluded from the SST as they made 40% or more errors in sentence completion.

Analysis of results consisted of a primary hierarchal regression analysis, secondary stepwise regression and exploratory one-way ANOVA of participants selected for high and low anxiety and rumination.

Descriptive statistics

Mean scores for descriptive information are provided in Table 1. The sample is matched for gender. Illness duration ranged between three months and 30 years,

meaning that there was a range of participants with experience of living with Parkinson's disease. Scores on the PHQ 8 and GAD 7 were in the normal ranges overall, as were scores on the RSES, PADL, RRS and PSWQ.

*Table 1. Overall Descriptive statistics*

| N | Gender | Mean | STDV | Range |
|---|---|---|---|---|
| 110 | *Female = 57 Male = 53* | | | |
| Age | | 64.606 | 8.083 | 44 – 84 |
| TICS-M | | 37.923 | 7.324 | 31-50 |
| Illness Duration | | 5.144 | 5.666 | .30 – 30 |
| H&Y | | 1.541 | .889 | 0 – 5 |
| S&E | | 83.727 | 15.377 | 10 – 100 |
| PHQ_8 | | 5.982 | 4.931 | 0 – 24 |
| GAD_7 | | 5.373 | 4.609 | 0 – 18 |
| RSES | | 15.936 | 2.117 | 10 – 20 |
| PADL | | 1.89 | .598 | 1 – 3 |
| RRS | | 37.246 | 11.208 | 7 – 70 |
| PSWQ | | 20.355 | 9.038 | 8 – 40 |

TICS-M: Modified Telephone Interview of Cognitive Status; H&Y: Hoehn and Yahr Scale; S&E: Schwab and England Scale; PHQ 8: Patient Health Questionnaire; GAD 7: General Anxiety Disorder Scale; RSES: Rosenberg Self Esteem Scale; PADL: Parkinson's Activities of Daily Living Scale; RRS: Ruminative Response Scale; PSWQ: Penn State Worry Questionnaire

As described in the methods section, Scores for Negative SST (SSTN) word selections were calculated as a proportion of positive to negative word selections ranging from 0 to 1 (0 = no word selections were negative and 1 = all word selections were negative). Scores for the IQ were calculated separately for each of the three possible interpretation endorsements (negative, positive and neutral) with scores ranging from 1 to 3 (1= most likely interpretation and 3= least likely interpretation) (see Table 2). (see Table 2).

*Table 2. Descriptive statistics for SSTN and IQ*

| IB Measure | Gender | N | Mean | STDV |
|---|---|---|---|---|
| **SST** | *Female = 52 Male = 49* | *101* | | |
| **SSTN** | | | **.302** | **.177** |
| **IQ** | *Female = 57 Male = 52* | *109* | | |
| **IQN** | | | **2.500** | **.387** |
| **IQP** | | | **1.791** | **.340** |
| **IQNu** | | | **1.712** | **.268** |

Note: Lower scores on the IQ indicates that participants were more likely to agree with the relevant scenario interpretation. Lower score on the SST indicate that participants were more likely to select positive word endorsements during sentence completion.

General Correlation Analysis

Illness Duration was negatively correlated with negative interpretations on the IQ but not on the positive, neutral interpretations on the IQ or SSTN (see Table 3). Age was negatively correlated with IQNu. All other correlations were not significant (see Table 3).

*Table 3*. Summary of Correlations for Interpretation Questionnaire and Scrambled Sentences Test

| | SSTN | IQN | IQP | IQNu |
|---|---|---|---|---|
| Variables | | *Pearson's r values* | | |
| Gender | .065 | .023 | .057 | -.105 |
| Age | -.068 | .093 | .050 | -.199* |
| TICS-M | .049 | .056 | .065 | .059 |
| Illness Duration | -.003 | - .198* | .117 | .140 |

* Indicates significant difference between variables at p < .05. **Indicates significant difference between variables at p < .01. ***Indicates significant difference between variables at p < .001.

Correlations between SSTN and IQ as dependent variables and a range of independent variables (GAD 7, RSES, PSWQ, PHQ 8, RRS, H&Y and S&E) are provided in Table 4. Scores for the GAD 7 indicate that the higher the score on

negative IQ interpretations (meaning that participants were less likely to endorse negative interpretations), the lower the scores were for anxiety. The opposite trend was significant for positive interpretations on the IQ where higher anxiety scores were correlated with participants being less likely to endorse positive interpretations. Results also identified that higher scores on the GAD 7 resulted in more endorsements of negative words in the SST. Scores for the RSES indicated that higher self-esteem resulted in fewer endorsements of negative interpretations on the IQ. Lower self-esteem correlated with fewer endorsements of neutral but not positive interpretations on the IQ. Lower self-esteem also correlated with more endorsements of negative words in the SST. On the PSWQ, lower levels of worry correlated to fewer endorsements of negative interpretations on the IQ. Higher levels of worry correlated with fewer endorsements of positive interpretations on the IQ and more selections of negative words on the SST. Scores on the PHQ-8 indicated that lower depression correlates with lower endorsement of negative interpretations on the IQ. Higher levels of depression are correlated to less endorsement of positive interpretations on the IQ and more endorsements of negative words on the SST. On the RRS, lower levels of rumination correlated with lower endorsements of negative interpretations on the IQ. Higher scores on the RRS were correlated with fewer endorsements of positive interpretations on the IQ and more selections of negative words on the SST. All other correlations were not significant.

*Table 4. Summary of Regression Analysis Correlations for negative cues on the Interpretation Questionnaire and Scrambled Sentences Test*

| | SSTN | IQ Negative | IQ Positive | IQ Neutral |
|---|---|---|---|---|
| Variables | | *Pearson's r values* | | |
| GAD_7 | .521*** | -.427*** | .475*** | .022 |
| RSES | -.248** | .212* | -.108 | -.173* |
| PSWQ | .473*** | -.361*** | .441*** | -.032 |
| PHQ 8 | .455*** | -.335*** | .403*** | -.019 |
| RRS | .502*** | -.431*** | .472*** | .032 |
| H&Y | .131 | -.130 | .116 | .042 |
| S&E | -.137 | .074 | -.072 | -.017 |

* Indicates significant difference between variables at p < .05. **Indicates significant difference between variables at p < .01. ***Indicates significant difference between variables at p < .001. Note: High scores on: the GAD 7 = higher levels of anxiety, on the RSES = higher self-esteem, on the PSWQ = higher levels of worry, on the PHQ-8 = higher depression, on the RRS = more rumination, on the H&Y = more physical symptoms of Parkinson's and on S&E = more symptoms of Parkinson's. Furthermore, higher scores on the IQ Negative, Positive and Neutral indicate fewer endorsements for these respective interpretations. High scores on the SSTN indicate higher proportions of interpretations for negative words.

## Primary Hierarchical regression models

The primary analysis consisted of a range of regression analysis models. To begin with, a range of hierarchical regressions were performed based on three models, consisting of three sets of predictor/independent variables (IV) (anxiety, mood and illness). Anxiety related variables involved scores on the GAD 7, RSES and PSWQ as these were judged to best measure this aspect. Mood related variables consisted of PHQ 8 and RRS. Illness related variables involved the H&Y and S&E scales. These predictor variables were assessed against the two dependent variable (DV) IB measures. The IB measures which were separated for interpretations of negative endorsements in the SST (SSTN) as well as negative (IQ Negative), positive (IQ Positive) and neutral (IQ Neutral) cues in the IQ.

## Scrambled Sentences Test correlations of Negative word cues

### Prediction of SSTN

*Model 1*

The same hierarchical model was applied to systematically test the relationship between the same predictor variables (IV's) as above and negative word selections on the SST (DV) (see Table 7). An initial multiple linear regression (Model 1) was performed to predict SSTN score using anxiety related measures, $F(3,97) = 13.511$, $p < 0.001$, with an $R^2$ of .295, accounting for 27% variance (adjusted $R^2$) in the model and large effect size (.42 based on Cohen's $f^2$). IB for negative cues on the SST is equal to .279 + -.008 (RSES), where higher scores indicate higher levels of self-esteem + .004 (PSWQ), where higher scores indicate more worry, + 0.14 (GAD_7) where higher scores indicate more anxiety. IB significantly increased by .014 points with each additional score on the GAD 7 ($t(97) = 2.615$, $p<.05$) with a confidence interval ranging between .003 to .025. Self-esteem as measured by the RSES ($t(97) = 1.069$, $p>.05$ and worry as measured by the PSWQ ($t(97) = 1.466$, $p>.05$ did not contribute to the model. Results indicate that anxiety (as measured by the GAD 7) was a significant predictor of increased IB endorsement of negative cues in the SST.

*Model 2*

A second regression (Model 2) involved the same SSTN score (IV) and anxiety related measures but added low mood/depression related measures (IV's), $F(5,95) = 9.174$, $p < 0.001$ with an $R^2$ of .326, accounting for 29% variance (adjusted $R^2$) in the model and large effect size (.48 based on Cohen's $f^2$). Scores for Model 2 indicate that IB for negative cues on the SST did not significantly correlate with the RSES, PSWQ or GAD 7 ($p>.05$ for all three variables). Similarly, there were no significant correlations between scores in the SST and PHQ 8 or RRS ($p>.05$ for both).

*Model 3*

The third regression (Model 3) included the same IV and DV's but added further variables assessing illness severity (H&Y and (S&E), $F(7,93) = 6.437$, $p < 0.001$ $R^2$ of .326, accounting for 28% variance (adjusted $R^2$) in the model and large effect size (.42 based on Cohen's $f^2$). Results indicate that rumination, depression, illness duration and illness severity do not predict negative cue endorsements on the SST test once anxiety related measures were in the equation.

*Table 5. Summary of Regression Analysis for Variables Predicting Interpretation bias of negative cues on the Scrambled Sentence Test*

| | Model 1 | | | | Model 2 | | | | Model 3 | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Variable | *B* | *SE B* | *β* | *p* | *B* | *SE B* | *β* | *p* | *B* | *SE B* | *β* | *p* |
| GAD 7 | .014 | .005 | .348 | .010 | .007 | .006 | .162 | .314 | .007 | .007 | .169 | .307 |
| RSES | -.008 | .008 | .096 | .288 | -.007 | .008 | .081 | .364 | -.006 | .008 | -.076 | .417 |
| PSWQ | .004 | .003 | .190 | .146 | .003 | .003 | .151 | .276 | .003 | .003 | .144 | .308 |
| PHQ 8 | | | | | .006 | .005 | .151 | .221 | .006 | .005 | .151 | .247 |
| RRS | | | | | .003 | .002 | .162 | .242 | .003 | .002 | .159 | .256 |
| H&Y | | | | | | | | | .007 | .023 | .034 | .760 |
| S&E | | | | | | | | | .000 | .001 | .011 | .922 |
| $R^2$ | | .295 | | | | .326 | | | | .326 | | |
| *F* for change in $R^2$ | | 13.511 | | | | 2.177 | | | | .051 | | |

Interpretation Questionnaire correlations of Negative, Positive and Neutral cue endorsements

Prediction of IQ Negative Interpretations

*Model 1*

An initial multiple linear regression (Model 1) was performed to predict negative interpretations assessed using the IQ Negative score (DV), on anxiety related measures (IV), $F(3,105) = 8.153$, $p < 0.001$, with an $R^2$ of .189, accounting for 17%

variance (adjusted $R^2$) in the model and medium effect size (.23 based on Cohen's $f^2$) (see Table 5). The regression equation for IB for cues on the IQ Negative is equal to 2.515 + .013 (RSES), where higher scores indicate higher levels of self-esteem + -.003 (PSWQ), where higher scores indicate more worry, + -0.28 (GAD_7) where higher scores indicate more anxiety. Results indicate that IB significantly increased by .028 points with each additional score on the GAD 7 ($t(105) = -2.383$, $p<.05$) with a confidence interval ranging between .052 to .005. Results indicate that participants are more likely to endorse cues negatively the higher their anxiety (GAD 7). However, no relationship between IB of negative cues on the IQ and self-esteem (RSES) or worry (PSWQ) were identified in this model.

*Model 2*

A second regression (Model 2) involved the same IQ Negative score (IV) and anxiety related measures but added low mood/depression related measures (IV's), $F(5,103) = 5.509$, $p < 0.001$ with an $R^2$ of .211, accounting for 17% variance (adjusted $R^2$) in the model and medium effect size (.27 based on Cohen's $f^2$). Scores for Model 2 indicate that IB for negative cues on the IQ did not significantly correlate with the RSES, PSWQ or GAD 7 ($p>.05$ for all three variables). Similarly, there were no significant correlations between scores in the IQ and PHQ 8 or RRS ($p>.05$ for both).

*Model 3*

The third regression (Model 3), included the same IV and DV's but added further variables assessing illness severity (H&Y and (S&E) as DV's, $F(7,101) = 4.080$, $p < 0.001$ $R^2$ of .220, accounting for 17% variance (adjusted $R^2$) in the model and medium effect size (.28 based on Cohen's $f^2$). Results indicate that rumination, depression and illness severity do not predict negative cue interpretations on the IQ test, once anxiety related measures are in the equation.

*Table 6. Summary of Regression Analysis for Variables Predicting Interpretation bias of negative cues on the Interpretation Questionnaire*

| | Model 1 | | | | Model 2 | | | | Model 3 | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Variable | *B* | *SE B* | *β* | *p* | *B* | *SE B* | *β* | *p* | *B* | *SE B* | *β* | *p* |
| GAD_7 | .028 | .012 | -.341 | .019 | -.020 | .015 | .238 | .185 | -.019 | .015 | -.225 | .216 |
| RSES | .013 | .017 | .071 | .454 | .010 | .017 | .055 | .557 | .013 | .018 | .069 | .485 |
| PSWQ | .003 | .006 | -.079 | .568 | .000 | .006 | .008 | .959 | .001 | .006 | .021 | .891 |
| PHQ 8 | | | | | .002 | .011 | .031 | .824 | -.001 | .011 | -.012 | .934 |
| RRS | | | | | -.009 | .005 | .257 | .103 | -.009 | .005 | -.258 | .104 |
| H&Y | | | | | | | | | -.040 | .051 | -.092 | .433 |
| S&E | | | | | | | | | -.003 | .003 | -.137 | .277 |
| $R^2$ | | .189 | | | | .211 | | | | .220 | | |
| *F* for | | 8.158 | | | | 1.439 | | | | .611 | | |

Prediction of IQ Positive Interpretations

*Model 1*

A separate multiple linear regression (Model 1) was performed to predict positive IB using the IQ Positive score (DV) on anxiety related measures (DV's), F(3,105) = 11.252, p < 0.001, with an $R^2$ of .243, accounting for 22% variance (adjusted $R^2$) in the model and medium effect size (.32 based on Cohen's $f^2$) (see Table 6). Positive IB for cue endorsements on the IQ is equal to 1.343 + .011 (RSES), where higher scores indicate higher levels of self-esteem, + .007 (PSWQ), where higher scores indicate more worry, + 0.26 (GAD_7) where higher scores indicate more anxiety. IB of positive cues significantly decreased by .026 points with each additional score on the GAD 7 (t(105) = 2.593, p<.05) with a confidence interval ranging between .006 to .046. Results indicate that participants are less likely to endorse positive cues the higher their anxiety (GAD 7). Results comparing this relationship to self-esteem (RSES) and worry (PSWQ) were not significant.

*Model 2*

A second regression (Model 2) involved the same IQ Positive score (IV) and anxiety related measures but added low mood/depression related measures (IV's), $F(5,103) = 7.466$, $p < 0.001$ with an $R^2$ of .266, accounting for 23% variance (adjusted $R^2$) in the model and large effect size (.36 based on Cohen's $f^2$). Scores for Model 2 indicate that IB for positive cues on the IQ did not significantly correlate with the RSES, PSWQ or GAD 7 ($p>.05$ for all three variables). Similarly, there were no significant correlations between scores in the IQ and PHQ 8 or RRS ($p>.05$ for both).

*Model 3*

The third regression (Model 3) included the same IV and DV's but added further variables assessing illness severity (H&Y and (S&E), $F(7,101) = 5.432$, $p < 0.001$ $R^2$ of .273, accounting for 22% variance (adjusted $R^2$) in the model and large effect size (.38 based on Cohen's $f^2$). Results indicate that rumination, depression, illness duration and illness severity do not predict negative cue endorsements on the IQ test once anxiety related measures were in the equation.

*Table 7. Summary of Regression Analysis for Variables Predicting Interpretation bias of positive cues on the Interpretation Questionnaire*

| | Model 1 | | | | Model 2 | | | | Model 3 | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Variable | *B* | *SE B* | *β* | *p* | *B* | *SE B* | *β* | *p* | *B* | *SE B* | *β* | *p* |
| GAD 7 | .026 | .010 | .358 | .011 | .014 | .012 | .197 | .255 | .013 | .013 | .184 | .296 |
| RSES | .011 | .014 | .067 | .463 | .013 | .014 | .084 | .357 | .011 | .015 | .070 | .460 |
| PSWQ | .007 | .005 | .182 | .175 | .005 | .005 | .122 | .397 | .004 | .005 | .112 | .444 |
| PHQ 8 | | | | | .005 | .009 | .077 | .564 | .008 | .010 | .117 | .409 |
| RRS | | | | | .006 | .004 | .205 | .177 | .006 | .005 | .207 | .177 |
| H&Y | | | | | | | | | .028 | .043 | .075 | .507 |
| S&E | | | | | | | | | .003 | .003 | .123 | .312 |
| $R^2$ | | .243 | | | | .266 | | | | .273 | | |
| *F* for change in $R^2$ | | 11.252 | | | | 1.596 | | | | .519 | | |

Prediction of IQ Neutral Interpretations

*Models 1-3*

A final regression analysis for variables predicting IB endorsement of neutral cues on the Interpretation Questionnaire was completed. All three multiple regression models incorporating the same anxiety ($F(3,105) = 1.336$, $p = .267$, with an $R^2$ of .037, accounting for 1% variance (adjusted $R^2$)), mood ($F(5,103) = .993$, $p = .426$, with an $R^2$ of .046, accounting for 0% variance) and illness ($F(7,101) = .660$, $p = .660$, with an $R^2$ of .047, accounting for 2% variance) measures as previous analysis, were not significant.

## Secondary Stepwise regression models

Stepwise regression models for both SSTN and IQ measures

Secondary analysis consisted of a single stepwise regression analysis to explore regression generated models for both the SSTN and IQ. The same

predictor/independent variables (GAD 7, RSES and PSWQ, PHQ 8 and RRS, H&Y and S&E scales) and dependent variables (IQ Negative, IQ Positive, IQ Neutral and SSTN) were explored.

Scrambled Sentences Test Negative word cues

Scrambled Sentences Test Negative word endorsements

A stepwise linear regression was also applied to test the correlation between the same variables and scores on the endorsement of negative cues for the SST (see Table 8). Stepwise linear regression was performed to predict negative IB using the negative endorsements on the SST, revealing two models. Two regression models were computed from the analysis. Results for Model 1 ($F(,99) = 36.869$, $p < 0.001$, with an $R^2$ of .271), accounted for 26% variance in the model and large effect size (.37 based on Cohen's $f^2$). IB for negative cues on the SST is equal to .190 + .021 (GAD 7), where higher levels of anxiety predicted more negative endorsements ($t(99) = 6.072$, $p> .001$) with a confidence interval ranging between .014 to .028. All remaining variables were excluded by the Model 1.

Results for Model 2 ($F(,98) = 21.361$, $p < 0.001$, with an $R^2$ of .304), accounted for 29% variance in the model and large effect size (.44 based on Cohen's $f^2$) (see Table 8). IB for negative cues on the SST is equal to .070 + .013 (GAD 7), where higher levels of anxiety predicted more negative endorsements ($t(98) = 2.702$, $p= .008$ with a confidence interval ranging between .004 to .023) + .004 (RRS), where higher levels of rumination predicted more negative endorsements ($t(98) = 2.130$, $p= .0.36$ with a confidence interval ranging between .000 to .008). All remaining variables were excluded by the Model 2.

*Table 8. Summary of Stepwise Regression Analysis for Variables Predicting Interpretation bias of negative cues on the Scrambled Sentences Test*

| | Model 1 | | | | Model 2 | | | |
|---|---|---|---|---|---|---|---|---|
| Included Variable | *B* | *SE B* | *β* | *p* | *B* | *SE B* | *β* | *p* |
| GAD 7 | .021 | .003 | .521 | <.001 | .013 | .005 | .331 | .008 |
| RRS (Model 2 only) | - | - | - | - | .004 | .002 | .261 | .036 |
| $R^2$ | | .271 | | | | .304 | | |
| *F* for change in $R^2$ | | 36.86 | | | | 4.536 | | |

## Interpretation Questionnaire endorsements

### Prediction on IQ Negative endorsements

A stepwise linear regression was applied to test predictors between the same independent variables and scores of negative cues for the IQ Negative (DV). Stepwise linear regression was performed to predict negative interpretation using the endorsements on the IQ Negative, F(,107) = 24.403, p < 0.001, with an $R^2$ of .186, accounting for 18% variance in the model and medium effect size (.23 based on Cohen's $f^2$). IB for negative cues on the IQ is equal to 3.052 + -.015 (RRS), where higher levels of rumination predicted more negative endorsements (t(107) = -4.940, p> .001) and a confidence interval ranging between .021 to .009. All remaining variables were excluded by the model.

### Prediction on IQ Positive endorsements

A stepwise linear regression was applied to test predictors of positive interpretations for the IQ Positive. Stepwise linear regression revealed a significant effect of the general model (F(,107) = 31.170, p < 0.001, with an $R^2$ of .226, accounting for 22% variance in the model and medium effect size (.29 based on Cohen's $f^2$). IB for negative cues on the IQ is equal to 1.603 + .034 (GAD 7), where lower levels of anxiety predicted more positive interpretations (t(107) = 5.583, p> .001) and a confidence interval ranging between .022 to .047. All remaining variables were excluded by the model.

Prediction on IQ Neutral endorsements

A stepwise linear regression was applied to test the predictors of neutral interpretations for the IQ Neutral did not result in any significant findings.

## Exploratory analysis of high vs. low scorers on anxiety and rumination measures

A series of one-way between subjects ANOVA's were conducted to compare the effects of participants who scored in high and low categories for anxiety (GAD 7) and rumination (RRS) on IB (see Tables 9 & 10). We used a method similar to that employed by other studies (Amir et al., 2005), taking the top and bottom 33 percentile of scores from the GAD 7 and RRS to determine High (scores of 6 and above for GAD 7 and 42 and above for RRS) and Low (scores of 2 and lower for GAD 7 and 30 and lower for RRS) scorers for anxiety and rumination respectively.

High vs. low anxiety

High and Low groups for IQ and SST groups were matched for age ($p>.05$). However, there was a significant difference in Illness Duration ($p=.032$) in the IQ conditions, where those in the high anxiety group had been living with Parkinson's disease for longer. There was a trend towards significance for illness duration in the SST group ($p=.063$).

There was a significant effect of anxiety on negative ($F(1, 72) = 21.501$, $p< .001$) and positive ($F(1, 72) = 26.649$, $p< .001$) cues interpretations in the IQ. Results indicate that participants in the high anxiety group ranked negative interpretations to be more likely than those in the low anxiety group. Results also indicate that those in the high anxiety group ranked positive interpretations to be less likely than those in the low anxiety group. The effect of anxiety on neutral cues ($F(1, 72) = .019$, $p= .891$) in the IQ was not significant. There was a significant effect of anxiety on endorsement of both negative ($F(1, 65) = 48.651$, $p< .001$) and positive ($F(1, 65) = 48.651$, $p< .001$) cues in the SST. Similar to results on the IQ, participants in the high anxiety group were more likely to select negative words and less likely to select positive words.

Analysis for negative endorsement of cues in the IQ measure indicated that the mean IB scores for the high anxiety group (M = 2.335, SD = .350) was significantly different than the low anxiety group (M = 2.687, SD = .300). These results indicate that those with high levels of anxiety endorsed more negative cues than those in the low anxiety group. The same analysis for positive endorsements in the IQ measure revealed that scores in the high anxiety group (M = 1.976, SD = .304) was significantly different to that of the low anxiety group (M = 1.616, SD = .295). These result indicate that those in the high anxiety group endorsed fewer positive cues. Post hoc analysis was also conducted on negative endorsement of cues in the SST measure. Scores for the high anxiety group (M = .411, SD = .174) were significantly different to that of the low anxiety group (M = .164, SD = .107). These results indicate that those with higher anxiety levels endorsed more negative cues than lower anxiety participants. Finally, scores for the high anxiety group (M = .589, SD = .174) were significantly different from those of the low anxiety group (M = .836, SD = .107). These results demonstrate that those with higher levels of anxiety, endorse fewer positive cues than those with lower levels.

*Table 9. Descriptive statistics for High vs. Low anxiety*

| | | N | Mean | STDV | Age | Illness Duration |
|---|---|---|---|---|---|---|
| IQ Negative | Low | 37 | 2.6865 | .300 | 63.919 (6.549) | 3.870 (.672) |
| | High | 37 | 2.3351 | .350 | 63.216 (6.254) | 6.489 (.573) |
| IQ Positive | Low | 37 | 1.6162 | .295 | | |
| | High | 37 | 1.9757 | .304 | | |
| IQ Neutral | Low | 37 | 1.6973 | .264 | | |
| | High | 37 | 1.6892 | .245 | | |
| SSTP | Low | 33 | .8365 | .107 | 63.559 (4.427) | 3.818 (2.874) |
| | High | 34 | .5892 | .174 | 62.618 (5.175) | 5.976 (1.638) |
| SSTN | Low | 33 | .1635 | .107 | | |
| | High | 34 | .4108 | .174 | | |

Note: Higher scores in the IQ refers to lower endorsement rankings for either Negative, Neutral or Positive statement endorsements. Higher scores in the SST indicates more endorsements of either Positive or Negative word selections.

## High vs. low rumination

High and Low groups for IQ and SST groups were matched for age and Illness Duration ($p>.05$). However, there was a trend towards significance for illness duration in the SST group ($p=.077$).

A final series of one-way between subjects ANOVA's were conducted to compare the effect of high and low scorers on the RRS for IB, using the same method as before. There was a significant effect of rumination on negative interpretation endorsement ($F(1, 70) = 38.279$, $p< .001$) and positive ($F(1, 70) = 40.766$, $p< .001$) interpretations in the IQ. Results indicated that those with high rumination rated negative interpretations to be significantly more likely than those in the low rumination group. Results also indicate that those in the high rumination group

ranked positive interpretations to be significantly less likely than those in the low rumination group. The effect of rumination on selection of neutral interpretations ($F(1, 70) = .123$, $p = .727$) in the IQ was not significant. There was a significant effect of rumination on negative ($F(1, 62) = 46.842$, $p < .001$) and positive ($F(1, 62) = 46.842$, $p < .001$) endorsement of cues in the SST. Again, those in the high rumination group selected significantly more negative word completions than those in the low group. They also selected significantly less positive word completions than those in the low rumination group.

Analysis for negative endorsement of cues in the IQ measure indicated that the mean IB scores for the high rumination group ($M = 2.272$, $SD = .339$) was significantly different than the low rumination group ($M = 2.703$, $SD = .243$). These results indicate that those with high levels of rumination endorsed more negative cues than those in the low rumination group. The same analysis for positive endorsements in the IQ measure revealed that scores in the high rumination group ($M = 2.019$, $SD = .274$) was significantly different to that of the low rumination group ($M = 1.608$, $SD = .272$). These results indicate that those in the high rumination group endorsed fewer positive cues. Post hoc analysis was also conducted on negative endorsement of cues in the SST measure. Scores for the high rumination group ($M = .416$, $SD = .172$) were significantly different to that of the low rumination group ($M = .182$, $SD = .088$). These results indicate that those with higher rumination levels endorsed more negative cues than lower rumination participants. Finally, positive endorsements of cues on the SST for the high rumination group ($M = .589$, $SD = .174$) were significantly different from those of the low rumination group ($M = .819$, $SD = .088$). These results demonstrate that those with higher levels of rumination, endorse fewer positive cues than those with lower levels.

*Table 10. Descriptive statistics for High vs. Low rumination*

| | | N | Mean | STDV | Age | Illness Duration |
|---|---|---|---|---|---|---|
| IQ Negative | Low | 36 | 2.7028 | .24318 | 65.081 | 4.211 |
| | High | 36 | 2.2722 | .33942 | 60.778 | 6.286 |
| IQ Positive | Low | 36 | 1.6083 | .27190 | | |
| | High | 36 | 2.0194 | .27445 | | |
| IQ Neutral | Low | 36 | 1.6889 | .21485 | | |
| | High | 36 | 1.7083 | .25341 | | |
| SSTP | Low | 32 | .8185 | .08828 | 64.910 | 4.248 |
| | High | 32 | .5843 | .17228 | 59.969 | 4.981 |
| SSTN | Low | 32 | .1815 | .08828 | | |
| | High | 32 | .4157 | .17228 | | |

Note: Higher scores in the IQ refers to lower endorsement rankings for either Negative, Neutral or Positive statement endorsements. Higher scores in the SST indicates more endorsements of either Positive or Negative word selections.

## Discussion

### Summary of findings

Primary analysis identified that increased levels of negative cue endorsement on two separate IB measures were correlated with higher levels of anxiety. Results also demonstrated that those with higher levels of anxiety were also less likely to endorse positive cues on the IQ. As expected, regression analysis did not identify any significant correlations for ambiguous cue interpretations in the IQ paradigm. Secondary stepwise analysis revealed slightly different results for associations between predictor variables and endorsements of negative cues on the IQ and SST. Results for the IQ identified a significant association with rumination (RRS) but not anxiety (GAD 7). However, the same analysis for negative endorsements on the SST

revealed significant results for both rumination and anxiety. Furthermore, stepwise analysis for positive interpretations on the IQ revealed an association with anxiety. All other analysis were not significant. In light of the above, our results confirmed hypothesis one and two, regarding the presence of IB and its correlation with anxiety but not depression. However, we did not find evidence for a correlation between IB and illness severity (hypothesis three).

Interpretation bias and anxiety

Our findings regarding anxiety scores being predictive of negative IB are consistent with other studies that have explored this relationship (Andrew Mathews & MacLeod, 2005; Richards, 2004). Typically, studies investigating this affect have done so using trait anxiety measures (Eysenck et al., 1987; Mogg, Bradley, & Hallowell, 1994). This study employed the GAD 7 as a more general measure of anxiety. These findings suggest fairly robust evidence for the role of anxiety in IB. However, the precise nature of how this bias begins and evolves is less clear. Some have argued that it is due to the process through which ambiguity is resolved by people (Hirsch & Mathews, 2012) while others have argued that it is the function of a bias in how situations are appraised, even in the absence of ambiguity (MacLeod & Mathews, 2012). Nevertheless, anxiety is consistently shown to be a mediating factor for IB in healthy participants (see Hallion & Ruscio, 2011 for meta-analysis). Our findings indicate that the same is true in participants who have Parkinson's disease.

Results of regression analysis identified that there were no significant correlations between endorsements of ambiguous cue interpretations amongst our cohort of participants and predictor variables in the IQ. These results indicate that participants were endorsing cues to be ambiguous at a consistent level, regardless of scores on predictor variables analyzed. These findings are particularly interesting as ambiguous endorsements can be considered to be the most accurate interpretations of the scenarios presented in the IQ. One may have predicted that more endorsements of ambiguous scenarios would have been correlated with those who had lower levels of anxiety, however, this was not reflected by our

results. Nevertheless, findings seem to indicate that participants were interpreting scenarios to be ambiguous with a similar likelihood to endorsements of positive interpretations on the IQ. These results indicate that factors such as anxiety and rumination are predictive of more extreme interpretations of either positive or negative outcomes but do not correlate to neutral scenarios when it is appropriate.

Interpretation bias and rumination

An interesting finding in our study is the correlation between rumination and IB on the both negative endorsements of scenarios in the IQ and SST based on stepwise analysis. Studies that have explored the association between IB and rumination using the RRS have not identified a direct correlation but have suggested that participants with higher scores on measures of rumination produced slower responses to homographs that were considered to display ruminative meanings (Mor et al., 2014). Our results are potentially consistent with arguments raised by other studies regarding the degree to which bias requires explicit processing, which has been noted in the Systematic Literature Review section of this thesis. It is interesting to consider whether this same process through which participants require time to consider responses is mediated by a degree of rumination that may be driving the results of our stepwise regression. It is noted that for both the SST and IQ measures, participants were afforded time to consider their responses, although the SST was limited to ten minutes. Both paradigms may have afforded participants an opportunity to consider and deliberate on answers, resulting in those more likely to exercise ruminative thinking patterns to conclude on negative interpretations. This would be consistent with other studies that have found that encouraging rumination in response selection prompts IB (Hertel & El-Messidi, 2006). Interestingly, the same analysis looking at positive interpretations on the IQ did not reveal a correlation with rumination but anxiety. These findings seem to indicate that while high levels of rumination result in negative interpretations, low levels of rumination do not correlate with positive interpretations of scenarios. The finding that lower levels of anxiety correlate with more positive interpretations is consistent with hierarchical analysis. Further investigations of the effect of

rumination may wish to consider rumination in its individual component parts, which have been suggested to be brooding and reflection (Burwell & Shirk, 2007) for a more detailed examination.

Investigation of high and low anxiety/rumination

Exploratory analysis of high and low anxiety participants found that those who scored highest on the GAD 7 made more endorsements of negative cues on both the IQ and SST. These findings further strengthen the association between anxiety and IB in our participants. The findings are also consistent with that of other studies that have demonstrated that those with higher levels of anxiety are more likely to negatively interpret ambiguous cues than low anxiety groups (Calvo, Estevez, & Eysenck, 1994; Calvo, Eysenck, & Castillo, 1997; Eysenck & Calvo, 1992; A. Mathews & MacLeod, 1994). This analysis also indicates that although participants were generally more likely to rate interpretations on the IQ as positive or neutral, there nevertheless remains a significant difference in bias endorsements when controlled for anxiety.

Exploratory analysis, specifically of participants with high and low level anxiety also investigated the degree to which ambiguous interpretations were endorsed on the IQ. Again, results indicate that the tendency to endorse ambiguous interpretations did not differ between high and low anxiety groups. These findings indicate that scores on the GAD 7 and other measures do not influence the likelihood of participants with Parkinson's disease endorsing ambiguous cues differentially. Results indicate that in general, participants endorsed ambiguous interpretations with a similar likelihood rating to that of positive interpretations. Our findings therefore, suggest that participants were less sensitive to ambiguous cue interpretations dependent on anxiety level despite being as likely to endorse ambiguity as they were positive interpretations. These results suggest that participants did not show a differential preference for neutral interpretations, regardless of anxiety level.

As well as looking at high vs. low scores on anxiety, we investigated the same effect for rumination on the RRS. The result of this series of analysis matched the pattern of results reported for anxiety. These results strengthen the argument for rumination playing an important role in IB in people with Parkinson's disease when measured with the IQ and SST. Again, findings that there were no differences in the number of neutral endorsements of cues on the IQ measures indicates that rumination largely encourages more extreme (positive or negative) interpretations.

Consideration of illness related influences

In contrast to the findings presented in the Systematic Literature Review section of this thesis, illness duration was not predictive of IB. As noted above, disease severity has been strongly associated with IB in other physical health conditions. This study employed specific disease related measures to explore this effect in Parkinson's disease. However, none of the statistical methods applied, revealed a general effect of illness severity on IB for either the IQ or SST. An obvious explanation for this may be due to the specificity of the stimuli used in this study compared to that of other studies. As explored in the Systematic Literature Review section of this thesis, studies investigating IB in chronic pain and fatigue have applied homographs and homophones that directly relate to symptoms of their respective conditions. As a result of this, the studies mentioned have developed paradigms that are specifically tied into the general problems their participants experience and are therefore subject to frequency biases (Pincus et al., 1996). Although this study complete two rounds of piloting and adjusted scenarios slightly to make them more age appropriate, they were not designed specifically for participants with Parkinson's disease. It is possible that this effected responses in a way that is not comparable to other studies.

Future research and clinical implications

This study is the first to explore IB in people with Parkinson's disease. As noted above, the study involved two rounds of piloting to adjust parameters to be more feasible for people with Parkinson's disease to engage in testing. This partly

involved editing scenarios to make them more age appropriate. Further studies may wish to explore specific scenarios in more detail to make them more specific to people with Parkinson's disease in the way that studies employing participants with physical health conditions have done. This may help to address whether illness severity contributes to IB in this population.

A particularly interesting finding is that of rumination being a reliable predictor of IB in both measures as revealed by stepwise analysis and the breakdown of high and low RRS scorers. Studies exploring the nature of depression in people with Parkinson's disease have previously highlighted the role of rumination in this process (Julien et al., 2016) as well as in general populations (Watkins, E; Brown, 2002). The findings of this study did not reveal correlations between depression as measured through the PHQ 8 but the results of other studies may suggest that associations between IB and the RRS are a marker of low mood/depression having an influence through rumination. More detailed investigations of this effect are required to develop our understanding of the role of rumination in IB in general.

In addition to general perspectives regarding rumination and its role in IB, it may be of interest for future studies to explore the role of response time on IB. In light of previous studies indicating that IB may require more explicit responses and the additional processing time required for rumination to take place, future studies may wish to insert more stringent time constraints on participant's performance to explore its effects on cognitive bias. As stated above, this study involved a ten minute time limit on the SST but not the IQ measure. This may have allowed participants to consider and ruminate over responses, possibly facilitating IB. Studies controlling for this effect would help to answer the question of whether time dependent responses contribute to IB or not.

Having established the IB is present in people with Parkinson's disease and that it can be predicted by anxiety and/or rumination, further research is required to explore the benefits of bias modification in this population. As discussed in the Systematic Literature Review section of this thesis, there is a shortage of bias modification studies in physical health conditions. However, its success in other

populations has been well established. Studies are required to demonstrate the validity of CBM-I for people with Parkinson's disease as a viable treatment for alleviating known anxiety problems in this group. It is also noted that the potential for CBM-I to be utilized as a home based treatment could benefit many people with Parkinson's disease who otherwise find it difficult to access regular psychotherapy due physical limitations. Such home based interventions would eliminate the need for clients to travel in order to receive their intervention, which is noted as being a difficulty for many people with Parkinson's disease (Grimm, Paul, & Wakeham, 2004). However, it should be noted that it may also deter those who are not as computer savvy, this reducing its efficacy to a different subsection of client with Parkinson's disease.

The result of this study support the presence of IB in people with Parkinson's disease. Our findings suggest that further research is required to replicate the results of this study and better support its argument. Clinical implications of these findings suggest that people with Parkinson's disease may benefit from therapeutic interventions that specifically target bias modification as a means of alleviating anxiety. Findings also indicate that rumination is an aspect of IB in people with Parkinson's disease that may require further investigation. This may be indicative of negative thinking processes that can be addressed using techniques such as cognitive behavioral therapy. People with Parkinson's disease may therefore benefit from therapists dedicating more time towards addressing these ruminative response patterns.

Limitations

The main limitation of this study could be said to be the lower than expected sample size of participants in the main study. Due to various reasons, more participants were excluded from final analysis than expected, resulting in the final sample being lower than what we had aimed for. However, results of all the analysis have revealed a medium to large effect size with confidence intervals falling within relatively expected ranges (i.e. lower and upper ranges have been consistent with predictions being made with the only question being the degree to

which predictor variables are affective). Nevertheless, further studies may wish to replicate the findings of this study to ensure more robust evidence.

The studies use of online measures presented several benefits in terms of data collection, such as participants being able to complete all tests at their homes and in their own time. However, this also presents some issues given that participants were not monitored during completion of their tests. Although some post testing investigations could be performed to obtain feedback and review the amount of time it took for participants to complete each section of the survey, there remains to be multiple factors that could not be controlled for. Firstly, all participants were asked to state whether they received support in completing the survey but this feedback is open to bias from participants not wanting to declare that they had help. Similarly, some participants may not have been aware of what may constitute support in this sense.an additional draw back to participants receiving support is during IB tasks is the possibility that their responses may have been influenced by how they wanted to appear in front of the people assisting them. Another factor is that participants may have taken long breaks between links or even within each testing session. This may have disturbed their overall performance across measures. A further limitation is that the environment in which participants performed the survey may not have been entirely conducive to test administration. Participants were instructed to perform tests in a quiet space, but this is difficult to ensure.

## Conclusion

This study is the first to explore IB in people with Parkinson's disease. Give the findings of studies investigating anxiety in people with Parkinson's disease and IB in other populations, it was predicted that a correlation would be identified in this population. It was also predicted that illness severity may be a predictive factor for IB given the findings reported in physical health conditions. The findings of this study have supported the presence of IB in people with Parkinson's disease and

that this is correlated with anxiety but not depression. However, the study has also identified that IB is predicted by rumination, developing interesting perspectives for future research. In contrast to physical health conditions, IB was not correlated with illness severity. The reason for this may be due to the specific scenarios provided. Further research is required to investigate the nature of rumination in people with Parkinson's disease and how it may inform treatment techniques.

## References


Aldao, A., Nolen-Hoeksema, S., & Schweizer, S. (2010). Emotion-regulation strategies across psychopathology: A meta-analytic review. *Clinical Psychology Review*, *30*(2), 217–237.

Allott, R., Wells, A., Morrison, A. P., & Walker, R. (2005). Distress in Parkinson's disease: Contributions of disease factors and metacognitive style. *British Journal of Psychiatry*, *187*, 182–183.

Amin, N., Foa, E. B., & Coles, M. E. (1998). Negative interpretation bias in social phobia. *Behaviour Research and Therapy*, *36*(10), 945–957.

Amir, N., Beard, C., & Bower, E. (2005). Interpretation bias and social anxiety. *Cognitive Therapy and Research*, *29*(4), 433–443.

Antonini, A., Martinez-Martin, P., Chaudhuri, R. K., Merello, M., Hauser, R., Katzenschlager, R., … Goetz, C. G. (2011). Wearing-off scales in Parkinson's disease: Critique and recommendations. *Movement Disorders*, *26*(12), 2169–2175.

Badra, M., Schulze, L., Becker, E. S., Vrijsen, J. N., Renneberg, B., & Zetsche, U. (2017). The association between ruminative thinking and negative interpretation bias in social anxiety. *Cognition and Emotion*, *31*(6), 1234–1242.

Bandelow, B., & Michaelis, S. (2015). Epidemiology of anxiety disorders in the 21st century. *Dialogues in Clinical Neuroscience*, *17*(3), 327–335.

Bar-Haim, Y., Lamy, D., Pergamin, L., Bakermans-Kranenburg, M., & Van Ijvendoorn, M. (2007). Threat-Related Attentional Bias in Anxious and Nonanxious Individuals : A Meta-Analytic Study. *Psychological Bulletin*, *133*(1), 1–24.

Beard, C. (2011). Cognitive bias modification for anxiety: Current evidence and future directions. *Expert Review of Neurotherapeutics*, *11*(2), 299–311.

Beck, A. (1976). *Cognitive therapy and the emotional disorders*. New York: International Universities Press.

Bolles, R. . (1970). Species-specific defense reactions and avoidance learning. *Psychological Review*, *77*, 32–48.

Borkovec, T. D. (1994). *The nature, functions, and origins of worry. In G. C. L. Davey & F. Tallis (Eds.), Wiley series in clinical psychology. Worrying: Perspectives on theory, assessment and treatment*.

Borkovec, T. D., & Inz, J. (1990). The nature of worry in generalized anxiety disorder: A predominance of thought activity. *Behaviour Research and Therapy*, *28*(2), 153–158.

Borkovec, T. D., Robinson, E., Pruzinsky, T., & DePree, J. A. (1983). Preliminary exploration of worry: Some characteristics and processes. *Behaviour Research and Therapy*, *21*(1), 9–16.

Borkovec, Thomas D, Alcaine, O. M., & Behar, E. (2004). Avoidance Theory of Worry and Generalized Anxiety Disorder. In *In R. G. Heimberg, C. L. Turk, & D. S. Mennin (Eds.), Generalized anxiety disorder: Advances in research and practice*

(pp. 77–108).

Brandt, J., Spencer, M., & Folstein, M. (1988). The Telephone Interview for Cognitive Status. *Neuropsychiatry Neuropsychol Behav Neurol*, *1*, 111–117.

Britton, J. C., Lissek, S., Grillon, C., Maxine, A., & Pine, D. S. (2012). Development of anxiety: the role of threat appraisal and fear learning. *Depress Anxiety*, *28*(1), 5–17.

Broen, M. P. G., Köhler, S., Moonen, A. J. H., Kuijf, M. L., Dujardin, K., Marsh, L., … Leentjens, A. F. G. (2016). Modeling anxiety in Parkinson's disease. *Movement Disorders*, *31*(3), 310–316.

Brown, R. G., & Fernie, B. A. (2015). Metacognitions, anxiety, and distress related to motor fluctuations in Parkinson's disease. *Journal of Psychosomatic Research*, *78*(2), 143–148.

Brozovich, F., & Heimberg, R. G. (2008). An analysis of post-event processing in social anxiety disorder. *Clinical Psychology Review*, *28*, 891–903.

Burwell, R. A., & Shirk, S. R. (2007). Subtypes of Rumination in Adolescence: Associations Between Brooding, Reflection, Depressive Symptoms, and Coping. *Journal of Clinical Child & Adolescent Psychology*, *36*(1), 56–65.

Butler, G., & Mathews, A. (1983). Cognitive processes in anxiety. *Advances in Behaviour Research and Therapy*, *5*(1), 51–62.

Calvo, M. G., Estevez, A., & Eysenck, M. W. (1994). Ego-Threat Interpretive Bias In Test Anxiety: On-Line Inferences. *Cognition and Emotion*, *8*(2), 127–146.

Calvo, M. G., Eysenck, M. W., & Castillo, M. D. (1997). Interpretation Bias in Test Anxiety: The Time Course of Predictive Inferences. *Cognition & Emotion*, *11*(1), 43–64.

Clark, D., & McManus, F. (2002). Information processing in social phobia. *Biological Psychiatry*, *51*, 92–1.

Constans, J. I., Penn, D. L., Ihen, G. H., & Hope, D. A. (1999). Interpretive biases for ambiguous stimuli in social anxiety. *Behaviour Research and Therapy*, *37*, 643–651.

Cook, S., Marsiske, M., & McCoy, K. (2009). The use of the modified telephone interview for cognitive status (Tics-M) in the detection of amnestic mild cognitive impairment. *Journal of Geriatric Psychiatry and Neurology*, *22*(2), 103–109.

Cristea, I. A., Kok, R. N., & Cuijpers, P. (2016). The Effectiveness of Cognitive Bias Modification Interventions for Substance Addictions: A Meta-Analysis. *PLOS ONE*, *11*(9), 1–19.

Davis, R. N., & Nolen Hoeksema, S. (2000). Cognitive inflexibility among ruminators and nonruminators. *Cognitive Therapy and Research*, *24*(6), 699–711.

Dissanayaka, N. N. W., O'Sullivan, J. D., Pachana, N. A., Marsh, R., Silburn, P. A., White, E. X., … Byrne, G. J. (2016). Disease-specific anxiety symptomatology in Parkinson's disease. *International Psychogeriatrics*, *28*(7), 1153–1163.

Dissanayaka, N. N. W., Sellbach, A., Matheson, S., O'Sullivan, J. D., Silburn, P. A., Byrne, G. J., … Mellick, G. D. (2010). Anxiety disorders in Parkinson's disease: Prevalence and risk factors. *Movement Disorders*, *25*(7), 838–845.

Dissanayaka, N. N. W., White, E., O'Sullivan, J. D., Marsh, R., Silburn, P. A., Copland, D. A., … Byrne, G. J. (2015). Characteristics and Treatment of Anxiety Disorders in Parkinson's Disease. *Movement Disorders Clinical Practice*, *2*(2), 155–162.

Djamshidian, A., & Friedman, J. (2014). Anxiety and depression in Parkinson's disease. *Current Treatment Options In Neurology*, *6*(3), 151–154.

Dugas, M. J., Gagnon, F., Ladouceur, R., & Freeston, M. H. (1998). Generalized anxiety disorder: A preliminary test of a conceptual model. *Behaviour Research and Therapy*, *36*, 215–226.

Dugas, M. J., Hedayati, M., Karavidas, A., Buhr, K., Francis, K., & Phillips, N. A. (2005). Intolerance of uncertainty and information processing: Evidence of biased recall and interpretations. *Cognitive Therapy and Research*, *29*(1), 57–70.

Egan, S. J., Laidlaw, K., & Starkstein, S. (2015). Cognitive behaviour therapy for depression and anxiety in Parkinson's disease. *Journal of Parkinson's Disease*, *5*(3), 443–451.

Erro, R., Pappatà, S., Amboni, M., Vicidomini, C., Longo, K., Santangelo, G., … Barone, P. (2012). Anxiety is associated with striatal dopamine transporter availability in newly diagnosed untreated Parkinson's disease patients. *Parkinsonism & Related Disorders*, *18*(9), 1034–1038.

Eysenck, M. W., & Calvo, M. G. (1992). Anxiety and Performance: The Processing Efficiency Theory. *Cognition & Emotion*, *6*(6), 409–434.

Eysenck, M. W., Macleod, C., & Mathews, A. (1987). Cognitive functioning and anxiety. *Psychol Res*, *49*, 189–195.

Eysenck, M. W., Mogg, K., May, J., Richards, A., & Mathews, A. (1991). Bias in Interpretation of Ambiguous Sentences Related to Threat in Anxiety. *Journal of Abnormal Psychology*, *100*(2), 144–150.

Faivre, F., Joshi, A., Bezard, E., & Barrot, M. (2019). The hidden side of Parkinson's disease: Studying pain, anxiety and depression in animal models. *Neuroscience and Biobehavioral Reviews*, *96*(September 2018), 335–352.

Foa, E. B., & Kozak, M. J. (1986). Emotional Processing of Fear. Exposure to Corrective Information. *Psychological Bulletin*, *99*(1), 20–35.

Goldin, P., Manber, T., Hakimi, S., Canli, T., & Gross, J. (2009). Neural Bases of Social Anxiety Disorder. *Archives of General Psychiatry*, *66*(2), 170–180.

Grimm, N., Paul, J., & Wakeham, A. (2004). Access to Speech Pathology Services by People with Parkinson's Disease in Queensland, Australia. *(Unpublished Report) Brisbane: University of Queensland*.

Hakamata, Y., Lissek, S., Bar-Haim, Y., Britton, J. C., Fox, N. A., Leibenluft, E., … Pine, D. S. (2010). Attention bias modification treatment: A meta-analysis toward the establishment of novel treatment for anxiety. *Biological Psychiatry*, *68*, 983–990.

Hallion, L. S., & Ruscio, A. M. (2011). A Meta-Analysis of the Effect of Cognitive Bias Modification on Anxiety and Depression. *Psychological Bulletin*, *137*(6), 940–958.

Hertel, P. T., & El-Messidi, L. (2006). Am I Blue? Depressed Mood and the Consequences of Self-Focus for the Interpretation and Recall of Ambiguous Words. *Behavior Therapy*, *37*(3), 259–268.

Hirsch, C. R., Clark, D. M., & Mathews, A. (2006). Imagery and Interpretations in Social Phobia: Support for the Combined Cognitive Biases Hypothesis. *Behavior Therapy*, *37*, 223–236.

Hirsch, C. R., & Mathews, A. (2012). A cognitive model of pathological worry. *Behaviour Research and Therapy*, *50*(10), 636–646.

Hirsch, C. R., Meeten, F., Krahé, C., & Reeder, C. (2016). Resolving Ambiguity in Emotional Disorders: The Nature and Role of Interpretation Biases. *Annual Review of Clinical Psychology*, *12*(1), 281–305.

Hobson, J., Edwards, N., & Meara, R. (2001). The Parkinson's Disease Activities of Daily Living Scale: A new simple and brief subjective measure of disability in Parkinson's disease. *Clinical Rehabilitation*, *15*(3), 241–246.

Hoehn, M. M., & Yahr, M. D. (1967). Parkinsonism : onset , progression , and mortality. *Neurology*, *17*, 427–442.

Hughes, A. M., Chalder, T., Hirsch, C. R., & Moss-Morris, R. (2017). An attention and interpretation bias for illness-specific information in chronic fatigue syndrome. *Psychological Medicine*, *47*(5), 853–865.

Huppert, J. D., Foa, E. B., Furr, J. M., Filip, J. C., & Mathews, A. (2003). Interpretation bias in social anxiety: A dimensional perspective. *Cognitive Therapy and Research*, *27*(5), 569–577.

Huppert, J. D., Pasupuleti, R. V., Foa, E. B., & Mathews, A. (2007). Interpretation biases in social anxiety: Response generation, response selection, and self-appraisals. *Behaviour Research and Therapy*, *45*, 1505–1515.

Jacob, E. L., Gatto, N. M., Thompson, A., Bordelon, Y., & Ritz, B. (2010). Occurrence of depression and anxiety prior to Parkinson's disease. *Parkinsonism and Related Disorders*, *16*, 576–581.

Joling, M., Van Den Heuvel, O. A., Berendse, H. W., Booij, J., & Vriend, C. (2018). Serotonin transporter binding and anxiety symptoms in Parkinson's disease. *Journal of Neurology, Neurosurgery and Psychiatry*, *89*(1), 89–94.

Jones, E. B., & Sharpe, L. (2017). Cognitive bias modification: A review of meta-analyses. *Journal of Affective Disorders*, *223*(July), 175–183.

Juang, C., & Knight, B. G. (2016). Age Differences in Interpreting Ambiguous Situations: The Effects of Content Themes and Depressed Mood. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, *71*(6), 1024–1033.

Julien, C. L., Rimes, K. A., & Brown, R. G. (2016). Rumination and behavioural factors in Parkinson's disease depression. *Journal of Psychosomatic Research*, *82*, 48–53.

Karsdorp, P. A., Kindt, M., Rietveld, S., Everaerd, W., & Mulder, B. J. M. (2008). Interpretation bias for heart sensations in congenital heart disease and its relation to quality of life. *International Journal of Behavioral Medicine*, *15*(3), 232–240.

Khaleghi, M., Leahy, R. L., Akbari, E., Mohammadkhani, S., Hasani, J., & Tayyebi, A. (2017). Emotional schema therapy for generalized anxiety disorder: A single-subject design. *International Journal of Cognitive Therapy*, *10*(4), 269–282.

Kish, S. (2003). Biochemistry of Parkinson's disease: is a brain serotonergic deficiency a characteristic of idiopathic Parkinson's disease? *Advances in Neurology*, *91*, 39–49.

Knight, B. G., Maines, M. L., & Robinson, G. S. (2002). The effects of sad mood on memory in older adults: A test of the mood congruence effect. *Psychology and Aging*, *17*(4), 653–661.

Kroenke, K, Spitzer, R., Williams, J., Monahan, P., & Lowe, B. (2007). Reconocimineto de Instalaciones de Maquinas - Google Libros. *Annals of Internal Medicine*, *146*(5), 317–325.

Kroenke, Kurt, Strine, T. W., Spitzer, R. L., Williams, J. B. W., Berry, J. T., & Mokdad, A. H. (2009). The PHQ-8 as a measure of current depression in the general population. *Journal of Affective Disorders*, *114*, 163–173.

Landau, S., Harris, V., Burn, D. J., Hindle, J. V., Hurt, C. S., Samuel, M., … Brown, R. G. (2016). Anxiety and anxious-depression in Parkinson's disease over a 4-year period: A latent transition analysis. *Psychological Medicine*, *46*(3), 657–667.

Lee, J. S., Mathews, A., Shergill, S., & Yiend, J. (2016). Magnitude of negative interpretation bias depends on severity of depression. *Behaviour Research and Therapy*, *83*, 26–34.

MacLeod, C., & Mathews, A. (2012). Cognitive Bias Modification Approaches to Anxiety. *Annual Review of Clinical Psychology*, *8*(1), 189–217.

Maillet, A., Météreau, E., Sgambato-Faure, V., Broussolle, E., Tremblay, L., Thobois, S., … Favre, E. (2016). The prominent role of serotonergic degeneration in apathy, anxiety and depression in de novo Parkinson's disease. *Brain*, *139*(9), 2486–2502.

Martin, M., & Alexeeva, I. (2010). Mood volatility with rumination but neither attentional nor interpretation biases in chronic fatigue syndrome. *British Journal of Health Psychology*, *15*(4), 779–796.

Mathews, A., & MacLeod, C. (1994). Cognitive Approaches To Emotion and Emotional Disorders. *Annu Rev Psychol*, *45*, 25–50.

Mathews, Andrew, & Mackintosh, B. (1998). A Cogn itive Model of Selective Processin g in An xiety. *Cognitive Therapy and Research*, *22*(6), 539–560.

Mathews, Andrew, & Mackintosh, B. (2000). Induced emotional interpretation bias and anxiety. *Journal of Abnormal Psychology*, *109*(4), 602–615.

Mathews, Andrew, & MacLeod, C. (2005). Cognitive Vulnerability to Emotional Disorders. *Annual Review of Clinical Psychology*, *1*, 167–195.

Menne-Lothmann, C., Viechtbauer, W., Höhn, P., Kasanova, Z., Haller, S. P., Drukker, M., … Lau, J. (2014). How to boost positive interpretations? A meta-analysis of the effectiveness of cognitive bias modification for interpretation. *PLoS ONE*, *9*(6), 1–26.

Meyer, T. J., Miller, M. L., Metzger, R. L., & Borkovec, T. D. (1990). Development and validation of the penn state worry questionnaire. *Behaviour Research and Therapy*, *28*(6), 487–495.

Mogg, K., & Bradley, B. P. (2018). Anxiety and Threat-Related Attention: Cognitive-Motivational Framework and Treatment. *Trends in Cognitive Sciences*, *22*(3), 225–240.

Mogg, K., Bradley, B. P., & Hallowell, N. (1994). Attentional Bias to Threat: Roles of Trait Anxiety, Stressful Events, and Awareness. *The Quarterly Journal of Experimental Psychology Section A*, *47*(4), 841–864.

Mor, N., Hertel, P., Ngo, T. A., Shachar, T., & Redak, S. (2014). Interpretation bias characterizes trait rumination. *Journal of Behavior Therapy and Experimental Psychiatry*, *45*(1), 67–73.

Moriyama, T. S., Felicio, A. C., Chagas, M. H. N., Tardelli, V. S., Ferraz, H. B., Tumas, V., … Bressan, R. A. (2011). Increased dopamine transporter density in Parkinson's disease patients with social anxiety disorder. *Journal of the Neurological Sciences*, *310*(1–2), 53–57.

Mulders, A. E. P., Moonen, A. J. H., Dujardin, K., Kuijf, M. L., Duits, A., Flinois, B., … Leentjens, A. F. G. (2018). Cognitive behavioural therapy for anxiety disorders in Parkinson's disease: Design of a randomised controlled trial to assess clinical effectiveness and changes in cerebral connectivity. *Journal of Psychosomatic Research*, *112*(February), 32–39.

Nerius, M., Fink, A., & Doblhammer, G. (2017). Parkinson's disease in Germany: prevalence and incidence based on health claims data. *Acta Neurologica Scandinavica*, *136*(5), 386–392.

Newman, M. G., & Llera, S. J. (2011). A novel theory of experiential avoidance in generalized anxiety disorder: A review and synthesis of research supporting a contrast avoidance model of worry. *Clinical Psychology Review*, *31*, 371–382.

Nolen-Hoeksema, S. (1991). Responses to Depression and Their Effects on the Duration of Depressive Episodes. *Journal of Abnormal Psychology*, *100*, 569–582.

Nolen-Hoeksema, S. (2000). The role of rumination in depressive disorders and mixed anxiety/depressive symptoms. *Journal of Abnormal Psychology*, *109*, 504–511.

Ochsner, K. N., Bunge, S. A., Gross, J. J., & Gabrieli, J. D. E. (2002). Rethinking Feelings : An fMRI Study of the Cognitive Regulation of Emotion. *Journal of Cognitive Neuroscience*, *14*(8), 1215–1229.

Ohman, A., & Dimberg, U. (1978). Facial expressions as conditioned stimuli for electrodermal responses: A case of "preparedness"? *Journal of Personality and Social Psychology*, *36*(11), 1251–1258.

Ohman, A., & Mineka, S. (2001). Fears , Phobias , and Preparedness : Toward an

Evolved Module of Fear and Fear Learning. *Psychological Review*, *108*(3), 483–522.

Pincus, T., Pearce, S., McClelland, A., Farley, S., & Vogel, S. (1994). Interpretation bias in responses to ambiguous cues in pain patients. *Journal of Psychosomatic Research*, *38*(4), 347–353.

Pincus, T., Pearce, S., & Perrott, A. (1996). Pain patients' bias in the interpretation of ambiguous homophones. *British Journal of Medical Psychology*, *69*(3), 259–266.

Pontone, G. M., Williams, J. R., Anderson, K. E., Chase, G., Goldstein, S. R., Grill, S., … Marsh, L. (2011). Anxiety and self-perceived health status in Parkinson's disease. *Parkinsonism and Related Disorders*, *17*, 249–254.

Razran, G. (1971). *Mind in evolution. An East-West synthesis of learned behavior and cognition. New York: Houghton Mifflin.*

Remes, O., Brayne, C., van der Linde, R., & Lafortune, L. (2016). A systematic review of reviews on the prevalence of anxiety disorders in adult populations. *Brain and Behavior*, *6*(7), 1–33.

Reynolds, G. O., Saint-Hilaire, M., Thomas, C. A., Barlow, D. H., & Cronin-Golomb, A. (2019). Cognitive-Behavioral Therapy for Anxiety in Parkinson's Disease. *Behavior Modification*, 1–28.

Richards, A. (2004). Anxiety and the resolution of ambiguity. In *In Cognition, Emotion and Psychopathology: Theoretical, Empirical and Clinical Directions, ed. J Yiend*.

Rosenberg, M. (1965). *Society and the adolescent self-image*.

Rude, S. S., Valdez, C. R., Odom, S., & Ebrahimi, A. (2003). Negative cognitive biases predict subsequent depression. *Cognitive Therapy and Research*, *27*(4), 415–429.

Rude, S. S., Wenzlaff, R. M., Gibbs, B., Vane, J., & Whitney, T. (2002). Negative processing biases predict subsequent depressive symptoms. *Cognition & Emotion*, *16*(3), 423–440.

Schoth, D. E., Beaney, R., Broadbent, P., Zhang, J., & Liossi, C. (2018). Attentional, interpretation and memory biases for sensory-pain words in individuals with chronic headache. *British Journal of Pain*, *13*(1), 22–31.

Schwab, R., & England, A. (1969). Projection techniques for evaluating surgery in Parkinson's disease. *Third Symposium on Parkinson's Disease*.

Seligman, E. P. (1970). On the generality of the laws of learning. *Psychological Review*, *77*(5), 406–418.

Sibrava, N. J., & Borkovec, T. D. (2006). The Cognitive Avoidance Theory of Worry. In *Worry and its Psychological Disorders* (pp. 239–256). Chichester, UK: John Wiley & Sons Ltd.

Spitzer, R. L., Kroenke, K., Williams, J. B. W., & Löwe, B. (2006). A Brief Measure for Assessing Generalized Anxiety Disorder. *Archives of Internal Medicine*, *166*(10), 1092–1097.

Thobois, S., Prange, S., Sgambato-Faure, V., Tremblay, L., & Broussolle, E. (2017). Imaging the Etiology of Apathy, Anxiety, and Depression in Parkinson's Disease: Implication for Treatment. *Current Neurology and Neuroscience Reports*, *17*(10), 1–8.

Tooby, J., & Cosmides, L. (1990). The Past Explains the Present: Emotional adaptations and the structure of ancestral environment. *Ethology and Sociobiology*, *11*, 375–424.

Treynor, W., Gonzalez, R., & Nolen-Hoeksema, S. (2003). Rumination Reconsidered: A Psychometric Analysis. *Cognitive Therapy and Research*, *27*(3), 247–259.

Vriend, C., Boedhoe, P. S., Rutten, S., Berendse, H. W., van der Werf, Y. D., & van den Heuvel, O. A. (2016). A smaller amygdala is associated with anxiety in Parkinson's disease: a combined FreeSurfer—VBM study. *Journal of Neurology, Neurosurgery & Psychiatry*, *87*(5), 493–500.

Watkins, E; Brown, R. . (2002). Rumination and executive function in depression: An experimental study. *Journal of Neurology Neurosurgery and Psychiatry*, *72*(3), 400–402.

Welsh, K., Breitner, C., & Magruder-Habib, K. (1993). Detection of Dementia in the Elderly Using Telephone Screening of Cognitive Status. *Neuropsychiatry Neuropsychol Behav Neurol*, *6*(2), 103–110.

Wenzlaff, R. M., & Bates, D. E. (1998). Unmasking a cognitive vulnerability to depression:How lapses in mental control reveal depressive thinking. *Journal of Personality and Social Psychology*, *75*(6), 1559–1571.

Wuthrich, V. M., & Rapee, R. M. (2019). Telephone-Delivered Cognitive Behavioural Therapy for Treating Symptoms of Anxiety and Depression in Parkinson's Disease: A Pilot Trial. *Clinical Gerontologist*, *42*(4), 444–453.

Zebrowitz, L. A., Boshyan, J., Ward, N., Gutchess, A., & Hadjikhani, N. (2017). The older adult positivity effect in evaluations of trustworthiness: Emotion regulation or cognitive capacity? *PLoS ONE*, *12*(1), 1–17.

# Appendices

## Appendix 1

Research Ethics
Office

Franklin Wilkins Building
5.9 Waterloo Bridge Wing
Waterloo Road
London SE1 9NH
Telephone 020 7848 4020/4070/4077
reo@kcl.ac.uk

KING'S College LONDON

Lonneke van Tuijl

14 June 2017

Dear Lonneke,

Reference Number: LRS-16/17-4729

Study Title: Does anxiety affect how people with Parkinson's look at the world?

**Review Outcome: Approved pending amendments/clarifications**

Thank you for submitting the above application for ethical approval. Your application has been reviewed and has been approved pending amendments. You are now required to address a number of issues before full approval is granted. These are specified in the feedback table below. Please respond to each point raised by the reviewer and amend your application form, and appendices, accordingly. **Please note that research involving human participants must not commence until your amended application has been reviewed and Full Approval has been granted.**

In order to amend the application, you will simply need to log on onto REMAS and modify the existing application. Once again, your academic supervisor will be required to provide verification.

**The submission of your amended application must be accompanied by a cover letter outlining the changes you have made in response to each of the Committee's requests.** For ease of completion we recommend that you cut and paste the feedback table from your outcome letter into your cover letter and respond to each point individually. The cover letter should be attached as a Supporting Document in section I9 of your application. Failure to attach a cover letter to your resubmitted application will result in your application being marked as 'Invalid' and returned to you by the Research Ethics Office prior to review.

If for some reason you choose not to proceed with this research ethics application, please inform the Research Ethics Office.
Yours sincerely,

Mr James Patterson

Senior Research Ethics Officer

For and on behalf of

PNM Research Ethics Panel

**Major Issues**

(will require substantial consideration by the applicant before approval can be granted)

**Minor Issues related to application** (the reviewer should identify the relevant section number before each comment)

1. Section B9

i. ''At the end of the SST, participants will be asked..'' Will all participants (pilot and main part of the study) be asked to do this? If so, please modify for clarification purposes.

ii. At what stage will participants provide you with their full name and email address? Will this be recorded on Qualtrics?

iii. As your study is conducted on the Internet, please provide us with the website address along with information on the security arrangements for this site.

iv. The consent form mentions that participants will be given the option of being contacted with results and/or information on future studies. Is this an automated 'tick box' function on Qualtrics? Please add to REMAS for clarification purposes.

2. Section C1 – Eligibility criteria, ''have received a diagnosis of Parkinson's Disease and can complete the **assessment** in a single session of a maximum of 60 minutes'' – I believe you mean 'complete the questionnaires and tasks''. If so, please rephrase.
3. Section C2:
i. Provide more information about the previous research participants who have agreed to be re-contacted. How are you accessing their contact details?
ii. How will participants be screened for eligibility? Please add your screening method to Section C2.
iii. ''We will contact eligible individuals who have taken part in prior research studies in the department and who have been consented to being contacted about future research opportunities. Following the pilot phase..'' – Please clarify (and rephrase) that at this stage it is only pilot phase participants who will be contacted this way.

Page 1 of 3

Ethics approval

iv. ''Participants who are interested will be asked to e-mail the researcher'' Is this both pilot and main study participants? If not, what is the recruitment/ consent process for the pilot study participants?

4. Section C4 – 'All participants (both pilot and main study) will receive a report of the findings..'' As this is not the case please rephrase, ie all participants will be given the option of receiving a report of the findings.

5. Section C8 – Please add this information to the information sheet

6 Section H6 – Please rephrase and clearly state that you will not commence with data collection unless approval (not review) has been granted by Parkinson's UK.

**7. Debrief form:** ''We will send you a summary of the study results when we have finished''. Please re-phrase as this will not be sent to all participants.

**Minor Issues related to recruitment documents**

8. The Panel assumes the Information Sheet will be configured as a landing page for the online survey.

**9. Participant Information Sheet**

i. Why am I being invited? Please mention that they have to be over the age of 18 and a UK resident, and inform them of the number of participants you are looking to recruit (135) including the fact that this number may be exceeded.

ii. Opting in and out of receiving information about future studies: Please provide information in the PIS on how, where and at what stage participants can do this.

iii. ''We will retain your personal information (name, date of birth and contact details) only if you say you wish to be contacted at the end of the study, and/or you wish to be informed about future research. This information will be kept separate from the results of the study.'' Please add that you will destroy personal data after you have contacted them with the findings of the study.

iv. Please state what will happen to all personal and anonymous data should the participant decide to stop halfway through the study or wish to withdraw before or after study completion (will it be destroyed or kept?). Is there a fixed time-point up until they can request for their data to be removed? If so, please state so in the PIS.

v. If you are planning on sharing anonymous data with researchers outside the study team, please state so in the PIS. For the participant's information, please also state how you will use your findings ie presentations, publications and that the participant will not be identified in the process.

**10. Consent form**

i. Your consent form is titled 'Participant Information Sheet'. Please change to 'Consent Form'.

ii. Please add a date alongside the version (header or footer).

iii. Please separate all information that is dedicated to consent, from all remaining non-consent related information ('permission to contact you' and 'instructions'). To do so, you can add a heading before the non-consent related information, such as 'Further Information'

iv. ''By pressing 'Continue' (below) you indicate that you understand the nature of the study and consent to take part.'' It is important that you have clear confirmation from the participant that they have read the information sheet – please rephrase accordingly.

v. ''By taking part in the study, you confirm that you understand that such information will be treated in accordance with the terms of the UK data Protection Act, 1998.'' Please rephrase ie ''By taking part in the study, you confirm that you consent to the processing of your personal information for the purposes explained to you and understand that such information will be treated in accordance with the terms of the UK Data Protection Act 1998.'

vi. If you are planning on sharing participant data with researchers outside the study core research team, please add this as a bulletpoint on the consent form.

vii. It is important that the participant confirms they have had the opportunity to consider the information, seek clarification and understand their involvement in the study. Please add this as a bullet point.

viii. It is important that the participant confirms they understand that their participation is voluntary and that they are free to withdraw at any time. Please add this as a bullet point.

ix. It is important that the participant confirms they understand that relevant data collected during the study may be looked at by individuals representing the research team at King's College London or from regulatory authorities, where it is relevant to their taking part in the research. And that they give permission for these individuals to have access to their data. Please add this as a bullet-point.

xPermission to contact you - ''We will use your email address to … we will then delete your name and contact details'' – You have not mentioned 'date of birth'. Please add this to match information given in section C2 of the REMAS form.

**Advice and Comments** (do not have to be adhered to, but may help to improve the research)

**Appendix 2**

Information Sheet

## INFORMATION SHEET FOR PARTICIPANTS

*REC Reference Number: LRS-16/17-4729*

# Does anxiety affect how people with Parkinson's look at the world?

Invitation

Regardless of whether you tend to worry or have anxiety, we are inviting you to take part in a study to help us understand some of the ways in which people think about common situations may relate to anxiety in people with Parkinson's. This information sheet tells you some more about the study to help you decide if you would like to take part. 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. If there is anything that is not clear or if you would like more information, please do not hesitate to contact one of the researchers listed below.

Why are you doing this study?

- People without Parkinson's who worry a lot or experience anxiety tend to look at the world around them in a different way than people who are not anxious and who do not worry. These differences may provide us with clues as to what causes or maintains the anxiety and suggest novel ways to help manage it.

- We know that worry and anxiety are common in people with Parkinson's. However, we do not know whether they share this same way of thinking about the world as those without Parkinson's who worry or are anxious. If they do, it opens opportunities for further research.

- This study is not a clinical trial. We are not testing a new treatment. We are looking to understand more about anxiety and worry in Parkinson's as a first

step towards developing an anxiety intervention that can be tested in future research.

Why am I being invited?

- We are inviting anyone with Parkinson's (both worriers and non-worriers) with a good command of English, with access to the internet and able to carry out a series of tasks lasting about one hour in total. It will also be possible to complete the first link to the study in approximately 25minutes and the second in 40 minutes sittings.

What am I being asked to do?

- Eligibility check and consent: If you express an interest in participating in this study. Eligibility will be confirmed via email and consent taken before the study begins.

- Main study (first link sent): We will first send you a link to some questionnaires where we will ask you to provide some basic information about yourself, such as your age and gender, when your Parkinson's started and some information about any current or past episodes of depression or anxiety requiring treatment. We will also ask you to complete some brief questionnaires to measure any current depression, anxiety or worry.

- Main study (second link sent): Once you have completed the first link, you will be automatically sent the second link in an e-mail. To complete the second link you will need a password which is included in the e-mail. In the second link, you will complete a short questionnaire, then asked to complete several short tasks that measure the types of thinking that we are interested in. For example, in one task, you will be asked to unscramble a set of words to make a sentence. In another, you will be asked to answer questions about some brief scenarios you have read. Although the tests will be done on the computer, there will be minimal typing involved, and most can be completed using the mouse.

- The main study (link one and link two) will take place online and should take around one hour (in total) to complete. We do ask you to complete the study in quiet surroundings with minimal distractions, and to complete the second link as soon as possible (preferably 24 hours since completing the first link).

- Telephone call: Once the online study has been completed, you will be contacted by a member of the research team for one final assessment. This will be completed on the phone or via skype. The telephone interview will involve questions designed to assess some basic cognitive processes. It will take approximately 20 minutes to complete.

Do I have to take part?

- No. Your participation is completely voluntary. If you agree to take part, you can stop before submitting your first responses. Once started, you can choose not to answer any question by simply skipping it. If you decide not to take part, or to stop, this will have no influence on your medical care or legal rights.

What are the advantages and disadvantages of taking part?

- We are not aware of any harm that you may experience by taking part. The tests are quite short and varied but you may feel somewhat tired by the end.

- You will not obtain any direct benefit from taking part in the research. However, we hope that you will find the study interesting and enjoyable.

- After you have finished we will send you information about the study and about anxiety and depression in Parkinson's more generally.

- Once we have finished the study and analysed the data, we will write to tell you what we found and how we plan to use the information in future research to help people with Parkinson's. To do this, we will hold on to your contact details (name and e-mail address) for 1 year following the study. We will keep this information separate from the responses you gave during the study. We are not able to provide you with personalised outcomes.

- Finally, you can opt to be informed of further research opportunities that may be of interest to you. If you opt for this, we will keep your contact details for 3 years after the end of the study. You will be in no way obliged to take part in future studies, and you can decide whether or not to take part in any research opportunities that we inform you of. You can opt out of receiving information about further research opportunities before the three years by e-mailing one of the researchers listed below.

What about my Parkinson's medication?

- We assume that almost everyone taking part in the study will be taking medication for their Parkinson's. You can do the test at any time that is most convenient for you. You do not have to make any changes to your normal treatment regime.

- We do ask you to provide some information about any medication that you are currently taking for your mood and Parkinson's. This is because such medication can affect the thinking processes we're trying to measure. Information about the medication you take will be completely confidential.
-

What happens to the information that I provide?

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR).

- All information collected as part of this study will be treated in accordance with the terms of the GDPR 2016. All data will be securely held on password protected servers, and only accessed by members of the research team. Your data will be retained for a period of ten years.

- Your responses will only be used for research and teaching purposes, and no information can be used to identify you. Should you provide any identifiable information in the comments section, then this will be removed.

- We will retain your personal information (name, date or birth and contact details) only if you say you wish to be contacted at the end of the study, and/or you wish to be informed about future research. This information will be kept separate from the results of the study.

Data Protection Statement

- The data controller for this project will be King's College London (KCL). The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest' You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you.

- You have the right to access information held about you in accordance with the General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection, and data portability.

- Questions, comments and requests about your personal data can also be sent to the King's College London Data Protection Officer Mr Albert Chan info-compliance@kcl.ac.uk. If you wish to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk.

What if I change my mind about taking part?

- You are free withdraw at any point of the study, without having to give a reason. Withdrawing from the study will not affect you in any way. You are able to withdraw your data from the study up until April 2018, after which withdrawal of your data will no longer be possible due to the data having been anonymised or committed to a final report. If you choose to withdraw from the study we will not retain the information you have given thus far.

- If you do wish to withdraw from the study, you may do so by contacting a member of the research team (details provided below).

How is the project being funded?

- This study is funded by a research grant to King's College London from Parkinson's UK.

What will happen to the results of the study?

- The results of the study will be summarised in a peer-reviewed publication. A copy of this publication can be obtained via the journal articles website. Alternatively, you may contact a member of the research team once the paper has been published. The anonymised data set will be publicly available as supplementary data.

- Results of the study will also be presented at scientific conferences. Presented data will be completely anonymous with no identifiable data included. As such, anyone at the presentation will not be able to know whether you took part in the study.

- The results will also be used as part of doctoral thesis for a Doctoral Degree in Clinical Psychology (Mazda Beigi – Trainee Clinical Psychologist).

Who can I contact for further information or if I have any concerns?

- The study is also being conducted by Dr Mazda Beigi, a Clinical Psychology Trainee at the Institute of Psychiatry, Psychology and Neuroscience at King's College London. To contact him, you can send an e-mail to Mazda.Beigi@kcl.ac.uk. Please feel free to contact him if you have any questions.

- This study is being conducted by Dr Lonneke van Tuijl, a researcher at the Institute of Psychiatry, Psychology and Neuroscience at King's College London. To contact her, you can send an e-mail to Lonneke.van_tuijl@kcl.ac.uk or call 02078480365. Please feel free contact her if you have any questions or queries.

- Alternatively, if you have any questions or concerns about the study, please contact one of the lead investigators: Professor Richard Brown (Richard.g.brown@kcl.ac.uk Tel no: 02078480773) or Dr Colette Hirsch (Colette.hirsch@kcl.ac.uk Tel no: 02078480697).

What if I have further questions, or if something goes wrong?

- If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information: pnm@kcl.ac.uk
- Professor Richard Brown (Richard.g.brown@kcl.ac.uk
- Dr Colette Hirsch (Colette.hirsch@kcl.ac.uk Tel no: 02078480697).

Thank you for taking the time to read this information. Feel free to take time to discuss this study with the people around you before deciding to take part. This study will stay active until April 30th, 2019, or until we have received at least 150 responses.

**Appendix 3**

Survey Link 1 – demographic information and measures

# Part 1 - Does anxiety affect how people with Parkinson's look at the world?

# Survey Flow

**Standard: Consent (2 Questions)**
**Standard: Demographics (10 Questions)**
**Standard: H&Y and S&E (2 Questions)**
**Standard: Cognitive Impairment Disclosure (1 Question)**
**Standard: PHQ-8 (1 Question)**
**Standard: GAD7 (1 Question)**
**Standard: RSES (1 Question)**
**Standard: WOQ (10 Questions)**
**Standard: PADL (1 Question)**
**Standard: RRS (1 Question)**
**Standard: Final Feedback (2 Questions)**

Page Break

Consent and instructions

Consent
REC Reference Number: LRS-16/17-4729

Does anxiety affect how people with Parkinson's look at the world?

Instructions:

Link 1 of 2

This first part of the study will ask you for some background information about yourself, your symptoms and generally how you are feeling.

If you agree to continue, please complete this first part of the study only once and in one sitting. Only start this first part of the study if you are sure that you will be free and uninterrupted for one hour to complete the questions and tasks.

Once started, you will have two hours before this first part of the study closes. You will not be able to restart. You are reminded that you can miss any questions that you prefer not to answer. Simply press 'next' to continue. You can ignore any prompts about missing answers.

You will be invited to provide any feedback that you think may be helpful. You will then be given options for us to contact you if you wish. When you have finished, you will reach a 'Thank you' page. You may choose to complete the second part of the study immediately after this one. Alternatively, you may complete the second part of the study by the next days.

The second part of the study can be completed by clicking on a separate link that will be sent to you after you have completed this first part.

Once you have finished the second part of the study (link 2), you will be contacted via email to arrange a time and date to complete a short telephone interview.

If you have any questions at all before starting, please contact us on our designated email address for this study (pwp-research@kcl.ac.uk). Alternatively, please contact Mazda Beigi (mazda.beigi@kcl.ac.uk) or Lonneke van Tuijl (Lonneke.van_Tuijl@kcl.ac.uk; 0207 848

0365).

Consent:

☐ Click here to confirm that you have read the participant information sheet (v1.2), and have had the opportunity to consider the information and ask any questions, and that these have been answered to your satisfaction. (1)

☐ Click here to confirm that you understand that your participation is voluntary and that you are free to decline to do any part of the study or to withdraw completely at any time, without giving any reason, and without your medical care or legal rights being affected. (2)

☐ Click here to confirm that you consent to being called on a number you provide, for a telephone interview, once you have completed the two parts of the online study. (8)

☐ Click here to confirm that you consent to the processing of your personal information for the purposes explained to you and understand that such information will be treated in accordance with the terms of the General Data Protection Regulation 2016 (GDPR). (3)

☐ Click here to confirm that you understand that information collected during the study may be looked at by appropriate individuals from King's College London, from regulatory authorities or from Parkinson's UK. By clicking here, you give permission for these individuals to have access to your data. (4)

☐ Click here to confirm that you understand that the information collected may be used to support other research in the future, and may be shared anonymously with other researchers not directly involved in the current study. (5)

☐ Click here to confirm that you understand that after completion of the study your data will be stored for up to 10 years, and that identifying information has been removed and therefore withdrawal in that time will not be possible. (6)

☐ Click here to confirm that you agree to take part in the study entitled: "Does anxiety affect how people with Parkinson's look at the world?". (7)

Demographic information

Age **Exploring Anxiety in Parkinson's Questionnaire**
**Age:**

_____

Sex **Gender:**

- ○ Male (1)
- ○ Female (2)
- ○ Would rather not say (3)

Employment Status **Current employment status:**

- ○ Retired (1)
- ○ Unemployed (2)
- ○ Employed (3)
- ○ Other, namely: (4)

_____

Diagnosis How many years (and months, if known) ago were you diagnosed with Parkinson's?

_____

Page Break

Are you taking any medication for your Parkinson's?

- ○ Yes (1)
- ○ No (2)

*Skip To: AnxDepHisory If Q223 = 2*

Please state any medication you are taking for your Parkinson's here (including dose & number of tablets taken per day in brackets after):

- ○ Levodopa or Carbidopa medications (Sinemet, Sinemet CR, Stalevo, Parcopa, Rytary, Duopa) (7) _____
- ○ Dopamine Agoinists (Ropinirole, Mirapex, Mirapex ER, Requip, Neupro, Apekyn) (8) _____
- ○ MAO-B Inhibitors (Rasagiline, Selegiline, Eldepryl, Xadago) (9) _____
- ○ COMT Inhibitors (Stalevo, Entacapone, tolcapone) (10) _____
- ○ Any others (11) _____

Page Break

Anxiety Depression History

Do you have a history of anxiety or depression?

- ○ Anxiety (1)
- ○ Depression (2)
- ○ Anxiety and Depression (3)
- ○ No (4)

*Skip To: End of Block If AnxDepHisory = 4*

Medication

Medication

Do you currently take any medication for your anxiety/ depression?

- ○ Yes (1)
- ○ No (2)

*Skip To: End of Block If MedicationAnxDep = 2*

Page Break

Medication Type

Please note your current anti-anxiety or anti-depressant medication (including daily dose in brackets after):

_____

Page Break

Dose History

Please note how long you have been on your current dose of the anti-anxiety or anti-depressant medication:

_____

○ **End of Block: Demographics**

☐ **Start of Block: H&Y and S&E**

H&Y Scale

H&Y

**Please select the number which most correctly describes the degree of your Parkinsonian symptoms**

- ○ I have **no** tremor or slowness (1)
- ○ I have tremor or slowness only **on one side** of my body (2)
- ○ I have tremor or slowness only **on one side** of my body, and I have **some problems with balance** (3)
- ○ I have tremor or slowness **on both sides** of my body (4)
- ○ I have tremor or slowness **on both sides** of my body, **and** I have **slight** problems with **balance** (e.g. on turning only) (5)
- ○ I have tremor or slowness on both sides of my body, **and** I have **noticeable problems with balance** (e.g. occasional falls due to balance problems) (6)
- ○ I have **great problems** due to slowness or balance, but **I am still able to stand or walk without help** (7)
- ○ I am in a (**wheelchair or bed)** unless I have help (8)

Page Break

S&E Scale

S&E

Please select the answer which most correctly describes your level of **independence**.

○ I am completely independent. I am **able to do all chores** without slowness, difficulty, or impairment, and I am **unaware of any difficulties.** (1)

○ I am completely independent, and I am **able to do all chores**. However there is **some slowness**, difficulty or impairment, and chores might take twice as long. (2)

○ I am completely independent in **most** chores, but I am aware of difficulties and slowness and **chores usually take twice as long.** (3)

○ I am **not** completely independent. Some chores take three to four times as long, and I must **spend a large part of the day with chores.** (4)

○ I depend on other people **to some degree**. I can do most chores, but exceedingly slowly and with much effort. **Some chores are impossible.** (5)

○ I depend on other people for **help with half of the chores. I have difficulty with everything**. (6)

○ I am very dependent on other people. I can assist with all chores, but **can do few chores alone**. (7)

○ With effort, now and then I can do a **few chores alone** or begin alone. I **need much help**. (8)

○ I can do nothing alone, but I can be a **slight help with some chores**. (9)

○ I am **totally dependent**, and more or less helpless. (10)

○ I have no control over swallowing, bladder control, and bowel functions, and I am **bed-ridden**. (11)

○ **End of Block: H&Y and S&E**

---

☐ **Start of Block: Cognitive Impairment Disclosure**

Cognitive impairment

If you have received any diagnosis (e.g., a dementia) that may effect your performance (e.g., memory issues) other than idiopathic Parkinson's Disease, please list this here:

_____

_____

_____

_____

_____

**End of Block: Cognitive Impairment Disclosure**

**Start of Block: PHQ-8**

PHQ-8

PHQ-8

The following set of questions asks about how you have been feeling over **the past two weeks**. Choose the response option that is closest to how you have been feeling. Do not answer the questions based on how you have felt at times in the past (more than 2 weeks ago).

Over the following two weeks, on how many days have you been bothered by any of the following problems?

| | Not at all (1) | Several days (2) | More than half the days (3) | Nearly every day (4) |
|---|---|---|---|---|
| Little interest or pleasure in doing things (1) | ○ | ○ | ○ | ○ |
| Feeling down, depressed or hopeless (2) | ○ | ○ | ○ | ○ |
| Trouble falling or staying asleep, or sleeping too much (3) | ○ | ○ | ○ | ○ |
| Feeling tired or having little energy (4) | ○ | ○ | ○ | ○ |
| Poor appetite or overeating (5) | ○ | ○ | ○ | ○ |
| Feeling bad about yourself- or that you are a failure or have let yourself or your family down (6) | ○ | ○ | ○ | ○ |
| Trouble concentrating on things, such as reading the newspaper or watching television (7) | ○ | ○ | ○ | ○ |
| Moving or speaking so slowly that other people could have noticed, or the opposite- being so fidgety or restless that you have been moving around a lot more than usual (8) | ○ | ○ | ○ | ○ |

GAD 7 Scale

GAD7

Over the past 2 weeks, on how many days have you been bothered by any of the following problems?

| | Not at all (1) | Several days (2) | More than half the days (3) | Nearly every day (4) |
|---|---|---|---|---|
| Feeling nervous, anxious or on edge (1) | ○ | ○ | ○ | ○ |
| Not being able to stop or control worrying (2) | ○ | ○ | ○ | ○ |
| Worrying too much about different things (3) | ○ | ○ | ○ | ○ |
| Trouble relaxing (4) | ○ | ○ | ○ | ○ |
| Being so restless it is hard to sit still (5) | ○ | ○ | ○ | ○ |
| Becoming easily annoyed or irritable (6) | ○ | ○ | ○ | ○ |
| Feeling afraid as if something awful might happen (7) | ○ | ○ | ○ | ○ |

Page Break

RSES

Below is a list of statements dealing with your general feelings about yourself. Please indicate how strongly you agree or disagree with each statement:

| | Strongly Agree (1) | Agree (2) | Disagree (3) | Strongly Disagree (4) |
|---|---|---|---|---|
| On the whole, I am satisfied with myself. (1) | ○ | ○ | ○ | ○ |
| At times I think I am no good at all. (2) | ○ | ○ | ○ | ○ |
| I feel that I have a number of good qualities. (3) | ○ | ○ | ○ | ○ |
| I am able to do things as well as most other people. (4) | ○ | ○ | ○ | ○ |
| I feel I do not have much to be proud of. (5) | ○ | ○ | ○ | ○ |
| I certainly feel useless at times. (6) | ○ | ○ | ○ | ○ |
| I feel that I am a person of worth, at least on an equal plane with others. (7) | ○ | ○ | ○ | ○ |
| I wish I could have more respect for myself. (8) | ○ | ○ | ○ | ○ |
| All in all, I am inclined to feel that I am a failure. (9) | ○ | ○ | ○ | ○ |
| I take a positive attitude toward myself. (10) | ○ | ○ | ○ | ○ |

WOQ

**Please click on the boxes below** to indicate any Parkinson's disease symptoms that you have experienced in the past month during an average day.

- ☐ Tremor (e.g. shaking of hands, arms or legs) (1)
- ☐ Any slowness of movement (e.g. walking, eating or dressing) (2)
- ☐ Mood changes (3)
- ☐ Any stiffness (e.g. rigidity of arms or legs) (4)
- ☐ Pain/aching (5)
- ☐ Reduced dexterity (e.g. difficulty buttoning or writing) (6)
- ☐ Cloudy mind/ slowness of thinking (7)
- ☐ Anxiety/ panic attacks (8)
- ☐ Muscle cramping (e.g. arms, legs or feet) (9)

Page Break

*Display This Question:*

*If WOQ = 1*

**Please** check Yes if your tremor (e.g. shaking of hands, arms or legs) usually improves or disappears after you take your next dose of Parkinson's medication or **check No** if this symptom does not improve or disappear after you take your next dose of Parkinson's medication.

- Yes (1)
- No (2)

---

*Display This Question:*

*If WOQ = 2*

Please check Yes if your slowness of movement (e.g. walking, eating or dressing) usually improves or disappears after you take your next dose of Parkinson's medication or check No if this symptom does not improve or disappear after you take your next dose of Parkinson's medication.

- Yes (1)
- No (2)

---

*Display This Question:*

*If WOQ = 3*

Please check Yes if your mood changes usually improve or disappear after you take your next dose of Parkinson's medication or check No if this symptom does not improve or disappear after you take your next dose of Parkinson's medication.

- Yes (1)
- No (2)

---

*Display This Question:*

*If WOQ = 4*

Please check Yes if any stiffness (e.g. rigidity of arms or legs) usually improves or disappears after you take your next dose of Parkinson's medication or check No if this symptom does not improve or disappear after you take your next dose of Parkinson's medication.

- ○ Yes (1)
- ○ No (2)

---

*Display This Question:*

*If WOQ = 5*

Please check Yes if any pain/ aching usually improves or disappears after you take your next dose of Parkinson's medication or check No if this symptom does not improve or disappear after you take your next dose of Parkinson's medication.

- ○ Yes (1)
- ○ No (2)

---

*Display This Question:*

*If WOQ = 6*

Please check Yes if your reduced dexterity (e.g. difficulty buttoning or writing) usually improves or disappears after you take your next dose of Parkinson's medication or check No if this symptom does not improve or disappear after you take your next dose of Parkinson's medication.

- ○ Yes (1)
- ○ No (2)

---

*Display This Question:*

*If WOQ = 7*

Please check Yes if your cloudy mind/ slowness of thinking usually improves or disappears after you take your next dose of Parkinson's medication or check No if this symptom does not improve or disappear after you take your next dose of Parkinson's medication.

- ○ Yes (1)
- ○ No (2)

---

*Display This Question:*

*If WOQ = 8*

Please check Yes if your anxiety/ panic attacks usually improves or disappears after you take your next dose of Parkinson's medication or check No if this symptom does not improve or disappear after you take your next dose of Parkinson's medication.

- ○ Yes (1)
- ○ No (2)

---

*Display This Question:*

*If WOQ = 9*

Please check Yes if your muscle cramping (e.g. arms, legs or feet) usually improves or disappears after you take your next dose of Parkinson's medication or check No if this symptom does not improve or disappear after you take your next dose of Parkinson's medication.

- ○ Yes (1)
- ○ No (2)

○ **End of Block: WOQ**

---

PADL

PADL

Please click on the description that best describes how your Parkinson's disease has affected your day-to-day activities in the last month. Please only choose one option.

○ No difficulties with day-to-day activites. For example: Your Parkinson's disease at present is not affecting your daily living. (1)

○ Mild difficulties with day-to-day activities. For example: Slowness with some aspects of housework, gardening or shopping. Able to dress and manage personal hygiene completely independently but rate is slower. You may feel that your medication is not quite as effective as it was. (2)

○ Moderate difficulties with day-to-day activities. For example: Your Parkinson's disease is interfering with your daily activities. It is increasingly difficult to do simple activities without some help such as rising from a chair, washing, dressing, shopping, housework. You may have some difficulties walking and may require assistance. Difficulties with recreational activities or the ability to drive a car. The medication is now less effective. (3)

○ High levels of difficulties with day-to-day activities. For example: You now require much more assistance with activities of daily living such as washing, dressing, housework or feeding yourself. You may have greater difficulties with mobility and find you are becoming more dependent for assistance from others or aids and appliances. Your medication appears to be significantly less effective. (4)

○ Extreme difficulties with day-to-day activities. For example: You require assistance in all daily activities. These may include dressing, washing, feeding yourself or walking unaided. You may now be housebound and obtain little or no benefit from your medication. (5)

Page Break

○ **End of Block: PADL**

☐ **Start of Block: RRS**

RRS

RRS

People think and do many different things when they feel depressed. Please read each of the items below and indicate whether you almost never, sometimes, often, or almost always think or do each one when you feel down, sad, or depressed. Please indicate what you **generally do**, not what you think you **should** do.

| | Almost never (1) | Sometimes (2) | Often (3) | Almost always (4) |
|---|---|---|---|---|
| Think about how alone you feel (1) | ○ | ○ | ○ | ○ |
| Think "I won't be able to do my job if I don't snap out of this" (2) | ○ | ○ | ○ | ○ |
| Think about your feelings of fatigue and achiness (3) | ○ | ○ | ○ | ○ |
| Think about how hard it is to concentrate (4) | ○ | ○ | ○ | ○ |
| Think "what am I doing to deserve this?" (5) | ○ | ○ | ○ | ○ |
| Think about how passive and unmotivated you feel (6) | ○ | ○ | ○ | ○ |
| Analyse recent events to try to understand why you are depressed (7) | ○ | ○ | ○ | ○ |
| Think about how you don't seem to feel anything anymore (8) | ○ | ○ | ○ | ○ |
| Think "Why can't I get going?" (9) | ○ | ○ | ○ | ○ |
| Think "Why do I always react this way?" (10) | ○ | ○ | ○ | ○ |
| Go away by yourself and think about why you feel this way (11) | ○ | ○ | ○ | ○ |
| Write down what you are thinking about and analyse it (12) | ○ | ○ | ○ | ○ |

| | | | | |
|---|---|---|---|---|
| Think about a recent situation, wishing it had gone better (13) | ○ | ○ | ○ | ○ |
| Think "I won't be able to concentrate if I keep feeling this way" (14) | ○ | ○ | ○ | ○ |
| Think "Why do I have problems that other people don't have?" (15) | ○ | ○ | ○ | ○ |
| Think "Why can't I handle things better?" (16) | ○ | ○ | ○ | ○ |
| Think about how sad you feel (17) | ○ | ○ | ○ | ○ |
| Think about all your shortcomings, failings, faults, mistakes (18) | ○ | ○ | ○ | ○ |
| Think about how you don't feel up to doing anything (19) | ○ | ○ | ○ | ○ |
| Analyse your personality to try and understand why you are depressed (20) | ○ | ○ | ○ | ○ |
| Go someplace alone to think about your feelings (21) | ○ | ○ | ○ | ○ |
| Think about how angry you are with yourself (22) | ○ | ○ | ○ | ○ |

End of Survey Link 1

Please let us know if you had any help while completing this study:

- ○ I had no help throughout (1)
- ○ I had some help throughout (2)
- ○ I had help all the way through (3)

If you have any further questions, feel free to email us at PwP-research@kcl.ac.uk
Please click to the next page to finish part 1 of the study.
Thank you.

○ **End of Block: Final Feedback**

**Appendix 4**

Survey Link 2 – Interpretation measures

# Part 2 - Does anxiety affect how people with Parkinson's look at the world?

# Survey Flow

**Standard: Consent (1 Question)**
**Standard: PSWQ (1 Question)**
**Standard: SST Practice (5 Questions)**

**BlockRandomizer: 1 - Evenly Present Elements**

- **Standard: SST (26 Questions)**
- **Standard: SST no cog load (23 Questions)**

**Standard: Stress Rating (2 Questions)**
**Standard: Interpretation Questionnaire (53 Questions)**
**Standard: Final Feedback (5 Questions)**

Page Break

Instructions and consent

Intro Consent
REC Reference Number: LRS-16/17-4729

Does anxiety affect how people with Parkinson's look at the world?

Instructions:
Link 2 of 2.

This is the second part of the study. In this section you will be presented with scenarios and asked to comment on how you would respond in those situations.

If you agree to continue, please complete the study only once and in one sitting.
Only start the study if you are sure that you will be free and uninterrupted for one hour to complete the questions and tasks.

Once started, you will have two hours before this second part of the study closes. You will not be able to restart.

You are reminded that you can miss any questions that you prefer not to answer. Simply press 'next' to continue. You can ignore any prompts about missing answers.

You will be invited to provide any feedback that you think may be helpful. When you have finished, you will reach a 'Thank you' page.

At the end, you will be contacted via email to arrange a convenient date for your telephone interview.

If you have any questions at all before starting, please contact us on our designated email address for this study (pwp-research@kcl.ac.uk). Alternatively, you can contact Mazda Beigi (mazda.beigi@kcl.ac.uk) or Lonneke van Tuijl (Lonneke.van_Tuijl@kcl.ac.uk; 0207 848 0365).

○ **End of Block: Consent**

**Start of Block: PSWQ**

PSWQ

PSWQ

Please rate each of the following statements on a scale from 1 ("not at all typical of me") to 5 ("very typical of me").

| | Not at all typical of me (1) (1) | (2) (2) | (3) (3) | (4) (4) | Very typical of me (5) (5) |
|---|---|---|---|---|---|
| My worries overwhelm me (1) | ○ | ○ | ○ | ○ | ○ |
| Many situations make me worry (2) | ○ | ○ | ○ | ○ | ○ |
| I know I should not worry about things, but I just cannot help it (3) | ○ | ○ | ○ | ○ | ○ |
| When I am under pressure I worry a lot (4) | ○ | ○ | ○ | ○ | ○ |
| I am always worrying about something (5) | ○ | ○ | ○ | ○ | ○ |
| As soon as I finish one task, I start to worry about everything else I have to do (6) | ○ | ○ | ○ | ○ | ○ |
| I have been a worrier all my life (7) | ○ | ○ | ○ | ○ | ○ |
| I notice that I have been worrying about things (8) | ○ | ○ | ○ | ○ | ○ |

## SST instructions and practice items

In this section you will be asked to unscramble a list of words to from a sentence. Each of the unscrambled lists contains six words, but must be unscrambled into sentences five-words in length. You may feel that some sentences can be completed with four words but it is important that you use five word sentences

Each list can be unscrambled into more than one sentence, but you should choose to unscramble the first sentence that comes to mind. Each word cannot be used more than once.

Unscrambled sentences should represent statements which would normally be followed by a full-stop. Unscrambled sentences should therefore not be questions which would require a question-mark at the end.

To unscramble the sentence, please click on numbers 1 to 5, with 1 representing the first word in the sentence, and 5 representing the last word so that the proper order of the sentence is indicated. Please try to answer as quickly as possible.

For example: has green child the eyes blue

The first example has been resolved as: "the child has blue eyes";
The second example has been resolved as: "the child has green eyes"

You will first be presented with two practice scrambled sentences, followed by twenty scrambled sentences for the main task.

Page Break

*

Practice question 1

_

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| long (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| the (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| fur (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| dog (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| had (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| cat (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Page Break

Well done, you have answered correctly.

Page Break

Practice question 2

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| friends (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| my (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| will (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| family (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| visiting (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| be (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Page Break

Well done, you have answered correctly.

For the main task, you will be given 10 minutes to complete as many questions as you can. Do not worry if you cannot finish them all in this time but try to complete as many as you can.

# SST main task

SST_introduction

The main task is about to start. Please unscramble the sentences as quickly as possible. When you are ready to start please continue onto the next page.
For a reminder of the earlier example, see here:

Page Break

SST_introduction

Also as part of the main task, you will be asked to remember a six-digit number which will be shown to you for 10 seconds. You will be asked to try and repeat this number at the end, but please do not take note of it on paper.

Please try your best to remember the number but do not worry if you cannot remember it by the end of the task.

Please press next when you are ready to be shown the number. After the number has been shown, please click next to begin the main task.

You have 10 minutes to complete the main task. Please complete as many questions as you can.

Page Break

Scrambled Sentences Test 1

SSTc_1

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| relaxed (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| strangers (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| feel (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| I (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| around (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| tense (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Scrambled Sentences Test 2

SSTc_2

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| tight (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| living (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| my (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| comfortable (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| expenses (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| are (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Scrambled Sentences Test 3

SSTc_3

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| talking (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| is (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| others (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| hard (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| to (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| easy (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Scrambled Sentences Test 4

SSTc_4

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| manage (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| can (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| I (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| can't (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| finances (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| my (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Scrambled Sentences Test 5

SSTc_5

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| succeed (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| my (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| most (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| fail (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| plans (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| of (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Scrambled Sentences Test 6

SSTc_6

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| person (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| boring (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| a (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| I (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| pleasant (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| am (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Scrambled Sentences Test 7

SSTc_7

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| bills (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| not (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| paying (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| easy (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| is (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| hard (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Scrambled Sentences Test 8

SSTc_8

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| do (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| invite (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| me (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| don't (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| others (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| out (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Scrambled Sentences Test 9

SSTc_9

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| faults (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| can (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| my (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| see (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| others (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| merits (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Scrambled Sentences Test 10

SSTc_10

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| afford (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| can (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| can't (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| expensive (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| I (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| things (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Scrambled Sentences Test 11

SSTc_11

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| my (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| is (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| daunting (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| fine (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| saying (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| opinion (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Scrambled Sentences Test 12

SSTc_12

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| don't (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| worry (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| I (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| money (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| about (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| do (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Scrambled Sentences Test 13

SSTc_13

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| performing (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| expectations (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| above (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| below (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| am (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| I (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Scrambled Sentences Test 14

SSTc_14

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| difficult (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| maintaining (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| easy (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| I (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| relationships (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| find (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Scrambled Sentences Test 15

SSTc_15

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| new (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| badly (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| end (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| ventures (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| will (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| well (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Scrambled Sentences Test 16

SSTc_16

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| into (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| will (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| get (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| debt (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| won't (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| I (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Scrambled Sentences Test 17

SSTc_17

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| will (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| my (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| achieve (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| won't (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| I (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| goals (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Scrambled Sentences Test 18

SSTc_18

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| others' (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| worried (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| opinions (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| indifferent (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| I'm (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| about (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Scrambled Sentences Test 19

SSTc_19

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| exciting (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| I (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| scary (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| future (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| the (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| find (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Scrambled Sentences Test 20

SSTc_20

| | 1 (1) | 2 (2) | 3 (3) | 4 (4) | 5 (5) |
|---|---|---|---|---|---|
| have (1) | ☐ | ☐ | ☐ | ☐ | ☐ |
| many (2) | ☐ | ☐ | ☐ | ☐ | ☐ |
| plans (3) | ☐ | ☐ | ☐ | ☐ | ☐ |
| future (4) | ☐ | ☐ | ☐ | ☐ | ☐ |
| no (5) | ☐ | ☐ | ☐ | ☐ | ☐ |
| I (6) | ☐ | ☐ | ☐ | ☐ | ☐ |

Page Break

*SST number recall*

SST Number recall

Please enter the number you were asked to remember at the start of this task:

_____

*Stress rating and feedback on SST*

Stress rating 1 Please indicate how stressed you are currently feeling on a scale from 0 to 100, with 0 being not stressed at all and 100 being extremely stressed. To answer, please click on the line to shift the bar into the correct location on the scale.

0 10 20 30 40 50 60 70 80 90 100

Stress ()

Page Break

*SST Feedback*

If you have any feedback for the 'unscrambling' task, whether positive or negative, please write below.

_____

## IQ instructions and practice

IQ Introduction

For the next section, you will be presented with 10 scenarios and asked to rank order three explanations as most to least likely, with the most likely explanation receiving a score of 1 and the least likely explanation receiving a score of 3.

You will also be asked to to rate how likely you believe it may be for these explanations to occur, with 0 being not likely and 8 being very likely.

There is no time limit in this section of the study.

---

Page Break

IQ example
Below is a step-by-step example of a scenario similar to those you will be presented with during the main task:

---

Once you have read the scenario, you will be asked a simple question regarding the content of the paragraph. This has been done in the example below:

---

---

*Next, you will be asked to rank order three explanations as most to least likely, with the most likely explanation receiving a score of 1 and the least likely explanation receiving a score of 3. This has been done in the example below:*

---

---

*Once you have rank ordered the three explanations, you will also be asked to rate how likely it is that you would think of this outcome if you were in the described scenario, with 0 being not at all likely and 8 being very likely. This has been done in the example below:*

---

---

*Once you have rated the likeliness of each explanation, you can move onto the next scenario until all 10 are completed.*

Please continue to the next page to begin the main task.

Page Break

Interpretation Questionnaire Scenario 1

IQ1 Scenario 1 of 10

Lately, you have had a busier schedule than usual and it is an effort to manage it. You decide to have a break and as you are walking outside, you become very aware of how you are feeling.

Page Break

IQ1c
What has been difficult to manage?

- ○ Your schedule (1)
- ○ The housework (2)

Page Break

IQ1_1 Scenario 1

Please rank the below statements from 1 to 3 on how likely they are to occur, with the most likely explanation receiving a score of 1 and the least likely explanation receiving a score of 3.

_____ You are feeling confident you can manage your schedule (1)
_____ You are feeling overwhelmed with your schedule (2)
_____ You feel you are doing as well as you can (3)

Page Break

QI1_2 How likely is it that you would think of this outcome? Please rate the following statements from 0 (not at all likely) to 8 (extremely likely).

| | 0 (not at all likely) (1) | 1 (2) | 2 (3) | 3 (4) | 4 (5) | 5 (6) | 6 (7) | 7 (8) | 8 (extremely likely) (9) |
|---|---|---|---|---|---|---|---|---|---|
| You are feeling confident you can manage your schedule (1) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| You are feeling overwhelmed with your schedule (2) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| You feel you are doing as well as you can (3) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

Page Break

Interpretation Questionnaire Scenario 2

QI2 Scenario 2 of 10

It is late at night and you are in a multi-storey car park trying to find your car. You have been looking for about ten minutes and still cannot find it. You hear a noise behind you and see a shadow of something.

Page Break

QI2c How long were you looking for your car?

- ○ Five minutes (1)
- ○ Ten minutes (2)

Page Break

*

QI2_1 Scenario 2

Please rank the below statements from 1 to 3 on how likely they are to occur, with the most likely explanation receiving a score of 1 and the least likely explanation receiving a score of 3.

_____ You see someone coming towards you looking threatening (1)
_____ You see a cat walking by (2)
_____ You see a security person approaching to help you (3)

Page Break

QI2_2 How likely is it that you would think of this outcome? Please rate the following statements from 0 (not at all likely) to 8 (extremely likely).

| | 0 (not at all likely) (1) | 1 (2) | 2 (3) | 3 (4) | 4 (5) | 5 (6) | 6 (7) | 7 (8) | 8 (extremely likely) (9) |
|---|---|---|---|---|---|---|---|---|---|
| You see someone coming towards you looking threatening (1) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| You see a cat walking by (2) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| You see a security person approaching to help you (3) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

Page Break

Interpretation Questionnaire Scenario 3

QI3 Scenario 3 of 10

Your family is organising a games night. The first game is a trivia game which is played in teams. As you remember previous games nights, you think about the contribution you will make to your team.

Page Break

QI3c What game was being played?

- ○ Pictionary (1)
- ○ A trivia game (2)

Page Break

QI3_1 Scenario 3

Please rank the below statements from 1 to 3 on how likely they are to occur, with the most likely explanation receiving a score of 1 and the least likely explanation receiving a score of 3.

_____ You will make an average contribution to your team (1)
_____ You will help your team do well in the trivia game (2)
_____ You won't be much help to your team mates (3)

Page Break

QI3_2 How likely is it that you would think of this outcome? Please rate the following statements from 0 (not at all likely) to 8 (extremely likely).

| | 0 (not at all likely) (1) | 1 (2) | 2 (3) | 3 (4) | 4 (5) | 5 (6) | 6 (7) | 7 (8) | 8 (extremely likely) (9) |
|---|---|---|---|---|---|---|---|---|---|
| You will make an average contribution to your team (1) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| You will help your team do well in the trivia game (2) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| You won't be much help to your team mates (3) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

Page Break

Interpretation Questionnaire Scenario 4

QI4 Scenario 4 of 10

It is your birthday today. As you are in a waiting room, you switch your mobile phone to silent. After your appointment, a glance at your phone confirms your expectation about how many birthday messages you would receive.

Page Break

QI4c Where did you turn off your phone?

- ○ The waiting room (1)
- ○ The reception area (2)

Page Break

QI4_1 Scenario 4

Please rank the below statements from 1 to 3 on how likely they are to occur, with the most likely explanation receiving a score of 1 and the least likely explanation receiving a score of 3.

_____ You have received a lot of birthday messages (1)
_____ You have received a few messages from your family (2)
_____ You haven't had many birthday messages (3)

Page Break

QI4_2 How likely is it that you would think of this outcome? Please rate the following statements from 0 (not at all likely) to 8 (extremely likely).

| | 0 (not at all likely) (1) | 1 (2) | 2 (3) | 3 (4) | 4 (5) | 5 (6) | 6 (7) | 7 (8) | 8 (extremely likely) (9) |
|---|---|---|---|---|---|---|---|---|---|
| You have received a lot of birthday messages (1) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| You have received a few messages from your family (2) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| You haven't had many birthday messages (3) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

Page Break

Interpretation Questionnaire Scenario 5

QI5 Scenario 5 of 10

You are taking a stroll on a quiet street near where you live. As you round the corner you see someone coming towards you on the same side of the road. As you meet, he stares straight at you and moves closer while raising his hand.

Page Break

QI5c Where are you walking?

- In a park (1)
- Along a road (2)

Page Break

*

QI5_1 Scenario 5

Please rank the below statements from 1 to 3 on how likely they are to occur, with the most likely explanation receiving a score of 1 and the least likely explanation receiving a score of 3.

_____ As you meet, he waves in recognition and gives you a friendly greeting (1)
_____ As you meet, he moves closer and raises his fist menacingly (2)
_____ As you meet, he adjusts his glasses and walks on past you (3)

Page Break

QI5_2 How likely is it that you would think of this outcome? Please rate the following statements from 0 (not at all likely) to 8 (extremely likely).

| | 0 (not at all likely) (1) | 1 (2) | 2 (3) | 3 (4) | 4 (5) | 5 (6) | 6 (7) | 7 (8) | 8 (extremely likely) (9) |
|---|---|---|---|---|---|---|---|---|---|
| As you meet, he waves in recognition and gives you a friendly greeting (1) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| As you meet, he moves closer and raises his fist menacingly (2) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| As you meet, he adjusts his glasses and walks on past you (3) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

Page Break

Interpretation Questionnaire Scenario 6

QI6 Scenario 6 of 10

You are with a group of new friends, on your way to the theatre.
You decide to tell a joke you heard recently. Everyone looks at you as you start telling the joke, and you see their expressions change when you get to the punch line.

Page Break

QI6c Where were you going when you told the joke?

- ○ The restaurant (1)
- ○ The theatre (2)

Page Break

*

QI6_1 Scenario 6

Please rank the below statements from 1 to 3 on how likely they are to occur, with the most likely explanation receiving a score of 1 and the least likely explanation receiving a score of 3.

_____ When you get to the end you see everyone starting to laugh (1)
_____ When you get to the end, some of them smile and another person starts telling a joke (2)
_____ When you get to the punch line everyone looks confused (3)

Page Break

QI6_2 How likely is it that you would think of this outcome? Please rate the following statements from 0 (not at all likely) to 8 (extremely likely).

| | 0 (not at all likely) (1) | 1 (2) | 2 (3) | 3 (4) | 4 (5) | 5 (6) | 6 (7) | 7 (8) | 8 (extremely likely) (9) |
|---|---|---|---|---|---|---|---|---|---|
| When you get to the end you see everyone starting to laugh (1) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| When you get to the end, some of them smile and another person starts telling a joke (2) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| When you get to the punch line everyone looks confused (3) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

Page Break

Interpretation Questionnaire Scenario 7

QI7 Scenario 7 of 10

Your teacher for an evening course has just written you an email attaching comments on your last assignment. The assignment is still in draft form but you have dedicated many hours and a lot of effort to it so far. As you open the document you see what they thought of it from the detailed comments on the margin.

Page Break

QI7c Who sent you the document?

- ○ Your teacher (1)
- ○ Your employer (2)

Page Break

QI7_1 Scenario 7

Please rank the below statements from 1 to 3 on how likely they are to occur, with the most likely explanation receiving a score of 1 and the least likely explanation receiving a score of 3.

_____ You see some comments from your teacher suggesting that your work leaves a lot of room for improvement (1)
_____ You see from the comments that your teacher is acknowledging the excellent work you have been doing (2)
_____ You see from the teacher that your supervisor is satisfied with your hard work and makes some suggestions (3)

Page Break

QI7_2 How likely is it that you would think of this outcome? Please rate the following statements from 0 (not at all likely) to 8 (extremely likely).

| | 0 (not at all likely) (1) | 1 (2) | 2 (3) | 3 (4) | 4 (5) | 5 (6) | 6 (7) | 7 (8) | 8 (extremely likely) (9) |
|---|---|---|---|---|---|---|---|---|---|
| You see some comments from your teacher suggesting that your work leaves a lot of room for improvement (1) | ○ | C | C | C | C | C | C | C | ○ |
| You see from the comments that your teacher is acknowledging the excellent work you have been doing (2) | ○ | C | C | C | C | C | C | C | ○ |
| You see from the teacher that your supervisor is satisfied with your hard work and makes some suggestions (3) | ○ | C | C | C | C | C | C | C | ○ |

Page Break

Interpretation Questionnaire Scenario 8

QI8 Scenario 8 of 10

You are on a train with several friends, it is a long trip and some of your friends are doing crosswords. One of them asks you if you have suggestions for the last word across. You offer an idea and your friend immediately reacts with a clear body language response.

Page Break

QI8c What game was your friend playing?

- Sudoku (1)
- Crossword (2)

Page Break

QI8_1 Scenario 8

Please rank the below statements from 1 to 3 on how likely they are to occur, with the most likely explanation receiving a score of 1 and the least likely explanation receiving a score of 3.

_____ From your friend's reaction you know it means "thanks" (1)
_____ From your friend's reaction you can tell they are delighted your answer correctly completes the crossword (2)
_____ From your friend's reaction you can tell that he is disappointed as he believes your answer is wrong (3)

Page Break

QI8_2 How likely is it that you would think of this outcome? Please rate the following statements from 0 (not at all likely) to 8 (extremely likely).

| | 0 (not at all likely) (1) | 1 (2) | 2 (3) | 3 (4) | 4 (5) | 5 (6) | 6 (7) | 7 (8) | 8 (extremely likely) (9) |
|---|---|---|---|---|---|---|---|---|---|
| From your friend's reaction you know it means "thanks" (1) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| From your friend's reaction you can tell they are delighted your answer correctly completes the crossword (2) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| From your friend's reaction you can tell that he is disappointed as he believes your answer is wrong (3) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

Page Break

Interpretation Questionnaire Scenario 9

QI9 Scenario 9 of 10

Your friend is going to the cinema tonight and asks you to recommend a film to watch. You pick out a film you think they will enjoy. The next day, your friend makes a comment about your taste in films.

Page Break

QI9c What did your friend ask you to recommend?

- A restaurant to go to (1)
- A film to watch (2)

Page Break

QI9_! Scenario 9

Please rank the below statements from 1 to 3 on how likely they are to occur, with the most likely explanation receiving a score of 1 and the least likely explanation receiving a score of 3.

_____ Your friend comments that the film was alright (1)
_____ Your friend comments that your taste in films is poor (2)
_____ Your friend comments that you have a great taste in films (3)

Page Break

QI9_2 How likely is it that you would think of this outcome? Please rate the following statements from 0 (not at all likely) to 8 (extremely likely).

| | 0 (not at all likely) (1) | 1 (2) | 2 (3) | 3 (4) | 4 (5) | 5 (6) | 6 (7) | 7 (8) | 8 (extremely likely) (9) |
|---|---|---|---|---|---|---|---|---|---|
| Your friend comments that the film was alright (1) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Your friend comments that your taste in films is poor (2) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Your friend comments that you have a great taste in films (3) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

Page Break

Interpretation Questionnaire Scenario 10

QI10 Scenario 10 of 10

Your favorite musician is coming to town and you would really like to see them. You don't want to go on your own and ask a friend if they want to come. Their reply confirms what you thought they would say.

Page Break

QI10c Who did you ask to go with you to see the musician?

- ○ A friend (1)
- ○ Your cousin (2)

Page Break

QI10_1 Scenario 10

Please rank the below statements from 1 to 3 on how likely they are to occur, with the most likely explanation receiving a score of 1 and the least likely explanation receiving a score of 3.

_____ Your friend says they are quite busy but will check their diary (1)
_____ Your friend says they don't want to see the musician with you (3)
_____ Your friend says they would like to see the musician with you (2)

Page Break

QI10_2 How likely is it that you would think of this outcome? Please rate the following statements from 0 (not at all likely) to 8 (extremely likely).

| | 0 (not at all likely) (1) | 1 (2) | 2 (3) | 3 (4) | 4 (5) | 5 (6) | 6 (7) | 7 (8) | 8 (extremely likely) (9) |
|---|---|---|---|---|---|---|---|---|---|
| Your friend says they are quite busy but will check their diary (1) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Your friend says they don't want to see the musician with you (3) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| Your friend says they would like to see the musician with you (2) | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

Page Break

*IQ feedback and end of Survey 2*

IQ feedback

If you have any feedback for the previous task, whether positive or negative, please write below.

_____

**End of Block: Interpretation Questionnaire**

**Start of Block: Final Feedback**

pt2_help Please let us know if you had any help while completing this survey

- I had no help throughout (1)
- I had some help throughout (2)
- I had help all the way through (3)

Findings summary Please click 'Yes' if you would like to receive a summary of the study findings once data collection is complete, and data has been analysed. If you would like to receive this, we will keep a note of your e-mail address and name in our secure password-protected database. You can contact us at any point to have your contact details removed before receiving a summary of the study findings.

- Yes (1)
- No (2)

Further contact

Please click 'Yes' if are interested in receiving information about research opportunities from our research team for which you may be eligible. If you select this, we will keep a note of your e-mail address and name in our secure password-protect database for up to two years following the end of the this study. Consenting to this in no way means that you are obliged to partake in future studies, and you can withdraw your details at any point by

mailing a member of the research team as listed in the participant information sheet.

- ○ Yes (1)
- ○ No (2)

Page Break

Final feedback
If you have any feedback regarding the the tasks you have just done, please write in the box below.

_____

_____

_____

_____

_____

Q567 Please click the red box at the bottom to finish the study.

○ **End of Block: Final Feedback**

## Appendix 5

TICS-M script and questions

Hello, can I speak to Mr/Ms……..

Hello my name is Mazda, I am calling from the King's College research team regarding our telephone appointment today. Are you free to talk now?

Thank you. Before we begin the telephone interview, can I check that the line we are on is clear and that you can hear and understand what I am saying?

Thank you so much for taking part in our research study, your participation is greatly appreciated.

(**If feedback already provided**) Thank you for the feedback you provided at the end of the survey. Was there anything else you would like to make me aware of?

**OR**: We noted that you had not left any feedback at the end of the survey which is fine, but I just wanted to check if there was anything that you would like to make us aware of, regarding the survey?

Thank you.

Do you use any hearing aids?

(**if so**) Are you using it now?

Just so that we are both sure that you can hear me properly, could you please repeat the following sentence ….. "The morning was bright and sunny" (**repeat if sentence is not repeated correctly**)

(**in case of two errors**) Thank you Mr/Ms….. I am a little concerned that we may not be able to hear each other properly. It is very important that you can hear me very well and I do not want to take up your time if you cannot make out everything I am saying. I suggest we suspend the call for today and I will arrange to contact you in the next three working days to confirm our next step. Thank you very much for your time today, it has been greatly appreciated.

That's great, thank you. The call today will take around 20 minutes. Will you be able to speak for this length of time today? It is quite important that you are in a quiet place with no outside distractions. Will you be able to complete the call today without any distractions?

(**If not**) I think it may be best if we arrange to speak at a different time when you will not be distracted. When would be convenient for you?

That's great, thank you. The purpose of my call today is to complete the final part of this research study. It will involve a brief test of general knowledge, memory and attention. You may find some questions easier than others. Please do not worry if you find some questions difficult, the idea is just for you to try your best.

You may also find that you have completed a similar set of questions before, in previous appointments with doctors or in research settings. This assessment is design to be completed over the phone. It is important that you do not write anything down or search for answers on your computer or phone as we go along.

Do you have any questions before we begin?

Are you happy to complete the assessment today?

Thank you, we can begin the assessment now. It should take between 10 – 15 minutes.

**********

1 – Please tell me your full name? ……

2 – What is the year we are in? …….

3 – What season is it? ……

4 – What month are we in? ……

5 – What is todays date? …….

6 – What day of the week is today? ……..

7 – What is your home address? ……..

8 – Please count backwards from 20 to 1 ……

(if participant makes any mistakes) Now, lets try that again. I would like you to count backwards from 20 to 1 ……..

9 - I am going to read a list of 10 words. Please listen carefully and try to remember them. When I am done, tell me as many words as you can, in any order. Ready? The words are:

1. Cabin
2. Pipe
3. Elephant
4. Chest
5. Silk
6. Theatre
7. Watch
8. Whip
9. Pillow
10. Giant

Now tell me all the words you can remember

10 - Now I'd like you to subtract 7 from 100. Then keep subtracting 7 from each answer until I tell you to stop. What is 100 take away 7? …… (93, 86, 79, 72, 65)

11 – What do people usually use to cut paper? ……

12 – How many things are in a dozen?

13 – What do you call the prickly green plant that lives in the desert?

14 – What does wool come from?

15 - Say this, "No ifs, ands or buts"

16 – Say this, "Methodist Episcopal"

17 – Who is the President of the United States right now? …… OR

Who is the Prime Minister of the United Kingdom right now? …….

18 – Who is the leader of the Labour Party? …… OR

19 – With your finger, tap 5 times on the part of the phone you speak into

20 - I'm going to give you a word and I want you to give me its opposite. For example, the opposite of hot is cold. What is the opposite of 'west'? ……

21 – What is the opposite of generous? ……..

22 - Earlier I read a long list of words to you. Please tell me all of the words that you can remember from that list.

1. Cabin
2. Pipe
3. Elephant
4. Chest
5. Silk
6. Theatre
7. Watch
8. Whip
9. Pillow
10. Giant

**********

Thank you so much for your time today and for your time in completing the online survey.

You will receive a debriefing sheet containing some information about the study by the end of the day. This will include information about how you can contact us if you have any further questions about your participation.

Thank you for your help Mr/Ms……

Goodbye

# Volume II

# Service Evaluation Project

**Mazda Beigi**

**Institute of Psychiatry, Psychology and Neuroscience**

**King's College London**

**Thesis submitted in partial fulfilment for the degree of**

**Doctorate in Clinical Psychology 2019**

**Service Evaluation Project**

# An investigation into the predictors for dropout in Southwark IAPT.

**Supervisor: Janet Wingrove**

## Table of Contents

## List of Tables and Figures

## Abstract

**Aim**: This study investigated critical demographic factors that may be predictive of higher dropout rates amongst clients who accessed the Southwark Improving Access to psychological Therapies (IAPT) service.

**Method**: demographic information from clients who accessed the service between 2011 and 2016 were extracted from the IAPTus database. We used a range of predictive factors, based on indicators identified in other studies investigating dropout rates in psychotherapy. The study identified a group of clients who dropped out of therapy after attending at least one session and a separate group who completed therapy (excluding those who may have been referred onto other services).

**Results**: we found that those accessing IAPT services were disproportionately dropping out of therapy based on gender, ethnicity, age and where they were in the care pathway. We also found that these groups were less likely to complete therapy than what would be expected.

**Conclusion**: consistent with other studies, gender and ethnicity seem to be predictive factors for dropout in IAPT. Our studies revealed that those of Caribbean decent and men were more likely to drop out of therapy and less likely to complete therapy than would be expected. Results indicate that those in lower age groups are also more likely to drop out of therapy while older adults are more likely to complete therapy. Analysis of dropout rates for clients engaged in different stages of the care pathway generally showed that those in Step 3 are not showing a risk of dropout while those in Step 2 are. We explore a range of possible explanations for this finding and consideration of other factors that may have contributed towards the results.

# Introduction

## Background

In 2008, the British government approved the Increasing Access to Psychological Therapies (IAPT) programme originally suggested by Lord Richard Layard and Prof David Clark. The service was intended to make it easier for unemployed members of the general public to access psychological support in order to prevent their mental health difficulties from reaching debilitative stages, thus affecting their ability to re-enter the workplace. Services offered through IAPT have proven to be popular with referral rates rising each year since IAPT first began (https://www.england.nhs.uk/mental-health/adults/iapt/). According to the latest, published Adult IAPT workforce census report (2015), IAPT services employ 6,897 employees, consisting of a range of professionals (https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/09/adult-iapt-workforce-census-report-15.pdf).

## IAPT key principles and stepped care approach

Designed to support people with common mental health difficulties. IAPT services primarily focus on one to one support but also provide group therapy for those who may benefit from it. IAPT services are characterised by three key principles (i) Evidence-based psychological therapies at the appropriate dose, (ii) an appropriately trained and supervised workforce, and (iii) Routine outcome monitoring (National Collaborating Centre for Mental Health, 2019). The first of these principles refers to a stepped care model where patients are assessed to identify the type pf treatment they require. In line with NICE recommendations, IAPT employs a two tier stepped care model where clients are triaged and assessed to gain a general background regarding the client, whether they have accessed mental health services before, a history of medical complications and to identify the specific difficulties they are experiencing most recently. This also provides an opportunity for clinicians to investigate risk and

whether a client is potentially subject to self-harm. Available treatments are explained to clients based on the information obtained. This could be a recommendation of low or high intensity therapy or signposting to other specialist services if IAPT is not deemed to be the most appropriate service for them. Step-2 involves low intensity therapy, often provided by Low Intensity CBT Therapists or Psychological Wellbeing Practitioners. This intervention is less resource intensive and includes guided self-help based on CBT, computerized CBT and psychoeducational workshops delivered by psychological wellbeing practitioners. Step-3 care however, involves face to face therapy with fully qualified and trainee therapists. Step-3 care offers a range of therapeutic interventions to meet the complex needs of clients that are referred. For example, this could involve somewhere between 6-12 one hour sessions of CBT, although it is not limited to this number. The role of therapy is to formulate a client's difficulties, address their goals for therapy and work towards achieving them.

Finally, outcome measures are used to monitor service user's progress and determine whether improvements in mood and daily functioning have been achieved. These measures can also be used to determine how successful a service has been and inform any potential changes/developments that may be required. Primarily, this involves the use of the Patient Health Questionnaire (PHQ-9) and Generalised Anxiety Disorder Assessment (GAD-7). These are first completed at screening and then on a regular bases (at each clinical contact) in order to monitor clients progress. Furthermore, depending on the client's difficulties, disorder specific questionnaires are also available to complete with clients to gain a more detailed measure of their difficulties.

IAPT success rate

In order to monitor and facilitate a quality service, IAPT services are committed to three national standards (i) access standard (referring to the number of people entering treatment) (ii) waiting time standards and (iii) recovery rate standards (IAPT Manual 2018).

Access standards

The recent Five Year Forward View for Mental Health report has set out a goal for IAPT services to support at least an additional 600,000 members of the public with depression and/or anxiety, per year by 2020/21 (IAPT Manual 2018). In this case, accessing IAPT is defined by clients completing at least one treatment appointment.

Waiting time standards

Referrals to IAPT services can be made through GP services or self-referral. IAPT also accepts referrals from other health care professionals when submitted. Waiting times are constituted by the amount of time it takes from referral (whether through GP or self) to when treatment has begun. Targets are that 75% of clients should have their first treatment session within 6 weeks of their referral and 95% within 18 weeks (IAPT Manual 2018).

Recovery standards

Recovery is measured through outcome measures completed by clients. These will often be PHQ-9 and GAD-7 scores but recovery scores can also be deferred to disorder specific measures (such as the Social Phobia Inventory) where applicable. Recovery is achieved when a client scores below caseness on relevant measures, at the end of treatment. The goals set for recovery in IAPT are stated in the national rate of recovery, 50% (IAPT Manual 2018).

Improving access to IAPT

Given the IAPT philosophy of improving access to members of the general public, ensuring that such access is equally achievable to all is paramount. National data reported in the IAPT Manual (2018) indicates that a significant proportion of certain demographic groups seem to be underrepresented in IAPT services:

1. Men
2. Member of Black and Minority Ethnic groups including those who do not have English as their first language.
3. People in prison and other ex-offenders.
4. People who have served in the armed forces.
5. Refugees and asylum seekers.
6. Members of the LGBTQ community.
7. People from low socioeconomic backgrounds.
8. People who provide care for others.
9. Older adults.
10. People with physical disabilities.
11. People with learning disabilities (IAPT Manual 2018).

The same manual presents a range of suggestions for how IAPT services can adapt to working with people in these underrepresented groups, such as employing more staff from black and minority ethnic backgrounds (BME) and adapting therapy to better suit people with learning disabilities or those whom English is not their first language (IAPT Manual 2018).

Dropout rates in IAPT

Studies reporting the rate of non-attendance and dropouts from psychotherapies present inconsistent findings with rates ranging from 15% to 57% (Baekeland & Lundwall, 1975; Marshall et al., 2016). Dropout rates specific to IAPT services have been more consistently placed at 42% to 48% (Byng et al., 2011; Chan & Adams, 2014; Glover, Webb, & Evison, 2010; Murphy, Mansell, Craven, Menary, & McEvoy, 2013; Richards & Borglin, 2011). It can be argued that this will negatively impact on at least two of the three national standards IAPT services are committed to (Access standards and Recovery Standards). This may be particularly significant for the long term success of IAPT services given that one recent study discovered that over one third of their participants had been referred to Southwark IAPT on more than one occasion (Hepgul

et al., 2016). Although, Hepgul and colleagues (2016) do not report the number of people who returned after dropping out of therapy. One study recently investigated re-referral patterns in IAPT services to assess how clients reengage, if at all. They discovered that a high number for clients fail to engage at all or dropout (75% of people with two referrals, 60% of those with three referrals, 58% of people with four referrals and 50% of people with five referrals) after re-referrals (Cairns, 2014). Cairns (2014) points out that there have been no studies to directly assess how those who dropout of therapy feel about returning.

Perhaps more clearly, dropouts from IAPT services negatively affect service recovery standards. Studies have indicated that those dropping out of therapy do so as a result of a wide range of difficulties that can be directly or indirectly influenced by their presenting psychological condition (Fernandez et al., 2015; Hans & Hiller, 2013). These clients are likely to present with high levels of anxiety and depression when they leave services and will consequently be recorded as people who have not reached recovery when their outcome measures are assessed.

As well as dropouts negatively influencing IAPT standards, a study exploring the cost of IAPT treatment for individual clients revealed that the average cost of treatment came to £493 for low intensity and £1416 for high intensity therapy (Radhakrishnan et al., 2013). The same study estimated that the cost per patient who reached recovery was £1043 for low and £2895 for high intensity therapy (Radhakrishnan et al., 2013). This amounted to each appointment costing £99 for low intensity and £177 for high intensity therapy (Radhakrishnan et al., 2013). The authors collected data from five separate primary care trusts and estimated that some 25% of clients dropped out of therapy entirely, meaning that their treatment was not concluded. They calculated that the cost dedicated to clients who dropped out of therapy amounted to £870,424 out of a total £5,952,366 spent on client contact.

Studies assessing dropout rates in psychotherapies have identified a range of predictive factors (Chan & Adams, 2014; de Haan, Boon, de Jong, & Vermeiren, 2018;

Marshall et al., 2016). A recent study conducted across two IAPT sites in Newham and Doncaster identified that demographic factors such as clinical risk outcome scores, IAPT outcome measure scores, illness duration and service (whether clients accessed Newham or Doncaster IAPT) were predictors of dropout (Di Bona, Saxon, Barkham, Dent-Brown, & Parry, 2014). Interestingly, the authors did not find evidence for there being a link to socio-demographic factors such as ethnicity. However, it is noted that this study consisted of 90.7% white clients and a relatively small sample size (n = 363), meaning that the sample may have lacked in power to convincingly assess ethnicity. Other studies have however, determined that demographic factors such as ethnicity (Gülüm, Soygüt, & Safran, 2018; Johns et al., 2019; Olver, Stockdale, & Wormith, 2011; Swift & Greenberg, 2012), gender (Baekeland & Lundwall, 1975; Thormählen et al., 2003; Wierzbicki & Pekarik, 1993), diagnosis (Fernandez et al., 2015; Hans & Hiller, 2013) and/or socioeconomic factors (Baekeland & Lundwall, 1975; Barrett, Crits-christoph, Gibbons, & Thompson, 2009; Beckham, 1992; Reis & Brown, 1999; Swift & Greenberg, 2012; Wierzbicki & Pekarik, 1993) can predict higher levels of dropout from psychotherapy. While others have found contradictory findings for demographics such as gender (Linardon, Fitzsimmons-Craft, Brennan, Barillaro, & Wilfley, 2018) and ethnicity (Di Bona et al., 2014; Jolley et al., 2015) not effecting dropout.

## Current Study

In light of the above, it is important for IAPT services to better understand and reduce the likelihood of clients dropping out of therapy. If we were to better understand these indicators, it is possible for IAPT services to pre-empt these additional risk factors by better supporting clients with engagement. The aim of this project is to identify whether client demographic information can serve as an indicator of increased likelihood to dropout of therapy.

The current study will use recorded data from IAPTus to identify potential indicators for dropout based on what demographic data is stored on this database and factors identified by other studies such as ethnicity, gender, diagnosis and severity of illness.

# Method

## Design and Procedure

All data for this study was collected from the IAPT internal patient database system (IAPTus – Improving Access to Psychological Therapies User System), used by Southwark IAPT. Information was collected on all clients who accessed the Talking Therapies Southwark service between 2011 and 2016 (start date of this service evaluation). These specific dates were chosen as the service experienced a restructuring shortly before 2011 which would have affected the way care was recorded.

Two separate groups of clients were assessed, those who dropped out (Dropout) and those who completed therapy (Completed). These groups do not capture client who have been referred to other services and are therefore not included in 'dropout' or 'completed' variables. The inclusion criteria for a client who dropped out of therapy was constituted by someone who attended at least one appointment before disengaging from Southwark IAPT. This is normally recorded as a dropout on the IAPTus database. Clients who completed therapy are those who are discharged after completing an agreed course of treatment and were discharged when it was mutually agreed between client and therapist due to their treatment coming to an end. There were no other inclusion/exclusion criteria applied for the study. All data was obtained through IAPTus.

## Participants

Data was collected in a range of demographic factors that may contribute towards a client's barrier to consistent engagement with services and potentially place them at higher risk of dropping out of therapy. In total, 4679 clients were identified as suitable under the inclusion criteria. Of this number 3383 clients had dropped out of therapy

(Dropout Group) and 1299 had completed therapy (Completed Group). Given that the computerised IAPTus programme is still relatively new and has been regularly evolving, filters and labels available for recording information have been completed in different ways. This means that information regarding some demographic details have been registered on IAPTus under multiple labels. These numbers did not always translate into completed records for all the demographic information that was being assessed.

*Table 1. Demographic data for Southwark IAPT clients*

| | **N** | **Dropout** | **Completed** |
|---|---|---|---|
| **Age** | 4679 | 3383 | 1296 |
| 18 - 39 | 3053 | 2267 | 786 |
| 40 - 69 | 1534 | 1091 | 443 |
| 70 plus | 92 | 25 | 67 |
| **Gender** | 4675 | 3377 | 1298 |
| Male | 1672 | 1250 | 422 |
| Female | 3003 | 2127 | 876 |
| **Ethnicity** | 3902 | 2844 | 1058 |
| White British, English, Scottish, Welsh, Northern Ireland | 2265 | 1639 | 626 |
| White European | 364 | 252 | 112 |
| Mixed Race | 270 | 209 | 61 |
| Caribbean | 503 | 403 | 100 |
| African or Other Black Algerian, Angolan, Eritrea, Ethiopia, Ghana, | 377 | 258 | 119 |

| | | | |
|---|---|---|---|
| Nigerian, Somalia, Sudanese, Uganda | | | |
| Arab, Iranian, Iraqi, Middle Eastern | 27 | 19 | 8 |
| China, Japan, Vietnam, Malaysia, Filipino | 35 | 24 | 11 |
| Colombia, Ecuador, Other Latin American | 61 | 40 | 21 |
| Indian, Pakistani, Bengali | 148 | 102 | 46 |
| **National Identity** | 4000 | 2895 | 1105 |
| British | 3143 | 2289 | 854 |
| Other | 857 | 606 | 1105 |
| **Disability Status** | 4048 | 2957 | 1091 |
| Has Disability | 582 | 408 | 174 |
| No Disability | 3466 | 2549 | 917 |
| **Long Term Condition** | 3878 | 2792 | 1086 |
| Has a Long Term Condition | 1578 | 1136 | 442 |
| No Long Term Condition | 2300 | 1656 | 644 |
| **Marital Status** | 2455 | 1784 | 671 |
| Single | 1192 | 863 | 329 |
| Married | 433 | 298 | 135 |
| Divorced | 106 | 71 | 35 |
| Widowed | 39 | 23 | 16 |
| Separated | 121 | 89 | 32 |

| | | | |
|---|---|---|---|
| Co-habiting | 269 | 209 | 60 |
| Long term relationship | 287 | 225 | 62 |
| Civil partnership | 8 | 6 | 2 |
| **Sexuality** | 3434 | 2409 | 1025 |
| Heterosexual | 2931 | 2050 | 881 |
| Lesbian/Gay | 218 | 152 | 66 |
| Bisexual | 91 | 69 | 22 |
| Unsure/do not know | 53 | 35 | 18 |
| Other | 17 | 14 | 3 |
| Unknown | 124 | 89 | 35 |
| **Referral Type** | 4430 | 3202 | 1228 |
| GP | 3002 | 2174 | 828 |
| Self-referral | 1428 | 1028 | 400 |
| **Diagnosis** | 1372 | 1020 | 352 |
| Schizophrenia | 2 | 0 | 2 |
| Depressive Episode | 448 | 317 | 131 |
| Recurrent Depressive Episode | 197 | 157 | 40 |
| Social Phobia | 59 | 43 | 16 |
| Panic Disorder | 74 | 62 | 12 |
| GAD | 212 | 165 | 47 |
| Mixed Anxiety and Depression | 275 | 201 | 74 |
| OCD | 34 | 23 | 11 |
| PTSD | 71 | 52 | 19 |
| **Outcome Measure Scores** | 4011 | 2952 | 1059 |
| GAD Mild Range | 1291 | 942 | 349 |
| GAD Moderate Range | 1217 | 891 | 326 |

| | | | |
|---|---|---|---|
| GAD Severe Range | 1412 | 1059 | 353 |
| PHQ Mild Range | 839 | 623 | 216 |
| PHQ Moderate Range | 1087 | 800 | 287 |
| PHQ Moderate Severe Range | 1088 | 785 | 303 |
| PHQ Severe Range | 997 | 744 | 253 |
| **Treatment Stage** | 4672 | 3373 | 1299 |
| Pre-treatment | 3042 | 2148 | 894 |
| Step 2 | 718 | 605 | 113 |
| Step 3 | 912 | 620 | 292 |

## Analysis

All data was analyses using SPSS 17. An initial Chi-Square analysis was performed to determine the influence of the above demographic data on dropout predictions by comparing Dropout vs. Completed clients over a range of possible predictors. Further pairwise comparisons were applied to evaluate the meaning of any significant analysis.

# Results

A series of Chi-square analysis were performed to determine any significance between the number of people dropping out of therapy and those attending to discharge based on the factors reported in Table 1. Where significance was detected, we conducted post-hoc analysis based on comparing proportions of each individual category by group using a z tests (Beasley & Schumacher, 1995). This method calculates standardised residuals from the contingency tables calculated during the omnibus chi-

square analysis, from which observations are made (MacDonald & Gardner, 2000). In this case, a residual with a larger value than 2.00 indicates significance, approximate to a two-tailed critical value of z at the typical .05 level (Beasley & Schumacher, 1995; Melenhorst, Rogers, & Bouwhuis, 2006). Frequency data from these contingency tables are used to calculate standardized residuals to approximate unit normal distributions (MacDonald & Gardner, 2000). These z transformed residual calculations were then used to determine which expected and observed results were significantly different from each other during pairwise comparisons.

Where more than two factors were compared, alpha correction was adjusted using the Sidak (1967) method as recommended by Beasley & Schumacher (1967) and MacDonald & Gardner (2000) (Sidak, 1967).

$$\alpha_{adj} = 1 - (1 - \alpha)^{1/f}$$

Where *f* refers to the number of comparisons performed. We also employed the Haberman (1973 & 1978) rule of thumb regarding standardized residuals with a greater than 2.00 value (Haberman, 1973, 1978). This was calculated based on a two-tailed value of Z, when using a unit normal table, approximating to the conventional $\alpha = .05$ level (Beasley & Schumacher, 1995).

This method was selected over Bonferroni correction due to its specific application for independent variables and slightly less conservative adjustment (MacDonald & Gardner, 2000).

Chi square analysis

Chi-square analyses revealed that there was a significant difference between Drop-out vs. Completion based on Gender ($\chi 2$ (1) = 8.278, p = .004) (See Figure 1 (a) & (b)).

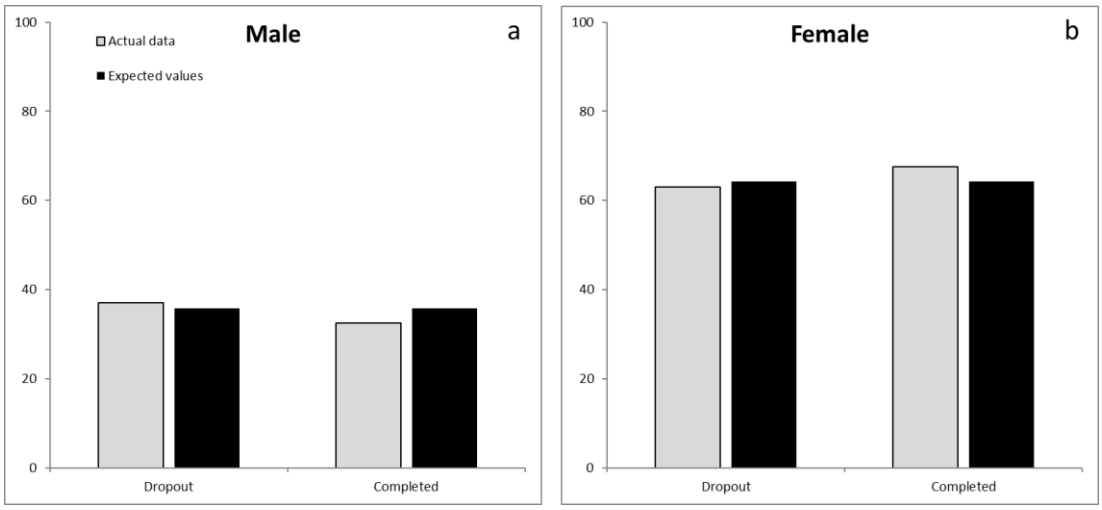


***Figure 1 (a & b)**. Percentages of clients dropping out of therapy and completing therapy vs. expected rates of dropouts and completers for both male (a) and female (b) clients.*

Chi-square analysis revealed a difference between Dropout vs. Completion rate of therapy based on Ethnicity ($\chi 2$ (8) = 25.960, $p < .001$) (See Figure 2 (a) & (b)).

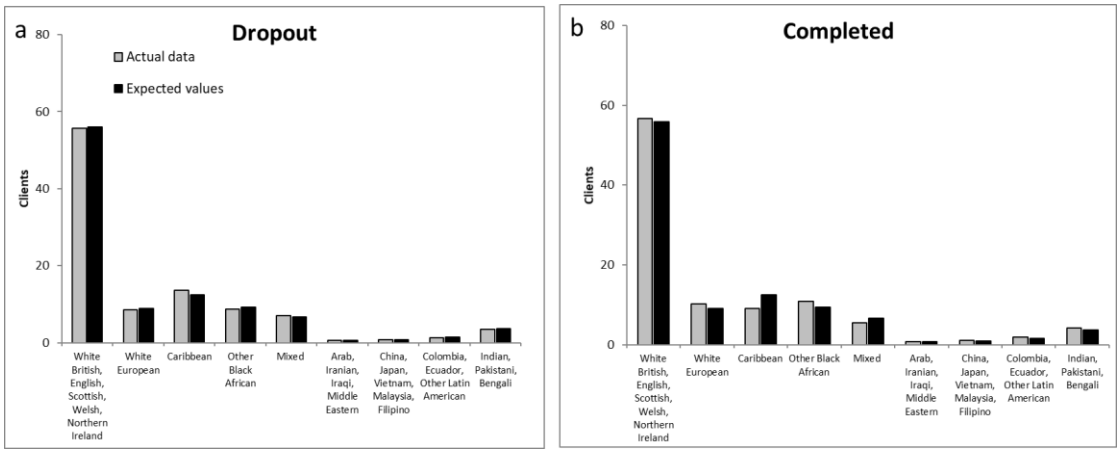


***Figure 2 (a & b)**. Overall rates of clients dropping out of therapy vs. expected rates of dropouts (a) as well as rates of clients completing therapy vs. expected rates of completing (b) based on Ethnicity.*

Similarly, there was a significant difference in expected levels of people dropping out dependent on Diagnosis ($\chi 2$ (8) = 17.718, $p = .023$). There was a significant difference in expected levels of people dropping out dependent on Age ($\chi 2$ (2) = 100.440, $p <$

.001). There was a significant difference in expected levels of dropout vs. completion based on Treatment Stage (Pretreatment vs. Step 2 vs. Step 3) ($\chi 2$ (2) = 63.945, p < .001). An analysis of Marital Status ($\chi 2$ (7) = 16.911, p = .018) also revealed a significant difference between those who did and did not drop out of therapy.

An analysis of those with and without Disability ($\chi 2$ (1) = 2.995, p = .084), revealed a trend towards significance. All further analysis, assessing, Sexuality ($\chi 2$ (5) = 3.272, p = .658), Referral Type ($\chi 2$ (1) = ,089 p = .765), National Identity ($\chi 2$ (1) = 1.509, p = .219) and Long Term Condition ($\chi 2$ (1) < .001, p = .994), failed to reach significance.

Post hoc analysis

Further investigation of Gender identified that 63% of people dropping out of therapy were women compared to an expected value of 64%. However, results indicate that only 37% of men dropped out of therapy compared to an expected percentage of 36% (See Figure 1). Similarly investigation of Gender identified that 67% of people completing therapy were women compared to an expected value of 64%. However, results indicate that only 33% of men completed therapy compared to an expected percentage of 36% (See Figure 1).

Further investigation of significant effects of Chi-square analysis were conducted after alpha correction, based on the Sidak (1967) and Haberman (1973 & 1978) methods. A corrected value for α based on nine comparisons for Ethnicity provided an adjusted value ($\alpha_{adj}$ = p<0.0057) for all remaining post-hoc tests. When converted to the unit table, this adjusted value for α results in a two-tailed critical value of $_Z$ = 2.77, meaning that any value greater than this would qualify as significant. Further analysis in light of this adjusted value revealed a significant difference between dropout vs completion for those from Caribbean backgrounds (14.2% dropout vs. 9.5% complete; $_Z$ =3.93, p<001) (see Figures 3).

All remaining comparisons (White British, White European, Black African and Other Black, Mixed, Middle Eastern, Far Easter and South American) did not reach

significance at the adjusted levels for $\alpha/_{Z}$, suggesting that there was no significant difference between those who dropped out vs. completed therapy (see Table 2).

*Table 2. Post hoc analysis of chi square based on standardized residuals.*

| | N | Dropout % | Completed % | $_{Z}$ value | P |
|---|---|---|---|---|---|
| **Ethnicity** | | | | | |
| White British, English, Scottish, Welsh, Northern Ireland | 2265 | 57.6 | 59.2 | -.88 | .522 |
| White European | 364 | 8.9 | 10.6 | -1.65 | .653 |
| Mixed Race | 270 | 7.4 | 5.8 | 1.73 | |
| Caribbean | 504 | 14.2 | 9.5% | 3.93 | <.001 * |
| African or Other Black Algerian, Angolan, Eritrea, Ethiopia, Ghana, Nigerian, Somalia, Sudanese, Uganda | 377 | 9.1 | 11.3 | -2.05 | .040 |
| Arab, Iranian, Iraqi, Middle Eastern | 27 | .67 | .76 | -.30 | .764 |
| China, Japan, Vietnam, Malaysia, Filipino | 35 | .84 | 1 | -.58 | .562 |
| Colombia, Ecuador, Other Latin American | 61 | 1.4 | 2 | -1.30 | .194 |
| Indian, Pakistani, Bengali | 148 | 3.5 | 4.2 | -1.07 | .285 |

*Note. Sidak corrected Alpha ($\alpha_{adj}$ = p<0.0064). Significant results are denoted by an asterisk.*

Given significant results revealing that men were more likely to drop out of therapy when assessing gender alone and that people from Caribbean backgrounds were more likely to dropout when assessing ethnicity alone, a further chi-square analysis combining ethnicity and gender was conducted. There was a significant difference in expected levels of people dropping out dependent on Ethnicity x Gender ($\chi 2$ (17) = 30.510, p = .023). Post-hoc analysis with a corrected value for α based on eighteen comparisons for Ethnicity x Gender revealed an adjusted value ($\alpha_{adj}$ = p<0.0028), resulting in a two-tailed critical value of $_{Z}$ = 2.99. Based on a number of pairwise

comparisons, a significant difference between dropout vs. completion for Caribbean males (4.2% dropout vs. 2.2% complete; $_Z$ =3.03, p = .002) was discovered. All remaining pairwise comparisons were not significant at the correct value for α (see Figure 3).

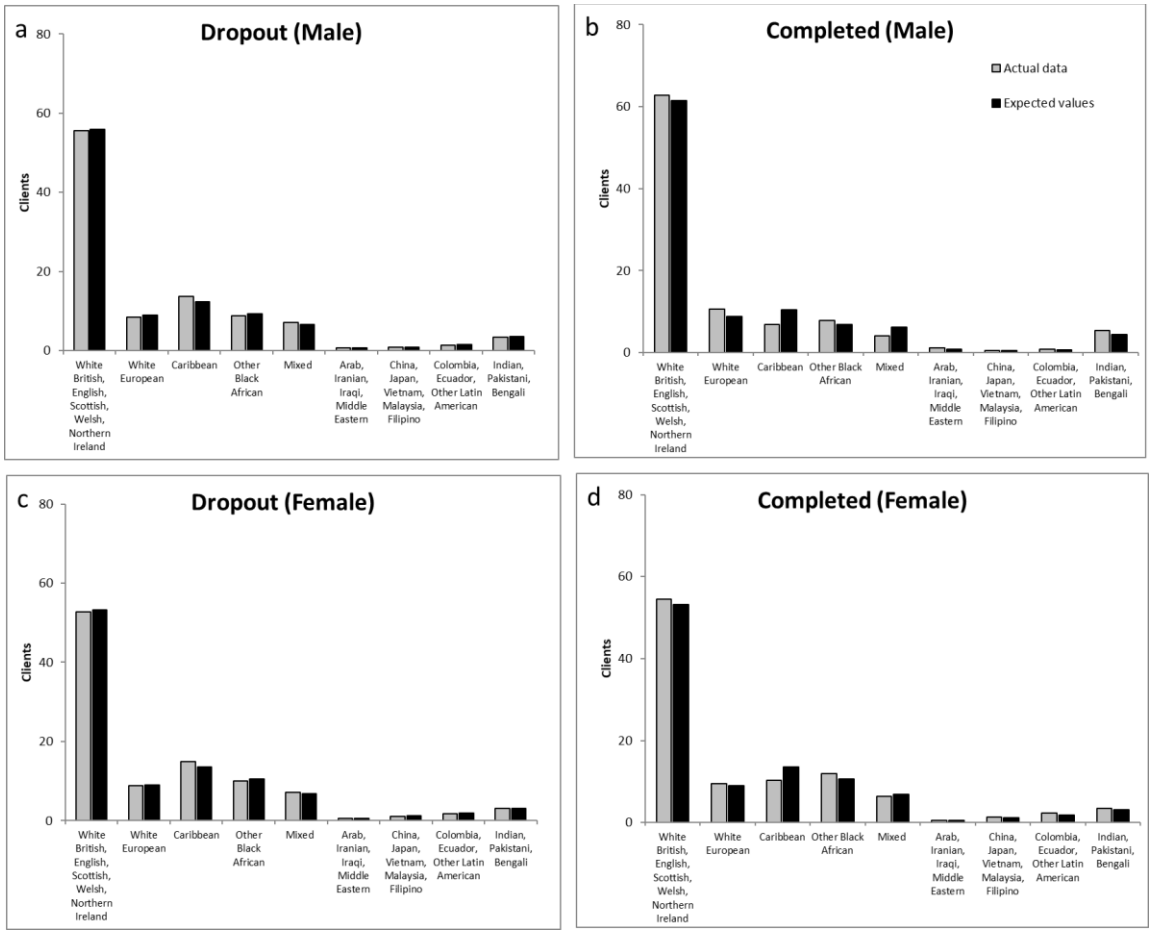


***Figure 3 (a, b, c & d)**. Overall rates of clients dropping out of therapy vs. expected rates of dropouts as well as rates of clients completing therapy vs. expected rates of completing based on Ethnicity and Gender.*

A corrected value for α based on three comparisons for Age provided an adjusted value ($\alpha_{adj}$ = p<0.017) for all remaining post-hoc tests, resulting in a two-tailed critical value of $_Z$ = 2.39. Further analysis in light of this adjusted value revealed a significant difference between dropout vs completion for those in the 18 to 39 (67% dropout vs.

60.6% complete; $_Z$ = 4.09, p<.001), and 70 plus (0.7% dropout vs. 5.2% complete; $_Z$ = -9.8, p<.001) age ranges but not the 40-69 (32.2% dropout vs. 34.2% complete; $_Z$ = -1.26, p>.05) range. Results revealed that people in younger age ranges were more likely to drop out of therapy while those in more advanced age ranges were more likely to complete therapy than dropout. All remaining pairwise comparisons were not significant at the correct value for α.

Given significant results revealing that men were more likely to drop out of therapy when assessing gender and that people from certain age ranges were more likely to complete therapy when assessing Age, a further chi-square analysis combining gender and age was conducted (See Figure 4). There was a significant difference in expected levels of people dropping out dependent on Gender x Age ($\chi 2$ (5) = 13.360, p < .001). Post-hoc analysis with a corrected value for α based on sixteen comparisons for Gender x Age revealed an adjusted value ($\alpha_{adj}$ = p<0.009), resulting in a two-tailed critical value of $_Z$ = 2.62. Based on a number of pairwise comparisons, a significant difference between dropout vs. completion for men in the 40-69 (25.8% dropout vs. 21.9% complete; $_Z$ =3.04, p = .002) were identified. These results revealed that men in 40-69 age group were more likely to drop out of therapy than would be expected. All remaining pairwise comparisons were not significant at the correct value for α (see Figure 4).

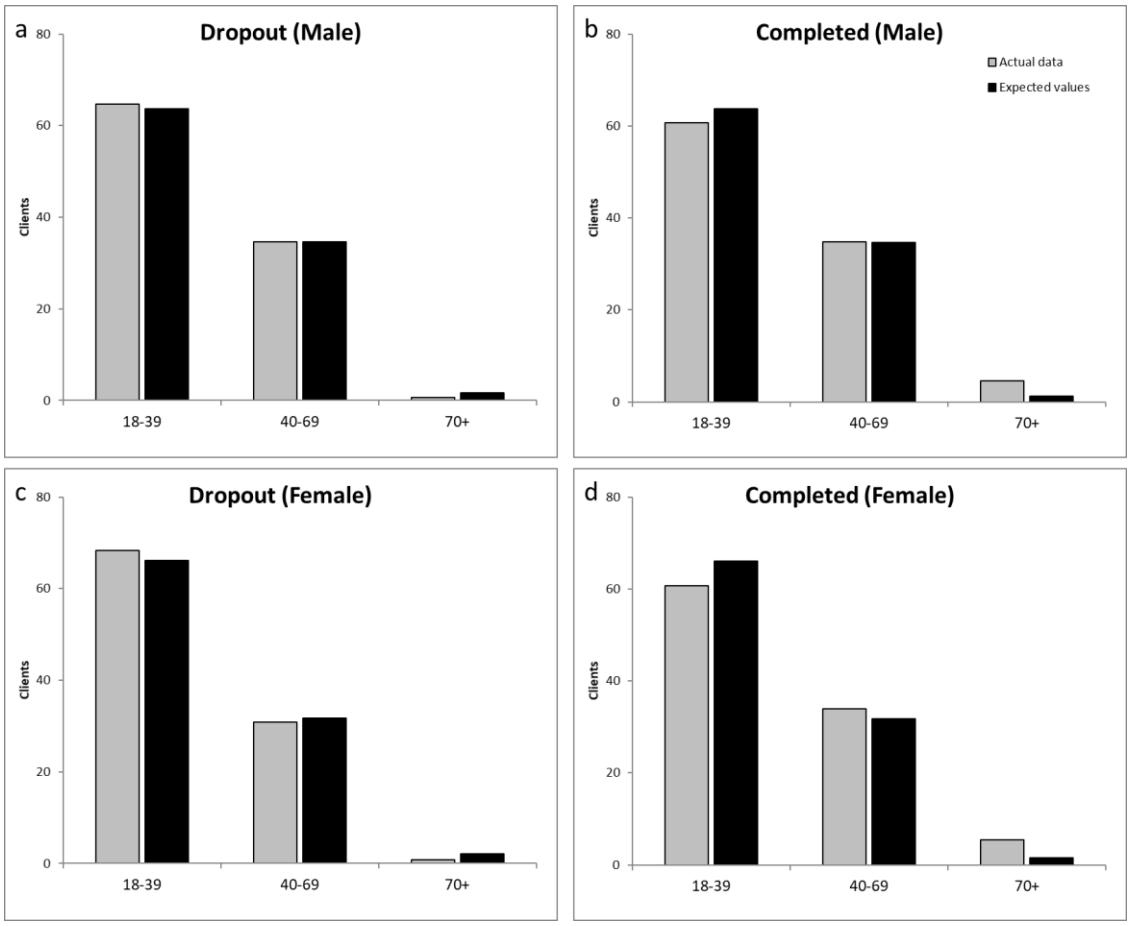


***Figure 4 (a, b, c & d)****. Overall rates of clients dropping out of therapy vs. expected rates of dropouts as well as rates of clients completing therapy vs. expected rates of completing based on Age and Gender.*

Post-hoc analysis with a corrected value for α based on two comparisons for Treatment Stage revealed an adjusted value ($\alpha_{adj}$ = p = 0.017), resulting in a two-tailed critical value of $_Z$ = 2.39. Based on the three pairwise comparisons, a significant difference between dropout vs. completion for pretreatment (63.7% dropout vs. 68.8% complete; $_Z$ =-3.30, p = .001), Step 2 (17.9% dropout vs. 8.7% complete; $_Z$ =7.84, p < .001) and Step 3 (18.4% dropout vs. 22.5% complete; $_Z$ =-3.17, p = .002) were identified. Results demonstrate that those accessing Step 2 were significantly more likely to drop out than expected. However, those in pretreatment and Step 3 were significantly more likely to complete therapy than expected.

Given significant results revealing differences in dropout vs. completion in Treatment Stage and Gender, a further chi-square analysis combining Treatment Stage and Gender was conducted (see Figure 5). There was a significant difference in expected levels of dropout vs. completion dependent on Treatment Stage x Gender ($\chi 2$ (5) = 72.826, $p < .001$). Post-hoc analysis with a corrected value for $\alpha$ based on six comparisons for Treatment Stage x Gender revealed an adjusted value ($\alpha_{adj} = p<0.009$), resulting in a two-tailed critical value of $_Z = 2.62$. Pairwise comparisons of dropout vs. completion for men in Pretreatment (24% dropout vs. 23.1% complete; $_Z = 0.62$, $p = .535$) was not significant. However, women accessing Pretreatment (39.7% dropout vs. 45.7% complete; $_Z = -3.74$, $p < .001$) were significantly more likely to complete therapy than would be expected. Based on a number of pairwise comparisons, a significant difference between dropout vs. completion for men in the Step 2 (6.9% dropout vs. 3.3% complete; $_Z =4.64$, $p < .001$) and women in Step 2 (11.1% dropout vs. 5.4% complete; $_Z = 5.93$, $p < .001$) were identified. Results indicate that both men and women are significantly more likely to dropout of therapy in Step 2 therapy then would be expected. Pairwise comparisons of dropout vs. completion for men in Step 3 therapy (6.2% dropout vs. 6.2% complete; $_Z = 0.1$, $p = .938$) was not significant. However, women accessing Step 3 care (12.2% dropout vs. 16.3% complete; $_Z = -3.75$, $p < .001$) were significantly more likely to complete therapy than would be expected.

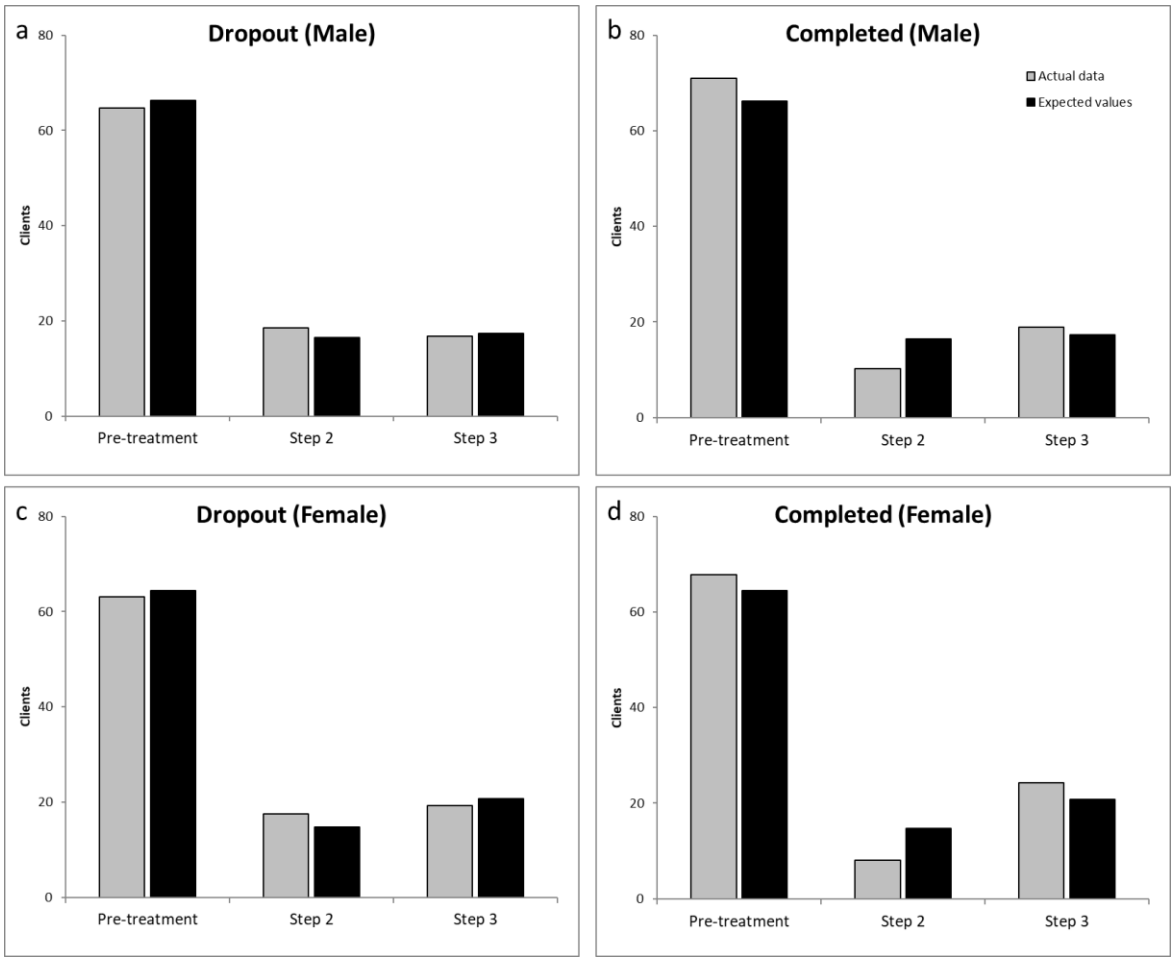


***Figure 5 (a, b, c & d)****. Overall rates of clients dropping out of therapy vs. expected rates of dropouts as well as rates of clients completing therapy vs. expected rates of completing based on Age and Gender.*

There was also a significant difference ($\chi 2$ (8) = 17.718, p = .023) in expected levels of people dropping out dependent on Diagnosis. However, no pairwise comparisons were significant after Alpha correction ($\alpha_{adj}$ = p<0.0057). Similarly, an analysis of Marital Status ($\chi 2$ (7) = 16.911, p = .018) also revealed no significant pairwise comparisons after alpha correction ($\alpha_{adj}$ = p<0.0064).

# Discussion

## Summary of findings

Identifying commonalities between clients who fail to complete IAPT treatment could help to better support those who present themselves to services. Results indicate that male clients attending Southwark IAPT, between 2011 and 2016 dropped-out of therapy at a larger rate than what would be statistically expected. Conversely, fewer women dropped out of therapy than would be expected. We also found that clients from the Caribbean were more likely to dropout of therapy than would be expected, specifically male's. Analysis of age categories indicated increased risk of dropout for younger clients while older adults were more likely to complete therapy. Analysis of dropouts based on where clients were in the care pathway demonstrated that client in pre-treatment and Step 3 care were more likely to complete those stages. However clients in Step 2 care were more likely to dropout. When assessed with gender, results demonstrated that women were significantly more likely to complete treatment in pre-treatment while men did not show an effect. Both men and women were more likely to drop out of care in Step 2. Women were more likely to complete therapy in Step 3 while men did not show an effect.

## General discussion

A general finding from our study is that men are more likely to dropout from therapy than what would be expected. This is generally consistent with research looking at the effect of gender on therapy engagement (Baekeland & Lundwall, 1975; Thormählen et al., 2003; Wierzbicki & Pekarik, 1993; Young, Grusky, Jordan, & Belin, 2000). Studies have argued that men tend to find it harder to engage in and maintain psychotherapy due to various reasons such as shame and self-esteem (Gum et al., 2006; Maramba & Hall, 2002; Nysaeter, Nordahl, & Havik, 2010). Others have discovered that men tend to prefer medication over therapy and therefore disengage or do not continue due to differences in expectations (Gum et al., 2006). However, other studies assessing the

effect of gender on dropout in IAPT have not found it to be a significant predictor (Di Bona et al., 2014; Gersh et al., 2017; Rubin, Dolev, & Zilcha-Mano, 2016) and others have suggested that females are actually more likely to drop out of therapy (Linardon et al., 2018). There are several explanations for these inconsistencies. For example, a significant difference between our findings and those of Di Bona and colleagues (2014) are that we specifically included clients who had attended one session of therapy in IAPT where their sample involved those who did not attend their first appointments. This may indicate that male clients are specifically more vulnerable to disappointments from initial sessions of therapy than women. It is interesting to consider the effect attending therapy may be having on male clients and whether they are deterred by the immediate therapeutic relationship. If this is the case, particular emphasis should be placed on the early therapeutic relationship with male clients. Furthermore, an important differentiation between this study and Linardon and colleagues (2018) is that they assessed clients with depressive disorders while we included all disorders. In light of this, gender predictions may be disorder specific, although we did not find this to be the case in our study. Finally, those in Rubin and colleagues (2014) study were largely student based, indicating that the more diverse population in our sample may have contributed to our findings.

A finding of particular interest is the fact that our study revealed a significant predictive factor for those of Caribbean backgrounds but not others. To the best of our knowledge, this is the first study to specifically identify Caribbean clients as being particularly susceptible to dropout as opposed to others who have treated ethnicity as a collective sample (Olver et al., 2011)or those who have defined ethnicity as Caucasian vs. non-Caucasian (Swift & Greenberg, 2014). Our results are consistent with studies that have found that those from ethnic minority groups are at greater risk of dropout than non-minorities (Olver et al., 2011). Studies have argued that this increased risk is due to a perception amongst people from ethnic minority groups that they will be perceived as different and that their needs will not be met (Gonzalez et al., 2010; Sue & Zane, 1985). A specific area of focus could be culture as suggested by

Norcross and Wampold (2011) (Norcross & Wampold, 2011). Studies have suggested that culture could be a critical component for predicting dropout, with those from BME groups finding psychotherapies difficult to relate to (Gülüm et al., 2018). Others have reported that people from black and minority ethnic groups are less likely to speak to their GP's regarding mental health issues to begin with (Cooper et al., 2013). However, our study indicates that this may not be relevant to all ethnic minorities but specific to some, in this case those from Caribbean backgrounds. Again, our findings are inconsistent with some other studies that have failed to identify ethnicity as a predictor of dropout (Di Bona et al., 2014; Johns et al., 2019). Similar to that of gender, it remains possible that Di Bona and colleagues (2014) findings are reflective of the fact that their sample of client who dropped out did not attend a single session. Again, our findings may indicate that the initial appointment for clients from Caribbean backgrounds are particularly important. Furthermore, in light of Cooper and colleagues (2013) findings that people from black and minority ethnic groups are less likely to consult GP's before they receive care, it is possible that one explanation for increased dropouts in our sample may be due to Caribbean clients being less informed and prepared for what treatment entails before they engage. Improvements in psychoeducation before the initial appointment may be helpful to moderate this.

Further analysis of our data established that it was specifically male Caribbean clients who were at increased risk of dropout. This may offer some explanation for why some studies fail to identify ethnicity related associations with dropout (Jolley et al., 2015) given the degree of specificity that may be required from the client cohort. It is not surprising that male Caribbean clients are dropping out at a rate that is higher than what would be expected, given that male and Caribbean clients have been found to be at greater risk independently. However, it is difficult to explain why it is only male clients from the Caribbean who are demonstrating increased risk of dropout and not others from the BME sample. Further research is required to address this issue in more detail.

Another interesting finding is that client age groups predicted the risk for dropout in multiple ways. Our findings indicate that those in younger age groups seem to be at higher risk of dropout when engaging in therapy. However, those in older adulthood are more likely to complete therapy than what would be expected while those in the middle age group were dropping out and completing therapy at expected rates. This finding is inconsistent with previous findings regarding age not predicting dropout in general (Di Bona et al., 2014; Garfield, 1994). However, our findings are consistent with a wide range of studies that have reported that younger client's dropout more than older adults (Linardon et al., 2018), that samples with younger clients reported higher levels of dropout in therapy (Barrett et al., 2009; Swift & Greenberg, 2012) and those that have identified a general association between age and dropout (Werbart, Andersson, & Sandell, 2014). However, our findings regarding clients in more advanced age groups (70 and above) being more likely to complete therapy than what would be expected is perhaps more novel. The findings are remotely consistent with that of Werbart and colleagues (2014) who despite finding an overall effect age, noted that older participants were less likely to dropout in their study. Our findings go beyond this to indicate that older adults are more likely than others to complete therapy. This may have important implications for how IAPT services are presented to older adults. Studies have argued that currently, mental health services, including IAPT are not reaching older adults as well as younger adults (Anderson, Connelly, Meier, & Mccracken, 2013; Chaplin, Farquharson, Clapp, & Crawford, 2015). However, studies have also shown that older adults demonstrate better completion rates (Walker & Clarke, 2001) consistent with our findings. One explanation for why clients in older age brackets may be more likely to complete therapy is that they face additional barrios to accessing support in the first place (Wuthrich, Frei, Pachana, & Oude Voshaar, 2015). Given these additional difficulties, older adults may be more committed to engaging and completing therapy than others. Another explanation may be that people in higher age brackets are more likely to be retired and therefore find it easier to engage with IAPT working hours. A further explanation may be related to findings that older

adults are least likely age group to seek support from medical professionals (Mackenzie, Scott, Mather, & Sareen, 2008). Our sample may have avoided older adults who may fall into this category by not including those who are simply referred but do not engage in any appointments. Instead, our sample of clients only include clients who have engaged at least once. Respective of older adult populations, our sample of clients may primarily consist of those older adults who are engaged and committed to attending therapy and therefore do not represent those who are harder to reach.

Further analysis of age combined with gender revealed that, it was only men in the middle aged (40-69) range that were more likely to dropout of therapy, with all remaining comparisons not reaching significance. These results are surprising, given that our analysis of age alone did not reveal a significant finding in this particular age range when collapsed across gender. These findings seem to indicate that while younger (18-39 age range) and older (70 plus age range) clients do not differ in their proportion of males and females who are either dropping out or completing therapy, men in the 40-69 age range are at risk of increased levels of dropout, relative to women of the same age, despite there not being an overall effect. This is consistent with our overall finding for Gender.

Our findings demonstrate predictors for increased levels of dropout for clients in Step 2 care. Conversely, those in Pretreatment and Step 3 care showed a significantly increased level of therapy completion. This effect was further broken down for gender, revealing that at pretreatment, women were significantly more likely to complete this stage of therapy while men dropped out and completed as would be expected. Both men and women showed significantly more dropouts in Step 2 than would be expected. However, only women showed a significantly greater likelihood of completing Step 3 care, while men showed no predictive rates for either dropout or completion. The findings indicate that those entering Step 2 care are more likely to drop out of therapy than clients in different stages of the care pathway. Remotely

consistent with findings regarding gender, women are more likely to complete therapy in Step 3 care, although men did not show a significant increase in risk of dropout at this stage. Interestingly, those in pretreatment showed a significantly greater rate of completion than would be expected. This perhaps suggests that those in the pretreatment stage of the care pathway are not being deterred by waiting lists and delays to accessing direct support. This is either inconsistent with other studies indicating that long waiting lists and organizational disorder can contribute to high dropouts, or evidence of efficient organizational Stability at Southwark IAPT (Werbart and colleagues 2014). In this paper, Werbart and colleagues (2014), ultimately found that those who engaged in therapeutic intervention in services that rated low for organisational stability and had longer waiting lists were more likely to dropout. They also found that in clinics that rated low in stability, more senior therapists experienced higher dropout rates. This effect was weaker in more stable clinics (Werbart et al., 2014). Werbart and colleagues (2014) provide evidence to suggest that clients are conscious of deficiencies in services and that these are impinging on their ability to sustain therapy.

Our findings revealed a general effect of Diagnosis on dropout expectancy. Results indicate that people are more likely to dropout of therapy due to their diagnosis. However, none of the subsequent pairwise comparisons met the adjusted significance value. Our findings are inconstant with those of other studies that have found specific implications for dropout based on disorder. Fernandez and colleagues (2015) completed a meta-analysis of dropout rates for clients engaging with CBT. They determined that one predictor for dropout was diagnosis with depression precipitating high levels of disengagement (Fernandez et al., 2015). Similar conclusions have been presented by Hans and Hiller's (2013) meta-analysis which revealed that a significant proportion of those accessing CBT for depression fail to complete treatment (Hans & Hiller, 2013). However, our study failed to demonstrate any significant risk factors for those with depression or any other specific disorder. One obvious reason for our failure to replicate previous findings is that we applied what could be considered to be

a conservative correction for the number of factors analysed when assessing diagnosis. As mentioned above, our initial analysis of those who did and did not complete therapy when controlling for diagnosis revealed a significant difference. However, this difference was not strong enough to maintain significance after Sidak correction. It may be that this analysis would benefit from additional power in the sample size. This is evidenced by the fact that our analysis for diagnosis contained 1327 clients whereas other comparisons such as that for ethnicity contained 3902 clients. We therefore recommend a cautions interpretation of this null result, given that we applied a conservative correction, had a small sample size and given that other studies have consistently produced an effect for diagnosis (particularly with depression).

Finally, a similar interpretation is recommended for our findings regarding marital status. Again, this analysis was significant before alpha correction on pairwise comparison. Although the number of clients in this case was higher (N=2455), the alpha correction was still conservative, given the number of pairwise comparisons involved. Further investigation into the effect of marital status on drop-out rates may be helpful to elaborate on this.

Recommendations for further research

It is important to note that there were various factors that were not controlled for in this study for different reasons, such as certain demographic characteristics not being recorded on IAPTus, which may nevertheless have influenced its results. Socioeconomic status is one such factor that has been identified as a predictor for dropout rates in therapy (Baekeland & Lundwall, 1975; Barrett et al., 2009; Beckham, 1992; Reis & Brown, 1999; Swift & Greenberg, 2012; Wierzbicki & Pekarik, 1993). As no such variable categorisation was available on IAPTus, this factor was not included in our analysis. One can speculate that those from BME communities may largely comprise of people from lower socioeconomic backgrounds. This is supported by the 2011 census in the UK which reported that those from Asian and Black groups comprised of the largest proportion of people in the UK (17.5 and 6.2% respectively)

that had never worked or been in long-term employment (see https://www.ethnicity-facts-figures.service.gov.uk/british-population/demographics/socioeconomic-status/latest). However, if this were reflective in our study, one may expect to have found more significant differences between expected levels of those who did and did not dropout of therapy from clients of different ethnicities. Our findings indicate that only those of Caribbean decent and specifically males in that category were dropping out at a higher rate than should be expected. A detailed breakdown of clients from different socioeconomic backgrounds may provide further insights into its contribution towards dropout rates.

An interesting area for further development could be the influence of particular therapists or indeed the specific characteristics that clinicians bring to therapy that may influence engagement. One study has argued that a client's subjective preference in what they look for in a therapist, such as gender are predictive of dropouts (Swift, Callahan, Ivanovic, & Kominiak, 2013). Swift and colleagues found that clients engaging in therapy are likely to favour certain qualities in their therapist that influences their level of engagement. Their meta-regression identified that when clients had their specific preferences for therapy met, this both improved outcome and reduced dropout (Swift et al., 2013). They found this to be the case for all clients, regardless of age, gender or ethnicity. It is interesting to consider whether the increased prevalence for dropout amongst men, younger clients and those of Caribbean decent are at least partly due to their needs not being met with regards to their therapist's intervention technique. Other studies have directly suggested that those from ethnic minority groups do not access therapy at all due to an assumptions that their specific needs will not be met (Gonzalez et al., 2010; Smith & Mcdowall, 2011). A more detailed investigation of this effect may be helpful to identify whether this contributed to the prevalence of those from Caribbean backgrounds dropping out. Similarly, it may be interesting to consider whether this is also the case for men. Although Swift and colleagues (2013) argue that customising therapy in this way is beneficial to all clients, our findings may indicate that not doing so is disproportionately more harmful for

some than others. To date, Studies that have attempted to match clients with therapists that are from the same gender and ethnicity have provided mixed results (Hatchett & Park, 2003; Maramba & Hall, 2002; Nysaeter et al., 2010). More detailed research in this area may be helpful.

Others have also argued that spirituality and religion may be qualities that clients consider to be important (Worthington, Hook, Davis, & McDaniel, 2011). This may be missing from modern psychotherapies that employ more secular dialogues. To this end, religion may be an interesting factor to add to future research. In our sample, religion may have been a factor that influenced results and perhaps more significantly applied to clients from the Caribbean and men.

A further consideration is based on a review by Roos and Werbart (2013) who argue that therapist competency is a determining factor to predicting dropout. The authors propose that a therapist's level of experience, skill and ability to provide empathy were predictive of clients dropping out of therapy. They also argue that the therapeutic alliance is a reliable predictor of whether clients will complete treatment or not (Roos & Werbart, 2013). Although some have argued that this is not the case (Fernandez et al., 2015), there is a large body of work to support the case for therapists being directly responsible for influencing dropout rates. It is interesting to consider the degree to which men, younger clients and those from the Caribbean are implicated by this. Given that those from BME backgrounds may enter therapy with a preconceived assumption that therapists will not understand their needs, it could be expected that they would be particularly susceptible to ruptures in the therapeutic alliance. However, our study has only identified an increased likelihood for Caribbean people dropping out of therapy but not other BME clients. It is difficult to theorise why this would only apply to male Caribbean clients and not others, if this is indeed a factor in our sample. Perhaps more credible is the possibility that men in general find it difficult to tolerate and work through conflict with a therapist. It is also interesting to consider that our study indicates that client in general are more likely to complete Step 3 care than Step

2. Given that Step 3 care is a more intensive form of therapy with greater client/therapist contact, our findings seem to contradict those of Roos and Werbart (2013). Further research is required to address whether male clients are dropping out of therapy in part, due to a failure on the part of therapists to work effectively with them. Such an issue would demonstrate a profound systematic failure on the part of services to provide treatment suitable for male clients. More focused research is required to shed light on this possibility.

Study limitations

Several limitations to the study have been alluded to above but will be further explored in this section. As noted, there are limitations to IAPT data regarding the specific type of demographic data recorded. An important identifier not stored on IAPTus is socioeconomic status. Given that previous research has consistently identified that socioeconomic status is correlated to higher dropout rates, it could have been interesting to confirm that in this study. Given the range of residents from different socioeconomic groups and ethnicities in Southwark (Southwark Demographic Fact Sheet, 2015, https://www.npi.org.uk/files/6614/7316/1332/Demography_and_deprivation_in_Southwark_and_Tower_Hamlets.pdf), one can speculate that financial limitations may have contributed to some clients dropping out of therapy. Further research should focus on socioeconomic status and dropout in Southwark IAPT to further explore this possibility.

Of the factors investigated, one area of particular interest was whether specific diagnosis contributes towards higher dropout rates. As, discussed above, studies have indicated that those with depression do seem to experience higher dropout rates than those with other difficulties. However, this study was hindered by the low number of descriptive data recorded regarding diagnosis in the IAPTus data sample. Of the 4678 participants involved, it is surprising that only 1372 of these were matched with a specific disorder. This ultimately reduced the reliability of any analysis given the

smaller sample size, comparative to other analyses. Identifying a trend towards higher dropout rates amongst specific disorders could contribute towards developing new approaches to better meet the needs of clients or encourage adaptations to service delivery to make therapy more accessible. It is therefore recommended that more emphasis is placed on describing disorders or symptoms experienced by clients in order to better understand any correlations between those dropping out of therapy and their specific difficulties.

The study design may also have benefited from a further refinement of the analysis to further explore within group correlations. For example, we have identified that male clients and those from the Caribbean are more likely to drop out of therapy than others. However, we have not explored the proportion of Caribbean clients who are male or female to further explore contributing factors behind dropout. Similarly, we have not assessed the proportion of men and women dropping out of therapy based on diagnosis or marital status. Given that both of these factors revealed a significant difference between those who complete therapy and those who dropout, further refinement of the data into male/female groups may have produced an effect.

Service recommendations based on findings

The results of this study indicate that male clients from the Caribbean and men in general are more likely to drop out of therapy than complete a course of therapy. We have also noted that younger clients are more likely to dropout whereas older adults are more likely to complete their therapy. Further analysis also revealed that clients are most likely to drop out of therapy when they are in the Step 2 care pathway. We have explored the implications for these findings above and addressed some recommendations for future research. In order to collect more detailed and specific information, it is recommended that feedback is obtained from clients that meet these demographic specifications. It is recommended that clients are be encouraged to complete feedback forms before therapy, stating what they are hoping to achieve and what specific type of service they expect to receive in IAPT. It is will also be important

for clients to compete feedback forms when disengaging from therapy to address why they are dropping out and why. A further recommendation is to complete focus groups for both men and those from the Caribbean. This should include both client who have and have not completed therapy to address why some have dropped out but also what encouraged others to complete treatment.

It may also be of interest to assess short and long term effects of treatment for clients, particularly those who did complete treatment to assess whether they received any measurable benefits and how long this may have been sustained. This may prove to be a helpful way of identifying whether those who are completing therapy are reporting any benefits or not. These details may be helpful for Southwark IAPT to address whether current provisions are suitably supporting male and Caribbean clients and if not, what changes may be helpful in better meeting their needs.

Dissemination of result

The results of this service evaluation will be reported to the Southwark and Lambeth IAPT service lead for their comments. The findings are due to be presented to staff at a weekly team meeting at Southwark IAPT. This presentation will involve discussion of the findings and further reflections regarding its implications for the service.

Leadership

This project has involved several leadership competencies in order to formulate and complete the service evaluation. The project offered opportunities to discuss potential projects and formulate questions based on service needs with supervisors, including the head of service.

Completion of the study involved independent learning of the IAPTus database and statistical analysis. It has also required frequent dissemination and discussion with supervisors to develop the wider investigation of dropout demographics and specific forms of analysis used.

As mentioned above, the result of the service evaluation will be presented to staff at a weekly team meeting. This will involve arranging a presentation and facilitating discussion and reflection to encourage a dialogue that can promote understanding and a need for change to better meet the needs of clients.

## Conclusion

In light of high costs associated with clients failing to complete therapy, we investigated the possible dimorphic indicators for those who may be at greater risk of dropping out of therapy. We assessed rates of dropout based on clients Age, Gender, Ethnicity, National Identity, Disability Status, Long Term Condition Status, Marital Status, Sexuality, Referral type , Problem Descriptor/diagnosis, Outcome Measure Scores and Treatment Stage. Results indicate that those male clients from Caribbean backgrounds, younger clients and men in general are dropping out of therapy at higher than expected rates.

Further investigation is required to explore whey clients from these demographics are not completing therapy at a rate that should be expected. These findings suggest that adaptations may be required to better support clients from these demographic groups to complete therapy.

## References


Anderson, D., Connelly, P., Meier, R., & Mccracken, C. (2013). Mental health service discrimination against older people. *The Psychiatrist*, *37*, 98–103. https://doi.org/10.1192/pb.bp.112.040097

Baekeland, F., & Lundwall, L. (1975). Dropping out of treatment: A critical review. *Psychological Bulletin*, *82*(5), 738–783. https://doi.org/10.1037/h0077132

Barrett, M. S., Crits-christoph, P., Gibbons, M. B., & Thompson, D. O. N. (2009). Early Withdrawel From Mental Health Treatment: Implications For Psychotherapy Practice. *Psychotherapy*, *45*(2), 247–267.

Beasley, T. M., & Schumacher, R. E. (1995). Multiple regression approach to analyzing contingency tables: Post hoc and planned comparison procedures. *Journal of Experimental Education*, *64*(1), 79–93. https://doi.org/10.1080/00220973.1995.9943797

Beckham, E. E. (1992). Predicting patient dropout in psychotherapy. *Psychotherapy: Theory, Research, Practice, Training*, *29*, 177–182.

Byng, R., Newbold, L., Qureshi, A., Weyer Brown, C., Bannon, J., & Pooler, J. (2011). The South West Improving Access to Psychological Therapies (IAPT) Evaluation Study. *Plymoth: PCMD*.

Cairns, M. (2014). Patients who come back: Clinical characteristics and service outcome for patients re-referred to an IAPT service. *Counselling and Psychotherapy Research*, *14*(1), 48–55. https://doi.org/10.1080/14733145.2013.770895

Chan, S. W. Y., & Adams, M. (2014). Service Use, Drop-Out Rate and Clinical Outcomes: A Comparison Between High and Low Intensity Treatments in an IAPT Service. *Behavioural and Cognitive Psychotherapy*, *42*(6), 747–759. https://doi.org/10.1017/S1352465813000544

Chaplin, R., Farquharson, L., Clapp, M., & Crawford, M. (2015). Comparison of access, outcomes and experiences of older adults and working age adults in psychological therapy. *International Journal of Geriatric Psychiatry*, *30*(2), 178–184. https://doi.org/10.1002/gps.4122

Cooper, C., Spiers, N., Livingston, G., Jenkins, R., Meltzer, H., Brugha, T., … Bebbington, P. (2013). Ethnic inequalities in the use of health services for common mental disorders in England. *Social Psychiatry and Psychiatric Epidemiology*, *48*(5), 685–692. https://doi.org/10.1007/s00127-012-0565-y

de Haan, A. M., Boon, A. E., de Jong, J. T. V. M., & Vermeiren, R. R. J. M. (2018). A review of mental health treatment dropout by ethnic minority youth. *Transcultural Psychiatry*, *55*(1), 3–30. https://doi.org/10.1177/1363461517731702

Di Bona, L., Saxon, D., Barkham, M., Dent-Brown, K., & Parry, G. (2014). Predictors of patient non-attendance at Improving Access to Psychological Therapy services demonstration sites. *Journal of Affective Disorders*, *169*, 157–164. https://doi.org/10.1016/j.jad.2014.08.005

Fernandez, E., Salem, D., Swift, J. K., Ramtahal, N., Fernandez E, Salem D, … Ramtahal N. (2015). Meta-analysis of dropout from cognitive behavioral therapy. *Journal of Consulting and Clinical Psychology*, *83*(6), 1108–1122. https://doi.org/http://dx.doi.org/10.1037/ccp0000044

Garfield, L. (1994). *Research on Client Variables in Psychotherapy*.

Gersh, E., Hallford, D. J., Rice, S. M., Kazantzis, N., Gersh, H., Gersh, B., & McCarty, C. A. (2017). Systematic review and meta-analysis of dropout rates in individual psychotherapy for generalized anxiety disorder. *Journal of Anxiety Disorders*, *52*(October), 25–33. https://doi.org/10.1016/j.janxdis.2017.10.001

Glover, G., Webb, M., & Evison, F. (2010). Improving access to psychological therapies: A review of the progress made by sites in the first roll-out year. *North East Public Health Observatory*.

Gonzalez, H., Vega, C., Williams, D., Tarraf, W., West, B., & Neighbors, H. (2010). Depression care in the United States: Too little for too few. *Archives of General Psychiatry*, *67*(1), 37–46.

Gülüm, V., Soygüt, G., & Safran, J. D. (2018). A comparison of pre-dropout and temporary rupture sessions in psychotherapy. *Psychotherapy Research*, *28*(5), 685–707. https://doi.org/10.1080/10503307.2016.1246765

Gum, A. M., Area, P. A., Hunkeler, E., Tang, L., Katon, W., Hitchcock, P., … Dickens, J. (2006). Depression Treatment Preferences in Older Primary Care Patients. *The Gerontologist*, *46*(1), 14–22.

Haberman, S. (1973). The Analysis of Residuals in Cross-Classified Tables. *Biometrics*, *29*(1), 205–220.

Haberman, S. (1978). *Analysis of qualitative data. Volume 1: Introductory topics*.

Hans, E., & Hiller, W. (2013). Effectiveness of and dropout from outpatient cognitive behavioral therapy for adult unipolar depression: A meta-analysis of nonrandomized effectiveness studies. *Journal of Consulting and Clinical Psychology*, *81*(1), 75–88. https://doi.org/10.1037/a0031080

Hatchett, G. T., & Park, H. L. (2003). Comparison of Four Operational Definitions of Premature Termination. *Psychotherapy: Theory, Research, Practice, Training*, *40*(3).

Hepgul, N., King, S., Amarasinghe, M., Breen, G., Grant, N., Grey, N., … Cleare, A. J. (2016). Clinical characteristics of patients assessed within an Improving Access to Psychological Therapies (IAPT) service: Results from a naturalistic cohort study (Predicting Outcome Following Psychological Therapy; PROMPT). *BMC Psychiatry*, *16*(1), 1–10. https://doi.org/10.1186/s12888-016-0736-6

Johns, L., Jolley, S., Garety, P., Khondoker, M., Fornells-Ambrojo, M., Onwumere, J., … Byrne, M. (2019). Improving Access to psychological therapies for people with severe mental illness (IAPT-SMI): Lessons from the South London and Maudsley psychosis demonstration site. *Behaviour Research and Therapy*, *116*(September 2018), 104–110. https://doi.org/10.1016/j.brat.2019.03.002

Jolley, S., Garety, P., Peters, E., Fornells-Ambrojo, M., Onwumere, J., Harris, V., … Johns, L. (2015). Opportunities and challenges in Improving Access to Psychological Therapies for people with Severe Mental Illness (IAPT-SMI): Evaluating the first operational year of the South London and Maudsley (SLaM) demonstration site for psychosis. *Behaviour Research and Therapy*, *64*, 24–30. https://doi.org/10.1016/j.brat.2014.11.006

Linardon, J., Fitzsimmons-Craft, E. E., Brennan, L., Barillaro, M., & Wilfley, D. E. (2018). Dropout from interpersonal psychotherapy for mental health disorders: A systematic review and meta-analysis. *Psychotherapy Research*, *0*(0), 1–12. https://doi.org/10.1080/10503307.2018.1497215

MacDonald, P. L., & Gardner, R. C. (2000). Type 1 error rate comparisons of post hoc procedures for. *Educational and Psychological Measuremen*, *60*(5), 735–754.

Mackenzie, C., Scott, T., Mather, A., & Sareen, J. (2008). Older Adults' Help-Seeking Attitudes and Treatment Beliefs Concerning Mental Health Problems. *The American Journal of Geriatric Psychiatry*, *16*(12).

Maramba, G., & Hall, G. C. N. (2002). Predictor of Dropout , Utilization , and Level. *Cultural Diversity and Ethnic Minority Report*, *8*(3), 290–297. https://doi.org/10.1037//1099-9809.8.3.290

Marshall, D., Quinn, C., Child, S., Shenton, D., Pooler, J., Forber, S., & Byng, R. (2016). What IAPT services can learn from those who do not attend. *Journal of Mental Health*, *25*(5), 410–415. https://doi.org/10.3109/09638237.2015.1101057

Melenhorst, A., Rogers, W. A., & Bouwhuis, D. G. (2006). Older Adults ' Motivated Choice for Technological Innovation : Evidence for Older Adults ' Motivated Choice for Technological Innovation : Evidence for Benefit-Driven Selectivity. *Psychology and Aging*, (July 2014). https://doi.org/10.1037/0882-7974.21.1.190

Murphy, E., Mansell, W., Craven, S., Menary, J., & McEvoy, P. (2013). Pilot Study of an Investigation of Psychological Factors Associated with First Appointment Nonattendance in a Low-Intensity Service. *Behavioural and Cognitive Psychotherapy*, *41*(4), 458–469. https://doi.org/10.1017/S1352465812000811

Norcross, J. C., & Wampold, B. E. (2011). What Works for Whom : Tailoring Psychotherapy to the Person. *Journal of Clinical Psychology*, *67*(February 2018). https://doi.org/10.1002/jclp.20764

Nysaeter, T. E., Nordahl, H. M., & Havik, O. E. (2010). A preliminary study of the naturalistic course of non-manualized psychotherapy for outpatients with borderline personality disorder: Patient characteristics, attrition and outcome. *Nordic Journal of Psychiatry*, *64*(2).

Olver, M. E., Stockdale, K., & Wormith, J. S. (2011). A meta-analysis of predictors of offender treatment attrition and its relationship to recidivism. *Journal of Consulting and Clinical Psychology*, *79*(1), 6–21. https://doi.org/10.1037/a0022200

Radhakrishnan, M., Hammond, G., Jones, P. B., Watson, A., McMillan-Shields, F., & Lafortune, L. (2013). Cost of Improving Access to Psychological Therapies (IAPT) programme: An analysis of cost of session, treatment and recovery in selected Primary Care Trusts in the

East of England region. *Behaviour Research and Therapy*, *51*(1), 37–45. https://doi.org/10.1016/j.brat.2012.10.001

Reis, B. F., & Brown, L. G. (1999). Reducing psychotherapy dropouts: Maximizing perspective convergence in the psychotherapy dyad. *Psychotherapy: Theory, Research, Practice, Training*, *36*.

Richards, D. A., & Borglin, G. (2011). Implementation of psychological therapies for anxiety and depression in routine practice: Two year prospective cohort study. *Journal of Affective Disorders*, *133*(1–2), 51–60. https://doi.org/10.1016/j.jad.2011.03.024

Roos, J., & Werbart, A. (2013). Therapist and relationship factors influencing dropout from individual psychotherapy: A literature review. *Psychotherapy Research*, *23*(4), 394–418. https://doi.org/10.1080/10503307.2013.775528

Rubin, A., Dolev, T., & Zilcha-Mano, S. (2016). Patient demographics and psychological functioning as predictors of unilateral termination of psychodynamic therapy. *Psychotherapy Research*, *28*(5), 672–684. https://doi.org/10.1080/10503307.2016.1241910

Sidak, Z. (1967). Rectangular Confidence Regions for the Means of Multivariate Normal Distributions. *Journal of the American Statistical Association*, *1459*(September). https://doi.org/10.1080/01621459.1967.10482935

Smith, J. G., & Mcdowall, J. (2011). dissociating sequence learning performance in Parkinson ' s disease : Visuomotor sequence acquisition and pattern judgment on a serial reaction time task. *Acta Neurobiol Ogiae Experimentails*, 359–380.

Sue, S., & Zane, N. (1985). The Role of Culture and Cultural Techniques in Psychotherapy A Critique and Reformulation. *American Psychologist*, (1982), 37–45.

Swift, J. K., Callahan, J. L., Ivanovic, M., & Kominiak, N. (2013). Further examination of the psychotherapy preference effect: A meta-regression analysis. *Journal of Psychotherapy Integration*, *23*(2), 134–145. https://doi.org/10.1037/a0031423

Swift, J. K., & Greenberg, R. P. (2012). Premature discontinuation in adult psychotherapy: A meta-analysis. *Journal of Consulting and Clinical Psychology*, *80*(4), 547–559. https://doi.org/10.1037/a0028226

Swift, J. K., & Greenberg, R. P. (2014). A Treatment by disorder meta-analysis of dropout from Psychotherapy. *Journal of Psychotherapy Integration*, *24*(3), 193–207. https://doi.org/10.1037/a0037512

Thormählen, B., Weinryb, R. M., Norén, K., Vinnars, B., Bågedahl-strindlund, M., Thormählen, B., … Vinnars, B. (2003). Patient factors predicting dropout from supportive-expressive psyhotherapy Patient Factors Predicting Dropout from Supportive-Expressive Psychotherapy for Patients with Personality Disorders. *Psychtherapy Research*, (December). https://doi.org/10.1093/ptr/kpg039

Walker, D. A., & Clarke, M. (2001). Cognitive behavioural psychotherapy : a comparison between younger and older adults in two inner city mental health teams. *Aging and Mental Health*, *7863*. https://doi.org/10.1080/13607860120038311

Werbart, A., Andersson, H., & Sandell, R. (2014). Dropout revisited: Patient- and therapist-initiated discontinuation of psychotherapy as a function of organizational instability. *Psychotherapy Research*, *24*(6), 724–737. https://doi.org/10.1080/10503307.2014.883087

Wierzbicki, M., & Pekarik, G. (1993). A meta-analysis of psychotherapy dropout. *Professional Psychology, Research and Practice*, *24*(2), 190–195.

Worthington, E. L., Hook, J. N., Davis, D. E., & McDaniel, M. A. (2011). Religion and Spirituality. *Journal of Clinical Psychology*, *67*(2), 104–214.

Wuthrich, V. M., Frei, J., Pachana, N. A., & Oude Voshaar, R. C. (2015). Barriers to treatment for older adults seeking psychological therapy. *International Psychogeriatrics*, *27*(7), 1227–1236. https://doi.org/10.1017/S1041610215000241

Young, A., Grusky, O., Jordan, D., & Belin, T. (2000). Routine Outcome Monitoring in a Public Mental Health System : The Impact of Patients Who Leave Care. *Psychiatric Services*, *51*(1).

Appendices

Appendix 1: Ethics Approval

South London and Maudsley NHS
NHS Foundation Trust

*APPENDIX 4: PROJECT PROPOSAL FORM (PPF) FOR CLINICAL AUDIT, SERVICE EVALUATION AND OTHER QUALITY IMPROVEMENT PROJECTS*

***SHOULD YOU REQUIRE ANY ASSISTANCE WITH COMPLETING THIS PROFORMA, PLEASE CONTACT YOUR LOCAL CLINICAL AUDIT PROJECT OFFICER OR, FOR TRUSTWIDE AUDITS, THE CLINICAL AUDIT & EFFECTIVENESS TEAM (DETAILS ARE AVAILABLE ON THE SLAM CLINICAL AUDIT & EFFECTIVENESS INTERNET SITE). FOR LOCAL TEAM-BASED OR CAG-WIDE PROJECTS PLEASE SEND YOUR COMPLETED PPF TO YOUR LOCAL AUDIT PROJECT MANAGER/OFFICER, FOR ETHICAL APPROVAL. FOR TRUSTWIDE PROJECTS PLEASE SEND YOUR COMPLETED PPF TO THE CORPORATE AUDIT DEPT. ALL RELEVANT CONTACT DETAILS ARE ON THE SLAM CLINICAL AUDIT & EFFECTIVENESS TEAM INTRANET SITE.***

| | |
|---|---|
| **1(a) Project lead details:** | |
| **Name: Mazda Beigi** | **Job title: Trainee Clinical Psychologist**<br>**Profession: Psychology** |
| **Work Address:** Talking Therapies Southwark<br>South London and Maudsley NHS Foundation Trust<br>Middle House \| Maudsley Hospital \| London \| SE5 8AZ | |
| **Telephone: N/A** | **E-mail: Mazda.beigi@slam.nhs.uk** |
| **Within CAG (please specify)** _____ Psychological Medicine_____<br>**Multiple-CAG (please specify)** _____<br>**Trustwide:** ☐ | |
| **1(b) Project Title: Predictors of drop-out rates in Southwark Talking Therapies** | |
| **Project start date: ASAP** | **Project end date: October 2018** |
| **1(c) Please tick ✓ one box: Is this project a:** | |

| **Clinical Audit** ☐<br>**(i.e. measures a standard)** | **Service Evaluation** ☒<br>**(e.g. patient survey)** | **Other Quality Improvement Project** ☐<br>**(please specify)**<br>_____ |
|---|---|---|

**2 (a) Overall project aim or purpose of the audit:**

Not all patients complete the therapy offered; and dropping out is associated with poorer outcomes.

The aim of this project is to see whether there are patient factors associated with a higher risk of dropping out of therapy. These indicators can help to better inform the service about what measures can be taken and changes made to better support these clients.

**2(b) Specific objectives. What are the audit standards or criteria?** The definition of a clinical audit is that it compares practice to agreed standards such as those defined in NICE guidelines and clinical policies, protocols and procedures. Please also state the source of your standards or criteria (for non-audit projects, clarify measures).

The criteria for this project is for patients to have accessed IAPT services and attended at least one appointment at Step 1, 2 or 3 intervention before dropping out. A drop-out is defined by a client leaving therapy before it was due to end – either at their request or disengagement. Demographic information for these clients will be compared to that of clients who completed therapy. I will look at clients who accessed IAPT between 2011 and 2016.

Demographic variables that will be used:

- Gender
- Sexuality
- Ethnicity/Nationality
- Disability
- Long term conditions
- Marital status
- Referral type (GP or self)
- Problem descriptor
- Outcome measure scores (PHQ-9 and GAD-7)

**2 (c) In which ways do you think the project will improve patient care / outcomes?**

The project is designed to reveal consistent indicators of risks to clients dropping out of therapy. If these risks are identified, proactive measures can be taken and changes made to service delivery to ensure that these clients are better catered to and help to increase the likelihood of their completing therapy. These changes may also improve the public image of Talking Therapies Southwark by providing a more client friendly service.

**3(a) Who will be on the audit steering group?**

Mazda Beigi

**3(b) What consideration has been given to the involvement of patients, carers or the public?**

☐ Full user involvement at all stages of the audit

☐ Partial user involvement (please state which stages) _____

☒ No user involvement (please state why not) ____Due to time constraints, service user involvement will not be possible at this stage but results of the initial audit may inform follow-up investigations involving clients. Furthermore, consideration should be given to the fact that those who have dropped out of therapy may not want to be contacted again by the service._____

**3(c) Are you planning to collect data on any of the following equalities protected characteristics? (please tick all that apply)**

Age ☒ Disability ☒ Ethnicity ☒ Gender re-assignment ☐

Pregnancy and maternity ☐ Religion or Belief ☒ Sex ☒ Sexual orientation ☒

***I will not be collecting any new data. I will be using data already uploaded onto IAPTus.***

**3(d) Will you analyse your results or service outcomes to see if there is variation between equalities protected characteristics?**

Yes ☒ No ☐

Comments: _____It is important to know whether people are disproportionately dropping out of therapy due to disability, ethnicity, gender, religion and sexual orientation._____

**4. Information Governance Requirements:** When planning an audit, each project should be evaluated with regard to whether **Personal Identifiable Information (PII)** needs to be used. Unless there is genuine justification, all PII should be taken out to effectively anonymise the data for audit and research purposes. If you are unsure or need guidance and advice, please contact: dataprotectionoffice@slam.nhs.uk **Personal identifiable information (PII)** is any piece of information which can potentially be used to uniquely identify, contact, or locate an individual including name, address, full post code, date of birth, gender, ethnicity, NHS number, photographs, videos, audio-tapes etc.

<table>
<tr><td rowspan="3">4(a) Will the data be fully anonymised?</td><td>☐ Yes X</td><td>☐ No (patient identifiers) ☐ No (staff identifiers)</td></tr>
<tr><td rowspan="2">If yes, how:<br><br>__Data will be taken from IAPTus and ID numbers will be given to replace names.__<br><br>_____<br><br>_____</td><td>If no, why not: _____<br><br>If no, which personal identifiers will be used:<br>_____</td></tr>
<tr><td>If no, have you made arrangements to gain consent from data subjects?<br>☐ Yes ☐ No</td></tr>
<tr><td>4(b) Where will the data be recorded?</td><td colspan="2">☐ Manual forms ☐ Electronic forms<br>☐ Electronic spreadsheet X ☐ Electronic database X<br>☐ Other (please specify)</td></tr>
<tr><td>4(c) Security arrangements</td><td colspan="2">☐ Locked cabinet X ☐ On shared folder on SLaM network X<br>☐ Locked office X ☐ On secure network outside SLaM<br>☐ Other (please specify) ☐ Files Password protected X<br>_____ ☐ Login required</td></tr>
<tr><td rowspan="2">4(d) Will the data be transferred outside SLaM</td><td colspan="2">☐ Yes, in an anonymised format ☐ Yes, outside the EU<br>☐ Yes, with identifiers ☐ No X<br>You must contact dataprotectionoffice@slam.nhs.uk to register any transfer of personal identifiable information in advance.</td></tr>
<tr><td>If yes, how?<br>☐ Physically in person<br>☐ Physically using a secure courier</td><td>☐ Electronically using NHS.net e-mail (NHSmail)</td></tr>
</table>

| | | |
|---|---|---|
| | ☐ Physically using registered mail services | ☐ Electronically using file encryption and other email<br>☐ Electronically using encrypted portable media<br>☐ Other (please specify) |

| | | |
|---|---|---|
| **4(e) Information Asset Owner:** (Individual responsible for the data) | Name: Mazda Beigi | CAG: Psychological Medicine |
| | Job title: Trainee Clinical Psychologist | Organisation: Talking Therapies Southwark |

**5) Data Collection (please answer ALL of the following questions)**

| | |
|---|---|
| **5(a) Where from?** e.g. clinical records/ePJS, INSIGHT/CRIS, other service records, direct from patients or clinicians, observations of practice, DATIX. | **IAPTUS records only** |
| **5(b) How?** The data source will obviously influence the method used to collect data. e.g. survey, interview, focus groups, data collection proforma. Please include any other significant aspects of your methodology. | **Summary IAPTUS records only** |
| **5(c) How much?** As a rough guide, a sample should include 20-50 cases. | **Approx 3000 cases** |
| **5(d) Pilot Audit? Y/N (recommended)** | **N** |

**6(a) With whom and where will the final report be shared? e.g. which committees or service meetings**

Talking Therapies Southwark team meetings

Date will be written as part of my service evaluation project as part of my doctoral thesis

**6(b) Who will take responsibility for disseminating the results of the project and following through recommendations and actions? And how and when will the recommendations and actions be evaluated, monitored and reviewed?**

Mazda Beigi will responsible for disseminating the results of the project to the Talking

Therapies Southwark team. The person of note in this team is Grace Wong, the Clinical Lead of the Service. The project results will inform recommendations and actions as determined by Grace to ensure the effectiveness and accessibility of the service across a range of client groups.

| **All completed projects must be followed up with a completed action plan form, available on the SLaM Clinical Audit & Effectiveness Intranet site http://sites.intranet.slam.nhs.uk/cg/default.aspx (Audit Report Template Appendix B)** | |
|---|---|
| 7) Project Approval | |
| **7(a) Information Governance Approval:**<br>IG Audit approval given by:<br>Mustapha Haruna<br>Date Audit IG approved: 25/07/2018 | **7(b) Project Ethical approval given by:**<br>Clinical Audit Ethical approval given by:<br>Dr Faisil Sethi<br>Date of Committee Approval: 24/07/2018<br>☐ Quality Governance Committee<br>☐ Drugs and Therapeutics Committee<br>☐ CAG Clinical Governance/Audit Committee |