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# **Portfolio of Doctorate in Health Psychology**

## **Thesis title:**

**Exploring the Role of Culture on the Experience and  
Perception of Healthcare and Daily Life in Patients  
with Persistent Physical Symptoms**

**By Katie L. Watts**

**For the qualification of Professional  
Doctorate in Health Psychology**

**School of Health Sciences**

**City, University of London**

**September, 2017**

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and realise now more than ever how lucky I am to have you.

## **DECLARATION**

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## **EDITORIAL STYLE**

The contents of this doctorate programme will employ the editorial style of the American Psychological Association (APA) as detailed in the Publication Manual of the American Psychological Association (5th edition).

## **ABBREVIATIONS**

|         |                                                                                 |
|---------|---------------------------------------------------------------------------------|
| ACT:    | Acceptance and Commitment Therapy                                               |
| AIMS:   | Abnormal Involuntary Movement Scale                                             |
| BCI:    | Behaviour Change Intervention                                                   |
| BCT:    | Behaviour Change Technique                                                      |
| BMA:    | British Medical Association                                                     |
| BME:    | Black Minority Ethnic                                                           |
| BPS:    | British Psychological Society                                                   |
| CAR:    | Cortisol Awakening Response                                                     |
| CBT:    | Cognitive Behaviour Therapy                                                     |
| CCG:    | Clinical Commissioning Group                                                    |
| CFS:    | Chronic Fatigue Syndrome                                                        |
| COM-B:  | Communication Opportunity Motivation – Behaviour (Model)                        |
| COPE:   | Coping Orientation to Problems Experienced (scale)                              |
| DAS:    | Dysfunctional Attitudes Scale                                                   |
| DHP:    | Division of Health Psychology                                                   |
| DPSYCH: | Doctor of Psychology                                                            |
| DSM:    | Diagnostic Statistical Manual                                                   |
| EHPS:   | European Health Psychology Society                                              |
| FIQ:    | Fibromyalgia Impact Questionnaire                                               |
| FODMAP: | Fermentable Oligosaccharides, Disaccharides, Monosaccharides and Polyols (diet) |
| GAF:    | Global Assessment of Functioning                                                |
| GP:     | General Practitioner                                                            |
| HCV:    | Hepatitis C Virus                                                               |
| HIV:    | Human Immunodeficiency Virus                                                    |
| HPA:    | Hypothalamic Pituitary Adrenal                                                  |
| HRSD:   | Hamilton Rating Scale for Depression                                            |

|         |                                                                           |
|---------|---------------------------------------------------------------------------|
| HWBs:   | Health and Well-being Boards                                              |
| IBS:    | Irritable Bowel Syndrome                                                  |
| ICF:    | International Classification of Functioning, Disability and Health        |
| ITT:    | Intention To Treat                                                        |
| MBCT:   | Mindfulness-Based Cognitive Therapy                                       |
| MBI:    | Mindfulness-Based Intervention                                            |
| MBSR:   | Mindfulness-Based Stress Response                                         |
| ME:     | Myalgic Encephalomyelitis                                                 |
| MSc:    | Master of Science                                                         |
| MU(P)S: | Medically Unexplained (Physical) Symptoms                                 |
| NHS:    | National Health Service                                                   |
| PESTLE: | Political, Economic, Sociological, Technological, Legal and Environmental |
| PHQ:    | Patient Health Questionnaire                                              |
| PIN:    | Personal Identification Number                                            |
| PPS:    | Persistent Physical Symptoms                                              |
| RADS:   | Reactive Airway Dysfunction Syndrome                                      |
| RE-AIM: | Reach, Effectiveness, Adoption, Implementation, Maintenance (Model)       |
| RCT:    | Randomised Controlled Trial                                               |
| SD:     | Standard Deviation                                                        |
| SLaM:   | South London and Maudsley                                                 |
| SMC:    | Standard Medical Care                                                     |
| SSD:    | Somatic Symptom Disorder                                                  |
| UKSBM:  | United Kingdom Society of Behavioural Medicine                            |
| WHO:    | World Health Organization                                                 |
| WSAS:   | Work and Social Adjustment Scale                                          |
| XMLV:   | Xenotropic Murine Leukaemia Virus                                         |

## **PRESENTATIONS AND PUBLICATIONS**

### **Conference presentations**

Watts, K., Turnbull, T., & Corcoran, P. (2017). A qualitative investigation into the experiences of genital herpes: Navigating the road back to psychosocial recovery. *Oral presentation at the Division of Health Psychology annual conference 2017, Cardiff.*

Watts, K., Turnbull, T., & Chalder, T. (2017). Exploring the role of culture on the experience and perception of healthcare and daily life in patients with Persistent Physical Symptoms. *Poster presentation at 5<sup>th</sup> Annual SHS Doctoral Research Conference 2017 at City, University of London.*

### **Further presentations**

Watts, K., Turnbull, T., & Chalder, T. (2017). Exploring the role of culture on the experience and perception of healthcare and daily life in patients with Persistent Physical Symptoms. *Oral presentation at the SHS PLD Seminar 2017 at City, University of London.*

Watts, K., Turnbull, T., & Chalder, T. (2017). Exploring the role of culture on the experience and perception of healthcare and daily life in patients with Persistent Physical Symptoms. *Oral presentation at the Persistent Physical Symptoms Service Launch Event in 2017 at the South London and Maudsley Hospital, London.*

### **In preparation for publishing**

Watts, K., & Chalder, T. (2017). Exploring the role of culture on the experience and perception of healthcare and daily life in patients with Persistent Physical Symptoms. *In preparation for the British Journal of Health Psychology.*

Watts, K., Turnbull, T., & Corcoran, P. (2017). A qualitative investigation into the experiences of genital herpes: Navigating the road back to psychosocial recovery. *In preparation for a journal specialising in sexual health.*

Watts, K. (2017). Event Review: To the DHP for giving me this opportunity: Diolch yn fawr iawn! *In preparation for Health Psychology Update.*

Watts, K., & Turnbull, T. (2017). The effectiveness of mindfulness-based cognitive therapy (MBCT) in treating PPS: A systematic review. *In preparation for the Mindfulness journal.*

# **SECTION 1: PREFACE**

# PREFACE

This portfolio documents both the academic and practical journey taken over the past two years as a Trainee Health Psychologist. More specifically, it demonstrates how I have been able to utilise my academic and practical skills, in order to achieve the competencies necessary to qualify. The individual competencies: Research, Consultancy, Behaviour Change Intervention, and Teaching and Training, as well as Generic Professional Competence, were all achieved while working as a Research Worker on a Cognitive Behaviour Therapy (CBT) trial for Persistent Physical Symptoms (PPS), at King's College London.

PPS, also known as Medically Unexplained Symptoms (MUS), are symptoms or syndromes that appear to be absent of a clear medical explanation. Examples of PPS include fibromyalgia, Irritable Bowel Syndrome (IBS), Chronic Fatigue Syndrome (CFS), functional neurological symptoms, non-cardiac chest pain and functional respiratory symptoms. Due to my role within my placement, as well as a specific interest within this research area, all competencies except for Consultancy and Teaching and Training are heavily focused within this field.

The thesis, entitled *"Exploring the Role of Culture on the Experience and Perception of Healthcare and Daily Life in Patients with Persistent Physical Symptoms"*, was originally proposed following information that Guy's and St. Thomas' Charity, who had funded the CBT trial, were interested in conducting research with black and minority ethnic (BME) patients living with different PPS. It was proposed that qualitative interviews would be conducted with a sample of patients who had enrolled on the trial in order to understand their experiences of living with PPS, their experiences of healthcare, and the potential role of any cultural factors. Executing this large qualitative study was a challenge, but it was also a great and enjoyable experience. It also enriched my understanding of PPS from the

patients' perspective, which I consider to be a particularly valuable asset when working in a patient-facing role. The systematic review, which focuses on mindfulness-based cognitive therapy (MBCT) randomised controlled trials (RCTs) for patients with common PPS (IBS, CFS, chronic pain and fibromyalgia), enabled me to expand my knowledge of the existing literature for another type of psychological therapy becoming increasingly popular in treating PPS. The process of conducting the review also helped me to exercise and refine my analysis and critiquing of studies.

The Consultancy project, entitled the *"Health Status Assessment Project"*, focused on the management of long-term conditions. This particular assignment aimed to understand the feasibility and necessity of a potential revolutionary and interactive mobile app that would help patients and healthcare professionals monitor and effectively manage chronic health conditions, such as diabetes, cancer and fibromyalgia. As this project was particularly complex, it was broken down into three distinct parts: the *Scientific Perspective*, *Patient Perspective* and *Business Perspective*. The scope of this assignment was therefore very wide, including the conduction of a review of existing mobile apps (Scientific perspective), conducting qualitative interviews with people living with long-term conditions and writing vignettes based on the findings (Patient perspective), and writing up the business plan (Business perspective). The breadth and depth of the project helped me to apply Health Psychology theory and existing research skills within new capacities. It also challenged me on many occasions to open my mind practically towards new skills and ways of working.

The Behaviour Change Intervention, entitled *"Cognitive Behaviour Therapy for Fibromyalgia"*, was born out of a particular interest in fibromyalgia after speaking to many patients with it. In addition I already had an awareness and understanding of CBT principles, and was keen to use these theoretical and practical skills to try



and help this population. Following ethical approval, I attended local support groups and delivered a CBT-based leaflet directly to the target population. Although I had gained a lot of experience in patient contact through my role as a Research Worker, I saw this as a great opportunity to meet people with fibromyalgia outside of a clinical setting. It also really opened my eyes to the wider issues affecting individuals with fibromyalgia as well.

For my first teaching case study, “*Health Promotion: Individual-Level Interventions*”, I prepared and delivered an MSc Health Psychology lecture as part of the Health Promotion module at City, University of London. The lecture was on how to effectively design, deliver and evaluate Individual-level Behaviour Change Interventions. Although I was confident in my knowledge of the topic, it was my very first experience of teaching at this level. It was an enjoyable experience being able to put together my own slides and activities, and I found it very rewarding. Within this lecture, I was keen to include my own examples of how real-life interventions had been designed and delivered within the London area. I felt that this really helped to bring to life the lecture and brought together well the academic and practical elements of the DPsych programme. This positive teaching experience led to the decision to integrate my own real-life practical experiences into teaching sessions wherever possible in the future.

My second teaching case study, “*The Patient with Medically Unexplained Symptoms*”, was part of an all-day workshop delivered to nurse practitioners from St. George’s Hospital. My teaching, which was delivered right at the start of the workshop, covered introductory information on PPS, including a descriptive explanation, the prevalence of symptoms, which clinics they are likely to present in, and their debilitating impact upon both patients and healthcare services. Once again, this teaching opportunity enabled me to introduce some of my own experiences of working with PPS patients. This teaching session was conducted

with healthcare professionals, which was a very different experience. Expectations were generally higher, and the content needed to be particularly engaging and tailored towards them and what they were likely to encounter within their day-to-day roles. This was a very useful exercise for me as a Trainee Health Psychologist.

The Training case study included within this portfolio, entitled “*Qualitative Research Methods*” was a workshop designed and run specifically for professionals who had little or no experience of conducting qualitative research. It was delivered in three distinct parts to a multidisciplinary team that included Clinical Psychologists, Cognitive Behaviour Therapists, psychiatrists and academic researchers based at the South London and Maudsley (SLaM) Hospital. As the training consisted of three individual sessions, it took a lot of time to properly research and design. As well as providing the right level of information, I was keen to include videos and training exercises in order to make the training course as enjoyable and influential as possible. For me, it was a rewarding experience, particularly as the audience all gained from it and learned something new. Furthermore, it received a very positive response from a highly respected and qualified team of professionals.

During the course of the DPsych, I have also attended and presented at several conferences, including an oral presentation at the British Psychological Society (BPS) Division of Health Psychology annual conference in September 2017, which enabled me to disseminate my own research to a wider audience. In addition, I have gained further experience in preparing papers for publication which has greatly developed my academic style of writing.

In conclusion, the DPsych programme has pushed me to new limits, and I have steadily observed myself grow as a Trainee Health Psychologist. This is not only in terms of my academic and research skills, but also in terms of my understanding of what it is to live with long-term health conditions, particularly PPS.

Perhaps most significantly, the DPsych training has given me the tools to take a reflexive and open-minded approach towards everything that I do day to day, including how I interact with both patients and healthcare professionals. Through the DPsych, I have learned that I will never stop learning, and I feel this has prepared me well for a career in Health Psychology.

## **SECTION 2: RESEARCH**

## **2A: THESIS**

# **Exploring the Role of Culture on the Experience and Perception of Healthcare and Daily Life in Patients with Persistent Physical Symptoms**

**Word count: 28,787**

## ABSTRACT

**Objectives:** PPS are common and incur large healthcare costs. BME populations experience relatively poor health, including higher rates of PPS, but are often difficult to reach. This research aims to understand BME experiences of living with PPS, of accessing and receiving healthcare, and the role and influence of cultural factors. The findings may be used to indicate whether current clinical guidelines and training may be in need of further review.

**Design:** Using thematic analysis, qualitative data was collected using semi-structured interviews.

**Methods:** 30 patients, 15 white British and 15 BME, were recruited through the PRINCE Secondary trial. Interviews were audio-recorded, transcribed and analysed inductively using thematic analysis. An adapted version of the framework analysis method was employed to identify key differences between white British and BME participant responses.

**Results:** Five themes emerged, entitled '*Beliefs surrounding the symptoms*', '*Putting on a strong face*', '*A need for social support*', '*Quality of life has been stripped away*', and '*Inconsistency within the NHS*'. These were also split into 15 sub-themes. BME participants had more complex symptoms; were more likely to retire from work; were less likely to report emotions as out of control; were less accepting of symptoms; were more religious; reported more frequent family conflicts; reported poorer experiences of healthcare, and had a greater preference for holistic therapies.

**Conclusion:** Future training and guidelines for healthcare professionals may need further revision, in order to accommodate differences between white British and BME patients, and deliver a culturally sensitive service. Psychoeducation can

improve patients' psychological wellbeing. CBT should be recommended for patients keen and able to return to work. ACT may also be of benefit to patients with PPS, particularly those demonstrating low self-efficacy and mental agility, but further robust evidence is required.

## 1. INTRODUCTION

### 1.1. What are persistent physical symptoms?

#### 1.1.1 *The different terms used in healthcare*

The term '*persistent physical symptoms*' (PPS) refers to experienced symptoms that appear to be absent of any medical explanation. In practice, this means that any medical tests, such as blood tests or scans are confirmed as '*normal*', or at the very least, cannot sufficiently explain the experienced symptoms (Marks & Hunter, 2015). Collectively, there are a number of terms that have previously been used to describe these types of symptoms. These include Medically Unexplained Symptoms (MUS) or Medically Unexplained Physical Symptoms (MUPS), Functional Disorder, Somatisation, Somatic Symptom Disorder, Complex Physical Symptoms, Bodily Distress Disorder and Idiopathic Symptoms (Marks & Hunter, 2015; Picariello, Ali, Moss-Morris & Chalder, 2015). Within the American Psychiatric Association's *Diagnostic Statistic Manual of Mental Disorders version 5* (DSM-5), these types of symptoms have been updated from Somatoform Disorders to Somatic Symptom Disorder (American Psychiatric Association, 2013; Dimsdale, Creed, Escobar, Sharpe, Wulsin et al., 2013). They are also often referred to by their individual miscellaneous terms, including Chronic Fatigue Syndrome (CFS), fibromyalgia syndrome, and Irritable Bowel Syndrome (IBS) (Nimnuan, Hotopf & Wessely, 2001; Sharpe, 2002).

While most individuals will experience PPS at some point in their lives, it is important to distinguish the difference between these types of symptoms, and those where a medical cause can be identified or where the symptoms quickly improve (Royal College of Psychiatrists, 2017). To elaborate on this point further, the DSM-5 states that in order to be classified as a Somatic Symptom Disorder (SSD), these unexplained symptoms are required to meet certain diagnostic criteria. Firstly, they



must be shown to have a significant effect upon a patient's ability to function in their daily life and must be considered clinically significant. Secondly, they must be accompanied by excessive and disproportionate thoughts and behaviours about the symptoms. Finally, the symptoms must be present for a minimum of six months (American Psychiatric Association, 2013). These are the types of symptoms that have been included within this thesis and they are referred to collectively here as PPS, following two recent patient surveys conducted within the United Kingdom (UK) that have reported this term preferable over MUS, Functional Disorder, Bodily Distress Disorder and Complex Physical Symptoms (Marks & Hunter, 2015; Picariello et al., 2015).

#### *1.1.2. A breakdown of PPS*

Functional neurological symptoms, which are generally seen either in primary care or neurology departments within secondary care, cover a wide range of symptoms and are considered to be a result of poor neurological functioning (Stone, 2011). Individual symptoms that these patients may present with include weakness, complex regional pain and other sensory symptoms such as dizziness, numbness, tingling, weakness, dissociative seizures, involuntary movements, cognitive dysfunction, low mood, sleep disorders, paralysis, speech problems, sensory changes and visual problems (Fink, Hansen & Søndergaard, 2005). A prospective cohort study of 300 neurology patients demonstrated that up to 30% of these presented with symptoms that were only "somewhat explained" or were "not at all explained" (Carson, Ringbauer, Stone, McKenzie, Warlow et al., 2000). Functional neurological symptoms can be very debilitating for patients physically and often have a poor prognosis (Ricciardi & Edwards, 2014). In addition, it can also be emotionally distressing. For example, Vroegop, Dijkgraaf and Vermeulen (2013) conducted a study comparing patients with functional symptoms against patients

living with medically explained neurological conditions. Generally, patient quality of life was reported to be worse in those with functional symptoms. More specifically, patients with functional symptoms exhibited greater physical disability including more extreme levels of pain, as well as poorer psychological and social functioning.

Functional respiratory symptoms are usually seen either in primary care or within respiratory clinics, and can present as chronic cough, dysfunctional breathing or hyperventilation, a dysfunction of the vocal cords, paroxysmal sneezing or frequent clearing of the throat (Butani & O'Connell, 1997). Chronic cough, also known as habit or idiopathic, is an unexplained persistent cough that has been present for at least eight weeks. In terms of prevalence within the UK, chronic cough is considered to account for approximately 12% of patients seen within respiratory clinics (Turner & Bothamley, 2016). While it has generally reported to be more common amongst the younger generation, including children and adolescents (Butani & O'Connell, 1997), chronic cough is also reported to be more common amongst females of menopausal age, and may potentially be triggered by hormonal changes (McGarvey & Ing, 2004). Dysfunctional breathing, also known as over-breathing, is another common condition seen within respiratory clinics. Like with other functional symptoms, dysfunctional breathing frequently co-exists with medically explained conditions, such as asthma (Anbar & Hall, 2012; Thomas, McKinley, Freeman & Foy, 2001).

Non-cardiac chest pain is frequently seen within primary care, cardiology clinics, and also within Accident and Emergency (A&E) departments. Individual symptoms are described as being very similar to the discomfort caused by heart disease or angina, and therefore patients presenting with these symptoms will almost always need to be thoroughly investigated (Schey, Villarreal & Fass, 2007). Often these symptoms are later attributed to Gastroesophageal Reflux Disease or 'acid reflux', which is considered to be the most frequent cause of non-cardiac chest

pain (Karlaftis, Karamanolis, Triantafyllou, Polymeros, Gaglia et al., 2013). In comparison with patients presenting cardiac-related chest pain, other patients with non-cardiac related symptoms are generally much younger, and are far more likely suffer from anxiety (Fass & Achem, 2011).

Fibromyalgia syndrome is typically seen in primary care or rheumatology clinics, and is primarily characterised by widespread pain and stiffness. However, there are often other accompanying symptoms, including fatigue, IBS, sleep disorders, headaches, low mood and poor cognitive functioning (Mease, 2005). Although often difficult to diagnose due to the absence of clear medical abnormality, fibromyalgia has been reported to affect at least one in 20 people (Jones, Atzeni, Beasley, Flüß, Sarzi-Puttini et al., 2015). It is also considered to be much more common amongst women, with around seven times more women presenting with the symptoms than men within a random sample (Wolfe, Ross, Anderson, Russell & Hebert, 1995). The true prevalence of fibromyalgia may be much higher though, as a systematic review and meta-analysis of seven studies has demonstrated that between 33% and 50% of all adults within the UK experience chronic pain, and between 14.2% and 16.1% live with chronic widespread pain (Fayaz, Croft, Langford, Donaldson & Jones, 2016).

Chronic Fatigue Syndrome (CFS), also known as Myalgic Encephalomyelitis or ME, is similar to fibromyalgia syndrome in that it is also characterised by extreme fatigue and may also include pain in the muscles, as well as cognitive dysfunction, sleep disturbance and low mood (Afari & Buchwald, 2003). While everyone may experience fatigue at some point, in the case of CFS the symptoms are generally more severe and difficult to live with on a day-to-day basis, having a significant impact upon an individual's ability to carry out their usual daily activities (Larun & Malterud, 2007). It has also been proposed that symptoms are more likely to be relieved through the introduction of gentle exercise, rather than through rest alone

(Fulcher & White, 1997). Similarly to fibromyalgia, CFS is also more commonly diagnosed in women, and usually manifests between the ages of early 20s and early 40s (Capelli, Zola, Lorusso, Venturini, Sardi et al., 2010). CFS is also considered to be very common. A meta-analysis of fourteen studies has reported a pooled prevalence of CFS of 3.3%. However, it is possible that this figure is too high due to a reported discrepancy between self-report assessment (3.3%) and clinical assessment figures (0.8%) which were calculated separately (Johnston, Brenu, Staines & Marshall-Gradisnik, 2013).

IBS, typically seen within either primary care or in gastroenterology clinics, is considered to be a disturbance of the digestive system and as stated earlier is often a symptom of fibromyalgia as well. The most common symptoms of IBS include diarrhoea, constipation, bloating and abdominal pain (Longstreth, Thompson, Chey, Houghton, Mearin et al., 2006). Other less common but associated symptoms include fatigue, low mood or anxiety, nausea, muscle or back pain, and heartburn. It is a common health complaint, with a meta-analysis of 81 population-based studies reporting a pooled prevalence of 11.2% (Lovell & Ford, 2012). Similarly to fibromyalgia and CFS, IBS is also more common in women. This may be attributable to the more frequent hormonal changes experienced by women (Lee, Kim, Sung, Park, Jin et al., 2007). Although a common condition, as demonstrated through qualitative interviews, for some individuals IBS is particularly chronic and debilitating, having a significant impact upon their lives (Rønnevig, Vandvik & Bergbom, 2009).

Another common functional gastrointestinal disorder is non-ulcerative functional dyspepsia, or recurring symptoms of indigestion (dyspepsia) in the absence of inflammation, with normal levels of stomach acid. Similarly to medically explained dyspepsia, or ulcerative dyspepsia, functional dyspepsia is known to trigger a range of physical symptoms within the upper abdomen, including pain and

discomfort, flatulence, belching, nausea or vomiting, and bloating (Fujiwara & Arakawa, 2014). Despite the unpleasantness of the symptoms, they do not lead to any serious health conditions such as cancer. They can also be controlled somewhat by avoiding dairy, spicy food, food high in fat, caffeine and alcohol (Barbera, Feinle & Read, 1995; Feinle-Bisset & Azpiroz, 2013). A population-based cohort study has also reported an association between weight gain and the onset of dyspepsia symptoms (Cremonini, Locke, Schleck, Zinsmeister & Talley, 2006), which suggests that weight loss may also be helpful in reducing the symptoms of dyspepsia.

#### *1.1.3. The trans-diagnostic nature of PPS*

While the description of these symptoms and syndromes may have individual differences, there are also many overlapping features of PPS which support the case for taking a trans-diagnostic approach towards them. For example, Fink and Schroder (2010) conducted a review of 978 patients predominantly seen within primary care. Their aim was to identify whether fibromyalgia, hyperventilation syndrome or dysfunctional breathing, non-cardiac chest pain, CFS, IBS and pain syndrome could be successfully diagnosed under the diagnostic term '*Bodily Distress Syndrome*'. They reported a significant overlap between individual diagnostic categories of the symptoms and Bodily Distress Syndrome of 95%, demonstrating PPS to be multi-factorial, and suitable for grouping. In further support of taking a unifying approach towards PPS, Nimnuan, Hotopf and Wessely (2001) conducted a cross-sectional survey of 890 patients seen within seven specialist outpatient clinics in two London-based hospitals. They reported that patients presenting with PPS across clinics tended to have similar demographic representations, in that they were significantly more likely to be female and below the age of 55. Simplifying the terminology by using one specific term for all

symptoms could help to make any future clinical guidelines clearer, and also assist with the prompt recognition and treatment of symptoms (Rosendal, Hartman, Aamland, van der Horst, Lucassen et al., 2017).

#### *1.1.4. The impact of PPS on the patient*

While PPS are poorly understood in terms of their cause, they are nevertheless real symptoms that can severely impact upon an individual's psychological well-being. Individuals are reported to experience emotional distress due to incessant worry about the potential cause of their symptoms (Royal College of Psychiatrists, 2017). Nettleton, O'Malley, Watt and Duffey (2004), who explored the narrative output from 20 neurology outpatients living with PPS, reported that patients experienced feelings of frustration due to 1) their uncertainty for the future, 2) their frustration that their PPS are poorly understood and are often considered to be psychological in nature, and 3) their frustration that their symptoms could not easily be treated. A meta-analytic review of 244 studies conducted by Henningsen, Zimmerman and Sattel (2003) that focused on four specific types of PPS including IBS, fibromyalgia, CFS and non-ulcer dyspepsia, reported that participants living with PPS are significantly more likely to exhibit symptoms of anxiety or depression than healthy patients, and even more likely than patients living with an organic medical condition. The findings from this review were later supported by Burton, McGorm, Weller and Sharpe (2011), who conducted a case-control study across five primary care practices in Scotland. They reported that depression and anxiety was present in 48% of patients who had been referred to secondary care, in comparison with 25% of controls. These findings are significant because they demonstrate a high prevalence of anxiety and depression amongst patients with PPS, but also show that PPS are likely to also be independent of anxiety and

depression. This discredits the perception that PPS may be a manifestation of an underlying psychological condition.

The proposed link between PPS and poor psychological health is in itself distressing for patients. Aamland, Malterud and Werner (2013), who conducted two focus groups with a purposive sample of twelve participants living with PPS, found that patients were troubled by the added burden that comes with living day-to-day with symptoms seemingly absent of a recognised medical explanation. This is consistent with an earlier qualitative study conducted by Nettleton (2006), which found that patients with functional neurological symptoms had reported struggling with the uncertainty of their symptoms, the lack of validation that came with them, and the consideration that their symptoms may have a psychological basis.

As well as functioning, there is evidence that PPS put a significant strain on patients' personal relationships. Wong, Drossman, Weiland, Morris, Leserman et al., (2011) for example, utilised the Zarit Burden Interview as well as the Relationship Satisfaction Scale with 152 partners of IBS patients, with a control group for comparison. The findings from this study strongly indicated reported burden scores to be significantly higher in partners of IBS patients than controls, with scores relative to the reported severity of symptoms. There is also evidence to suggest that the direction of the impact of symptoms on relationships may be only one way, as suggested above. Liu, Cohen, Schulz and Waldinger (2011) reviewed 101 US-based couples, following the self-completion of the Relationship Scale Questionnaire and the Somatic Symptom Inventory as well as further questionnaires measuring depression, anger and conflict. Mediated by anger, it was reported that insecurity within relationships appeared to lead to manifestations of PPS. Arnold, Crofford, Mease, Burgess, Palmer et al., (2008) conducted focus groups with 48 women living with a diagnosis of fibromyalgia, and reported that fibromyalgia had significantly impacted upon their romantic relationships, due to the added pressures

that it placed upon their partners in terms of work and running the home, as well as the loss of physical intimacy experienced due to the pain.

The significant impact of PPS upon day-to-day functioning has also been highlighted within further studies. Arnold et al., (2008) argued that social engagements were hard for individuals with fibromyalgia to organise and become involved in, due to the erratic nature of their symptoms. A further study by Lidén, Björk-Brämberg and Svensson (2015), who conducted a phenomenological-hermeneutic study with ten primary care patients, reported that narrative interviews had led to the identification of the theme *'feeling that the symptoms overwhelm life'*, describing how the onset of symptoms had led to big restrictive changes in terms of both independence and functioning. In addition, where there may not always be a significant relationship between symptoms and poor psychosocial functioning, certain PPS such as non-cardiac chest pain are likely to prompt severe anxiety, which is in itself linked to poor functioning (Shelby, Somers, Keefe, Silva, McKee et al., 2009).

#### *1.1.5. The impact of PPS on healthcare services*

PPS evidently has a significant impact upon healthcare services. Within primary care, they are estimated to account for anywhere between 33% and 45% of all consultations (Chew-Graham, Heyland, Kingstone, Shepherd, Buszewicz et al., 2017; Royal College of Psychiatrists, 2017). Within secondary care, the percentage of consultations for patients with PPS is generally estimated to be much higher (Chew-Graham et al., 2017). However, estimates tend to vary between departments and specialist clinics. Shivaji and Ford (2014) for example reviewed the number of new patient referrals to a gastroenterology clinic over a three year period and reported that out of 613 referrals, 34.9% had a functional gastrointestinal disorder such as IBS. Chambers, Marks and Hunter (2015) reported that roughly 50% of



patients presenting with chest pains in A&E were later found to have non-cardiac chest pain. In primary care and rapid access chest pain clinics, up to 80% of cases were non-cardiac in origin.

Due to the frequency of which PPS are seen, they place a significant strain upon services in terms of financial resource. Bermingham, Cohen, Hague and Parsonage (2010) conducted a review of existing literature to understand the overall financial cost of somatisation over one year, between 2008 and 2009. They reported the direct healthcare cost of PPS to be at £3 billion per year. These costs were further compounded by quality-adjusted life year costs, calculated at £9.3billion, and the cost of sick leave for businesses, estimated at £5.2 billion. Overall annual costs of PPS were therefore calculated at £18 billion in total (Bermingham et al., 2010; Chitnis, Dowrick, Byng, Turner & Shiers, 2014). The findings from this review were supported by another study focusing on the cost-of-illness and economic evaluations for patients with PPS. This review reported annual healthcare costs of between 432 and 5,353 USD per patient, with indirect costs such as disability allowance, accounting for a further 18,000 USD (Konnopka, Schaefer, Heinrich, Kaufmann, Lupp et al., 2012).

#### *1.1.6: Treating patients with PPS*

Studies provide strong evidence that healthcare professionals struggle to treat patients with PPS (Carson, Stone, Warlow & Sharpe, 2004; Maatz, Wainwright, Russell, Macnaughton & Yiannakou, 2016; Salmon, 2007), with the uncertainty of exactly how to treat them being at least partly attributed to limitations within the NHS (Maatz et al., 2016). Qualitative research has provided some insight into the direct effect that this has upon healthcare professionals, particularly General Practitioners (GPs). Wileman, May and Chew-Graham, (2002) conducted 15 semi-structured interviews with GPs to understand their attitudes towards treating

patients with PPS. The interviews uncovered feelings of inadequacy, as well as wariness and even resentment towards their patients. More recent studies suggest that there has been little to no change over the past 15 years, even within specialised clinics. Maatz et al., (2016) conducted 17 semi-structured qualitative interviews with senior healthcare professionals across hospitals in the North-East of England, and found that healthcare professionals considered consultations with PPS patients to be 'difficult' in terms of effectively communicating with the patient and understanding the nature of the symptoms and how to treat them. Within an earlier review by Salmon (2007), the narrative data provides some insight into the nature of these communication difficulties between doctor and patient. Firstly, there is a clash between patients' understanding and awareness of their symptoms, and healthcare professionals' knowledge of the absence of disease following all necessary investigations. This particular review recommended that healthcare professionals aim to find a common ground, whereby symptoms can be understood and approached from both sides. Nevertheless, it was recognised at the point of publication that this type of approach is not generally favourable amongst healthcare professionals and more recent studies, such as that conducted by Maatz et al., (2016), would suggest that this attitude has not changed within the past ten years. On the other hand, it is possible that difficulties in communication between healthcare professionals and patients, as discussed earlier, could be somewhat due to patients' alexithymia, i.e. the inability to express themselves and their feelings (Deary et al., 2007). However, evidence to support this is currently inconsistent at best.

New clinical guidelines have been published for commissioners including Clinical Commissioning Groups (CCGs), health service providers, and Health and Well-being Boards (HWBs) of how to treat patients with PPS. Within these guidelines, it states that healthcare professionals should assess patients' physical

and mental functioning, deliver psychoeducation, prescribe medication, and refer them for psychodynamic therapy or Cognitive Behaviour Therapy (CBT). In addition, it states that carers should also be provided with support, and plans to discharge patients should be made (Joint Commissioning Panel for Mental Health, 2017).

Psychoeducation refers to the provision of education and useful information to patients and caregivers, in order to help and support them towards changing their understanding and attitudes toward health conditions. This type of intervention can help those affected by a health condition to come to terms with it and cope with it more effectively (Oncology Nursing Society, 2016; Stafford & Colom, 2013). A flexible intervention, it can be delivered in a number of different formats, including individual or group face-to-face therapy, through printed booklets and leaflets, and even online (Oncology Nursing Society, 2016). Research strongly suggests that if used appropriately, this type of informative approach can be a very effective treatment. Donker, Griffiths, Cuijpers and Christensen (2009) conducted a meta-analysis of five randomised controlled trials (RCTs) detailing four individual psychoeducational interventions aiming to treat anxiety, depression and distress. Pooled results demonstrated a significant reduction in the number of psychological symptoms overall. Further individual studies since then have also provided evidence for the effectiveness of psychoeducational interventions in improving psychological health (Chen, Maheshwari, Franks, Trolley, Robinson et al., 2013; Luciano, Martínez, Peñarrubia-María, Fernandez-Vergel, García-Campayo et al., 2011).

CBT is a psychological therapy that focuses on the relationship between thoughts, or cognitions, and how they influence feelings or emotions and subsequently health-related behaviours (Mind, 2015). It has a particularly large evidence base across multiple health conditions, with systematic reviews demonstrating the effectiveness of CBT in treating psychological conditions such as anxiety (Hofmann & Smits, 2008), depression (Hofmann & Smits, 2008; Jennings &

Hewitt, 2015), schizophrenia (Jauhar, McKenna, Radua, Fung, Salvador et al., 2014) and even sleep insomnia (Trauer, Qian, Doyle, Rajaratnam, & Cunnington, 2015). In cases where co-morbid conditions exist, there is also evidence that CBT can significantly improve both physiological and psychological health. An example of this includes a trial for diabetes and depression, where both fasting glucose levels and depressive symptoms were significantly reduced following CBT treatment (Li, Xu, Hu, Tan, Zhang et al., 2017).

CBT has also been shown to be effective in treating patients with PPS. Individual RCTs have demonstrated the effectiveness of CBT in treating IBS (Moss-Morris, McAlpine, Didsbury & Spence, 2010) psychogenic non-epileptic seizures (Goldstein, Chalder, Chigwedere, Khondoker, Moriaty, Toone et al., 2010), and non-cardiac chest pain (Marks, Chambers, Russell, Bryan & Hunter, 2014). In addition, it has been shown to be even more effective than Graded Exercise Therapy (GET) in cases where PPS co-exist with significant anxiety or depression (Castell, Kazantzis & Moss-Morris, 2011). CBT has also been shown to help improve daily functioning in those with PPS. Reme, Grasdal, Løvvik, Lie and Øverland (2015) conducted a CBT work-based intervention with staff that were either signed off sick, were currently receiving disability payments, or were considered at risk of being signed off from work. Participants that received CBT as opposed to usual care were significantly more likely to engage at work, which was also reported 18 months later demonstrating the approach to have a long-term benefit. A systematic review and meta-analysis of 23 investigating the effectiveness of CBT in treating unexplained lower back pain concluded that CBT demonstrated long-term benefits in terms of reducing symptom severity, and in improving functioning and quality of life (Richmond, Hall, Copsey, Hansen, Williamson et al., 2015). Regardless of this, CBT can require a lot of dedication as some patients may require up to 20 sessions (British Association for Behavioural and Cognitive Psychotherapies, 2017), which

may not be practical for all patients in need of therapy. A report released in 2015 by Integrated Access to Psychological Therapy (IAPT), who deliver CBT as recommended by National Institute of Health and Clinical Excellence (NICE), revealed that of 1,123,002 referrals that terminated, only 42% actually finished a course of treatment (IAPT, 2015). It is important therefore to ensure that everyone is able to access psychological therapy, and therefore other therapy options gaining momentum should at least be considered for future use.

Acceptance and Commitment Therapy (ACT) is a relatively new therapeutic approach that emphasises the importance of behavioural change and commitment, integrating mindfulness principles with the need to reach a point of acceptance (British Association for Behavioural and Cognitive Therapies (BABCP), 2017).

Mindfulness, which promotes the Buddhist principles of being present in the moment by paying greater attention to one's own thoughts and feelings, has in itself been shown to be effective in improving psychological health outcomes (Gu, Strauss, Bond & Kavanagh, 2015). Based originally on the Relational Frame Therapy, ACT has been described as *"explicitly contextualistic... based on a basic experimental analysis of human language and cognition"* (Hayes, 2004). RCTs have shown ACT to be effective in reducing anxiety and depression, as well as effective in increasing the self-efficacy of patients living with PPS (Veehof, Oskam, Schreurs & Bohlmeijer, 2011; Wicksell, Kemani, Jensen, Kosek, Kadetoff et al., 2013).

Perhaps most significantly, it has been shown to increase mental agility on both a short-term and long-term scale (McCracken & Gutierrez-Martinez, 2011; Wicksell et al., 2012), which in theory would enable them to accept their current and potentially indefinite physical and psychological limitations.

Despite clear recommendations having been published, there is still evidence that healthcare professionals are unaware of how to help patients with PPS. Yon, Nettleton, Walters, Lamahewa and Buszewicz (2015) conducted in-depth

interviews with junior doctors based in hospitals within the UK to explore their knowledge and awareness of PPS, as well as their recommendations of how to improve the quality of training. Participants reported a lack of awareness in terms of what PPS are, what investigations should be conducted and how extensively, the potential co-morbidity of depression or anxiety, how PPS could be appropriately explained to patients, and how they could assist the patient in managing their symptoms in future. Similarly to the findings of Maatz et al., (2016) and Wileman et al., (2002), this study revealed that when treating patients with PPS, junior doctors experienced feelings of frustration and anxiety and worried that they would be incompetent when attempting to treat patients. This often led them to conduct unnecessary investigations, and even avoid seeing particular patients altogether. Participants also revealed within these interviews that negativity towards patients with PPS were sometimes fed down from senior healthcare professionals, influencing their own attitudes and behaviours towards symptoms. Another recent qualitative study conducted with both junior doctors and consultants across gastroenterology, cardiology, neurology and rheumatology (Warner, Walters, Lamahewa & Buszewicz, 2017), replicated these findings. Within this study, it was believed that there are still no clear guidelines in place, and while some senior clinicians appeared to be able to appropriately manage and treat patients with PPS themselves, this was largely due to their experience rather than any specific training or clinical guidelines.

Yon, Habermann, Rosenthal, Walters, Nettleton et al., (2017) administered web-based questionnaires to the directors of training programmes which concurred that there was very little training in place on PPS for healthcare professionals, and that there should be roughly up to three hours' training per year. As part of the same study, workshops were run with a multidisciplinary team including junior doctors, from which it was recommended that future training should include real-life

examples, videos and role-plays, in order to make it clear what constituted good and bad medical consultations. Despite these recommendations and the publishing of new recommendations for commissioners in relation to treatment, the findings from Warner et al., (2017) suggest that the message has not yet been filtered down from commissioners to healthcare professionals. Whether these guidelines will eventually be followed as intended is yet to be seen. One potential limitation in relation to these guidelines however, is that they have not been influenced by any qualitative studies conducted with patients themselves. Obtaining a good understanding of patients' expectations would have provided further insight on how to improve training for healthcare professionals. Research with patients is therefore needed in order to understand their experiences of accessing and using healthcare, and how they would expect any shortcomings in terms of healthcare to be addressed. The findings from this patient-led research may be used to help review clinical training and guidelines for the treatment of PPS, to make sure that patients receive the best possible treatment.

## **1.2. Predisposing, precipitating and maintaining factors of symptoms**

### *1.2.1. Predisposing factors*

The potential causes for PPS are somewhat unclear and are potentially varied. However, several potential causes for PPS as a whole have been addressed. Predisposing factors may include genetic factors, personality traits such as neuroticism, physical or sexual abuse, chronic mental or physical illness, and the presence of illness within the family during childhood. In terms of predisposing factors, the support for childhood traumas such as child abuse is particularly strong. Maniglio (2009) conducted a systematic review of reviews involving 270,000 subjects, studying the long-term consequences of childhood sexual abuse, and concluded participants subjected to abuse as a child were at a significantly greater

risk of developing medical and psychological disorders as adults. Within this review, childhood sexual abuse was demonstrated to precede a higher prevalence of chronic non-cyclic pelvic pain (Latthe, Mignini, Gray, Hills, & Khan, 2006), non-epileptic seizures (Sharpe & Faye, 2006), and other 'dissociative' or 'somatoform' disorders (Jumper, 1995; Rind & Tromovitch, 1998). Häuser, Kosseva, Üceyler, Klose and Sommer (2011) gave further support to these findings following their review of fibromyalgia patients, where they reported significant links between childhood sexual and physical abuse, and fibromyalgia symptoms. However, the link between child sexual abuse and fibromyalgia specifically is somewhat compromised within this study, due to larger effect sizes being associated with poor quality studies. Hotopf, Mayou, Wadsworth and Wessely (1999) also reported a link between childhood experiences and PPS through their birth cohort study examining high risk factors in childhood. Within this study, a significant relationship was found between the health status of participants' parents when they were aged 15, and the presence of PPS in their mid-30s. Nevertheless, cohort studies as a whole are subject to recall bias (Hotopf, 2002), which compromises study reliability.

Adshead and Guthrie (2015) introduced human attachment theory into the debate to explain a link between childhood experiences and PPS. According to this theory, when young children are emotionally or physically upset, they instinctively exhibit certain behaviours that would be responded to by an attachment figure, in order to reduce these feelings of distress. Within a healthy parent-child relationship, the child would learn how to manage negative feelings themselves, and in adulthood would reflect back on their childhood attachment experiences, thus instigating their own sense of self-worth (Ainsworth & Bell, 1970). In the case of insecure attachment, relationships with attachment figures do not successfully reduce feelings of distress and when these children become adults, they are more likely to adopt the role of being the patient (Adshead & Guthrie, 2015). Taylor,



Marshall, Mann and Goldberg (2012), who conducted a cohort follow-up study of frequent attendees across ten primary care practices in the UK, supported this theory. Of the 18% of identified patients that were found to have PPS within this study, insecure styles of attachment were particularly high, identified both through questionnaires and a telephone interview, as well as more frequent primary care consultations. However, it should be noted that as well as the study being at risk of recall bias, only a brief self-report measure was used to capture information on participants' attachment styles. Further research is therefore required to provide support for the relevance of human attachment theory.

Kendler, Walters, Truett, Heath, Neale et al., (1995) provided evidence for the role of genetic factors in self-reported PPS, following utilisation of the '*Virginia 30,000*' twins sample. Despite a model being fitted to assess the variance for 80 distinct relationships, genetic factors were reported to account for up to 49% of the total variance. Interestingly within this study, family environment was reported to have no effect upon the onset of symptoms. However, these findings should be viewed with caution, as it is not possible to say to what extent the family environment may have influenced twins' behaviour. Further to this point, a more recent twin study focusing on the prevalence of IBS reported very little difference between the concordance rates of monozygotic twins (28%) and dizygotic twins (27%). Environmental factors on the other hand, including oral contraceptives or Hormone Replacement Therapy (HRT), excess alcohol intake and anticholinergic drug therapy, were found to be significantly linked (Mohammed, Cherkas, Riley, Spector & Trudgill, 2005).

Certain personality traits have also been suggested to be a predisposing factor for PPS. Neuroticism for example, one of the main five personality traits, has been linked with PPS due to its associations with negative affect, general distress, increased sensitivity to stressful events, and depression and anxiety (Deary,

Chalder & Sharpe, 2007). There is support for this theory (Menon, Shanmuganathan, Thamizh, Arun, Kuppili et al., 2017; van Dijk, Hanssen, Naarding, Lucassen, Comijs et al., 2016), but it may be that neuroticism is linked more directly with psychological distress than PPS. Menon et al., (2017) who conducted a cross-sectional study over a three-year period within a tertiary care facility, reported that a large percentage of the 171 patients with PPS (52.6%) were suffering from psychological distress. These patients were found to have significantly higher levels of neuroticism, compared with those who were not psychologically distressed. In further support of this, van Dijk et al., (2016) used a case-control study to compare PPS patients with controls, and reported that while the PPS patients demonstrated higher levels of neuroticism there was little difference in the personality profile of PPS patients and those with medically explained conditions.

Another personality trait that has been linked with PPS is alexithymia, or the inability to express oneself including one's feelings (Deary et al., 2007). While it is understandable in a practical sense how alexithymia could potentially inhibit progress with healthcare professionals and therefore indirectly exacerbate PPS, studies on this have produced non-significant findings. Kooiman, Bolk, Brand, Trijsburg and Rooijmans (2000) conducted a cross-sectional study with outpatients from an internal medicine clinic. Approximately half of the patients included within the study were identified as having PPS. However, self-report questionnaires and interviews failed to identify a significant difference in terms of the prevalence of alexithymia between patients with PPS and those without. Anuk and Bahadir (2018) examined the link between physical and emotional abuse and PPS, using interviews and self-report questionnaires. While this study did report higher rates of alexithymia amongst PPS patients exposed to childhood physical and emotional abuse, limitations such as the purposive sampling method and the reliance on retrospective data compromise the reliability of these findings. This study also indicates that

alexthymia is likely be a personality trait shaped by experience, rather than an innate one.

Overall, the evidence for the role of predisposing factors is somewhat inconclusive. Generally there appears to be a stronger argument for the role of childhood experiences, rather than genetics and personality traits. Based on the limitations of the existing research, further longitudinal studies with large samples of patients with PPS are required in order to provide a more conclusive understanding of the role of predisposing factors.

### *1.2.2 Precipitating factors*

Precipitating factors may include stressful life events, acute physical or mental illness, and environmental factors such as war and natural disasters. Stressful life events can include anything from divorce to acts of terrorism, and there is certainly evidence to support their role within the onset of symptoms (Hatcher & House, 2003; van den Berg, Grievink, Yzermans & Lebret, 2005). Hatcher and House (2003) conducted a case-control study to investigate the relationship between stressful life events and CFS. They found that those with CFS were significantly more likely to have experienced stressful life events either three months or a year prior to being examined. A review by van den Berg et al., (2005) reported that out of 22 studies comparing rates of PPS between survivors of natural disasters and controls, in 18 studies the survivors exhibited significantly higher rates of PPS. Due to differences in terms of study design within the review, it is unclear exactly how common PPS is amongst survivors. However, a recent longitudinal study examining the prevalence of somatic symptoms in young survivors of the Lushan earthquake in China supported these conclusions. Their findings, reported at three and six months after the earthquake, showed there to be unusually high rates of tiredness and fatigue (52.0 and 46.1%), sleeping problems (58.4 and 48.4%) and

functional abdominal pain (45.8 and 45.4%) amongst survivors (Zhang, Zhu, Du & Zhang, 2015). Despite the longitudinal design appearing to strengthen the study, symptoms were only assumed to be PPS rather than a result of any existing pathology. Furthermore, questionnaires were administered at three and six months following the earthquake, but baseline scores were unavailable making it difficult to ascertain whether PPS was actually triggered by the earthquake.

Hickie, Davenport, Wakefield, Vollmer-Conna, Cameron et al., (2006) provided evidence for the link between acute infection and PPS. They followed patients for one year after acute infection with the Epstein Barr virus, the Ross River virus, or Coxiella Burnetii. Self-report, clinical assessment and patient interviews later demonstrated that 11% of participants had met the criteria for CFS at the six month follow-up. This was attributed most strongly to the severity of the acute infection, rather than any external factors. However, due to the small sample size, it was acknowledged that it was not possible to eliminate other risk factors for CFS. Nevertheless, the link between illness and PPS has been supported by other studies. Lombardi, Ruscetti, Das Gupta, Pfof, Hagen et al., (2009), identified traces of the Xenotropic Murine Leukaemia Virus (XMRV) in 67% of blood samples taken from CFS patients, in comparison with only 3.7% of blood samples taken from the healthy controls. Due to the overlap in symptoms, it is perhaps unsurprising that patients living with the Hepatitis C Virus (HCV) are more likely to present with fibromyalgia symptoms than healthy controls. Nevertheless, HCV patients were found to be significantly more likely to have fibromyalgia than patients with cirrhosis of the liver, suggesting that acute and severe infections are more likely to trigger PPS.

There is also some evidence that environmental factors such as air pollutants can trigger PPS, particularly respiratory symptoms. Brooks, Mark, Weiss & Bernstein (1985) studied the effect of just one exposure to irritant substances

such as smoke or fumes in ten participants, and reported that most participants when tested at a later date had developed reactive airway dysfunction syndrome (RADS), which continued for more than a year after the initial exposure. Although this particular study used a very small sample, it does provide evidence of the potential impact of environmental pollutants upon functional symptoms. A later systematic review by Groneberg-Kloft, Kraus, van Mark, Wagner and Fischer (2006) provided similar conclusions, demonstrating that air pollutants can trigger chronic cough and asthma-like symptoms in the absence of respiratory disease.

Functional respiratory symptoms, such as dysfunctional breathing, have also been linked with recognised respiratory disorders such as asthma, due to their frequent co-morbidity. Thomas, McKinley, Freeman, Foy and Price (2005) for example conducted a cross-sectional postal survey with patients from one GP practice. Positive screening scores for dysfunctional breathing, as reported through the Nijmegen questionnaire, were reported to be higher amongst asthmatic patients compared with patients not diagnosed with asthma. Nevertheless, it should be considered that within each of these studies, there is always the possibility that unexplained respiratory symptoms may have been simply misdiagnosed.

Like with the predisposing factors, the studies producing support for the role of precipitating factors are not without limitations. However, the findings from these studies appear to be consistent with one another, suggesting a clear link between emotive events and environmental factors, with PPS. An overview of this evidence however does seem to suggest that precipitating factors may only be directly relevant to specific PPS types, such as CFS and fibromyalgia, and functional respiratory symptoms, and may not be able to explain all presentations of PPS.

### *1.2.3. Maintaining factors*

Maintaining factors may include unhelpful health-related behaviours on behalf of the patient such as a lack of exercise and poor sleep hygiene, health-related beliefs, ethnic background - also a predisposing factor, and unhelpful behaviours from healthcare professionals. Specific examples of the latter may include the delivery of unhelpful or confusing information, or agreeing to send the patient for repeated clinical tests and investigations for their PPS (Price & Okai, 2016). Page and Wessely (2003) suggested that a number of maintaining factors can occur just through the doctor-patient exchange. This can include the provision of conflicting messages from different healthcare professionals, repeated investigations and treatments which can reinforce the patient's perception of their symptoms being organic in nature, and the assignment of a label which can validate symptoms for the patient. Kenny (2004) conducted interviews with 20 chronic pain patients and 22 pain specialists, and found that PPS was exacerbated by the continued miscommunication between healthcare professionals and patients who are more likely to approach patient symptoms from a psychological and biological standpoint respectively.

Other maintaining factors may exist at biological level with evidence suggesting that increased sensitisation to certain stimuli can trigger physiological changes, leading to presentations of fibromyalgia and CFS (Deary, Chalder & Sharpe, 2007). Jerjes, Peters, Taylor, Wood, Wessely et al., (2006) monitored the urine samples of 15 CFS patients and 20 healthy controls over three hour intervals. The findings demonstrated there to be reduced hypothalamic-pituitary-adrenal (HPA) activity within CFS patients, due to lower cortisol levels. Results from this particular study however should be viewed with caution, due to the small sample size. Furthermore, another study with a large sample has since contradicted these findings. Claassen-van Dessel, van der Wouden, Dekker, Rosmalen and van der

Horst (2017) examined the relationship between Cortisol Awakening Response (CAR) and the severity and duration of symptoms, within a mixed PPS population. No significant relationships were found, suggesting that CAR cannot explain onset or presence of PPS. However, due to the cortisol sampling procedures failing to match up to guideline regulations within this study, and due to the conflicting results with studies, more robust research is required to understand the proposed link between external stimuli and physiological change, and the onset of PPS.

Health-related beliefs are considered to be a predecessor of health-related behaviours, which can exacerbate poor health (Rosenstock, Strecher & Becker, 1998). The Illness Perception Questionnaire (IPQ) was originally designed in order to understand these cognitive processes. Made up of five individual subscales, it assesses how patients recognise illness through the symptoms (Identity), what patients think may have caused their illness (Cause), the expected duration of their illness (Timeline), what they perceive will happen because of their illness (Consequences), and whether they think an illness can be managed or cured (Cure control) (Weinman, Petrie, Moss-Morris & Horne, 1996). A fairly recent systematic review and meta-analysis of 188 papers covering a wide range of conditions has already reported strong pooled correlations between the subcomponents of the Illness Perception Questionnaire (IPQ) and a range of health-related outcomes, including depression, anxiety, and quality of life (Broadbent, Wilkes, Koschwanez, Weinman, Norton et al., 2015). However, most included studies within the review were cross-sectional in design rather than longitudinal, employing a wide variety of measures likely to differ in terms of validity and reliability. Most significantly however, this large review does not focus specifically on PPS. Due to the level of complexity of PPS, it may be that the IPQ is too simplistic to explain the cognitive processes behind them.

Following this brief review of the associated causes of PPS, it is not surprising that for many living with these symptoms the causes are considered to be unknown, due to the complexity of symptoms. Taking a biological approach is likely to be overly simplistic and unhelpful. The biomedical model, which was once considered the go-to model for healthcare, assumes that poor health can only be the result of biological factors (Wade & Halligan, 2004). As demonstrated by the evidence, PPS challenges the adequacy of the biomedical model due to their complexity, therefore supporting the view that a biopsychosocial explanation for health and proposed treatment would be more appropriate (Wade & Halligan, 2004). The biopsychosocial model takes into account all potential biological, psychological and social factors that may affect symptoms, and is considered to be a much more effective approach when it comes to designing a plan of effective treatment (Edwards, Stern, Clarke, Ivbijaro & Kasney, 2010). Nevertheless, the wide scope of evidence regarding the potential causes of PPS present a challenge in terms of obtaining an accurate overview within individual consultations of what may have caused the symptoms. This is particularly poignant when considering the limited amount of time healthcare professionals in the UK are now able to spend with patients (Baird, Charles, Honeyman, Maguire & Das, 2016).

#### *1.2.4. The role of ethnicity upon health and PPS*

Ethnicity may also act as both a predisposing and maintaining factor, due to black and minority ethnic (BME) groups generally fairing significantly worse in terms of health and well-being in comparison with white British groups, even after controlling for social and economic factors (Stevenson & Rao, 2014). The Office for National Statistics (2013) state that BME groups report significantly lower scores in terms of well-being than their white British counterparts. This disparity between ethnic groups was reported to be particularly pronounced between black African



groups and white British groups, with average well-being scores reported of 6.7 and 7.4 out of 10 respectively. Bangladeshi groups were also reported to have relatively low well-being scores with an average of 7.0 out of 10. Evidence suggests that BME groups are more prone than white British to both mental and physical health complaints (Missinne & Bracke, 2012; Parliamentary Office for Science and Technology, 2007). For example, with regards to mental health, white Irish groups present with higher rates of alcoholism and depression and are more likely to be admitted to hospital, while African Caribbean patients are up to five times more likely than other ethnic groups to be diagnosed and hospitalised with schizophrenia. It is also recognised that there is a much higher suicide rate amongst Asian women (Mental Health Foundation, 2017). This suggests that poor mental health is not always easily recognisable, and certain BME groups may be particularly vulnerable.

In terms of PPS specifically, there is evidence of ethnic differences in terms of prevalence. Verhaak, Meijer, Visser and Volters (2006) conducted a survey of 400,000 patients across 104 general practices in the Netherlands. Patients within this sample with PPS were more likely to be of non-Western origin than 'average' patients or those living with a diagnosed medical condition. Palmer, Macfarlane, Afzal, Esmail, Silman et al., (2007) conducted a large research study with 933 White Europeans and 1914 South Asians (1165 Indian, 401 Pakistani and 348 Bangladeshi), recruited through 13 general practices located in Birmingham, Oldham, Bolton and Ashton-under-Lyne. Their findings showed all South Asian groups to have significantly higher rates of chronic widespread pain when compared with the white European group. A further systematic review and meta-analysis by Dinoo, Khoshaba, Ashby, White, Nazroo et al., (2009) examining the relationship between CFS and ethnicity concluded that CFS is much more common amongst African Americans and native Americans than white Americans, with more severe symptoms. However, while PPS may be more common in BME groups, this is not

necessarily the case with all PPS. Kang (2005) reported within his review that while some studies had demonstrated higher rates of constipation amongst African Caribbean subjects compared with white American counterparts, other studies have reported higher rates of IBS amongst the white population. Bhopal, Cezard, Bansal, Ward and Bhala (2014) reviewed medical records in Scotland linking 4.65 million people from the 2001 Census to NHS hospitalisation and death records. Within this study, Poisson regression was used to calculate relative risk of IBS, which was found to be significantly more prevalent amongst white women than Pakistani women. This is despite the opposite being reported for organic gastrointestinal diseases such as ulcerative colitis.

Reasons for reported ethnic differences may be due to variances in how symptoms are perceived, as well as understandings of what they mean and their significance. Rahim-Williams, Riley, Williams and Fillingim (2012) for example conducted a systematic review of quantitative evidence focusing on the differences in sensitivity to pain between white Americans and African Americans. The 26 included studies were reported to have medium to large effect sizes, with tolerance to pain concluded to be much higher amongst white Americans. Similar findings have been reported when comparing South Asian males with white British males, with the former demonstrating a significantly lower threshold towards pain and being more likely to report it (Watson, Latif & Rowbotham, 2005). Kirmayer and Young (1998) examined illness narrative data across a mix of ethnic groups. They demonstrated within their review that PPS were understood to be either related to an organic disease or psychopathology, or were perceived to be an outward expression of inner conflict, social dissatisfaction or emotional distress.

Some evidence suggests that discrepancies between ethnic groups in terms of health and well-being may be also due to differences in coping strategies. Lam and Zane (2004) argued that white Americans were more likely to exercise primary

control than Asian Americans, i.e. were more inclined to manipulate their current environment in order to fit with their needs. In comparison Asian Americans adhered to secondary style coping, and so were more likely to try to change their thoughts and behaviours in order to adapt to their environment. With this in mind, it is reasonable to assume that ethnicity is likely to play a mediating role upon adopted coping strategies in times of adversity (Bailey & Dua, 1999; Rothbaum, Weisz & Snyder, 1982). Another study comparing the coping styles of 238 older white Americans and 206 Korean Americans experiencing stressful life events strongly supports this suggestion. Within this study, white Americans were reported to adopt a more active approach utilising planning strategies in order to cope with stressors, whereas Korean Americans were shown to adopt avoidant and emotionally focused coping mechanisms (Lee & Mason, 2014). More specifically related to PPS, Njoku, Jason and Torres-Harding (2005) examined the coping strategies of European Americans, African Americans and Latin Americans living with chronic fatigue. Through the completion of Coping Orientation to Problems Experienced (COPE) scales, it was found that African and Latin Americans were more likely to adopt avoidant coping styles, including denial, and therefore demonstrate less ability to adapt.

#### *1.2.5. Ethnicity and religion*

Religious coping has been shown to some extent to also be a protective factor for health related problems. A critical review reported that religious activity, such as prayer, can help to boost immunity, reduce any feelings of anxiety, reduce symptom severity and even reduce the number of days spent in hospital (Coruh, Ayele, Pugh & Mulligan, 2005). Religious beliefs are also known to influence health-related behaviours. Holt, Roth, Clark and Debnam (2014) adopted the Religion-Health Mediation Model in order to examine the relationship between

religion and health in African Americans. Their findings were that those who were more religiously engaged were more likely to avoid drinking alcohol, and more likely to eat healthier food. A more recent literature review by Park, Masters, Salsman, Wachholtz, Clements et al. (2017) has also shown that religious coping has benefits in terms of mortality and can also positively influence behaviours, leading to better physical and mental health outcomes. Reviews conducted prior to this have also concluded that religious and spiritual beliefs can act as a protective factor and promote improved health outcomes (Cotton, Zebracki, Rosenthal, Tsevat & Drotar, 2005; Chida, Steptoe & Powell, 2009). Despite the potential benefits, there is also evidence that some religious beliefs, such as believing that their poor health is a result of God punishing them, can have harmful effects on both mental and physical well-being (Lee, Nezu & Nezu, 2014). BME groups typically hold much stronger religious beliefs than those who identify as white British (Nandi & Platt, 2014). Njoku et al. (2005) reported differences in terms of religious coping styles between ethnic groups, with African Americans being significantly more likely to take comfort in their religious beliefs. Nevertheless, as BME groups on the whole evidently suffer much higher rates of poor health and well-being, as stated previously, it may be the case that ethnic minorities more regularly engage in negative religious coping behaviours.

#### *1.2.6. Ethnicity and social support*

Social support and relationships with healthcare services may contribute to the health discrepancies between ethnic groups. The presence of a good social support network has long been demonstrated to have beneficial effects upon both physical and mental health outcomes, both directly and by acting as a buffer (Carpenter, Fowler, Maxwell & Andersen, 2010; Shier, Ginsberg, Howell, Volland, Golden et al., 2013). As well as being shown to be helpful for the individual, social support has also been demonstrated to help reduce the burden on healthcare costs

(Shier et al., 2013). Ethnic differences in terms of social support have been detected. Das-Munshi, Becares, Dewey, Stansfeld and Prince (2010) reviewed the national survey data from 4281 patients belonging to a range of BME groups. Following multi-level logistic regression, they reported that individuals living in areas of a high own-group ethnic density were more likely to have better mental health, due to reduced incidence of ethnic discrimination and more social support. Cole, Matheson and Anisman (2007) examined the moderating effect of social support in white European and BME college students over one year. At the half-way point, BME students were less likely to succeed academically than white European students and demonstrate poorer well-being, due to having limited social support. The BME college students who did receive more positive social support enjoyed greater academic success.

#### *1.2.7. Experienced difficulties in treating BME patients with PPS*

BME groups are generally less likely to access healthcare services than their white British counterparts. A semi-structured qualitative interview study with hard-to-reach groups including BME patients suffering from poor mental health identified several key factors that may go some distance to explain the lower rates of healthcare access. These include the patients' own perceptions of their feelings of distress, their inability to discuss their health problems with their GP due to language barriers and not being able to use the services appropriately (e.g. not being aware of how to register with a local GP, or not knowing how to ring and book an appointment) (Bristow, Edwards, Funnel, Fischer, Gask, et al., 2011). Differences in terms of traditional medicinal practices are also likely to exist, which could also provide further explanation for BME populations being harder to reach (Struthers & Nicholls, 2004). Further studies conducted within the UK have demonstrated that BME groups consider their own religious and cultural values to

be somewhat undermined within NHS healthcare, due to healthcare professionals adopting a biomedical approach (Memon, Taylor, Mohebati, Sundin, Cooper et al., 2016). Factors such as these on behalf of the patient, teamed with the notable difficulty that healthcare professionals face when treating patients, suggests that BME patients with PPS are at a higher risk of not receiving healthcare and support. More research is required on the role that particular cultural factors, including coping styles, religious beliefs and social environment, play in terms of how PPS are perceived by BME patients and how they feel these symptoms would be best managed.

#### *1.2.8. Proposed research and aims*

In order to gain a better understanding of the patients living with PPS, it would be useful to understand patients' experiences in their own words. Due to the evident difficulties in treating PPS, it would also be useful to understand how symptoms have impacted upon day-to-day life, as well as their experiences of accessing and using healthcare in order to understand how this may potentially be improved. A detailed narrative comparison between white British and BME participants would help to expose key differences, thus provide some insight into how future treatment may need to be modified in order to be ethnically sensitive. The findings from this research could potentially be used to help design future interventions and written healthcare guidelines on how to effectively treat BME patients living with PPS. While adopting a more ethnically suitable approach may encourage patients to access healthcare services, healthcare professionals will be in a stronger and more informed position to advise BME patients with PPS on how to take an autonomous approach and actively make behaviour changes that benefit health. Providing this type of information shortly after patients first seek out help will mean that any health-related issues are likely to be managed effectively earlier on, reducing the likelihood

of patients returning for repeated healthcare appointments and investigations.

Based on this information, the aims of this thesis are to:

- 1) Understand BME experiences of living with PPS
- 2) Understand BME experiences of accessing and receiving healthcare
- 3) Understand the role and influence of cultural factors amongst BME participants

## CHAPTER 2: METHODOLOGY

### 2.1: Qualitative methodology

The aims of this research are threefold. Firstly, it is to understand BME experiences of living with PPS; secondly, to understand their experiences of accessing and receiving healthcare, and thirdly, to understand the role and influence of cultural factors. The descriptive and explorative nature of the research aims are therefore best served by a qualitative approach (Ploeg, 1999), due to their scope for capturing rich and detailed information that cannot be acquired through the use of quantitative methodologies. To elaborate further, the qualitative approach in general is described as a *“naturalistic, interpretative approach concerned with understanding the meanings that people attach to actions, decisions, beliefs, values and the like within their social world, and understanding the mental mapping process that respondents use to make sense of and interpret the world around them”* (Ritchie & Lewis, 2003).

Qualitative research is flexible in that it can be used in a wide variety of contexts in psychology (Willig & Stainton-Rogers, 2008). The selected method and how it is utilised however is largely dependent upon the researcher themselves, in particular the researcher’s own experience and perceptions of how the desired information would be best obtained. However, qualitative methodologies are also selected on the basis of what the specific aims are of the research, who the targeted participants are, and who this research is being conducted for. This is both in terms of the prospective audience and who funded the research, if applicable (Ritchie & Lewis, 2003).



### *2.1.1: Qualitative research interviews*

Qualitative research interviews are particularly effective when aiming to obtain sensitive data, as participants may feel relieved after sharing their stories (Elmir, Schmied, Jackson & Wilkes, 2011). Furthermore, many participants may feel uncomfortable sharing personal information within a focus group. There are also benefits in that individual interviews are more flexible in terms of time and location. The ability to capture sensitive information and logistically adapt to suit the requirements of participants, were particularly important considerations when selecting the most appropriate methodology to use. Semi-structured interviews were the chosen methodology chosen for this study, as they allow the researcher to control the interviews through a list of questions, while also providing the participant with freedom to express themselves (Gill, Stewart, Treasure & Chadwick, 2008).

### *2.1.2: Rationale for using qualitative methods to examine differences between groups*

Employing a qualitative methodology to look for similarities and differences between sub-groups enables the researcher to still capture and analyse rich and descriptive data, if further exploration and description is still required within this research area. Quantitative methodologies, such as RCTs and quasi-experimental research designs, can also be used to effectively compare sub-groups of data, and are frequently used in healthcare research to investigate the impact of health-related interventions (White & Sabarwal, 2014). However, these quantitative methodologies take a deductive approach, with participant responses limited by pre-determined variables, or existing hypotheses (White & Sabarwal, 2014). Due to the exploratory and descriptive nature of the research aims of this study, as well as the limited number of participants available for contact, a qualitative approach was considered more appropriate for this study.

The successful use of qualitative methodologies in studies performing sub-group data comparisons, further justifies its use for this research. Tonkin-Crine, Coenen, Fernandez-Vandellos, Krawczyk et al., (2011) conducted 52 qualitative semi-structured interviews with GPs in five European countries, using a framework analysis method to compare responses across countries to strategies used to promote antibiotic prescription, although this study identified mostly consistencies across nations. Another study by Gwede, Jean-Francois, Quinn, Wilson, Tarver et al., (2011) used semi-structured interviews to explore attitudes towards colorectal cancer across three ethnic groups: African Americans, those from English-speaking Caribbean countries, and those from Haiti. Their approach successfully identified key differences between groups in terms of how curable colorectal cancer was perceived, how it could be prevented, and where they would prefer to access information. As a final example of qualitative studies with sub-group comparisons, Paul, Ross, Bryant, Hill, Bonevski et al., (2010) compared smokers of high and low socio-economic statuses using focus groups. Key differences were identified in terms of social context, thus informing future anti-smoking campaigns.

## **2.2: The target group and how they were approached**

Participants who participated in the qualitative study were initially participants enrolled onto the PRINCE Secondary trial. Therefore, information has been provided on the trial initially, in order to provide the necessary context.

### ***2.2.1: The PRINCE Secondary trial***

The PRINCE Secondary trial is an RCT testing the clinical and cost effectiveness of a new approach of CBT in patients living with a diagnosis of PPS. Participants were either allocated to receive CBT with Standard Medical Care, or Standard Medical Care only. Due to pre-existing CBT trials with Chronic Fatigue

Syndrome patients (White, Goldsmith, Johnson, Potts, Walwyn et al., 2011), and dissociative seizures (Goldstein et al., 2010), patients presenting these particular syndromes/symptoms only were excluded from the trial and therefore the qualitative study.

Patients were recruited into the PRINCE Secondary trial following their attendance at secondary care clinics at Guy's and St Thomas' Hospital and King's College Hospital. Patients included within the trial had received at least one diagnosis from the following syndromes or individual symptoms: fibromyalgia or chronic widespread pain, non-cardiac chest pain, functional neurological symptoms, functional gastrointestinal symptoms including IBS and functional dyspepsia, and functional respiratory symptoms including dysfunctional breathing and chronic cough. Patients were only recruited into the trial if they had received confirmation of their diagnosis following diagnostic tests during a consultation with either a Consultant, a Specialist Registrar (SpR), or a Nurse Specialist. Patients with co-morbid conditions were not necessarily excluded from the trial, as long as these associated symptoms were either in remission or were considered less debilitating than relevant PPS. Other inclusion criteria for the PRINCE Secondary trial were those aged 18-70, a Work and Social Adjustment Scale (WSAS) score of a minimum of 10 indicating at least a moderate level of functional impairment (Mundt, Isaacs, Shear & Greist, 2002), and an ability to read and write in English. Exclusion criteria included alcohol and drug dependency, a daily intake of 10mg or more of Benzodiazepines, and being considered at imminent risk of self-harm.

### *2.2.2: Target group and setting: the qualitative study*

Ethical approval for the qualitative study was obtained through the Camberwell and St Giles Ethics Committee (see Appendix II). This was conducted as information relating to the qualitative study was included as part of the

submission of an ethical amendment for the PRINCE Secondary trial. Within the amended protocol (see Appendix III), it was clearly stated that participants may be approached to conduct an ad hoc qualitative interview. Once ethical approval was officially granted by the Committee, the approval letter and all developed documents including the updated PRINCE Secondary protocol were forwarded to all relevant Research and Development (R&D) departments within NHS trusts actively referring patients for the PRINCE Secondary trial (Appendix IV). Individual documents for the qualitative study included the participant information sheet (Appendix V), consent form (Appendix VI), topic guide (Appendix VII) and the debrief sheet (Appendix VIII). This was to ensure that all participating hospitals were aware that their registered patients may also be approached for the qualitative study following their enrolment onto the trial. Integrated Research Application System (IRAS) forms for PRINCE Secondary were also updated to include the qualitative study (Appendix IX). No trial participants were approached for the qualitative study until R&D departments had acknowledged and approved the new and amended documents.

Trial participants were not considered contactable unless they had provided their own consent to be contacted for future research. This was optional when providing their consent to participate within the trial. Participants who answered in the affirmative to be contacted were documented at the point of enrolment as approachable for the qualitative study.

### *2.2.3: Sampling strategy*

In order for both white British and BME participants to be equally represented within the qualitative study, a non-probability quota sampling strategy was selected. Purposive sampling was also employed within the BME and white British groups, with the aim to achieve a representative mix of different PPS and gender. Within the BME group, an attempt was also made to achieve a mix of ethnic identities. The

sample was limited to those who had provided their consent to be contacted for future research, and then to those who eventually returned their consent form.

#### *2.2.4: Sample size*

Guy's and St. Thomas' Charity (who funded the PRINCE Secondary trial and had invested interest in this qualitative research conducted), were keen for this qualitative research to consist of as many interviews with participants as feasibly possible. However, it was decided that recruitment should be ceased once 30 interviews were completed (15 white British and 15 BME). This was for two reasons. Firstly, this sample size was large enough to have accommodated a reasonable mix of PPS type and gender, as well as a mix of ethnic identities within the BME group, which would have been more difficult to achieve within a smaller sample size. Secondly, and most importantly however, data saturation had already been achieved within each group by this point.

#### *2.2.5: Definition of BME*

BME was defined within this study as any participants who did not classify themselves as white British, i.e. did not identify as white English, Welsh or Scottish. While the Institute of Race Relations (2017) defines BME as "*the terminology normally used in the UK to describe people of non-white descent*", white British was separated from other white groups within this study due to the potential cultural differences. To support this point, a study by Koutrelakos (2013) identified key differences between specific white groups (including Jewish, Armenian and Greek), and other white groups (including white European and pan-ethnic), particularly in terms of the strengths of their religious beliefs and ethnic identity. In addition to this, the Office for National Statistics lists 'white British' as separate from 'white Other', in recognition of ethnic differences (Office for National Statistics, 2016).

For all participants participating in the trial that had confirmed their willingness to be contacted for further research (as captured within their consent form), information regarding participants' ethnic identity was accessed through the demographic forms completed at baseline. This information on participants was stored alongside contact details, PPS type and gender within a password-protected spreadsheet accessible only to the researcher.

#### *2.2.6: Process of recruitment*

Due to the qualitative researcher being blinded to which treatment arm participants were allocated to within the PRINCE Secondary trial, participants were not approached until 20 weeks after trial enrolment. This was to ensure that the qualitative interviews did not clash with scheduled CBT sessions. Due to blinding, it is not known exactly how many qualitative participants received the CBT prior to their interview, but it was expected that a significant number of participants would have received the CBT. In an attempt to reduce any effect that this may have had upon responses, and to reduce the risk of un-blinding, participants were informed prior to the interview that the interviewer was blinded to their group allocation and therefore any CBT received as part of the trial should not be discussed.

Participants were contacted personally by the researcher via their previously stated preferred method of contact (telephone, text or email), where the qualitative study was briefly explained and interest was gauged. Those who expressed an interest were sent the detailed information sheet and consent form either via email or in the post. The information sheet explained the aims and objectives of the study, the potential benefits and drawbacks of taking part, and what their data would be used for. In addition, the information sheet informed participants that their participation within the study would remain confidential, and that they would remain anonymous throughout the analysis and write-up stage, with no quotes being

directly attributed to them. Participants were also informed of their right to refuse to answer questions if they did not feel comfortable answering, and were told of their right to stop the interview at any point and withdraw from the study. The information sheet also informed participants of the intention to audio-record the interview and that the purpose of this was that their interview could be listened to again by the researcher, transcribed and analysed. Participants were also reassured that interview recordings would be stored securely on password-protected computers at King's College London. These interviews would therefore only be accessible to researchers involved in the study. Prospective participants were also informed of the intention to publish this qualitative research within a peer-reviewed journal. Once participants were provided with the information sheet and consent form, they were advised to consider participation in the study for at least 48 hours.

Once signed consent forms were returned, participants were contacted by the researcher in order to arrange a suitable date and time for the interview. They were firstly invited to come for a face-to-face interview at King's College London. Face-to-face interviews were originally selected as it allows for a richer understanding of the participants and their responses, through the observation of body language and even verbal cues (Opdenakker, 2006; Willig & Stainton-Rogers, 2008). However, telephone interviews were also permitted following the requests of participants themselves. This was generally found to be more suitable for logistical reasons, and due to the debilitating nature of participants' symptoms. Telephone interviews were considered as a suitable alternative to face-to-face, due to their ability to capture data simultaneously with hard-to-reach populations (Opdenakker, 2006). This flexibility regarding how the data was captured was considered necessary in this case and arguably helped to obtain the required number of participants within the available timeframe. The researcher covered any travel expenses incurred as a

result of the interview, and all telephone calls were made by the researcher in order to avoid any cost to the participants.

### **2.3: Data collection method: Semi-structured (qualitative) interviews**

The individual topics that were to be covered within the interviews were deliberated and finalised well in advance. From here, the shape of the topic guide was considered as well as the individual questions. In order to deploy good practice, interview questions were open-ended and non-leading, thereby allowing the participant to lead the discussion themselves to a certain extent (Jacob & Furgerson, 2012).

#### *2.3.1: The topic guide*

The topic guide (see Appendix VII) was designed to ensure that participants were presented with easier questions near the beginning, followed by more challenging questions later on. This was to enable participants to develop a rapport with the interviewer, and grow in confidence when answering the questions (Jacob & Furgerson, 2012). At the start of the topic guide, there was an introduction, where participants were reminded of the information provided within the information sheet. In particular this referred to what the interview would aim to cover, the intention to audio-record the interview for transcription and analysis purposes only, and the participant's right to stop the interview or withdraw themselves from the research either during the interview or up to a certain date afterwards. The main body of the interview however consisted of four sub-sections: 1) their family and cultural/ ethnic background, 2) their PPS, 3) their experiences in accessing both primary and secondary healthcare for these symptoms, and 4) their daily life with the symptoms, particularly their work and social life. Examples of questions eventually included within the topic guide, were as follows:



*“Can you tell me a bit about your cultural background?”*

*“Can you tell me about your symptoms? Type of symptom, frequency etc.”*

*“Can you tell me about when you first went to seek medical advice for your symptoms?”*

*“How has your social life changed since you developed your symptoms? (If yes) how does this make you feel?”*

Questions included within the main sections were not necessarily discussed in the order of the questions presented within the topic guide. If certain topics were raised spontaneously, it was prioritised by the researcher for interviews to flow as naturally as possible. At the end of the interview, participants were invited to add any further commentary, or ask any questions regarding the study. Following the completion of interviews, each participant was provided with a debrief sheet and a copy of their signed consent form, which reminded them of how data would be stored, as well as the next steps in terms of the research study. Participants were also informed of their right to request a copy of the findings, and were also provided with the contact details of the researcher in case they had any questions or concerns in relation to the study.

#### **2.4: The researcher**

As a member of the PRINCE Secondary trial team, I was fortunate in that I already had access to the personal details of potential participants for the qualitative research, and following ethical approval of the study, I was able to directly contact prospective participants immediately. Having played a fundamental role in the recruitment of patients for the trial, in some cases I had already been formally introduced to potential qualitative participants within the hospital setting, which may have provided an advantage in that it would likely have instilled an element of authenticity and trust. However, as I already had an awareness of patient's

experience of PPS following previous discussions with patients, the likelihood of researcher bias was recognised to be high. Therefore, as the qualitative researcher and interviewer I understood the importance of detaching oneself from previous information in order to adopt an objective stance (Norris, 1997). This was to ensure that identified themes were not influenced by information external to the data provided within this qualitative research. Furthermore, in order to ensure that data collection and analysis process demonstrated rigour, it was important to approach the interviews systematically and reflexively. With this in mind, if another researcher were to have conducted the study, similar themes and conclusions in theory would have been reached (Mays & Pope, 1995).

## **2.5: Ethical considerations**

Guidelines were followed in order to obtain ethical approval from the Camberwell and St Giles Ethics Committee. In order to conduct this appropriately, the Informed Consent sheet was detailed and ensured to cover all necessary information. In particular it included information on the aims of the research, and their right to avoid specific questions and to stop the interview and/or withdraw. Whilst this information was first presented within the informed consent sheet, these main points were also re-iterated at the start of the interview. Within the informed consent sheet, participants were provided with the contact details of the primary researcher and their supervisor. Participants were also informed within the informed consent sheet that participant data would remain confidential and anonymous. This was also re-iterated within the introduction of the interview, where they were informed that rather than refer to participants by name, anonymity would be protected by the utilisation of a Personal Identification Number (PIN). For ease, the same PINs used within the trial for each participant were adopted.

It was acknowledged that participants may become distressed while being interviewed, due to them discussing their potentially debilitating PPS. In order to effectively manage this, as mentioned previously, participants were informed of their right to stop the interview, or withdraw themselves. Within the information sheet, participants were also informed that should they become distressed during the interview, they should seek help for this from their GP or from another qualified healthcare professional. The decision to allow for telephone interviews to be conducted as an alternative to face-to-face interviews was also partly ethically driven. Not only were participants given the option to travel to King's College London for the interview should they wish to leave the house for the day, if symptoms were severe they could do the interview from the comfort of their own home.

In order to ensure that patients' confidentiality and anonymity was honoured, interviews were recorded either face-to-face in a quiet room on University grounds, if the patient had opted to conduct their interview face-to-face, or they were conducted again in a private room over the telephone. In addition, only a password protected device was used to audio-record the interviews, and once interviews were completed they were immediately downloaded onto a secure server at King's College London. Interviews were not kept on the device, in case the device was mislaid at any point. Once completed, transcripts were encrypted, before being saved securely on the server. The researcher did not inform anyone of the password for these interviews, due to the potential breach of patient confidentiality that this could have caused. In a further attempt to protect patient confidentiality, as interviews were typed up they were referred to by their PINs only rather than any other information that could potentially identify them.

## **2.6: Transcripts**

Audio-recordings of all interviews were transcribed word-for-word, in order to recreate the interview on paper. This meant that any further vocal sounds such as 'erm', and any half-finished words or sentences were included within the transcript. In order to help with the analysis, all interviews were listened to again and written up personally by the researcher. In order to ensure that transcripts were as accurate to the spoken interview as possible, they were typed up as soon as possible following the completion of each interview. This helped with the contextual understanding of the interviews, which would likely have been lost to a certain degree should there have been a long delay. Following the completion of transcripts, they were re-read whilst listening to the audio-recording once again, to ensure that participants were not misrepresented within their transcripts.

## **2.7: Data analysis**

### *2.7.1: Thematic analysis and the rationale for use*

As the research aims were descriptive and exploratory in nature, interviews were analysed using an inductive style of the thematic analysis technique. Using an inductive approach allowed for themes to be devised from the data produced, rather than from the individual questions covered which expose the pre-conceived perceptions of the researcher (Willig & Stainton-Rogers, 2008). This type of qualitative analysis technique is perhaps the most frequently used technique within qualitative research, and is suitable for the analysis of descriptive data as well as interpretative data (Braun & Clarke, 2014). Thematic analysis is well established as a methodology, and has been successfully used in somewhat similar studies, including studies relating to Health Services Research (Golenko, Pager & Holden, 2012), patients' perceptions of nursing staff (Stewart, Burrow, Duckworth, Dhillon,

Fife et al., 2014), and patient experiences of living with illness, focusing on their beliefs with regards to their illness and treatment (Pouli, Das Nair, Lincoln & Walsh, 2014). The process of thematic analysis has been successfully broken down into six steps by Braun and Clarke (2006). All six of these individual steps were carefully followed here in order to successfully and competently execute the thematic analysis:

1. Making sure to become more familiar with the data – listening, transcribing and reading the data produced
2. Identifying an initial set of codes
3. Identifying the themes
4. Reviewing the themes
5. Defining and naming the themes
6. Producing a report - final analysis and write-up

#### *2.7.2: A framework analysis method and the rationale for use*

In order to identify any qualitative differences between self-identified white British and BME groups, an adapted version of the framework analysis method was employed. This type of method has been described as a “*systematic and flexible approach to analysing qualitative data*”, and it is most frequently used in conjunction with semi-structured interviews and thematic analysis (Gale, Heath, Cameron, Rashid & Redwood, 2013). Gale et al., (2013) identified several steps to follow in order to ensure correct employment of the method, the first few stages of which closely coincide with the stages initially outlined by Braun and Clarke (2006):

- 1) Transcription
- 2) Familiarisation with the interviews
- 3) Coding
- 4) Developing a functioning analytical framework

- 5) Effectively applying the analytical framework
- 6) Entering the data into the framework matrix produced
- 7) Interpreting the data

All qualitative data was analysed together before the identification of key differences between white British and BME participants, with the interview transcripts coded on an ongoing basis after the completion of each interview. With the traditional framework analysis method, data is organised into a spreadsheet Matrix (also known as Charting), with individual codes organised into columns and with participants in individual rows. However, within this study the researcher colour-coded the transcripts of white British and BME participants (purple for white British, red for BME), prior to developing the analytical framework. Items of data labelled with a specific code (with the participants' PIN number and PPS type also linked) were grouped together onto individual Word documents, with each separate Word document representing a different code. From here, a functioning analytical framework was created as the codes (Word documents) were easily grouped together (i.e. categorised). The use of colour coding white British and BME data meant that when reviewing the data overall in order to identify differences between the white British and BME groups, it was clear where both the similarities and differences were in terms of participants' responses. In summary, all identified steps of thematic analysis were employed, but these were integrated with steps 1-5, and 7 of the framework analysis method. The data was not however entered into a traditional framework matrix (step 6) as defined by Gale et al., (2013).

Thematic analysis and framework analysis methods have previously been used in together where researchers were interested in both the similarities and differences between distinct groups. For example, Tonkin-Crine, Yardley, Coenen, Fernandez-Vandellos, Krawczyk et al., (2011) conducted a qualitative study exploring patients' views of different interventions used within primary care for an

acute cough. The study was conducted over six European countries, and researchers were interested to see whether there were any differences between countries. Following translation into English where necessary and the application of thematic analysis, the framework analysis method was successfully able to identify differences in patient views across the different countries.

## **2.8: The Importance of reflexivity**

It is important to consider the potential impact of being an active researcher on the trial, and how it may have affected qualitative recruitment, data collection and interpretation of the research findings. In terms of recruitment in particular, due to the researcher having had previous contact with participants through the trial, participants may have felt obliged to consent to being contacted for future research. It is also possible that having already had professional contact with participants, past interactions may influence who eventually participates within the qualitative study. However, it could also be affected by the researcher feeling that certain trial participants may be more suitable for qualitative interviews and/or be more insightful than others. This would mean that certain participants who may be keen to be interviewed stand less chance of participating than others. Previous knowledge of participants may also lead the researcher to sub-consciously phrase questions in a certain way, which may lead participants to disclose certain information rather than other information. In addition, the researcher's interpretation of the qualitative data collected may also be skewed by previous knowledge or experience of participants. An example of this could be the expectation that if trial participants demonstrate low self-efficacy in terms of completing questionnaires on time, they may also report their PPS having a greater effect upon their ability to engage in daily activities.

In order to ensure that the data is honest and upstanding, it is the researcher's duty to reflect on these potential factors, and ensure that any existing

preconceptions or biases that may have been internalised are not expressed at the recruitment stage, at the point of interview, or while analysing the data. In order to effectively action the reflexive approach, the researcher is required to at least consider and be mindful of the different ways that preconceptions or bias may creep in and influence research findings (as described above). Other ways of how research findings could be affected are through preconceptions or biases relating to a participant's gender, age group, ethnic group, religious beliefs, political beliefs, sexuality and/or educational level. The researcher should always adopt a reflexive stance towards data collection and analysis to ensure that biases are not reflected at any point during the research process.

## **CHAPTER 3: RESULTS**

### **3.1: Introduction to results**

This section demonstrates the process, as well as the findings from the 30 qualitative interviews. Between May 2016 and May 2017, a total of 154 trial participants (both white British and BME) were identified as being eligible for contact, i.e. had provided their permission to be approached regarding future research. In total, 65 of these were invited to participate within the study on the rolling basis, either by telephone, text or email. Of those that were approached, 26 (40.0%) did not respond to their initial invitation, and 4 (6.2%) did not return their consent form by post after giving their verbal consent. Out of the five who provided reasons for their refusal to participate, four expressed a lack of interest in the study, and one disclosed a recent family bereavement. Out of the 65 trial participants contacted, 30 (46.2%) went on to participate in the study. Recruitment was ceased once it was perceived that a good mix of PPS type and gender had been included, and that data saturation had been achieved within both the white British and BME groups. Interviews ranged in length from 32 minutes and 49 seconds, to 80 minutes



and 27 seconds, with an average interview length of 57 minutes and 18 seconds. BME interviews were slightly longer on average than white British, averaging at 59 minutes and 44 seconds, compared with 54 minutes and 48 seconds. Please see Appendix X for the full interview schedule.

While all qualitative interviews were analysed by the main researcher, in order to improve inter-coder reliability and minimise any risk of researcher bias, a second qualitative research analyst was introduced to manually code four of the interview transcripts independently. Two of these transcripts were of interviews with white British participants, and two were of interviews with BME participants. Independent coding of the transcripts was later followed by a one-hour debrief session between both analysts, during which initial codes and labelling were discussed at length, as well as the general findings from interviews so far. Following the debrief session some codes were re-labelled in order to reflect the qualitative interpretations of both analysts.

### 3.2: Descriptive information

Five key themes were identified by the end of the analysis process, which were further broken down into 15 sub-themes. Please see Figure 2A1 below.

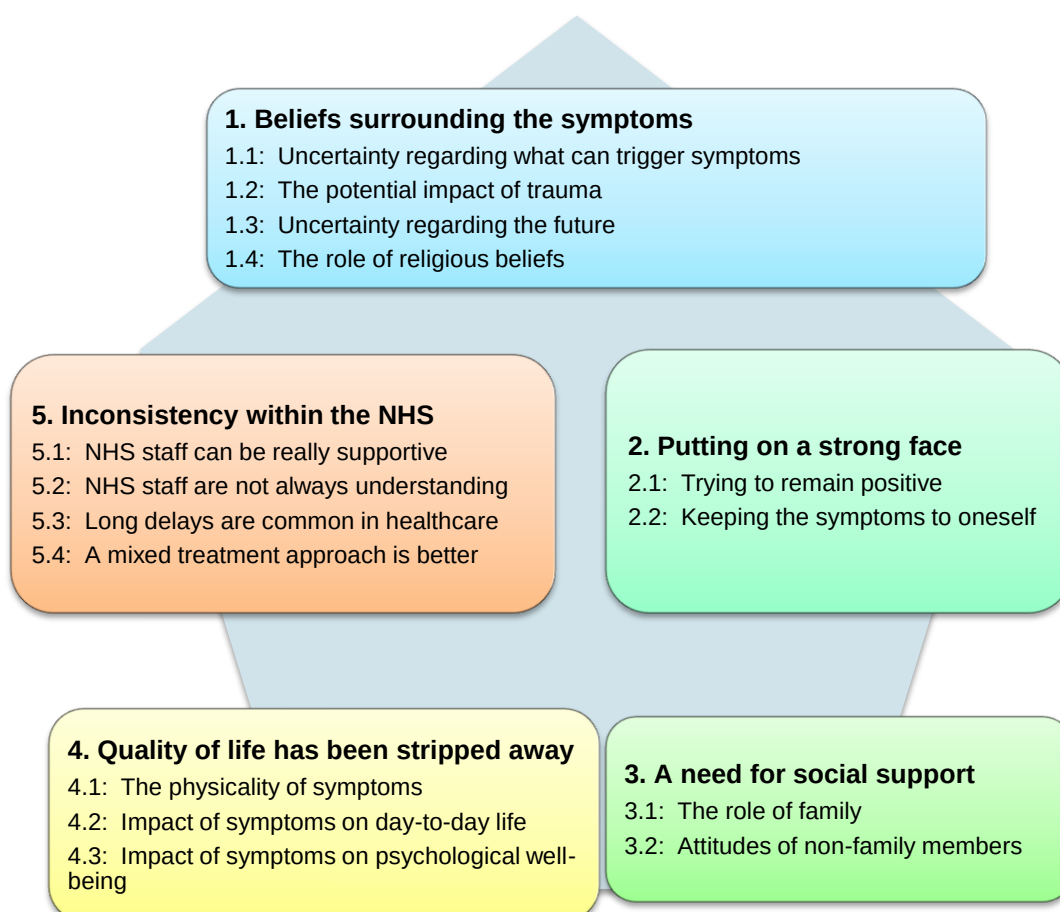


Figure 2A1. Themes and sub-themes

Differences between the white British and BME group have been acknowledged and highlighted within the results section below. In order to elaborate and help illustrate identified themes and sub-themes, participant verbatims have been selected and included as appropriate. In order to protect participant identity as promised, participants have been referred to by PIN allocated, as well as their PPS

type. For a full breakdown of identified codes as well as participant responses, please see Appendix XI.

Of the BME group, 11 participants were female and four were male. Six were currently living with their partner or spouse and children; four were living alone; two were living with a partner; one was living within the family home; one was living with a sibling, and one was sharing a room within sheltered accommodation. Nine participants completed their interviews over the telephone and six face-to-face, as requested. Table 2A1 provides more information on participant gender, PPS type and ethnic identity.

Table 2A1. Black and Minority Ethnic participants

| <b>Black and Minority Ethnic (BME)</b> |               |                                        |                                              |
|----------------------------------------|---------------|----------------------------------------|----------------------------------------------|
| <b>Participant No.</b>                 | <b>Gender</b> | <b>Persistent physical symptom</b>     | <b>Ethnic group</b>                          |
| P02002                                 | Female        | Fibromyalgia                           | White British and Sri Lankan                 |
| P02018                                 | Female        | Fibromyalgia                           | White Italian                                |
| P02021                                 | Female        | Fibromyalgia                           | White British and Indian                     |
| P02029                                 | Female        | Fibromyalgia                           | White Irish                                  |
| P02152                                 | Female        | Fibromyalgia                           | Hispanic (Colombian)                         |
| P01019                                 | Female        | Functional neurological symptoms       | Black African Caribbean (Jamaican and Bajan) |
| P01033                                 | Female        | Non-cardiac chest pain                 | Indian                                       |
| P01052                                 | Female        | Functional neurological symptoms       | Iranian                                      |
| P01053                                 | Male          | Non-cardiac chest pain                 | Black African Caribbean (Jamaican)           |
| P01061                                 | Male          | Dysfunctional breathing (Respiratory)  | White Irish                                  |
| P01079                                 | Female        | Functional belching (Gastroenterology) | Black African (Sierra Leone)                 |
| P02008                                 | Female        | Fibromyalgia                           | White British and Canadian                   |
| P02034                                 | Female        | Fibromyalgia                           | White Irish                                  |
| P01149                                 | Male          | Irritable Bowel Syndrome               | White Portuguese                             |
| P02195                                 | Male          | Abdominal pain and fatigue             | Kurdish                                      |

Of the 15 white British participants, the largest group (seven) lived alone; three lived with family members; two lived with partners; two lived in a flat-share, and one did not disclose this information. Of these participants, 12 completed their

interview over the telephone and three completed them face-to-face, as requested.

Table 2A2 provides more information on participant gender and PPS type.

Table 2A2. White British participants

| <b>White British</b>   |               |                                               |
|------------------------|---------------|-----------------------------------------------|
| <b>Participant No.</b> | <b>Gender</b> | <b>Persistent physical symptom</b>            |
| P01001                 | Female        | Functional neurological symptoms              |
| P01009                 | Female        | Functional neurological symptoms              |
| P01044                 | Female        | Fibromyalgia Syndrome                         |
| P01094                 | Female        | Irritable Bowel Syndrome (IBS)                |
| P01117                 | Female        | Irritable Bowel Syndrome (IBS)                |
| P01135                 | Male          | Irritable Bowel Syndrome (IBS)                |
| P01138                 | Female        | Chronic Cough                                 |
| P02031                 | Female        | Fibromyalgia Syndrome                         |
| P02032                 | Female        | Fibromyalgia Syndrome                         |
| P02038                 | Female        | Fibromyalgia Syndrome                         |
| P02040                 | Male          | Fibromyalgia Syndrome                         |
| P02010                 | Female        | Fibromyalgia Syndrome                         |
| P01172                 | Female        | Chronic cough                                 |
| P02170                 | Female        | Abdominal pain and burning (Gastrointestinal) |
| P01058                 | Female        | Functional neurological symptoms              |

### 3.3: Themes and sub-themes

#### Theme 1: Beliefs surrounding the symptoms

Within this theme, participants discussed their beliefs surrounding the cause and outlook of their symptoms. Within the first sub-theme, participants discussed their uncertainty regarding their symptoms. Within the second sub-theme however, many also disclosed their experiences of a physical or emotional trauma, demonstrating their beliefs that this may have been a contributor to their symptoms. Within the third sub-theme, participants discussed uncertainty regarding a potential cure for their symptoms. The final sub-theme acknowledged the religious beliefs of participants. Although religion was not linked as a cause of symptoms, some did express managing to find comfort through their religious beliefs.

### Sub-theme 1.1: Uncertainty regarding what can trigger symptoms

White British and BME participants' responses were similar in terms of the amount of confusion expressed regarding what may have caused their symptoms. Within both groups, many participants claimed to be uncertain about what had caused or triggered their symptoms in the first place, and claimed at this point to have no particular beliefs or suspicions about what the causes or triggers may have been.

*"From what I can gather, as far as I can remember, it's not something that my family had, so I don't know if it's hereditary or not. Erm, I'm, apart from about the thing in early 2000s, there's not much stress I've had in my life you know. I don't know, to be honest with you" (P02040, white British, Fibromyalgia).*

In a few cases, participants stressed that symptoms would tend to flare up in the absence of there being any warning, which made them even harder to control or manage.

*"... It comes on. I mean I could go to bed OK, get up in the morning and can't move. It's just a thing that just happens, and I don't know why it happens" (P02032, white British, Fibromyalgia).*

### Sub-theme 1.2: The potential impact of trauma

Another similarity between the white British and BME participants was that many participants from both groups had a history of trauma. Past physical traumas included injuries, medical procedures, physical abuse, illnesses or infections, and/or road accidents. In the vast majority of cases across both groups, participants had linked these experiences with their current symptoms, suggesting that they could have been a causal factor.

*"I assume that it happened when I fell out of my nan's loft, but I am not so sure, erm, the thing with my neck. It may have happened when I had a car*

*crash I suppose, because I had two in the space of a year. I had one in the beginning of the year and one at the end of the year... Then obviously when the physio did the traction thing it, it could have affected it there” (P01009, white British, Functional Neurological Symptoms).*

In terms of emotional trauma, both white British and BME participants reported experiences of bereavement, physical/verbal and sexual abuse, mental illness, poor relationships with family, and political/religious conflict. In cases of emotional trauma however, it was somewhat less common for the trauma to be linked with their symptoms, with many disclosing emotionally traumatic experiences independently.

*“When we were in Iran we had to say we were Muslim. We can’t obviously say we’re Atheist because it has an execution penalty for that... We had to flee Iran a couple of times and finally to England in 2002... I was growing up and I could see things and I could realise that, you know, also my father, he was an Atheist. My uncle who died in battle in Iran against the regime, he was also an Atheist” (P01052, BME, Functional Neurological Symptoms).*

Interestingly, a significant proportion of those who disclosed either physical or emotional traumas had also expressed uncertainty regarding what may have triggered symptoms. This suggests that they may have had an idea that trauma contributed to the onset of their symptoms, but did not feel certain of this and were open-minded to the idea of there may being other contributing factors. A minority of white British and BME participants recognised that stress caused by either work or life events had likely acted as a trigger or contributed towards their symptoms.

*“When I think about my background, I think about my, I think about [inaudible] with me, it increase the symptoms as well. When I’m worried as well, yeah because it’s definitely worrying me a lot, and it’s worry a lot that causes it” (P01079, BME, Functional belching).*

### Sub-theme 1.3: Uncertainty regarding the future

White British participants were more likely to report having initially had a positive outlook regarding their symptoms, expecting that something could be done to either significantly reduce their symptoms or cure them completely.

*"I think at the start I expected a quick cure, a simple change in something and it would be fine, and then maybe just one follow-up just to say "Everything's fine. We don't need to see you anymore". Yeah, they were my expectations" (P01135, white British, Irritable Bowel Syndrome).*

BME participants were more likely to report struggling to accept their symptoms as they were.

*"... Though I know there is no cure, though I have been to various hospitals and seeing various people, and I've been to pain management group meetings and workshops and in hospital stay to learn how to manage the pain, I still have not accepted it. I still cannot believe that there is absolutely nothing to bring the pain down to a more acceptable level. That is what I cannot accept" (P02018, BME, Fibromyalgia).*

While BME participants were more likely to express hope that they would see an improvement one day, or that a cure would be discovered at some point in the future due to likely improvements in treatments available, they were also more likely to express worry about how it may affect their long-term future.

*"I just think like, I've just turned 30, um, and we're talking about having children and doing all these things like really great normal things, and in the back of my mind I'm like, "Shit, how am I going to have children with this? Like, I'm already in pain, I'm barely struggling to like get myself going and then I want to add like more stress and just, like just, natural drama into the mix? I just find like the prospect of having children very overwhelming. I*

*don't, yeah I don't know what my body's going to do..." (P02002, BME, Fibromyalgia).*

#### Sub-theme 1.4: The role of religious beliefs

A difference between the white British and BME participants was that BME were much more likely to have been raised to be religious, or at least had a religious influence upon their life, which also impacted upon their personal values. They were also more likely to discuss having spiritual leanings, taking a particular interest in alternative teachings, spiritual healing and meditation.

*"When I was living in Colombia, when I was small, I used to go to the church every week anyway. I grew up in a very believing family anyway, that you always had to put God first and pray to God to help you to go through things in life, and as soon as you put God in your mind, that's your primer thing anyway. You always believe in, in that" (P02152, BME, Fibromyalgia).*

While neither BME nor white British participants linked religion as a causal factor for symptoms, BME participants did more commonly describe how they had sought comfort through their religious beliefs, e.g. through praying to God for pain relief or for the strength to continue.

*"Sometimes I think, you know, sometimes just with every step I take, you know God will help me get through this, you know, if something happens... God will help me. My father, after he helped me, I just pray" (P01033, BME, Non-cardiac chest pain).*

### **Theme 2: Putting on a strong face**

Within this theme, participants discussed how they did not want it to appear as though the symptoms were taking over their lives and bringing them down. Within the second sub- theme, participants described their need to demonstrate this strong



façade to others, by keeping their symptoms private and not openly discussing them at every opportunity.

#### Sub-theme 2.1: Trying to remain positive

Although fairly common amongst both groups, the white British participants were more likely to express defiance towards their symptoms as well as determination that their symptoms would not take over their life, particularly in terms of their daily activities. Instead, they discussed making a strong effort to carry on with their day regardless of symptoms, in an attempt to continue to lead as normal a life as possible.

*“... There is that element that in comes in, but I get over it. I don’t let it affect what I do, so yeah on a daily basis it’s there all the time, calmer when I’m quiet, erm, so, but I just tend to get on with stuff, and just, not ruling my life”*  
(P01001, white British, Functional Neurological Symptoms).

White British participants also more commonly stressed that even though their symptoms were debilitating, they had managed to gain some perspective, acknowledging that their current health and future outlook could be much worse. This approach had gone some way towards helping these participants to psychologically cope with their own symptoms.

*“It’s not the worst thing it could be kind of thing, you know it could be really, really bad, like I could have cancer or leukaemia or something, or something really bad. You know that’s what I’ve been telling myself all the way through”*  
(P01009, white British, Functional Neurological Symptoms).

While a number of white British and BME participants emphasised the importance of feeling and appearing ‘normal’ (i.e. not living with PPS), it was more common for BME participants to express how this had negatively affected them.

*“... I just try to do the best that I can do with it, and be really positive about it, although it like totally gets me down that I’m not a normal person...”*  
(P02002, BME, Fibromyalgia).

#### Sub-theme 2.2: Keeping the symptoms to oneself

A similarity between white British and BME participants was that they both commonly expressed the importance of keeping symptoms private and to themselves so as not to have a negative effect on those around them, particularly as there was nothing that others could do to help.

*“I’m the sort of person who keeps things to myself, I think, yeah, if something’s not quite right. I don’t go around telling the whole world, you know... I don’t know, it’s just my personality I think. When I was at work, I used to go into work feeling like pain and it was awful some days, but you know, just get on with it. There’s not much people can do is there really when you’re in that situation. They’ve all got busy jobs, and you’ve just got to get on with life really”* (P02170, white British, Abdominal pain and burning).

### **Theme 3: A need for social support**

This theme demonstrates the importance of a good social support network. Within the first sub-theme, participants discussed the nature of their relationships with their family, with those who had good relationships more supported and understood by family members. Within the second sub-theme, participants discussed non-family members such as friends, who often were less understanding.

#### Sub-theme 3.1: The role of family

Around half of all participants reported having a close and healthy emotional relationship with their family or significant others overall, seeing or speaking with them on a regular basis. A difference between the white British and BME

participants however was that BME participants were generally polarised in terms of their relationship with family. BME participants were much more likely to report ongoing family problems, disclosing a wide range of ongoing issues, including tension and stress relating to family illness, trauma, rebellion, recent separation and even rejection. This meant that their support network was likely to be affected.

*“...I don’t have any contact with [older brother], so he doesn’t bother to phone me, or, you know, ring me. Never wants to know how I’m living here. He knows I’m on my own and got lots of health problems, because he’s very angry because I married against my family, and since then he doesn’t want to make any contact, or any relationship with me... Sometimes this makes me a bit upset, from time to time, and on the top, you know, when I got domestic violence, I was more upset because, you know because of that person, I didn’t listen to my family and then this happened, you know, it was really, you know, hard for me” (P01033, BME, Non-cardiac chest pain).*

Other BME participants however had chosen to openly discuss their symptoms and their impact with family, which meant that they could deal with the symptoms closely together.

*“...Yes [wife and son] are upset about it, obviously yes they are upset about it, especially my wife...obviously it does have an impact on all of them because there are times where I’m in great pain. If we want to go and have a day out, you know, and I’m, you know, and I’m walking and I’m suddenly losing my, you know, if I walk a little bit, about 10, 15 minutes I get, I get very, I get tired and sore, and you just, you can’t because you’ve got pain all over your body sometimes... I don’t think they’re happy with it, you know, they don’t like it” (P02195, BME, Abdominal pain and fatigue).*

### Sub-theme 3.2: Attitudes of non-family members

Another similarity between the white British and BME participants was that while many participants felt that they received good support overall from others around them, it was common for participants to report that their symptoms had been poorly understood by others, which triggered feelings of frustration.

*“... Everyone at work knows I’ve got IBS because if they’re handing out cake, I can’t have it, and they’re like ‘Oh are you on a diet? Why are you on a diet? You’re thin enough’. It’s like, ‘well do you think that I don’t want to eat the cake?’ And I think that’s the problem, everyone thinks you’re making it up because it’s fashionable” (P01094, white British, Irritable Bowel Syndrome).*

A few participants, from both the white British and BME group, stated that many of their relationships, particularly friendships or relationships with employers, had broken down since the onset of the symptoms, due to a poor understanding from others of how the symptoms had impacted upon their life.

*“I’ve lost 99% of my friends, I’ve only got about three real friends now. I don’t hardly see anybody anymore, because 99% I’ll have to cancel any meetings, any leisure, any outings, because at the last minute I could not go, and they did not think that it was all due to my not being well, because looking at me, it doesn’t show that I’m in pain” (P02018, BME, Fibromyalgia).*

## **Theme 4: Quality of life has been stripped away**

Within this theme, participants discussed the impact that symptoms had had upon their day-to-day lives. Within the first sub-theme, participants provided a physical description of their symptoms. In the second sub-theme, participants discussed how physical limitations had brought about big compromises in terms of social life and

working life. The final sub-theme addresses the impact that the onset of symptoms had had upon psychological well-being.

#### Sub-theme 4:1: The physicality of symptoms

A similarity between white British and BME participants was the description they gave of their symptoms. It was particularly common for participants from both groups to report pain and IBS symptoms, regardless of their main presenting PPS. It was also common for both white British and BME participants to experience extreme fatigue and poor sleep.

*“Pain exhausts you, physically exhausts you, erm, but when I say really tired I mean I really cannot stand up anymore. I cannot even erm, wash, brush my teeth. That’s how exhausted I become” (P02018, BME, Fibromyalgia).*

A difference between white British and BME participants was that BME participants were more likely to report living with multiple PPS, and/or co-morbid medically explained conditions, meaning that their health problems were generally more complex and likely to be more difficult to treat.

*“... You get dizzy spells, I’ve passed out a couple of times, you know, pains in your chest, you know, where at some point you think you’re going to have a heart attack, you know, so it’s a combination of a lot of things. It really depends how far I let my shortness of breath, I try to contain it, I don’t get those sort of things but if I’ve got a long flight of stairs or I try to rush for something then I’ll end up getting it, like dizzy spells, numbness, you know where you’re tingling in your hands and pains in your chest so you really have to say, ‘oh it’s a bad day’” (P01061, BME, Dysfunctional breathing).*

#### Sub-theme 4.2: Impact of symptoms on day-to-day life

A similarity between both white British and BME participants was that they described previously having led fast paced, busy and independent lives, meaning that they had a certain perception and expectation of themselves.

*“I think, I’m such an extrovert as well, sort of loud character, and I feel I’ve always been, I’m always meant to be like, especially my family like, you know the one that holds it together, and the one that’s the middle child, like I’m meant to be the strong one, like the only one that’s like left for University or gone travelling, or you know, stuff like that...” (P01094, white British, Irritable Bowel Syndrome).*

A further similarity between white British and BME participants was in terms of how their hobbies were affected. Many from both groups discussed having previously indulged in active interests, including various types of sporting activities, gardening, dancing, travelling, or going out to the theatre or to eat. However, the onset of PPS had forced them to make major life changes, such as adopting certain relaxation techniques and pacing in order to cope.

*“I just go at my own pace, I don’t get myself concerned about rushing because I’m not going to get myself sick, to a point where I collapse which I have done in the past” (P01061, BME, Dysfunctional breathing).*

The onset of symptoms meant that they could no longer indulge in their previous interests as frequently, and in some cases they had had to give up their hobbies altogether.

*“Before I got sick, there was nothing that I liked more than going out to eat, or cooking. I love cooking, baking, it was such a passion, I really enjoyed it, and it just felt like that got stripped away, and I wasn’t able to enjoy those things anymore...” (P01094, white British, Irritable Bowel Syndrome).*

Both white British and BME participants discussed how PPS had negatively impacted upon their working life. However, there was a difference between the groups in terms of their response: while white British participants were more likely to report making adaptations at work, either by changing their role or responsibilities or by reducing their hours, BME participants were more likely to report retiring from work altogether.

*“I used to do voluntary work and I had to give up because I was making such a mess of it, and they thought I was just totally stupid, and I’d go in another day and I seemed to be doing OK”. (P02034, BME, Fibromyalgia).*

Another similarity between white British and BME participants was that PPS had had a big impact upon their social life, stopping them partaking in social activities that they used to enjoy, such as going to parties, clubs, restaurants, cinema, or going round to friends’ houses.

*“[What] I used to do is play darts, and things were, and I was working, so things went from erm, from those groups I’d be doing things all the time. Now, sometimes I don’t see another person in days. Erm I can’t think about, oh I love, used to love dancing, going to clubs. I go to parties now, on the odd occasion, and just have to sit there, because I can’t do it” (P01044, white British, Fibromyalgia).*

Several participants, both white British and BME, described experiencing a reduced tolerance of others since the onset of symptoms, which had led them to avoid certain characters.

*“There are certain friends that are not in my life now, but when I first had [fibromyalgia] I was really, really bad and didn’t know how to deal with it, erm, so like I [had friends] before I tolerated, I couldn’t anymore. I couldn’t bear to be in their company because they were really full on, really hyper, er,*

*kind of really highly strung people, whereas before I would be quite tolerant. Now I find that my tolerance levels of those sorts of people around me are just non-existent really, so I kind of again tend to withdraw” (P02010, white British, Fibromyalgia).*

In a few cases, participants reported how they felt they regularly let people down by either cancelling their plans with them entirely, or by inconveniencing them if/when they did attend (e.g. by making them feel obliged to make special allowances). These experiences tended to deter them from attending these types of social events.

*“I won’t go to a dinner party because I don’t want to put too much stress on the host having to make a separate meal, so I’ll just never go to people’s houses having meals or buffets, I’ll just completely avoid it...” (P01094, white British, Irritable Bowel Syndrome).*

#### Sub-theme 4.3: Impact of symptoms on psychological well-being

A difference between the two groups was that BME participants were much more likely to report feeling emotionally frustrated by living with symptoms in the absence of a clear diagnosis. This was due to not being able to explain their symptoms to others, and due to the lack of uncertainty regarding their health.

*“... I went home with the medication but I’m still having pains. So obviously, well I think they miss something, so I kept on going back, to get to the emergency, and they kept on saying everything’s alright, all the bloods, ECG... it’s OK... so what’s the pain then, what is it? And nobody, up to this day I still don’t know why I’m having the pain”. (P01053, BME, Non-cardiac chest pain)*

A similarity between white British and BME participants however was that many from both groups reported experiencing low mood and depression since they had



had their symptoms, due to the frustration they experienced as direct result of the symptoms, as well as the direct impact and stress that symptoms had had upon them and their lives.

*“It affects you big time, because you know what I mean, er in my brain I’m still 21 and I don’t want to be turning into an old man already because I’m only 52, so you do get upset mentally, because you don’t want to be that way. You want to be running down the road or whatever, chasing after a girl if you’re lucky enough but er, and if not you want to feel young and this does upset you very, very much mentally” (P01061, BME, Dysfunctional breathing).*

A further difference between the white British and BME participants was that white British participants were much more likely to express feeling sad that their symptoms had left them feeling as though they could no longer keep up, which led to them feeling as though they were getting left behind.

*“...When I do go out, I walk very slow because I am in a lot of pain, and I go out, everybody has to slow down for me. Or they carry on walking and then they’ll wait for me, and it makes me feel horrendous. That’s, that’s one more thing that I can’t do that I used to be able to. It’s one thing trying to keep up with the conversation with people, you know, I just, they yell back at me sometimes ‘Oh yeah such and such and such and such’, yeah it makes me feel terrible...” (P01044, white British, Fibromyalgia).*

A few others, mostly BME, also expressed feelings of anxiety, which had come on as a direct result of their symptoms. These feelings of anxiety were exacerbated by the fear that these symptoms may actually be an indication of a more life-threatening health problem.

*“It makes me feel that I’m... going to die. I’m on edge; I’ve always got my phone next to me. I’m always on edge on my arse, thinking that something could happen...I think the doctors said that I’ve got social anxiety, because that’s how it’s made me” (P01053, BME, Non-cardiac chest pain).*

Another difference between the groups was that BME participants were more likely to report being able to hide or manage their negative emotions. White British participants however reported not feeling in control of their emotional response to symptoms, frequently describing feelings of upset, anger or worry.

*“I think if I talk when I’m upset I can actually be quite emotional, to the point that it takes me a lot to cry. It could be the embarrassment, because as soon as people see you’re upset, they’re automatically going to ask you ‘Are you OK?’ and that’s the question that you dread, because you know that you’re going to ball up and cry afterwards, and the fact is nothing’s wrong. I’m not depressed because my dad’s died or you know, my cat got run over. I’m just depressed because I’ve got this” (P02031, white British, Fibromyalgia).*

## **Theme 5: Inconsistency within the NHS**

This theme highlights the inconsistency of participants’ experiences with the NHS. The first sub-theme demonstrates that many participants had had a positive experience at some point during their medical journey. However, the second sub-theme refers to participants’ experiences of also being dissatisfied at some point with the knowledge and attitudes of healthcare professionals. The third sub-theme refers to how participants felt the process was often too slow or interrupted, and the final sub-theme indicates participants’ attitudes towards the treatment approach taken, as well as what they would have expected.

### Sub-theme 5.1: NHS staff can be really supportive

A difference observed between the groups was that white British participants generally reported a more positive experience of NHS healthcare than BME participants. Many told stories that revealed positive experiences of the NHS at some point in their journey, including them finding NHS staff to be very caring, with a genuine motivation to help them understand their symptoms and manage them in an appropriate way.

*“They’ve always been great. [The Consultant] has always tried. He’s tried so many different things throughout the years. I mean we were on first name terms. I had his secretary’s phone number so if I ever had a really bad time, I could ring through and arrange to see him. They’re really supportive”*  
(P01117, white British, Irritable Bowel Syndrome).

Despite white British participants having more positive experiences with the NHS overall, BME participants more commonly reported having had positive experiences with their GP, describing them as very thorough and instrumental in getting them referred quickly to specialists for appropriate help as quickly as possible.

*“I mean 95% of it I would say is my GP because, I have to see him every two weeks anyway, and he’s always very, he always wants to make sure, you know, is everything OK. And also your mental (health), and whatever, and so at some point, I’ve been very short of breath the last couple of weeks, and then he’ll push me in to the specialist and the specialist will take it from there. And then from there they’ve put me to this, and so, I’d say my GP would be 95% the person that has pushed me in the right direction. I feel I’ve been pushed in the right direction”* (P01061, BME, Dysfunctional breathing).

In a very small minority of cases, participants also acknowledged the current pressure that the NHS in general is under. Amongst this group, there was the

general belief that NHS staff were doing the best that they could under very difficult circumstances.

*“I would say it was, it was excellent. Absolutely. I have huge respect for [NHS hospital] as a hospital. I know the NHS is getting a slamming at the moment, but we all know it isn’t the NHS’s fault. But you know, like I’ve been down to my local hospital this morning for something else and you know, it is just amazing how it works and the care that one gets” (P01138, white British, Chronic cough).*

#### Sub-theme 5.2: NHS staff are not always understanding

A similarity between groups was that the majority of both white British and BME participants had felt let down or abandoned with their questions unanswered at some point during the medical process, either in primary care or secondary care. This meant that they were unsure of what to do or where to go next in order to get further help.

*“... Well the bottom line, they did send me for a few tests, but obviously there was no change... I have to say [healthcare] was poor, because I was discharged with a serious condition. Most importantly, I cannot go to work in this condition. It is life changing, and so the fact that a life changing condition is able to lead to the medical specialists discharging me, I cannot be satisfied with that, or believe that it was an acceptable effort. It will never be an acceptable effort as long as I am left with this condition for life” (P01149, BME, Irritable Bowel Syndrome).*

Around half of participants expressed frustration at the lack of understanding that healthcare professionals, including GPs, had demonstrated towards them, as well as their failure to action appropriately. In the majority of these cases this was in the

context of healthcare professionals doubting the authenticity of symptoms, or not demonstrating enough understanding.

*“... Every time I’ve gone to the GP, I’ve gone to one in Sheffield as well forgot about that, and it was just like, ‘well you know you have a problem with lactose’, the end. And it’s like, “I already know that!”... The impression I got from doctors was that I was just like being a silly girl” (P01094, white British, Irritable Bowel Syndrome).*

BME participants were more likely to report that healthcare professionals, including therapists, had not always delivered an appropriate level of care towards them, which had left them feeling despondent. While some of these participants described not receiving the reassurance that they required, in other cases participants reported feeling that these professionals were simply going through the motions of doing a job, and had failed to listen intently or even demonstrate empathy towards them.

*“I’ve seen so many therapists, the physiotherapists, they understand, try their very best to understand the problem that you’ve having, but there is the other one that, they say yes, but they are always with their mouth and also with their head, but you can see that in their eyes that it’s completely somewhere else. They’re not really listening to you properly. It’s like looking at my mum who’s got dementia. I speak to her, she’s looking at me, but her eyes are gazing through me, if you know what I mean. She’s looking at me but not really seeing me, and that’s the feeling that I get from some of the people that I’ve seen and talked to” (P02018, BME, Fibromyalgia).*

### Sub-theme 5.3: Long delays are common in healthcare

A similarity between white British and BME participants was that the majority of each group had reported the general medical process to be too slow. In many cases, this was due to delays in primary care.

*“... First of all with the GP it’s really hard to get an appointment and they say the first clinic in the morning you have to phone, therefore you have to wait a really long time and then you wait, wait, wait, and then they then come back and ‘we’ll see what we can do’. Then after that went back again, because literally, I went to sleep, and you know when you literally have to move your whole body because if you move, you get a popping, kind of, and that was happening a lot. So I went back, got told the same thing. They said “Yeah you probably slept wrong”. Still no scans, nothing and no referral” (P01019, BME, Functional Neurological Symptoms).*

Around a third of participants - both white British and BME participants - commented that they had struggled to make an appointment with their GP. Often this was because the surgery was struggling in terms of capacity. In other cases, participants reported that they had a preferred GP to see and therefore found that they had to wait to see them.

*“My GP practice is rather overloaded with, and trying to get in to see any GP, let alone my own, it’s like trying to make an appointment with God. Some days you could be lucky, and other days, forget it. They have so many locums that I’m lucky if I see the same GP twice. So, like in, I don’t really like to discuss it with people that don’t really know me”. (P02038, white British, Fibromyalgia).*

Another similarity between white British and BME participants is that around half of both groups disclosed having been misdiagnosed at some point by a healthcare

professional. This only acted to further delay the process of receiving their diagnosis of PPS.

*“I think at the beginning they thought I was just like making it up, erm, and they thought I was just being trendy until I was admitted to hospital, and because of the pain they thought I had appendicitis, then Crohn’s. For about two weeks I had Crohn’s disease and I thought that was the worst thing that could ever happen” (P01094, white British, Irritable Bowel Syndrome).*

A further participant stated:

*“What happened was, when I went to [hospital name], they actually did a video link between them and [hospital name], and that’s when [Hospital name] rang me and told me it was cancerous, and then clearly when Professor [name] looked at the tests, when they did the endoscopy, he found out that it wasn’t, so when I went to see him, he told me, you know, the good news. So that was a bit off-putting” (P02170, white British, Chronic cough).*

While more frequently white British participants described a sense of disconnect within the NHS due to their confusing experiences of healthcare, a similarity between the white British and BME participants was that many had had to take matters into their own hands and chase up their GP or the hospital department in order to avoid any further delays.

*“Apparently I fell off, fell through a load of cracks. I think the secretary didn’t like me, erm, and made sure I didn’t get the follow-up appointments, so my daughter had to turn around and start nagging this secretary and I got one” (P02038, white British, Fibromyalgia).*

#### Sub-theme 5.4: A mixed treatment approach is better

Another similarity between white British and BME participants was that the majority from each group had described how healthcare professionals had chosen to prescribe them with medication in order to treat their symptoms. This was not desirable, due to reports of the medications not being effective, being addictive and having side-effects, such as on general alertness. Some also criticised healthcare professionals for being quick to prescribe anti-depressants, rather than them investigate their symptoms more thoroughly.

*“...[GPs] seemed sympathetic, but they didn’t really seem to know an awful lot about what to do or, that they were quick to dish out antidepressants which I found didn’t help me at all” (P02010, white British, Fibromyalgia).*

However, a similarity between both white British and BME participants was that the majority for both were either offered or received other medical interventions later on. These included physiotherapy, specialised pain management courses, pain injections and even psychological therapy. A difference between the two groups however was that BME participants were slightly more in favour of holistic treatments, and would have liked to have received more complementary treatment.

*“They should, if, they should first find out what the problem, the root of the problem, and they should provide erm, services, like, if it is counselling you need, if it is activities, whatever, to help us because they can treat like Austria. They are really good with erm, people like us, people in general, they care about their society, they provide services. For example, they sent patients or clients to have activities to help rebuild their lives, to rebuild their confidence, their self-esteem, so they can tackle the stress. They can tackle all this anxiety, and for them to go back to work...” (P01052, BME, Functional Neurological Symptoms).*



### 3.4. Summary of key differences

Please find below a summary table of the differences between white British and BME participants, as observed within this study.

Table 2A3. Key differences between white British and BME participant responses

|                                                                  | Key differences                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Theme 1:</b><br><i>Beliefs surrounding the symptoms</i>       | <ul style="list-style-type: none"> <li>– White British initially had a more positive outlook than BME</li> <li>– BME struggled more to accept PPS and their impact <ul style="list-style-type: none"> <li>– Still holding out for a cure</li> <li>– More concern for the future</li> </ul> </li> <li>– BME had a greater religious influence <ul style="list-style-type: none"> <li>– More likely to seek comfort through religious beliefs</li> </ul> </li> </ul>                                                                                                                                                    |
| <b>Theme 2:</b><br><i>Putting on a strong face</i>               | <ul style="list-style-type: none"> <li>– White British more defiant and determined that symptoms would not control their lives</li> <li>– White British often perceive that their health could be worse</li> <li>– BME more affected by not feeling like a “normal” person</li> </ul>                                                                                                                                                                                                                                                                                                                                 |
| <b>Theme 3:</b><br><i>A need for social support</i>              | <ul style="list-style-type: none"> <li>– BME polarised in their relationships with family <ul style="list-style-type: none"> <li>– More unresolved family conflicts</li> </ul> </li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                            |
| <b>Theme 4:</b><br><i>Quality of life has been stripped away</i> | <ul style="list-style-type: none"> <li>– BME more likely to have multiple PPS/ co-morbid conditions</li> <li>– BME more likely to retire from work than white British, who were more likely to adapt their working life instead</li> <li>– BME more frustrated by living without a diagnosis</li> <li>– White British more likely to feel sad that they could no longer go at the same pace as those around them</li> <li>– BME more likely to report anxiety regarding their symptoms, assuming them to be a symptom of something else</li> <li>– BME felt more in control of emotions than white British</li> </ul> |

|                                                        |                                                                                                                                                                                                                                                                                                                                                                                                         |
|--------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Theme 5:</b><br><i>Inconsistency within the NHS</i> | <ul style="list-style-type: none"> <li>– White British had more positive experiences of NHS healthcare overall</li> <li>– BME reported more positive experiences with their GP</li> <li>– BME more likely to report an inappropriate level of care by healthcare professionals, due to lack of reassurance or empathy</li> <li>– BME more in favour of holistic therapies than white British</li> </ul> |
|--------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

## 4. Discussion

### 4.1. Addressing the aims

Although the themes and sub-themes were identified following inductive analysis of the qualitative data, they have successfully addressed the aims. Discussion of the findings in relation to the aims and the significance of these findings within a wider context have been explored in detail below. As the data for white British and BME participants were analysed collectively, the findings will be discussed in similar fashion, with identified differences between white British and BME participants addressed and discussed wherever appropriate.

### 4.2. Discussion of the findings based on the identified themes

The first theme, entitled “*Beliefs surrounding the symptoms*”, described the beliefs that participants disclosed regarding their symptoms. Within this theme, participants referred specifically to uncertainty regarding the potential cause of their PPS, and their uncertainty regarding their future, which can largely be explained using the IPQ concepts (Weinman et al., 1996). Within the first sub-theme of Theme 1, “*Uncertainty regarding what can trigger symptoms*”, participants discussed their confusion surrounding what may have possibly caused or triggered

their symptoms, with many reporting no particular beliefs or suspicions. This sub-theme identifies closely with the 'Causes' subcomponent of the IPQ, as well as the 'Curability/Controllability' subcomponent. A second sub-theme, "*Uncertainty regarding the future*", where participants were unsure of what the future held for them, overlaps with both the 'Curability/Controllability' and 'Consequences' subcomponents. Based on this, when considering the findings from a previous review (Broadbent et al., 2015), it is reasonable to conclude that the IPQ can adequately account for the cognitive representations of PPS, and therefore may be used to predict the longer term health-related outcomes. As a preventative measure, knowledge of the cognitive processes could be used to guide healthcare professionals towards what information to cover within their future consultations with PPS patients.

Within this study, BME participants were more hopeful for a cure, but also expressed more worry for the future. The potential implications of this are that any feelings of psychological distress and anxiety surrounding symptoms are likely to be more prolonged amongst the BME population, which in itself contributes to the longevity and severity of symptoms (Kenny, 2004; Price & Okai, 2016). Previous RCTs conducted with chronic pain and fibromyalgia patients have demonstrated ACT to significantly reduce anxiety, depression and symptom severity, as well as increase self-efficacy, mental agility and functioning (Veehof et al., 2011; Wicksell et al., 2013). ACT may therefore be of benefit to the population included within this study, particularly BME patients. However, larger and more robust studies conducted with PPS populations are required before concluding whether ACT is effective enough to be included as a recommended therapy within clinical guidelines and training.

Within a separate sub-theme, entitled "*The role of religious beliefs*", BME participants were more likely to report having strong religious beliefs, and although

they did not realise these beliefs as being in any way linked with the cause of their symptoms, they were more likely to take comfort in them, in that they had faith that their symptoms would be relieved, or that they would be given the strength to continue through God. This finding is supportive of previous studies comparing BME groups with both white British and American groups, which demonstrated certain ethnic minority groups to have stronger religious beliefs (Nandi & Platt, 2014; Njoku et al., 2005). Evidence suggests that religious and spiritual beliefs can boost health outcomes (Chida et al., 2009; Cotton et al., 2005; Park et al., 2017). However, despite this, BME groups have been shown to experience poorer physical and mental health (Missine & Bracke, 2012; Office for National Statistics, 2013; Parliamentary Office for Science and Technology; Stevenson & Rao, 2014). While the reasons for this are somewhat unclear, there is some evidence that certain BME populations are less likely to disclose mental health problems to healthcare professionals, due to their religious beliefs. Semi-structured interviews with 26 Black Africans of faith reported that poor mental health was perceived by the church to be a sign of “weakness” and a “moral failing”, due to the expectation that they should be “spiritually strong”. These interviews also revealed that the first port of call following onset of mental illness was the church, where a spiritual approach would be taken rather than they be advised to seek out professional help (Mantovani, Pizzolati & Edge, 2017). A review by Lauber and Rössler (2006) also reported the negative influence of religious beliefs upon mental health stigma and disclosure amongst the Asian community. Within this research study, it could therefore be interpreted that BME participants felt more uncomfortable disclosing psychological distress, and therefore reported feeling more in control of their emotions than white British participants, particularly when considering that BME participants experienced more health co-morbidities, as well as more concern for the future. However, this theory is in no way conclusive and needs to be explored further.

Within the second theme, '*Putting on a strong face*', white British participants generally reported greater psychological resilience following symptom onset than the BME group. For the first sub-theme, entitled '*Trying to remain positive*', white British participants expressed a determination that their symptoms were not going to completely take over their life, and also actively attempted to reduce the perceived seriousness of their situation by comparing PPS with more serious health conditions, such as leukaemia. The reason for white British participants demonstrating a greater acceptance of PPS within this study could be explained by research in the USA that demonstrated non-white groups to be more likely to adopt avoidant coping strategies when exposed to stressful events, such as denial (Lam & Zane, 2004; Lee & Mason, 2014; Njoku et al., 2005). Once again, the findings suggest that striving to improve patients' psychological flexibility, mental agility and self-efficacy may be beneficial, and may be achievable through the use of ACT. However, the findings from previous evidence, as well as this current study, should be viewed with caution, due to the employment of small sample sizes within the studies, but also due to the possible danger of research having misinterpreted BME coping styles.

A further theme, '*A need for social support*', emphasised again the importance of a strong and positive social support network, thus supporting previous research studies that have reported the benefits of this upon physical and mental health outcomes (Carpenter et al., 2010; Shier et al., 2013). Poor quality relationships during adulthood have been linked to increased somatisation (Liu et al., 2011), or the adoption of the 'sick' role (Adshead & Guthrie, 2015). Within this study, white British participants were more consistently reported to have close and supportive relationships within their family network. While many BME participants also reported this, as a whole the BME group was polarised as many reported ongoing family conflicts. A lack of support within the family network could also be

further compounded by increased risk of discrimination or lack of support within the wider community (Das-Munshi et al., 2010). A tentative explanation for BME participants reporting less consistently supportive relationships with family members could be history of insecure attachment, which has been found to be more common amongst certain BME populations (Bakermans-Kranenburg, van IJzendoorn & Kroonenberg, 2005; Malda & Mesman, 2017). The study by Bakermans-Kranenburg et al., (2005) for example compared African and white children's scores on the Attachment-Q sort, and reported African children's mean scores to be significantly lower than those of white children, with maternal sensitivity the greatest predictor of attachment quality. Taylor et al., (2012) linked insecure attachment directly with an increased prevalence of PPS. However, the relationship between insecure attachment and PPS, particularly amongst BME populations, needs further clarification and supportive evidence.

Another theory for why BME groups may have reported more ongoing family conflicts within this study could be down to BME patients feeling the need to adapt their social environment in order to accommodate their physical needs. Lam and Zane (2004) argued that certain BME populations were more likely to try to adjust themselves in order to fit better with their current environment, in comparison with the white American population who were more likely to manipulate their environment to accommodate their own needs. Based on this argument, it may be that BME patients struggle to adapt within their current social environment following the onset of symptoms, due to the tension it would create (Bailey & Dua, 1999; Rothbaum et al., 1982).

Another reason for ongoing family conflicts may be due to the strain that is placed upon family members, including significant others. While relationships with partners were not discussed as such within the topic guide for this study, and therefore not greatly acknowledged within the findings in their own right, evidence

for their strain has been provided by Arnold et al., (2008), who found that fibromyalgia significantly impacted upon romantic relationships due to the additional pressure on partners to financially support them and run the home, as well as the loss of physical intimacy. These findings are supported by another study with IBS patients, which also showed that perceived burden on partners was positively correlated with the level of physical disability, suggesting a definite impact on the relationship on behalf of the partner (Wong et al., 2011).

Regardless of the potential reasons for reduced social support, all PPS patients require access to a positive social support network in order to boost their physical and mental health outcomes (Carpenter et al., 2010; Shier et al., 2013). It is therefore important to ensure that all patients with PPS have access. In cases where patients appear to be socially isolated, it may be useful for example for healthcare professionals to discuss the benefits of social support and even provide access to local support groups.

The need for participants to adapt following the onset of symptoms was evident once again within the fourth theme, where participants discussed their experiences of living with the symptoms day-to-day. Physical symptoms more often than not were described as painful, but other common symptoms included IBS, fatigue and difficulty sleeping. Due to the similar descriptions given of symptoms across both white British and BME groups, it would indicate that a simple trans-diagnostic approach may be suitable for application for patients with different types of PPS. That being said, BME participants within this study reported more complex symptoms, due to the existence of co-morbid conditions alongside symptoms. BME participants were also more likely to report multiple PPS. These findings lend some support to the review by Rahim-Williams et al., (2012), who stated that African Americans within the USA demonstrated a much lower threshold to their PPS, and were more likely to report them. This may also why BME participants within this

study generally expressed lower resilience towards their symptoms (Bailey & Dua, 1999; Lee & Mason, 2014; Njoku et al., 2005; Rothbaum et al., 1982). Nevertheless, greater complexity of symptoms amongst BME patients, places them at risk of a poorer prognosis in comparison to white British patients (Rosendal et al., 2017). Based on these findings, clinical guidelines for treatment should acknowledge the additional complexities of treating BME patients, meaning that current clinical guidelines may need to be further reviewed.

Within a further sub-theme, entitled '*Impact of symptoms on day-to-day life*', daily functioning for white British and BME participants alike were shown to be affected, with significant negative effects reported in terms of both their working life and social life, as well as their ability to regularly engage in their hobbies. These findings are therefore consistent with those of Lidén et al., (2015) study, where individuals with PPS symptoms reported their overwhelming impact upon daily functioning. This therefore supports previous research that has demonstrated PPS to have a major impact upon psychosocial functioning (Arnold et al., 2008; Lidén et al., 2015). Within the study by Arnold et al., (2008), participants discussed how their symptoms had forced them to change their day job or adapt their current role in order to accommodate their needs. BME participants within the current study however were more likely to report redundancy, or retirement from work altogether due to their ill health. This again could be explained by avoidant coping behaviours (Bailey & Dua, 1999; Lam & Zane, 2004; Lee & Mason, 2014; Njoku et al., 2005; Rothbaum et al., 1982), as well as increased adherence to the sick role (Adshead & Guthrie, 2015). CBT has been shown to be effective in helping individuals to manage their PPS, in order to improve their quality of life and reduce work-related disability (Richmond et al., 2015). Furthermore, a previous RCT by Reme et al., (2015) demonstrated a significant improvement in terms of ability to engage at work, following the provision of CBT. The benefits following treatment were still



maintained at 18 months, demonstrating a long-term and perhaps even permanent change. Based on the findings from this study, and from previous research, CBT should be considered in cases where patients with PPS are keen to return to work.

A further sub-theme, entitled '*Impact of symptoms on psychological well-being*', described the psychological and emotional impact of the symptoms on participants. More than half of all participants within this study stated that they experienced low mood and/or depression, alongside their physical symptoms. Several other participants also expressed feelings of anxiety, although this was presented less often within the interviews. The prevalence of low mood supports the findings from Burton et al., (2011), who reported within their case control study that depression and anxiety was significantly more prevalent in patients with PPS seen in primary care. It also acts as further support for Henningsen et al's (2003) meta-analysis that revealed the prevalence of anxiety and depression to be even more prevalent in patients living with PPS, than in healthy patients and those with medically explained conditions.

Many participants described their feelings of emotional frustration, borne out of them living without a medical diagnosis, or the absence of an explanation for their symptoms. This also made it difficult for them to explain their symptoms to others, and validate their related behaviours. For a few, the additional worry and stress brought about by the absence of diagnosis put a further strain on their general sense of well-being, including their physical symptoms. The findings from this study are therefore consistent with those from previous studies (Aamland et al., 2013; Nettleton et al., 2004; Nettleton, 2006). Nettleton (2006) in particular implicated the impact that the absence of diagnosis had upon psychological health, due to the uncertainty relating to the symptoms themselves, and the assumption that symptoms may be psychological. Interestingly within this study, white British participants were much more likely to report ongoing feelings of sadness that they

were unable to continue with the lifestyle that they had become accustomed to as a result of their symptoms. In addition, white British participants were also more likely to report feeling as though they were not in control of their negative emotions, which they described as a mix of anger, shame, upset, worry and embarrassment. This somewhat contradicts previous research findings, which had presented BME patients to generally exhibit higher rates of mental health problems than white British patients (Missine & Bracke, 2012; Office for National Statistics, 2013; Parliamentary Office for Science and Technology, 2007; Stevenson & Rao, 2014), including higher rates of suicide (Mental Health Foundation, 2017). The reasons for this are unclear. However, as stated previously, BME populations living with mental health problems are less likely to report them and seek out professional help, due to cultural barriers including linguistic differences and poor awareness of the NHS healthcare system (Bristow et al., 2011). To support this further, higher suicide rates are known to exist amongst Asian women and higher alcoholism and depression amongst the white Irish population (Mental Health Foundation, 2017). A study conducted with Asian women in comparison with white British women has indicated that mental illness perceptions are likely to differ, and that Asian women are less likely to refer themselves for available treatments (Taylor et al., 2013). This is not surprising, given recent reports that current programmes are still perceived to be lacking in cultural awareness and sensitivity (Karasz, Gany, Escobar, Flores, Prasad et al., 2016). Regardless of ethnic differences in terms of reporting mental illness, this study and previous research suggests that all patients with PPS are likely to be at high risk of depression, sadness and anxiety (Aamland et al., 2013; Burton et al., Henningsen et al., 2003; Nettleton et al., 2004; Royal College of Psychiatrists, 2017), even more so than patients living with recognised medical conditions (Henningsen et al., 2003). This again suggests that the uncertainty and confusion surrounding symptoms is a likely contributor to poor psychological well-being.

As low mood and anxiety is evidently linked with the uncertainty and lack of understanding of symptoms, patients should receive psychoeducation in order to alleviate any potential doubts or confusions surrounding the nature of PPS. This point has already been published within recent guidelines for healthcare commissioners (Joint Commissioning Panel for Mental Health, 2017). However, to elaborate on this further, they should ensure to focus on the prevalence of symptoms in order to reassure patients that they are not alone. Secondly, they should aim to discuss potential predisposing, precipitating and maintaining factors of symptoms, in order to help patients understand how they may be unintentionally exacerbating symptoms. By explaining these points in a simplistic way, patients will then be able to relay this information on to others. Psychoeducation in this context should also include briefing on CBT-based principles, in order to describe the nature of the relationship between thoughts, feelings and health-related behaviours. At this time, healthcare professionals should also explain the benefits of CBT and its effectiveness in treating anxiety and depression and perceived symptom severity (Marks et al., 2014; Goldstein et al., 2010; Moss-Morris et al., 2010). ACT, which may also be effective in treating anxiety, depression and symptom severity, as well as boosting self-efficacy and mental agility (Veehof et al., 2011; Wicksell et al., 2013), should also be further reviewed as a potential therapy to include specifically within future commissioner guidelines (Joint Commissioning Panel for Mental Health, 2017).

The final theme identified within the data referred to patients reported experiences of NHS healthcare for their PPS. The first sub-theme, entitled *“NHS staff can be really supportive”*, exemplifies how both white British and BME participants commonly reported having had a positive experience of the NHS at some point during their healthcare journey, due to NHS staff demonstrating genuine care and concern, as well as being quick to act in order to ensure they received the

help that they needed. However, within the second sub-theme, *“NHS staff are not always understanding”*, the majority of participants disclosed that at some point along the way they did not feel their symptoms had been taken seriously enough. This was expressed in two very distinct ways. Firstly, at least half of both white British and BME participants reported feeling a sense of abandonment and confusion regarding what they should do next following their consultation. Secondly, many participants felt that healthcare professionals were initially doubtful of symptoms and were dismissive. Some participants also reported poor treatment from specialists and other healthcare professionals, such as physiotherapists. Many stated that they did not feel they had been treated as an individual, and did not feel in any way reassured following consultations. These findings strongly support those of previous studies that have demonstrated healthcare professionals to exacerbate symptoms, particularly through the delivery of both unhelpful and inconsistent information (Page & Wessely, 2003; Price & Okai, 2016). As poor treatment by healthcare professionals was more commonly reported amongst BME participants, it once again lends support to the argument that there is still low cultural sensitivity within clinical guidelines (Karasz et al., 2016).

The next sub-theme, entitled *“Long delays are common in healthcare”* referred to the length of the medical process, which was considered by participants within this study to be too long. The reasons for this included the GP taking too long to refer, as well the length of time it takes to see a GP. In addition, a number of participants also reported being misdiagnosed with an organic condition, such as Crohn’s disease, which supports the assertion that healthcare professionals favour providing patients with a medically explained diagnosis where considered possible (Nimnuan et al., 2000). The implications of this were that a diagnosis of PPS took longer than anticipated, as patients already believed themselves to have a ‘real’ diagnosis. Delays were also caused by occasional mix-ups within the NHS, e.g.

between hospital departments, which was more commonly reported by white British participants. These long delays prompted many to follow-up with either their GPs or the hospitals they were seen in, in order to ensure that referrals to specialists or for aftercare were not lost. The findings from this study also revealed that patients were often prescribed medications for their symptoms first, which they were dissatisfied with due to the potential side effects and addictiveness of the medications. In addition to this, it also reinforced patients' beliefs that healthcare professionals consider PPS to be 'all in the mind' (Nettleton et al., 2004). This finding suggests that in cases where healthcare professionals are unsure of the best treatment, they may choose to resort to the biomedical model of medicine. This is consistent with previous studies conducted with healthcare professionals that have demonstrated poor awareness of how to effectively treat PPS (Carson et al., 2004; Maatz et al., 2016; Salmon, 2007; Wainwright et al., 2016; Wileman et al., 2002; Yon et al., 2015). Junior doctors within the UK recently disclosed a lack of self-confidence in identifying and effectively treating PPS, which by their own admission even led them to even avoid patients altogether. As this discomfort in treating PPS is likely exacerbated by the negativity of more senior healthcare professionals (Maatz et al., 2016; Warner et al., 2017), it is important that this is overcome. By educating healthcare professionals on the nature of PPS, it will help them to identify symptoms quickly, and therefore treat or refer patients on more promptly. Yon et al. (2017), who distributed online questionnaires to training programme directors, reported an inadequate level of training for junior doctors, despite their recommendation of three hours every year. Workshops with a multidisciplinary team including junior doctors themselves led to several recommendations. Firstly, it was recommended that real examples be included and discussed within the programme, as well as role play and videos. As discussed earlier, while this may indicate for healthcare professionals what other professionals consider good and bad consultations, it does not take into account what patients themselves consider to be satisfactory and helpful.

Regardless of dissatisfaction with being prescribed medications and feeling dissatisfied with the care they received, many participants did disclose also having received or been referred for a wider range of treatments later on, including non-pharmacological treatments such as physiotherapy, injections, psychological therapies such as CBT and counselling, and even pain management courses. BME participants within this study were particularly likely to favour these holistic approaches. This type of flexibility in terms of treatment approach indicates that despite reported shortcomings in terms of NHS treatment, healthcare professionals are adhering to a biopsychosocial approach, rather than a biomedical approach. Based on the findings from this study, it may be that quicker access to holistic therapies would be of benefit, particularly for BME patients.

#### *4.3. Limitations*

There were several limitations for this study. Firstly, participants were recruited through a Cognitive Behaviour Therapy trial for patients with PPS. Participants taking part in the trial and in this qualitative study were likely to be particularly motivated, as well as open-minded when it came to seeking out and accepting professional help for their symptoms hence this was unlikely to be a representative sample. There are likely to be many patients living with PPS who are much harder to reach and therefore engage with and treat, due to their failure to attend hospital appointments. This is likely to be particularly relevant in the case of BME patients who were not born in the UK, who are considered more likely to struggle with language and specific terms, less likely to know what to expect from healthcare professionals, and less aware of what medical and psychological treatments are available through the NHS. Further research is required in order to understand how these particularly hard-to-reach groups could successfully be accessed and treated within the NHS.

Another limitation of recruiting from a trial was that some participants would most likely have received the CBT, whereas other participants would not have. Due to blinding, it is difficult to reflect on the extent to which this would have impacted upon the findings in practice, due to the unknown numbers within each group. However, it is likely that those who received CBT as part of the trial reported more positive experiences of healthcare overall. While attempts were made at the beginning to reduce the potential impact of this, such as requesting that participants refrain from discussing their experiences of CBT as part of the trial and informing them that the researcher was blinded to their group allocation, it is still likely that reflections of healthcare were affected which needs to be taken into account.

Another limitation was that the qualitative researcher was also employed on the CBT trial, which may have biased the overall results. Qualitative participants would have already been familiar with the interviewer, and therefore it is possible that participants may have felt obliged to provide desirable responses or may have withheld negative feedback, particularly when discussing their experiences of NHS healthcare, perhaps due to fears that feedback could be disclosed to their consultant. Participant responses may also have been affected due to their awareness of the researchers' own ethnic background. This may have led participants to expect the researcher to make judgements based on their answers, which again may have deterred them from being completely honest in their responses. On a reflective note, while attempts were made to avoid this by being as professional as possible, it is still possible that the researcher could have interpreted participants' responses slightly differently based on their previous knowledge and experience of participants whilst working on the trial. It is also possible that the researcher's own experiences of using NHS healthcare may have influenced their own interpretation of the overall findings.

The third limitation is that for this qualitative study all non-white British participants were grouped together as 'BME'. While this was conducted due to the unfeasibility of conducting the number of interviews required to confidently compare between individual ethnic groups, there are inevitably cultural differences between groups that were not acknowledged within this study. Due to the practical limitations of time and resource, in order to tailor future healthcare more closely, similar research should aim to gain an understanding of the cultural differences *between* different ethnic groups. The findings from this prospective research can be built upon the findings from this qualitative study.

Another limitation is that all participants, both white British and BME, were originally recruited through London-based hospitals. As the main focus was on the experiences of BME participants, it is important to note that London as a city is ethnically diverse, particularly within the boroughs of Lambeth and Southwark where Guy's and St. Thomas and King's College Hospital are based. This would indicate that the experiences of the BME participants within this study may not be representative of BME populations across the UK. This is likely to be particularly true in cases where BME patients are located in predominantly white British areas elsewhere. In the case of this study, it was not feasible to conduct interviews with BME participants based in other parts of the UK. However, it should certainly be a consideration for any future studies that are conducted with BME participants.

The final limitation is related to sampling. A flexible quota sampling method was used, as well as a purposive sampling method in order to obtain a mix of PPS and gender. Therefore, some participants were approached before others in order to try and achieve this. In addition, the researcher also attempted to recruit BME participants from a range of ethnic backgrounds, as well as obtain a representative mix of male and female participants. This meant that not all participants were granted the opportunity to participate within the study, especially towards the end of



recruitment where participants were approached on an individual basis. Participants were also largely self-selecting, in that many who were initially approached did not respond to their invitation. Several others declined participation, or could not be contacted. However, as the prospective participants were already taking part in the trial, it was anticipated that some would not have time to participate, or would not be open to engaging in further research when asked, despite providing their consent to be contacted.

#### *4.4. Recommendations for future practice*

The first recommendation would be for healthcare professionals to ensure to deliver patients with psychoeducation within their consultations where possible, in order to inform patients and caregivers and help them to psychologically adjust (Stafford & Colom, 2013). Previous evidence, including meta-analyses, has already demonstrated that psychoeducation is effective in reducing both feelings of depression and anxiety (Donker et al., 2009). In addition to this, it has also been shown to have some effect in reducing the severity of symptoms (Chen et al., 2013; Luciano et al., 2011). Furthermore, psychoeducation can be delivered successfully to patients living with long-term conditions in a number of different formats, which include paper-based documents, via the internet or social media, and face-to-face (Oncology Nursing Society, 2016). In the case of PPS, psychoeducation should endeavour to cover how 'normal' PPS are within primary and secondary care. Within this study, the word 'normal' was expressed many times within the interviews, suggesting that normalisation of symptoms is important for people living with PPS, supportive of an earlier study (Dowrick et al., 2004). Based on the findings from this research and further recommendations outlined by Dowrick et al. (2004), psychoeducation should endeavour to express the close relationship between psychological factors and physical symptoms in order to provide any

necessary reassurance for patients that their symptoms are not a sign of a serious medical condition.

In order to help patients manage their PPS and reduce the impact they have on day-to-day functioning, healthcare professionals should consider referring patients for evidence-based psychological therapies. CBT has already been shown to be effective in helping those with chronic health conditions engage at work (Reme et al., 2015). As suggested within this study, this may be particularly relevant for BME patients, who appeared more likely than white British to retire from work. However, there are further factors to consider. Unemployment rates for the BME population as a whole are already much higher than for the white population, estimated at 7.8% and 4.0% respectively (Brown, 2017). In addition, BME individuals educated even to degree-level are still reported to earn significantly less (23.1%) than the white population, and despite being over-represented within the healthcare sector for example, the BME population is generally under-represented at the higher level positions (Equality and Human Rights Commission, 2017; Gateshead Council, 2016). This could provide further insight as to why some BME participants may be more likely to retire from work altogether following the onset of PPS. It highlights potentially further challenges for healthcare professionals, including CBT therapists, which need to be addressed.

Acceptance and Commitment Therapy (ACT), a new therapeutic approach that integrates behaviour change with acceptance (BABCP, 2017), may be an effective therapy for those who are struggling to come to terms with PPS and their impact on their lives. As previously stated, this is due to its potential ability to alleviate anxious or depressive feelings, improve patients' self-efficacy, increase patients' mental flexibility and enable patients to come to terms with and accept their health conditions (McCracken & Gutierrez-Martinez, 2011; Veehof et al., 2011; Wicksell et al., 2012; Wicksell, Kemani, Jensen, Kosek, Kadetoff et al, 2013). Within

the context of this study, mental flexibility could potentially also help patients to come to terms with the possibility of their symptoms being permanent, and help them to come to terms with any physical limitations. However, further robust studies with the PPS population are necessary to establish the effectiveness of ACT, and whether it should be included alongside CBT and psychoeducation as a recommended treatment within clinical guidelines.

As a final recommendation, it is important to ensure that all patients have access to social support. Based on the findings of this study, some patients, particularly BME, may be at risk of social isolation due to having more frequent family conflicts. It is therefore imperative that healthcare professionals delve deeper within consultations in order to understand the scale and quality of their patients' support network. If social support is not a prominent feature of patients' lives, healthcare professionals should consider referring their patients to local support groups for ongoing support and social networking.

#### *4.5. Recommendations for future research*

The findings from this study have demonstrated key differences between white British and BME participants, which should be further explored. Future research should be conducted with individual ethnic groups, due to likely differences between them which have not been explored here. A qualitative approach similar to the one used within this study, would provide greater insight into the day-to-day lives, cultural factors, and experiences and expectations of NHS healthcare between individual ethnic groups. This would inform how to deliver a more tailored and culturally sensitive approach, so that BME patients may receive treatment as early as possible.

Qualitative research should also be conducted with both healthcare professionals and BME patients in future, in order to understand how effective

current recommended multidisciplinary treatment, as recommended published by the Joint Commissioning Panel for Mental Health in 2017, actually is in treating PPS. While it is commendable that the importance of educating healthcare professionals on PPS is being taken much more seriously than previously, and that a multidisciplinary approach is being recommended, current training courses and guidelines have been designed by healthcare professionals, with no direct input from patients who live with PPS themselves. The potential result of this is that not all patients will likely receive what they themselves believe to be the most appropriate course of treatment for symptoms. Healthcare professionals and patients collaborating in the design of any future training and written guidelines will help to ensure that patients receive the best possible healthcare and outcomes, and that healthcare professionals feel confident when treating their patients.

Despite the usefulness of qualitative research, it should also be noted that qualitative research as a whole is limited in that it is generally subjective, based on the answers of a small sample size. This means that the research findings produced whilst using this methodology cannot realistically be generalised to the PPS population. Therefore, future amendments to clinical guidelines and training cannot be implemented based on the results from this study alone. Qualitative research studies such as this are valuable in that they can produce rich and detailed descriptive and exploratory data, clearly highlighting the key issues. Based on the qualitative research findings, larger scale studies with greater scientific rigour (such as RCTs) can then be used to produce more robust evidence that clinical guidelines and training for healthcare professionals should be amended.

#### *4.6. Researcher reflections on the research process*

The idea to conduct this particular study came about following news that Guy's and St. Thomas' Charity, who had funded the PRINCE Secondary trial, were

also very interested in further research with BME patients living with PPS. As I had already developed a personal interest in conducting research with marginalised groups, including BME, it seemed to me like a great opportunity. I was also pleased that I was able to invest so much time in a project that not only I found interesting, but also those around me. Further to that, I knew I was carrying out research that potentially could lead to a review of the quality of healthcare not only for BME patients, but all patients with PPS.

The fact that I was able to contact participants directly through the trial did make recruitment easier, in that I already did not have to worry about participants not having PPS. In addition, there was no risk of my recruitment clashing with that of the trial. Having said that, I still found recruitment to be very challenging, as understandably many that I contacted were dubious regarding speaking so candidly about their lives with PPS, particularly their experiences of primary and secondary healthcare which were not always that positive. In total, recruiting and carrying out all 30 interviews took me approximately a year to complete, due to a number of prospective participants either turning down the opportunity to take part, or not responding to their invitation at all which I sometimes found quite soul destroying. At one particularly low point, it really felt like I was never going to finish the number of interviews I needed! Of course, this was not helped by having to conduct 30 interviews alone, with 15 in each group. Ideally, I would have conducted a slightly smaller number, taking into consideration my workload for the DPpsych and my full-time placement. During the more difficult times, it was challenging for me to remain focused on the end goal and I found myself having to take steps back from the study now and again in order to refresh myself, before returning to it. Luckily, I had opted to transcribe my interviews and code them on an ongoing basis, rather than save them until the end of data collection. This really helped me to be organised, particularly when it came to analysing the data, as I already found that I had ideas of

what my main findings were, and what my themes could be. Once I had coded all my interviews, and extracted relevant verbatims from the transcriptions, the first draft of my themes and categories seemed to come together for me fairly quickly. At the end of the analysis process, I found that I had five main themes with 15 sub-themes in total with clear differences between white British and BME responses. All in all, I found that being organised with this project really did help everything to come together on time. I did worry at one point that my findings may have been influenced by my understanding of previous research findings, or even what I had expected to find. However, having read back through my transcripts I am confident that only the information shared through the interviews was reported following the analysis.

For me personally, the best part of this project was being able to conduct the interviews myself, for two distinct reasons. Firstly, while I have previously worked as a qualitative researcher in the past, I have had very little opportunity to exercise these learned skills in recent years and I found this a great opportunity to do that. Secondly, I enjoyed talking to the individuals themselves on a one-to-one basis, which I felt they enjoyed too due to them being so open during our discussion. One patient even referred to their interview as “therapeutic”. Once all participants had made the decision to take part, they chose to be very open and honest about how the symptoms had impacted on their lives and what they felt about the quality of healthcare that they had received, which I found to be very insightful. None of the participants interviewed chose to stop the interview or withdraw their data from the study, which was naturally a relief for me, but I also found it very telling as it showed to me how serious participants were about the project being undertaken. Many participants emphasised at the end of their interviews how important they felt a research study like this was for them, which I found extremely motivating as it reinforced my own feelings that my research project could make a positive

difference, particularly for those with PPS within the BME population. I also really felt like that I had gained from carrying out all the interviews and transcribing them myself, as it taught me so much about the day-to-day experiences of living with PPS, and opened my eyes to some of the difficulties experienced amongst the BME group. Perhaps prior to these interviews, I was not fully prepared for what I heard, as there is only so much that can be learned beforehand by reading through previous studies.

I opted originally to conduct qualitative interviews using the thematic analysis technique, for two main reasons. Firstly, I felt there was already enough evidence out there to rule out using a Grounded Theory approach. Secondly, while Interpretative Phenomenological Analysis (IPA) is often used for studies focusing on experiences, they are generally very time consuming exercises, and therefore only around ten interviews would be conducted for a thesis of this size. However, this was not suitable for this study, as I had hoped to capture a range of PPS, and also compare between white British and BME participants. While it should be remembered that this is a qualitative study rather than quantitative, by being able to interview more people, I was comfortably able to reach data saturation with a mix of participants within the white British and BME group, and enable a large number of participants to tell their story.

In terms of my least favourite elements of conducting this study, I have two. The first was doing the transcriptions straight after completing the interviews, which took a very long time especially there were so many interviews. Each interview took practically a whole working day to finish transcribing. My second least favourite part of conducting this qualitative study was the recruitment. For reasons I touched on previously, I found the whole recruitment process to be gruelling and frustrating. At times I also felt restricted in that I was limited to contacting people who were already part of the trial. If I was to possibly conduct this research again, I would have

contacted individuals through secondary care clinics and perhaps existing national patient organisations, the latter of which would have enabled me to collect a more representative data sample by interviewing BME patients based also outside of the ethnically diverse city of London. As stated within the limitations above, there is the possibility that the experience for BME patients living with PPS can differ, depending on where they are living. This would be another interesting avenue to venture down, and one that I definitely would not rule out doing myself in the future. Further to this, I would also like to explore and compare specific ethnic groups, in order to obtain a greater understanding of the differences between different BME populations.

Since the data and findings from this study were written up, I am happy to say that I have already had the opportunity to disseminate my research findings to a wide and influential audience. On 1<sup>st</sup> June 2017, I presented this study at a seminar meeting held within the School of Health Sciences (SHS) at City, University of London. As this was the first opportunity I had had to present the study I was fairly nervous about how it would be received, but the feedback was generally very positive. One week later on 8<sup>th</sup> June, I also gave a poster presentation of this study at the annual SHS Doctoral Conference, again held at City, University of London, which also had a positive outcome. Since finishing the study, I have also had the opportunity to disseminate my research externally. On Thursday 22<sup>nd</sup> June, I gave a fifteen minute presentation on the research process of this study and its key findings at a stakeholder meeting organised and held at the South London and Maudsley Hospital. This meeting was attended by CCG leads, charity staff, healthcare professionals and academics, who generally expressed interest and enthusiasm for the study and its findings. Finally, I also presented this study as part of a symposium for the UK Society for Behavioural Medicine (UKSBM) conference, held in



December 2017. Over the next few months, I hope to continue to disseminate these research findings and will seek out appropriate opportunities to do so.

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## **APPENDICES**

## APPENDIX I

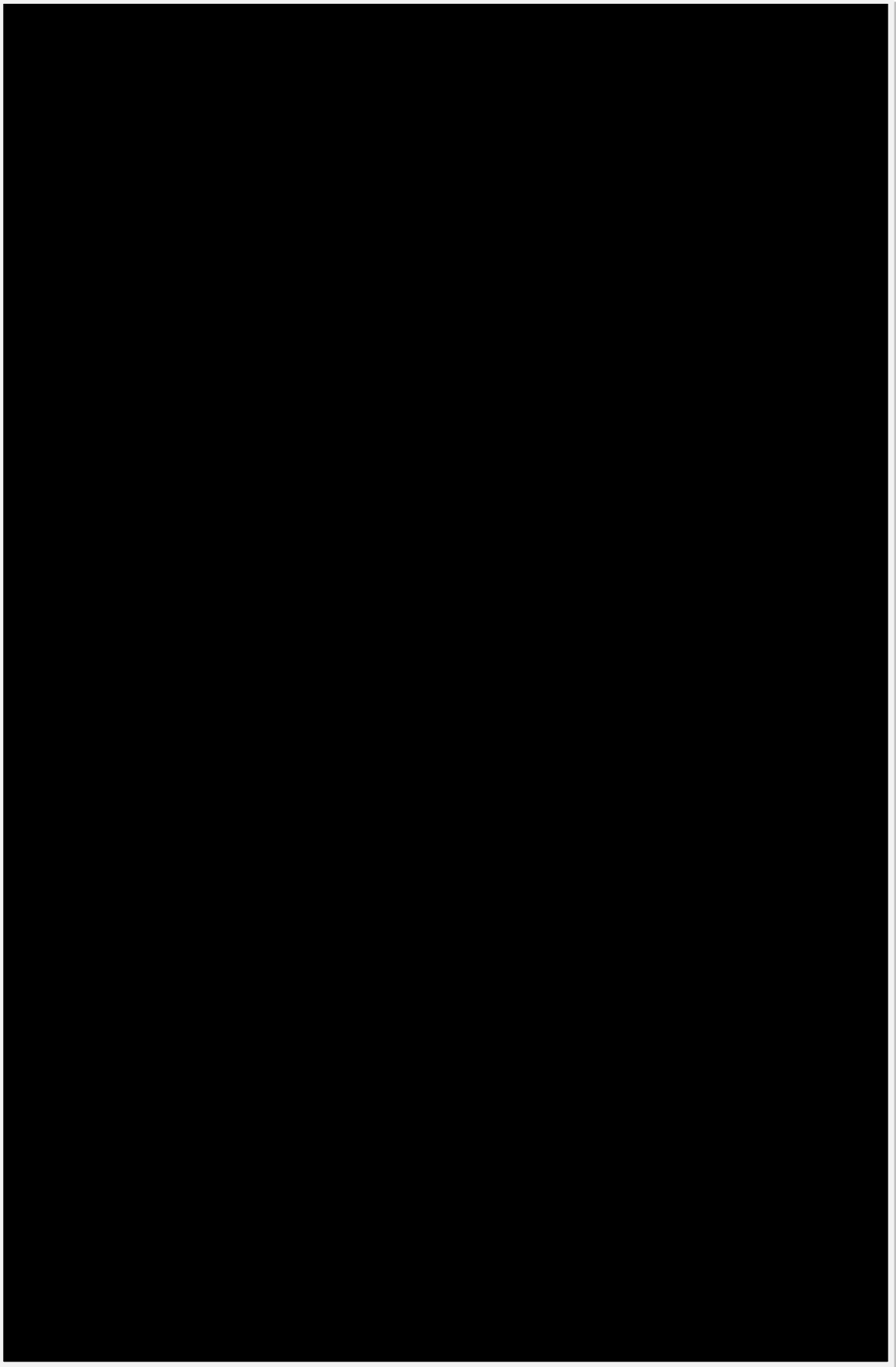
### Supervision plan: Research thesis

| Research        | Area of work (*outside of normal work)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            | Supporting evidence                                                 | Changes |
|-----------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------|---------|
| Research thesis | <p>Setting: Patients living with Persistent Physical Symptoms (Medically Unexplained Symptoms) currently taking part in the PRINCE Secondary Cognitive Behaviour Therapy trial (originally recruited through the Guy's and St. Thomas NHS Trust, and the King's College Hospital NHS Trust)</p> <p>Description:</p> <p>30 qualitative semi-structured interviews with patients living with persistent physical symptoms (15 White British participants, 15 Black and Minority Ethnic participants). The aims are to:</p> <ol style="list-style-type: none"> <li>1) To understand BME experiences of living with persistent physical symptoms</li> <li>2) Understand their experiences of accessing and receiving health care</li> <li>3) Understand the role and influence of cultural factors.</li> </ol> <p>1-hour Interviews are to be conducted either on the telephone or in person, dependent upon participant preference. Interviews will be transcribed and then analysed inductively, using Thematic Analysis. In order to identify how BME experiences may differ from White British, a framework analysis method will be employed.</p> | Thesis of 30,000 words (evidence of ethical approval in appendices) | N/A     |

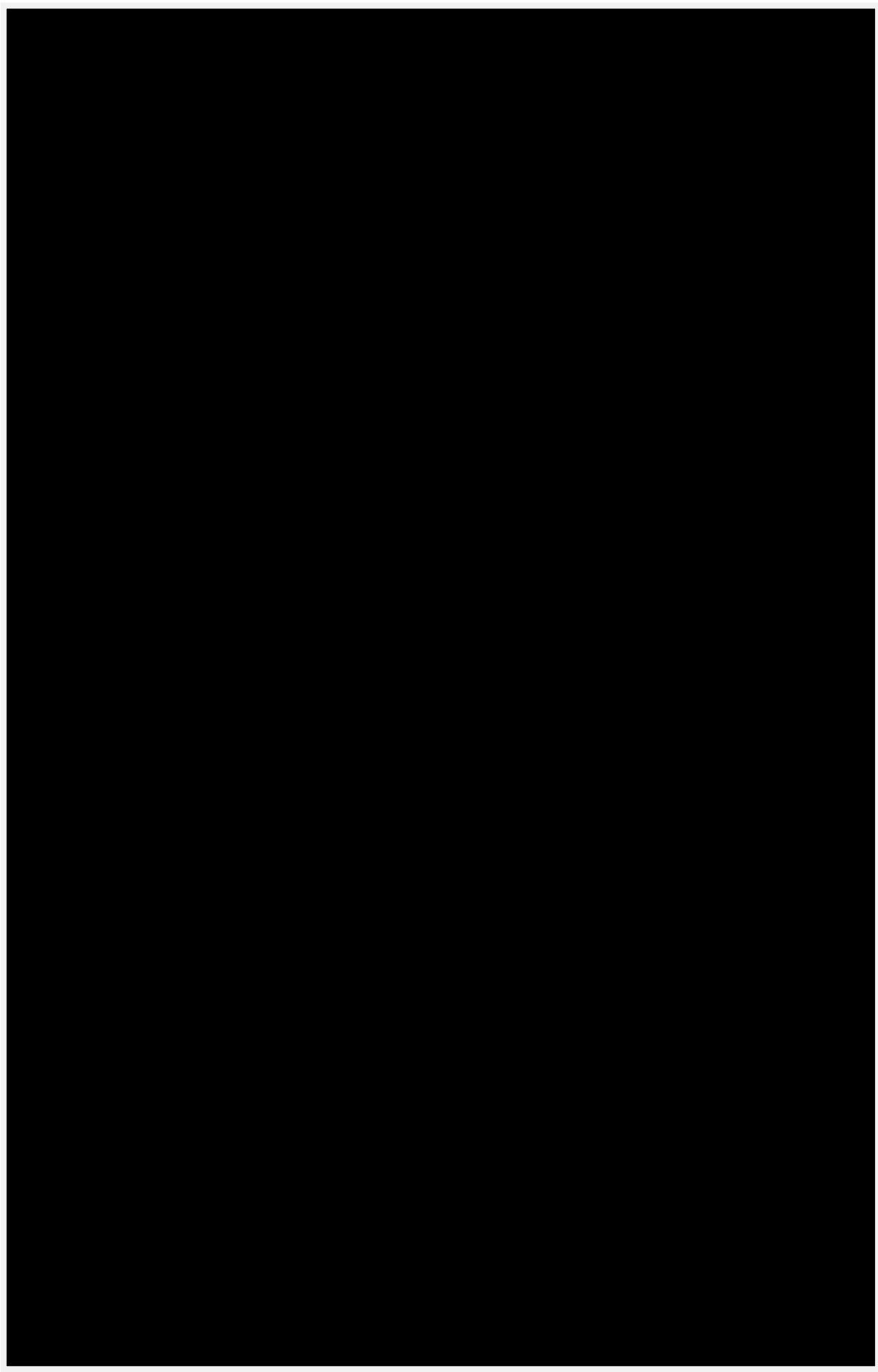
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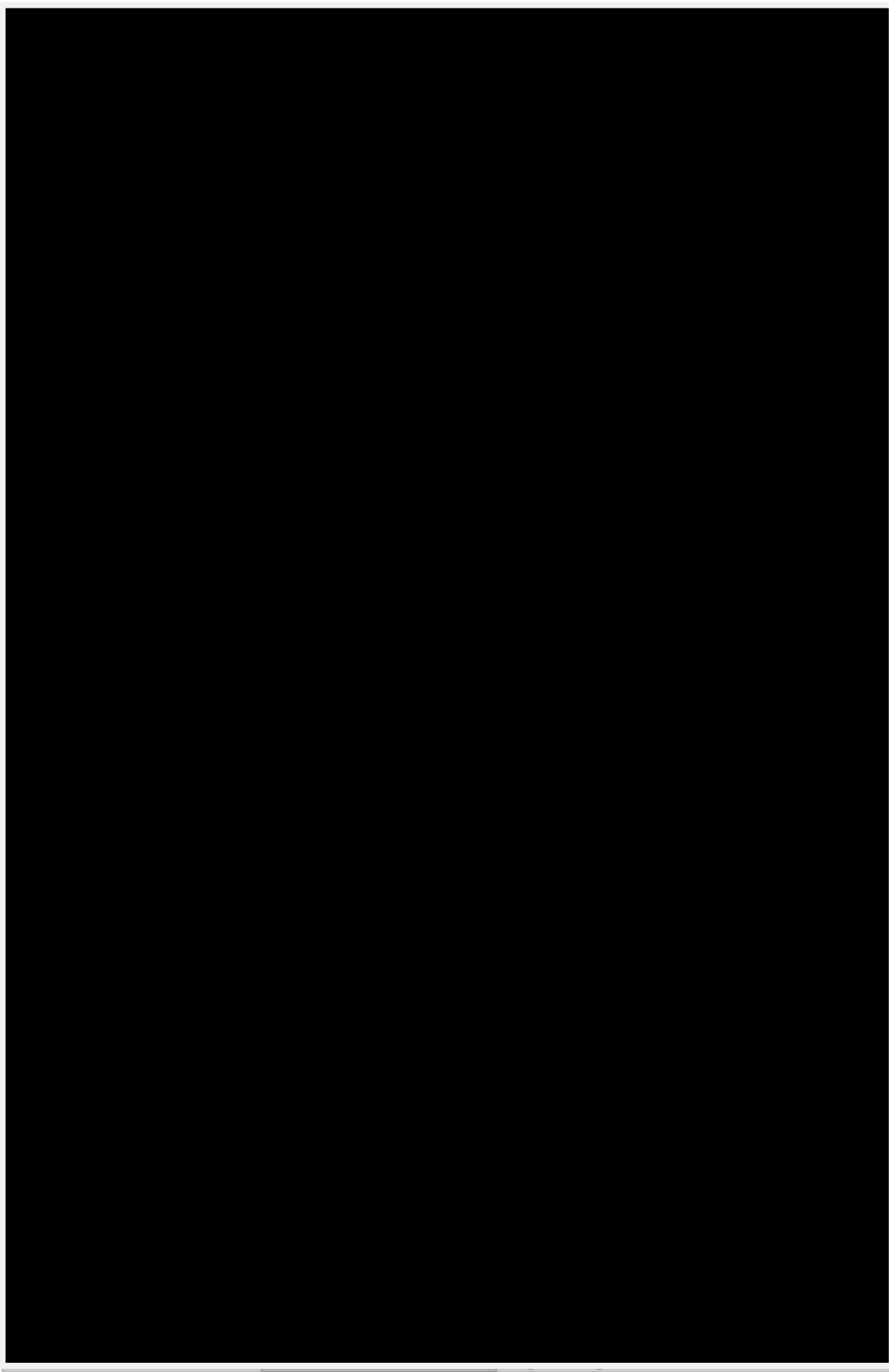
Supervisor: \_\_\_Dr. Tiece Turnbull\_\_\_\_\_

## APPENDIX II



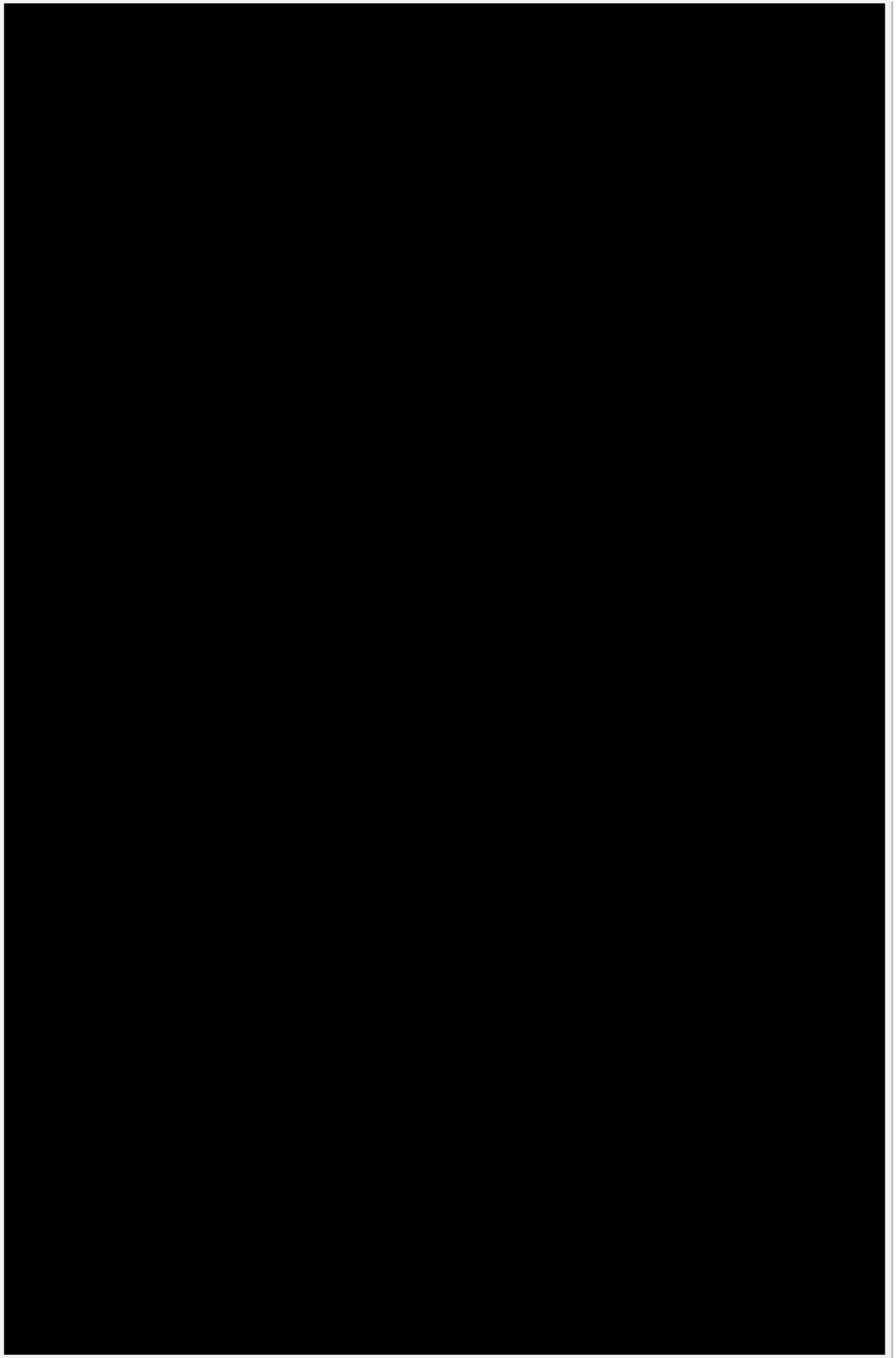


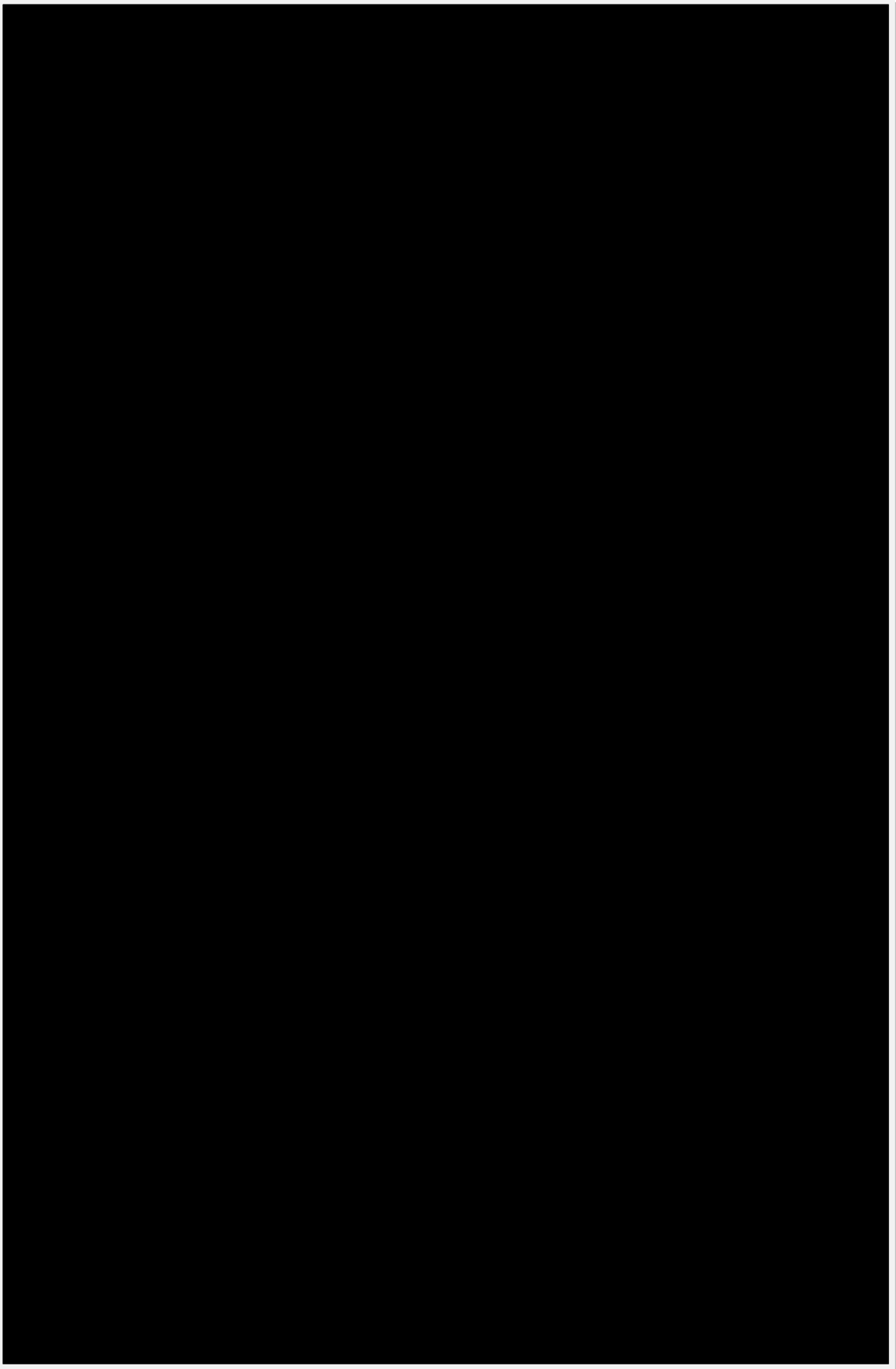


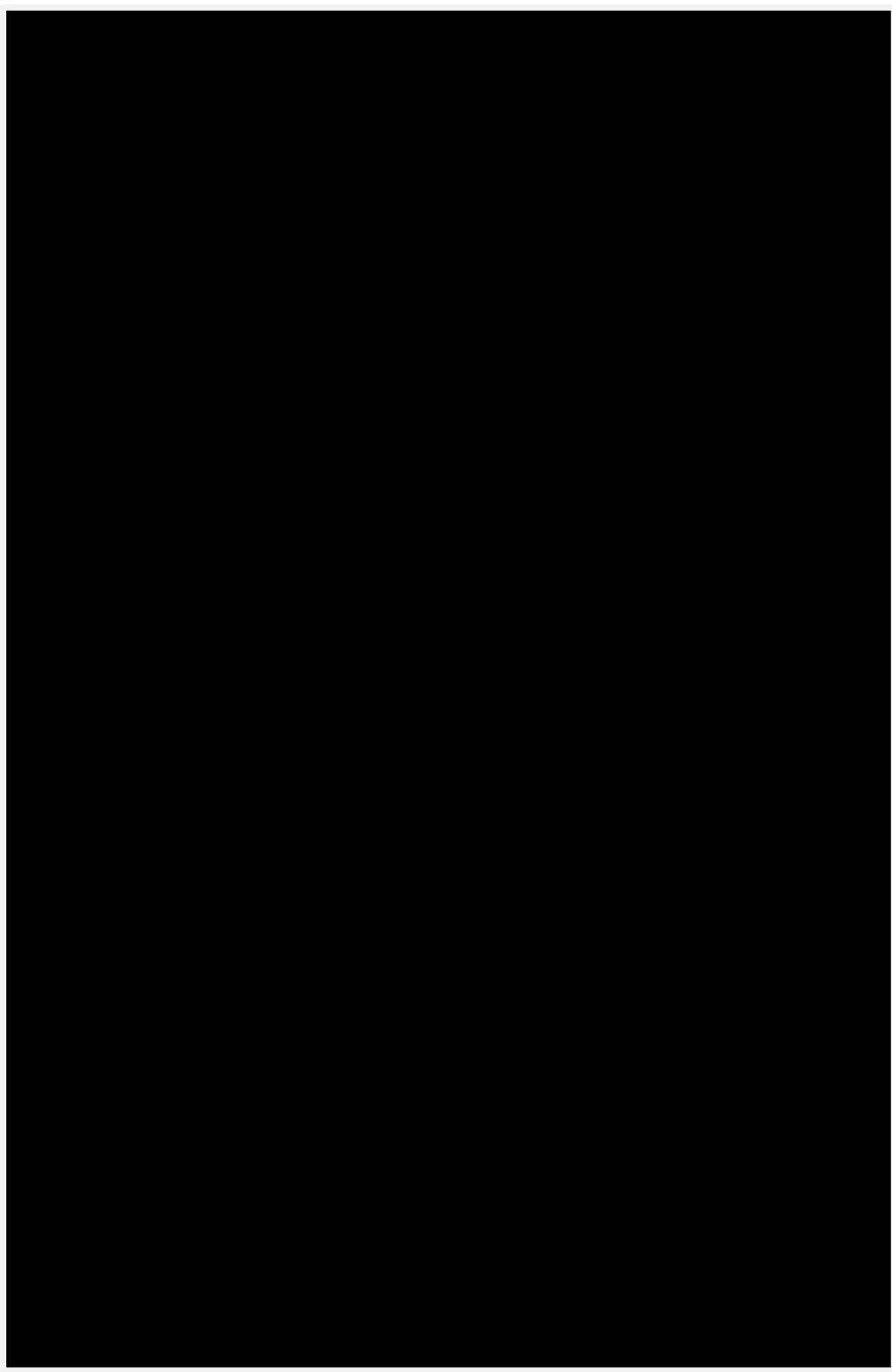




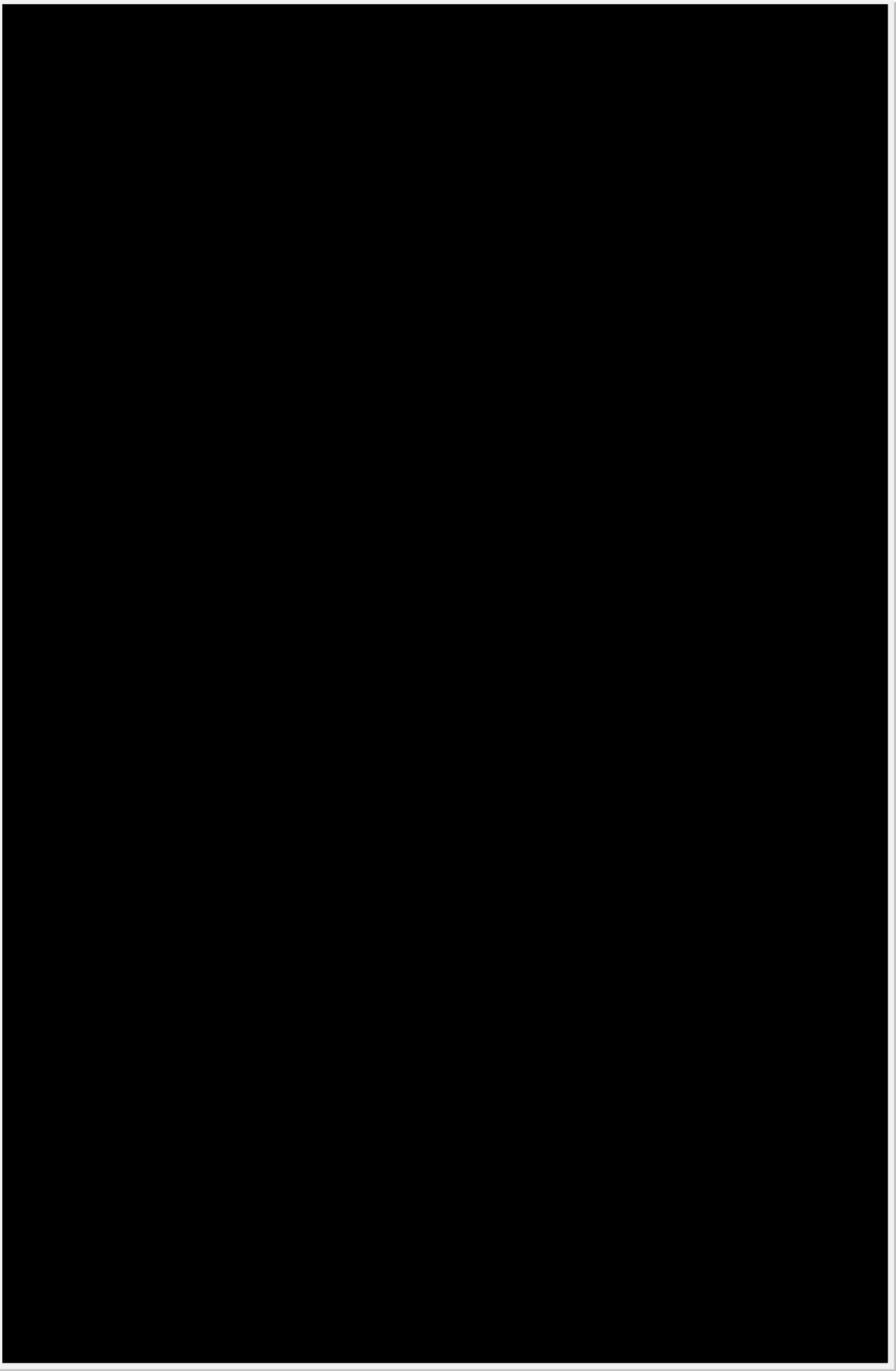
### APPENDIX III



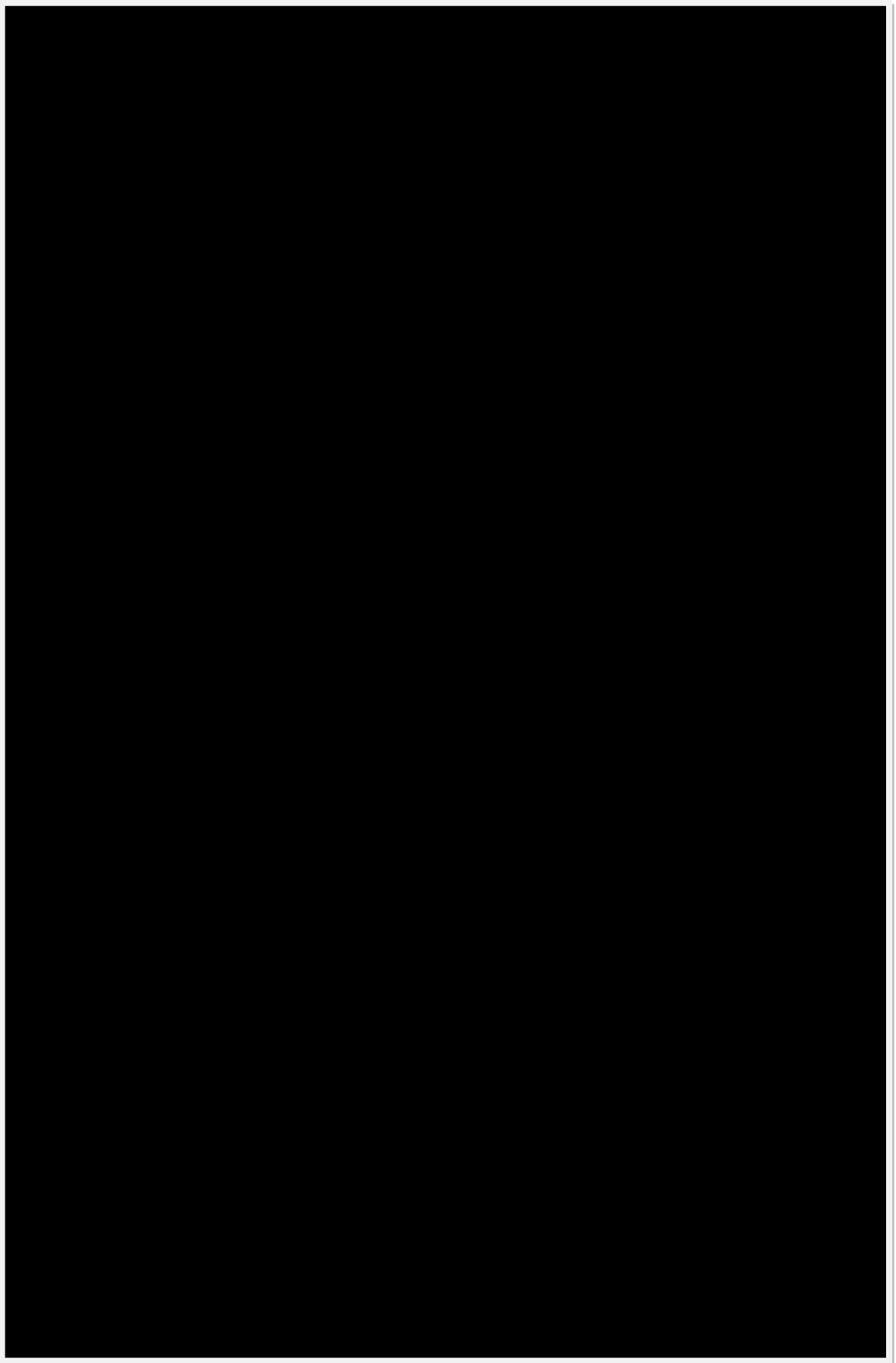




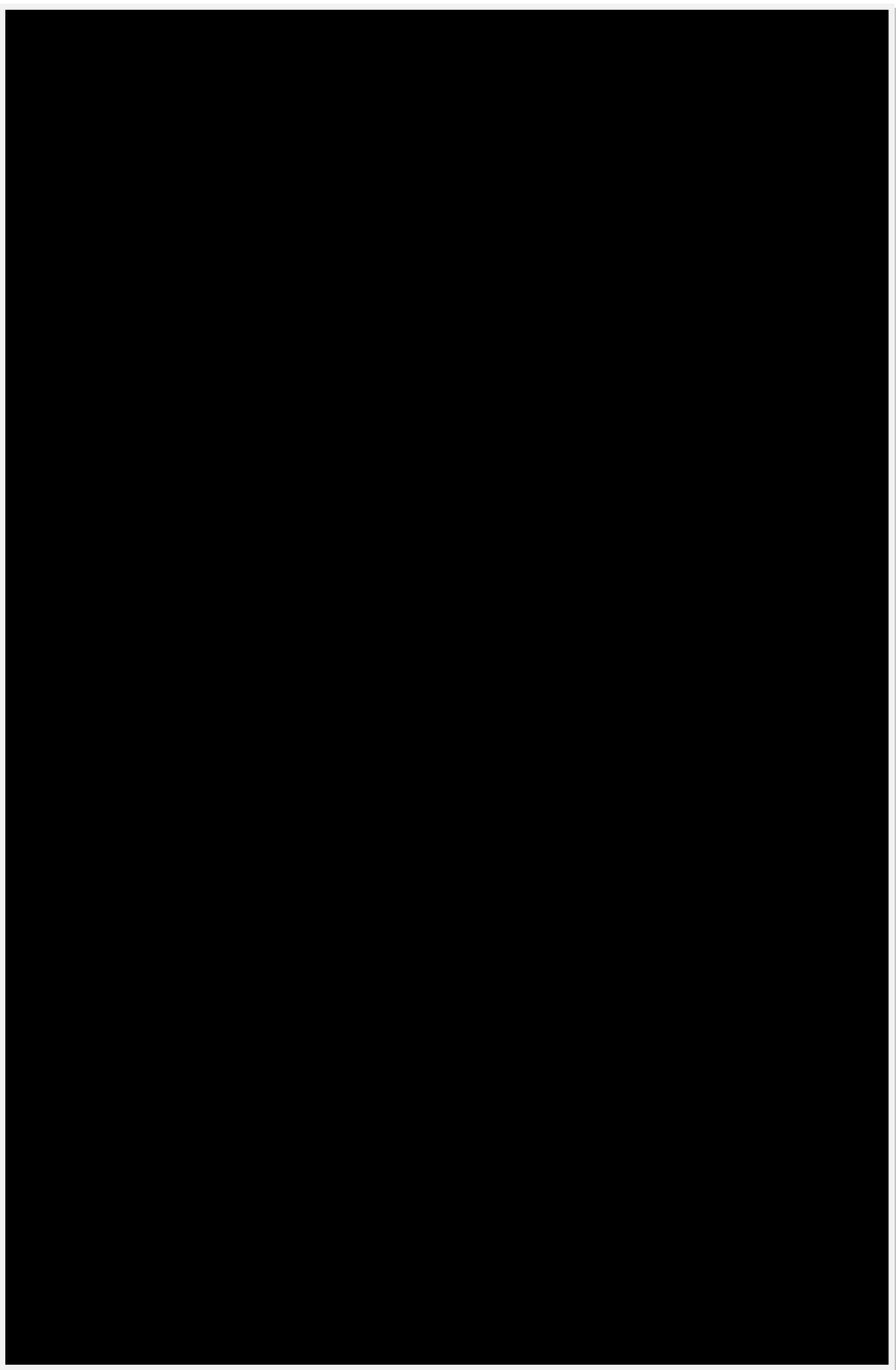
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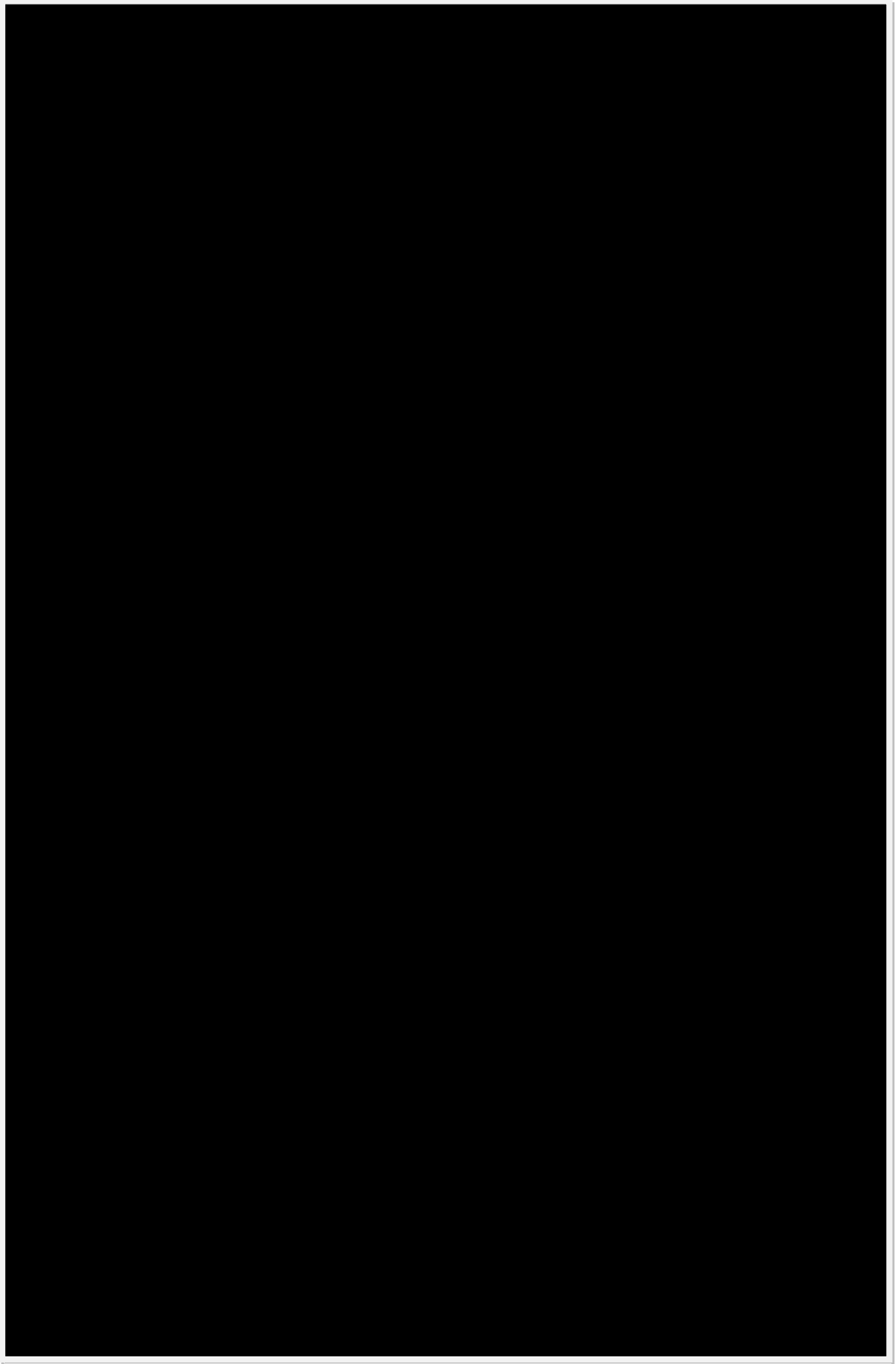


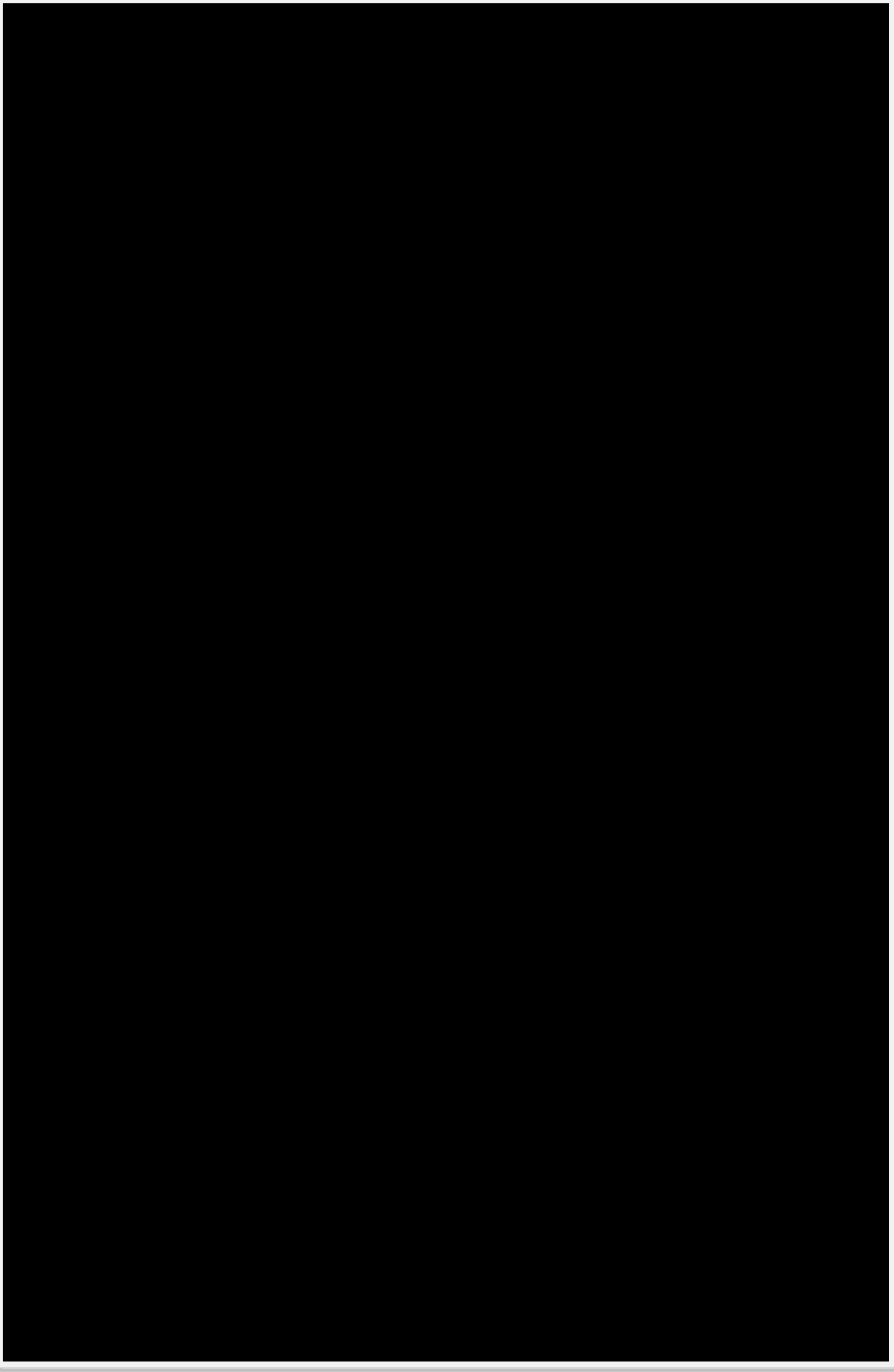
## APPENDIX IV













## PARTICIPANT INFORMATION SHEET

### Exploring the Role of Culture on the Experience and Perception of Healthcare and Daily Life in Patients with PPS

You are being invited to take part in a research study. It is important therefore that you understand why the research is being done and what it will involve, before you decide whether or not to participate. Please take your time to read the following information carefully. We are happy to answer any questions that you may have about the study.

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

We are undertaking a study to understand experiences of living with PPS, such as fibromyalgia, chronic pain, irritable bowel syndrome, respiratory symptoms (e.g. breathlessness), and neurological symptoms (e.g. tingling, abnormal movements or dizziness). This will be done through an interview with a researcher asking about your experience of symptoms in relation to healthcare services, personal beliefs, culture and daily life. The aim of the study is to gain a deeper understanding of the symptoms and how culture may have an impact upon symptoms.

#### Invitation to participate

You are being invited because we are aware that you are currently living with at least one type of PPS and are already participating/have participated in the PRINCE Secondary trial. In addition, you have given us permission to contact you about further research studies.

#### Do I have to take part?

No, your participation is completely voluntary. You are free to opt out of the study at any point without having to provide any reason to the researcher. There are no penalties for deciding to withdraw from the study.

#### What will happen to me if I take part?

A researcher will arrange to discuss the study at a time convenient for you. During this meeting, the researcher will explain the study procedure and answer any questions you may have about the study. You will be asked to complete a short demographics questionnaire and sign a consent form. The researcher will then interview you about your experiences of PPS. The interview should last no longer than one hour. You do not have to answer any questions you do not want to, and you are free to stop the interview at any point. The interview will be audio-recorded so that the researcher doing the

interview has a good record of your conversation so that they can listen to it afterwards and transcribe (type out) the interview. The interview audio-recording will be deleted after transcription. Audio-recording and transcribing the interview will help researchers to look for similar themes expressed by those taking part in the study. You will not be identified by any accounts or verbatim taken from your interview.

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

By taking part you will help us understand the role of culture on the experience and accessibility of healthcare services and daily living in those with PPS. This will hopefully help in the development of effective treatments to help people with these symptoms. The interview will provide you with the opportunity to talk about your own experiences, which you may find therapeutic

### **What are the possible disadvantages and risks of taking part?**

There are no foreseeable risks greater than typical everyday life associated with taking part in this study. However, sometimes people find talking about personal experiences upsetting. If, as a result of taking part in this study, you become concerned about your feelings you can talk to your GP or another healthcare professional.

### **Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be deemed as strictly confidential. All data collected will be stored on password-locked computer files, and any paperwork will be stored securely in locked cabinets within King's College London.

The researchers who contact you will need to keep your contact details at King's College London research sites only for the purposes of contacting you to arrange a meeting with you. This information will be securely stored and destroyed after the study. You will be allocated a participant code that will be used instead of your name on the transcribed interview and demographics questionnaire. This is to preserve your anonymity. This code will be used in any reference to the study, including publications. Participant codes will be stored on a password-locked computer, which will be only accessible to the researchers involved in this study. The audio-recordings of the interview will be deleted once they have been transcribed to preserve your anonymity. Any names given during the interview will be anonymised when the interviews are transcribed in order to preserve your anonymity and theirs.

If during the study the researcher becomes concerned about your well-being or about the implications of what you tell them regarding someone else's well-being, we would need to inform your GP or other health professionals. We would, of course, discuss this with you.

### **What happens to the results of the research study?**

We may wish to publish the findings of the research in scientific journals and we hope to present these findings at future meetings. In addition, we will talk to service providers about the findings of our research. If you would like a copy of the published findings, we can provide this at the end of the study.

**Withdrawal from the study**

Taking part in this study is entirely voluntary. You can withdraw from the study at any time without giving a reason and without this affecting your care.

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

The study is being funded by the Guy's and St Thomas' Charity, and organised by researchers at King's College London and the South London and Maudsley NHS Foundation Trust.

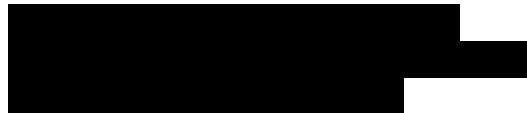
**Who has reviewed the study?**

Ethics approval has been granted by the London - Camberwell and St Giles Research Ethics Committee.

**Contact for further information?**

If you wish to discuss the study in greater detail, please contact the main researcher:

Researcher: **Katie Watts**



Thank you for reading this information sheet and for considering taking part in this study. If you decide to participate you will be provided with a copy of this information sheet.

## APPENDIX VI



An Academic Health Sciences Centre for London

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### CONSENT FORM FOR PARTICIPANTS

**Title of study:** Exploring the Role of Culture on the Experience and Perception of Healthcare and Daily Life in Patients with PPS

Research Ethics Ref: \_\_\_\_\_ Participant code: \_\_\_\_\_

Thank you for considering participating in this research. The researcher must explain the study to you before you agree to take part. Please ask the researcher if you have any questions arising from the Participant Information Sheet before you decide to join. You will be given a copy of this Consent Form to keep.

#### Please tick or initial each box

##### ***Mandatory***

Please tick or  
initial

I confirm that I understand that by ticking/initialing each box that I am consenting to that part of the study. I understand that it will be assumed that any blank boxes mean that I do not give consent for that part of the study. I understand that by not giving consent to any one part of the study could mean that I am considered ineligible for the study.

☐

I confirm that I have read and understood the Participant Information Sheet dated 20-01-2016 (version 1) for the above study and have had the opportunity to ask questions.

☐

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and without my medical care or legal rights being affected. Furthermore, I understand that I will be able to withdraw my data from the study up until the time of transcription or a date specified by the researcher.

☐

I give permission for a researcher to contact me by phone/text/email (please circle your preference) for the purposes of arranging a suitable date and time for interview.

☐

I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the UK Data Protection Act 1998. ☐

I consent to my interview being audio-recorded and transcribed. I understand that this will be done to help the researcher analyse the data more effectively, and that only the researchers will have access to this data. ☐

I understand that my confidentiality and anonymity will be maintained throughout, and that it will not be possible to identify me in any future publications. I understand that my identity will also not be revealed within the transcript. ☐

I agree to take part in the above study. ☐

### ***Optional***

I give permission to be contacted in the future by King's College London researchers who would like to invite me to participate in future research. ☐

Participant name (please print): \_\_\_\_\_

Date (DD/MM/YYYY): \_\_\_\_\_ Signature: \_\_\_\_\_

I confirm that I have explained the study to \_\_\_\_\_ (name of participant) and have answered any questions honestly and fully. ☐

Researcher name (please print): \_\_\_\_\_

Date (DD/MM/YYYY): \_\_\_\_\_ Signature: \_\_\_\_\_

1 copy of participant and 1 copy for study file.



## APPENDIX VII



KING'S HEALTH PARTNERS

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# Exploring the Role of Culture on the Experience and Perception of Healthcare and Daily Life in Patients with PPS

## Qualitative Topic Guide

### Introduction

- Thank you for agreeing to take part in this interview.
- I am a Research Worker /City University student working at King's College London.
- I am interviewing people with PPS to understand their experience of symptoms, healthcare and the role of culture within these.
- The interview will be no longer than 1 hour in length.
- With your permission, I would like to audio-record our interview today. This is for analysis and transcription purposes only.
- I will keep your information anonymous and confidential at all times. Your real name won't be used when I transcribe the interview.
- As a reminder, you do not have to answer any question you do not want to just say and we can move onto the next question. You have the right to stop the interview at any point and withdraw from the research.
- Any questions before we start?

### Section A.

Firstly I would like to ask you some personal questions about yourself and family.

- Can you tell me about your family?
  - Can you tell me about who you live with? (if not covered)
- Would you mind telling me what role your faith or spirituality plays in your life?
- Can you tell me about a bit about your cultural background?

## **Section B.**

Now I would like to ask you some questions about your PPS.

- Can you tell me about your symptoms? Type of symptom, frequency etc.
- When did you first experience these?
- Can you tell me whether you notice any other physical changes in your body when you experience your symptoms? (Prompt: before, during, after the symptoms)
  - If yes, could you please tell me more about them?
- When you notice your symptoms how do they make you feel emotionally?
- Can you tell me more about your feelings when you experience the symptoms? (Ask if specific feelings not mentioned)
  - Why do you think you feel this way?
  - How would you recognise you are feeling X?
  - How do you think your family would realise you are feeling X?
  - How would other people realise you are feeling X? (friends, strangers)
  - Could you tell me whether you feel in control of your emotions?  
Why do you think this is?
- When you experience your symptoms what do you do? Why? (Prompt: Are you able to find comfort in your faith or beliefs when dealing with your symptoms?)
- How long have you had your symptoms?
- What do you think caused your symptoms? In what way do you think cultural factors impact on your symptoms if any (Prompt: Place of worship, friends, family)

## **Section C.**

Now I would like to ask you some questions about your experiences accessing and using healthcare.

- Can you tell me about when you first went to seek medical advice for your symptoms? (Prompts: What happened, referral process)
- How did this make you feel?
- How did you find the process of referral to your consultant?
- Can you tell me about any advice or treatment you have been given?
- Can you tell me your thoughts and expectations about your treatment?

- What are your thoughts on the standard of care that you received through the NHS?
- Are there any recommendations you would make for future care and treatment?

### **Section D.**

This is the last section of the interview. I am going to ask some questions about your everyday life.

- Can you tell me about your everyday life before the symptoms?
- Can you tell me about your everyday life since the symptoms? (Prompts: work life, caring responsibilities)
- How has your social life changed since you developed your symptoms? If yes, how does this make you feel? (Prompt: Can you tell me more about your feelings? (If they don't label them easily) )
- Is there anything else that has changed in your social life? (Prompt: activities, relationships with others, working life)
- How do you express your emotions to people close to you?

Prompts:

- Why do you think this is?
- Has it always been like this for you? (If not, explore why)
- What about other people like colleagues or friends?
  - How have your family/friends responded to your symptoms? (If not covered in previous section)

### **Closing and Ending**

That's the end of my questions. Thank you very much for sharing your thoughts and experiences with me today. What you have told me will really help us to understand patients' experiences of PPS.

- Are there any final comments you would like to make?
- Is there anything you would like to ask me?

***End of interview***

## APPENDIX VIII



An Academic Health Sciences Centre for London

KING'S HEALTH PARTNERS

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### Debrief Sheet

#### **Exploring the Role of Culture on the Experience and Perception of Healthcare and Daily Life in Patients with PPS**

Thank you once again for participating in this study. Your time and your comments are greatly appreciated. As a reminder, your interview will be stored in a secured location at King's College London, and only the researchers will have access to it.

#### **What happens now?**

Your interview will be transcribed by the researcher, before being analysed. However, only the themes identified will be talked about – it will not be possible to identify you directly.

#### **What will happen to the themes?**

The researcher may eventually publish the completed study in an academic journal. A summary of the results will be made available to you if you would like them.

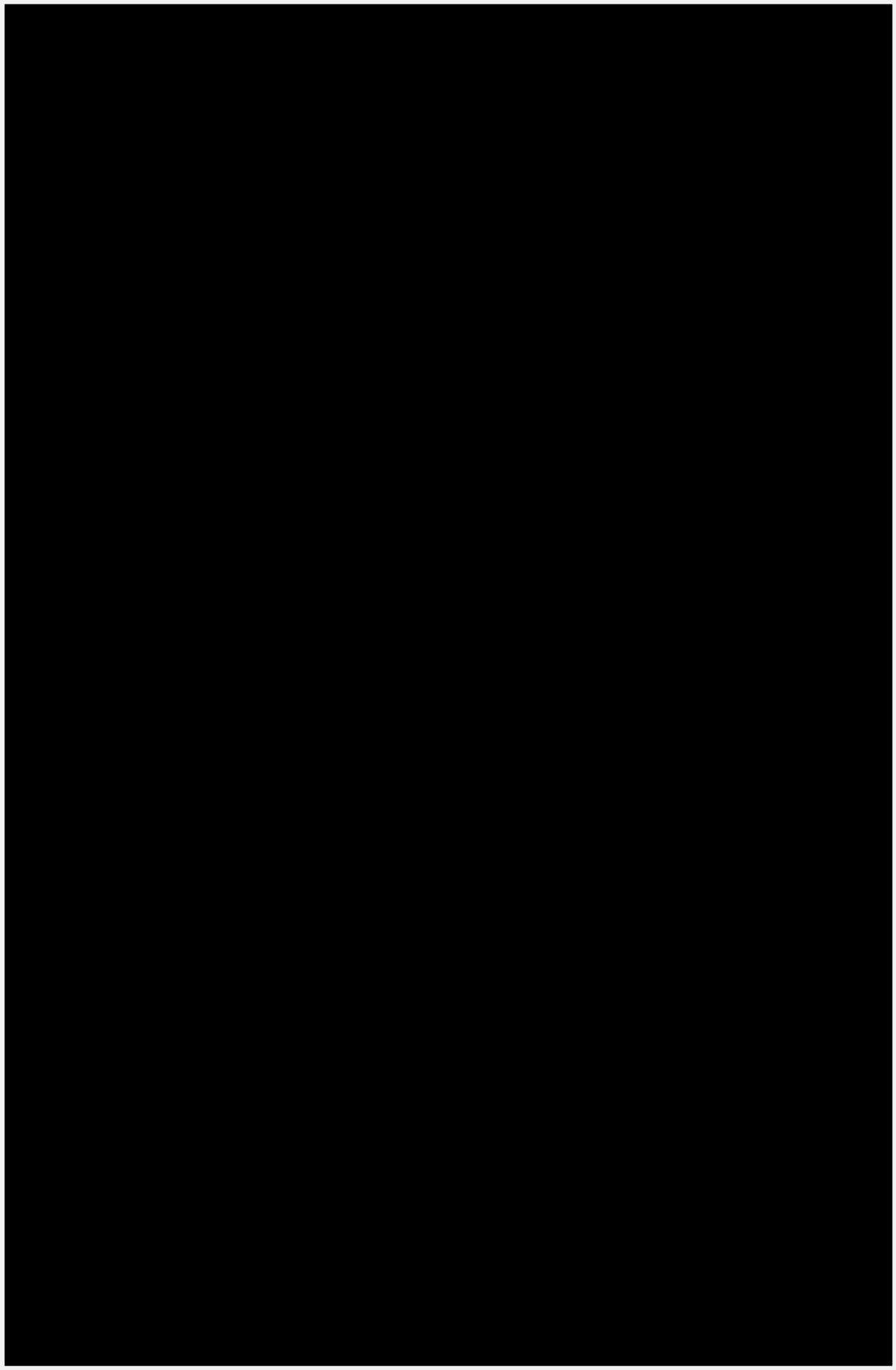
#### **Contact for further information?**

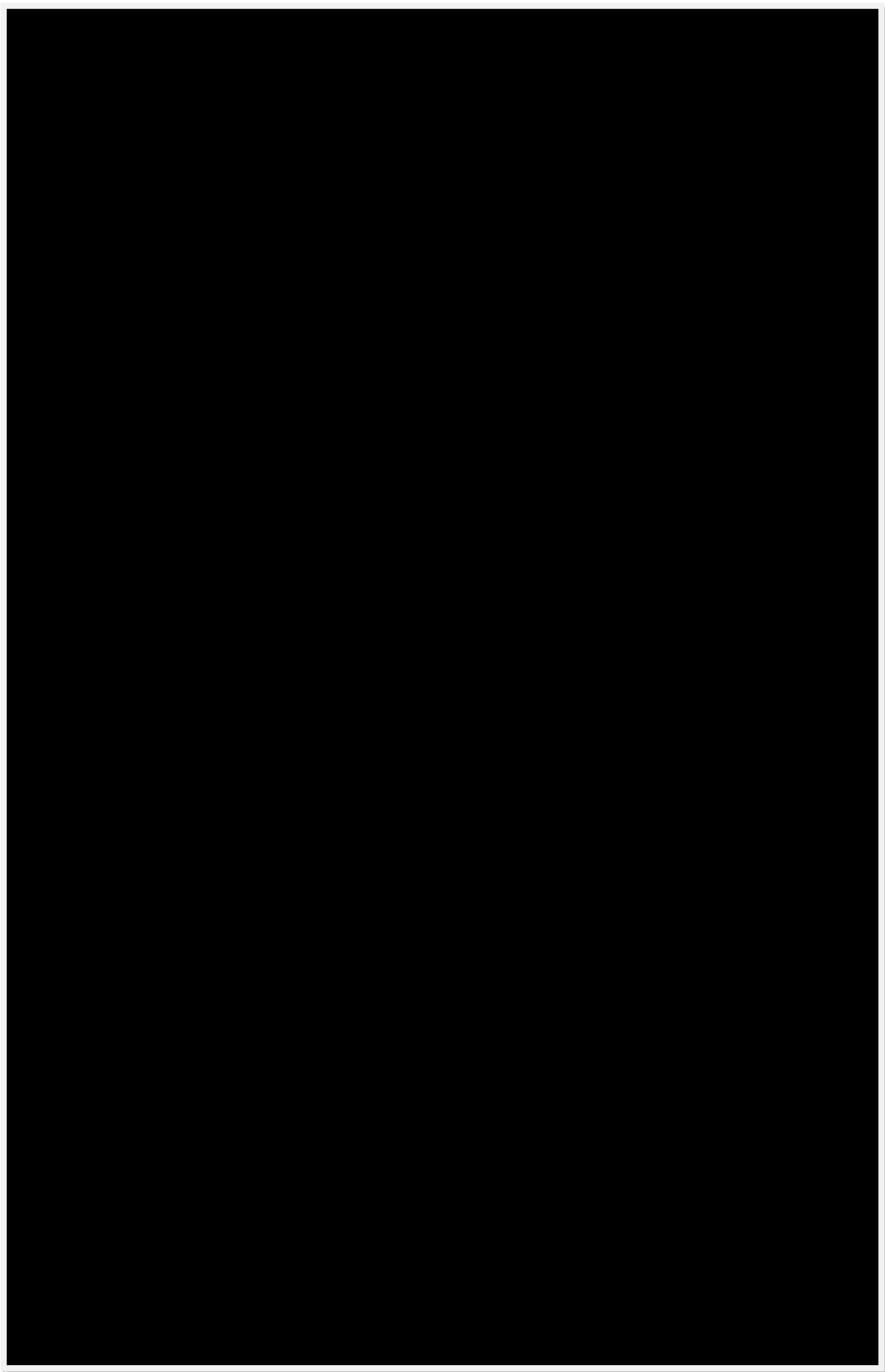
If you wish to discuss the study in greater detail, please contact:

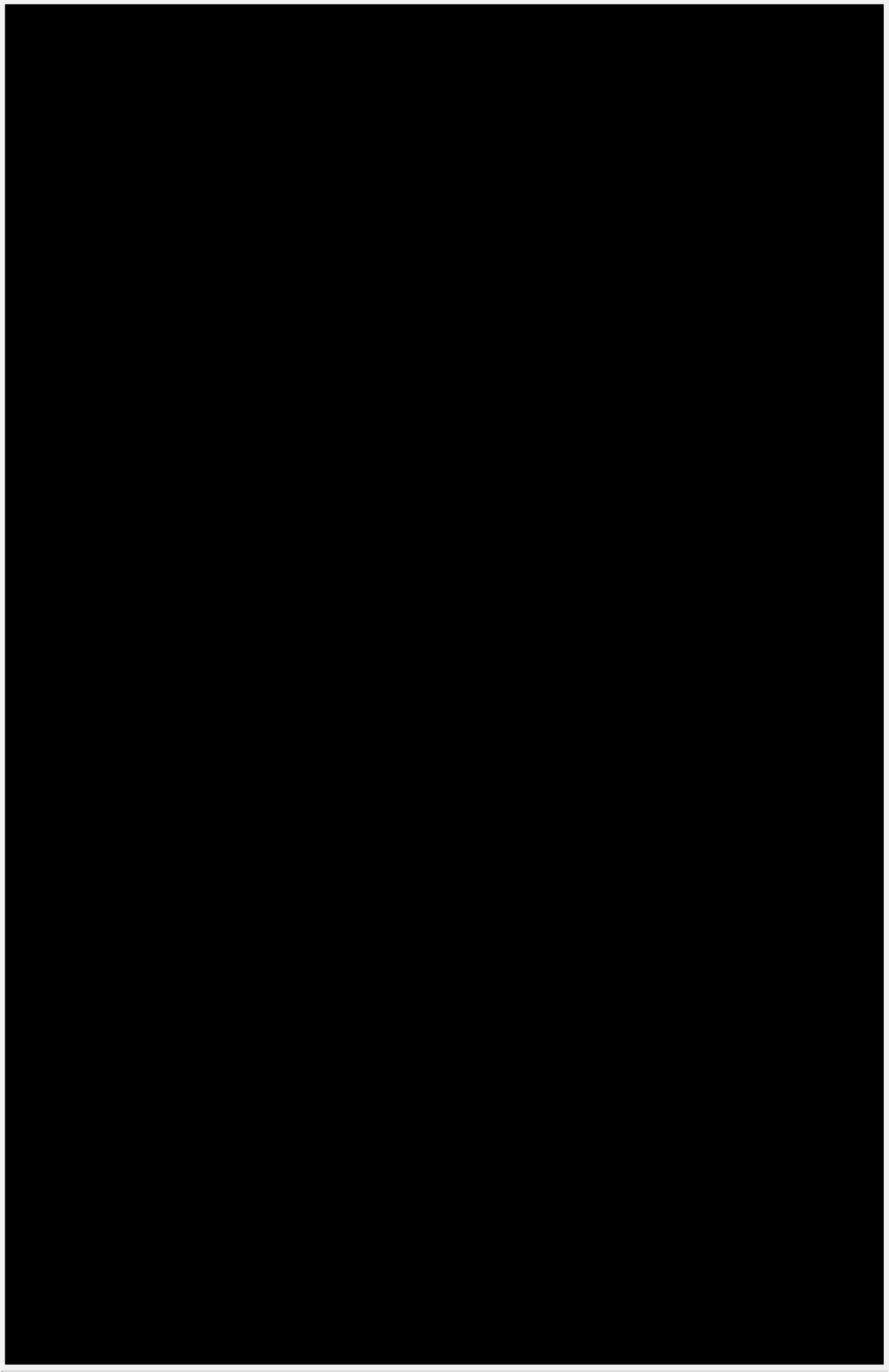
Researcher: **Katie Watts**  
Dept. of Psychological Medicine

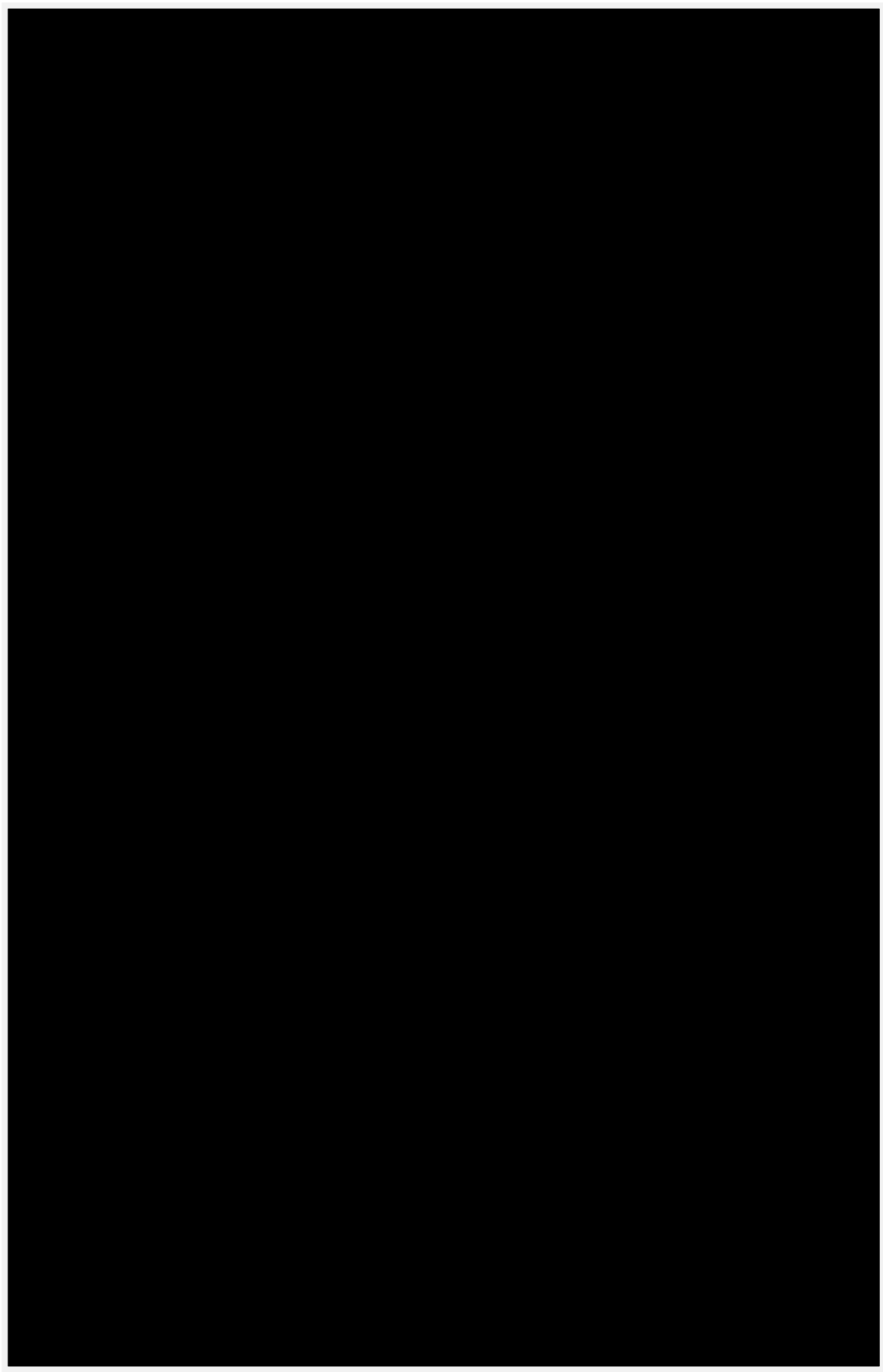


## APPENDIX IX

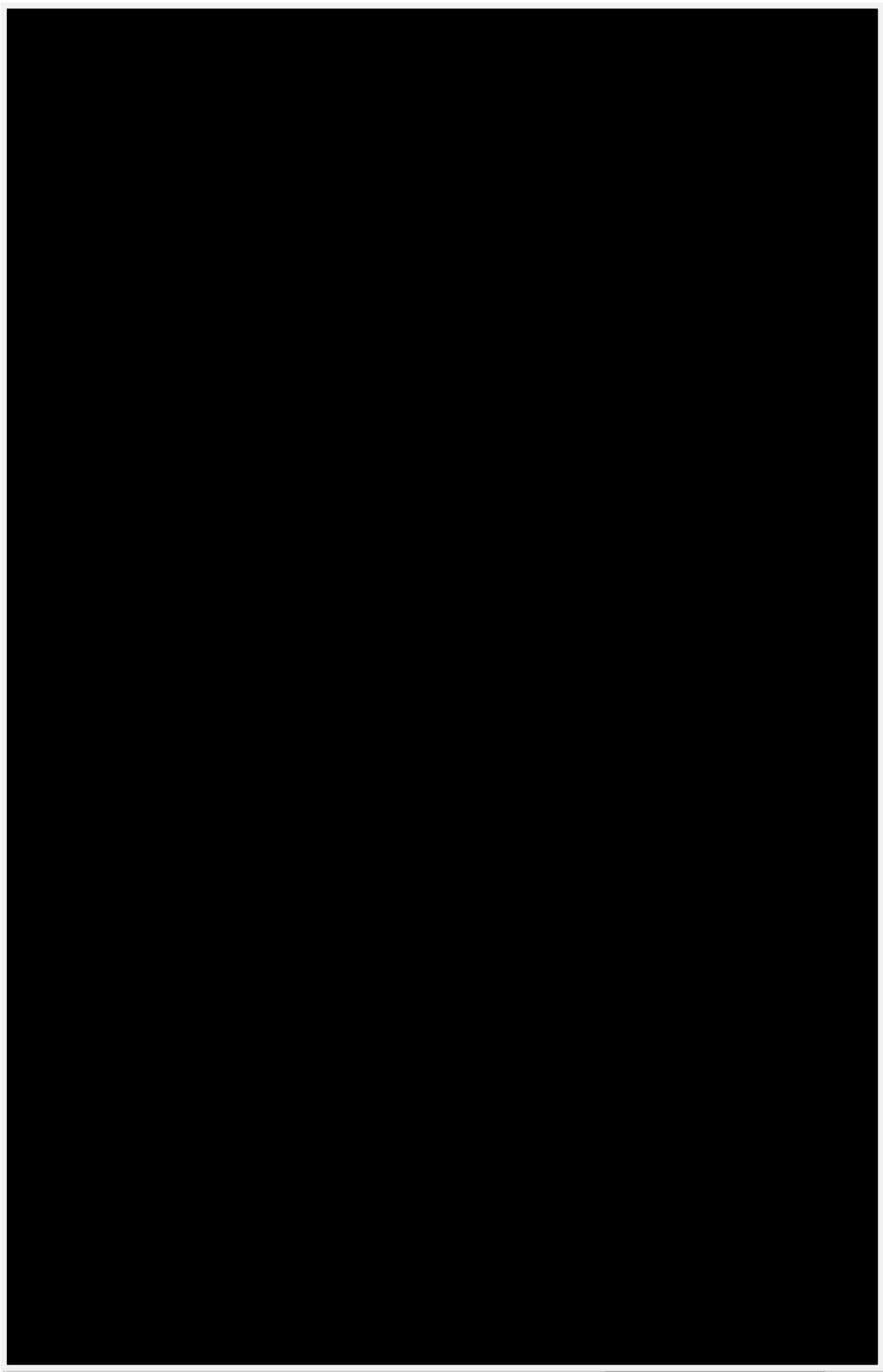


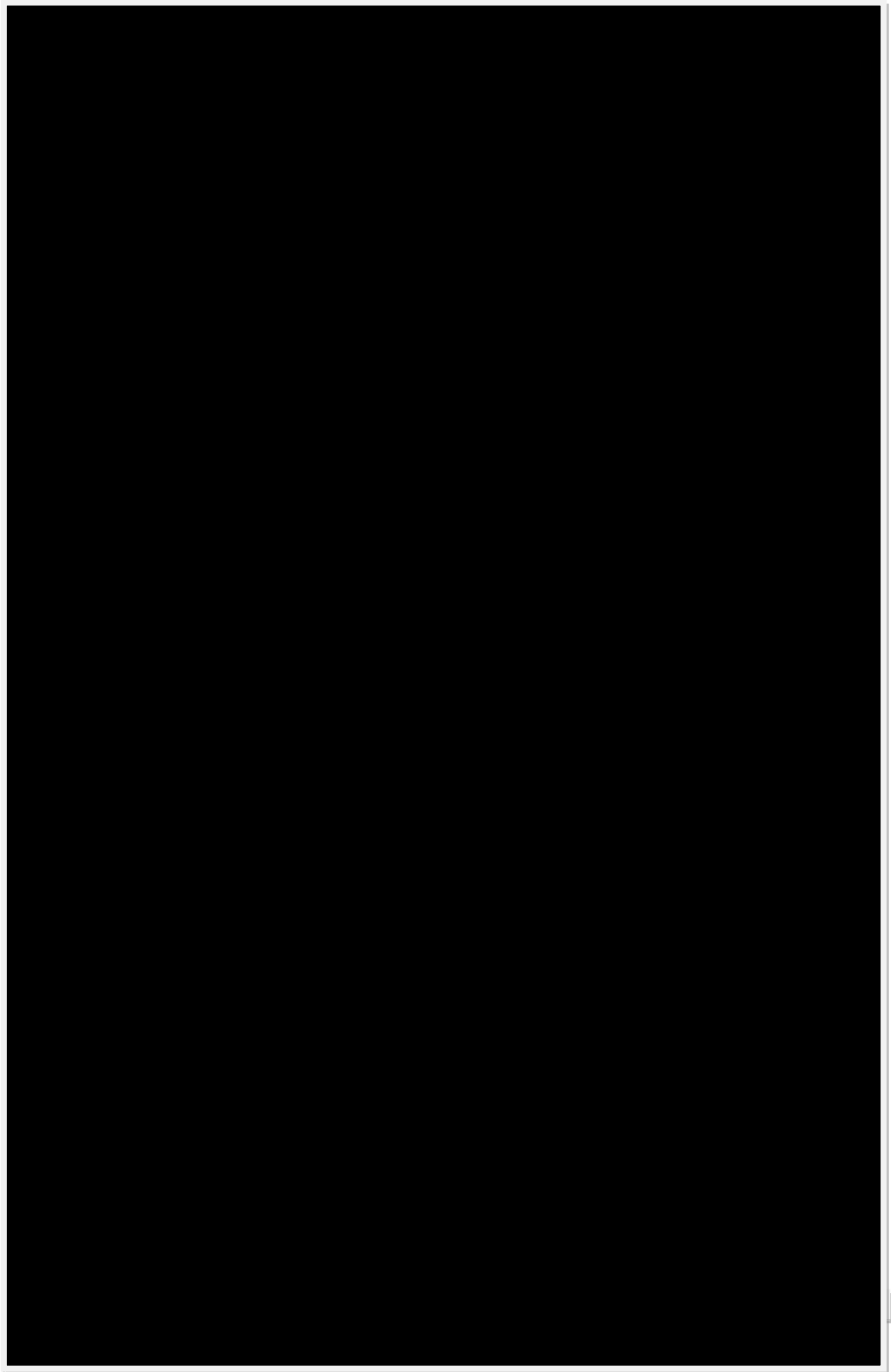












## APPENDIX X

### Exact Interview Schedule

| PIN    | Group            | Telephone/<br>Face-to-<br>face | First<br>contact | Second<br>contact | Third<br>contact | Date of<br>interview |
|--------|------------------|--------------------------------|------------------|-------------------|------------------|----------------------|
| P02029 | BME              | Telephone                      | 22/04/2016       |                   |                  | 04/05/2016           |
| P02008 | BME              | Face-to-face                   | 22/04/2016       |                   |                  | 05/05/2016           |
| P01001 | White<br>British | Face-to-face                   | 22/04/2016       |                   |                  | 06/05/2016           |
| P01009 | White<br>British | Telephone                      | 22/04/2016       |                   |                  | 10/05/2016           |
| P02018 | BME              | Telephone                      | 22/04/2016       |                   |                  | 11/05/2016           |
| P01019 | BME              | Face-to-face                   | 10/05/2016       | 23/05/2016        |                  | 24/05/2016           |
| P02010 | White<br>British | Telephone                      | 22/04/2016       | 18/05/2016        |                  | 26/05/2016           |
| P02021 | BME              | Telephone                      | 26/04/2016       | 26/05/2016        |                  | 27/05/2016           |
| P02002 | BME              | Face-to-face                   | 22/04/2016       | 18/05/2016        |                  | 03/06/2016           |
| P02034 | BME              | Telephone                      | 08/06/2016       |                   |                  | 17/06/2016           |
| P02031 | White<br>British | Telephone                      | 25/04/2016       | 16/05/2016        |                  | 29/06/2016           |
| P01044 | White<br>British | Telephone                      | 10/06/2016       |                   |                  | 30/06/2016           |
| P02032 | White<br>British | Telephone                      | 10/06/2016       |                   |                  | 01/07/2016           |
| P02038 | White<br>British | Telephone                      | 08/06/2016       | 24/06/2016        | 08/07/2016       | 15/07/2016           |
| P01033 | BME              | Telephone                      | 27/04/2016       | 03/06/2016        | 10/06/2016       | 15/07/2016           |
| P01061 | BME              | Face-to-face                   | 15/07/2016       |                   |                  | 29/07/2016           |
| P02040 | White<br>British | Telephone                      | 08/06/2016       | 24/06/2016        |                  | 03/08/2016           |
| P01052 | BME              | Face-to-face                   | 08/07/2016       | 02/09/2016        |                  | 09/09/2016           |
| P01053 | BME              | Face-to-face                   | 08/07/2016       | 05/09/2016        |                  | 28/09/2016           |
| P01079 | BME              | Telephone                      | 02/09/2016       |                   |                  | 07/10/2016           |
| P01135 | White<br>British | Telephone                      | 15/12/2017       | 03/01/2017        |                  | 13/01/2017           |
| P01117 | White<br>British | Telephone                      | 09/12/2016       |                   |                  | 15/01/2017           |
| P01138 | White<br>British | Telephone                      | 15/12/2016       | 19/01/2016        |                  | 20/01/2017           |
| P02152 | BME              | Telephone                      | 16/02/2017       |                   |                  | 03/03/2017           |
| P01094 | White<br>British | Telephone                      | 01/03/2017       |                   |                  | 09/03/2017           |
| P01172 | White<br>British | Telephone                      | 17/03/2017       |                   |                  | 03/04/2017           |
| P02170 | White<br>British | Face-to-face                   | 17/03/2017       |                   |                  | 07/04/2017           |
| P01149 | BME              | Telephone                      | 20/04/2017       |                   |                  | 28/04/2017           |
| P01058 | White<br>British | Face-to-face                   | 20/04/2017       |                   |                  | 05/05/2017           |
| P02195 | BME              | Telephone                      | 18/05/2017       |                   |                  | 26/05/2017           |

## APPENDIX XI

### Thesis: Codes list

Purple = White British responses

Red = BME responses

#### Beliefs surrounding the symptoms

- Uncertainty regarding what can trigger symptoms
  - Uncertainty around the cause  
(P02040)(P02038)(P01044)(P01138)(P02031)(P01172)(P02170) (P01058)  
(P01019)(P01033)(P01053)(P01061)(P01079)(P02034)(P02002) (P01149)
  - No warning for symptoms  
(P02032)(P01094)  
(P02008)(P01053)(P01061)(P02002)
- The potential impact of trauma
  - History of physical trauma  
(P02038)(P02010)(P01009)(P01001)(P02031)(P01094)  
(P01019)  
(P01033)(P01079)(P02018)(P02021)(P02029)(P02195)
  - History of emotional trauma  
(P02040)(P02010)(P01001)(P02032)(P01117)(P01138)  
(P01019)(P01033)(P01052)(P01053)(P01061)(P01079)
  - Stress is a trigger  
(P01117)(P02170)  
(P01052)(P01079)(P02029)
- Uncertainty regarding the future
  - Initial expectations for a cure/help to reduce symptoms  
(P01001)(P01135)(P01138)(P01172)(P02170)(P01058)  
(P02034)(P02021)(P02029)
  - Hope for the future  
(P02040)(P01009)(P01138)(P01094)  
(P02008)(P02002)(P02018)
  - Worry for the future  
(P02031)(P01094)  
(P01053)(P02034)(P02002)
  - Struggling to accept symptoms  
(P02010)(P01009)(P01172)(P01058)  
(P02008)(P02034)(P02018)(P02029)(P02152)(P02195)  
(P01149)

- Acceptance of the new life and symptoms  
(P01001)(P01117)(P01138)  
(P02008)(P02034)
- The role of religious beliefs
  - Raised in a religious family  
(P01044)(P01138)(P01172)(P01058)  
(P02008)(P01033)(P01052)(P01053)(P01061)(P01079)(P02034)(P02018)(P02029)(P02152)(P02195)(P01149)
  - No strong religious influence  
(P02040)(P02010)(P02038)(P01009)(P01001)(P02032)(P01117)(P01135)(P02031)(P01094)(P02170)  
(P01019)(P01052)(P01053)(P02002)(P02021)
  - Spiritual leanings  
(P02010)(P01138)(P02031)(P01058)  
(P02008)(P01019)(P01052)(P02021)(P02029)(P01149)
  - No spiritual leanings  
(P02032)(P01117)(P01094)  
(P01053)(P02002)(P02021)(P02195)
  - Supportive role of religion/ faith on symptoms  
(P01044)  
(P01033)(P01079)(P02018)(P02029)(P02152)
  - Religion is not a cause of symptoms  
(P01033)(P01053)(P01061)(P02002)(P02195)(P01149)

### Putting on a strong face

- Trying to remain positive
  - Defiance of symptoms  
(P02040)(P02010)(P02038)(P01009)(P01001)(P01044)(P01138)(P02031)(P02170)(P01058)  
(P02008)(P01019)(P01061)(P02002)(P02021)(P02029)(P02195)
  - My situation could be worse  
(P01001)(P01009)(P01044)(P01138)(P01172)  
(P02029)(P02021)
  - A desire to be 'normal'  
(P02010)(P01044)(P01094)(P02170)  
(P02002)(P02018)(P02021)(P02029)(P02152)(P01149)
- Keeping the symptoms to oneself
  - The need to keep private about symptoms  
(P02038)(P01009)(P01044)(P02032)(P01117)(P01135)(P02031)(P02170)  
(P02008)(P01019)(P01052)(P01053)(P01061)(P01079)(P02034)(P02021)(P02029)(P02152)

## A need for social support

- The role of family
  - Close to family  
(P01009)(P01001)(P02032)(P01117)(P01094)(P01172)  
(P02170)(P01058)  
(P02008)(P01019)(P01061)(p02021)(P02152)(P02195)
  - Family and close friends recognise and understand symptoms  
(P02040)(P02010)(P02038)(P01001)(P01044)(P01117)  
(P01135)(P01172)(P01058)  
(P02008)(P01019)(P01052)(P02034)(P02002)(P02018)  
(P02021)(P02029)(P02152)(P02195)(P01149)
  - Family conflict  
(P01044)(P01038)(P02031)(P02170)  
(P02008)(P01019)(P01033)(P01052)(P01053)(P01061)  
(P02034)(P02002)(P02029)(P01149)
  - Openness with family and close friends  
(P01009)(P01117)(P01058)  
(P02008)(P01033)(P02002)(P02018)(P02021)(P02195)  
(P01149)
  - Lack of openness with family  
(P02170)  
(P01052)(P01053)(P01061)(P01079)(P02034)(P02195)
  - Ill family culture  
(P01009)(P01172)  
(P01019)(P01079)(P02034)(P02002)(P02021)(P01149)
  - Romantic relationships  
(P01044)(P02031)(P01094)  
(P01061)
- Attitudes of non-family members
  - Poor understanding from non-family members  
(P02040)(P02010)(P01044)(P02031)(P01094)  
(P02008)(p01052)(P01053)(p02002)(P02034)(P02018)  
(P01149)
  - Lack of support from non-family members  
(P02010)(P02038)(P01001)(P01138)(P02031)  
(P01053)(P02152)
  - Good support from non-family members  
(P01001)(P01044)(P02032)(P01117)(P01138)(P01094)  
(P02170)(P01058)  
(P02008)(P01019)(P01052)(P01061)(P02002)(P02195)

## Quality of life has been stripped away

- The physicality of symptoms
  - Painful symptoms  
(P02040)(P02010)(P02038)(P01009)(P02032)(P01117)  
(P02031)(P01094)(P01058)

- (P02008)(P01019)(P01033)(P01052)(P01053)(P02002)
  - (P02018)(P02021)(P02029)(P02152)(P02195)
  - IBS symptoms
    - (P02010)(P01044)(P01117)(P01135)(P01094)
    - (P02008)(P01052)(P01079)(P02195)(P01149)
  - Fatigue
    - (P02040)(P02010)(P02031)(P01044)(P02031)
    - (P02018)(P02029) (P02152)(P02195)
  - Poor sleep
    - (P02040)(P02010)(P01001)(P02031)
    - (P02008)(P01019)(P01053)(P02034)
  - Multiple symptoms
    - (P02010)(P02040)(P01001)(P01058)
    - (P01053)(P01061)(P02034)(P02002)(P02018)(P02029)
    - (P02152)(P02195)
  - Comorbidity with organic medical conditions makes it worse
    - (P01117)(P02031)(P02032)
    - (P01033)(P01053)(P01061)(P01079)(P02034)(P02002)
    - (P02018)(P02152)(P02195)
- The impact of symptoms on day-to-day life
  - Busy life pre-symptoms
    - (P02040)(P02010)(P02038)(P01009)(P01001)(P01044)
    - (P01117)(P01135)(P02031)(P01172)(P02170)(P01058)
    - (P02008)(P01019)(P01052)(P01053)(P01061)(P02034)
    - (P02002) (P02018)(P02021)(P02029)(P02152)(P02195)
    - (P01149)
  - Negative impact on social life
    - (P02040)(P02010)(P02038)(P01009)(P01044)(P02032)
    - (P01117)(P01135)(P02031)(P01094)(P01172)(P01058)
    - (P02008)(P01019)(P01033)(P01053)(P01061)(P02034)
    - (P02002)(P02018)(P02021)(P02152)(P02195)(P01149)
  - Social withdrawal with symptoms
    - (P02040)(P02010)(P02038)(P01044)(P02032)(P01117)
    - (P02031)(P01094)(P01058)
    - (P01019)(P01033)(P01053)(P02034)(P02018)(P02029)
    - (P02152)(P01149)
  - Reduced tolerance for other people
    - (P02010)(P01001)(P02032)(P01058)
    - (P02002)(P02018)(P02021)(P02029)(P02152)
  - Previously ambitious and independent
    - (P01001)(P01135)(P01138)(P02038)(P01094)(P01058)
    - (P01061)(P02002)(P02152)(P02008)(P01019)(P02195)
  - Impact on hobbies
    - (P02038)(P01001)(P02010)(P01044)(P02032)(P01117)
    - (P01094)(P01172)
    - (P01019)(P01052)(P01053)(P01061)(P02034)(P02021)
    - (P02029)(P02195)(P01149)

- Adopting new activities to control symptoms  
(P02010)(P02040)(P02038)(P01044)(P02032)(P01117)  
(P01094) (P01138)(P02031)(P02032)(P01172)(P02170)  
(P02008)(P01019)(P01033)(P01052)(P01053)(P01061)  
(P01079)(P02034)(P02002)(P02021)(P02029)(P02195)  
(P01149)
- Needing to take care of oneself  
(P01094)(P02010)(P02040)(P02031)(P01009)(P02038)
- (P01044) (P01138)(P02031)(P01172)(P01058)(P02170)  
(P01061)(P02002)(P02034)(P02002)(P02018)(P02008)  
(P01019)(P01052)(P02029)(P02152)(P02195)
- Had to completely give up work  
(P01009)(P02032)(P01058)  
(P01033)(P01053)(P01061)(P02034)(P02018)(P02152)  
(P01149)
- Had to adapt working life  
(P02040)(P01044)(P01138)(P02031)(P01044)  
(P02008)(P01052)(P02002)(P02021)(P02029)(P02195)
- Work is challenging  
(P02040)(P02010)(P01009)(P02031)(P01094)  
(P01052)(P02195)
- The impact of symptoms on psychological well-being
  - Frustration of living without an clear diagnosis  
(P01009)(P01117)(P01135)(P02031)(P01058)
  - (P01019)(P01052)(P01053)(P01079)(P02018)(P02021)
  - (P02029)(P02152)(P02195)(P01149)
  - Frustration of living with symptoms  
(P02010)(P01044)(P01117)(P01135)(P02031)(P01094)  
(P01058)
  - (P02008)(P02034)(P02018)(P02029)(P02152)(P02195)  
(P01149)
  - Feeling left behind  
(P02010)(P01009)(P01044)(P02031)(P01094)  
(P02034)
  - Low mood and depression  
(P02010)(P01001)(P01044)(P02032)(P02031)(P01094)  
(P02170)(P01058)  
(P02008)(P01019)(P01033)(P01053)(P01061)(P01079)  
(P02152)(P02195)
  - Anxiety  
(P02031)(P01094)  
(P01052)(P01053)(P01079)(P01149)
  - Feelings of embarrassment or shame  
(P01172)(P01094)  
(P02029)(P01079)
  - Not in control of emotions  
(P02010)(P01001)(P01044)(P02032)(P01117)(P01135)
  - (P02031)(P01094)(P01058)  
(P01019)(P01033)(P01079)(P02018)(P02152)(P01149)



- In control of emotions  
(P02040)(P02038)(P01001)  
(P02008)(P01052)(P01061)(P02034)(P02002)(P02021)  
(P02029)(P02195)

## Inconsistency within the NHS

- NHS staff can be really supportive
  - NHS did their best for me  
(P02010)(P02038)(P01009)(P01001)(P01044)(P02032)  
(P01138)(P02031)(P01172)(P02170)  
(P01061)(P02034)(P02002)(p02018) (P02029)(P02152)
  - GP is helpful  
(P01009)(P01138)  
(P01061)(P02034)(P02002)(P02018)(P02152)
  - Referral process was quick and straightforward  
(P01009)(P01001)(P02031)(P01172)(P02170)  
(P01052)(P01061) (P02002)(P02018)(P02021)(P02152)
- NHS staff are not always understanding
  - Feeling abandoned by health professionals  
(P02040)(P02010)(P01117)(P01135)(P02032)(P02031)  
(P01094)(P01172)(P01058)  
(P02008)(P01019)(P01033)(P01052)(P01053)(P01079)  
(P02034) (P02002)(P02021)(P02029)(P02195)(P01149)
  - Lack of understanding of GPs/ health professionals  
(P02040)(P02010)(P02038)(P01009)(P02032)(P01094)  
(P01058)  
(P02008)(P01019)(P01053)(P01079)(P02034)(P02018)  
(P02021) (P02029)(P02195)(P01149)
  - Needing more understanding and help from healthcare professionals (P02010)(P01094)(P01058)  
(P02008)(P01053)(P02034)(p02002)(P02018)(P02021)  
(P02029)(P02195)(P01149)
  - Unprofessional medical approach by GPs  
(P02010)(P01009)(P01135)(P01138)(P01094)  
(P01052)(P02018)(P01149)
  - Unprofessional medical approach by specialists and other health professionals  
(P02010)(P01135)(P02170)(P01058)  
(P01019)(P01053)(P02002)(P02018)(P02195)(P01149)
- Long delays are common in healthcare
  - Medical process too slow  
(P02040)(P02010)(P02038)(P01009)(P01001)(P01135)  
(P01094)(P02170)(P01058)

- (P02008)(P01019)(P01052)(P01053)(P02034)(P02002)  
(P02018)(P02029)(P01149)
    - Hard to see the same GP  
(P02040)(P02038)(P01117)(P01094)(P01172)  
(P02008)(P01033)(P02002)(P02029)(P02152)
    - Misdiagnosis from GPs/specialists  
(P02040)(P02010)(P02032)(P01117)(P01138)(P02031)  
(P01094) (P02170)(P01058)  
(P02008)(P01019)(P01053)(P01079)(P02018)(P02029)  
(P02195)
    - Disconnect within the NHS  
(P02010)(P01001)(P01044)(P01094)(P02170)(P01058)  
(P01079)(P02002)(P02195)  
Having to take the lead with health professionals  
(P02010)(P02038)(P01135)(P01138)(P01058)  
(P02008)(P01052)(P01053)(P02002)(P02195)(P01149)
- A mixed method approach is better
  - Prescribed medication  
(P02040)(P02010)(P02038)(P01001)(P01044)(P02032)  
(P01117) (P01138)(P02031)(P01172)(P02170)  
(P02008)(P01019)(P01053)(P01079)(P02034)(P02002)  
(P02018)(P02021)(P02029)(P02152)
  - Alternative treatments and advice  
(P01009)(P01001)(P02032)(P01135)(P01138)(P01094)  
(P02170)  
(P02008)(P01019)(P01052)(P01053)(P01061)(P02002)  
(P02018)(P02021)(P02029)(P01149)
  - Health professionals should be more open to holistic approaches  
(P01001)(P01135)(P02031)  
(P02008)(P01019)(P01052)(P01079)(P02029)

## APPENDIX XII

### Workplace evaluation reports

#### Professional Doctorate in Health Psychology

#### Workplace Evaluation Report

##### Section 1 - To be completed by the Trainee:

|                                        |              |
|----------------------------------------|--------------|
| Trainee's name                         | KATIE WATTS. |
| Name of workplace contact              | T. Clalder   |
| Nature of work and competence assessed | RESEARCH     |

##### Section 2 – to be completed by the Workplace Supervisor:

Views on the Trainee's Performance on above piece of work. Please also comment on any reason for delays in the completion of this piece of work and report any periods of prolonged absence.

Katie conducted a large qualitative study exploring patients with fibromyalgia views on their experience of healthcare, living with the symptoms. She compared those with Black and ethnic minority groups with white British, using thematic analysis and framework method. She also completed a systematic review on the efficacy of mindfulness based CBT for medically unexplained symptoms.

##### **Declaration**

I verify that the above named Trainee has undertaken the above mentioned piece of work. I am of the opinion that it has been completed to a satisfactory professional standard.

Signature: [Redacted]

Date: 1/9/2017



School of Health Sciences  
City University  
Northampton Square  
London EC1V 0HB  
Programme Director – Dr Angeliki Bogosian  
Email: [Redacted]  
Tel: [Redacted]

Professional Doctorate in Health Psychology

Workplace Evaluation Report

**Section 1 - To be completed by the Trainee:**

|                                        |                    |
|----------------------------------------|--------------------|
| Trainee's name                         | Katie Watts        |
| Name of workplace contact              | Dr Caroline Stokes |
| Nature of work and competence assessed | RESEARCH           |

**Section 2 – to be completed by the Workplace Supervisor:**

Views on the Trainee's Performance on above piece of work. Please also comment on any reason for delays in the completion of this piece of work and report any periods of prolonged absence.

Katie's qualitative research project was conducted to a high standard. Her systematic review was similarly well executed.

**Declaration**

I verify that the above named Trainee has undertaken the above mentioned piece of work. I am of the opinion that it has been completed to a satisfactory professional standard.

Signature:

*Caroline Stokes*

Date:

8/9/2017



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## **SYSTEMATIC REVIEW: 2B**

# **The effectiveness of mindfulness-based cognitive therapy (MBCT) in treating PPS: A systematic review**

**Word count: 6420**

## **2B.1: INTRODUCTION**

### **2B.1.1: Rationale**

PPS, also known as MUS, *Body Distress Syndrome*, and *Functional Symptoms*, are a collection of syndromes or symptoms that appear to be absent of a clear medical diagnosis (Marks & Hunter, 2015). Very common examples of PPS include fibromyalgia, CFS, IBS, and chronic pain. PPS are frequently seen within primary and secondary care (Nimnuan, 2001; Steinbrecher, Koerber, Frieser & Hiller, 2011), and are estimated to account for over £3 billion per year in healthcare costs alone (Bermingham, Cohen, Hague & Parsonage, 2010). CBT, a psychological therapy that focuses specifically on the relationship between thoughts, feelings and behaviours, has already been shown to be an effective treatment for PPS (Menon, Rajan, Kuppli & Sarker, 2017), and due to its existing evidence base, is listed as a standard psychological treatment (Joint Commissioning Panel for Mental Health, 2017). However, there is also a growing evidence base for mindfulness-based interventions (MBIs). Based on Buddhist principles where individuals are taught to focus on the present moment and approach daily stressors differently (Mental Health Foundation, 2017), mindfulness has been successfully adapted for use within the Western world. Mindfulness-based stress reduction (MBSR), originally developed in order to treat chronic pain (Kabat-Zinn, 1982), has been shown to benefit a wide range of mental and physical health problems (Grossman, Nieman, Schmidt & Walach, 2004; Johansson, Bjuhr & Rönnbäck, 2011; Witek-Janusek, Albuquerque, Chroniak, Chroniak, Durazo-Arvizu et al., 2008).

MBSR was originally combined with CBT in order to reduce the risk of relapse in depression (Teasdale, Segal, Williams, Ridgway, Soulsby et al., 2000). So far, reviews of the existing evidence have concluded that MBCT may be as

effective in treating PPS as MBSR, with both more effective than less specific MBIs (Lakhan & Schofield, 2013). Systematic reviews on MBIs in general have indicated that MBCT may reduce symptom severity, reduce depression and anxiety, and improve quality of life for those with PPS (Aucoin, Lalonde-Parsi & Cooley, 2014; Hilton, Hempel, Ewing, Apaydin, Xenakis et al., 2017; Lakhan & Schofield, 2013). However these findings were not conclusive, due to the limited number of MBCT studies included within each review, particularly RCTs (Aucoin et al., 2014; Hilton et al., 2017; Lakhan & Schofield, 2013). The reviews also criticised the existing studies for their high risk of bias, or unclear risk due to inadequate reporting (Aucoin et al., 2014; Hilton et al., 2017).

Evidence for the effectiveness of MBCT in treating CFS is particularly weak. Rimes and Wingrove (2013) conducted a single pilot study for patients with CFS (as included within the review by Lakhan & Schofield, 2013), which reported a reduction in symptom severity, level of impairment and depressive symptoms. A further exploratory uncontrolled study has suggested MBIs may reduce symptom severity, improve physical functioning, and reduce levels of depression and anxiety in those with CFS (Suraway, Roberts & Silver, 2005). However, exploratory and pilot studies do not possess the scientific rigour needed for conclusive evidence.

This systematic review proposes to re-examine the effectiveness of MBCT in selected PPS. Similarly to the MBI review by Lakhan and Schofield (2013), this review will focus upon IBS, fibromyalgia and CFS, with the expectation that more robust and high quality MBCT studies with these PPS populations would have been conducted since. Medically unexplained chronic pain will also be included within the review, due to its prevalence and overlap with fibromyalgia. Studies that have included the above PPS within an RCT will also be considered for inclusion. A greater understanding of the effectiveness of MBCT within the PPS population will

help to inform healthcare professionals of the most appropriate treatment for PPS, which has the potential to improve healthcare outcomes for patients.

### **2B.1.2: Review questions**

This review will examine the quality of the evidence for MBCT as an effective treatment for PPS. It will review the findings and take a systematic approach towards reviewing the methodological approaches taken. The aims of this review are therefore to:

- 1) Understand the effectiveness of MBCT in reducing symptom severity, relieving depression and anxiety, and improving quality of life, in patients with IBS, chronic pain, fibromyalgia and CFS.
- 2) Assess the quality of the RCTs in order to understand whether there is now conclusive evidence that MBCT can be an effective treatment for PPS.

Unlike previous reviews that have focused only on specific Symptom Severity or Quality of Life measures, this review will be more inclusive. Symptom Severity will therefore also encompass other symptom severity measures (such as symptom intensity and frequency). Quality of Life will also include measures of general health, impairment, disability, functioning, interference, impact, life satisfaction and participants' impression of change.

## **2B.2: METHOD**

### **2B.2.1: Search strategy**

A systematic approach was taken in order to look for appropriate research studies. Between 20<sup>th</sup> July and 8<sup>th</sup> August 2017, a thorough search was conducted within the following electronic databases: Ovid Full Text, PsycArticles, PsycInfo,



Embase, Medline, CINAHL, Cochrane Central Register of Controlled Trials (CCRCT), PubMed, ScienceDirect, Scopus and Web of Science. The following search terms were employed within the databases in order to generate results:

- 1) "mindfulness" or "mindfulness-based" or "mindfulness-based cognitive therapy" or "MBCT" or "mind-body"
- 2) AND "somatization" or "somatic" or "somatoform" or "medically unexplained symptoms" or "MUS" or "functional symptoms" or "unexplained symptoms" or "unexplained pain" or "chronic pain" or "idiopathic pain" or "functional pain" or "fibromyalgia" or "irritable bowel syndrome" or "IBS" or "CFS" or "chronic fatigue syndrome"
- 3) AND "randomized" or "randomised" or "RCT" or "randomised controlled" or "randomized controlled" or "randomly allocated" or "randomly assigned"

Reference lists of previous systematic reviews were also searched through in order to ensure that an inclusive review of MBCT was achieved (Aucoin et al., 2014; Hilton et al., 2017; Lakhan & Schofield, 2013). For a more detailed breakdown of the search strategy for each database, please see Appendix II.

## **2B.2.2: Selection criteria**

All studies eligible for inclusion conducted an MBCT intervention for patients with either fibromyalgia, chronic pain, IBS or CFS. In order to qualify as MBCT and be included within the review, at least one session of mindfulness meditation in collaboration with CBT needed to be delivered in any format (i.e. face-to-face, by telephone or online). Only RCT study designs were eligible, and therefore all included studies contained either a control or delayed treatment group, or a comparison therapy group. Comparison therapy groups could be either drug

therapy, or any psychological therapy excluding mindfulness and/or CBT. All studies were conducted with adults (aged 18 and over), and published in English. Studies that employed participants with a diagnosed medical condition, such as arthritis or irritable bowel disease (IBD) were excluded, as were non-specific MBI studies or MBSR studies. Outcomes were reviewed and then extracted from each study, including symptom severity (including pain intensity and frequency), anxiety and depression, and quality of life (including general health, functioning, disability, impairment, impact and interference). Studies containing at least both baseline and post-intervention data were included, so that the impact of the interventions could be assessed. Follow-up data was extracted only if available, in order to provide further insight into the effectiveness of MBCT. Only studies using validated scales, or scales that had been successfully employed within previous studies with acceptable Cronbach's  $\alpha$  were included. There were no limitations on the years of publishing, although due to MBCT being relatively recent, it was anticipated that studies would have been conducted within the last ten years.

### **2B.2.3: Process of reviewing data**

The PRISMA 2009 Flow Diagram was followed in order to identify eligible trials for inclusion (Moher, Liberati, Tetzlaff, Altman & Prisma Group, 2009). The search terms were entered into each database in order to generate results. Following this, all identified duplicates were removed. Titles of all results were screened, as well as the abstracts of potentially relevant studies. Full text articles were then accessed where titles and abstracts suggested potential inclusion within the review, or where it was not clear from the abstract whether the study may be eligible for inclusion. These full text articles were then read through in order to check eligibility. Single study selection was employed.

#### **2B.2.4: Cochrane Risk of Bias Tool**

The Cochrane Risk of Bias Tool was designed in order to identify the risk of bias within randomised controlled trials (Higgins, Altman, Gøtzsche, Jüni, Moher et al., 2011), and has been frequently employed to assess bias risk in systematic reviews (Aucoin et al., 2014; Krogsbøll, Jørgensen, Larsen & Gøtzsche, 2012). It assesses the level of bias across several areas, including 1) Selection Bias: Random sequence generation and Allocation concealment; 2) Reporting Bias: Selective reporting; 3) Attrition bias (incomplete outcome data); 4) Performance bias: Blinding (participants and personnel); 5) Detection bias (outcome assessment); 6) Any other sources of bias. For each criteria outlined above, studies were awarded High Risk, Low Risk, or Unclear ratings. Based on this information, studies were then given an overall rating. In cases where studies were deemed to be not at high risk or low risk, they were awarded a Moderate rating. Please see Appendix III for a breakdown of study assessment. Single coding of the risk of bias was used.

#### **2B.3: RESULTS**

The search strategy led to the identification of 2324 titles. 338 duplicates were initially removed and the remaining records were reviewed. The remaining abstracts were read through, and the full text for potentially relevant studies was obtained (n=65). The majority of these were also excluded due to their focus on MBSR or non-specific MBI, or because they were not RCTs. Ten studies were included within the final analysis. Please see below for a flow diagram of the study selection process, using the Prisma 2009 template (Figure 2B1).

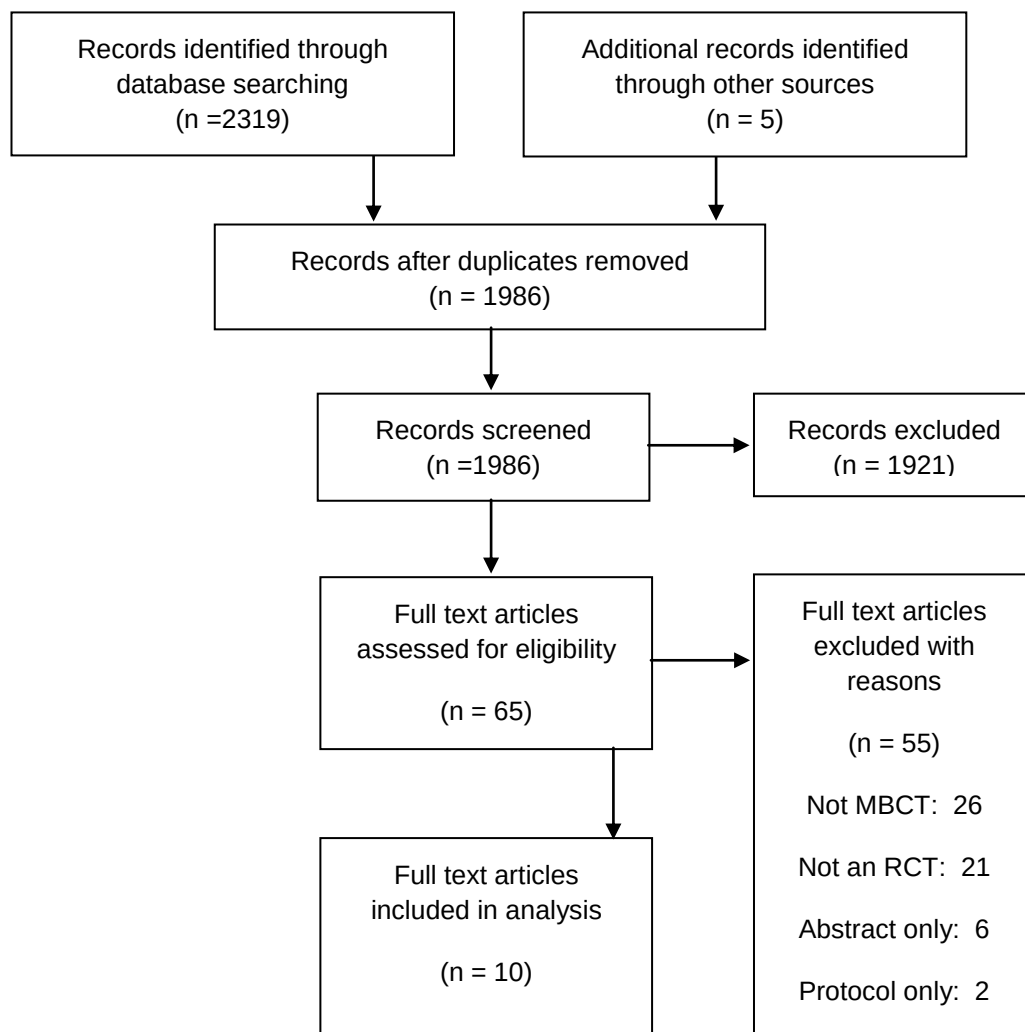


Figure 2B1. Flow diagram of study selection

As a guide for data extraction, the Prisma 2009 Checklist was consulted. The Prisma 2009 checklist, or Prisma Statement, was originally designed to try and improve the quality of systematic reviews by providing detailed guidance of what information to include (Moher et al., 2009). With regards to data extraction, the checklist provided clear instruction to extract and report data on participants, interventions, comparisons, outcomes and study design. The checklist also indicated to report on study size and the lengths of follow-up times, as well as effect sizes and confidence intervals. While data extraction within this review was guided

by the Prisma 2009 Checklist, it was also reliant upon the objectives of the study, i.e. to investigate the effects of MBCT upon symptom severity, anxiety and depression, and quality of life. Data within included studies that did not address these objectives were not extracted and therefore are not discussed within this review.

### **2B.3.1: Study characteristics**

Of the ten studies included, four were on chronic pain (Day, Thorn, Ward, Rubin, Hickman et al., 2014; de Jong, Peeters, Gard, Ashih, Doorley et al., 2017; Dowd, Hogan, McGuire, Davis, Sarma et al., 2015; Zgierska, Burzinski, Cox, Kloke, Stegner et al., 2016), one on fibromyalgia (Parra-Delgado, Latorre-Postigo, 2013), three on IBS (Asadollahi, Mehrabi, Neshatdoost, Kalantari, Afshar et al., 2014; Ljótsson, Falk, Vesterlund, Hedman, Lindfors et al., 2010; Ljótsson, Hedman, Andersson, Hesser, Lindfors et al., 2011), one on CFS (Rimes & Wingrove, 2013), and one on multiple PPS where fatigue, gastrointestinal symptoms and back pain were included (van Ravesteijn, Lucassen, Bor, van Wheel & Speckens, 2013). All studies were published between 2010 and 2017. The majority of these (70%) were conducted in Europe, with two from the Netherlands, two from Sweden (Ljótsson et al., 2011; Ljótsson et al., 2010), one from Spain (Parra-Delgado & Latorre-Postigo, 2013), one from the UK (Rimes & Wingrove, 2013) and one from Ireland (Dowd et al., 2015). Two were conducted in the USA (Day et al., 2014; Zgierska et al., 2016), and one in Iran (Asadollahi et al., 2014).

Studies employed a mix of comparison groups. The majority (60%) had a control, wait-list control, usual care or delayed treatment (DT) group (Asadollahi et al., 2014; Day et al., 2014; de Jong et al., 2017; Parra-Delgado & Latorre-Postigo, 2014; Rimes & Wingrove, 2013; Zgierska et al., 2016). Of the remaining studies, comparison therapy groups were Stress Management (Ljótsson et al., 2011),

Enhanced Usual Care (Van Ravesteijn et al., 2013), Pain Management Psychoeducation (Dowd et al., 2015), and an online discussion forum (Ljotsson et al., 2010). Five studies (50%) included eight weekly 2-2.5 hour-long group sessions of MBCT face-to-face within a clinical setting (Day et al., 2014; de Jong et al., 2017; Rimes & Wingrove, 2013; van Ravesteijn et al., 2013; Zgierska et al., 2016). Parra-Delgado and Latorre-Postigo (2013) delivered eight 2.5 hour sessions over a three month period. Asadollahi et al., (2014) did not provide detailed information regarding how MBCT was delivered. All five studies that tested face-to-face MBCT employed a qualified mindfulness teacher (de Jong et al., 2017; Rimes & Wingrove, 2013; Parra-Delgado & Latorre-Postigo, 2013; van Ravesteijn et al., 2013; Zgierska et al., 2016). For each of these, participants were provided with homework exercises (such as meditation) to complete in between sessions.

Three studies delivered MBCT using an online or computerised programme which participants worked through remotely (Dowd et al., 2015; Ljotsson et al., 2011; Ljotsson et al., 2010). Dowd et al., (2015) delivered twelve 20-minute MBCT sessions in audio-visual format, which were delivered twice-weekly over a six-week period. Participants were kept alert to the next session's availability via email (Dowd et al., 2015). The other two studies delivered online MBCT over ten weeks and provided participants with access to a closed online discussion forum, as well as online therapists who could provide feedback and support (Ljotsson et al., 2011; Ljotsson et al., 2010). Online MBCT programmes were based on previously tested approaches (Dowd et al., 2015, Ljotsson et al., 2011; Ljotsson et al., 2010).

Eight out of ten studies included follow-up analyses. The length of follow-ups for studies were two months (Asadollahi et al., 2014; Rimes & Wingrove, 2013), three months (Ljotsson et al., 2010; Parra-Delgado & Latorre-Postigo, 2013), six months (Dowd et al., 2015; Ljotsson et al., 2011; Zgierska et al., 2016), and nine

months (van Ravesteijn et al., 2013). Day et al., (2013) and de Jong et al., (2017) did not follow-up after post-intervention analyses.

The total number of participants included within all studies was 718 (mean = 71.8; SD = 57.2). The majority of studies however included much smaller samples than the mean, with six studies (60%) randomising less than 25 participants into each group (Asadollahi et al., 2014; Day et al., 2014; de Jong et al., 2017; Parra-Delgado & Latorre-Postigo, 2013; Rimes & Wingrove, 2013; Zgierska et al., 2016). The remaining RCTs included between 98 and 61 participants to receive MBCT, with similar numbers reported within the control groups (Dowd et al., 2015; Ljotsson et al., 2010; Ljotsson et al., 2011; van Ravesteijn et al., 2013). Five studies (50%) included information on power analysis calculations in order to justify sample size. However, two of these studies reported not achieving their target (de Jong et al., 2017; Ljotsson et al., 2011). One study justified its small sample size, stating that this was anticipated due to it being a pilot study (Day et al., 2014). The four remaining studies provided no justification for sample size (Asadollahi et al., 2014; Parra-Delgado & Latorre-Postigo, 2013; Rimes & Wingrove, 2013; Zgierska et al., 2016).

The majority of studies (80%) provided descriptive statistics on gender and age. These studies demonstrated that the vast majority of participants were female, with the percentage ranging from 75-100% across studies (mean = 84.6; SD = 9.8). The mean ages of participants ranged from 34.6 to 52.9 years (mean = 44.0; SD = 7.1). Seven studies (70%) reported on calculations of potential differences between groups at baseline, and in five studies no significant differences were found in terms of baseline data or demographics. Four studies (40%) reported significant differences in baseline data (Asadollahi et al., 2014; Parra-Delgado & Latorre-Postigo, 2013; Rimes and Wingrove, 2013, Zgierska et al., 2016). However, only

two studies controlled for these differences (Parra-Delgado & Latorre-Postigo, 2013; Rimes and Wingrove, 2013).

Validated and/or previously tested self-report measures were employed for all studies, and where Cronbach's  $\alpha$  were reported these were either acceptable or good. Two studies employed online symptom diaries in order to monitor symptom severity, such as the Gastrointestinal (GI) diary (Ljotsson et al., 2011) and the online headache diary (Day et al., 2014), both of which were based on diaries tested within previous studies. Please see Appendix IV for the Data Extraction table, where individual outcome measures for each study are reported.

### **2B.3.2: Assessment of bias risk**

Most studies (90%) provided information on the method used to randomly allocate participants. Only one study did not provide this information (Asadollahi et al., 2014). Most of these studies (70%) demonstrated that random allocation outcomes were not foreseeable to participants prior to their enrolment (Dowd et al., 2015; Ljotsson et al., 2011; Ljotsson et al., 2010; Parra-Delgado & Latorre-Postigo, 2013; Rimes & Wingrove, 2013; van Ravesteijn et al., 2013, Zgierska et al., 2016). For the remaining studies, whether allocations were foreseeable prior to enrolment was unclear. With regards to performance bias, only one study somewhat blinded participants to their treatment group by not disclosing the differences between treatments (Ljotsson et al., 2011). Three studies claimed that they did not, or that it was not possible to blind participants or research staff (Day et al., 2013; Dowd et al., 2015; Zgierska et al., 2016). For the remaining studies however, not enough information was provided to make a judgement. Regarding detection bias, only two studies indicated that outcome assessors were not blinded to the participant treatment group (Day et al., 2014; Zgierska et al., 2016).



In the vast majority of studies (80%), an informative level of information regarding attrition rates was provided. Of the two studies that did not, one did not provide reasons for withdrawals or how any missing data would be handled (Parra-Delgado & Latorre-Postigo, 2013). The other study did not provide reasons for two withdrawals, and two further participants were not acknowledged (Asadollahi et al., 2014). Generally, withdrawal rates were low, with the majority reporting rates between 5.4% and 21.6% at the point of follow-up. Only two studies reported notably high attrition rates of 33.3% (Day et al., 2014) and 59.7% (Dowd et al., 2015). In four studies (40%), Intention-To-Treat (ITT) analysis was performed (Dowd et al., 2015; Ljotsson et al., 2011; Parra-Delgado & Latorre-Postigo, 2013; Zgierska et al., 2016), and in three of these, only ITT analysis was reported (Ljotsson et al., 2011; Parra-Delgado & Latorre-Postigo, 2013; Zgierska et al., 2016), indicative of selective outcome reporting. Parra-Delgado and Latorre-Postigo (2013) also biased the findings of their research by only providing a breakdown of what was statistically significant, omitting other information on between-group effect sizes, intra-group changes and changes in outcomes.

In terms of recruitment bias, a few studies employed self-referral methods, meaning that participants were not officially confirmed to have PPS by a healthcare professional (Dowd et al., 2015; Ljotsson et al., 2011; Ljotsson et al., 2010). Rimes and Wingrove (2013) requested therapists to recruit CFS patients into the study, which introduced bias in two ways. Firstly, participants may have been more receptive to therapy than the average CFS patient, had a positive experience of therapy, or known what the results of the study were likely to show. Secondly, if participants were known to therapists it is possible they would have felt pressure to participate.

Overall, the risk of bias within the ten included studies was reasonable. Five studies (50%) were judged to be at low risk of bias overall (de Jong et al., 2017;

Ljotsson et al., 2011; Ljotsson et al., 2010; Rimes & Wingrove, 2013; van Ravesteijn et al., 2013), and four (40%) at moderate risk (Day et al., 2014; Dowd et al., 2015; Parra-Delgado & Latorre-Postigo, 2013; Zgierska et al., 2016). For the remaining study, the risk of bias was unclear due to an inadequate level of reporting (Asadollahi et al., 2014).

### **2B.3.3: Results of individual studies**

Due to the heterogeneity of the studies in terms of PPS type, study size and the various measures employed within individual studies, particularly for the quality of life assessment, it was considered that it would not be appropriate to perform a meta-analysis. The findings of individual studies have been discussed below, categorised under '*Symptom Severity*', '*Anxiety*' and '*Depression*' which will be examined as two separate constructs, and '*Quality of Life*'. The results have also been documented separately by PPS type. For most studies, significance levels and effect sizes were reported.

#### *Symptom severity*

##### IBS

The three studies reporting upon the effect of MBCT upon symptom severity provided mixed results. Two studies reported significant improvements upon IBS severity following MBCT in comparison with the control group, with moderate to large effect sizes (Ljotsson et al., 2010; Ljotsson et al., 2011). Ljotsson et al., (2011) reported particularly significant effects upon bloating ( $d=0.94$ , 95%, CI: 0.46, 1.41,  $P<0.001$ ) and primary symptoms ( $d=0.83$ , 95%, CI: 0.36, 1.29,  $P<0.001$ ). Both of these studies also reported similar findings at follow-up, indicating a long-term improvement. However, Asadollahi et al., (2014) reported only a non-

significant improvement post-intervention ( $d=0.28$ ,  $P=0.07$ ), with any improvement lost at follow-up ( $d=0.03$ ,  $P=0.58$ ).

### Chronic pain and fibromyalgia

Findings for chronic pain and fibromyalgia were also mixed. Of the five available studies, only two reported any significant within-groups effects post-intervention upon pain reduction, intensity and frequency, with medium to large effect sizes (Day et al., 2014; Parra-Delgado & Latorre-Postigo, 2013). Only small within-group effect sizes were reported post-intervention for cervical pain ( $d=0.31$ , 95% CI: -0.42, 1.02), and no effect was observed at all for dorsal, right arm, left arm, or right leg pain (Parra-Delgado & Latorre-Postigo, 2013). Following between-groups analysis, only two out of four studies reported medium-to-large effect sizes for MBCT (Day et al., 2014; Zgierska et al., 2016), and only for one of these studies was the difference between groups significant (Zgierska et al., 2016). The two remaining studies reporting on pain severity showed no improvement post-intervention (de Jong et al., 2017; Dowd et al., 2015).

Three studies provided some evidence for the long-term benefit of MBCT for pain severity (Dowd et al., 2015; Parra-Delgado & Latorre-Postigo, 2013; Zgierska et al., 2016), with either greater significance or slightly larger effect sizes within groups reported in comparison with post-intervention (Dowd et al., 2015; Parra-Delgado & Latorre-Postigo, 2013). Only one study reported a significant improvement and large effect size between groups at follow-up ( $d=0.86$ , 95% CI: 0.2, 1.9;  $P=0.045$ ) (Zgierska et al., 2016).

### CFS and PPS (mixed)

For the remaining two studies, reductions were observed in terms of symptom severity. van Ravesteijn et al., (2013) reported a significant reduction in symptoms within the MBCT group post-intervention ( $d=-1.61$ , 95% CI: -2.50, -0.71,

$P < 0.05$ ). Between-groups analysis also demonstrated significant reductions in fatigue ( $P = 0.014$ ) (Rimes & Wingrove, 2013), and physical symptoms in general with a large negative effect size ( $d = -1.17$ , 95%, CI: -2.57, 0.23) (van Ravesteijn et al., 2013). Reductions in symptom severity were also evident within both studies at follow-up. van Ravesteijn et al., (2013) reported a significant within-groups effects of MBCT on symptoms at follow-up ( $d = -1.44$ , 95%, CI: -2.60, -0.28,  $P < 0.05$ ), and both studies reported either significant between-group effects ( $P = 0.01$ ) (Rimes & Wingrove, 2013), or small to moderate negative effect sizes between groups ( $d = -0.40$ , 95%, CI: -1.99, 1.20) (van Ravesteijn et al., 2013).

### *Anxiety*

### IBS

All three studies reported reductions in anxiety following MBCT. Within-groups analysis demonstrated significant reductions in anxiety, with effect sizes ranging from  $d = 0.33$  (Ljotsson et al., 2011) to  $d = 0.64$  (Ljotsson et al., 2010). However, of the two studies reporting between-groups effects, only Ljotsson et al., (2010) reported a significant benefit of MBCT. While Ljotsson et al., (2011) did report a small to moderate effect size between groups post-intervention ( $d = 0.33$ , 95%, CI: 0.04, 0.62) using the Visceral Sensitivity Index, this was not reported as significant. Furthermore, between-groups analysis using the anxiety scale of the HADS demonstrated no effect ( $d = 0.04$ , 95%, CI: -0.25, 0.32).

Follow-up analyses provide weak evidence that MBCT may have a long-term positive effect upon anxiety. Significant small to moderate effect sizes within groups were reported within two studies (Asadollahi et al., 2014; Ljotsson et al., 2011), and a further reduction in health anxiety was noted at follow-up within the remaining study, although this did not quite reach significance level ( $P = 0.06$ ) (Ljotsson et al., 2010). Between-group analyses demonstrated there to be no long-

term benefit of MBCT in comparison with Stress Management ( $d=0.14$ , 95%, CI: -0.16, 0.44,  $P=0.647$ ) (Ljotsson et al., 2011).

### Chronic pain and fibromyalgia

Only two out of five studies reported on the effects of MBCT upon anxiety (de Jong et al., 2017; Dowd et al., 2015), with the former reporting on the effects of MBCT on both anxiety and depression combined. For both of these studies, within-groups analyses demonstrated only a small to moderate and non-significant effect of MBCT post-intervention. Between groups analysis also demonstrated a non-significant effect of MBCT post-intervention, with a reported effect size of  $d=-0.10$  (Dowd et al., 2015). Follow-up analyses also indicated no long-term benefit of MBCT upon anxiety either within the MBCT group ( $d=-0.12$ ,  $P>0.05$ ) or between groups ( $d=-0.10$ ,  $P>0.05$ ) (Dowd et al., 2015). Day et al., (2013) and de Jong et al., (2017) did not conduct follow-up analyses.

### CFS and PPS (mixed)

The two remaining studies provided little evidence for the effect of MBCT on anxiety (Rimes & Wingrove, 2013; van Ravesteijn et al., 2013). A significant reduction in anxiety was only reported within the MBCT group for one study (van Ravesteijn et al., 2013), and for both studies between-groups analyses demonstrated non-significant effects post-intervention. Follow-up analyses within the MBCT groups provided mixed results, with one study demonstrating a continued significant reduction in terms of physical symptoms within (van Ravesteijn et al., 2013), and the other reporting a continued non-significant reduction in anxiety (Rimes & Wingrove, 2013). Between-group analyses for both studies however demonstrated MBCT to have a non-significant benefit at follow-up.

## *Depression*

### IBS

Mixed results were also reported for the effects of MBCT upon depression. Two out of three studies reported significant reductions in depressive symptoms within the MBCT group post-intervention (Asadollahi et al., 2014; Ljotsson et al., 2011), with a small to moderate effect size of  $d=0.41$  reported (Asadollahi et al., 2014). While one study reported a significant difference between groups with a small to moderate effect size ( $d=0.43$ , 95%, CI: 0.00, 0.86,  $P<0.05$ ) (Ljotsson et al., 2010), the other study reporting between-groups effects found no benefit of MBCT at all ( $d=0.01$ , 95%, CI: -0.28, 0.29) (Ljotsson et al., 2011). The follow-up within-groups analyses demonstrate a possible long-term benefit of MBCT upon depression (Asadollahi et al., 2014; Ljotsson et al., 2011). However only one study reported their findings as significant (Ljotsson et al., 2011), and available between-groups analyses at follow-up demonstrated no benefit for MBCT ( $d=0.08$ , 95%, CI: 0.22, 0.38,  $P=0.817$ ) (Ljotsson et al., 2011).

### Chronic pain and fibromyalgia

Only two studies reported on the effects of MBCT upon depression alone, which produced mixed results. Parra-Delgado and Latorre-Postigo (2013) reported a significant reduction in depressive symptoms with a large effect size post-intervention ( $d=0.82$ , 95%, CI: 0.06, 1.55,  $P<0.001$ ). de Jong et al., (2017) reported a significant improvement for the MBCT group amongst the Per-Protocol sample ( $P=0.04$ ), but not the ITT sample ( $P=0.26$ ). Between-groups analysis for the two studies also produced mixed results, with one study demonstrating a significant difference post-intervention (Parra-Delgado & Latorre-Postigo, 2013), and the other reporting no difference amongst either the Per-Protocol sample ( $P=0.23$ ) or the ITT sample ( $P=0.48$ ). Parra-Delgado and Latorre-Postigo (2013) reported a continued

significant improvement at follow-up both within the MBCT group ( $d=0.86$ , 95% CI: 0.09, 1.59,  $P<0.001$ ), and in comparison with the control group ( $P=0.006$ ).

#### CFS and PPS (mixed)

There was some evidence of short-term benefit of MBCT within the two remaining studies. A reduction in depressive symptoms was reported within the MBCT group (van Ravesteijn et al., 2013), and for MBCT in comparison with the control group ( $P=0.038$ ) (Rimes & Wingrove, 2013). Within-groups and between-groups analyses did not produce any significant results at follow-up, although there was reported to be a small reduction in depressive symptoms amongst the MBCT groups (Rimes & Wingrove, 2013; van Ravesteijn et al., 2013).

#### *Quality of life*

#### IBS

Only two studies reported on quality of life. However in both cases there was evidence that MBCT could have a positive effect. Moderate to large between-groups effect sizes were reported, ranging from  $d=0.47$  on the Sheehan Disability Scale, to  $d=0.93$  on the IBS-QOL scale (Ljotsson et al., 2010). Ljotsson et al., (2011) also reported moderate between-group effects for MBCT in comparison with the Stress Management group ( $d=0.51$ , 95% CI: 0.23, 0.80). Follow-up analyses for both studies demonstrated between-groups effects to remain significant at follow-up, however the benefit of MBCT over comparison therapies was reported to reduce over time ( $d=0.31$ , 95% CI: 0.01, 0.61,  $P<0.001$ ) (Ljotsson et al., 2011).

#### Chronic pain and fibromyalgia

The five studies focused on chronic pain and fibromyalgia provided evidence of improvement upon quality of life following MBCT. Within-groups analyses demonstrated MBCT to significantly reduce pain interference (BPI) ( $d=-0.76$ ,

$P < 0.0001$ ) and improve Satisfaction with Life ( $d = 0.90$ ,  $P < 0.0001$ ) (Dowd et al., 2015). Improvements in mental health ( $d = 0.57$ ,  $P = 0.003$ ) and Vitality ( $d = 0.50$ ,  $P = 0.017$ ) were also shown, following analyses of the ITT sample (de Jong et al., 2017). Parra-Delgado and Latorre-Postigo (2013) also reported significant within-group effects upon fibromyalgia impact post-intervention, following use of the FIQ scale ( $d = 1.13$ , 95% CI: 0.33, 1.87,  $P < 0.001$ ).

Between-groups analyses provided less consistent findings. While Dowd et al., (2015) reported no difference in terms of pain interference ( $d = 0.04$ ,  $P > 0.05$ ), significant differences with small to moderate between-group effect sizes were reported for Satisfaction with Life ( $d = 0.59$ ,  $P < 0.05$ ), ability to manage emotions as measured through the PGIC scale ( $d = 0.46$ ,  $P = 0.011$ ), ability to deal with stressful events ( $d = 0.62$ ,  $P = 0.001$ ), and ability to enjoy pleasant events ( $d = 0.41$ ,  $P = 0.025$ ). While significant between-group effects with moderate to large effect sizes were also reported for Mental Health and Vitality amongst both the ITT and Per-Protocol samples (de Jong et al., 2017), in another study between-groups effects were only significant when compared with the Completer Sample ( $d = -1.29$ ,  $P < 0.01$ ), and not the ITT sample (Day et al., 2014). No significant differences were found between groups for Physical Functioning, Role Limitations (Physical), Role Limitations (Emotional), Social Functioning, Pain or General Health. No significant improvements were observed within the other studies (Day et al., 2014; Parra-Delgado & Latorre-Postigo, 2013; Zgierska et al., 2016).

Follow-up analyses provided some evidence for the long-term effects of MBCT. Small to moderate effect sizes were reported for ability to manage emotions ( $d = 0.36$ ,  $P = 0.039$ ) and deal with stressful situations ( $d = 0.36$ ,  $P = 0.044$ ), although there was no significant effect upon ability to enjoy pleasant events ( $P = 0.631$ ) (Dowd et al., (2015). Two further studies provided evidence for a long-term effect upon quality of life. Parra-Delgado and Latorre-Postigo (2013) reported significant



within-group effects for MBCT ( $d=0.94$ , 95% CI: 0.17, 1.67,  $P<0.001$ ), whereas Zgierska et al., (2016) reported a large but non-significant effect size when comparing MBCT with Usual Care ( $d=0.68$ , 95% CI: -1.0, 14.0,  $P=0.209$ ).

#### CFS and PPS (mixed)

The two remaining studies again demonstrated mixed evidence for the benefit of MBCT. van Ravesteijn et al., (2013) demonstrated significant within-groups effects when using the Physical Role sub-scale and the Visual Analogue Scale (EuroQoL) post-intervention. However, between-groups analyses demonstrated the benefit to be non-significant on the Visual Analogue Scale ( $P>0.05$ ). Rimes and Wingrove (2013) reported a significant between-groups effect of MBCT upon work and social adjustment (WSAS) post-intervention ( $P=0.04$ ), although reported a non-significant effect of MBCT upon Physical Functioning ( $P=0.124$ ) (Rimes & Wingrove, 2013). Follow-up within-groups analyses demonstrated significant long-term improvements in terms of Physical Functioning, Physical Role, Bodily Pain, and General Health (van Ravesteijn et al., 2013). Long-term within-group effects were also evident within the CFS study, although significance was only reported when comparing the two and six-month follow-up data for the MBCT group ( $P=0.004$ ). Non-significant findings were reported for Physical Functioning at follow-up ( $P=0.345$ ), and a comparison of pre-treatment and six-month follow-up data also produced non-significant results ( $P=0.051$ ) (Rimes & Wingrove, 2013).

## **2B.4: Discussion**

This review of ten RCTs had two main aims: 1) To understand whether MBCT can effectively reduce symptom severity, reduce anxiety and depression, and improve quality of life in individuals with PPS; 2) Understand the quality of the

existing RCTs within this area, in order to assess the validity and reliability of the evidence. Due to variations across studies in terms of PPS type, the control group interventions, and the various measures employed by studies, it was not considered appropriate to conduct a meta-analysis.

The findings did generally show that MBCT is be effective in reducing symptom severity in IBS (Ljotsson et al., 2011; Ljotsson et al., 2010), CFS (Rimes & Wingrove, 2013), and in a mix of PPS (van Ravesteijn et al., 2013), which supports the findings of previous reviews (Aucoin et al., 2014; Hilton et al., 2017; Lakhan & Schofield, 2013). Chronic pain and fibromyalgia studies also demonstrated MBCT to reduce pain severity, intensity and frequency (Day et al., 2014; Parra-Delgado & Latorre-Postigo, 2013; Zgierska et al., 2016), although with varying levels of success. Only one IBS study did not demonstrate a long-term reduction in symptom severity following MBCT (Asadollahi et al., 2014). However, it is difficult to ascertain the possible reasons for this, due to limited information available for this study.

In terms of alleviating anxiety, these studies suggest that there is some evidence that MBCT may slightly or moderately reduce anxiety for those with IBS (Ljotsson et al., 2010; Ljotsson et al., 2011). van Ravesteijn et al. (2013) demonstrated that MBCT may reduce anxiety in those with multiple PPS. It does not appear that MBCT has much effect in reducing anxiety in those with chronic pain and/or fibromyalgia or CFS. However, further studies are required, due to only two chronic pain studies reporting effects on anxiety within this review (de Jong et al., 2015; Dowd et al., 2015), and only one CFS study (Rimes & Wingrove). In terms of depression, MBCT was shown to be effective for IBS (Asadollahi et al., 2014; Ljotsson et al., 2011; Ljotsson et al., 2010), and CFS short-term (Rimes & Wingrove, 2013). However, this was not reported for multiple PPS (van Ravesteijn et al., 2013). In terms of chronic pain, while de Jong et al., (2017) reported weak evidence for MBCT treating depressive symptoms, it was only following analysis of

the Per-Protocol sample, which is unlikely to be representative due to these participants potentially being more motivated and open to MBCT.

The strongest evidence came following the review of MBCT and its effects upon quality of life, as significant improvements were reported in those with IBS (Ljotsson et al., 2011; Ljotsson et al., 2010), CFS (Rimes & Wingrove, 2013), chronic pain (Day et al., 2014; Dowd et al., 2015), fibromyalgia (Parra-Delgado & Latorre-Postigo, 2013), and in multiple PPS types (van Ravesteijn et al., 2013). These findings support those of previous MBI reviews for functional bowel disorders, chronic pain and PPS in general (Hilton et al., 2017; Lakhan & Schofield, 2013). However, the findings for MBCT within this review are more defined due to MBCT being examined separately from other MBIs.

#### **2B.4.1: Limitations**

There were a number of limitations within this review. The first limitation is the lack of studies that employed a robust sample size, increasing the risk of error. In addition, four studies were pilots rather than full RCTs. While it was not a limitation that could be controlled due to the lack of studies, it does compromise the quality of the evidence. Furthermore, there are high percentages of female participants, which limits the generalisability of the findings to the whole population. While PPS is generally more common in females, future studies are required to employ a higher proportion of male participants in order to be representative. Another limitation of this review was the heterogeneity across included studies. While heterogeneity was already inevitable due to the variations across PPS types, there were differences in terms of follow-up length, comparison group, how the MBCT intervention was delivered (e.g. face-to-face or online), and which outcome measures were employed.

Other limitations were related to bias. At the study selection stage, there was a moderate risk of publication bias. While attempts to avoid this were originally made by conducting a wide search through multiple databases and looking through any existing grey literature for further RCTs, attempts to contact authors in order to obtain access to further unpublished work were not undertaken which needs to be taken into consideration. Secondly, only single study selection was used due to time constraints and limited resource. Double study selection would have been more suitable due to the increased probability that only studies matching the defined inclusion criteria were actually included. A further limitation relates to the coding of the level of risk within studies. While the review did include a higher than anticipated number of 'Low risk' studies, only single coding of the risk of bias within selected studies was employed. This somewhat compromises the reliability that a fair risk of bias (e.g. Low or High) was attributed to each study. Double coding would have increased the probability that studies within the review had been interpreted correctly, and judged fairly.

Other limitations, noted when conducting the risk of bias assessment, were that there was a lack of blinding across all included studies. While it is acknowledged that the blinding of participants, research staff and even outcome assessors may not always be practical, it can still compromise the integrity of research. Furthermore, studies generally employed self-report measures in order to capture data, which compromises the quality of data quality due to participant subjectivity and memory. On a final note, many studies employed self-referral methods, which meant that participants were not medically confirmed to have met the criteria for PPS.

## **2B.4.2: Conclusions**

It can be concluded following this review that MBCT is likely to have at least a small positive effect in treating symptom severity, anxiety and depression, and in improving quality of life for patients living with PPS. This indicates therefore that the evidence-base for MBCT as a treatment for PPS has been strengthened, having positive implications for future healthcare. The implications of this are that MBCT may be helpful as an alternative treatment to CBT and other MBIs in the future. We can also conclude however that more RCTs with larger sample sizes are required, and that conclusive evidence for the effectiveness of MBCT in treating PPS has not yet been produced. More low-risk and representative studies with robust sample sizes are required, particularly for CFS, which continues to be under-researched despite promising findings from the existing pilot study.

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## **APPENDICES**

## APPENDIX I

### Supervision Plan: Systematic review

| Research             | Area of work<br>(*outside of<br>normal work)                         | Supporting<br>evidence            | Changes                                                                                                                                                                                                                                                 |
|----------------------|----------------------------------------------------------------------|-----------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Systematic<br>review | Psychological<br>factors associated<br>with BME patients<br>with MUS | Systematic review<br>(6000 words) | <p><i>Changed to:</i></p> <p>Systematic<br/>review relating to<br/>the FODMAP<br/>diet.</p> <p><i>Changed to:</i></p> <p>The effectiveness<br/>of mindfulness-<br/>based cognitive<br/>therapy in treating<br/>Persistent<br/>Physical<br/>symptoms</p> |

Supervisee: \_\_\_Katie Watts\_\_\_\_\_

Supervisor: \_\_\_Dr. Tiece Turnbull\_\_\_\_\_

## APPENDIX II

### Search strategy

| Date of search                                   | Database                                                                                     | Dates included in search | Search terms                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | No. of results |
|--------------------------------------------------|----------------------------------------------------------------------------------------------|--------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------|
| 22 <sup>nd</sup> – 24 <sup>th</sup><br>July 2017 | Ovid<br>(Ovid Full Text,<br>PsycARTICLES Full Text,<br>PsycINFO,<br>Embase,<br>Ovid MEDLINE) | All                      | "mindfulness" or<br>"mindfulness-based" or<br>"mindfulness-based cognitive therapy" or<br>"MBCT" or "mind-body"<br>AND<br>"somatization" or<br>"somatic" or<br>"somatoform" or<br>"medically unexplained symptoms" or "MUS" or<br>"functional symptoms" or<br>"unexplained symptoms" or<br>"unexplained pain" or<br>"chronic pain" or<br>"idiopathic pain" or<br>"functional pain" or<br>"fibromyalgia" or "irritable bowel syndrome" or "IBS" or<br>"CFS" or "chronic fatigue syndrome"<br>AND<br>"randomized" or<br>"randomised" or "RCT" or<br>"randomised controlled" or<br>"randomized controlled" or "randomly allocated" or "randomly assigned"<br>Limits: Full Text | <b>1,186</b>   |
| 27 <sup>th</sup> – 28 <sup>th</sup><br>July 2017 | Cochrane Central Register of Controlled Trials (CCRCT)                                       | All                      | "mindfulness" or<br>"mindfulness-based" or<br>"mindfulness-based cognitive therapy" or<br>"MBCT" or "mind-body"<br>AND<br>"somatization" or<br>"somatic" or<br>"somatoform" or<br>"medically unexplained symptoms" or "MUS" or<br>"functional symptoms" or<br>"unexplained symptoms" or<br>"unexplained pain" or<br>"chronic pain" or<br>"idiopathic pain" or<br>"functional pain" or                                                                                                                                                                                                                                                                                       | <b>217</b>     |

|                             |        |     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |            |
|-----------------------------|--------|-----|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------|
|                             |        |     | "fibromyalgia" or "irritable bowel syndrome" or "IBS" or "CFS" or "chronic fatigue syndrome"<br>AND<br>"randomized" or "randomised" or "RCT" or "randomised controlled" or "randomized controlled" or "randomly allocated" or "randomly assigned"                                                                                                                                                                                                                                                                                                                                                   |            |
| 31 <sup>st</sup> July 2017  | CINHAL | All | "mindfulness" or "mindfulness-based" or "mindfulness-based cognitive therapy" or "MBCT" or "mind-body"<br>AND<br>"somatization" or "somatic" or "somatoform" or "medically unexplained symptoms" or "MUS" or "functional symptoms" or "unexplained symptoms" or "unexplained pain" or "chronic pain" or "idiopathic pain" or "functional pain" or "fibromyalgia" or "irritable bowel syndrome" or "IBS" or "CFS" or "chronic fatigue syndrome"<br>AND<br>"randomized" or "randomised" or "RCT" or "randomised controlled" or "randomized controlled" or "randomly allocated" or "randomly assigned" | <b>79</b>  |
| 2 <sup>nd</sup> August 2017 | PubMed | All | "mindfulness" or "mindfulness-based" or "mindfulness-based cognitive therapy" or "MBCT" or "mind-body"<br>AND<br>"somatization" or "somatic" or "somatoform" or "medically unexplained symptoms" or "MUS" or "functional symptoms" or "unexplained symptoms" or "unexplained pain" or                                                                                                                                                                                                                                                                                                               | <b>220</b> |

|                                |               |     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |           |
|--------------------------------|---------------|-----|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------|
|                                |               |     | "chronic pain" or<br>"idiopathic pain" or<br>"functional pain" or<br>"fibromyalgia" or "irritable<br>bowel syndrome" or "IBS"<br>or "CFS" or "chronic<br>fatigue syndrome"<br>AND<br>"randomized" or<br>"randomised" or "RCT" or<br>"randomised controlled"<br>or "randomized<br>controlled" or "randomly<br>allocated" or "randomly<br>assigned"                                                                                                                                                                                                                                                                                                                           |           |
| 6 <sup>th</sup> August<br>2017 | ScienceDirect | All | "mindfulness" or<br>"mindfulness-based" or<br>"mindfulness-based<br>cognitive therapy" or<br>"MBCT" or "mind-body"<br>AND<br>"somatization" or<br>"somatic" or<br>"somatoform" or<br>"medically unexplained<br>symptoms" or "MUS" or<br>"functional symptoms" or<br>"unexplained symptoms"<br>or "unexplained pain" or<br>"chronic pain" or<br>"idiopathic pain" or<br>"functional pain" or<br>"fibromyalgia" or "irritable<br>bowel syndrome" or "IBS"<br>or "CFS" or "chronic<br>fatigue syndrome"<br>AND<br>"randomized" or<br>"randomised" or "RCT" or<br>"randomised controlled"<br>or "randomized<br>controlled" or "randomly<br>allocated" or "randomly<br>assigned" | <b>74</b> |
| 7 <sup>th</sup> August<br>2017 | Scopus        | All | "mindfulness" or<br>"mindfulness-based" or<br>"mindfulness-based<br>cognitive therapy" or<br>"MBCT" or "mind-body"<br>AND<br>"somatization" or<br>"somatic" or<br>"somatoform" or<br>"medically unexplained<br>symptoms" or "MUS" or                                                                                                                                                                                                                                                                                                                                                                                                                                        | <b>14</b> |

|                                                    |                   |     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |             |
|----------------------------------------------------|-------------------|-----|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------|
|                                                    |                   |     | "functional symptoms" or<br>"unexplained symptoms"<br>or "unexplained pain" or<br>"chronic pain" or<br>"idiopathic pain" or<br>"functional pain" or<br>"fibromyalgia" or "irritable<br>bowel syndrome" or "IBS"<br>or "CFS" or "chronic<br>fatigue syndrome"<br>AND<br>"randomized" or<br>"randomised" or "RCT" or<br>"randomised controlled"<br>or "randomized<br>controlled" or "randomly<br>allocated" or "randomly<br>assigned"                                                                                                                                                                                                                                         |             |
| 8 <sup>th</sup> August<br>2017                     | Web of<br>Science | All | "mindfulness" or<br>"mindfulness-based" or<br>"mindfulness-based<br>cognitive therapy" or<br>"MBCT" or "mind-body"<br>AND<br>"somatization" or<br>"somatic" or<br>"somatoform" or<br>"medically unexplained<br>symptoms" or "MUS" or<br>"functional symptoms" or<br>"unexplained symptoms"<br>or "unexplained pain" or<br>"chronic pain" or<br>"idiopathic pain" or<br>"functional pain" or<br>"fibromyalgia" or "irritable<br>bowel syndrome" or "IBS"<br>or "CFS" or "chronic<br>fatigue syndrome"<br>AND<br>"randomized" or<br>"randomised" or "RCT" or<br>"randomised controlled"<br>or "randomized<br>controlled" or "randomly<br>allocated" or "randomly<br>assigned" | <b>529</b>  |
| <b>Total (databases)</b>                           |                   |     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | <b>2319</b> |
| 1 <sup>st</sup> -8 <sup>th</sup><br>August<br>2017 | Other<br>sources  | All |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | <b>5</b>    |
| <b>Total (All sources)</b>                         |                   |     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | <b>2324</b> |



# APPENDIX III

## Bias risk for included RCTS

| Author and date           | PPS type     | Random sequence generation | Allocation concealment | Reporting bias | Attrition bias | Performance bias | Detection bias | Other bias | Overall bias rating |
|---------------------------|--------------|----------------------------|------------------------|----------------|----------------|------------------|----------------|------------|---------------------|
| Ljótsson et al., (2011).  | IBS          | LOW                        | LOW                    | HIGH           | LOW            | LOW              | UNCLEAR        | HIGH       | LOW                 |
| Ljótsson et al., (2010).  | IBS          | LOW                        | LOW                    | LOW            | LOW            | UNCLEAR          | UNCLEAR        | HIGH       | LOW                 |
| Asadollahi et al., (2014) | IBS          | UNCLEAR                    | UNCLEAR                | UNCLEAR        | UNCLEAR        | UNCLEAR          | UNCLEAR        | UNCLEAR    | UNCLEAR             |
| Rimes & Wingrove (2013)   | CFS          | LOW                        | LOW                    | LOW            | LOW            | UNCLEAR          | UNCLEAR        | HIGH       | LOW                 |
| Dowd et al., (2015)       | CHRONIC PAIN | LOW                        | LOW                    | LOW            | HIGH           | HIGH             | UNCLEAR        | HIGH       | MODERATE            |

| Author and date                        | PPS type     | Random sequence generation | Allocation concealment | Reporting bias | Attrition bias | Performance bias | Detection bias | Other bias | Overall bias rating |
|----------------------------------------|--------------|----------------------------|------------------------|----------------|----------------|------------------|----------------|------------|---------------------|
| de Jong et al., (2017)                 | CHRONIC PAIN | LOW                        | UNCLEAR                | LOW            | LOW            | UNCLEAR          | UNCLEAR        | LOW        | LOW                 |
| Day et al., (2014).                    | CHRONIC PAIN | LOW                        | UNCLEAR                | LOW            | LOW            | HIGH             | HIGH           | LOW        | MODERATE            |
| Zgierska et al., (2016)                | CHRONIC PAIN | LOW                        | LOW                    | HIGH           | LOW            | HIGH             | HIGH           | LOW        | MODERATE            |
| Parra-DeIgado & Latorre-Postigo (2013) | FIBRO        | LOW                        | LOW                    | HIGH           | UNCLEAR        | UNCLEAR          | UNCLEAR        | UNCLEAR    | MODERATE            |
| van Ravesteijn et al., (2013)          | MIXED        | LOW                        | LOW                    | LOW            | LOW            | UNCLEAR          | UNCLEAR        | UNCLEAR    | LOW                 |

## APPENDIX IV

Data extraction table

| Author and year                              | PPS type     | N (MBCT)                          | N (Control)                    | Female %<br>(Mean: 84.6%<br>SD: 9.8) | Mean age<br>(44.0; SD: 7.1) | Control group<br>intervention      | Follow-up                              | Assessed outcomes                                                                                                                                                                               | Findings                                                                                                                                                                                                                                                                                      |
|----------------------------------------------|--------------|-----------------------------------|--------------------------------|--------------------------------------|-----------------------------|------------------------------------|----------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| van Ravesteijn et al.,<br>(2013)             | Mix          | 61                                | 56                             | 75.2%                                | 47.1                        | Enhanced Usual<br>Care (EUC)       | 9 months                               | PHQ-15 (Symptom Severity); Whiteley<br>Index (Anxiety); PHQ-9 (Depression);<br>VAS (QoL); SF-36 (all sub-scales<br>(QoL));                                                                      | MBCT showed sig. improvement in mental<br>functioning (on QoL). No differences in terms of<br>physical functioning, or health status when<br>comparing between groups. MBCT group<br>demonstrated bigger improvements post-<br>intervention generally than EUC group.                         |
| Parra-Delgado &<br>Latorre-Postigo<br>(2013) | Fibromyalgia | 15                                | 16                             | 100.0%                               | 52.9                        | Control                            | 3 months                               | VAS (Symptom severity); BDI<br>(Depression); FQ (QoL)                                                                                                                                           | Significant reduction for MBCT group in fibromyalgia<br>impact post-intervention, and reduced depressive<br>symptoms at follow-up. Reduction in symptom<br>severity (lumbar pain) post-intervention but not<br>maintained. Small improvements for cervical and left<br>leg pain at follow-up. |
| Rimes & Wingrove<br>(2013)                   | CFS          | 16                                | 19                             | 78.4%                                | 43.5                        | Wait-list control                  | 2 months;<br>Six months<br>(MBCT only) | Chalder Fatigue Scale (Symptom<br>Severity); WSAS (QoL); Physical<br>Functioning (QoL); HADS (Anxiety and<br>depression);                                                                       | MBCT had sig. reduction in symptom severity, over<br>control, and at follow-up. MBCT also reported better<br>outcomes for impairment (QoL) and depression.                                                                                                                                    |
| Dowd et al., (2015)                          | Chronic pain | 62 (ITT);<br>23 (Actual)          | 62 (ITT); 27<br>(Actual)       | Not given                            | Not given                   | Pain Management<br>Psychoeducation | 6 months                               | BPI sub-scales (2): Pain intensity<br>now, Pain intensity on average<br>(Symptom Severity); HADS (Anxiety<br>and Depression); Life Satisfaction<br>(QoL); Pain interference (QoL); PGC<br>(QoL) | Significant improvements for pain interference in<br>both groups; Reduction in pain intensity not<br>maintained at follow-up; Significant improvements in<br>well-being superior for MBCT group; Significant<br>reduction in pain right now in MBCT.                                          |
| de Jong et al., (2017)                       | Chronic pain | 26 (ITT); 19<br>(Per<br>Protocol) | 14 (ITT); 14<br>(Per Protocol) | 75.0% (ITT)                          | 50.7                        | Wait-list                          | 18 months                              | QIDS (Depression); HDRS<br>(Depression); BAI (Anxiety); VAS -<br>Average pain intensity (Symptom<br>Severity); BPI - Pain interference<br>(QoL); PGC (QoL)                                      | ITT showed no significant differences at all following<br>MBCT. Per-Protocol between-groups analyses<br>showed significant improvement in MBCT group over<br>time for QIDS-C. No significant differences for HDRS.                                                                            |

| Author and year          | PPS type     | N (MBCT)                   | N (Control)                 | Female %<br>(Mean: 84.6%;<br>SD: 9.8) | Mean age<br>(44.0; SD: 7.1) | Control group<br>intervention    | Follow-up | Assessed outcomes                                                                                                                                      | Findings                                                                                                                                                                                                                                                                                                                                             |
|--------------------------|--------------|----------------------------|-----------------------------|---------------------------------------|-----------------------------|----------------------------------|-----------|--------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Day et al., (2014)       | Chronic pain | 19 (ITT); 9<br>(Completer) | 17 (ITT); 15<br>(Completer) | 88.9%                                 | 41.7                        | Delayed Treatment<br>(Wait-list) | N/A       | Online headache diary (Symptom Severity); BPI - Pain intensity (Symptom Severity); BPI - Pain interference (QoL)                                       | Significant reductions in pain interference for Completer analyses compared to DT (but not for ITT). No change seen in online headache diary.                                                                                                                                                                                                        |
| Asadolahi et al., (2014) | IBS          | 10                         | 10                          | 100.0%                                | 34.8                        | Control                          | 2 months  | IBS-SSS (Symptom Severity); SCL-90-R (Anxiety and depression)                                                                                          | No significant reduction in symptom severity at either timepoint. Anxiety and depression significantly reduced post-intervention, but reduction in depression was not significant at follow-up.                                                                                                                                                      |
| Ljótsson et al., (2011)  | IBS          | 98                         | 97                          | 79.0%                                 | 38.9                        | Stress Management                | 6 months  | GSRs-IBS (Symptom Severity); VSI (Anxiety); HADS (Anxiety and Depression); IBQ-QoL (QoL)                                                               | Small-medium effect size for MBCT vs. Control for symptom severity post-intervention and at follow-up. Medium effect size for QoL post-intervention and a small effect at follow-up (QoL). Small-medium reductions in anxiety for MBCT vs. Control on VSI, but not HADS. No difference between groups for depression post-intervention at follow-up. |
| Ljótsson et al., (2010)  | IBS          | 42                         | 43                          | 84.7%                                 | 34.6                        | Control                          | 3 months  | GI symptom diary (Symptom Severity); GSRs-IBS (Symptom Severity); IBS-QoL (QoL); Sheehan Disability Scales (QoL); VSI (Anxiety); MADRS-SR (Depression) | Symptom severity largely improved within the MBCT group but not control. Between group analysis showed a large between-groups effect for QoL, and improvements on all secondary measures for MBCT.                                                                                                                                                   |
| Zgierska et al., (2016)  | Chronic pain | 21                         | 14                          | 80.0%                                 | 51.8                        | Usual Care                       | 6 months  | BPI-Pain intensity (Symptom Severity); Oswestry Disability Index (QoL)                                                                                 | ITT analysis showed MBCT group had significantly reduced pain severity compared with controls, and with between groups large effect size at follow-up.                                                                                                                                                                                               |

## **2C: PUBLISHABLE PAPERS**

- 1. A qualitative investigation into the experiences of genital herpes: Navigating the road back to psychosocial recovery Prepared for: *Sexually Transmitted Infections Journal***
- 2. The effectiveness of mindfulness-based cognitive therapy (MBCT) in treating PPS: A systematic review: Prepared for: *Mindfulness Journal***
- 3. Event review:  
To the DHP for giving me this opportunity: Diolch yn fawr iawn!  
Prepared for: *Health Psychology Update***

**Word count: 10,649**

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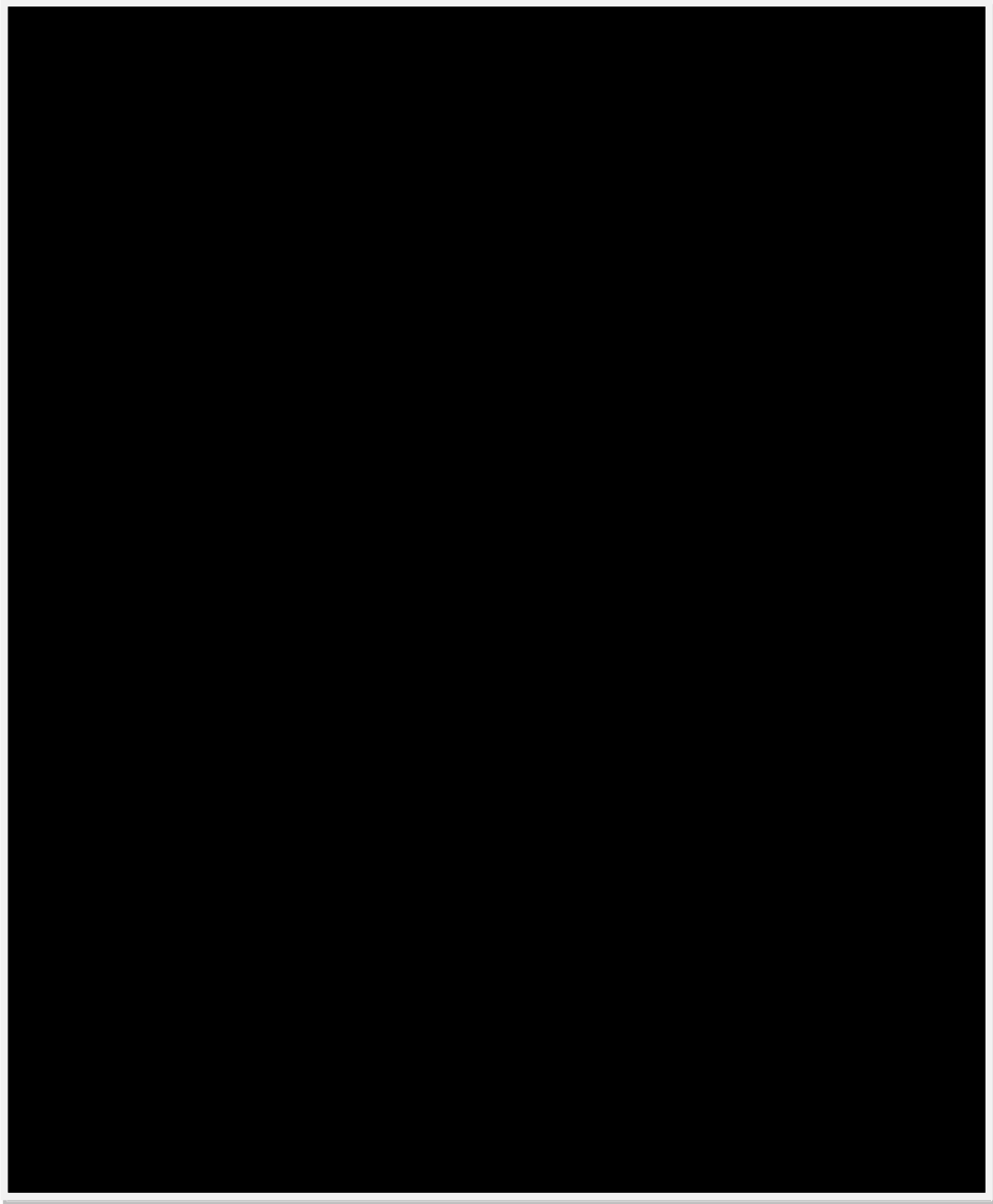
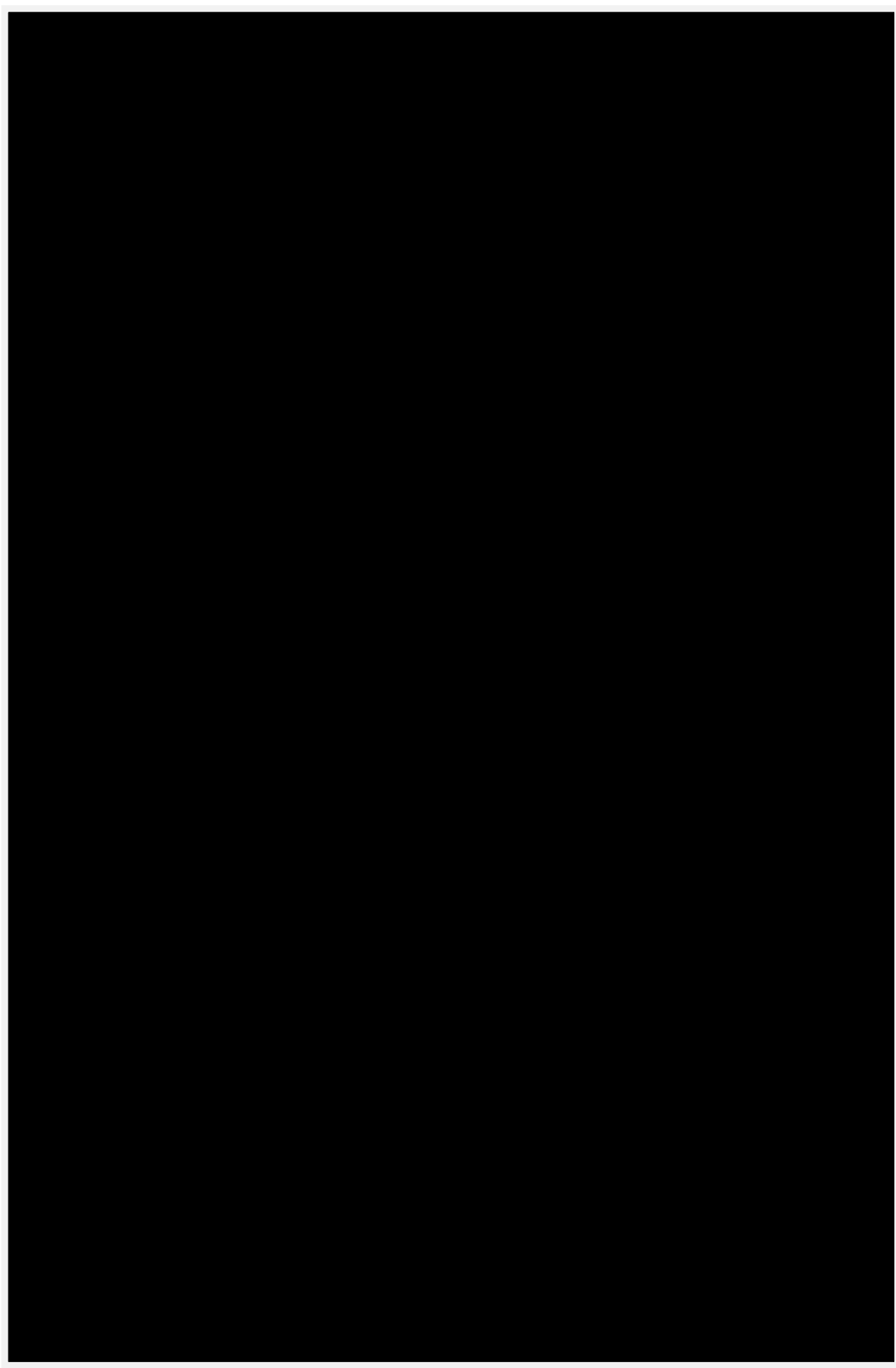
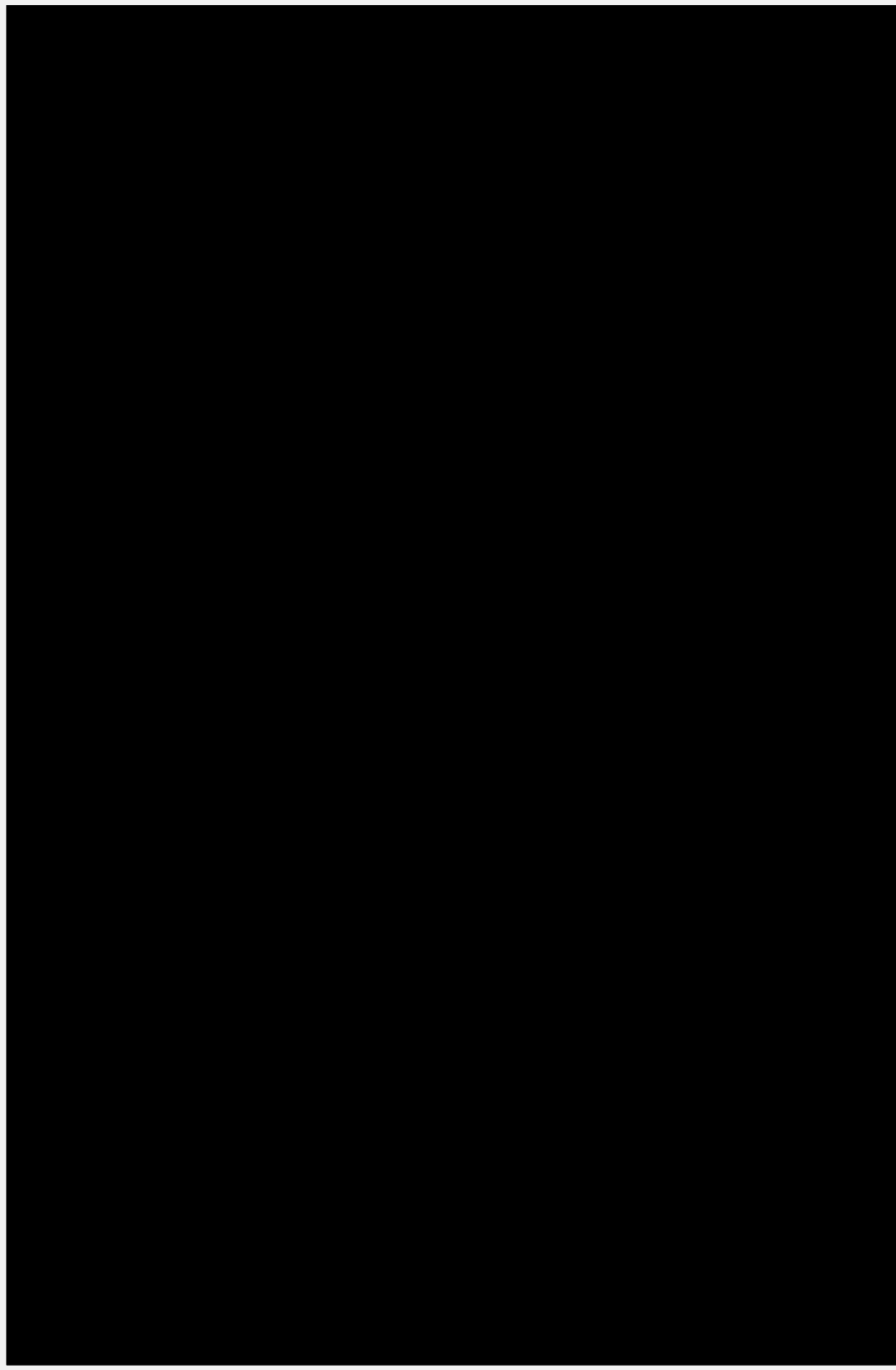


Table I. Data extraction table





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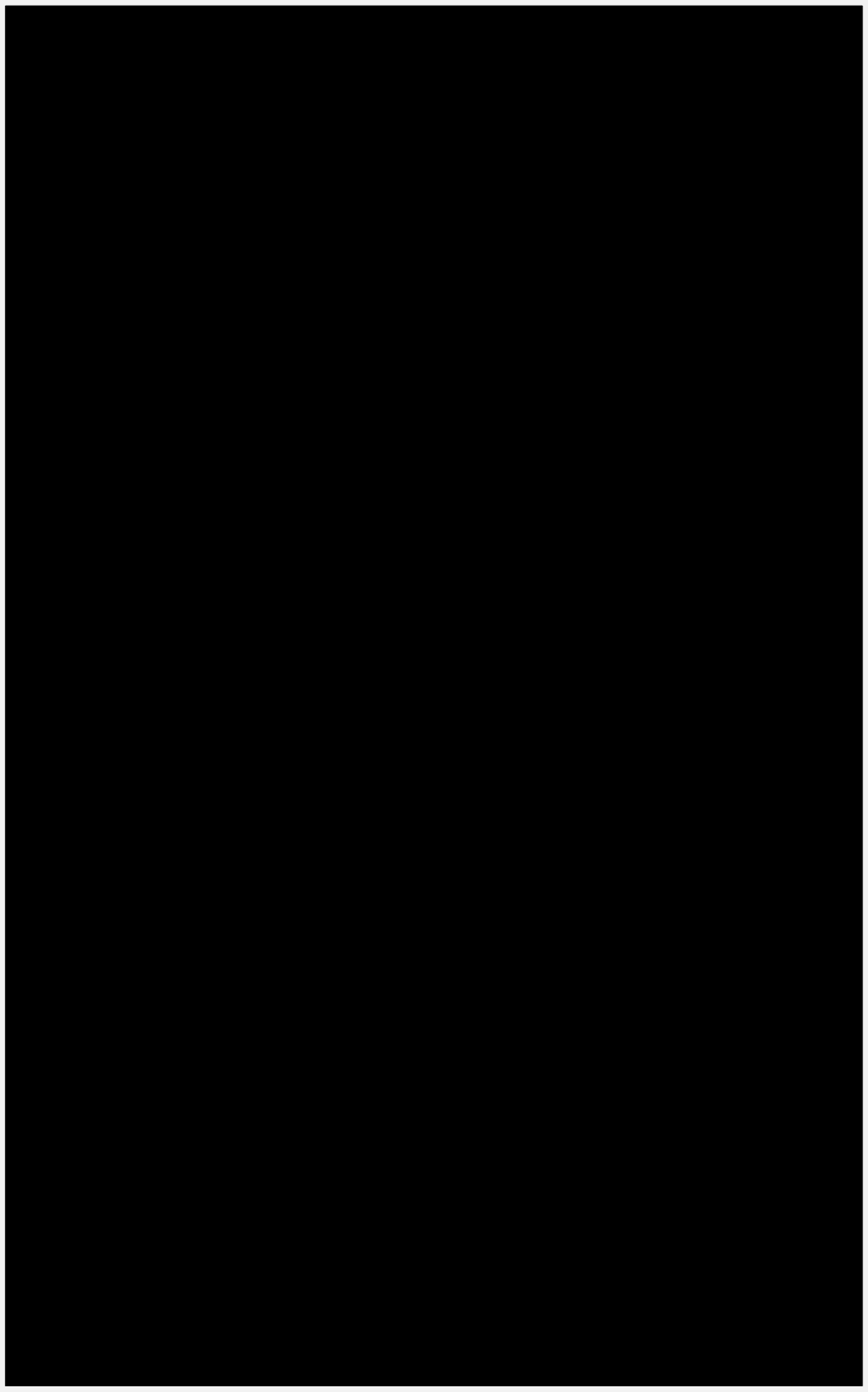
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| Yes, the U.S. should take action to reduce greenhouse gas emissions    | 85%        |
| No, the U.S. should not take action to reduce greenhouse gas emissions | 15%        |

# **SECTION 3:**

# **PROFESSIONAL PRACTICE**

## **3A: CONSULTANCY**

### **Health Status Assessment Project**

**Word count: 3227**



### **3A: Consultancy: Health Status Assessment Project**

#### **3A.1: What is consultancy?**

Consultancy is defined as *“providing a professional or technical service to benefit a specific client (i.e. a third party), where a fee-for-service or equivalent relationship exists...”* (Shugan, 2004). To explain further, consultants use their expertise within a certain area of interest in order to deliver informed and objective advice, identify ways of overcome any outstanding problems, and enhance the performance of their client’s organisation (Management Consultancy Association, 2016).

In order to ensure client satisfaction, the consultant is required to deliver a strong performance that goes beyond technical ability. It is also important for consultants to recognise unspoken expectations of their client, which may be both personal and professional (Bergholz, 1999; Chelliah & Davis, 2011). Examples of expectations that go beyond contractual obligations may include free advice, a personable and fun working partnership, and additional time to listen to needs or concerns (Chelliah & Davis, 2011). It is therefore important to manage these expectations effectively in a way that ensures the client is satisfied (Bergholz, 1999). While there are clear advantages for clients in that they can improve their service by employing a consultant with specialist knowledge, there are also advantages for consultants. This includes being able to expand their knowledge, gain experience in managing client expectations, and build new working relationships.

This report covers my own experience of consultancy. In order to conduct, evaluate and reflect upon my experience, I will be considering each of the Seven C’s, within the C’s framework (Cope, 2000). This framework includes the following: Client – understanding the client, the project and their objectives; Clarify –

understanding what the consultant requires; Create – using techniques to ‘create’ a solution to the identified problem (e.g. by conducting research); Change – understanding current factors that may be preventing or leading to change, and implementing the solution to overcome that; Confirm – measuring the extent that the intervention has made a difference; Continuing – ensuring that any change is long-term; Closing – close the working relationship with the client with a review of what the consultant and the client has learned from the project, as well as any future work required.

### **3A.2: Assessment of requests for consultancy, planning consultancy, and establishing and maintaining working relationships with clients**

I first became aware of my client shortly after posting a message on social media enquiring about any potential consultancy opportunities. An associate got in touch with me after they had previously conducted research for the Tuke Institute, confirming that the Chairman was keen for further assistance. I promptly sent an email to them, and received a reply suggesting we hold a Skype meeting to discuss his requirements and my availability. Prior to our first Skype meeting, I conducted my own research into the background of the Tuke Institute and previous research projects. From this, I discovered that the client is a qualified psychiatrist, immunologist, and patient-advocate, and that the Tuke Institute is a non-profit organisation set up with the aim of improving and adapting health services. This is to ensure that patient-centred healthcare is delivered in the most effective way to meet the requirements of chronically unwell patients. In their own words, the Institute aims to *“translate the reality of illness into health-effective medical practice, an approach that integrates all the domains of medicine (prevention, diagnosis, treatment, and rehabilitation); all the professional domains within clinical medicine (nursing, physical, mental, and social medicine); and welcomes contributions from*

*diverse traditions of medicine*” (Tuke Institute, 2016). I found it admirable that the Tuke Institute had been set up without the aim of financial gain, and morally I considered them an attractive client to work with.

My first Skype session with the client took place on 29<sup>th</sup> June 2016. I understood that the overall aim of this project, entitled *‘Health Service Assessment’*, was eventually to introduce a new mobile app for patients living with long-term conditions, which could then eventually be integrated within the NHS. However, my personal involvement would be to conduct the necessary background research and build a business case for the app. Having read what I had regarding the previous work of the Tuke Institute, I was initially concerned that I would not be experienced enough to perform to the level that they were likely accustomed to. However, following personal introductions, I relaxed as the client quickly demonstrated an intuitive understanding of my personal capabilities and strengths, including project management and qualitative research skills. As the Tuke Institute is a non-profit organisation, it was confirmed during the initial call that any consultancy would be voluntary.

Our second meeting took place on 15<sup>th</sup> July, and involved a more in-depth discussion of the individual project tasks and responsibilities. We jointly discussed a step-by-step process of what was required, and divided the consultancy into three distinct parts – the *Scientific Perspective*, *Patient Perspective* and *Business perspective*. Following this meeting and being aware of what the aims and objectives were, I composed a draft version of the contract and sent it to the client for comments. Following a revision of the completion dates, the contract was officially signed on 20<sup>th</sup> July (see Appendix II). Within the contract, each individual part was given a deadline for completion which was 31<sup>st</sup> August; 31<sup>st</sup> October, and 31<sup>st</sup> December, which I proposed in order to ensure the consultancy was completed on schedule. We agreed for Skype meetings to be arranged on an ad hoc basis,

and for minutes from each Skype meeting to be typed up immediately after each meeting and stored electronically within the Podio platform. Tasks and any written documents would also be reviewed on an ongoing basis. Details of the individual tasks within each section are documented in detail below.

It became apparent within our second meeting, that the Process Consultation Model by Schein (1990) was the most appropriate model for this project due to the collaborative nature of the work itself. The Process Consultation model presents that the client and consultant work as a team in order to answer any questions and identify solutions. In the case of this project, neither the client nor myself were sure at the beginning of the current app market and how this and discussions with patients may eventually affect the business case, so it was a journey of discovery for both the client and consultant.

### **3A.3: Conducting consultancy and monitoring its implementation**

#### *3A.3.1: Conducting research from a scientific perspective*

This part of the consultancy was to gain an initial understanding of what software was already in existence. This involved conducting a manual search within the Apple store to identify apps for those living with long-term conditions, such as HIV, diabetes, depression, schizophrenia, chronic pain and cancer. Due to the large volume of apps available, a purposive mixed sample of 24 apps were selected and downloaded onto a smartphone. Each app was then reviewed individually in terms of its usability, user interface, its interaction of software with healthcare professionals (i.e. do they have access to data and are patients able to provide feedback), its advertising, the type of programming modules and packages used, its size and cost to download, the measures of health used and aspects of health covered. For the latter, apps were referenced against the International Classification of Functioning, Disability and Health (ICF) checklist (World Health Organization,

2003), to investigate whether apps had incorporated each of the following: impairments of body functions; impairments of body structures; activity limitations and participation restriction; environmental factors, and other contextual information. The ICF is the World Health Organization's (WHO) framework for health, designed to provide a more realistic measure of health and disability (WHO, 2016). Ratings already provided by current users were also reviewed. Based on all this information, the apps were finally given an independent rating of zero to five stars. All information on the individual apps was organised and stored online within the Podio website, to allow for the client to review the information on an ongoing basis. This in-depth analysis provided a good understanding of competitor apps, particularly their strengths and limitations. Overall, it was concluded that the quality of existing health apps was poor, particularly as almost all failed to include key parts of the ICF checklist. Furthermore, it was observed that the more advanced health apps generally incurred a considerable cost to the patient. Therefore, we were able to conclude from this review that there was a market gap. A separate report was later written on request to clearly highlight the extent to which the ICF is covered (see Appendix III). The agreed deadline of 31<sup>st</sup> August for *Scientific Perspective* was generally met, which enabled a smooth transition into the second part of the consultancy. The only exception was the ICF report, which was completed in December 2016 as an additional task.

### *3A.3.2: Conducting research from a patient perspective*

Now that we understood the market, we had a better understanding of what to potentially include in discussions with patients; to understand what the main problems are for patients living with the different conditions, and their preferences when monitoring their health through a mobile app. In order to gather information to help create the vignettes, and due to my previous qualitative experience, it was

agreed that qualitative telephone interviews should be conducted with individuals living with long-term conditions. In order to prepare, I composed a topic guide, which was later revised following feedback from the client (see Appendix IV for the revised version). Following an advertisement on social media asking for participants, six interviews were eventually conducted with individuals living with various conditions, including fibromyalgia, chronic migraine, Type-2 diabetes, ulcerative colitis, hypothyroidism and CFS. During the interviews, they were asked about their condition, their symptoms and associated problems, their relationship with healthcare professionals, and their current use of health-related mobile apps. This included the strengths and weaknesses of those apps, what they would ideally like to be able to log into a health app, how they would like to enter the information (e.g. in either a 5-point or a 10-point scale to indicate mood), and how they would like information to be displayed. Notes were made during the interviews and interviews were listened to again, rather than being analysed in full due to time and resource restrictions. The insight created from the interviews provided me with the information to create three vignettes in detail (see Appendix V). These vignettes were written, reviewed by the client, and then revised to prepare for one to be eventually included as part of a pitch presentation. The deadline of 31<sup>st</sup> October for the *Patient Perspective* was adhered to. However, vignettes continued to be adapted while the final part was under way.

### *3A.3.3: Conducting research from a business perspective; preparing a business case*

The final part of the consultancy required the composition of a business case for the provision of the app. Prior to writing the business case, entitled '*Health Status Assessment Project: Business Perspective*' (see Appendix VI), I conducted my own research to understand exactly what should be included, as this was

unfamiliar territory to me. I used the guide provided by Workfront, Inc. (2016). The following information was therefore included within the document: *An Executive Summary; Finance; Introduction and Overview; Business Objectives; Benefits and limitations; Option Identification Selection; Outline Plan; Market Assessment; Risk Assessment; Project Approach*. Three further headings were also included within the Business Case document – *Scope, Impact and Interdependencies, Purchasing Strategy; and Recommendations*. However, following discussion regarding the content, it was agreed that this additional information would later be provided by the client.

Within *Introduction and Overview*, information was included on how effective or ineffective services are in terms of managing health and cost; how much service usage is a result of long-term conditions; how integrated services may be effective in reducing service-usage and cost; what is needed for effective integrated services, and how the introduction of this app might reduce financial and social costs. The *Finance* section included an example of how the overall cost may be calculated using a whole-cost framework, while the *Outline Plan* included a Gantt chart of a provisional timeline for 2017. This required consideration of the different stages likely to occur following on from this project, including legal procedures, research and development, product development, manufacturing, acquiring of the necessary licences and personnel, marketing and the app's launch. The Market Assessment included a thorough consideration of the political, economic, sociological, technical, legal and environmental factors involved – otherwise known as a PESTLE analysis (PESTLE Analysis, 2016). *Risk Assessment* included not only the risks of introducing the mobile app, but also led to a consideration of what opportunities may emerge from knowing this in advance and what plans should be put in place to ensure that any dangers are avoided. The final task of the project was to conduct further research, and report back to the client how to produce a successful

promotional video. This information was delivered via Skype. In order to keep it concise, I discussed the five-step outline provided by Ruffell (2016). I also referred to useful hints and tips provided by Stockman (2011).

As within the contract, the final part of the consultancy was completed by 31<sup>st</sup> December 2016. The final discussion, which was held on 28<sup>th</sup> December, included a final revision of all tasks within the contract, to ensure that I had met all contractual obligations.

### **3A.4: Evaluating the impact of consultancy**

While it was not originally agreed within the contract, I proposed that the mobile app be evaluated in the future on a short-term and long-term basis following successful launch, using the RE-AIM evaluation model by Glasgow, Vogt and Boles (1999). Originally designed to evaluate the impact of health promotion interviews on public health, this model can also be consulted in advance to encourage careful planning and consideration of key aspects, such as the app's external validity (Glasgow et al., 1999). The framework has been demonstrated to be effective and is used on a frequent basis (King, Glasgow & Leeman-Castillo, 2010). Within this context, I suggested that the framework could be used to evaluate each of the following: how many of the target population have become aware of and have downloaded the app at three months, and at the one year mark (Reach); how effective the app is at integrating health services and managing patient health (Effectiveness); how many General Practitioners/nurses encourage patients and use the app within their practices, and how many NHS surgeries have accepted the app as part of general practice (Adoption); how consistently the app is used, what costs have been incurred or saved, and what adaptations have had to be made. This can refer to adaptations to the app itself, as well as adaptations within general



healthcare practice (Implementation); and to what degree the app has been accepted and integrated for long-term use (Maintenance).

The client was asked to complete a qualitative evaluation form, in order to provide detailed written feedback (please see Appendix VII). This information assisted me with my reflexive analysis of consultancy.

### **3A.5: A reflexive approach**

Generally, I enjoyed the consultancy experience, especially the opportunity of working with my client as I found them to be very personable, inspiring and understanding. We had a collaborative working partnership which enabled the client and I to share individual skills in order to obtain what was needed. My skills primarily related to conducting research and conducting qualitative interviews, writing and drawing on elements of Health Psychology where required, such as the RE-AIM evaluation model (Glasgow et al., 1999).

At this stage in my career, I was glad that I had the opportunity to utilise the Process Consultation model of consultancy. I felt that this worked well for this particular project, and I doubt I would have felt confident enough to adopt the Expert model, where the client is understood to be the expert but have little involvement within the consultancy process, or the Doctor-Patient model where I would have been identified as the expert looking to find ways of identifying solutions (Schein, 1990). While I fear the Expert model may have encouraged me to act less often on initiative, the expectations incurred by the Doctor-Patient model I expect would have been too high, given that I still feel I need time and space to grow and develop my client managing skills. The need to develop these skills was also evident from the client feedback, which identified that improvements could still be made in terms of contract setting, writing business cases, taking the lead during meetings, and

adapting to clients' use of different technologies. All of this constructive feedback and suggestions for future training I took on board. I considered it very useful at this point in my career as in the future I acknowledge that I am likely to come across demanding clients who expect these consultancy skills to be already established.

Despite the positive experience overall, I admit that I found the demands of this project to be very high. Whilst I still managed to meet deadlines as acknowledged within the feedback, I often struggled due to the volume of work. I even started to worry that the consultancy could start to impede on other work or University related demands, particularly as some tasks demanded quick adaptation and the learning of new skills, such as working with new online platforms (e.g. Podio). At first, the Podio interface frustrated me greatly and I felt that it slowed me down, leading to the investment of more time than initially anticipated. Some required tasks were also completely new to me. For example, I had to write a Business Case, where I needed to act on my own initiative and conduct further research to fully understand what was required. Referring to the Locus of Control theory, which suggests that individuals can either attribute internal factors or external factors (Rotter, 1954), I came to the conclusion that I would hold myself responsible for my own learning and successful completion of tasks, rather than attribute it to any external factors such as workload. This led to the dedication of additional time and prioritisation of work in order to overcome these challenges. I also conducted further research and individual tasks where necessary to further help with my development. An example of this is that prior to writing the Business Case, I wrote a brief two-page guide of what was necessary to include, before writing it out in full. This task was a helpful exercise for me as I anticipate undertaking further consultancy projects in future. That said, I also found at times that I had to discourage my client from trying to introduce new tasks, which would

have led to the failure of meeting agreed deadlines. Judging from the feedback, I believe that I managed this well.

Overall, the consultancy has enhanced feelings of self-efficacy (Bandura, 1977), in terms of project management. However, the constructive feedback has opened my eyes and made me very aware of what to consider, and what I need to improve on. While I very much approached the consultancy project as a great opportunity on this occasion, I would not accept a project of this magnitude in future without agreed payment cited within the contract due to the volume of work involved. Now that I am aware of how demanding consultancy can be, I will ensure that there is an agreed payment stated within the contract and that all tasks are realistically viable within a certain timeframe.

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# APPENDICES

## APPENDIX I

### Supervision Plan: Consultancy

| Consultancy | Area of work<br>(*outside of<br>normal work)                                                                            | Supporting<br>evidence                                                                                     | Changes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|-------------|-------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Case study  | A systematic review on stress management, to be conducted for an externally-based client (no further details available) | Case study report (3000 words)<br><br>Evaluation form completed by client<br><br>Workplace evaluation form | <p><i>Changed to:</i></p> <p>Setting: The Tuke Institute (Dr Rupert Whitaker – Chairman)</p> <p>Description:</p> <p>A 3-part project for Dr. Rupert Whitaker, to understand the need for a mobile application to help with the management of long-term conditions.</p> <ol style="list-style-type: none"> <li>1) Scientific perspective:<br/>Review of existing health-related software</li> <li>2) Patient perspective: To create some skeleton vignettes of patients who will use the mobile app, following interviews with people living with long-term conditions</li> <li>3) Business perspective:<br/>To write a business case on the effectiveness of health services, current costs of managing health conditions, demonstrate how a mobile app could reduce overall costs. Also, provide information on how to develop promotional material, e.g. videos.</li> </ol> |

Supervisee: \_\_\_Katie Watts\_\_\_\_\_

Supervisor: \_\_\_Dr. Tiece Turnbull\_\_\_\_\_

## APPENDIX II

### Consultancy Contract

The Tuke Institute

[www.tukeinstitute.org](http://www.tukeinstitute.org)

**Client:** Dr Rupert Whitaker (Chairman of the Tuke Institute)

**Consultant:** Katie Watts (Trainee Health Psychologist)

#### Rationale

The Tuke Institute is an independent think-tank, founded by Dr Rupert Whitaker. The organisation aims to change health services for the better, to ensure that healthcare is delivered to meet the full requirements of chronically ill patients. In order to further deliver on this, the Tuke Institute is interested to know what existing software (mobile apps) there are currently for patients living with chronic conditions and to what extent they are meeting their requirements. From here, actions can be taken to provide new software (a mobile app) which can be downloaded and used by patients in order to accurately monitor and feedback on health.

#### Aims

- To conduct research from a scientific perspective, by reviewing what software is already out there. To research:
  - The usability/applicability of existing software
  - Whether existing software are used for individual conditions
  - What variables/ aspects of health does existing software cover?
    - Which aspects of the ICF are not covered?
  - How health is measured - what evidence is there that these measures are the best ones to use to show change/ improvement in health?
  - How software interacts with clinical side - who can use the data and how are they using that data?
    - Is it used to measure clinical effectiveness of clinicians or services? At which levels?
  - What is the user-interface like?
  - Reviews of existing software
  - How the mobile apps are advertised (language) - for the business-perspective
  - What programming modules are used - e.g., natural language interfaces, graphics packages, etc.

*KW*



- To conduct research from a patient-perspective, delivering on the following:
  - Identifying several key conditions that affect adult health in significantly different ways and create some skeleton vignettes - HIV; relapsing-remitting neurological disease (epilepsy; Parkinsonism; MS); diabetes; burn-trauma; etc.
  - Engineering forward what the key problems are for each such condition
  - Identifying which problems are not covered by these vignettes
- To conduct research from a business-perspective and develop a business case for software. For this the following will need to be understood:
  - How effective services are in terms of health, and in terms of cost
  - How much service-usage occurs due to chronic conditions
  - How integrated services reduce this
  - What is needed for enabling integrated services
  - How this might reduce costs – financial costs but also social costs (a whole-costs framework to be used for analysis)
  - How to develop promotional material (e.g. a 3-minute video)

#### Schedule

The proposed research will commence on Wednesday 29<sup>th</sup> June, following confirmation and outline of the work to be delivered. The schedule is broken down as follows:

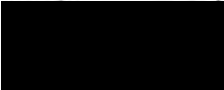
- Part 1 – Scientific Perspective: To be completed by 31<sup>st</sup> August 2016
- Part 2 – Patient Perspective: To be completed by 31<sup>st</sup> October 2016
- Part 3 – Business Perspective: To be completed by 31<sup>st</sup> December 2016

Meetings with the client will be organised on an ad hoc basis, as per required.

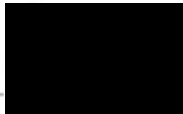
#### Budget

It was agreed that this consultancy work will be unpaid.

**Client:** Dr Rupert Whitaker (the Tuke Institute Chairman)

Sign:  Date: 20.7.2016

**Consultant:** Katie Watts (Trainee Health Psychologist)

Sign:  Date: 22/07/2016

## APPENDIX III

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## APPENDIX IV

# Mobile applications for chronic health conditions

## Discussion guide - Revised

### Introduction

- Thank you for your interest in taking part in this interview.
- I am a doctoral student in Health Sciences at City University, conducting some research on behalf of the Tuke Institute, which is an independent organisation aiming to create make health services work better for people who are ill
- I am asking questions of people with chronic health conditions around their use of health-related apps. It takes about 30 minutes.
- Is this something you'd be willing to help out with?
- Do you have a health condition? (check inclusion criteria)
- (If yes to health condition) What we are looking to understand is:
  1. Your experience of using mobile apps – particularly healthcare apps
  2. Understand about any apps you are using to help monitor your health, and what you like/ don't like about the app
  3. What features you consider necessary/ unnecessary, in order to monitor your own health in a way that's most helpful to you
  4. What other features you consider necessary/ unnecessary for mobile apps in general
- I would like to audio-record our interview today. This is so that we can analyse your interview, and use the information you give us to help us build an description of what a typical person might want from their health app
- I will keep your information confidential and anonymous, and you can skip any question you don't want to answer or just finish the discussion whenever you want
- Do you have any questions at this point?

### Section A: Chronic condition

- Would you mind telling us a little bit about you: your age, and what you do for a living, if anything?

- You have also indicated that you are living with a chronic health condition.  
Would you mind disclosing which condition you are currently living with?
  - When did you first get diagnosed with this condition?
- What types of symptoms do you tend to get with your condition?
- What problems did it cause you at first (search: physical, mental, social)?
- What problems does it cause you now?
- How do you monitor the changes over time?
  - How does monitoring the problems you have over time, help you to manage your own health?
- How many times roughly over the last six months have you visited a healthcare professional (e.g. nurse/ GP/ Specialist, Physiotherapist, CBT therapist/ Counsellor) in order to review your condition?
  - (For each mentioned) Would it help to see them more or less often?  
Please explain.

## **Section B: Current usage of mobile applications (including healthcare)**

I would now like to ask you some questions about your use of mobile apps.

- First of all, do you have a smartphone that you use regularly?
  - iPhone/iPad or Android?
- (If yes to owning smartphone) How often do you use the apps on it, per day/per week?
- Have you downloaded any mobile applications to keep track of your own health?
  - Which mobile applications for tracking your health have you downloaded?
  - How do they help you do what you want to do?
- Is there one or two apps that you like to use to monitor your health? Which ones?
  - How often do you use this app/these apps?
    - What do you like about this app?
    - What do you not like about this app?
    - To what extent do you find the app helpful to you in terms of tracking your health?

## **Section C: Expectations for an effective mobile application**

I would now like to get your opinion on more specific features for tracking health.

- If you think back to how you track the effects that your health condition has on your physical, mental and social life, what would you ideally like an app to do in order to allow you to track your health in a way that's really useful to you?  
(Probe on physical/psychological/social health and life)
- When you want to tell the app how your health is, how do you like best to do that? (Wait for spontaneous responses, then probe)
- How would you prefer to see your health tracking information displayed for you? (Wait for spontaneous responses, then probe)
- Would you like/ not like to be able to share your health information through your smartphone with your GP/Consultant/other health professional?
  - (If yes) How would that help you?
  - How do you think that would help your health professional?
  - What else do you feel the app would need in order for you to use the mobile app in this way (if anything)?

#### **Section D: Other mobile application features**

We understand that there are other features within apps that may/ may not also be important, so we would like to get your opinion on some we have thought of.

- Would you like/ not like to be able to use the app to message or speak to others living with the same condition? Why?
- What would you like to see first as you open up the app?
  - What would you like to see after that?
  - What would you not want to see?
- What are your thoughts on other features (if not already discussed):
  - Font size
  - Colour
  - Language used
  - Size of the app
  - Use of different types of media (e.g. videos/ podcasts)
- What are your thoughts regarding confidentiality/ security/ privacy (if not already discussed)?
- If you had to pay for an app to be able to use it, what would you consider to be an acceptable cost (either one-off, or monthly/ annually)?
- Anything else that is important re mobile apps that we haven't already discussed?

## **Section E: General healthcare**

I just want to ask a few final questions relating to healthcare in general.

- How do you find accessing your healthcare?
- How would you say communication is (of your health condition) between you and health professional(s)?
- When you discuss your health with health professionals, what aspects of your health do they tend to cover? (Wait for spontaneous responses)
  - (e.g. your moods, social support, sex life, your job, housing situation etc.)
    - To what extent is this/are these discussed? Any actions taken by your health professional?

Thank you for your time today. We hope to be able to use this information to get a better idea of what health app users really want from their apps, so that we can hopefully move forward with this in the future. You've been very helpful.

## APPENDIX V

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| Research and development         |        |        |        |        |        |        |        |        |        |        |        |        |
| Product development              |        |        |        |        |        |        |        |        |        |        |        |        |
| Acquiring necessary licenses and |        |        |        |        |        |        |        |        |        |        |        |        |
| Hiring of personnel              |        |        |        |        |        |        |        |        |        |        |        |        |
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## APPENDIX VII

### Evaluation form for Katie Watts

#### Consultancy: The Tuke Institute – Health-Status Assessment Project

**Client name:** Dr Rupert Whitaker

**Client Job Title:** Executive Chairman

**Organisation:** The Tuke Institute

*Please comment on the consultant's quality of work overall.*

Very good.

*Was there anything particularly good about the consultant's performance?*

Ms. Watts was highly collaborative, good at communicating, flexible and supportive. She adapted to the online platform for project-management and communication well and also notably used established interviewing-skills to create very helpful case-reports to be used in product-communication in the future.

*Is there anything in particular that requires improvement?*

She will need to learn more about the process of consulting, including contract-setting and negotiations, Terms and Conditions, cloud or app-software for project-management (e.g., Podio, Merlin), estimates and billing (e.g., Zoho Invoice), professional presentation of such documents, etc.. While she evidenced clear interest in the project and was very pleasant to work with, the emotional work of handling clients with warmth and enthusiasm needs to be put more to the front, as well as being proactive in leading meetings; she will also have to deal with difficult clients in the future and there should be some training put in place for that too.

She needs to be more knowledgeable of, and pro-active in, working with clients' ways of working re: online-platforms etc., which requires fast adaptation to different technologies and methods; this is partly a question of exposure (and thus experience) and partly knowledge of technologies—again, this should be taught at university. She will also need to learn more about building business-cases and finding the information that is necessary for that from disparate areas (public health, occupational health psychology, occupational medicine, health economics, etc.); this is also something that should be taught in a course at university.

In terms of health psychology specifically, she might benefit from learning more about the application of cognitive knowledge as to how clinicians use and misuse information, how to describe the quality and reliability of such information, how the products of consulting can be used to affect policy-making (e.g., in health-services' design), etc.: additionally, I think that understanding the interface between clinical health psychology, public health psychology, and policy-making needs to be more actively addressed in the future through applied training.



Most of these comments are reflective of my perceptions of the preparation for consulting provided by the university, not of Ms. Watts herself. Perhaps the School of Business/Management could provide a course specific to health-scientists' consulting.

***Were your needs as the client met by the consultant?***

Yes, very well. The project was slightly unusual and cross-disciplinary but we broke it down into several comprehensible parts and these were largely achieved in a good, collaborative manner.

***Please comment on the consultant's professionalism e.g. keeping to appointments, meeting deadlines, enthusiasm for the project, approachableness, etc.***

Ms. Watts was always approachable and pleasant to work with, and she handled well the multiple stresses from disparate projects external to mine and the demands on her time. She was always on time and very good at keeping to project-timeframes, while ensuring work was completed to deadline. Even though she adapted well to changed priorities and foci of the project, she was also careful to prevent mission-creep, which is essential for a consultant and I also found helpful.

***Any other comments?***

Just that it was a pleasure to work with her and I would readily do so again.

## APPENDIX VIII

### Workplace evaluation reports

#### Professional Doctorate in Health Psychology

#### Workplace Evaluation Report

##### Section 1 - To be completed by the Trainee:

|                                        |             |
|----------------------------------------|-------------|
| Trainee's name                         | KATIE WATTS |
| Name of workplace contact              | T. Chaudhry |
| Nature of work and competence assessed | CONSULTANCY |

##### Section 2 – to be completed by the Workplace Supervisor:

Views on the Trainee's Performance on above piece of work. Please also comment on any reason for delays in the completion of this piece of work and report any periods of prolonged absence.

Katie worked with Dr Whittaker to evaluate the background to enable the development of an app for long term conditions. All was split into 3 parts:  
a) the science b) the patient perspective  
c) the business perspective. The client was delighted with Katie's contribution from a Health Psychology perspective.

##### **Declaration**

I verify that the above named Trainee has undertaken the above mentioned piece of work. I am of the opinion that it has been completed to a satisfactory professional standard.

Signature:

[Redacted Signature]

Date:

20/4/2017



School of Health Sciences

City University

Northampton Square

London EC1V 0HB

Programme Director – Dr Angeliki Bogosian

Email:

Tel:

Professional Doctorate in Health Psychology

Workplace Evaluation Report

**Section 1 - To be completed by the Trainee:**

|                                        |                    |
|----------------------------------------|--------------------|
| Trainee's name                         | Katie Watts        |
| Name of workplace contact              | Dr Caroline Stokes |
| Nature of work and competence assessed | CONSULTANCY        |

**Section 2 – to be completed by the Workplace Supervisor:**

Views on the Trainee's Performance on above piece of work. Please also comment on any reason for delays in the completion of this piece of work and report any periods of prolonged absence.

Katie's consultancy project focused on developing a mobile app. It was thoroughly researched and she put an enormous amount of work into it.

**Declaration**

I verify that the above named Trainee has undertaken the above mentioned piece of work. I am of the opinion that it has been completed to a satisfactory professional standard.

Signature:

[Redacted Signature]

Date:

14/4/2017



**School of Health Sciences**

City University

Northampton Square

London EC1V 0HB

Programme Director – Dr Angeliki Bogosian

Email:

Tel:

[Redacted Contact Information]

## **3B: BEHAVIOUR CHANGE INTERVENTION**

### **Cognitive Behaviour Therapy Leaflet for Fibromyalgia**

**Word count: 3184**

### **3B: Behaviour Change Intervention: Cognitive Behaviour Therapy Leaflet for Fibromyalgia**

#### **3B.1. What are Behaviour Change Interventions (BCIs) and why are they necessary?**

Behaviour Change Interventions (BCIs) are designed as a way to encourage individuals or groups to alter their behaviour patterns in order to improve their health (Michie, van Stralen & West, 2011). BCIs may be used within the context of multiple health behaviours, including reducing alcohol consumption (Michie, Whittington, Hamoudi, Zarnani, Tober & et al., 2012), smoking cessation (Bartlett, Sheeran & Hawley, 2014) and increasing physical activity (Foster, Hillsdon, Thorogood, Kaur & Wedatilake, 2005), and can be executed at individual, community and policy level (National Institute for Health and Care Excellence, 2017).

The Behaviour Change Wheel, designed by Michie et al., (2011) following their review of nineteen behaviour change frameworks, is comprised of three levels. At the core lies the COM-B model, which states that in order to ensure an intervention can be effective, the target subject or group must be '*Capable*' at a psychological and physical level of making behaviour changes, must have the '*Opportunity*', and must have the '*Motivation*'. At the next level, the wheel embodies nine separate Behaviour Change Techniques (BCTs) including Training, Education and Enablement. These can be selected based on what may be considered the most effective approach for the target audience. The outer level of the wheel contains seven distinct policy categories including Guidelines, Legislation and Communication/Marketing, thus demonstrating the various ways that BCTs can be disseminated to a wider group. Altogether, the Behaviour Change Wheel provides a useful guide of what to consider when designing interventions, including the

identification of any potential facilitators and barriers, whilst highlighting the range of techniques available (Smits, McCutchan, Wood, Edwards, Lewis et al., 2016).

### **3B.2: Designing and implementing interventions to change health-related behaviours**

Fibromyalgia is a long-term condition primarily characterised by widespread pain and fatigue. Other symptoms may include IBS, stiffness in the muscles, headaches, disturbed sleep and brain fog (NHS Choices, 2016). Although not widely known, it is thought to be a common ailment affecting as many as much as 5% of the population. The causes for fibromyalgia are unclear, but triggers are thought to be viral infections, operations, and traumatic physical and/or emotional life events (Arthritis Research UK, 2016).

There is currently no cure for fibromyalgia, and current treatments such as painkillers, anti-depressants, sleeping tablets, muscle relaxants, antipsychotics and anticonvulsants (NHS Choices, 2016), are often not effective due to the complexity of the symptoms. These medications often also have side-effects (Hawkins, 2013). Evidence suggests that non-pharmacological treatments, such as CBT, can be effective in helping fibromyalgia patients to manage their own symptoms. A systematic review by Bernardy, Klose, Busch, Choy and Hauser (2013) of 23 RCTs reported a definite improvement in terms of symptom severity, mood and functioning following CBT treatment for fibromyalgia. However, face-to-face CBT generally has a considerable drop-out rate of 26.2%, mostly attributed to the type of environment and the number of CBT sessions (Fernandez, Salem, Swift & Ramtahel, 2015). This would suggest face-to-face CBT may not always be suitable. Written self-help has been shown to be just as effective (Anderson, Lewis, Araya, Elgie, Harrison et al., 2005; Perkins, Murphy, Schmidt & Williams, 2006), and in 2010 Fibromyalgia Action UK (FMA UK) produced a comprehensive booklet on how to manage the symptoms

(Fibromyalgia Action UK, 2016). According to guidelines set by NICE (2012), treatment needs to be accessible and tailored in order to be effective. As fibromyalgia often causes brain fog and memory problems (NHS Choices, 2016), it is feasible that a detailed booklet would contain too much information, and succinct leaflets may be more suitable. However, the usability of a leaflet needs to be investigated further.

The initial idea for this intervention was to provide fibromyalgia sufferers with just enough information to improve their health literacy and increase self-efficacy by empowering them to manage their own symptoms (Bandura, 1977). Self-efficacy has been demonstrated to be a good indicator of behaviour change (Bandura & Adams, 1977). A recent meta-analysis of 204 studies demonstrated self-efficacy to have a moderate effect size overall on behavioural intention, and at least a small to moderate effect size on actual behaviour change (Sheeran, Maki, Montanaro, Avishai-Yitshak & Bryan, 2016). A successful leaflet intervention delivered on a wider scale could eventually lead to positive financial implications for the NHS, due to a reduction in the number of consultations with GPs and referrals to secondary care. Currently, it is estimated that the annual cost of PPS including fibromyalgia exceeds £3 billion (Chitnis, Dowrick, Byng, Turner & Shiers, 2011).

Due to the existing evidence base for CBT I developed a CBT leaflet and tested it with a small sample of the fibromyalgia population over several weeks. In order to help produce the leaflet, a recent booklet currently being tested with patients as part of the PRINCE Cognitive Behaviour Therapy trial (a clinical trial for patients living with PPS, of which I am currently a member of the research team for), was modified and adapted into a concise leaflet format. The primary outcome was work and social functioning, and secondary outcomes were symptom severity and mood (depression and anxiety). In order to achieve this, instructions were provided on how to increase physical activity, improve sleep hygiene, and improve eating and

breathing behaviours. All of these have been shown within previous studies to have a direct effect on functioning, symptom severity and mood. Busch, Schachter, Overend, Peloso and Barber (2008) for example conducted a systematic review investigating the effects of exercise on physical functioning and symptoms in those with fibromyalgia. A meta-analysis of six studies provided good evidence that moderate exercise improves functioning and overall well-being. Another study by El-Salhy, Lillebø, Reinemo, Salmelid and Hausken (2010) which introduced a health programme consisting of exercise, eating behaviours and reassurance for IBS sufferers, reported significant long-term improvements in symptom severity and quality of life. Busch, Magerl, Kem, Haas, Hajak et al., (2012) also demonstrated significant improvements in pain threshold and mood following deep and slow breathing (DSB) intervention for chronic pain syndrome, while Martinez, Miró, Sánchez, Diaz-Piedra, Cáliz et al., (2014) reported sleep hygiene treatment to significantly improve quality of sleep. Although these behaviours were not measured directly within this intervention, the impact of the behaviour changes was observed through changes to work and social functioning, symptom severity and mood.

As well as the behaviour changes and information on the CBT model, this leaflet employed established BCTs such as Training, to provide information and tips on how to make these behaviour changes. Secondly, the leaflet employed Education by providing factual information on fibromyalgia, including the types of symptoms experienced and its prevalence, in order to increase their understanding of the condition. Finally, the leaflet used Enablement by providing information on where to seek out further information and/or support (Michie et al., 2011). Previous interventions using these BCTs provide evidence of their effectiveness in reducing symptom severity and disability. Cedraschi, Desmoules, Rapiti, Baumgartner, Cohen et al., (2004) for example, conducted an RCT to demonstrate the efficacy of an educational six-week self-management programme for fibromyalgia. Outcomes



at six months were significantly more positive in terms of functioning and quality of life for those receiving the treatment. In addition, a past review of various coping skills training for fibromyalgia, including relaxation techniques, pacing and physical activity, has demonstrated training to be effective in reducing symptom severity and disability (Sandstrom & Keefe, 1998).

For a clear explanation of the intervention including outputs, outcomes and eventual impact of the CBT-based intervention, please see the logic model below.

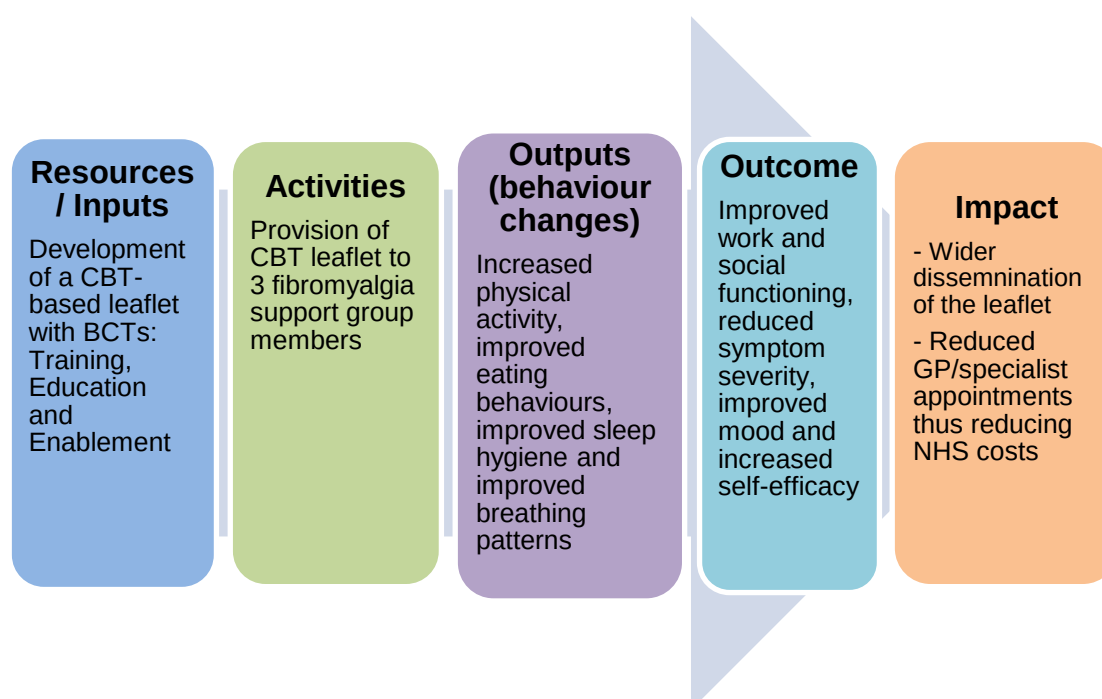


Figure 3B1. Logic model for CBT-based leaflet for fibromyalgia

An evaluation model for health promotion was considered and followed when designing this intervention. ‘*An Outcome Model for Health Promotion*’ by Nutbeam (1998), stressed the importance of improving and measuring ‘*Health and Social Outcomes*’ – such as day-to-day functioning, symptom severity and mood. ‘*Intermediate Health Outcomes*’ (e.g. healthy lifestyle changes) were covered through the introduction of various symptom management techniques including physical activity, improved sleep hygiene and improved eating and breathing behaviours. As stated previously, their effects upon work and social functioning,

symptom severity and mood were monitored. '*Health Promotion Outcomes*' including health literacy was targeted through the provision of factual information about fibromyalgia and the introduction of the CBT model. Finally, '*Health Promotion Actions*' was also covered through the introduction of the CBT model and the introduced behaviour changes.

### **3B.3. Providing expert opinion and advice based on the existing evidence, and directing the implementation of the intervention**

My initial action was to contact the Director of the organisation Fibromyalgia Awareness UK, to discuss potentially producing the leaflet for individuals living with fibromyalgia based on the existing evidence for CBT and behaviour changes using BCTs, and to also conduct a brief needs assessment. It was agreed that this CBT-based leaflet with recommended behaviour changes was suitable and that there was a need for this type of intervention, particularly for newly diagnosed patients. I was then granted permission via email to attend their support groups and invite their members to participate within this leaflet intervention.

Following the production of all necessary written materials including the Information Sheet (Appendix II), Consent form (Appendix III), Debrief sheet (Appendix IV) and the leaflet itself (Appendix V), the documents were checked by my workplace supervisor before being submitted within my study application to the King's College London Ethics Committee. Within my application, I stated that I would be assessing the impact of the leaflet using standardised questionnaires only including the PHQ-9 (Kroenke & Spitzer, 2002), PHQ-15 (Kroenke, Spitzer & Williams, 2002), WSAS (Mundt, Marks, Shear & Greist, 2002) and the GAD-7 (Spitzer, Kroenke, Williams & Löwe, 2006). Please see Appendices VI to IX for these questionnaires. Permission was also sought from the corresponding author to use the WSAS, and evidence of this was provided. The full application was

submitted on Friday 28<sup>th</sup> October, and a letter of approval was received on Friday 25<sup>th</sup> November. At this point I got back in contact with the Director of Fibromyalgia Awareness UK, who put me in contact with the support group leaders for Wickford Essex and Ealing.

I attended the Dulwich support group on Tuesday 17<sup>th</sup> January. Following a brief introduction of my job role and my academic background, I discussed the purpose of testing this leaflet and provided information on the leaflet itself. In general, this involved discussing the use of health psychology principles, such as BCTs, and the importance of behaviour change and how these could impact upon health. In order to illustrate this further, the CBT model was introduced within this context. It was also important to establish within the first meeting the level of interest and perceived relevance to support group members, and address any queries. Those who expressed interest were provided with prepared packs of information, containing a short instruction page, an information sheet, a consent form, the leaflet itself, the baseline questionnaire set and two prepaid envelopes so that the consent form and questionnaires could be posted back separately. While it was acknowledged that postal response rates were likely to be poor and that completing forms during the support groups would have ensured a higher response rate, this could not be conducted, for two reasons. Firstly, they would have been unable to read the information sheet and consent form thoroughly before agreeing to participate, and secondly, reading and completing the forms would have been too disruptive for the meeting. Prospective participants were instructed that in order to take part, they should complete the consent form and questionnaires and return them separately, before reading the leaflet and following it for one month. Eight out of ten support group members present expressed interest and took home the initial pack. The same process was repeated on Thursday 26<sup>th</sup> January at the Wickford

Essex support group, where again eight support group members took away the information.

Despite the initial interest, only 50% across both groups eventually returned these consent forms and questionnaires even following a text reminder, with four returned from the Dulwich group and four from the Wickford group. On Friday 17<sup>th</sup> February, I attended the Ealing support group for the first time. Eight names were taken, but the return rate was particularly poor with only two completed consent forms and questionnaires returned. On Wednesday 22<sup>nd</sup> February and Thursday 23<sup>rd</sup> February, I attended the Dulwich and Wickford groups for the second and final time and provided follow-up packs including the questionnaires, an evaluation form and the debrief sheet.

#### **3B.4. Communicating the processes and outcomes of interventions**

During the follow-up support group meetings, participants openly discussed the impact of the CBT leaflet, as well as whether they had found it easy to follow. I invited those who did not complete the questionnaires to also take away an evaluation form with a prepaid envelope in order to maximise feedback on the leaflet. However, these additional evaluation forms were not returned. On Friday 17<sup>th</sup> March, due to cancellation of the Ealing support group, I contacted the two active participants, and posted follow-up packs to their home addresses. Of the ten participants in total who sent back their consent forms and baseline questionnaires, only seven (70%) also returned their follow-up questionnaires. In the few cases where there was little to no feedback on the leaflet itself within evaluation forms, following permission via text I gained additional feedback over the phone. Six evaluation forms were eventually completed.

Scores from questionnaires were totalled for each person per questionnaire and entered into an Excel spreadsheet (see Table 3B1). Total scores for each questionnaire were then averaged by the total number of returned questionnaires, using formulas to calculate average scores for both the pre and post-leaflet questionnaires.

Table 3B1. Pre and post-intervention scores

|                          |                        | Pre-leaflet<br>WSAS score<br>N=10 | Post-leaflet<br>WSAS score<br>N=7 (70%) | Pre-leaflet<br>PHQ-9 score<br>N=10 | Pre Difficulty<br>score<br>N=10 | Post-leaflet<br>PHQ-9 score<br>N=7 (70%) | Post difficulty<br>score<br>N=7 (70%) | Pre-leaflet<br>PHQ-15 score<br>N=10 | Post-leaflet<br>PHQ-15 score<br>N=7 (70%) | Pre-leaflet<br>GAD score<br>N=10 | Post-leaflet<br>GAD score<br>N=7 (70%) |
|--------------------------|------------------------|-----------------------------------|-----------------------------------------|------------------------------------|---------------------------------|------------------------------------------|---------------------------------------|-------------------------------------|-------------------------------------------|----------------------------------|----------------------------------------|
| Wickford                 | MMB                    | 28                                | 19                                      | 11                                 | 2                               | 9                                        | 1                                     | 18                                  | 13                                        | 9                                | 6                                      |
| Wickford                 | JR                     | 17                                | 20                                      | 11                                 | 1                               | 10                                       | 1                                     | 20                                  | 17                                        | 9                                | 7                                      |
| Wickford                 | PT                     | 24                                | 31                                      | 14                                 | 1                               | 17                                       | 1                                     | 15                                  | 20                                        | 8                                | 6                                      |
| Wickford                 | PC                     | 33                                |                                         | 23                                 | 2                               |                                          |                                       | 23                                  |                                           | 16                               |                                        |
| Dulwich                  | VJF                    | 33                                | 35                                      | 12                                 | 1                               | 13                                       | 2                                     | 13                                  | 15                                        | 0                                | 0                                      |
| Dulwich                  | SB                     | 30                                | 31                                      | 22                                 | 3                               | 21                                       | 2                                     | 17                                  | 18                                        | 21                               | 21                                     |
| Dulwich                  | AC                     | 33                                | 34                                      | 11                                 | 2                               | 14                                       | 2                                     | 20                                  | 21                                        | 6                                | 7                                      |
| Dulwich                  | JG                     | 34                                |                                         | 22                                 | 2                               |                                          |                                       | 13                                  |                                           | 14                               |                                        |
| Ealing                   | SH                     | 29                                | 34                                      | 18                                 | 3                               | 22                                       | 3                                     | 15                                  | 17                                        | 12                               | 19                                     |
| Ealing                   | ALP                    | 27                                |                                         | 5                                  | 2                               |                                          |                                       | 13                                  |                                           | 7                                |                                        |
|                          | TOTAL                  | 28.8                              | 29.1                                    | 14.9                               | 1.9                             | 15.1                                     | 1.7                                   | 16.7                                | 17.3                                      | 10.2                             | 9.4                                    |
| <i>Changes in scores</i> |                        |                                   |                                         |                                    |                                 |                                          |                                       |                                     |                                           |                                  |                                        |
|                          | WSAS:                  | -0.3                              |                                         |                                    |                                 |                                          |                                       |                                     |                                           |                                  |                                        |
|                          | PHQ-9:                 | -0.2                              |                                         |                                    |                                 |                                          |                                       |                                     |                                           |                                  |                                        |
|                          | PHQ-9 Difficulty score | 0.2                               |                                         |                                    |                                 |                                          |                                       |                                     |                                           |                                  |                                        |
|                          | PHQ-15:                | -0.6                              |                                         |                                    |                                 |                                          |                                       |                                     |                                           |                                  |                                        |
|                          | GAD-7:                 | 0.8                               |                                         |                                    |                                 |                                          |                                       |                                     |                                           |                                  |                                        |

For all questionnaires, higher scores indicated a greater level of impairment. A comparison of pre and post-leaflet average scores demonstrated very little change in terms of functional impairment and depression, and a slight worsening in symptom severity with an average increase in score of 0.6. However, there was a modest reduction in anxiety of 0.8 points (out of a maximum score of 21), suggesting a slight positive effect upon participants' psychological well-being. Anxiety reduction has actually been demonstrated to reduce perceptions of pain and the severity of IBS (Fond, Loundou, Hamdani, Boukouaci, Dargal et al., 2014; Jensen, Petzke, Carville, Fransson, Marcus et al., 2010).

As only six evaluation forms were completed and posted back, it was somewhat difficult to fully evaluate the participants' perception of the leaflet. However, this was anticipated to some extent and so only written qualitative and verbal feedback was sought. Please see Appendix X for the evaluation feedback. Both written and verbal comments indicated that the CBT leaflet was easy to follow, and relevant to them. Within the follow-up support group meetings, a few stated that they had been introduced to some of this information previously, but for them it had acted as a useful refresher, even if they felt they were unable to physically attempt all of the behaviour changes. However, the feedback indicated that more information should have been included than what could realistically be provided within the leaflet. More specific comments were that the list of fibromyalgia symptoms was not extensive enough; that there were not enough examples of how CBT works to improve the management of symptoms, and that there should have been an additional section on financial benefits and further help currently available, including eligibility for a Freedom Pass, a Blue Badge, and Dial-A-Ride. Although not mentioned specifically within the feedback, during the groups there were frequent discussions relating to the FODMAP diet, which is designed to help treat IBS by eliminating certain foods from their diet. As this approach has already been demonstrated as effective in symptom management (Roest, Dobbs, Chapman, Batman, O'Brien et al., 2013), in hindsight the leaflet could have contained information on this.

### **3B.5. Promoting psychological principles, providing psychological advice to aid policy decision making, and disseminating psychological knowledge to address current issues**

Although the findings provide some evidence of the efficacy of the leaflet, it cannot be considered conclusive due to the low number of responses. Should this

intervention be repeated, it will need to be conducted across a larger number of support groups in order to obtain a robust sample of the fibromyalgia population. In addition, there should also be the inclusion of a control group for comparison (Steckler & McLeroy, 2008). Ideally, a RCT research design would be employed, due to this design's ability to eliminate potential biases (Akobeng, 2005). Furthermore, while it was only possible to assess the impact of the CBT leaflet in this case, should the leaflet be trialled on a larger scale, participant health outcomes should be assessed over a longer duration, e.g. at six and twelve months, which would measure its true effectiveness as an intervention for fibromyalgia. The intervention would also ideally be thoroughly evaluated, using one of the established models used within health psychology (Glasgow, Vogt & Boles, 1999; Nutbeam, 1998). It was not practical to evaluate on this occasion due to time constrictions and anticipated high drop-out rates over a longer duration (Parker & Dewey, 2000). An evaluation of the intervention in the future will determine whether the intervention is accessible to the target group, as well as effective. It will also demonstrate whether the intervention is easy to adopt, and easy to implement and maintain, e.g. within psychological services (Glasgow et al., 1999). The findings from the evaluation, if positive, should be widely disseminated in order to promote the use of CBT-based leaflets with integrated behaviour changes using BCTs, in order to treat fibromyalgia. The findings can also be used to influence and advise future policy decision making when it comes to future implementation of treatment within psychological services.

The experience of designing the leaflet and attending support groups has been a big learning curve, as it has alerted me to the challenges of conducting research with this population. While the majority of those spoken to within the groups were willing to participate, it was difficult to maintain engagement or monitor the extent to which they were following the leaflet in between groups. This is true

even for those who completed and posted back the forms. While my experience of this intervention has enabled me to sympathise with fibromyalgia patients, I also empathised towards CBT therapists helping to treat fibromyalgia patients.

Regardless of this, I thoroughly enjoyed the experience of being welcomed into the support groups and listening in on meetings. This experience was particularly invaluable in terms of gaining insight into the real issues affecting fibromyalgia patients.

### **3B.6. Contributing towards the evolution of ethical and professional standards in health and applied psychology**

Based on experiences of this intervention, fibromyalgia patients should have the right to play an active role in the design and development of any future fibromyalgia interventions (e.g. leaflets and booklets). This would ensure that the issues most important to fibromyalgia patients themselves are included, rather than just the issues that health professionals consider the most important. This would mean that interventions are more tailored towards this population, and are more likely to be accepted amongst the fibromyalgia community.



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# APPENDICES

## APPENDIX I

### Supervision Plan: Behaviour Change Intervention

| Intervention | Area of work<br>(*outside of<br>normal work)                                                                                   | Supporting<br>evidence                                                                  | Changes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
|--------------|--------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Case study   | 10-minute<br>Cognitive<br>Behaviour Therapy<br>intervention<br>introduced to GPs<br>(in order to change<br>practice behaviour) | Case study report<br>(3000 words)<br><br>Workplace<br>supervisor's<br>evaluation report | <p>Changed to:</p> <p>Setting: Fibromyalgia support groups in Dulwich, Wickford Essex and Ealing</p> <p>Description:</p> <p>A Cognitive Behaviour Therapy (CBT) leaflet to be introduced within support groups. Leaflet will include information on fibromyalgia symptoms and prevalence, the CBT model, and different techniques in order to manage symptoms (information on good sleep hygiene, helpful breathing techniques, the benefits of exercise, and how to improve eating/drinking habits).</p> <p>Participants will be asked to complete a consent form and questionnaires monitoring work and social functioning, depression, symptom severity and anxiety. They will be asked to read and follow the leaflet for one month, and at the next support group one month later, complete the same questionnaires to monitor improvement.</p> |

Supervisee: \_\_Katie Watts\_\_\_\_\_

Supervisor: \_\_Dr Tiece Turnbull\_\_\_\_\_



## APPENDIX II

Version Number: 2 25/11/16



### INFORMATION SHEET FOR PARTICIPANTS

*REC Reference Number: LRS-16/17-3897*

#### COGNITIVE BEHAVIOUR THERAPY LEAFLET FOR FIBROMYALGIA

You are being invited to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully.

##### **1. What is the purpose of the study?**

We are undertaking a study to look at the effectiveness of using a Cognitive Behaviour Therapy (CBT) based leaflet as treatment for fibromyalgia. More specifically, we are investigating whether this intervention has any effect upon depressive symptoms, anxiety, and physical symptom severity. We are also investigating to see whether the leaflet has any effect upon work and social functioning.

While there is already evidence that face-to-face CBT treatment is helpful, we recognise that it may not be easy to commit to. Therefore, a CBT-based leaflet specifically tailored to treat fibromyalgia may be more suitable. However, whether it could be used as an effective alternative to face-to-face CBT is yet to be seen.

##### **2. What do you mean by 'a CBT-based leaflet intervention'?**

This simply means that if you choose to take part, a new leaflet will be given to you that will potentially be giving you new information. We hope that this information would be helpful for you.

##### **3. Why have I been invited to take part?**

We are contacting you because we know that you have fibromyalgia. In addition, we are inviting people aged 18 or older, who have not had any CBT-based treatment within the last 6 months. As all information is written in English, anyone who takes part will need to be able to read and write in English to a good level. We are inviting you because we believe that you fit this description.

##### **4. Do I have to take part?**

No. It is up to you.

##### **5. What will happen to me if I take part?**

If you are interested in taking part, we will take basic contact details from you and answer any further questions you may have. We will then provide you with a pack, containing an information sheet, consent form, four questionnaires, two envelopes and the CBT-based leaflet. The questionnaires will be asking you about your mood, how frequently you are bothered by your physical symptoms, and your daily

functioning. We would ask you to complete and post back your signed consent form and completed questionnaires to us in the two separate envelopes. This is just to keep your questionnaire answers separate from your personal details. We would then ask you to read through the leaflet and follow it for one month. At the end, we will get in touch (either in person at the next support group meeting, over the phone or via email) with the questionnaires which we will ask you to complete once more. This will be followed by a short evaluation form on the leaflet itself.

**6. How long will I be in the study?**

If you agree to take part in the study, you will be involved for one month.

**7. What are the possible disadvantages and risks of taking part?**

It is possible that while completing questionnaires and looking over the CBT-based fibromyalgia leaflet that you may end up thinking more about your feelings and your symptoms. For some, this may be upsetting. If as a result of taking part in the study or answering the questionnaires, you become concerned about your feelings you can talk to your GP. I would also strongly encourage you to raise this with us.

**9. What are the possible benefits of taking part?**

By taking part you will help us understand more about alternative ways that CBT-based treatments can be effectively delivered to people with fibromyalgia. We hope you will also get some helpful information about your condition and how to manage it in different ways.

**10. Are there any restrictions on what I can do?**

There will be no restrictions on your diet or lifestyle during the study. However, the leaflet may provide you with information on possible lifestyle changes.

**11. Will my taking part in this study be kept confidential?**

Any information collected about you during the course of the research will be kept strictly confidential. We will need to keep your contact details at the research sites but only for the purposes of contacting you about your questionnaires. This information will be securely stored and destroyed after the study. Any other information about you will have your name and contact details removed so that you cannot be recognised from it. We will not identify you in our computers or publications by name and will only refer to you by participant number, which will be used in place of your name in case of any future publications. All information will be stored on password protected computers and paperwork will be stored securely in a locked office. Although this is unlikely, we would need to inform your GP if we became concerned about your well-being. We would, of course, discuss this with you.

**12. What will happen if new information becomes available?**

Sometimes, new information might become available about the treatment that is being tested. In the unlikely case that this happens during the course of the study, we will contact you to discuss with you whether you want to continue.

### **13. What happens when the study is over?**

Once the study is over, we will see whether the CBT-based fibromyalgia leaflet has helped to improve your work and social functioning, your mood, and symptom severity.

### **14. What happens to the results of the research study?**

There is a chance that the results will be published in scientific journals and may be presented at meetings. However, we will not identify you in any report/publication. If you would like a copy of any published findings, we will be happy to provide this.

### **15. Discontinuation of the study**

At any time, we have the right to end your participation in the study for any reason. If, later on in the month it is concluded that you do not have capacity to consent, we would like to be able to continue to use any information already collected in an anonymised form.

### **16. Withdrawal from the study**

Taking part in this study is entirely voluntary. Although the duration of the study is one month, you can stop taking part in the study at any time without giving a reason and without this affecting your care at all, now or in the future. Should this happen, no new information will be collected from you. However, information collected may still be used. If you decide after the one month that you are involved in the study that you no longer wish for your data to be included within the analysis, you have 7 days to notify the researcher of this.

### **17. Who is organising and funding the research?**

The study is funded by researchers at the Institute of Psychiatry, Psychology and Neuroscience (King's College London). Prof. Trudie Chalder will be overseeing the study.

### **18. Who has reviewed the study?**

Ethics approval has been granted by the KCL College Research Ethics Committee.

### **19. Contact for further information?**

If you have any questions or require more information about this study, please contact us using the following details:

Researcher: **Katie Watts**

[Redacted]  
[Redacted]  
[Redacted]

Supervisor: **Professor Trudie Chalder**

[Redacted]  
[Redacted]  
[Redacted]

If you feel that this study has harmed you in any way, you can contact the PNM Research Ethics Committee, at:

Chair: PNM Research Ethics Committee

Email: [Redacted]

Thank you for reading this information sheet. You will be given a copy to keep. If you have understood the contents of this sheet and wish to take part, please complete the consent form. If you have any questions, please feel free to ask them now.

**Thank you for reading this information sheet and for considering taking part in this research.**

## APPENDIX III

Version Number 2. 25/11/16



### CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDIES

**Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.**

**Title of Study: Cognitive Behaviour Therapy Leaflet for Fibromyalgia**

**King's College Research Ethics Committee Ref:** *REC Reference Number: LRS-16/17-3897*

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

**I confirm that I understand that by ticking/initialling each box I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes mean that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element I may be deemed ineligible for the study.**

**Please tick  
or initial**

☐

#### ***Mandatory***

**Please tick  
or initial**

1. I confirm that I have read and understood the information sheet dated 25/11/2016 Version 2 for the above study. I have had the opportunity to consider the information and asked questions which have been answered satisfactorily.
2. I understand that I will be able to withdraw my data up to 1 week after my final questionnaires are completed.
3. I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the UK Data Protection Act 1998.

☐☐☐

4. I understand that my information may be subject to review by responsible individuals from the College for monitoring and audit purposes. ☐
5. I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications following this study. ☐
6. I have informed the researcher of any other research in which I am currently involved or have been involved in during the past 6 months ☐

***Optional***

7. I agree that the research team may use my data for future research and understand that any such use of identifiable data would be reviewed and approved by a research ethics committee. (In such cases, as with this project, data would/would not be identifiable in any report). ☐
8. I agree to be contacted in the future by King's College London researchers who would like to invite me to participate in follow up studies to this project, or in future studies of a similar nature. ☐
9. I understand that the information I have submitted may be published and if so I wish to receive a copy of it. ☐

---

**Name of Participant**

---

**Date**

---

**Signature**

## APPENDIX IV

Version Number: 2 25/11/16



### DEBRIEF SHEET FOR PARTICIPANTS

*REC Reference Number: LRS-16/17-3897*

#### COGNITIVE BEHAVIOUR THERAPY LEAFLET FOR FIBROMYALGIA

Thank you once again for participating in this study. Your help with the study is greatly appreciated. As a reminder, all your information will be stored in a secured location at King's College London, and only the research team will have access to it.

#### **What happens now?**

Your information (questionnaire scores and your evaluation feedback) will be analysed by the researcher to see whether there has been any change in terms of your work and social functioning, your mood and your symptom severity since the introduction of the leaflet. The findings will then be written up into a report.

#### **What will happen to the research findings?**

It is possible that research findings may be published in an academic journal. A summary of the results will be made available to you if you would like them.

#### **What if I change my mind about the study?**

If you change your mind about your data being included in the study, you have one week following your questionnaires being handed in to contact the researcher at [REDACTED], to let them know. Otherwise, your data may still be included within the final report.

#### **Contact for further information regarding the study?**

If you wish to discuss the study in greater detail, please contact:

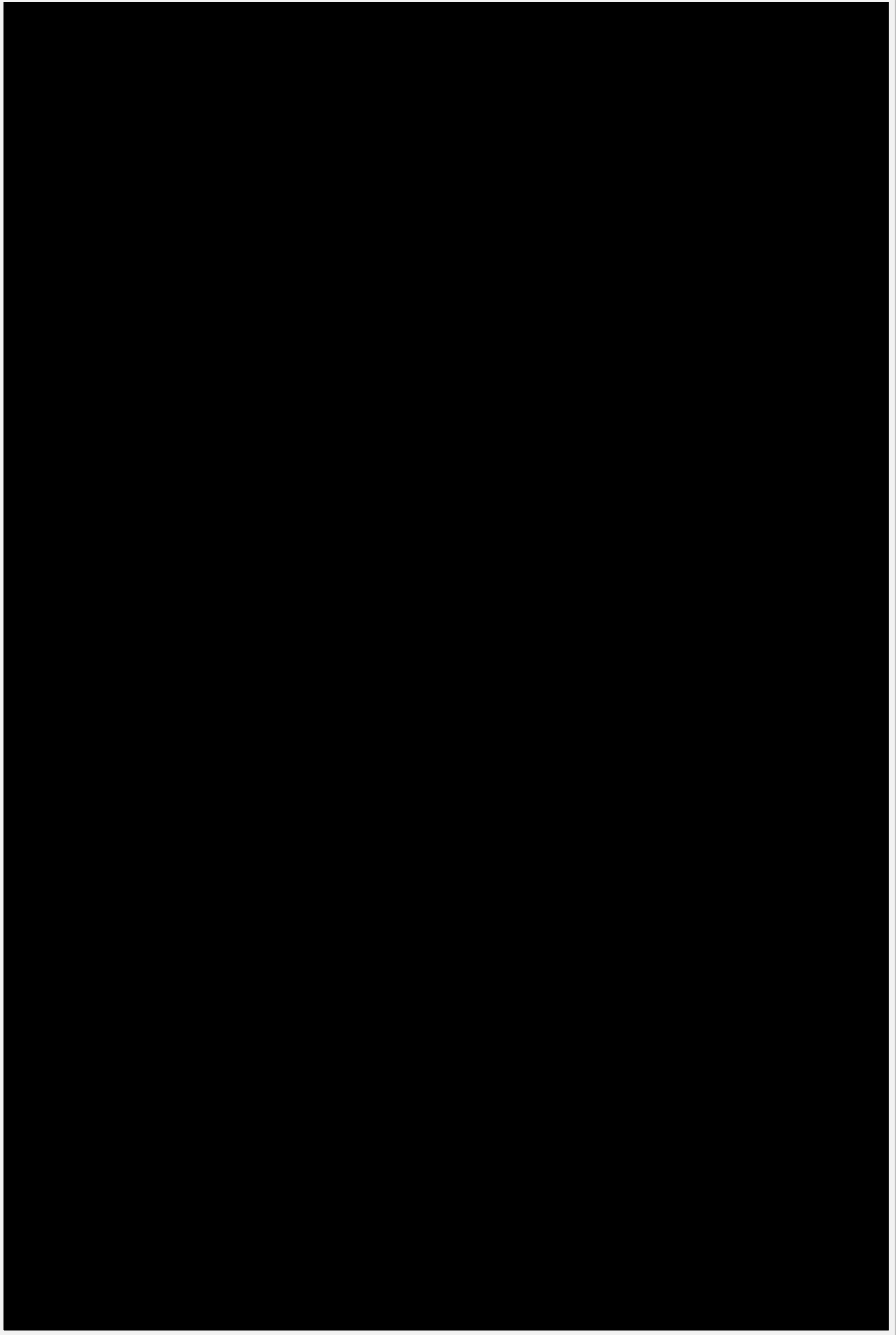
Researcher: **Katie Watts**  
Dept. of Psychological Medicine

[REDACTED]  
[REDACTED]

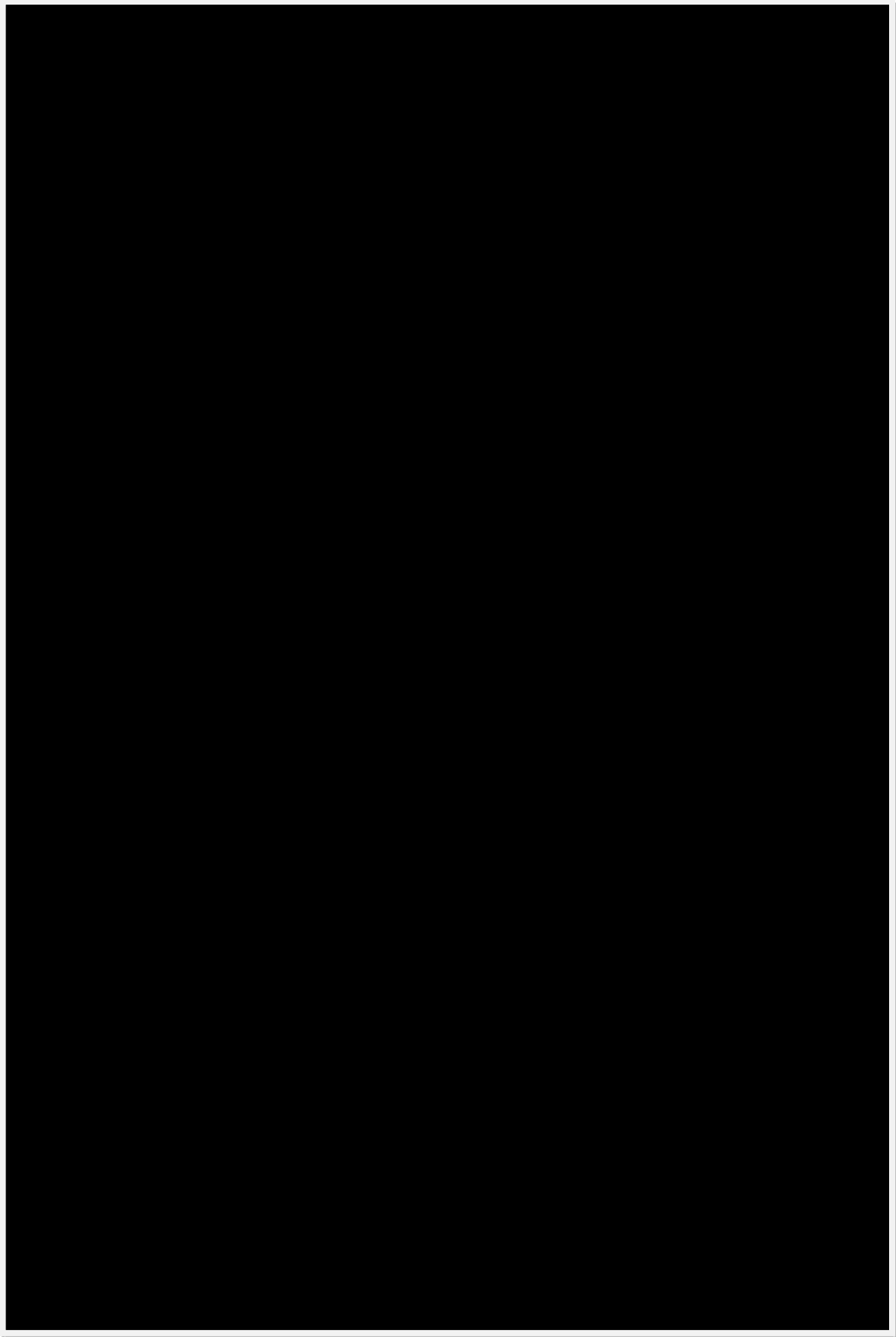
If you have any concerns in relation to your physical and psychological health, you can speak with your GP who will be able to advise you.

**Thank you once again for taking part in this research.**

## APPENDIX V







## APPENDIX VI

### Work and Social Adjustment Scale (WSAS)

Rate each of the following questions on a 0 to 8 scale: 0 indicates *no impairment at all* and 8 indicates *very severe impairment*.

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

## APPENDIX VII

### Patient Health Questionnaire (PHQ-9)

#### Part A

Over the last 2 weeks, how often have you been bothered by any of the following problems?

|           |                                                                                                                                                                                 |          |                         |
|-----------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------|-------------------------|
| <b>1.</b> | <b>Little interest or pleasure in doing things</b>                                                                                                                              | <b>0</b> | Not at all              |
|           |                                                                                                                                                                                 | <b>1</b> | Several days            |
|           |                                                                                                                                                                                 | <b>2</b> | More than half the days |
|           |                                                                                                                                                                                 | <b>3</b> | Nearly every day        |
| <b>2.</b> | <b>Feeling down, depressed or hopeless</b>                                                                                                                                      | <b>0</b> | Not at all              |
|           |                                                                                                                                                                                 | <b>1</b> | Several days            |
|           |                                                                                                                                                                                 | <b>2</b> | More than half the days |
|           |                                                                                                                                                                                 | <b>3</b> | Nearly every day        |
| <b>3.</b> | <b>Trouble falling or staying asleep, or sleeping too much</b>                                                                                                                  | <b>0</b> | Not at all              |
|           |                                                                                                                                                                                 | <b>1</b> | Several days            |
|           |                                                                                                                                                                                 | <b>2</b> | More than half the days |
|           |                                                                                                                                                                                 | <b>3</b> | Nearly every day        |
| <b>4.</b> | <b>Feeling tired or having little energy</b>                                                                                                                                    | <b>0</b> | Not at all              |
|           |                                                                                                                                                                                 | <b>1</b> | Several days            |
|           |                                                                                                                                                                                 | <b>2</b> | More than half the days |
|           |                                                                                                                                                                                 | <b>3</b> | Nearly every day        |
| <b>5.</b> | <b>Poor appetite or overeating</b>                                                                                                                                              | <b>0</b> | Not at all              |
|           |                                                                                                                                                                                 | <b>1</b> | Several days            |
|           |                                                                                                                                                                                 | <b>2</b> | More than half the days |
|           |                                                                                                                                                                                 | <b>3</b> | Nearly every day        |
| <b>6.</b> | <b>Feeling bad about yourself – or that you are a failure or have let yourself or your family down</b>                                                                          | <b>0</b> | Not at all              |
|           |                                                                                                                                                                                 | <b>1</b> | Several days            |
|           |                                                                                                                                                                                 | <b>2</b> | More than half the days |
|           |                                                                                                                                                                                 | <b>3</b> | Nearly every day        |
| <b>7.</b> | <b>Trouble concentrating on things, such as reading the newspaper or watching television</b>                                                                                    | <b>0</b> | Not at all              |
|           |                                                                                                                                                                                 | <b>1</b> | Several days            |
|           |                                                                                                                                                                                 | <b>2</b> | More than half the days |
|           |                                                                                                                                                                                 | <b>3</b> | Nearly every day        |
| <b>8.</b> | <b>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</b> | <b>0</b> | Not at all              |
|           |                                                                                                                                                                                 | <b>1</b> | Several days            |
|           |                                                                                                                                                                                 | <b>2</b> | More than half the days |
|           |                                                                                                                                                                                 | <b>3</b> | Nearly every day        |

|           |                                                                                       |          |                         |
|-----------|---------------------------------------------------------------------------------------|----------|-------------------------|
| <b>9.</b> | <b>Thoughts that you would be better off dead, or of hurting yourself in some way</b> | <b>0</b> | Not at all              |
|           |                                                                                       | <b>1</b> | Several days            |
|           |                                                                                       | <b>2</b> | More than half the days |
|           |                                                                                       | <b>3</b> | Nearly every day        |

Part B

|           |                                                                                                                                                                                       |          |                      |
|-----------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------|----------------------|
| <b>1.</b> | <b>If you checked off <i>any</i> problems, how <i>difficult</i> have these problems made it for you to do your work, take care of things at home, or get along with other people?</b> | <b>0</b> | Not difficult at all |
|           |                                                                                                                                                                                       | <b>1</b> | Somewhat difficult   |
|           |                                                                                                                                                                                       | <b>2</b> | Very difficult       |
|           |                                                                                                                                                                                       | <b>3</b> | Extremely difficult  |

## APPENDIX VIII

### Patient Health Questionnaire (PHQ-15)

During the past 4 weeks, how much have you been bothered by any of the following problems?

|     |                                                                           |   |                     |
|-----|---------------------------------------------------------------------------|---|---------------------|
| 1.  | <b>Stomach Pain?</b>                                                      | 0 | Not bothered at all |
|     |                                                                           | 1 | Bothered a little   |
|     |                                                                           | 2 | Bothered a lot      |
| 2.  | <b>Back pain?</b>                                                         | 0 | Not bothered at all |
|     |                                                                           | 1 | Bothered a little   |
|     |                                                                           | 2 | Bothered a lot      |
| 3.  | <b>Pain in your arms, legs, or joints: knees, hips, etc.)?</b>            | 0 | Not bothered at all |
|     |                                                                           | 1 | Bothered a little   |
|     |                                                                           | 2 | Bothered a lot      |
| 4.  | <b>Menstrual cramps or other problems with your periods [Women only]?</b> | 0 | Not bothered at all |
|     |                                                                           | 1 | Bothered a little   |
|     |                                                                           | 2 | Bothered a lot      |
| 5.  | <b>Headaches?</b>                                                         | 0 | Not bothered at all |
|     |                                                                           | 1 | Bothered a little   |
|     |                                                                           | 2 | Bothered a lot      |
| 6.  | <b>Chest pain?</b>                                                        | 0 | Not bothered at all |
|     |                                                                           | 1 | Bothered a little   |
|     |                                                                           | 2 | Bothered a lot      |
| 7.  | <b>Dizziness?</b>                                                         | 0 | Not bothered at all |
|     |                                                                           | 1 | Bothered a little   |
|     |                                                                           | 2 | Bothered a lot      |
| 8.  | <b>Fainting spells?</b>                                                   | 0 | Not bothered at all |
|     |                                                                           | 1 | Bothered a little   |
|     |                                                                           | 2 | Bothered a lot      |
| 9.  | <b>Feeling your heart pound or race?</b>                                  | 0 | Not bothered at all |
|     |                                                                           | 1 | Bothered a little   |
|     |                                                                           | 2 | Bothered a lot      |
| 10. | <b>Shortness of breath?</b>                                               | 0 | Not bothered at all |
|     |                                                                           | 1 | Bothered a little   |
|     |                                                                           | 2 | Bothered a lot      |
| 11. | <b>Pain or problems during sexual intercourse?</b>                        | 0 | Not bothered at all |
|     |                                                                           | 1 | Bothered a little   |
|     |                                                                           | 2 | Bothered a lot      |
| 12. | <b>Constipation, loose bowels, or diarrhoea?</b>                          | 0 | Not bothered at all |
|     |                                                                           | 1 | Bothered a little   |
|     |                                                                           | 2 | Bothered a lot      |
| 13. | <b>Nausea, gas, or indigestion?</b>                                       | 0 | Not bothered at all |
|     |                                                                           | 1 | Bothered a little   |
|     |                                                                           | 2 | Bothered a lot      |
| 14. | <b>Feeling tired or having low energy?</b>                                | 0 | Not bothered at all |
|     |                                                                           | 1 | Bothered a little   |
|     |                                                                           | 2 | Bothered a lot      |
| 15. | <b>Trouble sleeping?</b>                                                  | 0 | Not bothered at all |
|     |                                                                           | 1 | Bothered a little   |
|     |                                                                           | 2 | Bothered a lot      |

## APPENDIX IX

### Generalised Anxiety Disorder (GAD-7)

Please read each statement and record a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past two weeks. There are no right or wrong answers. Do not spend too much time on any one statement. This assessment is not intended to be a diagnosis. If you are concerned about your results in any way, please speak with a qualified health professional.

|    |                                                          |   |                         |
|----|----------------------------------------------------------|---|-------------------------|
| 1. | <b>Feeling nervous, anxious or on edge</b>               | 0 | Not at all              |
|    |                                                          | 1 | Several days            |
|    |                                                          | 2 | More than half the days |
|    |                                                          | 3 | Nearly every day        |
| 2. | <b>Not being able to stop or control worrying</b>        | 0 | Not at all              |
|    |                                                          | 1 | Several days            |
|    |                                                          | 2 | More than half the days |
|    |                                                          | 3 | Nearly every day        |
| 3. | <b>Worrying too much about different things</b>          | 0 | Not at all              |
|    |                                                          | 1 | Several days            |
|    |                                                          | 2 | More than half the days |
|    |                                                          | 3 | Nearly every day        |
| 4. | <b>Trouble relaxing</b>                                  | 0 | Not at all              |
|    |                                                          | 1 | Several days            |
|    |                                                          | 2 | More than half the days |
|    |                                                          | 3 | Nearly every day        |
| 5. | <b>Being so restless that it is hard to sit still</b>    | 0 | Not at all              |
|    |                                                          | 1 | Several days            |
|    |                                                          | 2 | More than half the days |
|    |                                                          | 3 | Nearly every day        |
| 6. | <b>Becoming easily annoyed or irritable</b>              | 0 | Not at all              |
|    |                                                          | 1 | Several days            |
|    |                                                          | 2 | More than half the days |
|    |                                                          | 3 | Nearly every day        |
| 7. | <b>Feeling afraid as if something awful might happen</b> | 0 | Not at all              |
|    |                                                          | 1 | Several days            |
|    |                                                          | 2 | More than half the days |
|    |                                                          | 3 | Nearly every day        |

**Please note:** These results are intended as a guide to your health and are presented for information purposes only. They are not intended to be a clinical diagnosis. If you are concerned in any way about your health, please consult with a qualified health professional.

## APPENDIX X

| <b>Evaluation form questions</b>                                          | <b>Comments</b>                                                                                | <b>N (%)</b> |
|---------------------------------------------------------------------------|------------------------------------------------------------------------------------------------|--------------|
| What did you like most about this leaflet and why?                        | <i>Clear and informative information</i>                                                       | 3 (50%)      |
|                                                                           | <i>Liked the information on pacing</i>                                                         | 1 (16.7%)    |
|                                                                           | <i>Made me think more positively about eating and drinking better, and exercising</i>          | 1 (16.7%)    |
|                                                                           | <i>Liked the use of colour and illustrations</i>                                               | 1 (16.7%)    |
| What did you like least about this leaflet, and why?                      | <i>N/A</i>                                                                                     | 3 (50%)      |
|                                                                           | <i>Already familiar with information (sleep hygiene) – does not work</i>                       | 1 (16.7%)    |
|                                                                           | <i>'What is fibromyalgia?' section does not include enough information/ explanation</i>        | 1 (16.7%)    |
|                                                                           | <i>Would have liked more colour</i>                                                            | 1 (16.7%)    |
| How engaging/unengaging did you find the leaflet to be?                   | <i>Engaging</i>                                                                                | 4 (66.7%)    |
|                                                                           | <i>Unengaging – hard to stay focused on it</i>                                                 | 2 (33.3%)    |
| How easy/ not easy did you find the information to understand and follow? | <i>Easy to read and follow</i>                                                                 | 4 (66.7%)    |
|                                                                           | <i>Struggled to follow it all and get up at the same time as so tired</i>                      | 1 (16.7%)    |
|                                                                           | <i>No answer given</i>                                                                         | 1 (16.7%)    |
| Would you have liked more information, or less information?               | <i>Good amount of information</i>                                                              | 3 (50%)      |
|                                                                           | <i>More information (e.g. on CBT)</i>                                                          | 3 (50%)      |
| How relevant did you find the leaflet's content to be for you?            | <i>Relevant</i>                                                                                | 5 (83.3%)    |
|                                                                           | <i>Should have been written by someone with fibromyalgia</i>                                   | 1 (16.7%)    |
| How do you feel the leaflet could have been improved?                     | <i>More information on symptoms (e.g. vertigo and tinnitus)</i>                                | 3 (50%)      |
|                                                                           | <i>More information in general</i>                                                             | 1 (16.7%)    |
|                                                                           | <i>More relaxation techniques</i>                                                              | 1 (16.7%)    |
|                                                                           | <i>Would have liked more examples of how CBT works</i>                                         | 1 (16.7%)    |
|                                                                           | <i>More information on financial benefits, CA card, Blue Badge, Dial A Ride, Freedom pass.</i> | 1 (16.7%)    |
|                                                                           | <i>Fine as it is</i>                                                                           | 1 (16.7%)    |
| Any other comments?                                                       | <i>Theory behind it is good</i>                                                                | 2 (33.3%)    |
|                                                                           | <i>Have had CBT before</i>                                                                     | 1 (16.7%)    |
|                                                                           | <i>This information is best given at time of diagnosis</i>                                     | 1 (16.7%)    |
|                                                                           | <i>Colours soothing, and text size appropriate</i>                                             | 1 (16.7%)    |

## APPENDIX XI

### Workplace evaluation reports

#### Professional Doctorate in Health Psychology

#### Workplace Evaluation Report

##### Section 1 - To be completed by the Trainee:

|                                        |                               |
|----------------------------------------|-------------------------------|
| Trainee's name                         | KATIE WATTS                   |
| Name of workplace contact              | T. Calder                     |
| Nature of work and competence assessed | BEHAVIOUR CHANGE INTERVENTION |

##### Section 2 – to be completed by the Workplace Supervisor:

Views on the Trainee's Performance on above piece of work. Please also comment on any reason for delays in the completion of this piece of work and report any periods of prolonged absence.

Katie developed a cognitive behaviour therapy leaflet for patients with Fibromyalgia from support clinics. The leaflet included psycho-education, techniques for managing symptoms and mood. This was evaluated in a pilot study. There was some positive feedback from those who read it and some recommendations for changes.

##### Declaration

I verify that the above named Trainee has undertaken the above mentioned piece of work. I am of the opinion that it has been completed to a satisfactory professional standard.

Signature:

[Redacted Signature]

Date:

24/6/2017



School of Health Sciences

City University

Northampton Square

London EC1V 0HB

Programme Director – Dr Angeliki Bogosian

Email:

Tel:

[Redacted Contact Information]



**Professional Doctorate in Health Psychology**

**Workplace Evaluation Report**

**Section 1 - To be completed by the Trainee:**

|                                        |                               |
|----------------------------------------|-------------------------------|
| Trainee's name                         | Katie Watts                   |
| Name of workplace contact              | Dr Caroline Stokes            |
| Nature of work and competence assessed | BEHAVIOUR CHANGE INTERVENTION |

**Section 2 – to be completed by the Workplace Supervisor:**

Views on the Trainee's Performance on above piece of work. Please also comment on any reason for delays in the completion of this piece of work and report any periods of prolonged absence.

Katie's behaviour change intervention (a CBT leaflet for members of a fibromyalgia support group) was well thought through and appropriate for the patient group.

**Declaration**

I verify that the above named Trainee has undertaken the above mentioned piece of work. I am of the opinion that it has been completed to a satisfactory professional standard.

Signature:

[Redacted Signature]

Date:

16/6/2017



**School of Health Sciences**

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Programme Director – Dr Angeliki Bogosian

Email:

[Redacted Email]

Tels:

[Redacted Phone Numbers]

## **3C: TEACHING AND TRAINING (TEACHING)**

- 1. Health Promotion: Individual-Level Interventions**
- 2. The Patient with Medically Unexplained Symptoms**

**Word count: 2197**

## **3C: Teaching and Training**

### **3C: Teaching**

In order to achieve the Teaching element of the Teaching and Training competency, I delivered two teaching sessions on different topics, to two different audiences (please refer to Appendix I for the Teaching supervision plan). Below I have documented the process undertaken for both teaching sessions, including how I have evaluated them using a reflective approach to enhance self-awareness and learning (Northway, 2000). Reflective practice has been demonstrated to be particularly helpful when attempting to comprehend complex situations (Mann, Gordon & MacLeod, 2007).

#### **3C.1: . Teaching session 1. Health Promotion: Individual-Level Interventions**

##### **3C.1.1: The reflective framework: The Gibbs' Reflective Cycle (1988)**

In order to implement a reflective stance for this session, I referred to the Gibbs' reflective cycle for guidance (Gibbs, 1988). This particular model has six individual stages, and has been established as an effective tool for reflection and learning (Wilding, 2008). The six stages include a description of the event, i.e. who the audience were, where and for what purpose they were being taught, and what happened before, during and after. It also includes an analysis of feelings, an evaluation of the experience, a conclusion of what could be improved in future, and an action plan of how to implement this in future practice. I have described and evaluated my experience of the first teaching session below, to loosely cover these stages.

### **3C.1.2: Planning and designing teaching programmes that enable students to learn about psychological knowledge, skills, and practices**

#### *3C.1.2.1: Assessment of teaching needs*

The opportunity to teach arose following an invitation from the MSc Health Psychology Programme Director at City, University of London, to deliver the majority of an ad hoc three hour session on '*Individual-Level Interventions*', which forms part of the Health Promotion module. I was informed that individual behaviour interventions were still an integral part of the course and coverage was required for successful completion of an assessment. In this particular case, teaching needs were largely directed by the Health Promotion module syllabus.

#### *3C.1.2.2: Preparation of appropriate teaching materials*

In order to effectively deliver the required information, I received the existing slides from the Programme Director, and adapted them to cover each of the following: the different approaches to behaviour change, using examples within healthcare settings; steps taken when designing a behaviour change intervention, introducing the Behaviour Change Wheel, and the COM-B model (Michie, Maartje & van Stralen, 2011); how to effectively evaluate a health behaviour change intervention using the RE-AIM model (Glasgow, Vogt & Boles, 1999). For the latter, I referred to my own MSc Health Promotion assignment, which helped me to deliver the information in a way that was closely tailored to the needs of the audience.

Materials for the teaching included PowerPoint slides, which were designed to be logical and easy to follow. Group activities were integrated to ensure the audience remained engaged, one of which was a three-minute mindfulness activity using a video where pulse rates were taken before and after. Mindfulness was included to demonstrate how psychological health directly impacts physical health,

and to demonstrate how to effectively manage stress (Chiesa & Serretti, 2009).

Towards the end of the teaching, students formed groups and designed an intervention for their chosen behaviour, including how they planned to evaluate it using the RE-AIM framework.

### **3C.1.3: Planning and implementing assessment procedures, and delivering the teaching session**

Evaluation forms were designed and printed in advance, and administered at the end of the teaching to obtain student feedback. Feedback-seeking behaviour has been shown to facilitate adaptation and improve future performance (Crommelinck & Anseel, 2013). I was anxious prior to the session as I had never taught University students, nor been required to engage a large group for a substantial length of time. I was also unsure whether my real-life examples would effectively illustrate the different types of interventions, and whether the students would engage in group exercises. However, in order to appear professional and be prepared, I made sure to arrive early on the day, run through my slides beforehand, and test the mindfulness video with the sound. During the teaching session, students appeared to listen intently and seemed engaged, which made the experience positive for me and enhanced my feelings of self-efficacy for teaching (Bandura, 1977a). As the session concluded, I felt confident that I had delivered the session to the best of my ability.

### **3C.1.4: Evaluating the teaching session**

The evaluation forms, which were open-ended in order to obtain rich and detailed qualitative data, supported that belief that the teaching session had been successful, due to their positive comments (please see Appendix II for a summary of student feedback, and Appendix III for an evaluation report from Dr Turnbull).

Generally the mindfulness activity was well received, with one student remarking within their feedback: *"[It was] very engaging – wish all lectures would include three minutes of mindfulness"*. Many also expressed their appreciation that I had included personal examples of interventions, which I had used to place information within a day-to-day context. One student stated the following: *"I liked how the content was presented and the use of examples from your own work especially"*. Perhaps most importantly though, students were generally in agreement that learning needs were met: *"The lecture was relevant to our assignments, so it gave us more ideas for our project"*. All of this feedback naturally acted as positive reinforcement.

Constructive feedback on the evaluation forms included that I should include less text on slides: *"Some of the slides were hard to read/ text heavy"*. On reflection, this was due to fear that I may forget key information. One student also felt that I delivered the lecture at a fast pace, meaning that there were infrequent pauses for questions. While there was group discussion, more would have facilitated preparation for the group work (Beard, 1997). Moving forward, I intend to continue including a similar ratio of slides and group activities. Key changes will be to include less text, speak slower, and allow for more group interaction. This experience has given me the confidence to make these changes for future teaching sessions.

### **3C.2: Teaching session 2: The patient with Medically Unexplained Symptoms**

#### **3C.2.1: A reflective framework: Rolfe, Freshwater and Jasper (2001)**

For this session, I have referred to a different reflective framework in order to further enhance my knowledge and professional development. The framework for reflective practice by Rolfe, Freshwater and Jasper (2001), has already been demonstrated to complement learning in practice (Lahteenmaki, 2005). This model

encourages consideration of thoughts and feelings, actions taken, and how these were consequential for the teacher and audience. It also encourages consideration of what the experience may teach oneself about their relationship with the audience, and how personal experience could contribute to the session. Furthermore, it requires consideration of how to improve teaching in the future and address relevant issues, as well as consider the consequences of not addressing them. In addition to this model, I was mindful to implement the constructive feedback from my previous teaching session.

### **3C.2.2: Planning and designing teaching that enables students to learn about psychological knowledge, skills and practices**

#### *3C.2.2.1: Assessment of teaching needs*

My second teaching opportunity came unexpectedly from a healthcare professional requesting help to run a workshop entitled “*The Patient with Medically Unexplained Symptoms*” for nurse practitioners. I was informed that the audience were likely to have had very little understanding of MUS, and so it was agreed prior to the session that I would prepare PowerPoint slides and activities for an introductory session on the subject. Audience expectations of the teaching session, as well as their perceived level of knowledge, were clarified at the beginning of the workshop, confirming that this particular group currently had little to no understanding of MUS, and were looking for general information relating to the impact of MUS, its presentation, and how to effectively treat MUS.

#### *3C.2.2.2: Preparation of appropriate teaching materials*

I aimed to effectively cover the different terms for MUS, its prevalence, the physical/ psychological/ financial implications for patients and health professionals,

and how to recognise MUS in a clinical setting. In addition, I included two educational videos from the NHS website and a vignette, as education and modelling are established BCTs (Michie, van Stralen & West, 2011), due to their effects on self-efficacy (Bandura, 1997b). The implications of including these were that nurse practitioners should feel more empowered to recognise and manage MUS. In order to evaluate learning, pre and post-questionnaires had previously been produced to capture perceived knowledge and confidence of understanding MUS, as well as qualitative feedback for the full workshop (please see Appendix IV and V).

I found the preparation stage to be somewhat stressful at first as the opportunity arose at short notice and I was keen to design a better teaching session this time around. I was also conscious that it would likely be a different teaching experience due to their clinical background. This feeling was only enforced when I was informed that the MUS teaching was the final day of a training course, which made me think that they were likely fatigued. This is where my previous experience and feedback forms were useful for preparation, as it meant that I could feel more confident in selecting activities and suitable media platforms to keep my audience engaged. I was also feeling more self-assured due to my work-based focus on MUS, making it easier to draw upon personal experiences.

### **3C.2.3: Delivery of the teaching session**

I arrived early but felt somewhat unsettled due to factors outside of my control, with the session delayed 30 minutes due to late arrivals. However, following on from quick introductions and a re-confirmation that for most the aim was to gain a broad overview of MUS, I was able to conduct my teaching. I definitely felt more confident in my own ability as the group exercises, vignette and video seemed to be well-received. As well as pausing occasionally to introduce anonymous examples of



MUS patients I had encountered, I also invited the class to share stories, of which some obliged. While initially happy with my teaching plan, I realised that I needed to adapt in order to ensure I finished promptly. Therefore, I skimmed through the numerous terms for MUS, and chose to play only one selected NHS video, suggesting they watch the other in their own time. This worked well, as in practice one video felt sufficient for illustrating the point. Immediately after teaching, I felt drained, but happy with how the content of the session had been received. Despite one nurse leaving early, others appeared to enjoy learning about MUS, even if they did not frequently encounter it themselves.

### **3C.2.4: Evaluating the teaching session**

Feedback was on the whole workshop rather than my teaching session in particular. However, from the feedback I was able to see a great improvement in their knowledge of MUS, with average scores on the Knowledge questionnaire increasing from 4.7 out of 10, to 8.2. Confidence of recognising and treating MUS also hugely increased, from an average of 3.2 to 7.2 out of 10. Please see Appendix IV for a breakdown of Knowledge and Confidence scores. In terms of more general feedback, ranging from 1 to 8 where 1 was reflective of a positive outcome, content of the workshop and the handouts were given average scores of 2.2 and 2.1 respectively, demonstrating that the nurses approved of the information that had been covered. Presentation however had a slightly weaker average score of 3.1, which was disappointing. As qualitative feedback generally did not provide much information however, it was difficult to gauge to what extent my own presentation style was at fault. Positive comments differed, but amongst these were statements that I was *“friendly and helpful”*, that video clips of real-life experiences were appreciated, and that the course was necessary as it covered information that had not been taught previously: *“In general learning about MUS/PPS was helpful as*

*some is not discussed/ thought in university training*". Constructive criticism was limited, particularly in relation to my teaching session within the workshop. However, within the comments it was suggested that a patient speaker be invited, rather than use a role play between facilitators. I felt this was an excellent idea and one that we could easily action. Immediately following the workshop, I put forward this suggestion for the next time the workshop was due to run. Please see Appendix V for general and qualitative feedback.

Overall, I am satisfied with how the teaching session went. The audience were not as fatigued as I had feared, and I sensed a certain level of respect, which I perceived to be due to my knowledge of the subject. In addition, I felt my delivery was more relaxed, and there were no specific comments relating to the amount of text on slides, the speed of delivery, or the time spent on slides. Pre and post questionnaires indicated a marked improvement in terms of knowledge and confidence, indicating that needs had been met. While there did appear to be criticism surrounding presentation, I am confident that with more practice this will continue to improve and become fluid. Therefore, I will endeavour to continue gaining as much teaching experience as possible.

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## **APPENDICES**

## APPENDIX I

### Supervision Plan: Teaching

| Teaching and training  | Area of work (*outside of normal work)                                                                                                                                                                                                                                                                                               | Supporting evidence                                                                                                                                                                                                    | Changes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
|------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Case study: Teaching 1 | <p>Setting: City, University of London.</p> <p>Description: An MSc Health Psychology lecture to students as part of the Health Promotion module. The lecture will cover Individual-level Behaviour Change Interventions (BCI), including steps to designing BCIs, and how to evaluate BCIs (e.g. by using the RE-AIM framework).</p> | <p>Case study report (2000 words).</p> <p>Evaluation forms completed by students.</p> <p>Evaluation form (signed by Dr. Tiece Turnbull who was present for the teaching session).</p> <p>Workplace contact report.</p> | N/A                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| Case study: Teaching 2 | Supervision of MSc student conducting an LGBT study with PPS patients.                                                                                                                                                                                                                                                               | <p>Case study report (2000 words – combined with Teaching 1).</p> <p>Workplace contact report.</p>                                                                                                                     | <p><i>Changed to:</i></p> <p>Setting: King's College London</p> <p>Description: IMPARTS teaching session on Medically Unexplained Symptoms, for nurse practitioners from St. George's Hospital</p> <p>This session will cover what medically unexplained symptoms are (including different terms), their prevalence, their impact upon patients and patients. The session will aim to include group activities, group discussion and relevant videos, in order to try and keep the audience engaged.</p> |

Supervisee: \_\_Katie Watts\_\_\_\_\_

Supervisor: \_\_Dr. Tiece Turnbull\_\_\_\_\_

## APPENDIX II

### Evaluation form: Teaching session 1

| Evaluation form questions                                 | Comments                                                                                                                                                                                                              | N (%)                                                                            |
|-----------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------|
| What did you enjoy most about this session, and why?      | How it was presented <ul style="list-style-type: none"> <li>Clear</li> <li>Excited, motivated and fresh lecturer</li> <li>Easy to follow</li> <li>Working like a team</li> </ul>                                      | <b>5 (41.7%)</b><br>2(16.7%)<br>1 (8.3%)<br>1 (8.3%)<br>1 (8.3%)                 |
|                                                           | Helpful for assignment                                                                                                                                                                                                | 4 (33.2%)                                                                        |
|                                                           | The mindfulness exercise <ul style="list-style-type: none"> <li>It was relaxing</li> </ul>                                                                                                                            | <b>3 (25%)</b><br>1 (8.3%)                                                       |
|                                                           | Liked the use of real life examples                                                                                                                                                                                   | 2 (16.7%)                                                                        |
|                                                           | Informative                                                                                                                                                                                                           | 2 (16.7%)                                                                        |
|                                                           | Interactive activities                                                                                                                                                                                                | 1 (8.3%)                                                                         |
|                                                           | Showed that behaviour change is possible (as shown at individual level)                                                                                                                                               | 1 (8.3%)                                                                         |
| What did you enjoy the least about this session, and why? | Group work <ul style="list-style-type: none"> <li>Hard to put together all the information</li> </ul>                                                                                                                 | <b>4 (33.2%)</b><br>1 (8.3%)                                                     |
|                                                           | Some slides difficult to read                                                                                                                                                                                         | 1 (8.3%)                                                                         |
|                                                           | Some slides were text heavy                                                                                                                                                                                           | 1 (8.3%)                                                                         |
|                                                           | Reading some slides word for word                                                                                                                                                                                     | 1 (8.3%)                                                                         |
|                                                           | Could have left out studies from presentation                                                                                                                                                                         | 1 (8.3%)                                                                         |
|                                                           | Mindfulness meditation                                                                                                                                                                                                | 1 (8.3%)                                                                         |
|                                                           | Covered too fast at times                                                                                                                                                                                             | 1 (8.3%)                                                                         |
|                                                           | Not applicable                                                                                                                                                                                                        | 3 (25%)                                                                          |
|                                                           | (Left blank)                                                                                                                                                                                                          | 1 (8.3%)                                                                         |
| How engaging did you find this session to be?             | Engaging <ul style="list-style-type: none"> <li>Scored 8/10</li> <li>Relevant content</li> <li>Mindfulness helped make it engaging</li> <li>Group work helped to make it engaging</li> <li>New information</li> </ul> | <b>11 (91.7%)</b><br>1 (8.3%)<br>2 (16.7%)<br>2 (16.7%)<br>2 (16.7%)<br>1 (8.3%) |

|                                                                                            |                                                                    |                  |
|--------------------------------------------------------------------------------------------|--------------------------------------------------------------------|------------------|
|                                                                                            | Interested in current work role discussed (as Research Worker)     | 1 (8.3%)         |
| Did you feel there were enough / not enough participatory activities during the session?   | Enough participatory activities                                    | 9 (75%)          |
|                                                                                            | No opinion                                                         | 1 (8.3%)         |
|                                                                                            | (No information given)                                             | 2 (16.7%)        |
| Did you find the slide contents to be organised and easy to follow?                        | Organised / easy to follow                                         | 8 (66.7%)        |
|                                                                                            | Slides too text heavy                                              | 1 (8.3%)         |
|                                                                                            | Text too small on slides                                           | 1 (8.3%)         |
|                                                                                            | Helpful                                                            | 1 (8.3%)         |
|                                                                                            | More detail could have been given on specific examples and studies | 1 (8.3%)         |
| Did you find the session's content to be relevant to your own needs as part of the course? | Yes                                                                | <b>12 (100%)</b> |
|                                                                                            | ▪ Helped me to think of presentation I have in a few months        | 1 (8.3%)         |
|                                                                                            | ▪ Relevant for assignment                                          | 1 (8.3%)         |
| How do you feel the lesson could have been improved?                                       | Not applicable                                                     | 6 (50%)          |
|                                                                                            | Could have included more group discussion                          | 1 (8.3%)         |
|                                                                                            | More detail on studies/story telling needed                        | 1 (8.3%)         |
|                                                                                            | More time needed on some slides to take notes                      | 1 (8.3%)         |
|                                                                                            | Using sweets as rewards for good students                          | 1 (8.3%)         |
|                                                                                            | (Left blank)                                                       | 3 (25%)          |
| Any other comments?                                                                        | Left blank                                                         | 6 (50%)          |
|                                                                                            | No                                                                 | 1 (8.3%)         |
|                                                                                            | Thank you!                                                         | 1 (8.3%)         |
|                                                                                            | Very well done – excellent delivery! Thank you                     | 1 (8.3%)         |
|                                                                                            | Thanks for your lecture – it was great!                            | 1 (8.3%)         |
|                                                                                            | Great job!                                                         | 1 (8.3%)         |
|                                                                                            | Well done!                                                         | 1 (8.3%)         |



## APPENDIX III

### Professional Doctorate in Health Psychology

#### Workplace Evaluation Report

##### Section 1 - To be completed by the Trainee:

|                                        |                                                                                                                                                                                                                                           |
|----------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Trainee's name                         | Katie Watts                                                                                                                                                                                                                               |
| Name of workplace contact              | Dr Caroline Stokes / Professor Trudie Chalder                                                                                                                                                                                             |
| Nature of work and competence assessed | Teaching (Teaching and Training competence)<br><br>MSc Health Psychology: Individual Behavioural Change Interventions lecture (part of the Health Promotion module)<br><br>City University London – Friday 12 <sup>th</sup> February 2016 |

##### Section 2 – to be completed by the Workplace Supervisor:

Views on the Trainee's Performance on above piece of work. Please also comment on any reason for delays in the completion of this piece of work and report any periods of prolonged absence.

Katie provided an excellent lecture to MSc students at City University. This was reflected in the feedback gained and I concur with students.

##### **Declaration**

I verify that the above named Trainee has undertaken the above mentioned piece of work. I am of the opinion that it has been completed to a satisfactory professional standard.

Signature:

[Redacted Signature]

Date:

19/02/2017



School of Health Sciences

City University

Northampton Square

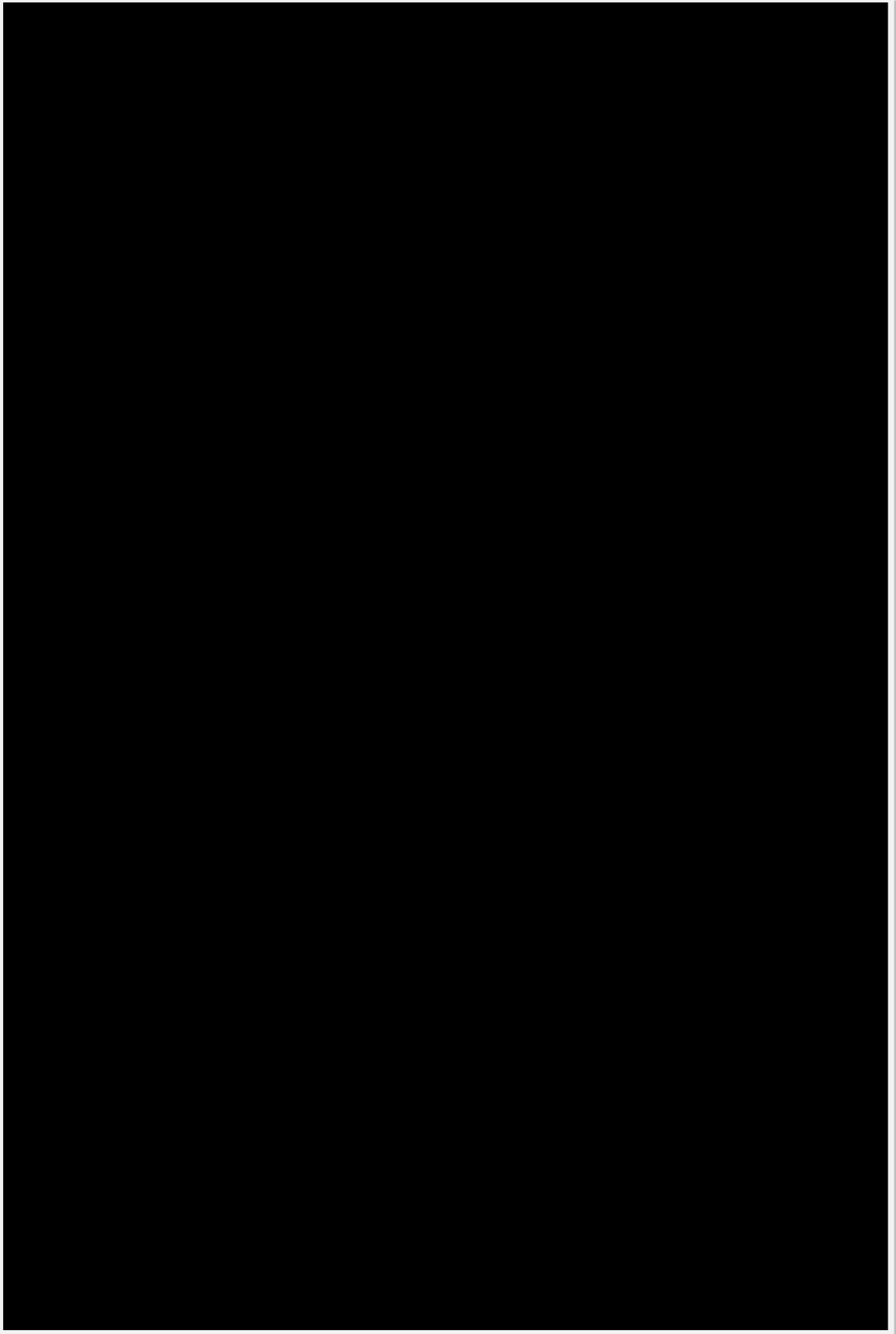
London EC1V 0HB

Programme Director – Dr Angeliki Bogosian

Email:

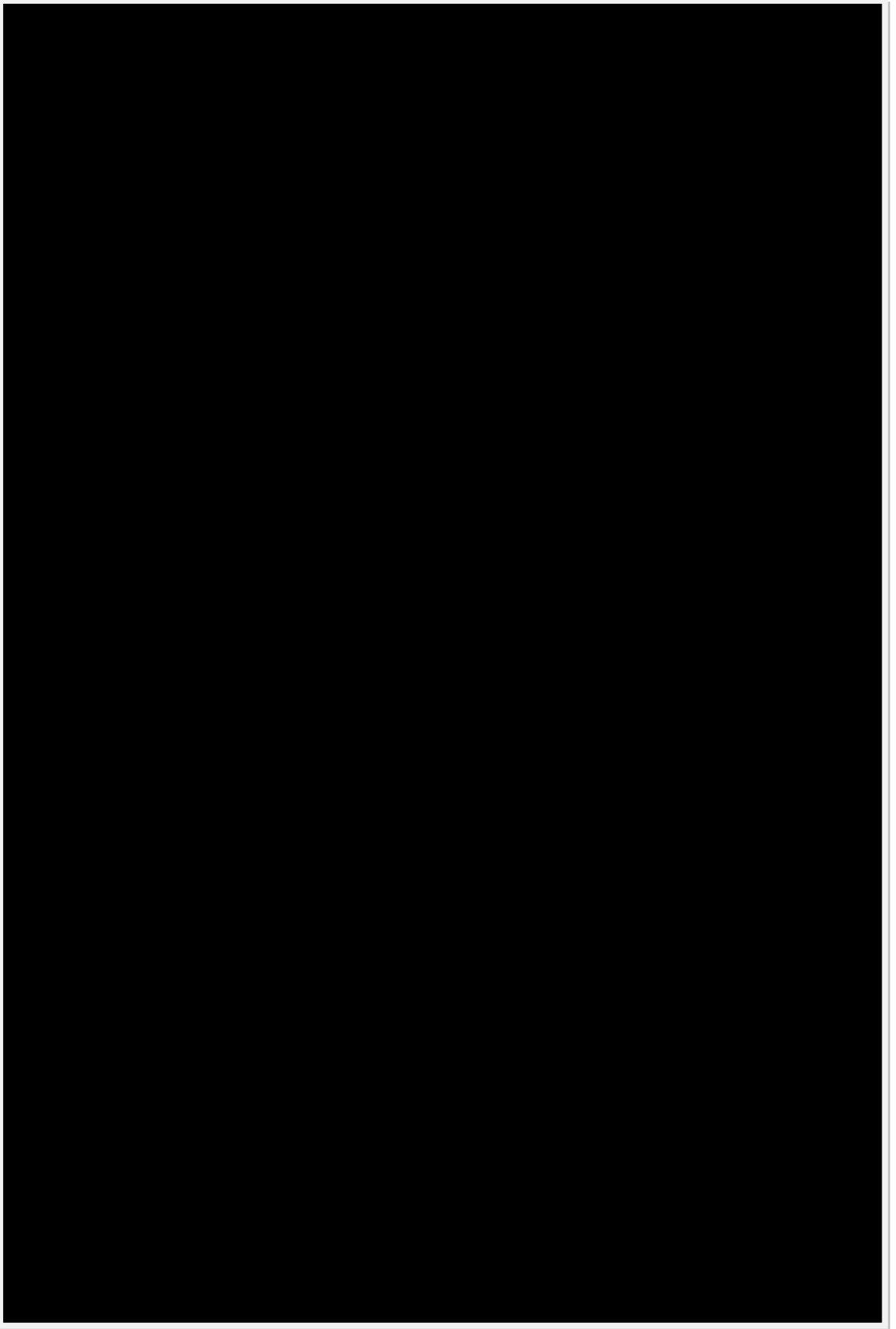
Tel:

## APPENDIX IV





## APPENDIX V





## APPENDIX VI

### Workplace evaluation reports

#### Professional Doctorate in Health Psychology

#### Workplace Evaluation Report

##### Section 1 - To be completed by the Trainee:

|                                        |                                                                                  |
|----------------------------------------|----------------------------------------------------------------------------------|
| Trainee's name                         | KATIE WATTS                                                                      |
| Name of workplace contact              | T. Chalder                                                                       |
| Nature of work and competence assessed | TEACHING AND TRAINING:<br>THE PATIENT WITH<br>MEDICALLY UNEXPLAINED<br>SYMPTOMS. |

##### Section 2 – to be completed by the Workplace Supervisor:

Views on the Trainee's Performance on above piece of work. Please also comment on any reason for delays in the completion of this piece of work and report any periods of prolonged absence.

Katie trained nurses from St George's Hospital on the basis of medically unexplained symptoms including prevalence, the effect on patients and the NHS. She also included videos, exercises and discussion to facilitate learning. Participants gave positive feedback and a knowledge evaluation showed an improvement in knowledge after the training.

##### **Declaration**

I verify that the above named Trainee has undertaken the above mentioned piece of work. I am of the opinion that it has been completed to a satisfactory professional standard.

Signature: [Redacted]

Date: 21/8/16



School of Health Sciences

City University  
Northampton Square  
London EC1V 0HB

Programme Director – Dr Angeliki Bogosian

Email: [Redacted]

Tel: [Redacted]

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Professional Doctorate in Health Psychology

Workplace Evaluation Report

**Section 1 - To be completed by the Trainee:**

|                                        |                        |
|----------------------------------------|------------------------|
| Trainee's name                         | Katie Watts            |
| Name of workplace contact              | Dr Caroline Stokes     |
| Nature of work and competence assessed | TEACHING AND TRAINING. |

**Section 2 – to be completed by the Workplace Supervisor:**

Views on the Trainee's Performance on above piece of work. Please also comment on any reason for delays in the completion of this piece of work and report any periods of prolonged absence.

Katie has completed a wide range of teaching and training sessions. Her presentations have been carefully prepared and delivered at a high standard, appropriate to her audience.

**Declaration**

I verify that the above named Trainee has undertaken the above mentioned piece of work. I am of the opinion that it has been completed to a satisfactory professional standard.

Signature:

[Redacted Signature]

Date:

22/2/2017



**School of Health Sciences**

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Programme Director – Dr Angeliki Bogosian

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## **3D: TEACHING AND TRAINING (TRAINING)**

### **Qualitative Research Methods**

**Word count: 1093**



### **3D: DPsych: Teaching and Training**

#### **3D.1: Training: Qualitative research methods**

In order to complete the Training element of the Teaching and Training competency, I designed and delivered a training programme on “*Qualitative Research Methods*”. This course aimed to effectively cover relevant data collection methods, data sampling methods and data analysis techniques.

#### **3D.2: The reflective framework: Gibbs’ Reflective Cycle (1988)**

In order to reflect on my experience, I referred to the Gibbs’ (1998) reflective cycle, which considers a description of the event, feelings, evaluations, analysis, general and specific conclusions and action plans (Gibbs, 1998).

#### **3D.3: Planning and designing training programmes that enable students to learn about psychological knowledge, skills and practices**

The decision to deliver this course followed a discussion with healthcare professionals and academics, where I was informed that many within these professions had limited understanding of qualitative research. Although qualitative research is frequently used within physical and mental health (Crowe, Inder & Porter, 2015), previous uncertainty of how to assess its relevance and validity (Mays & Pope, 2000), and recent under-representation within top research journals (Gagliardi & Dobrow, 2011), may explain poor awareness. Further needs assessment was conducted at the beginning of the course, as the audience were asked to disclose their experience. The vast majority had not conducted qualitative research in a long time or had very limited knowledge.

### **3D.4: Delivering the training programme**

Training was held within South London and Maudsley (SLaM) Hospital. Due to limited availability, the training was conducted over three one-hour sessions on 24<sup>th</sup> May, 21<sup>st</sup> June and 19<sup>th</sup> July 2016. Due to limited knowledge of qualitative research, I covered basic and more advanced information using PowerPoint slides, general discussion, activities and media. The relevant information was sought from books, journals and websites. The first session provided an overview and aimed to show the versatility of data collection methods and their pros and cons. Although largely introductory, some discussion was encouraged, as were questions. An evaluation form was administered to obtain initial feedback on content and delivery. Feedback was reviewed and the next session adapted accordingly.

The second training session covered data sampling and how qualitative research has been used in healthcare. This was supported by the inclusion of a ten minute video of an example of 'Participatory Action Research'. This added variety to the presentation, and videos in general have been shown to enhance learning (Willmot, Bramhall & Radley, 2012). A second evaluation form was administered at the end, and reviewed to analyse whether adaptations had been effective, and to see what else could be improved.

The final session included an introduction of the main qualitative analysis techniques: Grounded Theory, Thematic Analysis and Interpretative Phenomenological Analysis (IPA). It covered their pros and cons, with step-by-step processes demonstrating of how to do it (Braun and Clarke; 2006; Charmaz, 2006; Willig and Stainton-Rogers, 2008). Following the introduction of each technique, I invited the group to analyse passages of text (see Appendices II to IV) individually or in pairs, and then for themes to be discussed collectively. However, following the first exercise, in order to keep within time, it was agreed further exercises should be

completed later. An introduction to Framework Analysis followed (Gale, Heath, Cameron, Rashid & Redwood, 2013), which has been demonstrated to work in conjunction with other techniques, enabling effective analysis of sub-groups within data (Tonkin-Crine, Yardley, Coenen, Fernandez-Vandellous, Krawczyk et al., 2011). The session finished with an introduction to the role of technology within qualitative research, for which I selected a short promotional video for NVivo (QSR International, 2012). However, as the sound could not be adjusted to a moderate level, it was agreed that it could be watched later on. To conclude, there were opportunities for questions and general discussion.

I was keen to make a good impression. As well as researching and preparing materials at least one week in advance, I repeatedly read through my slides, and opted for smart-casual dress to ensure I was comfortable and presentable. I also arrived early in order to be prepared. Being organised in this way helped me to relax, and subsequently enjoy the sessions more. The knock-on effect of this was greater spontaneity, disclosing my own experiences of qualitative data collection. I also ensured that training sessions finished on time.

### **3D.5: Planning and implementing assessment procedures, and evaluating the training course**

Although confident in my knowledge of qualitative research, I was anxious as I was aware that expectations were high. Evaluation forms, designed in advance to capture rich qualitative feedback, were distributed at the end of each session which helped as it enabled me to take forward positive and negative feedback. After the first session, I noted that further audience participation would have been preferred by some, as would less wordy slides and the inclusion of media (such as videos). In response, I included one on Participatory Action Research which appeared to be of particular interest, and a short promotional video on NVivo. I also

strived to include less text, built in further points for discussion where possible, and included more frequent activities, particularly within the final session.

Overall feedback at the end of the training course was also obtained (please see Appendix V for overall feedback, and Appendix VI for an Observers report from Dr Caroline Stokes). Overall feedback was very positive, with 77.7% of attendees stating that their objectives had been either completely or mostly met. The training generally was considered “*organised*” and “*clear*”. In addition, both written and verbal feedback showed that the included exercises and videos really brought the course to life. Perhaps the biggest compliment for me personally was that I was described as an “*informative and engaging*” speaker, which I found encouraging. Constructive criticism was limited, but included that more exercises would have been preferred, and that the course should have been held over half a day. However, this was unavoidable due to the limited time available and difficulties with scheduling.

I feel that I have gained tremendously from the experience of running this course, as it was my first opportunity to train healthcare professionals. Nevertheless, I would have preferred to run all three sessions together, as there were fewer attendees for the second session. Other considerations to take forward are that technology should always be tested beforehand. I felt embarrassed when the sound for the NVivo video failed, and sensed disappointment from the group. I also feel going forward that I should be more mindful not to be overly ambitious with the level of content. Overall however this was a positive experience that has boosted my self-regulatory efficacy for training professionals in future (Bandura, 1989).

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# **APPENDICES**

## APPENDIX I

### Supervision Plan: Training

| Teaching and training      | Area of work (*outside of normal work)                                                                                                                                                                                                                                                         | Supporting evidence                                                                                          | Changes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|----------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Case study 1<br>(Training) | <p>Setting: King's College London</p> <p>Description: IMPARTS training on Medically Unexplained Symptoms, for nurse practitioners from St. George's Hospital</p> <p>This workshop will cover what medically unexplained symptoms are, mechanisms, mediators/ moderators and interventions.</p> | <p>Case study report (1000 words).</p> <p>Observers report (500 words).</p> <p>Workplace contact report.</p> | <p><i>Changed to:</i></p> <p>Setting: South London and Maudsley Hospital.</p> <p>Description: 3-part qualitative research training for Cognitive Behaviour Therapists, Clinical Psychologists, and academic researchers with limited knowledge of qualitative research</p> <p>Part 1: Introduction to qualitative research and coverage of qualitative methodologies.</p> <p>Part 2: Data sampling, and how qualitative research has been used within the area of health</p> <p>Part 3: Qualitative analysis techniques, including how software can help with analysis (NVivo)</p> <p>The training session will involve discussions, training exercises, and videos</p> |



## APPENDIX II

### Grounded Theory Exercise

*“... Emotionally, yeah I get fed up, I find that I get irritable, and I will rise to anger quickly, so I need to keep that in check. I never used to do that. I’m not saying anything drastic, but I did have a big argument with my sister last year, erm, I hit her. I actually whacked her one, but she did say she was provoking me afterwards. I just completely lost it and it was over something really stupid. It was my younger sister I’m really close to, well we spend a lot of time together, and erm, and I just said to her “Can you just shut up now, enough is enough”, and she said “well, why are you saying [inaudible]”, and I just... Oh I felt awful, I felt awful. The minute I did it, I wanted to take it back, like anybody would. So she went home the next day, it was the weekend so she was staying with me, and I just said “I’m sorry” and she said “no, just leave it”, so we didn’t speak for a couple of weeks, but then we did, and now we’re fine, but she understood where it was and she could, because everybody notices that I’m irritable...”*

## APPENDIX III

### Thematic Analysis Exercise

A participant talking about their PPS:

*"... It was happening every so often for a couple of years and I made a note of it, was this bang in my head. I've explained to the neurologist, it was... I could be doing nothing or I could be at work, and I'd get this, it was like, erm, oh I can't explain it, it was almost like someone had banged something really loudly, and you jump, but that's what it felt like and sounded like in my head, and it, it literally made me like, in fact, they had to take me down to A&E while I was at work because it happened, where I went completely, I was just on the verge of, of erm fainting. One of the women in the office she came running over and I went "Oh!" and she said "what's wrong?" and I said "I don't know I feel terrible", BP had shot up and stuff, erm, and it was happening every so often, it would wake me in the nights..."*

## APPENDIX IV

# Interpretative Phenomenological Analysis (IPA) Exercise

A participant talking about their PPS:

*“... When it first happened I thought is this ever going to go away? Is it ever gonna go away, and I’d feel erm, quite, I can rationalise things. I’m quite good at that. Erm, but there was a period in, it was 2012, funnily enough it was in March again, and I went into a very deep depression, and it just came over me. People talk about a black cloud weighing down on them and it was just like that, and I felt terrible, absolutely awful. I wouldn’t speak to anybody, I was avoiding people, I was even avoiding my daughter, saying ‘I’m fine, don’t come up’ but I was suicidal, but it, I didn’t attribute it to the symptoms. It just came out of nowhere...”*

## APPENDIX V

### Evaluation form: Training (overall feedback)

| Evaluation question                                                                       | Comment                                                                                                                                                              | N (%)            |
|-------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------|
| What was the main learning you were hoping to gain from this qualitative training course? | To learn how to do qualitative research                                                                                                                              | 3 (33.3%)        |
|                                                                                           | Open minded                                                                                                                                                          | 2 (22.2%)        |
|                                                                                           | "Overview of qualitative methods"                                                                                                                                    | 2 (22.2%)        |
|                                                                                           | Learn about methodologies                                                                                                                                            | 1 (11.1%)        |
|                                                                                           | Wanted a refresher course on qualitative methods                                                                                                                     | 1 (11.1%)        |
| To what extent do you feel that your learning needs have been met/ not met?               | Completely met                                                                                                                                                       | 6 (66.6%)        |
|                                                                                           | Mostly met                                                                                                                                                           | 1 (11.1%)        |
|                                                                                           | Methods were covered in a simple way                                                                                                                                 | 1 (11.1%)        |
|                                                                                           | (Blank)                                                                                                                                                              | 1 (11.1%)        |
| Was there anything you particularly liked about the course overall? If so, what?          | Presentation style                                                                                                                                                   | <b>3 (33%)</b>   |
|                                                                                           | <ul style="list-style-type: none"> <li>▪ Good presentation style, very clear"</li> </ul>                                                                             | 1 (11.1%)        |
|                                                                                           | <ul style="list-style-type: none"> <li>▪ "Excellent presentation"</li> </ul>                                                                                         | 1 (11.1%)        |
|                                                                                           | <ul style="list-style-type: none"> <li>▪ "Informative and engaging speaker"</li> </ul>                                                                               | 1 (11.1%)        |
|                                                                                           | Overall structure                                                                                                                                                    | <b>3 (33.3%)</b> |
|                                                                                           | <ul style="list-style-type: none"> <li>▪ "As it was divided into 3 sections, it was manageable to understand"</li> </ul>                                             | 1 (11.1%)        |
|                                                                                           | <ul style="list-style-type: none"> <li>▪ Well organised slides</li> </ul>                                                                                            | 1 (11.1%)        |
|                                                                                           | Videos and exercises                                                                                                                                                 | <b>2 (22.2%)</b> |
|                                                                                           | <ul style="list-style-type: none"> <li>▪ "The video in the first session, second session about the school" (<i>Participatory Action Research example</i>)</li> </ul> | 1 (11.1%)        |

|                                                                                              |                                                                                                                |                  |
|----------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------|------------------|
|                                                                                              |                                                                                                                |                  |
|                                                                                              | Good introduction                                                                                              | 1 (11.1%)        |
|                                                                                              | "Very clear layout of information, scope for group discussion, video clips and exercises to illustrate points" | 1 (11.1%)        |
| Was there anything that you did not particularly like about the course overall? If so, what? | Not applicable                                                                                                 | <b>5 (55.5%)</b> |
|                                                                                              | <ul style="list-style-type: none"> <li>▪ N/A we just ran out of time</li> </ul>                                | 1 (11.1%)        |
|                                                                                              | <ul style="list-style-type: none"> <li>▪ Nothing, it was excellent</li> </ul>                                  | 1 (11.1%)        |
|                                                                                              | Would have liked more examples                                                                                 | 1 (11.1%)        |
|                                                                                              | Run as half a day rather than broken up                                                                        | 1 (11.1%)        |
|                                                                                              | (Blank)                                                                                                        | 3 (33.3%)        |
| Is there any way that you feel the course could be improved?                                 | N/A                                                                                                            | 4 (44.4%)        |
|                                                                                              | Inclusion of an example study                                                                                  | 1 (11.1%)        |
|                                                                                              | (Blank)                                                                                                        | 4 (44.4%)        |
| Any other final comments?                                                                    | "Very good - thanks"                                                                                           | 1 (11.1%)        |
|                                                                                              | "Many thanks!"                                                                                                 | 1 (11.1%)        |
|                                                                                              | Thank you!                                                                                                     | 1 (11.1%)        |
|                                                                                              | No                                                                                                             | 1 (11.1%)        |
|                                                                                              | (Blank)                                                                                                        | 5 (55.5%)        |

## APPENDIX VI

### Professional Doctorate in Health Psychology

#### Workplace Evaluation Report

##### Section 1 - To be completed by the Trainee:

|                                        |                       |
|----------------------------------------|-----------------------|
| Trainee's name                         | Katie Watts           |
| Name of workplace contact              | Dr Caroline Stokes    |
| Nature of work and competence assessed | Teaching and training |

##### Section 2 – to be completed by the Workplace Supervisor:

Views on the Trainee's Performance on above piece of work. Please also comment on any reason for delays in the completion of this piece of work and report any periods of prolonged absence.

Katie designed and delivered a series of three one-hour talks on qualitative methodology. The aim of these sessions was to teach a group of clinicians and researchers about methods of qualitative data collection, data sampling and qualitative data analysis. The audience had limited knowledge and experience in this area.

Katie pitched the level of her training appropriately, taking into account the background and experience of her audience. She started with basic concepts and developed these into more advanced information. Her first lecture gave an overview of different methods of data collection and clearly outlined the pros and cons of each. She allowed time for discussion and questions which engaged her audience and allowed them to develop a deeper level of understanding of the topic. Katie's second session focused on data sampling and demonstrated its utility in health research. She showed a short video which the audience found helpful in illustrating how qualitative data sampling can be applied health research settings.

The third lecture focused on qualitative analysis techniques and again clearly outlined each method presented and their relative strengths and weaknesses. She asked the audience to try out each technique on a piece of text which enhanced engagement and allowed for experiential learning to enhance understanding.

Following each session, Katie gave out evaluation forms to be completely anonymously by every member of the audience. She took on board the feedback each week in order to adapt her next lecture.

Katie had obviously put a lot of thought into preparing her lectures and they were well structured and easy to follow for an audience with limited experience in this area. Concepts were well explained but pitched at a level that did not patronise a group of highly educated health professionals and researchers used to attending academic meetings. Each lecture was engaging and made use of research

examples, short videos and interactive exercises to illustrate her points and ensure the learning objectives were met. Her slides were clear but she was able to make use of constructive feedback that early slides were quite dense, and reduce the amount of information on each slide for later lectures.

Katie was flexible with the running order of her lectures, allowing time for discussion and questions where appropriate, but was able to bring her audience back to the lecture and move on in order to get through the material in the time allowed. She had planned to include a few more exercises and show an extra video, but agreed with the audience to omit these owing to time constraints and to enable her to focus on the important points in her lecture.

The audience enjoyed these training sessions and gave positive verbal feedback.

#### Declaration

I verify that the above named Trainee has undertaken the above mentioned piece of work. I am of the opinion that it has been completed to a satisfactory professional standard.

Signature:



Date:

24.01.17

# **SECTION 4:**

## **GENERIC PROFESSIONAL COMPETENCE**

**Word count: 2841**



## **4: Generic Professional Competence:**

### **Research Worker on a Cognitive Behaviour Therapy Trial**

#### **4.1: Placement and reflections on the role**

Since I enrolled on the DPsych Health Psychology programme in September 2015, I have used the remainder of my three-year fixed-term contract at King's College London within the department of Psychological Medicine as my full-time placement. At King's College London, I have been employed as a Research Worker on an RCT, testing the effectiveness of CBT with SMC versus SMC only, amongst patients living with PPS (please see Appendix II and III for workplace contract and work attendance record). In the early stages of my placement, I familiarised myself with the academic literature, educating myself in terms of what PPS is, prior to helping with the development of the PRINCE research protocol, questionnaire design and other written materials. Although not originally within the job description, I also adopted the majority of the administrative duties, including recruitment for the Data Monitoring and Ethics Committee (DMEC) and the Programme Steering Committee (PSC), setting up meetings with the Programme Management Group (PMG), and taking minutes within meetings before distributing them to the team.

Once the recruitment for the RCT had started, my day-to-day role drastically changed, as it started to involve lots of travelling to participating hospitals, which at first included all hospitals within the King's College Hospital NHS Trust, and Guy's and St. Thomas' NHS Trust. Following introductory presentations of the trial and personal introductions to clinical staff, my main responsibility was to discuss the trial with any patients referred following their consultations. If the clinician thought they may be suitable for the trial, I screened them and provided prospective participants with whatever information they required. If I was in attendance at the hospital clinic, patients were referred to me in person. If I was not able to be present, clinicians

were instructed to forward contact details either through the provision of clinic letters or patient details via email. In order to maximise recruitment of suitable patients, it was fundamental for me to maintain a good relationship with all clinicians and regularly remind them to refer. While this was challenging due the number of active clinics across departments and hospitals, I feel that I did manage to achieve this.

Over the two years that I have been enrolled on the DPsych and almost three years working at Kings College London, I have developed on both a professional and personal level (please see Appendix IV for the Continuous Professional Development log). Prior to this role, apart from my one year working as an voluntary Assistant Psychologist within Child and Adolescent Mental Health Services, I had very little experience of working directly with patients, and no experience at all of working with adults with complex psychological and physical health problems. What I feel this position has given me first and foremost is an in-depth understanding of the nature of PPS and the impact that these symptoms have upon not only the patients, but also upon the NHS. I feel that this has given me a unique opportunity to perceive PPS from both an academic standpoint, and from the patients' perspective, which has enabled me to develop a rounded, sensitive and empathetic approach. Having so much direct involvement with patients within my role has also helped me to become more acutely aware of the importance of the legal, professional and ethical guidelines as outlined by the BPS Code of Conduct (BPS, 2009). Due to having regular access to confidential data throughout my role, and while completing my thesis, it was important for me to demonstrate awareness of the Data Protection Act (1998) (Legislation.GOV.UK, 2005). In regards to ethical principles, I have also ensured to demonstrate each of the following towards healthcare professionals, researchers and patients alike: respect, responsibility, integrity and competence, both within my day-to-day role and throughout my completion of the DPsych.

I also feel that my current role has enabled me to develop as a researcher. Prior to this position my practical research experience was predominantly qualitative. Whilst the opportunity arose to utilise my qualitative experience for my thesis, the experience of working on an RCT was completely new and an important learning curve, considering that RCTs are such a widely used and respected research design (Akobeng, 2005; Sorensen, Lash & Rothman, 2006). I also became extremely aware of the practical day-to-day challenges of running trials and the relentless effort required in order to ensure that the study is a success. What I learned in particular, is how challenging it can be recruiting for trials and maintaining patient engagement over the duration of their involvement, particularly as in the case of this trial participants were enrolled for a full year. This meant that flexibility was necessary to ensure that the required recruitment numbers were achieved. I also learned of the importance of strategic planning at the start of the trial, and the importance of a dedicated and organised Trial Manager being able to foresee practical challenges before they occur and knowing how to address them.

Although my day-to-day role was somewhat limited and occasionally repetitive, it did open the door to new opportunities which I was able to capitalise on and use as evidence for professional development. For example, I requested the opportunity to help with the development and delivery of presentations to various hospital departments within King's College Hospital and Guy's and St. Thomas' Hospital (King's Health Partners), introducing the RCT prior to recruitment. This generally involved presenting to nurses, SpRs and Consultants, which greatly benefited me in the early stages of my role as Research Worker. As well as this, my thesis project itself was thirty qualitative interviews conducted with PPS patients already taking part in the RCT, which meant that I had a pool of PPS patients who had already given permission to be contacted. In addition, if I had any general questions relating to my research or thesis writing, or even management of stress, I

was already working in an environment where advice and support was readily available. This I found was also true when designing and conducting my systematic review.

#### **4.2: Further opportunities taken**

There was frequently the opportunity to become involved in various teaching roles, which I often volunteered for. For example, on Tuesday mornings within the South London and Maudsley hospital, weekly 9-10am slots are available for delivering ad hoc presentations, teaching and training to all staff including Cognitive Behaviour Therapists, Clinical Psychologists, Psychiatrists and academic researchers. I therefore took the opportunity to deliver a three-part qualitative research training workshop, following confirmation that many regular attendees have limited knowledge of conducting qualitative research within healthcare. Not only did this opportunity enhance my confidence as a researcher with something new to offer the team, I was able to use this experience for the DPsych programme, especially the Training element. Another opportunity that arose, was to become involved in delivering the IMPARTS training programme for nurse practitioners from St George's Hospital. For this, I produced my own slides and used them to present what is meant by PPS, where PPS patients are likely to be seen and how to recognise them, the impact that PPS has on both patients and healthcare professionals, and the financial implications of PPS. Once again, this was a fantastic opportunity for me to work with another group of healthcare professionals, and at the same time use this experience to fulfil part of the Teaching and Training competency for the DPsych.

Although not a teaching role per se, once I had finished the analysis of my thesis interviews, I took opportunities to further improve my presentation skills, while also acting to disseminate and obtain early feedback on my work. On 1<sup>st</sup> June 2017,

I presented my thesis research at a Peer-Led Development (PLD) Research Seminar session, held by the School of Health Sciences (SHS) at City, University of London. Due to my workload around that time, and because I had only just finished analysing my data, I had had little opportunity to draw upon my discussion points and recommendations. Nevertheless, I was pleased that I had managed to deliver my presentation within the allocated time frame, and that questions following the presentation were more curious than critical. This made me feel more confident as I had already submitted a poster presentation based on the same project, which was due to be presented at the Doctoral Research Conference within the SHS only a week later.

On the day of the poster presentation, 8<sup>th</sup> June 2017, my poster was criticised due to the overuse of colour and text. Although I was disappointed, I recognised that it was a valuable take home message when designing future poster presentations. In addition, I was pleased that I achieved top marks for my ability to answer research-based queries. What was even more memorable for me during this conference was that I also got to speak with several individuals living with PPS themselves. They seemed particularly engaged with the study, which validated my own beliefs that this research could really help the PPS population. On 22<sup>nd</sup> June 2017 I once again presented my research findings, this time at a PPS stakeholder event held within the South London and Maudsley NHS Trust. Present in the audience were clinical leads from London-based hospitals, CCG representatives, consultants, GPs, psychologists, charity representatives and service users. As well as it being a good opportunity for me to raise my personal profile, it was great to be able to disseminate my research and findings to an influential audience where the findings were of particular interest. Overall feedback following the meeting from attendees, as well as from my workplace supervisor and the organisers of the event, was very encouraging. In particular, the organiser, a Consultant Liaison Psychiatrist

known to me for the past two years, commented that he felt I had greatly improved as a researcher and presenter, which was lovely to hear. His comments also led me to reflect myself on what I have achieved in terms of research and presentations over the past two years, and how inexperienced I was in comparison when I embarked on the DPsych programme back in September 2015.

Regarding conferences, in September 2017 I attended the BPS DHP annual conference to present another research study entitled *“I have genital herpes, now what?” Navigating the road back to psychosocial recovery*. While not directly related to my placement or thesis, it is still a piece of work that I believe holds great relevance, particularly for healthcare professionals, and the findings should be disseminated to those working within Public Health. At the time of doing the interviews, I was moved by some of the open testimonies of those who volunteered to take part and I hope that I accurately and articulately portrayed their perspectives when I presented the study in September. In December 2017, I was further able to present my thesis research as part of the ‘Managing PPS in diverse populations’ symposium, at the UK Society of Behavioural Medicine (UKSBM) conference in Liverpool.

#### **4.3: Further experiences and reflections**

Generally working and studying for the DPsych full-time has worked for me, although not without grit and determination. What I learned at any early stage was that the path would not always run smoothly as a Research Worker and a DPsych student. For example, at times it was difficult for me to meet the expectations and agendas of the DPsych and my role as a Research Worker, although this admittedly became much easier to manage over time. It is perhaps for this reason that opportunities to fulfil the requirements of the DPsych did not often arise during my placement, in stark contrast to my initial expectations that opportunities would

naturally present themselves. An example of where I struggled was when I was seeking out a consultancy project back in June 2016. I had initially sent an email to the research team and trial investigators, asking whether they could provide me with contacts within separate organisations. Although initially provided with a lead, I never received a response when I contacted them, leaving me frustrated and despondent. During my second attempt, I spoke with a Professor based at another University who believed I could be of help. However, a short discussion with them led to the conclusion that I did not have the required credentials or experience, which temporarily affected my feelings of self-efficacy (Bandura, 1977). I realised at this point that if I wanted to be able to deliver on all competencies, I would have to think more proactively and outside of the box. It was only after placing an advertisement on social media that I was provided with another name. Following some tentative emails and Skype discussions regarding the requirements and the written contract, this individual became my client for my consultancy project.

Another issue occurred when designing my BCI. Being involved in a CBT trial, I had mistakenly thought that I could exercise CBT techniques with fibromyalgia patients face-to-face. However, as I am not a qualified CBT therapist, I was blocked from conducting any face-to-face CBT work with patients, which in all honesty I considered fair. There was also the issue of my project impeding recruitment for the trial. My eventual solution was to create a CBT leaflet and recruit participants from support groups, following approval from my workplace supervisor, the Director of Fibromyalgia Awareness UK, and the King's College London Ethics Committee. I was unable to complete this competency during working hours due to its incompatibility with my role, and so this research was conducted in my own time.

A further issue that I encountered throughout the duration of the DPsych is that I wanted to attend as many conferences as possible, such as the combined European Health Psychology Society (EHPS) and DHP conference in August 2016,

and the 1<sup>st</sup> Applied Health Practitioner Conference on 30<sup>th</sup> March 2017. This was at my own expense and so I had no choice but to limit the number of conferences that I attended over the two years that I was enrolled on the DPsych. Conferences, as well as seminars and workshops, are expensive and although students would obviously benefit from attending more regularly, I cannot help but feel that attendance is largely restricted by cost. Bursaries are often available, and I was fortunate enough to win one of these in order to allow me to attend the BPS DHP annual conference in 2017, for which I was very grateful. Nevertheless, bursaries are competitive and students often miss out. Having made this point, City, University of London and King's College London often hold events open to students and staff alike. A recent example of this was the Doctoral Research Conference held at City, University of London in June 2017. These types of events give students the opportunity to present their work and answer questions, as well as review other research which is fundamental for students and their development.

#### **4.4: Final thoughts and future plans**

My experiences over the last two years have also given me valuable insight as to how I would like my career to progress. As I approached the end of the DPsych, I became concerned about the future of NHS and how that will impact upon the recognition of Health Psychology, which is already grossly underfunded. However, ideally I would initially like to train as a Cognitive Behaviour Therapist, gain further experience of other psychological therapies, and complete training to become a qualified smoking cessation trainer. These active practitioner roles would enable me to continue with the patient contact that I currently enjoy the most in my Research Worker post. Following this, I would like to one day be able to combine these skills with my Health Psychologist training in order to eventually focus on the management of long-term conditions, including fibromyalgia which I have become



particularly familiar with over the last two years. Although not an immediate priority, one day I welcome the opportunity to train as a lecturer and become more involved in future research projects, which would help me to become a rounded and versatile Health Psychologist.

To summarise, as opportunities to fulfil the requirements of my DPsych were not immediately made available to me over the past two years, I feel I have learned a valuable lesson from that. To put it simply, I have come to realise that we are ultimately responsible for our own professional development, for creating our own contacts within the Health Psychology industry and maintaining those professional relationships, and for disseminating our own research. Since the start of the DPsych I have tried to take advantage of and create as many new opportunities for myself as possible in order to demonstrate my own personal drive and employability, and deliver a good body of work for the DPsych. I am both proud and glad that I have taken such a proactive approach and have gained as much experience as I could over the last two years, as I believe that this has prepared me psychologically for what may be a turbulent career as a Health Psychologist, particularly if working within the NHS.

## REFERENCES

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## **APPENDICES**

## APPENDIX I

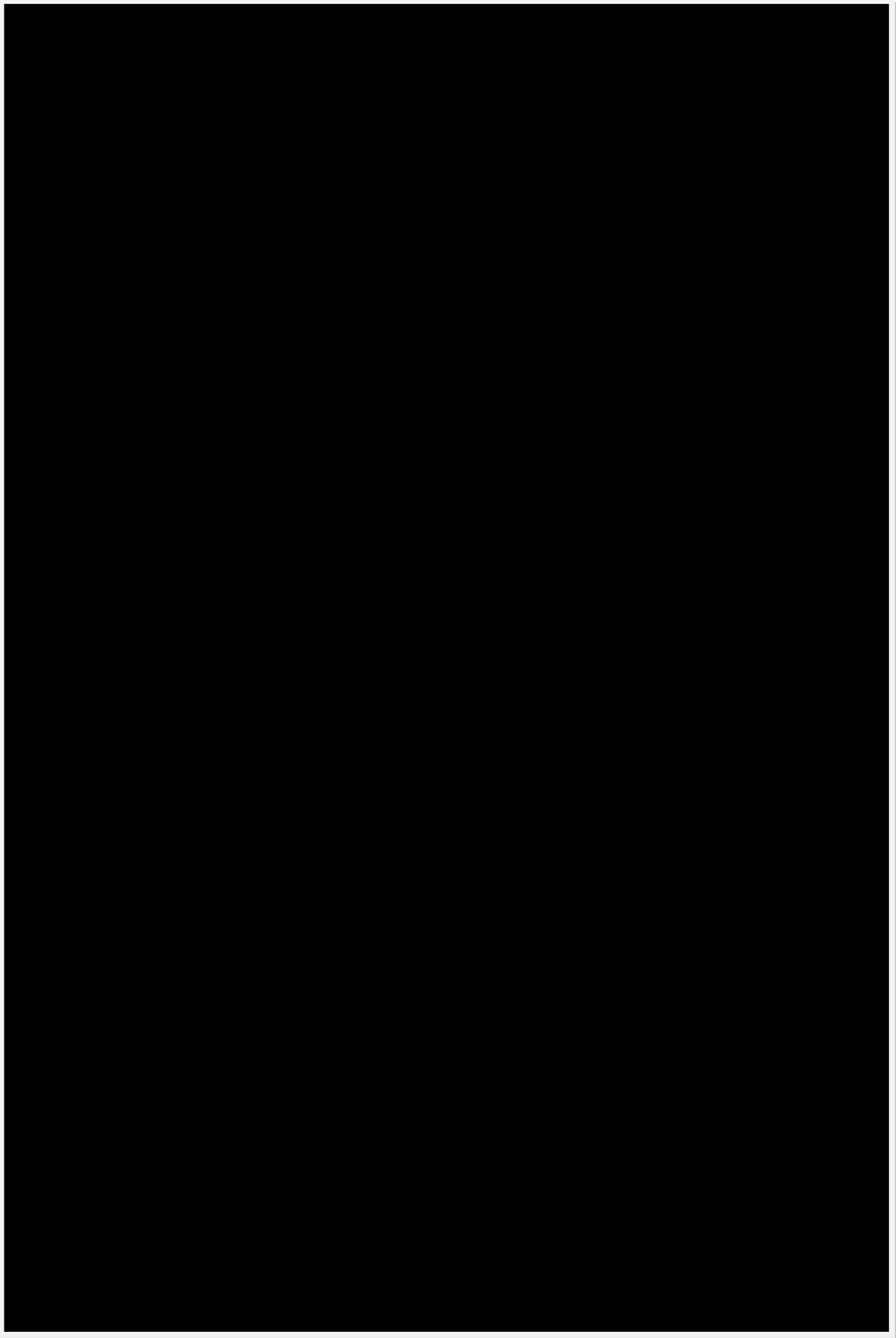
### Supervision Plan: Generic Professional Competence

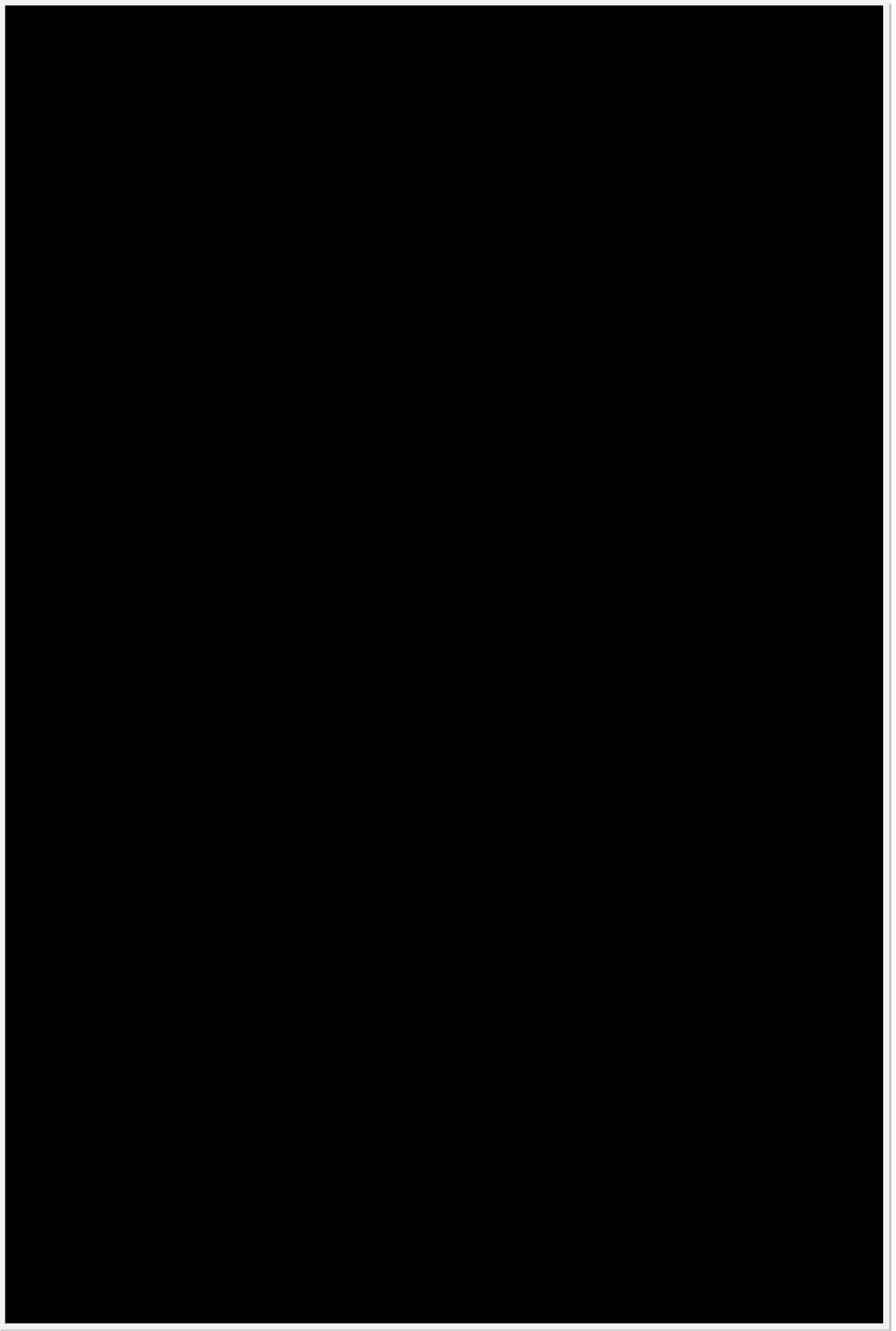
| Generic professional competency                                                                     | Area of work (*outside of normal work)                                                                                                                                                                                                                                                                                                                                                                                                                                        | Supporting evidence                                                                                                                                                                                                                                                                                                                             | Changes |
|-----------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------|
| Supervised practice                                                                                 | All                                                                                                                                                                                                                                                                                                                                                                                                                                                                           | Practice log entries<br><br>Workplace contracts (signed)<br><br>Contract of Employment (signed)<br><br>Health and Safety procedures (signed)                                                                                                                                                                                                    | N/A     |
| Establishing the generic professional competence required to become a chartered Health Psychologist | Setting: King's College London<br><br>Description:<br><br>Working as a Research Worker/Assistant on a Cognitive Behaviour Therapy trial for patients with medically unexplained symptoms. Main responsibilities include recruiting patients in to the trial, completing questionnaires with and regularly following up with participants, working closely with healthcare professionals. However, the role is very flexible, with opportunities for professional development. | Supplementary study report (3000 words) providing information on how this placement has facilitated the professional development and competence required to be a chartered Health Psychologist<br><br>Continuous Professional Development Log<br><br>Certificates of attended workshops<br><br>Workplace supervisor's contact evaluation report | N/A     |

Supervisee:     Katie Watts    

Supervisor:     Dr. Tiece Turnbull

## APPENDIX II







## APPENDIX III

### Work Attendance record

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## APPENDIX IV

### Professional Doctorate In Health Psychology Training Programme

#### Continuous Professional Development (CPD) Log

| <b>Trainee's Name: Katie Watts</b>          |                                                                                                                                            |                           |                                                    |
|---------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------|---------------------------|----------------------------------------------------|
| <b>Supervisor's Name: Dr Tiece Turnbull</b> |                                                                                                                                            |                           |                                                    |
| <b>Date</b>                                 | <b>Activity Name</b>                                                                                                                       | <b>Length of activity</b> | <b>Type of activity</b>                            |
| 12/10/2015                                  | Professional Skills – Ethics workshop                                                                                                      | 1 day                     | Workshop                                           |
| 02/11/2015                                  | Consultancy workshop                                                                                                                       | 1 day                     | Workshop                                           |
| 18/11/2015                                  | Initial meeting with student with plan to co-supervise on an LGBT study relating to Persistent Physical Symptoms (PPS)                     | 1 hour                    | Supervision meeting with student and co-supervisor |
| 26/11/2015                                  | Meeting with supervised student to discuss written documents for LGBT study for PPS                                                        | 1.5 hours                 | Supervision meeting with student                   |
| 07/12/2015                                  | Quantitative Research Methods workshop                                                                                                     | 1 day                     | Workshop                                           |
| 28/12/2015                                  | Completion of Online Academies Cognitive Behaviour Therapy Diploma (with Distinction)                                                      | Approx. 6 months          | Course                                             |
| 22/01/2016                                  | Presentation on Persistent Physical Symptoms and a Cognitive Behaviour Therapy trial to Respiratory consultants at King's College Hospital | 25 minutes                | Presentation                                       |
| 01/02/2016                                  | Qualitative Research Methods workshop                                                                                                      | 1 day                     | Workshop                                           |
| 12/02/2016                                  | MSc Health Psychology lecture to City University students on Individual-level Behaviour Change Interventions                               | 2 hours                   | Lecture                                            |
| 07/03/2016                                  | Systematic Review workshop                                                                                                                 | 1 day                     | Workshop                                           |
| 09/05/2016                                  | CBT skills workshop                                                                                                                        | 1 day                     | Workshop                                           |
| 24/05/2016                                  | Qualitative Research Methods training to healthcare professionals and academic researchers (Part 1)                                        | 1 hour                    | Training                                           |

|                            |                                                                                                                               |                                            |                                          |
|----------------------------|-------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------|------------------------------------------|
| 06/06/2016                 | Teaching and Training workshop                                                                                                | 1 day                                      | Workshop                                 |
| 21/06/2016                 | Qualitative Research Methods training to healthcare professionals and academic researchers (Part 2)                           | 1 hour                                     | Training                                 |
| 29/06/2016                 | Consultancy meeting                                                                                                           | 1 hour                                     | Consultancy meeting                      |
| 15/07/2016                 | Consultancy meeting                                                                                                           | 30 mins                                    | Consultancy meeting                      |
| 19/07/2016                 | Qualitative Research Methods training to healthcare professionals and academic researchers (Part 3)                           | 1 hour                                     | Training                                 |
| 27/07/2016                 | Consultancy meeting                                                                                                           | 1 hour                                     | Consultancy meeting                      |
| 03/08/2016                 | The Patient with Medically Unexplained Symptoms (own teaching session included as part of a workshop co-run with a colleague) | 1.5 hours (teaching) /<br>1 day (workshop) | Teaching delivered/<br>workshop (co-run) |
| 10/08/2016                 | Consultancy meeting                                                                                                           | 1 hour                                     | Consultancy meeting                      |
| 23/08/2016 –<br>27/08/2016 | Attendance at the joint European Health Psychology Society and Division of Health Psychology (DHP) annual conference          | 4 days                                     | Conference                               |
| 30/08/2016                 | Consultancy meeting                                                                                                           | 1 hour                                     | Consultancy meeting                      |
| 15/09/2016                 | Consultancy meeting                                                                                                           | 1 hour                                     | Consultancy meeting                      |
| 30/09/2016                 | Consultancy meeting                                                                                                           | 1 hour                                     | Consultancy meeting                      |
| 02/11/2016                 | Consultancy meeting                                                                                                           | 1 hour                                     | Consultancy meeting                      |
| 11/2016                    | City University student representative training course (online)                                                               | 1.5 hours                                  | Online training course                   |
| 24/11/2016                 | Consultancy meeting                                                                                                           | 1 hour                                     | Consultancy meeting                      |
| 29/11/2016                 | The Patient with Medically Unexplained Symptoms – Workshop co-run with a colleague                                            | 1 day                                      | Workshop (co-run)                        |

|                         |                                                                                                       |           |                                  |
|-------------------------|-------------------------------------------------------------------------------------------------------|-----------|----------------------------------|
| 13/12/2016              | Consultancy meeting                                                                                   | 1 hour    | Consultancy meeting              |
| 28/12/2016              | Consultancy meeting (final wrap-up session)                                                           | 1 hour    | Consultancy meeting              |
| 24/01/2017              | Attendance at Fibromyalgia Awareness UK to promote leaflet (Dulwich branch)                           | 2 hours   | Behaviour Change Intervention    |
| 26/01/2017              | Attendance at Fibromyalgia Awareness UK to promote leaflet (Wickford branch)                          | 2 hours   | Behaviour Change Intervention    |
| 17/02/2017              | Attendance at Fibromyalgia Awareness UK to promote leaflet (Ealing branch)                            | 2.5 hours | Behaviour Change Intervention    |
| 22/02/2017              | Attendance at Fibromyalgia Awareness UK to promote leaflet (Dulwich branch) – Follow-up               | 1 hour    | Behaviour Change Intervention    |
| 23/02/2017              | Attendance at Fibromyalgia Awareness UK to promote leaflet (Wickford branch) – Follow-up              | 2 hours   | Behaviour Change Intervention    |
| 17/03/2017              | Telephone follow-up with BCI participants from the Ealing branch                                      | 30 mins   | Behaviour Change Intervention    |
| 30/03/2017              | Attendance at the 1 <sup>st</sup> Practitioner Applied Health Psychology Conference                   | 1 day     | Conference                       |
| 08/05/2017              | Psychological Interventions workshop                                                                  | 1 day     | Workshop                         |
| 01/06/2017              | City University London - SHS PLD Seminar. Delivered a presentation on thesis                          | 1 hour    | Presentation/ seminar meeting    |
| 08/06/2017              | Attendance and poster presentation of thesis at SHS 5 <sup>th</sup> Doctoral annual conference        | 1 day     | Conference and presentation      |
| 22/06/2017              | Presentation of thesis at a stakeholder meeting hosted by the South London and Maudsley hospital      | 20 mins   | Presentation                     |
| 25/07/2017              | Good Clinical Practice (GCP) training – Refresher                                                     | 3 hours   | Course                           |
| 06/09/2017 – 08/09/2017 | Attendance and oral presentation at the DHP annual conference in Cardiff – Presentation on 07/09/2017 | 3 days    | Conference and oral presentation |

## APPENDIX V

### Workplace evaluation reports

#### Professional Doctorate in Health Psychology

#### Workplace Evaluation Report

##### Section 1 - To be completed by the Trainee:

|                                        |                                 |
|----------------------------------------|---------------------------------|
| Trainee's name                         | KATIE WATTS                     |
| Name of workplace contact              | T. Chalder.                     |
| Nature of work and competence assessed | GENERIC PROFESSIONAL COMPETENCE |

##### Section 2 – to be completed by the Workplace Supervisor:

Views on the Trainee's Performance on above piece of work. Please also comment on any reason for delays in the completion of this piece of work and report any periods of prolonged absence.

Katie has adhered to the ethical, legal and professional standards required as a health psychologist. She has been employed in this capacity for 3 years. She has always carried out all of her responsibilities diligently and responsibly. She has completed all of her competencies in record time as well as working full time.

##### **Declaration**

I verify that the above named Trainee has undertaken the above mentioned piece of work. I am of the opinion that it has been completed to a satisfactory professional standard.

Signature: [Redacted]

Date: 12/9/2017



School of Health Sciences

City University

Northampton Square

London EC1V 0HB

Programme Director – Dr Angeliki Boasjian

Email: [Redacted]

Tel: [Redacted]

Professional Doctorate in Health Psychology

Workplace Evaluation Report

**Section 1 - To be completed by the Trainee:**

|                                        |                                 |
|----------------------------------------|---------------------------------|
| Trainee's name                         | Katie Watts                     |
| Name of workplace contact              | Dr Caroline Stokes              |
| Nature of work and competence assessed | GENERIC PROFESSIONAL COMPETENCE |

**Section 2 – to be completed by the Workplace Supervisor:**

Views on the Trainee's Performance on above piece of work. Please also comment on any reason for delays in the completion of this piece of work and report any periods of prolonged absence.

Katie has always conducted herself in a highly professional manner.

**Declaration**

I verify that the above named Trainee has undertaken the above mentioned piece of work. I am of the opinion that it has been completed to a satisfactory professional standard.

Signature:

[Redacted Signature]

Date:

06/09/2017



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Programme Director – Dr Angeliki Bogosian

Email:

[Redacted Email Address]

Tel:

[Redacted Telephone Number]