MANAGING LONG TERM SYMPTOMS, WITH COMPLEX CAUSES: A SURVEY OF PATIENT AND GENERAL PRACTITIONER EXPERIENCES

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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"*The body itself is a screen to shield and partially reveal the light that's blazing inside your presence"* –Rumi

ABSTRACT

The term 'Medically Unexplained Symptoms' (MUS) refers to a constellation of symptoms that have a low probability of disease pathology. It is a clinical area that General Practitioners (GPs) have frequent contact with; managing the challenge of how to reduce the reported discrepancy between patient expectation of cure and the provider approach of symptom management. The aim of this current study is to explore how patients and GPs understand MUS and its management, considering how their understandings overlap and diverge, how any differences are negotiated and how this can inform future collaborative care interventions for MUS. Six patients and four GPs were recruited from one practice, and an interview design was used to explore their experiences of managing MUS. The qualitative data were analysed using the framework approach, with patient and GP interview data being analysed separately, before being synthesised. Three conceptual themes emerged from GP and patient interviews- *understanding of the symptom(s), the emotion response, the validating relationship,* with one further conceptual theme present for patient interviews- *deciding what gets shared in the consultation.* The study results provide some support to existing research that have suggested that patients do have a complex understanding of their MUS symptoms. There was also a shared belief between participant groups that the relationship between patient and GP was important in the management of MUS, however a gap in communication between patient and GP was also highlighted. The results are considered in relation to existing interventions that are used to open up the shared dialogue between patient and GP. The clinical implications of introducing a shared decision making approach to MUS consultations are discussed, alongside implications for future research of how this intervention might be piloted.

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ABBREVIATIONS

CCG   Clinical Commissioning Groups

FS   Functional Symptoms

GP   General Practitioner

HRA   Health Research Authority

IBS   Irritable Bowel Syndrome

IPA   Interpretative Phenomenological Analysis

ME   Myalgic Encephalomyelitis

MUS   Medically Unexplained Symptoms

NHS   National Health Service

PROMS   Patient Reported Outcome Measures

REC   Research Ethics Committee

SDM   Shared Decision Making

CHAPTER ONE: INTRODUCTION

This study explored how patients[1] and GPs understand and manage symptoms that cannot be medically explained. The study used semi-structured interviews with GPs and patients with medically unexplained symptoms (MUS), to explore in what ways understanding overlapped and diverged and how any differences were negotiated within the patient-GP relationship. In this chapter, I will begin by providing an overview of what is meant by the term Medically Unexplained Symptoms, exploring how it is defined by the literature and how it is experienced by different stake holders – at service, patient and GP level. I will then move on to discuss the literature on current approaches for MUS management in primary care, and the extent to which consultations for MUS are viewed as satisfactory for patient and GP. Finally, I will consider the different approaches used to support the process of decision making in healthcare and the anticipated challenges that may occur when using decision making tools in the management of MUS. The section will conclude with the research questions of this study.

1.1 Medically Unexplained Symptoms (MUS): Terminology

Medically Unexplained Symptoms, is the term used to describe the persistent physical symptoms of patients that cannot be adequately explained by physical disease or observable biomedical pathology (Peveler, Kilkenny & Kinmonth, 1997; MUS Positive Practice Guideline, 2014). It has been suggested that MUS in primary care is viewed by healthcare professionals as a 'working hypotheses' for a constellation of symptoms that have a low probability of organic disease and is a disorder of function rather than structure (Burton, 2012; Murray et al., 2016). These symptoms can vary in how they cluster together and in their severity, giving rise to a variety of terms used throughout the MUS literature and across different clinical domains. They include symptoms that cluster together to form diagnosable functional syndromes, such as fibromyalgia, chronic fatigue, chronic pain, as well as symptoms that are nonspecific to a syndrome – nonspecific MUS- and symptoms that have sufficiently high levels of clinical distress to

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[1] *It is recognised the term 'patient' may be perceived as assuming a biomedical perspective, however it is used to aid identification of the subjects that this study refers to, and the primary care context that this study and the studies reviewed are predominately based within.*

be recognised in the psychiatric classification system as Somatoform disorder (ICD-10, 2016).

Unsurprisingly, there is disagreement in the literature on the appropriateness of using MUS as a generic reference term to help identify patients with such symptoms. One argument has been that it helps to position the problem away from the patient and on to the medical professionals' lack of explanation (Peveler et al., 1997), however others state that this term unhelpfully suggests a dualistic message that symptoms are either biological or psychological (Creed, Henningsen & Finet et al., 2011). Moreover, in one study in which patients rated MUS related terminology, 'persistent physical symptoms', rather than 'functional' or 'Medically Unexplained Symptoms', was the preferred term (Marks & Hunter, 2015). This was believed to reflect patient preference for wanting to move away from generic terms that do not support understanding, or have cross-cultural relevance (Creed et al.). This highlights not only the challenge for both patients and healthcare professionals in how they develop a shared understanding of the symptoms that are nonspecific to a diagnosable syndrome or disease, but also the differences between what patients view as relevant terminology in contrast to the terms used by researchers and health professionals.

1.2 Medically Unexplained Symptoms (MUS): Prevalence in Primary care

Both the broad spectrum of MUS and the variation in how MUS is defined and measured between studies complicates appraising the actual prevalence rate of MUS in primary care. Where the prevalence of Somatoform disorder has been measured by diagnostic interview with surveyed primary care patients, the low rates reported and consistency found between 14 different countries (0.1-3%), suggests that severe forms of the MUS spectrum is relatively rare in primary care (Gureje et al., 1997). Although other studies that have used different measurement criteria for Somatoform disorder have reported higher prevalence rates of Somatoform disorder in primary care population (10.9- 16.1%) (Dewaal & Arnold et al., 2004; Steinbrecher et al., 2011), the rates suggest that the number of patients presenting to primary care that would meet diagnostic criteria for somatoform disorder still remains low. In contrast, the prevalence of milder symptoms that do not have a medical explanation are high, with reports that only 26% of the common symptoms that adults present to primary care with – chest pain, fatigue, dizziness, headaches, swelling, back pain, shortness of breath, insomnia, abdominal pain and numbness- have identifiable biological causes (Kroenke &

Mangelsdorff., 1989). This suggests that whilst severe forms of MUS are rare within primary care, managing milder symptoms that are either medically unexplained or comorbid with illness are routinely seen within primary care, and become clinically meaningful when the symptoms persist (>3 months) and impact on patient distress and functional ability. Evidence suggests that compared to patients with other chronic conditions, patients with MUS have a lower quality of life, show greater impairment in functioning and worse mental health (Smith, Monson & Ray., 1986 ;Koch et al., 2007). This implies that although observable causes for the symptoms cannot be found, it does not make the patients any less justified in accessing help and support for symptoms that for some are experienced as disabling or more so, than chronic conditions with observable pathology.

Although the impact of MUS on the patient is clear, the understanding of what factors increase a patients vulnerability of experiencing MUS symptoms, is less so. Research examining the demographic and clinical characteristics associated with medically unexplained symptoms, suggest that these symptoms are more likely to occur in females, where people are older, less educated and unemployed and where people are non-western in origin (Verhaak et al., 2006). However, this is in contrast with earlier research that found that people who were younger (16-25 years), female, reported more symptoms (explained and unexplained) and were employed showed a greater association with having MUS (Nimnuon et al., 2001). Such differences between studies may reflect the difference between study samples-patients who frequently attend with persistent MUS (Verhaak et al.) and patients who experience MUS (Nimnuon et al.). The implications being that the difference potentially reflects a difference in help seeking behaviour between older and younger patients, whereby although young patients may experience more MUS symptoms, it is older people who are more likely to frequently attend to primary care with MUS or other comorbid symptoms that may increase the opportunity for MUS to be identified.   In addition, there is also evidence to suggests that difference variables are associated with the different types of MUS that people experience, for example fatigue has been associated with the experience of having a recent serious illness of a close relative, neuroticism, depression and anxiety, whereas pain was associated with years of education being <12 years and 2 or more current general illnesses (McBeth & Tomenson et al.,2015).Only when there was concurrent depression or anxiety were shared factors found, which included an association found between childhood abuse and MUS. As such, in addition to general factors associated with MUS, there may also be specific factors that are associated with different presentations of MUS. Furthermore, the study suggests that some symptoms that are

unable to be medically explained may also exist independently from psychological factors of childhood trauma, anxiety depression.

1.3 Medically Unexplained Symptoms (MUS): Service Implications

The cost of Medically Unexplained Symptoms (MUS) to the NHS is an estimated £3.1 Billion (Bermingham et al., 2010), making the review of the treatment pathway for MUS a prioritized need (Department of Health, 2011; NHS England The Five Year Forward View, 2016). With 1 in 5 new consultations in primary care being with patients with MUS (Burton, 2003; Kroenke, 2007; Konnopka, 2012), it is a clinical area that GPs have frequent contact with; at times placing high demand on limited resources. There is increasing need for GPs to be able to manage MUS, with the view being that once significant pathology has been ruled out, they have a key role in reducing the overuse of unnecessary and costly investigations and treatment, through increasing monitoring of symptoms, and encouraging self-management and watchful waiting of symptoms (CSL Mental Health Project Team, 2010; NHG Guideline on Medically Unexplained Symptoms, 2013). The challenge that presents is the possible discrepancy in the consultation between patient expectation of cure and the provider approach of symptom management, and the cost implications at patient, GP and service level if this discrepancy is not recognised and resolved.

1.3.1 Service Use: Frequent Attenders

The cost effective provision of services is an area of understandable scrutiny for providers and commissioners of NHS services. Frequent attendance at primary care has been associated with people managing chronic conditions, with an increased prevalence of physical and psychological symptoms over non-frequent attenders, and a higher number of hospital referrals and prescriptions over a year (Heywood & Blackie et al., 1998) and at 3 years (Smits et al., 2009). Consistent with such clinical characteristics, the evidence suggests that the range of reported symptoms, extent of worry about illness consequences, and a long timeline perspective are important cognitive representations of illness (illness perceptions) that have been shown to predict later service use (Frostholm et al., 2005). Although this highlights the importance of patient illness beliefs and emotions in service use, it is unclear from the literature the extent to which symptoms that are explained or unexplained have a greater impact on the frequency of accessing services (Kroenke et al., 1994; Fiddler et al, 2004; Smits et al., 2009).

One prospective study of patients accessing secondary health care (n= 295), found that although the number of physical symptoms reported at the initial appointment showed a linear relationship to service use over 6 months, no association was found for whether the symptoms were explained or unexplainable, and that the number of symptoms was a greater predictor of service use than health anxiety (Jackson et al., 2006). Although no relationship was found between symptom type and service use, this might reflect inaccuracies in clinical decisions regarding the type of symptoms-explainable or unexplainable; it may also be that differences between such symptom types are not apparent over the study's follow up period. For example, a 3 year cohort study of people whose attendance placed them in the top 10% of primary care consultations, found that one in seven were still frequently attending 2 consecutive years later. Referred to as 'persistent frequent attenders' by the study, they were found to consist of individuals who had more social problems, more anxiety, medically unexplained symptoms, and chronic physical health conditions- particularly diabetes, than both non frequent attenders and frequent attenders at 1 year (Smits et al., 2009). Although the study recognises that the results cannot indicate to what extent frequent attendance in primary care is providing containment of the problem for the person, the study benefits from being based on a large sample size (n= 28,860 patients) from a range of GP centres (n =5), increasing the validity and generalizability of the results. That being said, the two studies highlight the difficulty of not only understanding how to meaningfully define frequent attendance, but also the extent to which the association of frequent attendance with medically unexplained symptoms can be understood as representing something that is specifically to do with MUS rather than the complex care needs that people have managing multiple co-existing symptoms. This suggests, along with the conclusion of one systematic review that "no generally accepted definition of frequent attenders" exists in the literature (Vedsted & Christensen,2005), that further understanding is needed of how frequent attendance is defined in clinical practice, and to what extent MUS contributes to this and the reasons why.

1.4 Medically Unexplained Symptoms (MUS): Patient Perspectives

The literature considered so far highlights the nebulous nature of MUS, and in turn the difficulties in the early identification and management of such symptoms. This next section moves on to explore the literature concerned with how MUS has been perceived by patients and GPs, and the frames of reference people use to explain the seemingly 'unexplainable'.

1.4.1 Illness representations: How do people view their condition?

How a patient appraises their symptoms and the resources available to manage them are believed to have an influence on subsequent consultation behaviour -who they seek support from and how they present their symptoms (Petrie et al., 2007), as well as the extent to which the symptoms become chronic (Brown, 2004). The Self-Regulation model of illness (Leventhal et al, 1984) has provided a framework for understanding how a person's internal illness beliefs (the illness identity, thoughts about causes and likely consequences of symptoms, how long the symptoms will last) are likely to affect what type of action a person takes or thinks is necessary to cope with their symptoms.

There are some suggested theoretical explanations of MUS, which suggest that unconscious psychological conflict underpins MUS and that management focus is likely to involve supporting people to reframe their symptoms within a psychological understanding (Janet, 1889; Breuer & Freud, 1893; Lipowski, 1968; Brown, 2004). However, evidence suggests that patients' understanding of their symptoms are in fact multifaceted, comprising of consideration of both physical and psychosocial causes (Liden, Bjork-Bramberg & Svensson, 2015). In a qualitative study concerned with exploring patient experiences of GP consultations for MUS, it was found that across all participants, regardless of whether or not their GP had received training to help patient's consider the role of psychosocial factors, participants had complex and fragmented accounts for their symptoms, which included the interaction of psychosocial factors with disease causes. However, they believed that such understandings were too hard to convey in brief GP consultations, with concern that they would be 'burdening' GPs with talk of psychosocial issues (Peters et al., 2009). It would seem that a barrier to what is discussed in the consultation, is not necessarily an unwillingness to consider psychosocial factors, but the difficulty in finding a way to 'pull the multiple threads together' to talk about them, as well as feeling safe enough within the consultation to do so.

Similarly, research that has explored the illness representations in patients diagnosed with non-epileptic seizures (NES) found that patients again provided a varied account for their symptoms and a readiness to accept a biopsychosocial understanding (Green, Payne & Barnitt., 2003). That said, it was noted by the researchers that people found it difficult to think about how their symptoms might change over time, or that they may have some control over them. It was proposed that this may reflect the difficulty for these patients - who were being interviewed following their diagnosis of NES - to construct a new illness identity, which would provide the foundations for developing a

timeline and feelings of symptom control. This suggests that without test results being anchored to a clear explanation for their symptoms, one that is built within a person's own illness representations, reassurance from negative test results may add very little to patients' understanding of their symptoms (Petrie et al., 2006) or may even be discounted by their existing illness beliefs (Lucock et al., 1997; Brown, 2004). In summary it would seem that finding ways to bring together the threads of understanding people already have about their symptoms, may help to provide a sense of control and empowerment over their symptoms. Understanding the factors that facilitate and inhibit a person sharing their existing understandings of their symptoms in the consultation, and to what extent understanding of symptoms can be co-constructed between 'patient' and healthcare professional, appear to be important for improvement to MUS management.

1.4.2 The experience of MUS management in primary care

Studies investigating patient experience of MUS management highlight the variability within the patient group as to what is important to them within the consultation. Evidence from qualitative research indicates that some patients with MUS have been concerned about the nature of GP explanations for their symptoms, reporting that explanations can either be 'rejecting' or too 'colluding' with their symptoms (Salmon, Peters & Stanley, 1999), whilst other studies found that patients were less concerned about the explanation given, but wanted a clearer understanding of the management plan and how they can self-manage the symptoms (Dwamena et al., 2009; Houwen et al., 2017). Although the varied reports of what patients want from their consultation must be considered within the context of their stage of symptom management, for example people with persistent MUS may place greater importance on having a clear management plan rather than explanation, overall there appears to be a gap between what a patient hopes for and what they actually get from the consultation.

Knowing what information is appropriate to discuss in consultation with their GP appears to be one area of difficulty, which may prevent a patient from sharing their bio-psycho-social understanding of their symptoms. Reports from patients with MUS that they would not feel comfortable talking to their GP about psychological health (Peters et al., 2009) or that they expected that the support offered would not be helpful for that need (Murray et al., 2016), suggests that there is an underlying lack of trust in their health care provider's ability to understand and provide reliable information for all aspects of their experience (Branch, 2000). Experiencing a healthcare system that separates physical health from mental health may add to this perception, conveying a dualistic social message that mind and body are understood and treated separately,

giving rise to expectations about the role their GP has in managing their health (Hussain & Chochrane, 2004; Murray et al., 2016). Furthermore, public awareness of the effects of NHS and austerity may also increase scepticism about in whose interest decisions are being made. For example, interviews with a Canadian sample of patients who were accessing publicly funded services for managing MUS found that some patients held the perception that the suggestion of psychological intervention from a health professional was to infer that they should be able to fix themselves and that this was being provided as a way for the doctor to not prescribe or discontinue prescribing medication (Atkins et al., 2016).

That said, it may also be that patients are detecting their GP's own discomfort with managing MUS. One primary care study, which used videoed consultations to support patients (n =17) to reflect on their experience of the MUS consultation, found that a frequently reported theme by patients was that they felt uncomfortable with the approach taken by their GP, with non-verbal communication and lack of conveyed empathy making them feel like they were an inconvenience. Themes of there being a perceived mismatch between patient and GP agendas, perceived lack of consultation preparation and lack of felt GP transparency about limits of understanding about the symptoms, highlight the importance of a person centred approach to communication, and what patients may want this to look like in clinical practice (Houwen et al., 2017). Interestingly, this study also highlighted that half of the sample that met the study criteria of people attending for consultation primarily for MUS, contained people who did not report any concerns regarding their consultation. Although the study focus was on people who experienced problems with their consultations only, further exploration of people's accounts of what makes the experience problem free or satisfactory may also help to understand the nuances of MUS and the approaches needed for primary care management.

1.5 Medically Unexplained Symptoms (MUS): General Practitioner Perspectives

Evidence suggests that GPs have a strong desire to understand and help their patients (Stone, 2014). However, where symptoms do not fit a specific disease model, the consultation approach can become less clear and can be experienced as frustrating for some GPs who are uncertain of how best to help (Steinmetz & Tabenkin, 2001; Wileman, May, Chew-Graham, 2002; Stone, 2014; Brownell et al., 2016). The decision to provide a somatic (biomedical) intervention in such a consultation has been said to be

influenced by a fear from the treating GP that serious disease pathology will be missed (Murray et al, 2016), as well as concern that patients may not accept a psychosomatic explanation and treatment (Woivalin et al., 2004). Such concern may result in the psychological interventions not being put forward by health professionals, despite evidence and clinical guideline recommendations for psychological management of MUS (Kellett et al., 2016; NICE, 2006). This was evident in a study of health professionals experience of managing MUS (n = 12 GPs, n = 6 speciality others), where concern was shared that by introducing the option of a psychological intervention to a patient, this might unhelpfully convey to the patient that they think the problem is "all in your head". As such, some health professionals stated they avoided suggesting psychological treatment as one of the options for managing MUS (Brownell et al., 2016).

The influence of patient expectation on GP consultation test ordering behaviour has received investigation. In a cross-sectional study of GPs, it was found that consultations where symptoms were medically unexplained lead to twice as many requests for laboratory tests (Van der Weijden et al., 2003). Although this is perhaps not surprising if significant pathology is needing to be ruled out, the study also found that patient's pre-consultation expectations for tests were positively related to test ordering behaviour of GPs. This could be suggestive of difficulties occurring in managing patient expectations within the consultation, potentially influenced by a professional reported drive to 'fix it' (Howman et al., 2016; Brownell et al., 2016) or the GPs professional experience and confidence in managing complex consultations (Stone, 2014). However, acknowledged in the study is that the conclusions are limited by not collecting the GP's reasons for their decision, and if it was based on their expectation of the patient, then to what extent was this accurately perceived by the GP and to what extent non-prescribing options were considered as possible treatment options in managing MUS for both the patient and the GP.

1.6 Medically Unexplained Symptoms (MUS): Treatment Approaches in Primary Care

With the absence of a specific disease treatment pathway for health professionals to follow, a particular focus for MUS interventions has been on patient-provider communication, with the recommendations made to commissioners to provide a stepped care approach whereby the intensity of the treatment is proportional to the severity of the symptom (CSL Mental Health Project Team, 2010; Joint Commissioning Panel for Mental Health, 2016).

1.6.1 A Stepped model of care

Watchful waiting

Watchful waiting has been an approach used in the management of chronic conditions, especially where the evidence base for curative intervention has been unclear (Chodak, 1994). In MUS management, this approach appears to take the form of GPs providing regularly scheduled appointments to patients with MUS, whereby brief physical examinations are used to monitor signs of disease (Heijmans et al., 2011). This decision to actively monitor symptoms for progression and intervening when deemed clinically necessary is informed by the reported increased risk of causing iatrogenic harm to the patient, from unnecessary diagnostic procedures or over prescribing of unnecessary medication (Burton et al., 2012). The evidence of the acceptability of watchful waiting treatment option to patients with MUS is limited, however research from patients managing a chronic health condition suggest that even if patients find this to be an acceptable treatment option for themselves initially, the ongoing pressure to pursue 'active treatments' from family, support groups, or healthcare professionals can contribute to a change in their decision (Chapple et al., 2002). This highlights how the quality of the information that patients may get about all treatment options may vary according to the health professional preferences and that the patient's decision may also change with time and following the discussions they have with others. The challenges of making an informed decision in clinical care are recognised within the NHS, and the use of decision aid tools are being encouraged in some areas of health as a method of presenting objective information in a way that supports the patient to make a decision based on the values they hold (see NHS Shared Decision Making, 2016; Stacey, Légaré & Lewis et al., 2017).

Self-management

Self-management as a treatment option in chronic conditions, including MUS, has been outlined in several government white papers (Department of Health, 1999; 2005), defined as being:

> '…the ability to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life'
>
> (Barlow et al., 2002).

It has been viewed as an effective way to bridge the gap between the demand on health services from people with chronic conditions and the limited supply of services. It requires patients' active involvement in managing their condition through processes of taking ownership of their illness needs, activating resources and integrating the chronic illness into their lives (Schukan-Green et al., 2012). However, how this is done and the extent of the impact that this may have on health professionals involved in providing such support, lacks clarity and exploration (Barlow et al., 2012). In addition, further research is required to understand what forms of self-management would be appropriate for the varying needs of patients with MUS and what they perceive their role to be in increasing their quality of life with MUS. There is some suggestion that a potential barrier to self-management may be the comorbidity of other conditions that the patient is managing and is having to prioritize (Elliott et al., 2007), as well as the effects of lowered mood, motivation and self-efficacy (Bair et al., 2009).

Referring for psychological support

Where the treatment need of the patient is unable to be managed sufficiently by low intensity support, GPs are advised to refer their patient on for specialist psychological support. The most recent treatment development in the area of MUS has been the expansion of Increasing Access to Psychological Therapies to assist with primary care level support of long term health conditions and MUS (Department of Health, 2011). The treatment rationale being that mood effects MUS and that Cognitive Behavioural Therapy (CBT) or a therapeutic approach that blends traditional CBT with mindfulness, acceptance and/or compassion (Third wave / generation approaches), can be used to treat anxiety and depression that underlies MUS (Kellett et al., 2016). Early evaluation of this service development has shown promising results in which pre-post-depression scores, as measured by PHQ-9, showed a large effect size (0.25) and a similar large effect for anxiety scores (0.31) as measured by the GAD-7 (Kellett et al.). However, further research is needed to assess the medical cost offset of this approach, for example measuring patient healthcare use in a certain time period, to get a clearer understanding of the impact of treating anxiety and depression on physical symptoms. In addition, the treatment approach may only meet the needs of some people with MUS, which suggests that again more research is needed to consider which patients and potentially forms of MUS, are most suited to an IAPT based approach. This study also highlighted that there was considerably lower referral rates for patients with MUS than patients with other long term chronic conditions. It is unclear if this can be accounted for by GPs perception that patients would not be open to a referral for psychological support

or that this was actual preference of the patient. Further research exploring the factors that influence both GP and patient decision may help to identify any barriers to the management options for MUS and increase understanding on how best to address these.

1.6.2 Enhanced management

Enhanced management has been viewed as a way to provide treatment in an environment familiar to the patient, by front line staff integrating low level specialist support into their consultation. Defined as a structured treatment model, which uses a biopsychosocial understanding of symptoms and strategies to increase resilience and self-management (Rosendal et al, 2013), enhanced care training has been piloted across primary care sites (Gathogo and Benjamin, 2013). Shown to have comparative outcomes to CBT, enhanced management was found to show a low to medium effect size in post-treatment symptom severity and at 12 months follow up (Van Dessel et al., 2014). CBT was found to have a higher number of dropout rates, which the authors suggest is possibly indicative of the acceptability of psychological treatment to the patient. However, previous reviews on the effectiveness of enhanced management for MUS has reported that no firm conclusions can be made due to the differences seen in the forms of enhanced management delivered, which includes reattribution techniques only, CBT only, reattribution and CBT, as well as the varying intensity of the treatment (Rosendale et al, 2013). Collectively it would seem that two tentative conclusions can be taken from this. Firstly, that frequent contact with the GP may be better than a brief intervention and help support patient-doctor communication (Joint Commissioning Panel for MUS, 2016). Secondly, the lack of difference between two active treatments (enhanced management and CBT) may suggest that outcome is being affected by nonspecific therapy factors due to the consultation being more structured and promoting the patient to be an active partner in the treatment. Having a structure for GPs to work from might be addressing the challenges highlighted in primary care MUS consultations, that patient narratives can be unfocused (Olde Hartman et al., 2013) and often overwhelming for the GP (Murray et al., 2016), which may heighten feelings of frustration for both and impact on the consultation.

Reattribution

Building on the principles of person centred care, Reattribution is a structured intervention that has been used in primary and secondary care to support patients in making the link between psychosocial issues that they may be experiencing and the

physical symptoms they report (Dorwick, Gask & Hughes et al., 2008). Despite its uptake amongst practitioners and the reported increase in patient satisfaction (Morriss, Dowrick, & Salmon, 2007), clinical outcomes have remained unchanged (Aiarzaguena., et al. 2007). Research exploring the potential barriers of reattribution for primary care MUS patients found that focusing an intervention just at GP level, did not adequately address the factors that affect patients' decisions about what they discuss with their GP, for example how the relationship was perceived by the patient as well as any prior beliefs about the role of the GP (Peters et al., 2009). It would suggest that the success of this intervention is determined by the extent to which a GP is able to access the patient's frame of reference for understanding their illness. This might be limited by a range of factors, such as limited consultation time and lack of diagnostic openness by the GP (Murray et al., 2016).

1.7 Satisfaction with treatment decision

There is evidence to suggest that the clinical decision on how best to manage patient symptoms, is more gradual, less certain and less satisfying for GPs when symptoms are assessed as being both somatic and psychosocial in nature (Andre et al., 2012). This is perhaps not surprising given the number of barriers (n =379) that have been reported in a systematic review of the challenges of diagnosing MUS, which include understanding the co-morbidity between medically explained and unexplained symptoms, considering the socio-legal context of symptoms (illness legitimacy of the sick role), and having imperfect diagnostic tools (Murray et al., 2016). It has also been suggested that the lack of GP satisfaction may be reflective of the professional culture that GPs, particularly clinicians with less experience, may hold regarding the acceptability of MUS as a real and important experience (Stone, 2014), or a professional culture in which MUS is valued but that the therapeutic skills they use with their patients are not (Salmon et al., 2007). Taken together, these findings imply that the uncertain consultation may require a greater amount of time to provide an individualised approach to understanding and managing the symptoms, and that the professional culture of the consulting GP may affect how satisfied they can be with a clinical decision of MUS and any subsequent management.

        The orientation of both the GP and the patient, in regards to what they expect their role to be within the consultation, may also affect the extent to which satisfaction is reported from the consultation. Although there has been a movement from a disease focused and paternalistic care to patient focused and collaborative care in the clinical

approach taken (Laine & Davidoff, 1996), patients show variation in the amount they expect to be involved in the consultation, particularly in older adults (Bastiaens et al., 2007; Butterworth & Campbell, 2014), as well as health professionals in the extent to which collaboration is encouraged (DiMatteo, 1998). Despite potential differences between GP and patient, research looking at the effect that GP – patient congruence on orientation preference has on patient satisfaction found that this was not based on the level of agreement in the consultation but on the GP's patient centred orientation, even in patients who have a medically orientated approach (Krupat et al., 2000). This suggests that patient satisfaction is concerned with both the style and content of the consultation, and the extent to which the patient perceives their contribution in the consultation to be listened to and perceive themselves to be viewed by the GP as an equal in their relationship (Butterworth & Campbell, 2014). This would support the humanistic position that fundamental to outcome is the therapeutic relationship and showing acceptance of the patient and their position, and that empathy and genuineness is perceived by the patient (Rogers, 1959).

1.8 Decision Making

The literature reviewed so far, highlights the extent to which MUS challenges the idea of conventional medicine. Without objectifiable tests or evidence base to guide management, it is a clinical area with much uncertainty. As such, there is a reliance on there being good patient-provider communication, to not only develop a shared understanding of the problem but to end up with a treatment plan that is aligned with a patient's preference and values, without compromising the professional obligation to maintain both duty of care to patient and cost-effective care for the service. To help think about how these agendas are negotiated, this next section will begin by outlining the process involved in decision making and consider the approaches used to support clinical decisions made between patient and provider.

1.8.1 The information processing model

The diverse nature of the clinical issues presenting in primary care, requires GPs to make use of different decision making processes to judge the nature of a problem and treatment options. In addition, patients too make decisions about what part of the illness narrative to share in the consultation and what provided information is attended too. The information processing model has been used to help understand what influences the decisions that people make; including how people decide what to attend to in their environment and how this is accommodated within a person's existing emotions and

motivations for a decision to be made (Johnson, 1999; Bekker, 2010). Two forms of processing are said to be used either simultaneously or separately; these are heuristic thinking (rules of thumb, unconscious process and simple analysis) and systematic (analytic, conscious, detailed analysis) (Acker, 2008; Bekker, 2009). Heuristic strategies such as probability reasoning - the extent to which symptom presentation is perceived as being similar to a known understanding of disease - has been observed to help with quick decision making and risk assessment in health professionals (André,Borgquist, & Mölstad, 2003), whilst social heuristics such as the status of a doctor have been said to impact on how patients see the role of doctors in managing their health (Marewski & Gigerenzer, 2012).

However, such short cuts to thinking may also impede medical decision making. In a recent systematic review of the cognitive biases associated with medical decisions made by physicians, one to two thirds of case scenarios showed an association between cognitive bias and diagnostic inaccuracies, the most common cognitive biases researched in this area being-availability bias- judgements based on ease of recall rather than probability, anchoring effects- not updating initial premature appraisal with new information and overconfidence bias- acting on intuition or haunches rather than information (Saposnik, Redelmeier, Ruff et al., 2016). Although the studies reviewed were unable to clarify the nature of the relationship shared between specific cognitive biases and medical decision outcome, it does highlight the potential for cognitive biases to have an unhelpful influence on medical decision making and the need for strategies that can encourage the use of systematic thinking and meta cognitive awareness of the intuitive processes being used.

1.8.2 Informed decision making

Since the Health and Social Care Act 2012, a shift has been seen in how decisions are made in public service spending, with greater autonomy and decision making ability placed at local rather than government level (NHS Five Year Forward View, 2014). Arguably this has also been reflected in government policy, emphasising the need that decisions about patient care should consider not only professional experience, but also the wishes and wants of the people who are experts by their own experiences, as seen in "No decision about me without me" (DoH, 2012). As such, there has been a move towards developing the delivery of person centred care; exploring ways to strengthen the patient-professional communication as part of a collaborative care approach.

Informed decision making in routine clinical care positions the decision away from a paternalistic view of this being only the responsibility of the treating healthcare professional, and increases patient involvement (Woolf et al., 2005; Department of Health, 2012). This requires that the patient has access to evidenced based information, presented in a suitable format for them to make an informed decision about preferences for treatments. However, there is evidence to suggest that the information provided to patients may not encourage collaboration, with concerns raised that the facts of treatment and what is believed to be necessary for patients to know is being emphasised, rather than providing information to support the active engagement of patients (Bekker, Luther & Buchanan, 2010).

This might be a particular issue in the area of MUS management, whereby there is limited evidence based information regarding how the symptoms are understood and what the appropriate management options are. Where studies have looked at GPs decision to offer medical management of MUS, they have found that this treatment decision has been associated with patients increasing the number of physical complaints and the consultation being longer, as opposed to the patient requesting a medical approach (Salmon et al., 2006; Edwards et al., 2010). However, the reasons for informing the chosen approach for patient and GPs were not documented in the study. The findings could be due to patient heuristics about how distress is appropriately communicated and managed in primary care, as well as GPs own beliefs that may have prevented them from understanding and adequately exploring the context of the patient's symptoms (Van der Weijden, 2003). Additional barriers to understanding the context of symptoms might be created by environmental and systemic factors. It has been put forward that the appointment time constraints may influence what information is provided about available management strategies (Hansen et al., 2012), as well that the compensatory recognition for GPs is placed on procedures provided rather than the decision making process that supports the patient to get to that point in their treatment (Lewis & Pignone, 2009).

1.8.3 Shared decision making

The process of the informed decision has moved from being an informed choice that the patient makes on their own, to a collaborative shared decision between patient and the health professional. Shared decision making has been cited as a way to reduce the overuse of unnecessary treatment, particular where there is clinical equipoise, and helps to promote the rights of the patient to be involved in their health (Coulter & Collins, 2011). Furthermore, the literature around treatment adherence suggests that

explanations that are developed in partnership with patients and considers their existing health beliefs increases not only reported increased patient satisfaction but also adherence to treatment recommendations (Martin et al., 2005). For patients with MUS, this may be particularly important in decisions made about when to discontinue with further tests or medication, reducing the need for patient initiated second opinions, which has been said to increase the risk of conflicting advice (Payne et al., 2014).

However, Shared Decision Making (SDM) research is limited in its application to MUS, which possibly reflects the unique starting position of being medically uncertain about the cause of the symptoms and its management. One study that looked at rates of SDM in primary care patients with chronic conditions, did include patients with Irritable Bowel Syndrome (IBS), a functional disorder that is believed by many to be a form of MUS, and found that the greatest predictor of lower SDM scores were from patients who were younger and reported more general health concerns (P< 0.001), followed by those who had IBS (P= 0.05) (Fullwood et al., 2013). Although the lower SDM found in certain patient groups might be reflecting patients who were less satisfied with their health status and who were attributing this to lack of SDM, the results may also suggest that there may be difficulties in establishing a shared conversation when the GP and patient are less clear on how to label the symptoms together. Additionally, review data from the 2005-2016 National Surveys on patient satisfaction with care and decisions, suggests that in addition to health needs, patient age may contribute to the extent to which people feel involved in their care. Younger patients (18-24 years old) with complex health needs felt the least positive about discussing aspects of their care with their health professional and reported that information provided did not support their understanding (Care Quality Commission, 2016). Such data is collected across multiple care providers, making it difficult to know to what extent this reflects patients' experience within one sector of care. That said, it does highlight the importance of contextual factors that may give rise to the level of power and agency people perceive to hold when making decisions about their care, which may fluctuate over time (Hoggett, 2001) and in different social contexts (Glenister, 1994) .

1.9 Challenges of shared decision making in MUS

A systematic review of 38 studies on professionals' views on implementing Shared Decision Making found that time constraints (22/38), the intervention's inapplicability due to patient characteristics (18/38), and the intervention's inapplicability due to the clinical situation (16/38) were the top three cited reasons for not routinely implementing in

clinical practice (Légaré et al., 2008). The review mainly consisted of physicians reporting experiences of introducing SDM in routine practice and suggests that decisions about who would be suitable to use SDM were made without consultation with the patient. Considering the literature on GP-patient communication in MUS consultations, there is indication that there may be additional barriers when establishing a shared conversation for this patient group.

1.9.1 Different frames of understanding

Studies that have looked at GP-patient communication within the MUS consultation, suggest that a particular difficulty for establishing SDM may be to do with the differences found between the patients' frame of understanding of their symptoms and their GPs', as well as differences in treatment expectations (Salmon, 1999; Allegretti et al., 2010). In a study that conducted paired interviews with GPs and their patients with low chronic back pain, it was found that greatest divergence was seen in the explanatory models used for symptoms and treatment goals and expectations (Allegretti et al., 2010). Patients were found to adopt a biomedical model, looking for pain reduction, which was resistant to the GPs biopsychosocial approach and treatment goal of improving functioning. Such findings are in contrast to studies outlined in section 1.3.1, whereby illness representations shared by individuals with MUS have been multifaceted, combing psychological and physiological factors (Green, Payne & Barnitt, 2003; Liden, Bjork-Bramberg & Svensson, 2015). One explanation for this difference may be found in the literature that suggests that resistance to psychological explanations of MUS may be more about people wanting to emphasise a point; that their symptoms are severe and legitimate, rather than reflecting their understanding of the cause (Horton-Salway, 2001). In summary, it would seem that to support a shared conversation between patient and GP it is important to consider what concerns are potentially being communicated by any interactional differences, and that the relationship needs to be one of mutual acceptance to enable the co-construction of a new illness narrative between GP and patient.

1.9.2 Multiple and complex symptom presentation

Another challenge for establishing patient preferences in their MUS management may be that symptom narratives are often complex and confusing for both patient and GP (Olde Hartman et al., 2013; Stone, 2014; Peters et al., 2009; Brownell et al., 2016). In a synthesis of GPs' experiences of managing multi-morbidity in patients, it was found that GPs managed the reported difficulties in eliciting patient preferences by some prioritising their own agenda or their patients, whereas others tried to avoid making a decision or

used additional tests to support the decision (Sinnott & Mc Hugh et al.,2013). Similar findings have been found in MUS consultations, with one study finding in their review of videoed MUS consultations, that where patient's presented with multiple symptoms, GPs were seen to explore the beliefs that patients held for one or two symptoms, but did not incorporate these beliefs into the reassurance that was then provided (Olde Hartman et al., 2013). It would seem that there is a struggle to know how to meaningfully incorporate the patient view with that of the professional, resulting in one view point getting prioritised over the other. Furthermore, where there is increasing uncertainty, the need for both patient and GP to be in control of the consultation may be heightened, which may increase the likelihood that symptoms are then made sense of separately.

1.10 Study rationale

Whilst research on GP-patient communication suggests that GPs and patients hold different frames of understanding MUS, how these differences are negotiated and management options decided on is relatively under researched. Predominately, the focus has been at the population and behavioural level of patient and GP experiences. For example, quantifying speech focus within the consultation as a proximate for what is important for the patient and how this is responded to by the GP (Olde Hartman et al., 2013), or patients' pre-consultation expectations and GPs' test ordering behaviour (Van der Weijden et al., 2003). Although this provides indication of the complexity of the patient presentation and challenge of the MUS consultation, they are unable to explore the process of managing medical uncertainty between the patient and the GP and how differences in understanding and management expectations are negotiated.

Where qualitative research has been completed, the focus has been on exploring patients or GPs individual experiences of MUS management (Salmon, Peters & Stanley, 1999; Dwamena et al., 2009; Nunes et al., 2013; Stone, 2014; Houwen et al., 2017), providing a rich detailed account of the general challenges that present individually to participants from a MUS population group and GP population, but which again do not capture the process of how this is managed between GP and patient. To my knowledge, only one qualitative study has compared and contrasted patient and practitioner experiences to explore this aspect. This study used Interpretative Phenomenological Analysis (IPA) to explore the experiences of MUS management in 18 patients and 18 practitioners recruited from two urban provinces in Canada. The study highlighted the shared frustration and concern between patient and professionals, with the researchers suggesting that the act of highlighting such sameness as opposed to difference may help

with the patient-professional relationship by increasing empathy and fostering greater collaboration (Atkins et al., 2013). However, replication of the study would be needed in the UK to verify the transferability of such results to UK primary care and MUS management, as well as further exploration with patients and GPs as to what they think has helped or would be helpful in facilitating a shared understanding in the patient-GP relationship. As such, this study aims to explore how patients and GPs in the UK understand and manage MUS.

1.11 Research Questions

The aim of this current study is to explore how patients and GPs understand MUS and its management. The following research questions will be addressed:

- How are medically unexplained symptoms understood and managed by patients and GPs?

- What way does their understandings overlap and diverge?

- How are differences in understandings negotiated?

- How can this inform shared decision making interventions to manage medically unexplained symptoms more effectively in practice?

CHAPTER TWO: PROTOCOL DEVELOPMENT

This chapter provides information on how the study protocol was developed, based on the site visit made to the General practice that had expressed an interest in supporting the study, the feedback received from patient and GP study consults and the process of NHS ethics committee review. Details of how these aspects informed the final study protocol will be outlined, along with details of the study design, recruitment framework and sample, and proposed method of data generation and analysis. In order to explore the lived experiences of patients and GPs managing and treating MUS, a qualitative, semi structured interview was selected as the approach to use in line with the aims of the study, as it explores the unique meanings that people attach to their experience (Willig, 2013), as well as highlighting the social processes involved, and where there is the potential for change in the social context (Chamberlain & Murray, 2008. p396).

2.1. Service Context

Recruitment was planned from one GP practice in South Yorkshire who had declared an interest in participating. This practice was reported to have a high proportion of patients who were non-English speakers and have come to the UK from other countries, as well being situated within an area of low economic-status. There were 7 GPs at the practice to manage the clinical needs of the 9,500 patient population that the practice was approximated to serve, holding an estimated MUS caseload of 300 people. The protocol for managing MUS at this practice was reported as being patient-centred, framing and managing the symptoms using either a biomedical route or psychological route dependant on patient related factors. Appointments were booked by patients on the day and got triaged by need.

2.1. 1 Site Visit

A visit was made to this practice during the planning stage which provided an opportunity to see the challenges that presented both for patient and GP in a consultation for symptoms with complex causes and also assess the logistics of introducing recording equipment in to the consultation, in line with one of the methods being discussed (*see study design for details*).

I sat in on a total of six 10 minute consultations related to MUS, all with the same GP. All cases gave verbal consent to the consulting Doctor for me to be present for the purpose of training, and were a mixture of male and female working age patients.

Consultation started by the patient sharing their symptoms and inquiry by the Doctor as to what their own understanding of the symptoms were. It was noted that patients symptoms were often multiple and that there was already some shared idea between patient and GP - even if vague- of the potential causes for their symptoms.

Options for management were varied and included delaying investigation-"*shall we wait?*", doing a blood test but discussing the difficulties of diagnosis by exclusion, putting the patient's request for a secondary care referral into context of the existing negative test results, and asking if the patient still wanted a referral to be made, and the suggestion that relaxation might help to ease the pain.

Difficulties observed in the consultation were as follows:

- The number of symptoms that the patients presented with and how to prioritise them in the consultation time.

- Barriers to GP-patient communication for non-English speakers, with family members interpreting for their relatives.

- The short amount of time in a consultation to complete physical health checks and psychosocial assessment of need, without prioritising one over the other.

- The system pressures on appointment slots and people asking for medication '*just in case*' they cannot get an appointment or see the same doctor when they need to.

In regards to having time to set up any potential study equipment, there was only a short gap between patients and this was used to quickly write an entry on the patient seen and check to see who their next patient was. It was felt that introducing equipment would be placing too much demand on the already limited time constraints of the consultation and was not seen as a viable option at this practice.

2.2 Study design

The method of individual interviews to survey the experiences of both patients and GPs was considered to be the most suitable approach to take. Interviews would be completed at one time point and would include questions that facilitated the participant in wider reflections of their experiences, so as to capture the fluctuating experiences of MUS (Dwamena et al., 2009).

Several alternative approaches were considered. To explore the process of the consultation and reduce the potential of recall error in remembering events, there was discussion of recording MUS related consultations and using the method of interpersonal process recall (adapted by Elliot from Kagan,1980) with patients and GPs. This is an approach where both the GP and patient would be asked to comment separately on the recorded consultation by pausing the recording when they felt it important to comment. Although this had the benefit of being an approach directed by the participants as opposed to researcher led, on reflection this approach was not appropriate for the ad hoc nature of consultations and the extra demands this would place on the GP to obtain consent for recording and setting up the equipment.

Keen to retain the study focus on understanding the process of communication between patient and GP, it was proposed that the study would interview patient and GP dyads separately but directly compare and contrast their experiences of a recent MUS consultation they had shared. It was thought that introducing a dyad aspect to the design would provide a novel approach that could further contribute to the field of research, by providing greater specificity on the process occurring between GPs and patients in the MUS consultation. As such, it was anticipated that recruitment of patients and GPs would come from the same practice.

2.3 Sample Selection

Patient eligibility was based on the following criteria: Aged between 18-65 years; identified by the general practitioner as having "medically unexplained symptoms", had such symptoms for 3 months or more; have frequent attendance status based on clinical judgement of the identifying GPs; have sufficient spoken English and capacity to provided informed consent and take part in the interview. Patients would not be approached if GPs identified them as having a comorbid diagnosis that might impact on their wellbeing and/or the study findings. This might include patients who experience significant difficulty recollecting past consultation experiences or patients who may experience distress being asked to share their experiences.

GP participants would be nominated by the patients taking part in the study, who were asked to suggest a GP from the practice who had the most involvement with the care for their symptoms. A small sample of 3 GP's from an Academic Department of Primary Care in a school of medicine would also be interviewed to maximise variation in professional experience of managing adults with MUS at different practices in Yorkshire, UK.

2.3.1 Sample Size

For this methodology, the number of patients depends on the data elicited and the conceptual themes emerging from the study (Strauss & Corbin, 1990). Although it would be desirable for the sample size to be determined by theoretical saturation, in practice this is seldom achieved and the pragmatic sample size set for this study was between 8-10, which is the precedent established for a Doctorate in Clinical Psychology qualitative research project. As such, the study aimed to get 5 patient-GP paired interviews and 3 interviews with GPs in the Academic Department of Primary Care.

2.3.2 Recruitment Framework

It was anticipated that patients would be recruited purposefully in that the participating practice would be asked to identify patients with MUS who were deemed by their GP to have frequent attendance to the practice with unsatisfactory symptom management and those who have well managed symptoms. The guiding definition provided to GP's as to what constitutes 'MUS' will be informed by Peveler et al. (1997) criteria of there being a presentation of physical symptoms and lack of explanation by a recognizable physical disease. This has been a definition used widely in MUS research, with it being viewed as a way to stay close to how GPs define MUS in their routine clinical practice. Identified cases would then be checked by the GP research lead at the practice to make sure they meet MUS clinical criteria.

Confirmed patients with MUS would be mailed out by the practice, providing them with a practice covering letter that briefly introduced the study, a study information sheet and consent form, and a freepost return envelope. Received expression of interests, as indicated by a returned consent form, would be followed up by the lead researcher by a phone call to introduce the study and agree a date for their interview.

GP-patient dyads for the pairing of interviews were thought to be identified according to who the patient, at the point of expressing their interest, names as the GP they have seen the most frequently about their symptoms. It was felt that this method of identifying GPs would enable patients to direct the studies recruitment of GPs and provide additional data to who the patient predominately identifies their MUS care with. In circumstances where the nominated GP declined study involvement, brief reasons for decline would be sought and the patients named GP would be approached. For any reason a patient could not be analysed as a dyad, this would be coded for and included in the analysis. Where a GP received more than one nomination from patients taking part

in the study, then the GP could participate in one interview for each patient involved in the study.

GPs from the Leeds University Academic school of Primary Care would be sent a study expression of interest email, providing study information details, consent form and evidence of ethical approval. They would be invited to express their interest in the study by contacting the lead researcher on the details provided.

2.4 Interview Procedure

Figure 1. shows the study procedure through to patient and GP interviews. Participants that opt in to the study by returning the consent form would be contacted by phone by the lead researcher. This phone call would enable initial introductions and provide opportunity to address any questions, confirm their consent and arrange a telephone interview slot. To provide further context for the interview data collected, all patient participants would also be asked for permission to access their medical records following their interview. This would consist of using a study proforma to record from the medical records the number of visits to the GP in the last year, type and duration of longest held MUS symptom and the other organizations or services that the patient has accessed for their symptoms over the 12 month period.

Questions from the GP and patient topic guide would be used to semi structure the interviews, which would last between 20-30 minutes for GPs and 30-60minutes for patients. General open ended questions would be asked initially to illicit rich descriptions of what the individual's experience was of MUS, including how this is managed within the patient-GP relationship. All interviews would be carried out over the telephone and would be recorded. Although it has been said that telephone interviews are likely to produce shorter responses and with the absence of non-verbal data may lack the richness of face to face interviews (Breakwell, 2006), for reasons of being more convenient to the patient, it was believed to be the most appropriate method of data collection to use for this study.

At the end of every interview, participants would be asked if they want to receive a summary of the results and given the opportunity to provide their feedback on the themes identified. They would also be asked to confirm if there was anything that they have shared that they would like removing at the write up, and to contact myself within a week of the interview if they do decide they would like to withdraw information. If the patient revealed in the research interview that they were unhappy about the service they had received at the practice, then they would be advised that they have the option to

follow the practice's usual complaints procedure that is detailed on the practice website, and that complaints are held in a separate folder and are not detailed in the patient record and therefore future care will not be affected.

To maximise variation and contrast in professional experience, GPs from the University of Leeds Academic Department of Primary Care (n =3) were initially planned to be invited by email to participate to explore their views and experiences of managing adults with MUS at different practices in Yorkshire, UK. Following receipt of management permission from the Academic Department of Primary Care, it was anticipated that an email would be sent to academic GPs requesting that study expression of interest be indicated through replying to the email sent. The email would have attached a study information sheet, a consent form, and the confirmation of ethical approval. Interviews would follow the same procedure as outlined for GPs and patients above, however academic GPs would not be part of a patient-GP dyad and as such the semi structured interview focus would be on their experiences and practice of MUS management in general, rather than specific cases.

Following the completion of an interview, all audio files would be uploaded to an encrypted password protected university networked drive. Where a transcription service was used, this would be from the university approved list of transcribers who would have been asked to read and sign a transcriber confidentiality statement. All transcribed interviews from each group would be checked for accuracy, whereby I would listen to the audio recording against the transcript provided and make changes accordingly.
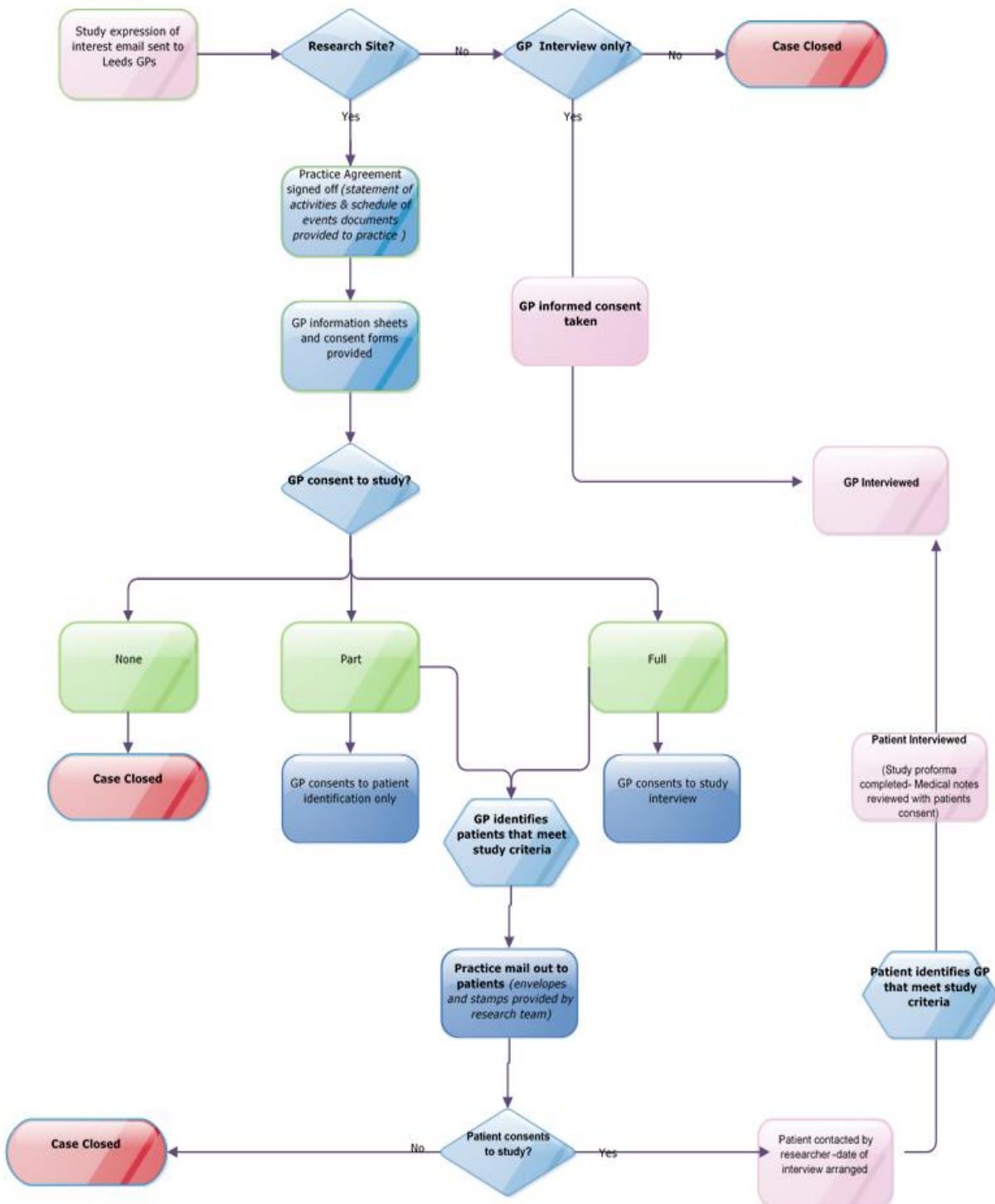
Figure 1: *Recruitment flow chart for the pilot study*

2.5. Informed Consent

All participants would be asked to read the study information provided and contact the lead researcher should they have any questions about taking part. Participants would be asked to opt in to the study by returning their consent form. Consent would then be confirmed over the phone by the lead researcher at point of first contact and before interviews are scheduled.

2.6 Anonymity and confidentiality

All participants would be asked at point of consent to create their own unique identifier-a pseudonym- which could be used throughout the study. Participants would be reminded that no data from within the dyad would be shared with either the participating GP or patient, unless there was a duty of care that needed to be followed with the patient reporting harm to self or others. Patients that had nominated their GP, would be informed that they would not be made aware of their GPs decision to take part as this would not affect their own involvement with the study.

An email approach would be used to invite expression of interest in the study from GPs within the Academic School of primary care. Individual contact details would not be used, but a group email address (where by individual addresses are not visible) or an email sent out on behalf of the lead researcher by the department.

All participants were informed in the study information and consent forms that a pseudonym would be used to support with anonymity of their responses, however that contextual information and direct quotes may be included in the write up. To maintain confidentiality, information perceived as potentially identifiable or sensitive, which had not been requested by the participant to be removed, will be analysed and referred to at the group level, rather than at the individual level.

2.7 Harm to others

All participants would be reminded throughout the interview of the option to pause or stop the recording if they feel distressed at any point. If participants were to become upset by what they were sharing and want to continue with the interview, supportive counselling would be provided by myself (clinical psychologist in training). Where it is felt that patients may benefit from additional support for their needs, this would be

explored with them and it was anticipated that I would need to assess in the moment with them the immediacy and form of support needed.

All participants would be reminded that they do not have to talk for the full allotted time and a manageable length of time for the interviews would be agreed with the participant prior to being interviewed. This would consist of agreeing to complete the interview in two phone calls if necessary or reducing the interview duration.

2.7.1 Discrepancies between practice identified MUS and patient reported MUS
Recruitment was initially based on individual GPs assessment and referral of MUS patients. However, evidence suggests that patients may not identify with having a 'functional' diagnosis when health professionals have referred them into a study (Fullwood et al., 2013), as such both patient and GP guidance was sought in developing the study documents, and careful consideration was made on the appropriate term for 'MUS'.

2.8 Information governance and data protection

Data would be accessed by people in the research team. Where transcribing services are used, a signed transcriber confidentiality statement would be requested and provided.

Returned contact detail forms and consent forms would get stored in a locked filing cabinet at the University of Leeds, in the office of the doctorate programme research coordinator. Recording would be done using one password protected dictaphone and deleted after uploading to the secure university server, the M-Drive.

All study documents would either be confidentiality shredded or deleted from the university secure server after 3 years from when the study ends, in line with the University of Leeds data protection policy.

2.9 Data Analysis

The framework approach was thought to be the most appropriate method for analysing the data, with patient and GP interview data being analysed separately, before being synthesised. The framework approach uses a thematic matrix to manage the data and provides a systematic and transparent approach to how data analysis moves from the descriptive to the explanatory – also referred to as outlining the 'analytic hierarchy'

(Ritchie and Lewis, 2003 p.212). Originally a qualitative approach that was developed for systematically conducting social policy research (Ritchie & Spencer, 1994), the approach has been applied in healthcare research (Smith & Firth, 2011, Ali et al., 2017). This has included primary care research, for example using the framework approach to explore GPs views and local policy on managing multi-morbidity and areas concerned with patient participation, prescribing and clinical decision making (Smith et al., 2010; Bower et al., 2011; Solomon et al., 2012), and as such was felt to be a suitable method for this study to use in a primary care context. The analysis procedure followed in this study would be iterative, moving between the three phases outlined by Ritchie and Lewis (2003) and Smith and Frith (2011) of data management, descriptive accounts and explanatory accounts. The end result of the analysis would be the production of a conceptual framework that captures what is found for patients and GPs; explaining the processes occurring at local level and generating recommendations.

Details for each of the phases of analysis, along with examples, are provided in section 3.6 of the final study methodology.

2.9. 1 Alternative approaches considered

The framework method of analysis was considered most appropriate for understanding the context of the current local guidelines for managing MUS in primary care, as well as the effectiveness of this clinical approach for GPs and patients.   Unlike inductive methods of qualitative analysis, such as Interpretive Phenomenological Analysis (IPA; Smith 1996), and Grounded Theory (Corbin & Strauss, 1990), the framework approach focuses on the questions being asked of the data a priori, which are informed by the needs that have been identified and questions being asked at local level (Ritchie & Lewis, 2003). Although IPA would enable a detailed understanding of both GPs and patients lived experience of MUS, the study was aiming to extend the detailed descriptions of the experience of MUS that already exist in the literature (Salmon, Peters & Stanley, 1999; Dwamena et al., 2009; Atkins et al., 2013; Nunes et al., 2013; Stone, 2014; Houwen et al., 2017) into understanding the process involved in how symptoms are understood and managed between GP and patient.

A Grounded Theory approach was also considered as this would enable the dynamic nature of how a person perceives their experience to be captured (Blumer, 1969; Strauss & Corbin, 1990). It was felt that developing a theory that was grounded in the research data, rather than fitting narratives to an existing theory, may provide greater authenticity to the lived experiences shared and reduce the 'marginalized voice' of

chronic illness (Charmaz, 2008). Although there are various forms of Grounded theory, with different theoretical positions and epistemologies, common to them all is the procedure of theoretical sampling. For this, the number of patients would be determined by the data elicited and the conceptual themes emerging from the study (Strauss & Corbin, 1990). In this respect, sampling to develop an unfolding theory and explore ambiguities in the data may require more participants then would be advisable for a Doctorate in Clinical Psychology qualitative research project, which is between 8-10. As such, it was felt that the sample size may not be enough to capture the nuanced nature of MUS, which may limit the quality of the 'theory' developed (Charmaz, 2006 p.18).

2.10 Data Validity

Achieving trustworthiness of the data would be completed through the procedures recommended by Chiovitti & Piran (2003), which included:

1. Letting participants guide the inquiry process- generating interview questions from previous interviews and consulting with GP and patient representatives on the interview topic guides.

2. Checking the theoretical construction generated against participants meanings of the phenomenon- verify concepts generated by asking participants to review the conceptual framework generated and incorporating feedback in to further refinement of concepts and themes.

3. Using participants actual words in the conceptual framework- consider the words in context and the different meanings they have for participants.

4. Clarifying researcher bias- use a personal journal to support reflection and keep a clear audit trail of how themes were generated.

Quality checks of the data collected would be verified through data triangulation between patient and GP interview. Supervision would also be used to ensure quality of both the categories and the hypothesis being generated.

2.11 Researcher Reflexivity

As the interpretation that I bring to the research will invariably be shaped by past experiences, it is important that I consider where my own potential is for bias.

My interest in the area of MUS has come from clinical training and the health related placements that I completed in secondary care. During these I sensed not only the patient's anxiety about meeting with a psychologist for their symptoms and their concerns that this meant their symptoms were not real, but also the team's concern with how best to manage symptoms with a "functional overlay" and whether current systems were unhelpfully reinforcing illness behaviours. In knowing this, my approach to patients in the study was to emphasise my role as a researcher rather than a psychologist, and to remind them of the study focus and how this was not part of their standard care for their symptoms. I remained watchful of being pulled into advice giving, and remained neutral if the topic of system structures arose.

In addition to having an interest in the area of MUS, the concept of power and how this gets acknowledged by health professionals and negotiated in the therapeutic relationship has also been an area that I have considered greatly, not only in my professional experience but also in my personal experience of communicating with health professionals. As such, I entered into this research from a position of interest in tools that could support with collaboration in patient care, whereby the person accessing a service would have the opportunity to be as actively involved in decisions about their care as they would want to be. This has lead me into the area of shared decision making- a framework of communication applied to areas of physical health management, and recently an emergence in the area of mental health- and whether such a framework could be a viable option in supporting MUS management in primary care. Acknowledging that my own disposition is for patient choice and advocacy, I tried to remain neutral to hearing the broad range of views on preferences in the patient-professional relationship, utilizing opportunities to reflect with my supervisors on the interviews, and also completing the majority of GP interviews once patient interviews had been completed.

2.12 Study Informants

Patient and GP involvement was had throughout the initial development phase of the study protocol, to help develop a study that was reflective of the needs and views of both patients and GPs, with results that could be of clinical relevance.

2.12.1 GP consultation

An expression of interest email was sent to the Academic Department of Primary Care in the University of Leeds, asking for GPs to express their interest in consulting on a study concerned with medically unexplained symptoms in primary care. One GP replied, who also expressed a willingness to act as a field supervisor and for their practice to be involved in recruitment.

Guidance was sought on the appropriate reference terms to use in the study materials in regards to 'Medically Unexplained Symptoms'. It was advised by the GP to make reference to the symptoms being 'long term' with 'complex causes rather than the initial suggestion of 'atypical' or 'unknown' causes, and that any reference to medically unexplainable causes should be limited. Concern was shared that the term commonly used in research in this area -Medically Unexplained Symptoms -might undermine the work done by GPs to move the patient on from seeking a diagnosis to managing symptoms. It was also expressed that the term 'MUS' might imply that GPs had uncertainty about their patients diagnosis and management plan. The term 'functional' was also discussed and was considered by the GP to be less well understood by their patients and would be more vulnerable to misinterpretation in their view, as such it was agreed that neither MUS or Functional would be the main reference terms used for such symptoms.

In addition to developing and reviewing study rationale, reference terms and interview protocol, this GP also provided a supporting statement to the ethics committee that outlined the need and practice support of this study (see Appendix 5). The GP believed there to be a high proportion of patients who presented with medically unexplained physical symptoms at their practice and that this area represented a significant workload for GPs there. This was in reference to the time spent on normalising symptoms in primary care, trying to understand the complex presentation of not one but multiple and extreme symptoms, as well as managing their own and their patient's discomfort at thinking that inadequate care was being provided. Additionally, it was shared that a Clinical Commissioning Group (CCG) priority was to establish continuity of care for all

patients, as a way to develop trust, build up symptom narrative and prevent unplanned A&E admissions. This GP felt that the important and relevant questions to consider in this research would be to what extent continuity of care helps with this patient group and keeping the symptoms 'contained', as well as the extent to which they got the same response from everyone that they saw.

2.12.2 Patient consultation

Access to patient consultation was gained via the consulting GP, who was able to recommend a patient who had lived experience of long term symptoms with complex causes who was willing to consult on the study. Study materials were reviewed by the consulting patient, as well as feedback obtained on the relevancy of the research rationale and testing out the study explanation given at the initial approach to participants. In general they felt that the study was interesting and was relatable to their own experiences of finding it difficult to share their own understanding of their symptoms with their GP. In addition it was reported that finding ways to make the consultation feel more patient centred would be of benefit.

Initially it was proposed that the interview would be introduced to participants in the following way:

> "…*an interview to further understanding on how patients and their GP's understand and manage long term symptoms which cannot be medically explained or that have atypical causes.*"

Feedback from the consulting patient on this introduction was as follows:

1.) The explanation was clear, however 'atypical' was recommended to be replaced by either the words unusual, uncommon, unknown causes.

2.) The explanation is accessible and lay person friendly

3.) The term 'medically unexplainable symptoms' should be avoided in any further elaboration, as might not mean much to people and if it is being used by GPs, then it might not be shared with the patient.

When asked how they would feel talking in greater depth about their experiences, they shared that they thought it might help to give a person a "birds eye view" of their experiences, and that they already felt more positive and passionate after having spoken briefly about their experiences and that this came from a place of spending so long trying to "mask" the problems. They did not report any concerns with the initial proposal of using the method of paired interviews, which they had stated was a method of providing

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"useful" feedback to the practice regarding the level of shared understanding found between patients and GPs.

One further contact was had with the consulting patient Subsequent contact helped finalise the patient study documents and study protocol, which had been required to be amended following the outcome of the initial Research Ethic Committee review.

2.13 Ethics feedback

The study's initial submission for Research Ethic Committee (REC) review was on September 2017. This was reviewed a further three times before full approval was provided in January 2018 (Appendix 1). Table 1 provides the feedback obtained from the committees and how this influenced the method used in the study. Their main concern was that the dyad aspect of the study would risk the "breakdown" of the patient-GP relationship, as patients or GPs may be able to identify themselves in the publication of the results. Despite the dyad aspect of the study being removed, concern remained that recruitment for patients and GPs would only be from one practice, increasing the risk of participants identifying themselves or each other.

This concern was acknowledged, however it was felt that the risk of 'breakdown' between patient and GP had been reduced by the participants only being asked to share their general experiences of MUS management and not specific details about their experiences. Although participants may still share specific details or provide contextual identifiers, despite not being directly asked, it was felt that in adherence to the ethical principles described in the Belmont Report (1979) for respect for persons, the level of confidentiality should be the choice of the research participant as an autonomous agent. Participants should therefore be given the choice about how they want such data handled, enabling respondents to specify particular pieces of their data that should remain confidential at the end of their interview. In addition it was clarified that if the University perceived there to be potential risk for harm to individuals if the results were published, the University of Leeds policy for all Doctoral theses is that there is an option at submission to embargo all access to the thesis both physically and online, for a set number of years.

Table 1: *The process of REC review and the refinement of the study idea*

ETHICS PANEL	DECISION	RATIONAL	SUGGESTION	RESPONSE
Leeds East Research Ethics Committee 17/YH/0285	*Unfavourable opinion*	*"Potential for a relationship breakdown to occur, it was considered that this could be quite significant, between both the patient, GP, and the practice."* *"…concerned that the first time the comments might be seen could be through*	*The patient and GP dyad group could still be used; however measures should be put in place to discuss any issues following the interview to prevent any relationship breakdown*	The protocol was amended to outline the measures put in place to manage any issues following the interview. The measures included were: - Option of university embargoing sensitive data (up to 20 years), if publication of results are deemed to be detrimental to relationship between patient, GP, or practice. -Participants will all be provided with the option of a debrief telephone session to discuss any issues following the interview. Where patients have reported concerns regarding the management of their care by their GP, then as per new protocol, they will be advised to follow the anonymised

		the published results of the study"		complaints procedure outlined on the practice website.
		"....too small and focussed, and the results too easily identifiable as only one GP practice was being used, this would make anonymity almost impossible and compromise confidentiality"		
Cornwall & Plymouth Research Ethics Committee **17/SW/0242**	*Unfavourable opinion*	*"...the patient-GP dyad method could potentially destroy or alter the patient-GP relationship."*	*"ethical concerns would not be raised if the GP was to be interviewed independently to gather generic opinion, rather than specifically matching them to their patient."* *" the Committee wished to strongly recommend*	The dyad aspect of the study was reconsidered. As such, the study proposed that it will no longer be looking at GP patient dyads, and patient and GPs will be interviewed separately about their general understanding and experience of MUS and its management.

			using GPs from a separate practice to patients to avoid the potential for GP-patient relationship breakdown."	
Leeds East Research Ethics Committee	*Provisional opinion*	*"concerns for disruption to the relationship between the GP and the patient with the current study design..."*	*"…Provide robust assurance that the relationship between GPs and patients would not be negatively affected and explain how this would be the case."*	Letter from the GP leading on the study at the practice wrote a letter to assure REC that the number of patients potentially eligible for the study was sufficiently high enough to protect patient anonymity. It was acknowledged that the study could recruit patients with whom GP respondents have a working relationship and may be able to identify them from research output, however this would be addressed at multiple stages of the research process-data collection, data cleaning, and dissemination of research results.

2.14 Protocol development work: The outcome

2.14.1 Process Findings

The process has highlighted the barriers and facilitators of developing and setting up a clinically relevant study in the 'real' world, which are detailed below.

Barriers

Qualitative research into the therapeutic relationship was highlighted as a concern when a dyad method was proposed for a therapeutic relationship that was current. From what has been reported regarding the local CCG priority for all patients in primary care - continuing care to build the illness narrative and prevent A&E admissions- it is possible that this view is widely held, with understandable concerns for anything that may potentially threaten the relationship. For the research ethics committee, it would seem there was an implicit assumption that patients were able to routinely see the same GP for this relationship to take on this significance, as well as anticipating that difficulties would be disclosed from both GP and patients and that the first time the GP or patient would be aware of this would be from the results of the study. It was interesting to see how this view was in contrast to the patient representative and GP consulting on the study, both of whom perceived the study as providing a method of constructive feedback, with a hope that this could help improve the relationship, rather than "destroy" it. It would seem that in addition to the method of dyads being used to explore the relationship in primary care being a barrier, there was a wider concern that it would be inviting blame.

Facilitators

An important factor that helped with the process of developing the study and getting it set up, was identifying a GP who would be involved throughout the process, which included leading on the study at the practice. Being able to provide ethics with the number of potential participant's eligible was helpful in assessing potential anonymity of patient participants. In addition to this, it was important to evidence how patients would be given the choice to say at what level they would be happy to have their data included in the write up, providing participants with the choice at the level of anonymity they want, rather than the decision being made on their behalf.

The site visit that was also made, helped to think about the structure of the consultation and the feasibility of certain study designs and procedures. This provided an opportunity to also meet the GPs, as well as build an understanding of what was clinically relevant to the needs of the practice. This helped to provide evidence of the feasibility of the approach being proposed.

Lastly, accommodating some of the suggestions made by the research ethics committee did help to simplify and focus the study. However, it was also important that I persisted on other areas that were deemed important from the consultations had with both the patient and GP consulting on the study, and reiterating the rational for why certain aspects were deemed important to retain.

2.14.2 Implications on final study methodology
The aim of the study was to explore how patients and GPs understand MUS and its management. This was going to be achieved by addressing the following research questions:

- How are medically unexplained symptoms understood and managed by patients and GPs?

- What way does their understandings overlap and diverge?

- How are differences in understandings negotiated?

- How can this inform shared decision making interventions to manage medically unexplained symptoms more effectively in practice?

The aim of the study did not change following patient, GP and ethics review. However, changes were made to the study protocol and final study methodology. Table 2. summarizes the changes made to the study following the development work, with further detail provided in the next section.

Table 2: *Summary of methodology changes following protocol development work*

DEVELOPMENT WORK	FEEDBACK	FINAL METHODOLOGY
GP Consultation	*Difficulty in getting recent MUS rather than pre-existing as need a history and known to service for it to be classed as MUS.*	Study focused on persistent MUS (unexplained symptoms >3 months). Inclusion criteria indicated duration of symptoms.
	Frequent attendance is not getting at the real challenge of managing this patient group-may capture well managed MUS, or illness co-morbidity.	Frequent attendance was initially removed following GP feedback. However, following REC 2 comments, this was negotiated to be frequent attendance based on the clinical judgement of the GP rather than arbitrary number of consults over a specified period.
	CCG priority- to what extent does continuity of care a.) happen at the practice b.) contain the complex symptoms in primary care.	Initial protocol included a medical note review to help capture patient service use for symptom management. This was removed in the final methodology due to REC 2 feedback.
	'Long term symptoms with complex causes', to be used in study material rather than 'medically unexplained symptoms'.	Language in the study materials and in the aim and research questions for the study were altered to reflect the preferred terminology to use instead of 'MUS'.
	Patients to be directed back to their GP or given Samaritans number, if risk disclosed. If appropriate, direct them to ask for a referral to the IAPT team via GP.	Risk information was added to the interview schedule to act as a prompt.
Site Visit	*Adhoc consultations and time pressures in the consultation would make it difficult for the GP to introduce the study and set up any recording equipment needed to capture the consultation process.*	Individual interviews were completed to survey the experiences of both patients and GPs. The initial protocol outlined that this would incorporate a 'dyad'

		aspect to capture the relational processes occurring between patient and GP. This dyad aspect was removed in the final methodology following REC 2 feedback.
Patient Consultation	*Dyad aspect is a useful method of providing feedback to the practice about the process occurring between patient and GP in complex symptom consultations.*	Although the dyad aspect of the study was removed following REC 2 feedback, the final methodology was approved that patient and GPs could be recruited from the same practice.
	Change any reference to 'atypical' causes, for 'unusual', 'uncommon', or 'unknown' causes. *Avoid reference of MUS*	Use of the word 'atypical' symptoms to refer to MUS was removed from protocol and in language used to introduce the study.
REC Review 1	*A recommendation that a method other than pseudonyms was used, e.g. 'Participant A'*	Participants anonymization was altered from pseudonyms to participant labels e.g. 'Participant A'. Participant information sheets were updated to reflect this change.
	Potential for conflict to occur as there were no measures in place to resolve any issues which may be brought up following the interview	Potential conflict would be addressed by providing participants with the option of a debrief telephone session to discuss any issues following the interview.
	The Committee was concerned that the first time the comments might be seen could be through the published results of the study.	The university's right to place an embargo on the thesis (up to 20 years) was included in the methodology.

REC Review 2	The current defined patent group would not give an idea of the severity/demand on the health service, the relationship with the health service, or the exact problem the patient themselves would be having. They stated that using patients who were frequent attenders with medically unexplained symptoms, for example, could give more meaningful results.	Inclusion criteria altered to include frequent attendance as determined by the clinical judgement of the study GP.
	Ethical concerns would not be raised if the GP was to be interviewed independently to gather generic opinion, rather than specifically matching them to their patient.	Individual interviews were completed to survey the experiences of both patients and GPs. The focus of this was altered to generic experience, rather than shared experience within the dyad. Changes made to the participant information sheets and interview schedules to reflect this.
REC Review 3	Ongoing concerns for the disruption to the relationship between the GP and the patient with the current study design [individual interviews, not dyad, but at the same practice].	Confidentiality process updated. Participants were asked to specify the level of confidentiality of their interview post –interview.
	Committee noted that access to participants' medical records would be required to verify information given by participants and queried why this was and that this would make the patient identifiable.	Reference to reviewing medical records was removed.

CHAPTER THREE: FINAL METHOD

This chapter provides information on the final study that was developed with the feedback and guidance that came from the Research Ethic Committees, GP field supervisor and the patient study informant. The focus of this chapter will be to provide the revised study design, the recruitment framework and further details on the method of data generation and analysis used. Details regarding the service, sample, the process of informed consent, the ethical considerations, information governance and data validity have remained unchanged and will not be repeated in full here.

3.1 Study design

A qualitative approach, using semi-structured interview was still believed to be the most appropriate approach to use in line with the aims of the study, for reasons previously stated. Due to the concerns raised regarding the dyad aspect in the study development work, the design was adjusted so that patient and GPs would be interviewed separately without a necessary association, about their general experiences of MUS.

Recruitment of patients and GPs occurred at the same practice. This was considered to be an important part of the quality control framework for the study, supporting the overall trustworthiness of the qualitative results by increasing credibility of the conclusions made and helping to provide some control over contextual factors to increase the transferability and dependability of the results.

3.2 Sample Selection

The eligibility criteria for patient participants remained unchanged. However, GP participants were now eligible to participate if they were from the recruiting practice and had clinical experience of managing Medically Unexplained Symptoms. GPs from the Academic Unit of Primary Care in a school of medicine were going to be approached to participate if GP recruitment needed to be opened up further.

3.2.1 Sample Size

For reasons previously stated, the sample size aimed for between 8-10 participants, consisting of a minimum of 4 patient and 4 GPs interviewed.

3.2.2 Recruitment Framework

Patients were recruited purposefully, with the participating practice identifying patients with MUS who were deemed, based on clinical judgement, to have frequent attendance to the practice and had a presentation of physical symptoms with lack of explanation by a recognizable physical disease.

Identified cases were then checked by the lead research GP to make sure they met MUS clinical criteria. A study invitation letter, which was signed by the lead research GP and written on practice headed paper was then enclosed in the patient study packs provided (Appendix 2). The study packs that were sent by the practice contained a study information sheet, a consent form, a contact details form (Appendix 3 and 4) and a freepost envelope. Patients were only contacted by the study team once they had opted in by returning their signed consent form and contact details. GPs were recruited to the study via a presentation to practice staff, where they were invited to express their interest in the study by contacting the lead researcher on the details provided or returning their consent forms in the free post envelopes provided to the practice.

Participants were identified and interviewed following the process outlined in Figure 2. Where it was possible, GPs who had expressed an interest in taking part in the interviews were booked in for an interview once patient interviews were completed. This was done in an attempt to remain neutral when hearing the GPs narrative. Recruitment occurred throughout March-June 2018.
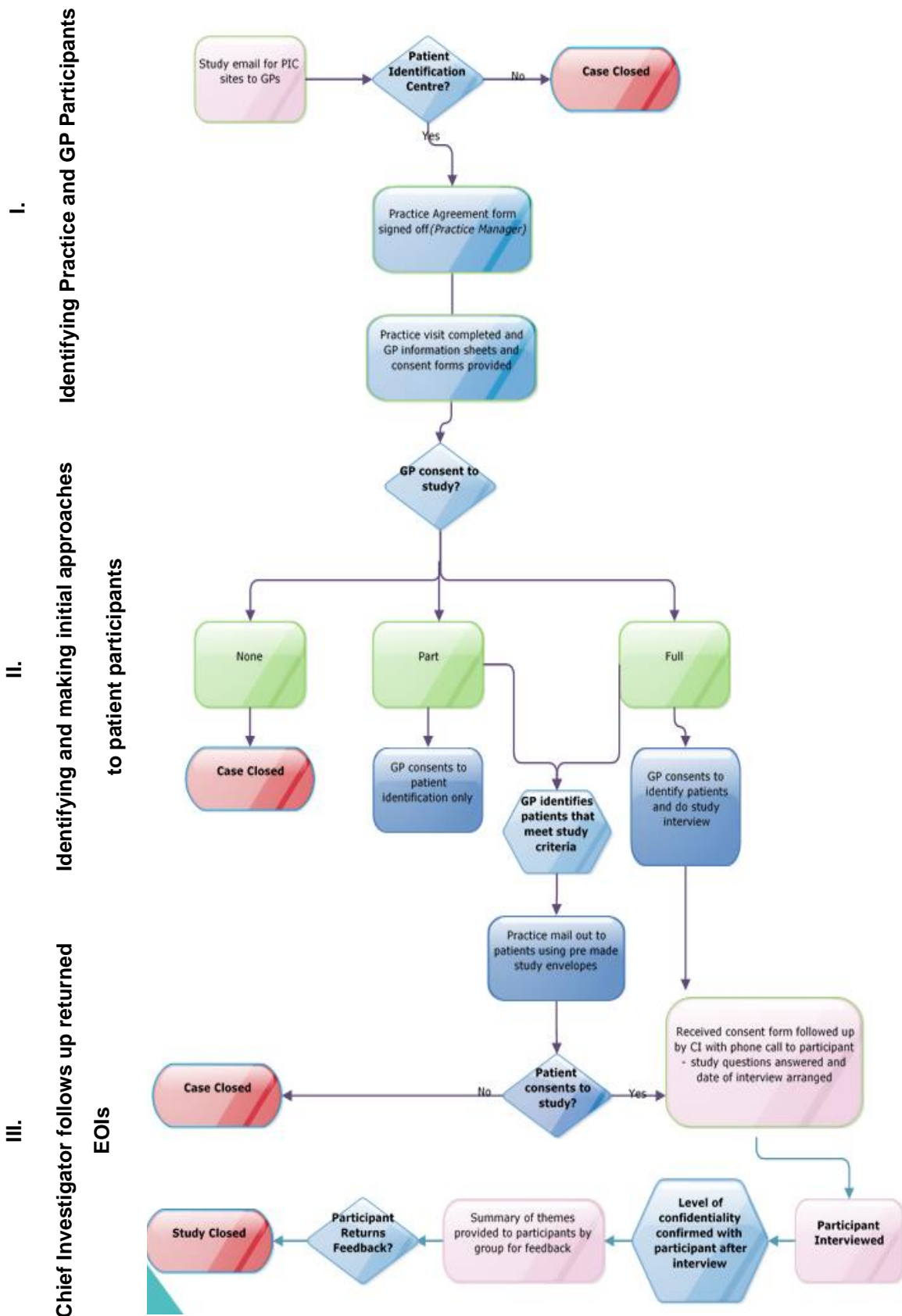
Figure 2: *Recruitment flow chart for the approved study*

3.3 Participants

As all participants had to be living in the catchment area of the recruiting surgery, the social deprivation score was calculated for the practice using http://dclgapps.communities.gov.uk/imd/idmap.html. A score of 1 out of 32,844 indicates the most deprived area in England to the largest number being the least deprived area. The score for the area was 2,389 out of 32, 844 within England.

All GPs recruited to the study had spent the majority of their career in general practice at the same surgery. The sample consisted of GPs that were currently practicing at the surgery and GPs that had within the last two years retired.

3.4 Interview Procedure

Participants that had opted in to the study were contacted by phone by the lead researcher. The phone call was less than 20 minutes and provided opportunity to remind the participant of the study, address any questions, confirm their consent and arrange an interview slot. Participants were reminded that unless they had a particular preference for not completing the interview over the phone, then the next contact over the phone would be recorded, but that they could stop the recording at any time.

Questions from the GP and patient topic guides, as shown in Figures 3 and 4, were used to semi-structure the interviews. General open ended questions were asked initially to illicit rich descriptions of what the individual's experience was of MUS. Subsequent questions were based on the literature reviewed in section one, and were broadly concerned with the following concepts for both patient and GP: the symptom narrative of the complex symptom(s)- the effect and impact, the process of developing symptom understanding, symptom management, the patient-GP relationship.

Data collection and analysis were interrelated, whereby themes generated in initial interviews informed further questions and topics to be covered in subsequent interviews so that later interview questions became more focused. For example, a question was introduced after the initial two GP interviews to explore how GPs decided what information got discussed with the patient. Similarly for patients, with a theme of patient involvement emerging from the initial interviews, the extent to which patients wanted to be involved in decisions made about their complex symptoms was included in subsequent interviews. Where GPs or patients

requested shorter interviews, the number and order of the questions on the interview schedules were adjusted to priorities gathering participants perceptions on their complex symptoms and management of them.

Concept	Instructions / Questions
Introduction	Introduce self, study, interview, any questions? Begin interview: **Tell me about yourself...**
Patient's symptom narrative: effect & Impact	**Can you tell me about your experience of living with long term symptoms that have complex / unknown causes...?** **How, if at all, were you affected by their being complex / unknown causes for your long term symptoms?** *What thoughts did you have? How did you feel? Impact on you and your relationships?* *P: why do you think that was? Was it worse/ better at some points more than others?*
Process of understanding	**How do you make sense of these symptoms?** *What has been helpful / not helpful to you in understanding your symptoms? Do you have any particular concerns about your symptoms- if so, what are they?* **How has your understanding of these symptoms changed over the time you've had them?** *P: why do you think these changes have occurred? Responses of others? When did your understanding begin to change?*
Symptom management	**How do you cope with the symptoms?** *What have you found to be most helpful / not so helpful?* **What are the treatment options that have been suggested by others?** *By who? Helpful / unhelpful? Did you have any expectations about management options?* *P: why do you think that was? How did that make you feel? Did you feel a particular way towards any of the options outlined? What were your thoughts? How did you respond?*
Relationships	**Can you think of a time when there has been disagreement or misunderstanding within a consultation for your symptoms?** *What did you do? How did you feel? What helped the consultation?* **What advice would you give to other patients who are seeing their GP for symptoms with complex / unknown causes?**
Concluding the Interview	**How has this interview effected how you have thought about your experience of managing your symptoms with unknown causes?**

Figure 3: *Patient topic guide*

Concept	Instructions / Questions
Introduction	Introduce self, study, interview, any questions? Begin interview: **Tell me about the practice and the type of patients that you see...** *P: how as a practice do you define 'frequent attenders?*
GPs narrative: effect & impact	**Can you tell me about your experience of working with long term symptoms that have complex /unknown causes...?** **In what ways does the experience of their being an unknown cause for a symptom, affect a.)You as a GP b.) The consultation c.) the practice** *P: why do you think that is? What makes it easier / hardier to manage?*
Process of understanding	**How do you make sense of these symptoms?** *What has been helpful / not helpful to you in understanding their symptoms?* **How has your understanding of these symptoms changed throughout the consultations?** *P: why do you think these changes have occurred? Responses of others?*
Symptom management	**How do you manage these symptoms within the consultation?** *What has been most helpful / not so helpful for you, your clients in general?* **What are the treatment options provided for patients with MUS?** *Did you have any expectations about the management options you consider? What effect if any do they have on what management options you share with your patients? P: why do you think that is? How does that make you feel? How did you respond?*
Relationships	**Can you think of a time when there was disagreement or misunderstanding within the consultation?** *What did you do? How did you feel? What helped the consultation?* *If not- what do you think has helped with this being avoided?* **What advice would you give to other GPs who are seeing patients for symptoms with complex / unknown causes?**
Concluding the Interview	**How has this interview effected how you have thought about your experience of managing symptoms with unknown causes?**

Figure 4: *GP topic guide*

At the end of every interview, participants were asked if they wanted to receive a summary of the results and informed that they would have the opportunity to provide their feedback on the themes identified. In addition, all participants were asked again at the end of their interview to confirm the level of confidentiality for what they had shared, and if there was anything they did not want including in the write up. This provided an opportunity for respondents to specify any particular pieces of their data that should remain confidential, as well as further opportunity to discuss with them any sensitive areas and answer any questions they may have regarding the research.

Following the completion of an interview, the audio file was uploaded to an encrypted password protected university networked drive. To support data familiarity, all the interviews from each group were transcribed by myself. All transcripts were checked for accuracy, whereby I listened to the audio recording against the transcript provided and made changes accordingly.

3.5 Ethics

Ethical approval for this study was granted by Full Research Ethic Committee Review by the Leeds East sub-committee in January 2018. Full HRA approval and local Research and Development approval was granted in February 2018 (see Appendix 1). Practice level agreement was provided subsequently, with the practice reviewing and signing the schedule of events form. Prior to external approvals the study was reviewed by two academic panels at the University of Leeds.

3.5.1 Anonymity and confidentiality

Patient participants were sampled from a list of 300 patients that met study criteria for Medically Unexplained Symptoms, which was considered high enough to reduce the risk of GPs being able to subsequently identify individual patients from outputs of the research. In addition, GPs were not informed which patients took part, nor were individual GPs aware of who from the 300 cases had been considered by the lead GP as meeting both inclusion/exclusion criteria, which includes meeting frequent attender status ($n=$ 72). A sample of GP participants was also taken from the expressions of interest received from the GPs at the practice and information about which GPs opted in were not provided to the practice or patients. All

participants were allocated a participant identification label at point of consent, for example 'Patient A' or 'GP B'.

It is recognised that the need to maintain participant confidentiality and anonymity in research, whilst also providing rich and detailed accounts of people's unique experience, can pose an ethical dilemma in qualitative research (Kaiser, 2009). As it is important to treat research participants as 'autonomous agents' (Belmont Report, 1979), it was felt that a choice over the level of confidentiality should be provided to the research participant by informing them at the start of the interview of the option to pause recording at any time, or request that specific data be removed up to one week after the interview. Participants were again reminded of the option to remove sensitive data at the end of the interview.

All participants were informed in the study information and consent forms that a pseudonym would be used to support anonymity of their responses, however that contextual information and direct quotes may be included in the write up.

3.6 Data Analysis

The framework approach was used in the analysis of the data, with patient and GP interview data being analysed separately, before being synthesised. The analysis was an iterative procedure that moved between the three phases outlined by Ritchie and Lewis (2003) and Smith and Frith (2011) of data management, descriptive accounts and explanatory accounts. Further details of this analysis process is described below.

3.6.1 Data management
Initial codes and categories for the data were generated by going through each of the transcripts line by line, thinking about what the essence of the sentence was about. An excel spreadsheet was used to help create a coding matrix, which helped to break up the transcripts in to data chunks. Key phrases from the transcript that were felt to capture an initial code – a pocket of information that seemed to capture emotion, processes, the relationship between events- were then used to provide in vivo codes. Using in vivo codes is an essential part of Framework Analysis, as it has been reported to be a way of staying close to the data (Ritchie & Lewis, 2003). The essence or function of what is being captured in the descriptive code was then considered, with this appraisal then informing the development of a category. As

coding moved through the transcript, these categories became more abstract as similar codes were found and clustered together.

Figure 5. Provides an example of the coding matrix developed to support the process of moving from initial data sourced codes to categories from Patient B's transcript. The coding matrix process was applied to both Patient A and Patient B's transcripts, as well as a separate coding matrixes being developed for GP A and GP B's transcripts. Rather than just have one example from each participant group, two examples were used as a way to get some variation in the initial categories developed.

	A	B	C	D
1	Interview Transcript: Patient B, 52 year old female, Fibromyalgia since 2012, white-british, long term sick	Description (In Vivo Codes)	Preliminary Throughts (What is this about)	Initial Catagories
9	I were thinking 'I bet I am one of those people that he's going to say 'your blood is fine, it's fine' and then in a few months' time 'sorry, there is nothing we can do for you'. And I've got it in to me head- doctors knew how I felt –and they reassured me 'no it is nothing'.	I bet I am one of those people...And I've got it in to me head-doctors knew how I felt	feeling unlucky / Dr's knowing the feeling	feeling unlucky / view about doctors knowing how you feel
10	Pain started getting worse and worse and me leg- I'd lay in bed and I'd cry, bottom of me back and I had a lot of trouble with bottom of me neck-it frightened me. It goes on and on and I've been to the doctors and they have given me tablets but I phoned up.. and then...and some mornings I can't move.	It goes on and on	feeling overwhelmed.	feeling frightened
11	I phoned the doctors-and I say 'I really need to see a doctor-I just cannot move- me neck, I can't get out of bed -"oh well we can put your tablets up- put your gabapentin up". I want no more tablets! I am having far too many tablets, my life has changed in such a big way.	I phoned the doctors-and I say 'I really need to see a doctor-I just cannot move-me neck, I can't get out of bed /I want no more tablets! I am having far too many tablets	not feeling understood	help seeking / no more tablets
12	I don't go out no more, er..the anxiety-me panic attacks – real bad panic attacks- I just cry all the time- I'm going to get sad now..[crying]..	I just cry all the time- I'm going to get sad now	feeling overwhelmed and sad	crying all the time

Tabs: Patient A Initial codes | Initial Catagories and Themes A | **Patient B Initial codes** | Initial Catagories ...

Figure 5: *Example of coding matrix used to analyse initial transcripts for both patients and* GPs

Following the initial construction of a list of categories for the two patient participants and two GP participants, the two participant groups were separately reviewed for areas of category overlap using post-it notes. As indicated in Figure 6, overlapping categories were amalgamated together into sub-categories (orange post-it notes). These sub-categories were then considered and clustered in to themes initially using the conceptual framework of clinical decision making: *health beliefs and expectations, management options, values and preferences* to order the data, but was subsequently expanded to capture the variety and additional themes emerging.

This process formed the basis of a coding index, which would list by each theme the sub-categories that were associated with it, and was applied to subsequent interview data. Any new categories identified in the process were then incorporated into either existing themes and sub-categories or encouraged the creation of new ones (see appendix 6 for examples).
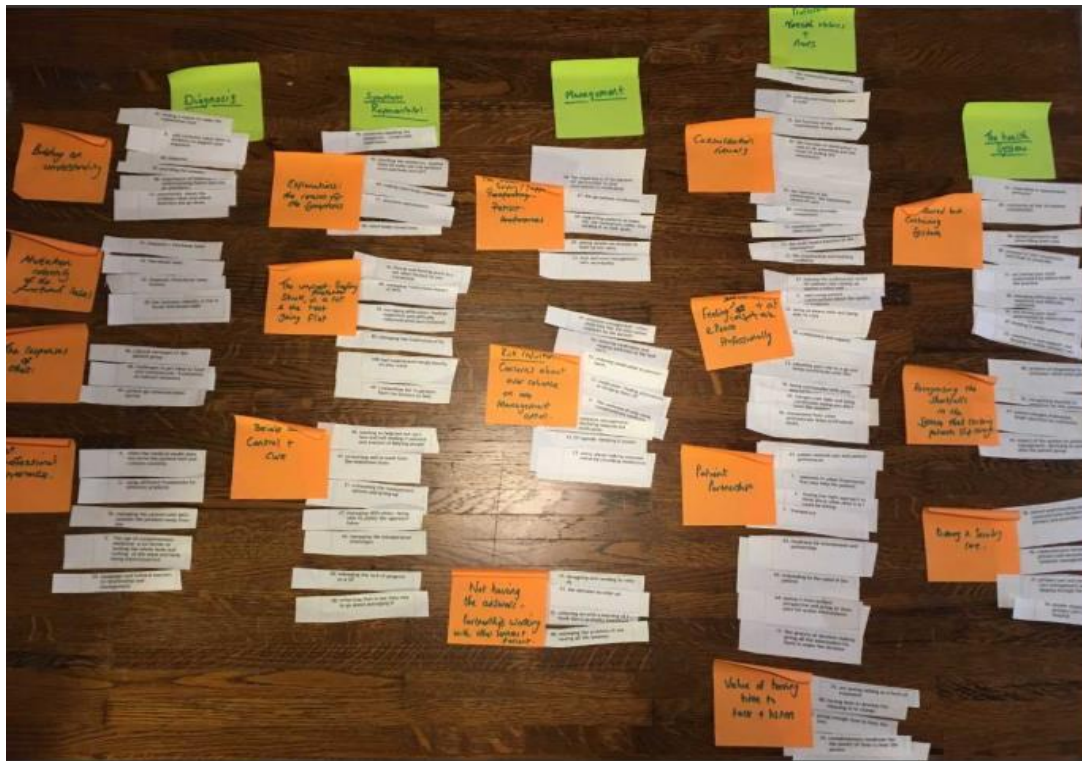
Figure 6: *The process of grouping the initial combined categories in to sub-categories and themes*

3.6.2 Descriptive accounts and explanatory accounts

Once all transcripts had been coded, the next phase of data analysis was to synthesize the variation within the data set. This was done through generating a series of maps for each of the individual themes. Figure 7 shows how a thematic map was created to highlight how issues related to each other within the sub-categories identified and also how they related to other subcategories. This also enabled me to see any patterns occurring at the individual level, as well as group level. Meanings of the codes were constantly checked against the original transcripts to make sure that the codes were not losing their context.
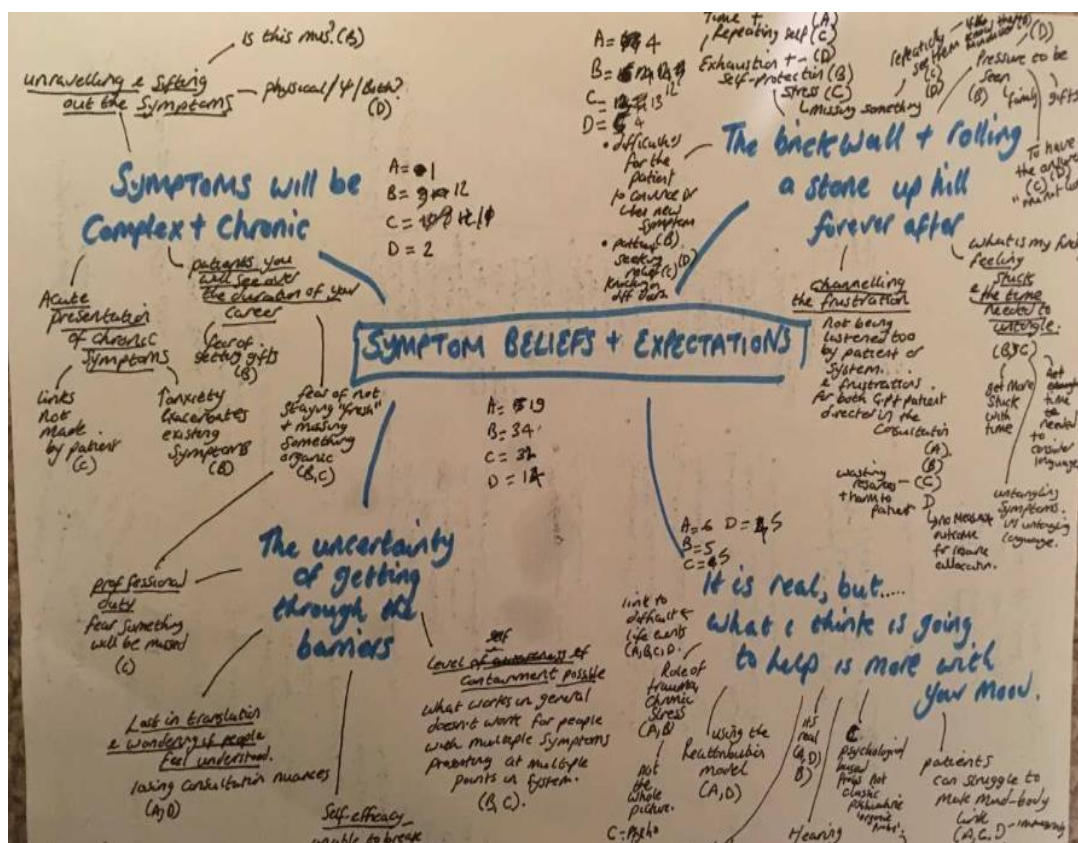
Figure 7: *Thematic map of the GP theme "symptom beliefs and expectations"*

An overall thematic map was also created for both the patient and GP group of participants, as shown in Figure 8. These were then compared and contrasted and more abstract concepts were generated to develop an explanatory account of how patients and GPs understood and managed medically unexplained symptoms. The end result of the analysis was the production of a conceptual framework and generating recommendations. Where participants had consented at interview to being sent a study summary sheet of the results, these were sent out via the email addresses the participants had provided at the initial contact. Participants were provided with a summary of the themes from their participant group (patient or GP) and a copy of the conceptual map. Participants were asked to reply to the email with any feedback that they had about the themes or map and that this would be included in the discussion. A summary of the themes for both participant groups and the conceptual map was provided to the GP field supervisor who was overseeing the study at the practice. They were also asked to review and provide email feedback, which again would be included in the discussion.
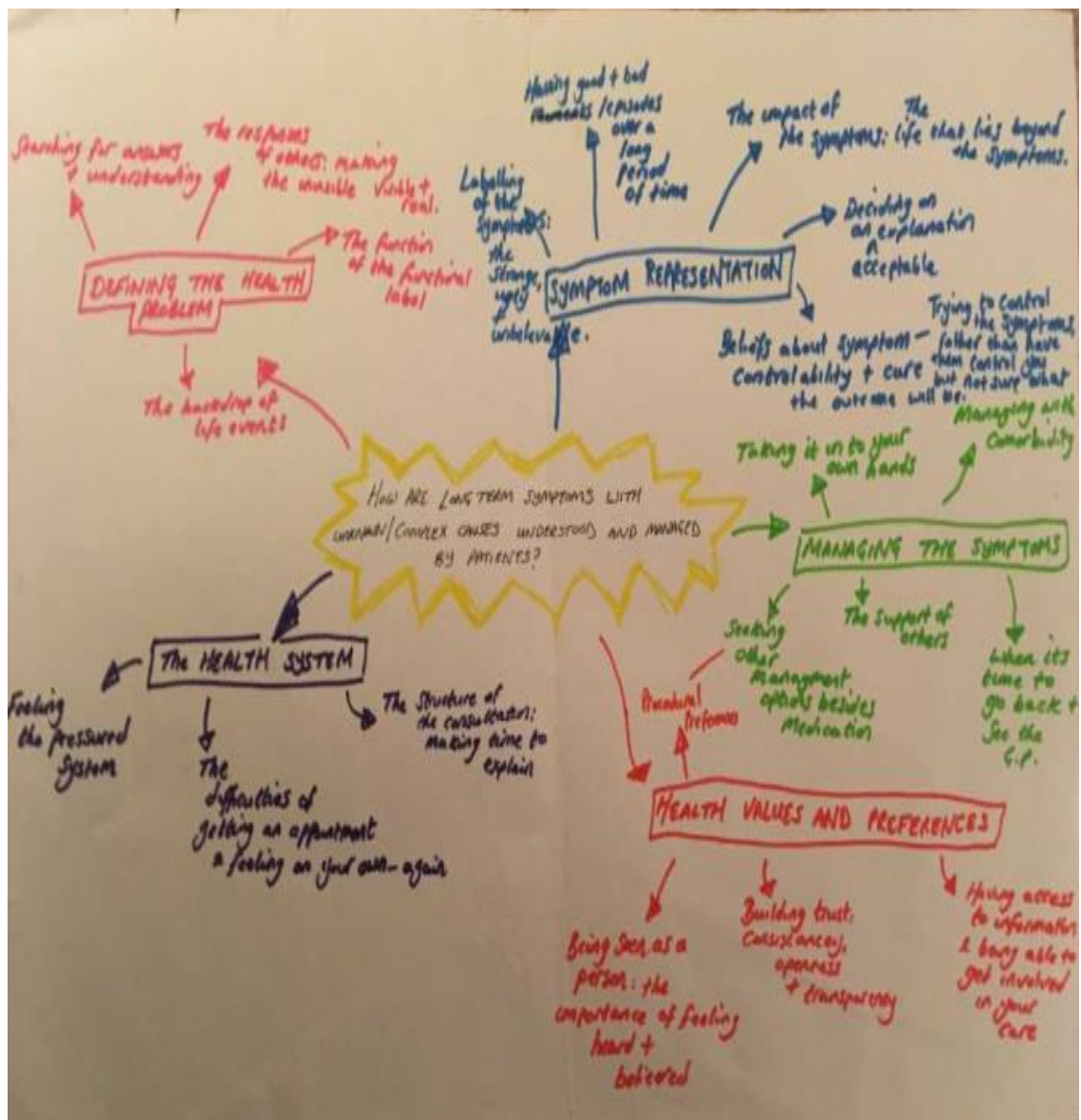
Figure 8: *Example of overall thematic map for patient's experiences of understanding and managing their MUS*

CHAPTER FOUR: PATIENT RESULTS

This chapter will begin by providing context for the patient interview data collected and pen portraits for each of the patient participants. The main and subthemes from the participant's data will be presented in a table and supplemented further by rich description of the themes presented. Illustrative extracts will be provided throughout, with direct comparisons being made between participants reported experiences of managing MUS.

4.1 Patient participants

A total of 300 patients were deemed eligible on an initial screen for patients with MUS. Following the full application of the inclusion/exclusion criteria, a mail out was completed for 72 patients. Six patients opted in to the study, ranging between 44-62years of age (see Table 3). All patients had chronic symptoms, with duration of the longest held symptom varying from 2-20 years. All patients reported chronic pain and for most of the participants they had received a functional label for their symptoms of Fibromyalgia (n =4), whilst two patients had not.

Table 3: *Participants' demographic and symptom information*

Participant	Age	Gender	Ethnicity	Complex symptoms	Occupational status
Patient A	*52*	*Male*	*White-British*	*Fibromyalgia*	*Employed, Part time Support Worker*
Patient B	*52*	*Female*	*White-British*	*Fibromyalgia*	*Long term Sick, worked in café*
Patient C	*53*	*Female*	*White-British*	*Persistent pain in legs, suspected restless leg syndrome*	*Employed, part time health screener and volunteers*

Patient D	*48*	*Female*	*White-British*	*Fibromyalgia*	*Employed Full time commercial manager*
Patient E	*62*	*Female*	*White-British*	*Fibromyalgia*	*Medically retired Nurse*
Patient F	*44*	*Male*	*Arab*	*Chronic pain and muscle weakness in upper back*	*Long term sick / refugee status, worked in Education prior to living in UK*

4.2 Patient pen portraits

These pen portraits aim to contextualise the data collected and illustrate the uniqueness of people's accounts. Although medical note review had originally been proposed to provide context to the participants interviews, ethical permission for notes review was not given due to concerns about potential threats to anonymity. As such, pen portraits were provided for each participant, with the rich descriptions provided for each enabling the reader with a holistic understanding of each individual, which may not have been conveyed through the use of individual quotes alone (Hollway & Jefferson., 2013).

4.2.1 Patient A
Patient A had been living with pain for 7 years, which he was trying to manage through a combination of using the behavioural techniques learnt from pain management, making healthy lifestyle changes in terms of diet and exercise, and also taking prescribed medication that he was currently reducing. He had a history of depression before the onset of his pain, which at times in the past has required secondary and tertiary care involvement. He was particularly concerned that health professionals were attributing his physical health symptoms to being something that "was all in my head" and when the study was first introduced, questioned if this was my position too. He did not identify with the label given for his symptoms, and it was clear that he wanted greater understanding of both the mind and body and how they might interact.

He focused a lot in the interview about his suspicions that health professionals were withholding sharing their professional opinion about what they thought his symptoms were, or withholding further investigations. He felt that this might be occurring out of a professional fear of causing either him harm through triggering him to have a 'breakdown' or a system breakdown through spending money that the NHS did not have. Patient A seemed to manage this distrust by trying to "get on with it" without "bothering" his GP, and felt "lucky" to have the support of his wife, faith, friends and employer, all helping to provide him with a feeling of acceptance and stability that help to manage distressing thoughts that at times could be suicidal in nature.

He was the only person who talked of having a variety of areas in his life that he felt supported in, and the role of his faith in coping. He felt that the interview had helped him to realise the extent of support he had and how 'good' life was for him at the moment. At times in the interview it felt as though he had expected me to judge or reject what he had to say and my neutral and curious position was reiterated to him, to help encourage him to share what he felt comfortable to.

4.2.2 Patient B

Patient B had been living with pain and exhaustion for 5 years, and was currently caught in a cycle of feeling unable to engage in the areas of life that were important to her, becoming increasingly frustrated and low in mood, which appeared to be perpetuating the cycle further. This cycle was further exacerbated by co-existing COPD and the anxiety she experienced leaving the house. She was also grieving for the loss of her mum, whose death happened around the onset of multiple stressors including managing the pain.

She predominately managed the pain by taking prescribed medication, which she stated on many occasions during the interview that she did not want to take, particularly as she had taken a number of intentional overdoses in the past. Although she had attended pain management, she had found the experience frustrating and could not see how the techniques related to something she did not feel she could control. Similar to patient A, she did not identify with the label that had been suggested by her doctor for her symptoms. Although she did not identify with the label, she welcomed the support of the online fibromyalgia group, and the immediate sense of not being on her own if she was having a difficult day.

She came across as someone who prides herself on working hard and being emotionally and physically "strong" for others, anticipating that others will only

push her away, rather than show care. At times she would become tearful during the interview, which she would dismiss as just something that she did now, rather than her tears being justified for the experiences she was describing. Patient B was most focused on sharing her beliefs about the symptoms and the impact that the symptoms had on her. She was open to discussing accessing additional support for the depression she described as being secondary to her pain and was contemplating engaging with the mental health team at her surgery for further support. She appeared to welcome the opportunity to talk freely, and thanked me for the time that I gave to speak with her.

4.2.3 Patient C

Patient C had been living with pain for the last 'few years', however was only affected when she was lying down or resting. She had taken the doctors lack of follow up on her initial concern of what the pain could be as indication that it was not serious and could be something that she self-managed with painkillers if it got particularly bad. She had looked up on the internet what it could be and identified with the symptoms described for 'restless leg syndrome'. The pain did not impact on her daily activities, which she described as being very busy filled with working, volunteering, going to the gym and providing childcare for her son- her schedule being so busy, that we found it hard to find a time to do the interview.

She experienced tiredness with the pain, but was unsure if this was due to her co-existing difficulties with low mood and anxiety, which she had for the past 30 years. She did not feel that the pain was associated with her low mood, stating that if it were that would mean the pain was psychological and she did not think it was. She had been diagnosed with cancer 5 years ago, which had initially been misattributed by her usual GP as lumps associated with aging. However, patient C showed no concern that this could happen again, stating that now because of her medical history, she would be listened to if she raised concern with her GP that the pain maybe cancer related.

She came across as someone who manages life's challenges by keeping busy, but also finds it hard to assert her needs to others. She described herself as being a passive person in consultations, however following the cancer diagnosis the fear it could happen again now makes her speak up. She was the only person who talked about pain not impacting on her usual routine, and was also one of the few people who did not mention suicide. There was also little spontaneous reference to the support of others, although this was one of the shorter interviews conducted,

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and may have come up if we had talked for longer. Patient C had the greatest focus on the health system and how the changes made it harder to consult her GP before she went ahead with changes to her care.

4.2.4 Patient D

Patient D was 'diagnosed' with fibromyalgia 4 years ago, after experiencing long standing difficulties with their thyroid, mouth ulcers and hip pain. She recalls 'always' being in physical pain during her primary school years, which was attributed at the time as growing pains. She talked about the low mood being secondary to her pain, and that the thoughts of the constant pain being never ending, as well as trying to manage the pain alongside the additional family stress that co-existed. Patient D believed that these factors had all contributed to experiencing a "breakdown" and thoughts about ending her life with the pills she had available. She feels that the suicidal thoughts were in part a side effect of the medication she was on, and continues to take the anti-depressants that were prescribed at the time.

She described her symptoms as not only impacting on her but also her husband and their relationship, with her feeling no longer able to go out unless it was a special occasion that she had time to prepare herself for. Since her diagnosis she has felt able to share information about the condition with others, and is more able to cope with the symptoms. She credits the online fibromyalgia group as having "saved my life" after her breakdown, and manages the pain using alternative medicine suggested by the group.

She came across as a person who in most areas of her life has been, whether through choice or need, focused on the needs of others. At the Doctors she experienced someone who was focused on her needs and a shared search for the answer was sought. She valued the involvement, which she states brought with it feelings of being cared for and treated as a person. Out of all the patient interviews, patient D spoke the most about defining the problem, particularly the role of the label and reflecting on life events. She also talked the most about managing the symptoms through self-management, and compared to other patient participants, also had a greater focus on how the structures within the health system had supported her involvement in her care.

4.2.5 Patient E

Patient E had been living with severe back pain for nearly 20 years, although has experienced sciatica in her back since the age of 17, which she attributes to having

fallen badly as a child during sports activity. She also saw her earlier gynaecological problems as also being linked to her current symptoms. She experienced soreness of skin, aching limbs and continuous pain, and identified with the label that her GP had given to her symptoms –fibromyalgia.

Since the diagnosis she had found a lot of helpful fibromyalgia information online, and had concluded that the reason for her pain was due to having too much factor-p, which made her hypersensitive to normal pain. Prior to taking early retirement due to her health, she worked as a mental health nurse, but describes getting burnt out both by the distress she was witness too with little support, and also physically by lifting and rolling people without proper resources in place. She approached Occupational Health once she had her diagnosis and requested a change in her job to support her health needs. Since getting her diagnosis she felt it had provided her with a sense of control over the symptoms.

She had the support of her husband at home, who would also share in reading up on fibromyalgia. In addition to taking analgesics to manage the pain, she also looked for alternative medicine that may help, as well as opportunities to participate in research in this area. She likened being approached with this study as taking two tramadol- she felt valued and appreciated that that her surgery had thought of her.

She came across as someone who has spent many years both in personal and professional roles being a carer of other people's needs, and finding it hard to get space for her own to be seen and feel valued. She has managed challenges in life through adopting a 'what will be, will be' attitude, which at times others would take advantage of and leave her feeling frustrated that her own needs would be pushed aside by theirs. She was extremely appreciative of the time spent listening to her narrative in the interview- not only reiterating her thanks at the end of the interview, but also in a follow up email after. She had welcomed the opportunity the interview had given her to gently light up some of what she referred to as 'my dark corners' and felt that in doing so it had helped her appreciate her own value.

4.2.6 Patient F

Patient F had been living with back pain for 9 years, which he was trying to manage through prescribed medication that he could get in the UK and when he returned to visit his wider family in the Middle East. He had also undergone physiotherapy in the UK, where he learnt that he also had weak muscles in his neck.

Patient F described the pain as "coming in waves" and would at times spread from his neck to his shoulder blades and back, where at times he has been unable to move his neck. Dependant on the acute nature of the pain, he would try and manage the pain through taking hot baths and herbal medication, only taking stronger analgesics if the pain was acute. He felt that the pain impacted on his mood due to his inability to do the things he thinks he should be doing socially, and the exhaustion of trying to provide for family and needing to just sleep rather than be with his children. He also felt that the pain was impacting on his memory of events.

At present he is unemployed and on long term sickness, however before leaving for the UK he worked in education and had involvement with a Refugee Project. He moved with his wife and children to the UK 10 years ago, and is supported by the Refugee Project in the UK. Although he would make reference to his current living situation, he seemed more hesitant to speak when further inquiry was made. Although participant F stated he understood the rationale for asking about psychosocial factors, he did not feel that this was relevant to his experience of pain. He welcomed seeing different doctors to find different ways of looking at his symptoms, hoping to find something that could fix the pain and found it to be a problem when he had to see the same GP.

The interview was conducted in English, with difficulties understanding each other on the phone being managed by either talking around the topic or giving examples to illustrate what we meant. The focus of the interview was on the impact of his symptoms and how he was managing them. This was one of the shorter interviews, however he was happy to be contacted again if further information was needed.

Results from the patient interviews

Data from all six patient interviews were included in the analysis. The five main themes were based broadly around the conceptual framework of clinical decision making, and consisted of: symptom beliefs and expectations, defining the health problem, managing the symptoms, what's important in my symptom management, and the experience of the system. The contribution of each participant to each theme and subtheme is indicated in Table 4. These frequencies are used 'qualitatively', to illustrate the importance of each component for the patients. The

main themes and the subthemes that were found to contribute to them will now be outlined.

Table 4: *Patient themes and subthemes and frequency of utterances by patient*

Themes / *Subthemes*	Pat. A	Pat. B	Pat. C	Pat. D	Pat. E	Pat. F
	Frequency of Utterances					
SYMPTOM BELIEFS AND EXPECTATIONS	26	49	10	29	14	18
When 'normal' becomes acute and chronic	6	13	3	6	6	7
The impact on self and others: 'What if I can't?'	14	29	6	17	6	7
It controls me or I control it	6	7	1	6	2	4
DEFINING THE HEALTH PROBLEM	24	27	10	27	22	6
Getting a label in the search for answers	12	9	6	11	6	3
The response of others	8	9	1	7	9	2
Life before the symptoms	4	9	3	9	7	1
MANAGING THE SYMPTOMS	22	32	16	38	14	13
Deciding what is right for you and your symptoms	15	5	9	18	12	6
Going (back) to see the GP	2	10	3	6	1	4
Feeling that I'm not on my own with 'strange symptoms'.	5	7	0	9	6	1
The tablets don't work-what else is there?	8	8	2	7	1	3
WHAT'S IMPORTANT IN MY SYMPTOM MANAGEMENT	24	13	21	11	24	***ND***
Not being seen (as just a patient, a robot, or a number)	4	3	8	3	8	*ND*
The relationship	8	5	8	0	6	*ND*
Becoming more involved in your care: 'Do I really want to be taking these?'	9	3	4	5	9	*ND*
'In house' management	2	2	1	3	1	*ND*
THE EXPERIENCE OF THE SYSTEM	6	9	9	16	3	1
Your 10-minute slot	1	3	5	0	1	0
(In)consistency	2	3	2	4	2	1
When time is 'made'	3	3	2	12	0	0

***ND-** Not Discussed topic*

4.4 Theme 1: Symptom beliefs and expectations

Theme 1 refers to the beliefs and expectations that people had about the symptoms they were experiencing. Patients described experiencing multiple symptoms, which either were perceived as originating from separate conditions that co-existed or made up from one condition that encompassed other existing symptoms. People described knowing what was normal for their own body, and expected that

deviations from this was a symptom of something needing to be followed up. This is described further in the sub-theme 'When 'normal' becomes acute and chronic' which details how life experiences, both directly and indirectly, had contributed to the beliefs participants had about their physical symptoms and how the episodic nature of chronic symptoms brought an expectation that 'good' days would be followed by 'bad' days.

The sub-theme 'The impact on self and others: 'What if I can't?'' provides an overview of the various ways that people reported being affected physically, socially and psychologically by the painful sensations they all reported, whereby people spoke openly about the depths of this pain and how they had responded in their most despairing times. Participants also described a variety of factors that contributed to managing their distress, which included discussing the role of the family, their friends, their faith and past experiences of managing deviations from "the best laid plans".

The sub theme 'It controls me or I control it' outlines the various ways that patients set about taking back the control that the uncertainty of their symptoms had initially taken from them. A central issue was trying to do something that helped them to build an understanding of their symptoms. Further facilitators and barriers to establishing a sense of control over the symptoms are detailed within this sub-theme.

4.4.1 Sub-theme: When 'normal' becomes acute and chronic

Participants spoke of knowing their own body and appeared to use this as a subjective measure of what was 'normal' for them. Both Patient B and D spoke of initially putting their pain down to the usual aches and pains that everyone experiences, whilst patient F initially attributed his pain to sleeping awkwardly on his neck. However with symptoms increasing or becoming stronger in intensity, explanations moved from pain and tiredness being normal experiences to ones indicative of something being 'wrong' and it became harder to 'ignore' as it impacted on their usual daily routine, or was no longer responsive to how they were trying to manage it. Patient B became concerned when she started to notice how more effort was needed to be able to get up and on with her day:

> "At first you think 'oh everyone has pains', but when you're
> sat down and how hard it takes you to get up on certain
> days- that's not normal." (59)

All patients spoke of going to the doctors when their symptoms persisted. Patient A and E had concerns that the symptoms would be confirmed as being related to mental health problems that either they themselves had a past history of or that ran in the family. In contrast patient B had been with her friend when they received a terminal diagnosis of cancer and had known other people who had missed diagnoses of cancer. She was concerned that her symptoms were of cancer and that this would not be detected by a blood test. Patient D also initially thought that her mouth ulcers were possible symptoms of mouth cancer, and initially went to the dentist for a check-up. Patient F did not state what he thought the symptoms were initially only that "it is the worry that something is happening" that makes him go to the doctors with the pain. Patient C had experienced a past diagnosis of cancer, which initially had gone undetected by her GP. Despite this, patient C stated she did not suspect the pain in her leg to be anything to do with her past cancer diagnosis, and felt that if there was sufficient concern shown from the GP then she would be followed up due to her past history. In this respect, a past diagnosis of cancer was perceived as enhancing the level of attention and consideration given to physical symptoms reported, whereas a past diagnosis of mental health brought with it a concern that symptoms would be labelled as "being all in your head".

Symptoms were rarely on their own, with patients describing a constellation of symptoms which had been diagnosed at different points in time, and were largely viewed as being separate rather than interacting with their pain. The exception to this were Patients D and E who both reported childhood memories of pain, and felt that their diagnosis of fibromyalgia had encapsulated the spectrum of problems they had experienced throughout life which included gynaecological related problems, thyroid, ulcers and IBS.

All participants spoke about living with a variety of symptoms over a long period of time, making the narrative around the symptoms and their experiences harder for them to tell and for others to piece the complexity together at times. Although symptoms were long standing, patients spoke of experiencing an acute exacerbation in their symptoms, which for some happened at night time and when lying down and for others would fluctuate throughout the day or over a period of months. Patient A was focused on embracing the good days he experienced with his symptoms, despite anticipating the effect afterwards:

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"You want to…it's like my granddaughter is here today, and today is a good day so I can mess about with her and chuck her up and down, but you do have an effect afterwards, but it's nice to be able to do that initially. On a bad day, you are not going to do that." (58)

Patient B also spoke of wanting to be the "fun nan" and on a "good day" felt that she was able to fulfil this role. She spoke of not feeling like she could refer to herself as "disabled" or "ill" because her symptoms varied from being able to being unable to function and perceived herself as not necessarily looking ill. In this respect fluctuating symptoms can be seen as impacting on the aspects of a person's identity and what people feel they have permission to identify with. This may hold greater implications for how such dynamic and fluctuating symptoms sit within the less flexible parts of the system, such as benefits.

4.4.2 Sub-theme: The impact on self and others: 'What if I can't?'
Patients spoke of feeling 'brittle', unable to bend to accommodate social demands others would place on them and perceiving themselves as unable to take much conflict before 'breaking'. There were also reports suggestive of some patients finding it hard to also trust their bodies to engage fully in family and social life, thinking "what if" the symptoms recur, and would need time to mentally 'prepare'. All participants besides patient C, spoke of the emotional changes that came after the pain, which included feeling scared, frustrated and low by the symptoms. Patient F described his symptoms as making him feel "isolated from the world", where he was unable to spend meaningful time with his family because he was in pain and tired, but that the difficulties he was experiencing with sleep meant that he also began dreading going to bed. Patient D highlighted that for her, the symptoms had gone from trying to manage a 'tiredness' that came with her other symptoms and had become 'exhaustion', which had cued her to go to her GP for help:

"It was just the fact that I was getting really down with it-feeling so rubbish, and there was stuff I couldn't do and tired- no not tired- exhausted-I would do the house work and then would have to have a couple hours sleep after, as I was absolutely physically exhausted. I would have to sleep

> *when I come in from work-have a couple of hours sleep, and*
> *I thought I can't carry on like this."* (6)

In this example, Patient D also suggests the impact that managing such symptoms had on her mood, and describes a life that similar to patient F had become focused around completing priority tasks, such as work, rather than replenishing activities. For some even the priority tasks were no longer possible, with one patient sharing that the guilt she would feel at not being able to complete the house hold chores whilst her husband was at work, would result in her spraying room spray to pretend that she had been doing something, concealing the true extent of the support that she needed.

Patient E described withdrawing from her friends by unplugging the phone and getting her husband to open the door and pretending she was not in. From what she described, it was not the pain that stopped her from going out, but more the thought she might let someone down by not giving as much as she used to in the relationship. Similarly, patient B would respond to her friend's invitations to go out by saying she was busy and unable to go out with her friends or saying she was "fine" when people asked her if she was okay. Patient B's response came from a belief that her friends would not understand the fluctuation in how she felt, and she reasoned that if the doctors were unable to understand her symptoms, then other people would also struggle. Instead she put her energy in to trying to keep her emotions down, which would then come tumbling out when someone showed concern, and heightened feelings of guilt about the lies she was saying to her friends, which she also recognised as preventing them from understanding what she was managing. The symptoms also impacted on patients' partners, with time spent either going to appointments with them, reminding them of appointments or encouraging them to seek further help when they see the distress of their partner at home. With difficulties sleeping and going out socially, patients reported that activities shared together with their partner had decreased. The exception to this was patients A and E, who spoke with gratitude about the understanding and compassion that their partners held for them. This was in contrast to other patients who felt that their partners did not understand or believe in the diagnosis they had received for their symptoms.

At the most extreme ends of the extent of impact that the symptoms had it varied from patient C reporting that she is able to "just get on with it" and manages by keeping busy and keeping moving, to patients A, B and D all sharing that the

depths of their despair at going through life with such symptoms, has meant that at times they could not see a way to carry on. Patient A describes:

> *"I mean I do have days where I think I want to end it all, but I am never going to do that. I mean you might feel it, but there is a difference between feeling that I've had enough and actually doing something like jump off a roof. No, my life is too rich and so is the next day… and that is the sort of philosophy that doesn't make me give up on today."* (30)

Patient D states that it was not just the pain, but managing this alongside "other things going on" in her life at that point and thoughts that she had no quality of life. Patient B stated she had taken three overdoses in the past, and now finds it hard to trust herself with the medication she is on for her pain and finds it frightening that Doctors continue to prescribe her medication for pain rather than suggest anything else. Looking back now, patients wondered to what extent this was a side effect of the medication they had been taking, and credit changes made to pain medication, increased access to online support, getting a diagnosis, and reconnecting with their faith as factors helping to reduce the distress.

4.4.3 Sub-theme: It controls me or I control it

Participants spoke of living with the uncertainty of their symptoms. They had either been told by their GP that there was no cure for their symptoms and it was about trying to manage them, or patients had realised that pain relief was unable to "fix" the pain that persisted. Patient F shared that despite him believing that the pain cannot be treated with medication that will "work" for his pain, he feels it is important to try all treatment options available to him, which included going to have his weight and bloods checked if all else had been exhausted. It seemed that patient F took comfort in knowing he was doing something in response to his pain, and that regular monitoring of his health was still classed as a viable treatment option once all else had been tried, as this helped to manage the fear of 'what if' the symptoms are something new. Participants C, D and E all spoke of increasing their control over the symptoms by gaining understanding about them through their diagnosis. Patient C was content with the understanding she had found online and felt a sense of control over her pain when she saw that the pain subsided with using a cushion under her legs and using pain killers when it was at its worse. Patient D stated that

before this point she felt like she was getting nowhere and likened it to "banging your head against a brick wall" with the frustration and hopelessness building at being told by her GP they were not yet clear on how best to manage the symptoms. Patient E stated it was the "fumbling about and not knowing" that was the hardest part of managing her condition , and that once she had this through a diagnosis she felt as though she had control over the condition. She went on to say that she manages the anxiety about what could happen by not dwelling on it, which also included not thinking about "death".

Patient A and B were also unsure what the outcome would be of their symptoms, with patient A stating that he had found a suggestion online that symptoms might go into "remission" but he was unsure if it would for him. Patient B stated that living with the uncertainty of her condition meant she never knew if she was "dying or if you're not", because she was living with the belief that her symptoms could be signs of cancer. She felt frustrated that she could not find a way to exit a cycle she recognised she was in:

> *"I feel like I'm a hamster in a wheel- I get up, I think I'm*
> *going to have bath, put some make up and have a normal*
> *day, but my life is 'I'm always going to do it' [rather than do*
> *it]. I cannot get off this wheel."* (80)

This extract also highlights the exhaustion that patient B felt from her symptoms and the powerlessness that she felt in being able to have control over them. This was particularly evident in her description of having attended a pain management class, in which she stated she was being taught how to control the pain, which she did not feel ready for, thinking "I cannot help the pain".

4.5 Theme 2: Defining the health problem

Theme 2 refers to the process of making the symptoms visible, starting with a search to answer the questions that arise with the experience of such symptoms. These are questions that not only the participants have about what is going on for them, but also the questions asked by friends, family and the wider system- health professionals, insurance companies and benefits assessments. Participant's distress from the symptoms seemed to be heightened by the frustration that these were symptoms that are not visible to others and reliant on the subjective appraisal

of individuals. Some patients were okay with this, however others found it brought with it thoughts of not being believed or that other people were not truly able to understand the severity of their symptoms if they had not experienced anything like this themselves. There was concern that instead, in the absence of objective tests and a disease specific diagnosis, people would make their own assumptions about what was happening, which both patient A, B and E felt trivialised the extent of their pain.

Participants spoke of their sources of support coming from people who had lived experiences of the process they were on with managing their symptoms, as well as health professionals, other agencies and family members that showed active interest in understanding their situation by showing their support in reading material and sharing information with them. This was in contrast to experiences prior to their symptoms whereby participants described life experiences that involved loss and social disconnection whilst managing increased responsibility for the care and needs of others.

4.5.1 Sub-theme: *Getting a label in the search for answers*
Participants spoke of going in to the consultation hoping it would fill the gaps in their own understanding. The function of getting this understanding was not only to help manage the symptoms, but to provide reassurance from their own fears of what the symptoms might be, as well as provide some justification to themselves as well as others, for how they were feeling and what they were or weren't able to do. Patient A showed the most concern that people were presuming his symptoms were "all in his mind". From what patient A had shared, he had been in hospital with mental health problems prior to the onset of his pain, and did not agree with the diagnosis he had got in relation to his distress then, which conveyed a wider perception that he held, of not expecting to be understood by health professionals. Similarly, patient B was searching for justification and validation of how she felt. She found it unhelpful when she would go to the doctors with new symptoms and be told it was her fibromyalgia, as she felt this did not give her an adequate reason for how she felt and did not feel that her pain was being understood. She states:

> *"If someone told me tomorrow I had cancer and it was terminal, I would be quite happy with it, because I would know then that the illness that I have got, is a reason for why I feel the way I feel…" (45)*

Her desperation for having "a reason" for feeling can be detected in this extract, and that she felt that having a diagnosis for something that she feared would bring her some relief from the uncertainty she was living with. In contrast the majority of the participants could identify with the functional label they had for their symptoms. Participants reported that having a label was a way to provide symptom coherence and visibility to the hidden problems they were managing and gave permission to be able to ask for help or decline requests put to them. Patient D explained that prior to the diagnosis she would just "get on with it" at work, using tablets to try and manage the pain. However since the diagnosis she has been able to provide people with information about the condition and speak up about what adaptations could be made to her shift to help manage the pain. Similar to this, patient E stated she did not feel she could approach occupational health with a "*vague set of symptoms*", and needed confirmation from the GP before help could be accessed at work. For patients C, D, E, and F, who could identify with the label either they or their GP gave to their symptoms, the label enabled them with what they had hoped for- validity and symptom coherence, without necessarily needing to know what caused the symptoms. This seemed to be where it differed for patient A and B, who both felt that the label given to their symptoms by their GP did not help them understand their symptoms, but actually prevented them from seeking further understanding. Patient A stated:

> *"…is it fibromyalgia, because yes I have this joint pain, but*
> *have they just labelled me [with that] to give me tablets to*
> *shut me up- so that's my thoughts on it…"* (10)

Both patient A and B wondered if the label was more about the GPs lack of understanding of their symptoms, with patient B questioning how they could diagnose her with having this condition through a blood test alone, stating " *they don't really know its fibromyalgia. I've had no scans or anything…"* In this respect, she firmly holds on to the belief that only a scan will be able to confirm the absence of disease. However, despite not believing in the label, patient B states she has joined online forums for the condition. Similar to patient D, both spoke of belonging to an online group that they found supportive and meant they were not on their own. It would seem that although the label does not meet her needs for understanding, it does provide access to the support of others and a sense of connection.

4.5.2 Sub-theme: The responses of others

Patients got various messages about their symptoms from the people around them, which at times could be confusing and frustrating. Patient A spoke of his insurance company needing to have the diagnosis of fibromyalgia 'confirmed' regarding a recent claim he put in for an accident. However, this approach was at odds with the health professionals that he encountered, which he states *"[it] wasn't about it being invisible and saying what it was and wasn't"*. In addition he spoke of his readiness to hear what people would say about his symptoms and that with time he had become more open to various ways his condition could be understood. From describing his experiences with health professionals, he would initially hear their understanding as a judgement that he wanted to rebuff, but with time was able to view such professional opinion as an alternative position to consider. For patient B this perception of judgement was heightened even further by the belief that most doctors did not believe in fibromyalgia and that they would not be interested in the symptoms she was approaching them with:

> *"A lot of these doctors, without being rude, don't want to*
> *know. You walk in and they look at you like 'what can I do*
> *for you again', and you think pardon-their lips didn't move*
> *and they didn't speak to me face. I think they think that*
> *because quite a few doctors don't believe in fibromyalgia."*
> *(40).*

Patient D and E also spoke of feeling judgement from friends and family, which came out of their loved ones lack of understanding for what they were trying to manage. Patient E spoke of the shame she felt at her colleagues seeing her take multiple tramadol at work, and what that may mean about how appropriate it was that she was at work caring for others. Patient D shared that her husband commented that "you're always at the doctors or hospital", which left her wanting to show to him that this was not her fault and she was justified in her actions. In contrast, patient F shared that his family encouraged him to see new doctors, as this brought with it opportunity to learn about different treatments that may help him with his pain. Such experiences highlight two sides of the same problem, which as patient E states occurs "*when people around you can't see what is going on, they can't understand it either*", and instead people just "*put on you*" their understanding, which might not reflect what is actually happening.

4.5.3 Sub-theme: Life before the symptoms

There was a strong sense from all patients that life pre- symptoms contained themes of either loss or isolation, and increased responsibility for the care of others. These losses were varied in nature consisting of loss of youth, loss of loved ones, and loss of social resources.

Patient A shared that he had not been able to go out much as he brought his daughter up on his own, and described himself as having been a "*heavy drinker*" and "*heavy smoker*", suggesting that the priority at that time had not been his health and was more about doing what he needed to do to get by. For patient B, the pain that she felt at the death of her mum after 5 years was still raw, and she acknowledged the profound change it had on her; "*losing me mum was a big big impact on me life. I've never been the same person [cries]*". She described herself as someone who "*would do anything for anyone*", and alongside managing her health, supported her friend with terminal illness, as well as her mum. Themes of abandonment and loss, which included her long term job were evident in the experiences she described. This was similar to patient E, who also described caring for her mum whilst trying to manage her own health needs, work and family life. She described having traditional segregated roles within the family and that being the only girl, she was expected to take on the caring role of others. Even in her role at work she found she was unable to get the support needed to manage the high levels of distress she was encountering and found it preferable working in a lower paid job instead:

> "*I went to work in Primark and it were the best job I've ever had. It were the poorest paid job I'd ever had but the team support-it were fabulous. Better then health professionals and things-it were all very back stabby [as a nurse]. It wasn't a particular healthy environment…*" (2)

She spoke of the losses she saw happening around in the environment she lived in, with loss of industry impacting on the resources in the area, which included the loss of the good reputation that the neighbourhood had. She described that people now had to "*fight for what they needed*", which included healthcare. Patient F did not directly speak of his experience moving to the UK, but as mentioned in the impact that his pain was having on him, he was left feeling "*isolated*" from the world. He had moved with his wife and 6 children and described living in accommodation

that he felt had added to his pain and decline in health. That's said, he felt supported by the refugee centre and felt settled starting a new life in the UK, despite having limited wider family around him.

4.6 Theme 3: Managing the symptoms

Theme 3 refers to the various ways that patients manage their symptoms. Patients spoke of not just responding to their physical symptoms but also responding to their perceptions of the GPs as being too busy or not believing the condition that their symptoms had been labelled with. As such, patients described taking an active role in managing their symptoms, which was guided by the beliefs they held about them. Often management was also being done alongside managing other problems that co-existed, which also impacted on the extent to which the patient felt able to get involved in managing their symptoms. Deciding to go to the doctors either with new symptoms or existing ones, was influenced by a number of factors that included following the advice of others to go to the doctor, the fear of new symptoms or increase in type or frequency of pain, as well as going in hope that any changes in symptoms would support with developing an understanding of what was happening. Patients had mixed views about the role of medication in managing their symptoms, with a common view being that the cost of the side-effects was not worth the small gains that were achieved in getting pain relief. Other treatments were also discussed and are outlined in the sub-theme 'T*he tablets don't work- what else is there?'* Common to all patients was a theme of not wanting to feel that they were on their own managing their symptoms. In addition to having support from health professionals, there were three key areas that were highlighted as important sources of support- family, friends and work- that are discussed in turn in the sub-theme 'F*eeling that I am not on my own with 'strange symptoms''.*

4.6.1 Sub-theme: Deciding what is right for you and your symptoms
All participants displayed a level of active involvement in how they decided what explanations for their symptoms was most applicable to their situation, as well as deciding what was the best course of action for them in managing their symptoms. Participants spoke of trying to regain control over their symptoms by trying to make sense of what could not be medically explained. This was done through directly asking questions to health professionals or by looking up their symptoms on "Dr Google", and appraising how applicable this was to their experiences. Patient C felt that she did not need a diagnosis from her GP, as she was content with the

explanation and guidance she had found online for her symptoms and management of pain. She stated that the symptoms must be either physical or psychological and reasoned that as the pain did not appear to change according to how she felt, it was likely to be purely physical.

In contrast, Patient A had spoken a lot to health professionals about his symptoms and was curious about the suggestion from health professionals that mood could impact on his symptoms. He reflected that if this was so, then he too had also expected that his pain would get worse or better depending on how his mood was, which had not been the case. He was unsure how to integrate the two perspectives that he held, which was that pain felt like a "physical illness", which might be occurring due to damaged tissue from manual work that he had done in his past, but also that his symptoms may also be a form of "mental illness" that consists of producing some form of "phantom pain". He concluded that if some of his pain was to do with his mood, then it would need to be "deeper than depression".

This was similar to Patient B, who although initially stated that she thought her symptoms were to do with an undiagnosed cancer, she went on to wonder if her symptoms were to do with something "deep within", as although she does not think she is "mental", she stated "in life you shouldn't be this sad". From what both patient A and B described, they entertain the thought that pain could also be existing outside of their conscious awareness. An alternative perspective on this came from Patient D, who accepted the diagnosis of fibromyalgia as an explanation for her symptoms. Although she was aware of research and comments on forums for fibromyalgia that suggested links between childhood trauma and causing fibromyalgia, she was not sure how applicable this was to her and did not know if some of her childhood memories would be consider a "trauma". She believed that knowing what caused her to have fibromyalgia was not important, but how she managed the symptoms she has now. It would seem that for some of the patients, particularly those who had not yet felt understood and heard, establishing a cause or symptom explanation that the person was able to identify with, was the important aspect for their symptom management.

From what patients described, how they perceived the GP and both the type and immediacy of the support they were able to provide, impacted to what extent they would consult their GP about management options or adhere to the advice given. Patient A shared his concern at being perceived as a "*bother*" by the GPs, viewing

them as busy and described himself as taking a "*getting on with it yourself*" attitude, which he applied to managing the pain relief medication he was on. He would evaluate to what extent the medication was 'working' and if it didn't take the pain away then he would reduce or stop taking what was prescribed.

Patient B focused less on managing the medication and was more concerned with deciding how best to get the help that she needed for her pain. She stated that because she had perceived the GP as "not doing anything", she had needed to go to the hospital. Patient B was concerned that she was not getting the scan that she strongly believed she needed for her symptoms to be diagnosed and searched to try and get what she believed she needed, regardless what the GP had said.

Similarly, patient C felt that nothing was "*moving forward*" with the concerns she had raised about her pain, and decided to look up the symptoms herself and work out what it could be and how to manage them. In relation to the prescribed medication she takes to manage how she feels, she adjusts this according to how she is feeling. Although she recognises it would be advisable to do this under GP guidance, she cites finding it difficult to get a GP appointment and get access to the help she needs in the moment when she is making the decision.

Patient D used the immediate feedback she gained from the online forum to help make her decision about coming off of the pain relief she was taking. Although she felt well informed by her GP about the possible side effects of the medication, with the initial agreement being to monitor for side effects for them to review together necessary changes, patient D decided to replace her prescribed medication for cannabis seed oil and used it in the same quantity that she was taking the prescribed pain relief. She described the approach she takes with symptom management as the following:

> *"I think it is just a case of trial and error. Try and work out*
> *what works for you and if it doesn't work it doesn't work, and*
> *if it does it's a bonus sort of thing." (40)*

Patient E also described herself as a "*self-manager*" who would learn about what was effective management for her through trying out a range of management options she came across. She reasoned that this was a necessary approach to take in the relative absence of evidence for the range of options available, and that getting actively involved in her management also came from her own

"*discontentment*" that things were not happening as quickly as she would like, which would prompt her to "*say it*" when in the consultation with her GP, rather than go along with what was suggested by her GP.

For patient F, the focus was on having access to prescribed pain relief and hearing about new treatments available for him to try. He explained that this would mean he would get medication both inside and outside of the UK, and would request to see different GPs as an opportunity to find out if there were more possible options for him to try.

4.6.2 Sub-theme: Going (back) to see the doctor

Participants described multiple reasons why they would continue to go to the doctors with their persistent symptoms, despite no treatment being available. This included partners who were being affected by the symptoms at night (Patient A), new health professionals raising concerns following their initial assessment of the patient's symptoms (patient C), dentist stating it was a problem more suitable for a GP to investigate (patient D) and wider family who advised going to different doctors to try and find new treatments (patient F). For patient E, it was not necessarily about having encouragement from others to go the doctors, but more in the absence of feeling understood by others around her that she sought 'kinship' with talking to another health professional who she felt with their similar medical training would be able to "*see through my eyes but not through my eyes*" and be understood without having to put her pain in to words.

Changes in the intensity of the pain or frequency were also causes of worry for participants and would motivate people to see their GP. Both Patient B and F spoke of feeling "frightened" of experiencing a pain they weren't 'familiar' with, with this new form of pain triggering worry about what it could be. It was not just fear that seemed to motivate patients to go to the GP, as patients also spoke of hope that the doctor would be able to understand them this time and suggest something that might make a difference. When patient A's symptoms persisted, he decided to go back and see the same GP but this time going in to the consultation prepared with his research about what it could be. Patient D also spoke of returning to the consultation with new evidence, hoping that it would make a difference:

> "*I was going with different symptoms, like this is hurting now- so surely this is telling us something now…*" (8)

Unlike patient A, the new symptoms she was experiencing were providing patient D with more evidence to support her position that something was going on with her health, and returned to the same GP until they reached an understanding about what was happening. Since getting a diagnosis that she can now relate her symptoms too, Patient D states that she feels she is now able to manage the symptoms without going back to her GP, because ultimately she knows what works best for her body.

4.6.3 Sub-theme: The tablets don't work-what else is there?

All patients spoke about the role that medication had in the management of their pain. The type of medication being taken ranged from over the counter pain killers and anti-inflammatories that would be taken when pain was acute, to trying various prescribed medication such as Co-codamol, Gabapentin and Tramadol. Patients varied in their expectations of the medication being able to get rid of their pain. Patient A felt that the side effects that came with the prescribed medication outweighed the benefits he had seen with taking the medication. He had recently been experiencing problems with his stomach, which he attributed to making him consider the side effects of the medications he was taking and evaluating if it was worth continuing on them, stating "you can't keep chucking everything in to your body and think that everything's going to be okay". He felt that there was an expectation of cure from taking the medication, and that this came from the GP rather than the patient:

> "Don't just accept the tablets that they give you, because if
> they aren't working, then don't take them, because the GPs
> will just chuck everything at you and expect that to cure you-
> and that is not the case." (68)

This extract implies that there is also a perception of it being the GP who initiates or maintains the prescribing of medication, rather than it necessarily being a request or resistance that comes from the patient. Patient B also held a similar view, that she had a preference not to take medication, which had been heightened after her last overdose, yet the response she felt she often received from health professionals was "its fibromyalgia and have pain killers". For patient B it was beginning to feel personal, that despite perceiving that her GP knows "quite a bit" about her, having shown the distress the symptoms were causing her, that the

response had been to offer her more tablets, which she had perceived as them doing "nowt" to help her. It is likely that this perception is reflective of her wider beliefs that she is 'unfixable' and that no one can help her with her symptoms.

In contrast to both these views, patient C described managing her pain using a combination of self-management techniques and pain relief when acute. She seemed to have accepted the position that she had read online that "nothing more could be done" and spoke of following the advice online, rather than questioning it further. A similar pattern of responding was also seen when she spoke of the medication she took for managing how she felt, stating that although she sometimes wondered about side effects of long term usage, that her doctors would have brought it to her attention if there was anything that she needed to be concerned about. This seems incongruent to her actual experience of having her symptoms of cancer that she had initially raised to her GP being misattributed to growing older, and nearly missed. In this respect it seems likely that not thinking too much about what is happening helps to keep the anxiety low, and the requests for other treatment options to a minimum.

Surgery was another treatment option that had been pursued by one patient, suggesting that for him it was still about treating, rather than managing the problem. Patient F stated that he had been advised against this request by his GP:

> *"The doctors have said that to treat it with surgery it would*
> *be difficult… and recommend that medication was better*
> *than the surgery, because surgery on the neck, is not*
> *100%....I am happy to do anything, just to get rid of the*
> *pain…"(5)*

This extract shows that although the argument is made that surgery does not guarantee pain relief, the alternative suggestion of medication is heard by patient F as having a higher guarantee of achieving his aim of being rid of the pain. This highlights how the suggestion of medication may be put forward to reduce the risk of harm and further exacerbation of pain from unnecessary procedures. However, the unintentional consequence of encouraging the patient to see other less invasive options as equally viable, possibly creates an expectation that the medication will be able to treat, rather than manage the pain.

Having the opportunity to explore alternative medicine was raised by patient D and E. Patient D stated her GP had suggested acupuncture to her, and although

this had been helpful she could only get three sessions on the NHS and could not afford to pay for it regularly. Patient D stated she felt there were limitations on what GPs were able to offer people who had conditions with a broad spectrum of symptoms, and had got further ideas on how to manage the pain from an online forum. Both patients recognised that the evidence for alternative medicine was anecdotal, but in the absence of anything else having worked were open to trying.

Although medication was the main management option discussed by patients, other management options had also been encouraged by their GP. Both patient A and B had been referred to pain management, with varying success. Patient A shared that he believed he was sent to pain management to "get some understanding" of his condition, but he was not sure. He still used the exercises he had been shown there and shared that the level of validation and concern shown with his symptoms; "I believed that they believed"-made him 'emotional'. Similarly, patient B also perceived her referral to pain management to be about furthering her own and her GPs understanding of what was happening. She had initially got "excited" by the referral thinking she was going to the hospital to see a neurologist, and was disappointed when she turned up at the sports centre for pain management.

> *"What I'm trying to do is get some help for this pain-what is the point. What is that doing with my pain? The reason for it all was to manage your pain, to control your pain. But I can't stand it, because I cannot help the pain." (78-79)*

This referral did not fit within Patient B's understanding of her pain and reinforced a message that she was not being taken seriously. What did help was talking to the physiotherapist at the end, and feeling that she had been seen as "a lady who does need help" when she was asked if she was under a mental health team.

4.6.4 Sub-theme: Feeling that I am not on my own with 'strange' symptoms

In addition to feeling supported by health professionals, patients identified three key areas in their lives that helped them to not feel on their own with their symptoms. First it was having the support of their partners. Patient A stated that he did not have "a word to express" how much his wife's support and understanding meant to him, and would not disturb him when he needed to rest. Patient B states that she

perceives her husband as not agreeing with the diagnosis she has and has said about "getting some money together" to go private for the scan she is requesting. Patient D spoke of how although she felt her husband did not understand her daily pain, it was him who helped her get the support she needed from her doctor when she felt she could no longer continue on, that in the moment of absolute despair he was there for her. Similarly patient E described her husband as "a bit of a star" reading up on her condition and talking through things together, stating "If it weren't for him then I would be a right mess". For these patients it would seem that although it differed to what extent support was felt from their partner, they had an ally in their corner in their most vulnerable times.

The second area that contributed to not feeling on their own was support of friends. Patient A spoke of the acceptance he felt from his friends that when he said "even the doctors don't know what causes it", that they accepted and hadn't asked further questions. In contrast, Patient B did not see the point in speaking to her friends about her symptoms, believing that they would not be able to understand it if the doctor were not able to. She found it hard to receive the support that was shown to her, feeling guilty and ashamed when she would get upset in front of others. This left her in a dilemma of wanting the support of others to go to her appointments, but not feeling able to ask for the support. For patient B she felt more at ease accessing support online, and although she did not necessarily identify with the diagnosis of her condition, she really valued the support she got from the forum, stating that "I'm not on my own-it's not just me, like when I'm down , there's lots of people". Similarly, patient D also spoke of the value she got from her online friends she had from the forum. It would seem that the instant nature of being able to connect with others who may understand your pain and be able to provide suggesting on how to manage, was more appealing then attending a support group in person. She states:

> "…there's thousands online, and so you put a message out
> to the group and you thousands responses back-me phone
> is pinging all the time!" (54)

For patient D, it was also important that the group was specifically for her condition, declining to attend the local fibromyalgia support group that was merging with the ME group, as she believed it to be not as relevant hearing about people's experiences of ME. This seemed to strengthen her symptom identity as being one

aligned with the fibromyalgia group, rather than in a more general sense of relating to others living with long term health conditions.

The third area mentioned was feeling supported by work. Both patient A and D spoke of how work had accommodated their symptoms by either being mindful of the shift patterns that were allocated, or being responsive to the requests for additional help to meet the demands of the job. For patient D having seen that other people are willing to help her at work when she was now asking for it means she did not have to push herself beyond what she felt able to do physically, stating that "I know me limitations and I don't push myself in a 'this is something I need to do and I can't'." For patient E, even though she felt work got better "very quickly" after having occupational health involved, it was not enough to manage the demands she was continuing to experience in other areas of her life. She spoke about the lack of support she had from her wider family, and how reducing the demand of work by retiring early was what was needed for her to be able to cope:

> *"...there's a lot of stress on me to be a nurse 24 hours a day and you're not allowed to be supported…. It made it out of proportion [the stress on the pain]. The best thing I did was to stop working, as I couldn't do all of that without breaking up." (27-28)*

4.7 Theme 4: What's important to me in symptom management

Theme 4 refers to the various aspects of their care that are important to them in the management of their symptoms. Of central importance appeared to be the quality of the relationship held between patient and their GP, and the extent to which the patient perceived that the GP related to them as a person and that the understanding that was developed was just as unique as the individual themselves. In the sub-theme '*Not being seen (as just a patient, a robot or a number)'*, the barriers and facilitators to feeling heard are also outlined. Patients described the importance of building both trust and openness within the relationship and the extent to which these aspects are enhanced or compromised by past medical history. Dependant on whether this has been past physical or mental health problems, patients present two different perceptions on how GPs respond to hearing their medically unexplainable symptoms. With having increased access to information, patients also spoke of getting more involved in their care, using 'Dr

Google' to fill in gaps in their understanding. Details on the barriers and facilitators of, as one patient referred to it as being an "expert patient", is outlined in sub-theme below and contrasted against more traditional views on the role of the patient and GP. Lastly patients spoke of feeling that their care was being 'held' within the practice, as oppose to referring on. Patients presented a variety of views, which included feeling that more tests were needed to help reach an understanding, as well as the opposing position that a series of investigations delayed the process of getting on with managing the symptoms. These positions are outlined further in the sub-theme ''In house' management'.

4.7.1 Sub-theme: Not being seen (as just a patient, a robot, or a number)

When patients spoke about what was important to them in their symptom management, feeling believed was the dominating issue, with differences occurring in how patients felt this was being conveyed. Patient A spoke of GPs not seeming to "have time" and that sometimes he did not feel that he was believed in what he was saying.   Whilst his initial perception of GPs not having time could be consider in a literal sense of the time pressures on consultations, it would seem that what is being described is more of a feeling of being prematurely dismissed and not taken seriously. Such perceptions maybe particularly heightened with awareness of how busy GPs are and not wanting to be seen as a bother. This was a concern that patient C reported, that meant she found it hard to speak up and share her concerns in the consultation in case she was seen as "wasting time or feeling that you are being a bit silly".

In contrast, on occasions where patient A has felt understood, he believes the difference was that he perceived the health professional to be showing genuine concern for him and his situation. That the personal approach taken was conveying to him that he was being seen as an individual, rather than a "robot" that has a standard way of functioning. Patient D echoed the importance of being treated as an individual, rather than feeling that a standard approach was being taken regardless of the presenting need. She credited the person centred approach as helping to build her own confidence in managing the symptoms:

> *"It makes you feel a lot better and I would say cared for, and*
> *more capable of dealing with what you've got because you*
> *know that your opinion matters –you're not just a patient or*
> *a number, you do matter as a person…" (51)*

For patient B and C, feeling believed was about being able to see that the GP has a caring manner and is genuinely interested in what they are sharing. Patient C spoke of the difficulties she has getting this from the telephone consultations that she has for her medication reviews, stating:

"Seeing the expressions, I feel as though I am being listened to a bit more when it's face to face…" (18)

For patient C, she cited telephone consultations as another barrier for her in not always consulting with her GP when making changes to her medication, as she did not always feel comfortable talking about how she felt on the phone and wanted to get a sense of the person she was speaking to before she did.

Patient E spoke of the importance of having 'kinship' with the doctor that she sees, which she gets from talking to another health professional about her symptoms and builds further by speaking "woman to woman". From what she describes, credibility of her symptoms is supported by the unspoken understanding that she perceives as existing between health professionals. She particularly appreciated the gesture shown of her GP considering her for this study, explaining it provided her with a sense of feeling valued:

"You know when I got that letter about this study that did as much good as two tramadol, because someone was interested in me- me as me, rather than a collection of strange symptoms…" (42)

This is again similar to the need to be seen as an individual first, and the compassion shown for them with their symptoms is likened to a pain relief in itself. Collectively, participant's comments also suggest a level of social pain that accompanies the symptoms and is seeking relief.

4.7.2 Sub-theme: The relationship

Patients identified two interlinking areas that were important to them in the patient-doctor relationship. The first area was feeling that you could trust in the doctor's ability to help you. Patient A spoke openly about his lack of trust in the medical profession in general to be able to "think outside the box" to understand symptoms,

which he felt had possibly been influenced by what he has seen in the media, but also further reinforced through past unsatisfactory consultations, which included a misdiagnosis- "…I just thought, well you don't really care what you are doing do you." Patient B also shared a similar scepticism about health professionals in general, stating that she believed that "half the time their diagnoses are just so wrong". Her past experiences of caring for her mum during her illness and the misinformation she got, as well as her current experiences of her own symptoms has contributed to her position of "I've got no faith in them". As such she finds it difficult to be reassured by doctors telling her not to worry about her current symptoms or the blood test results that come back to normal, anticipating that she will be one of the people that things go wrong for. For patient B, the difficulties that she experiences with getting appointments and seeing a doctor is becoming personal, taking it as evidence that "they don't want to see me no more".

Patient C in contrast did not have this perception, despite also having had an experience of feeling like her concerns were dismissed. She felt that since her diagnosis of cancer, she trusted that health professionals would now follow up her concerns if she had any. This may also be touching on the area of 'credibility' and that patient C now feels able to speak up and be heard due to what happened previously with her symptoms of cancer being initially misattributed to the ageing process. For patient C it was not just about trusting that the doctor would attend to her concerns, but also trusting in her own ability to speak up, stating "I now won't let things pass". Patient C's unsatisfactory experience did not seem to have been generalised to trusting other GPs, identifying factors that contributed to that situation happening- GP was nearing the end of their career, they had a good relationship and were a similar age, and she trusted the doctors more than she did her own opinion. It seemed that in thinking about the contextual factors that had contributed to that situation, she was able to feel a sense of control and reassurance that she could trust other GPs with her concerns.

The other area overlapping with trust, is the need for there to be an 'openness' in the relationship- a willingness to share. Unlike patient C who felt that because of her past diagnosis of cancer her symptom concerns would be followed up, patient A talks of this feeling different when the condition is a mental health problem. He felt that his history of depression was the only understanding that was being used to make sense of his current symptoms, but that this was not openly being talked about with him. He stated:

> *"Professional people, I think without telling you –they don't
> want to tell you-it's more of a mental problem then a
> physical problem....because they think we are going to have
> a breakdown!" (30)*

Not only did patient A think that GPs were withholding sharing with him, but this was also evident in his own responses to letting his GP know he had stopped some of his pain medication. This was about a fear that the approach would not be consistent if he had to see another GP, stating that "I'll never get them [medication] back again" if he were to see someone else.

Both patient A and E spoke about 'openness' as being a personal quality that the GP has, rather than it being something that they can be taught in their training.

> *"... The best thing is to have that in your relationship with
> your doctor and know how they view 'expert patients',
> because yeah every doctor will see 'expert patient' in a
> different light wont they- convenient sometimes, an asset at
> others, and a bloody nuisance- nobody likes a know all!"*
> *(38)*

In this extract patient E seems to hint that GPs might have a particular view of what their own role is within the relationship and may differ to what extent they are open to having two 'experts' in the room exploring the problem. Patient A feels that one factor impacting on this openness is to do with generational differences between GPs, stating that it is harder for people to move with the time not necessarily on medical advances but on patient communication. Patient B describes a consultation where she felt genuinely cared for by the GP she had seen, that the difference had been that this GP was not just there because it was her job, but because she genuinely cared and described this feeling as though the doctor was saying "*I'm a doctor, but I am here for you. I'm not here because I'm a doctor*".

For patient E the personal qualities of the doctor were that important to her that if she could wait to see a doctor, she would try and ring on a day that she knew they were in. It seems that although a symbiotic relationship is held between trust and openness within the relationship- that authenticity and a genuine interest in

what the patient is saying have been the crucial foundations for building openness and trust over time.

4.7.3 Sub-theme: Becoming more involved in your care: 'Do I really want to be taking these?'

Ways in which patients got involved in their care was varied. The importance of seeking out further information to help build awareness, and increase confidence in questioning medical opinion was highlighted. Patient A commented on the changing role of the patient with the increase access to information:

> *"…It's not like it was 30 years ago where we've not got that much available information to us. Now we can actually question people in this position where you couldn't have done before." (21)*

Patient B and E also spoke of the importance of reading up and questioning what was being suggested by the GP, rather than just taking it without consideration of what the side effects might be. Patient A, C and D and E spoke of using 'Dr-Google', with patient A acknowledging that he recognises you need to be careful when using it because the information won't be "clear cut". Patient A and D both stated that they rarely bring in their own research to the consultation to discuss with their GP. Patient A states he has done so when he has really needed to- when he felt he had not been listened to and to strengthen what he was saying to his GP, suggesting that bringing in research might be perceived by some patients as a way to increase credibility of what they are saying. In contrast patient C stated that although she has been taking medication for the last 30 years, she was not sure why and had not thought about the long-term effects of the medication either. She wondered if she had remained on them because she was "addicted to them", but felt if this was so then her GP would have informed her and weaned her off. For this patient, it would seem she has a more traditional view of what the role of the GP is, and although feels it is important to be involved in your care, stating "you've got to fight for what you really want" in relation to getting the care you need, she is also reliant on the GP to inform her of what she might want to consider. Patient E also acknowledges her wariness of being perceived as telling people how to do their job. She attributes this discomfort and awareness of who is the person asking for help, as being influenced by her past professional experiences where she did

not feel as a nurse she could challenge the psychiatrist and concludes "I suppose a bit of that settles on you doesn't it-like dandruff!".

Patient D recognises that what the GP might advise as management options to consider are evidence-based management options for her pain, which are different to the ones she is currently trying. Although she feels she could discuss it with her GP, she admits there is "no research in to it". This might suggest that a barrier for some patients of sharing what they are considering as management options, might be the anticipation of it not being taken seriously with the lack of evidence base for it. Although this stops patients from sharing, it would seem that it does not stop patients from trying to see what works for them.

Another way of getting themselves heard in their care seemed to be through resisting against what was being suggested, not just directly through questioning, but also indirectly through changing GPs and not adhering to advice that has been given. Patients also described seeing the effect that their word had in the consultation and how this influenced their subsequent response. Patient A described a situation where he felt that the GP had not acted on the test result information he had given his GP, stating that when the GP had asked for another blood test and sample to be done, that he thought he was not going to rush to get this done due to how the GP had responded. In this situation it would seem that patient A did not know why he was having to repeat the blood test, and may have risked thoughts of not being believed. In a different example, patient D spoke of going back to her GP and discussing the side effects she was experiencing, and that because of the concerns she had raised about continuing, was tried on a new medication instead. When the side effects became too much with that medication she went back again and asked what alternatives there were, whereby her GP advised her about a TENs machine. With patient D, she could begin to see how what she said could influence the consultation and increase her confidence that she would be heard.

Patient E highlighted that there could also be a downside of continually being involved in your care and being regarded as an "expert patient". She felt that whilst she liked being involved, the level of involvement in her care would be dependent on the nature of what the consultation was about. There were certain areas that she did not feel were meant for her and was happy to be guided by the GP. She wondered if at times, because her professional background was known at the practice, that a "liberty" could be taken with putting the care back on to her, rather than assess and treat the problem with her being seen at the practice.

Patient E also made suggestions about what else would help her feel involved with her care. She requested that GPs provide more information on local groups relevant to her condition that she could attend, as well as continuing to be notified of any research opportunities. She stated that "being given an opportunity to participate in a professional study, you feel like you've got some value."

4.7.4 Sub-theme: 'In house' management

Patients spoke about noticing how their care was 'held' by the practice, rather than referring outside primary care, with patient E stating she thought they were "shy" at referring on at times. The dominant view was that GPs would refer on when they did not know what to do, however there was contrasting views on whether the decision to refer on was delayed or appropriate. As mentioned previously, patient C felt that referring on would now happen due to her past history of cancer, so did not share the concerns reported by other participants.

Patient A and B both spoke of not getting the necessary investigations they felt they had needed for their symptoms to be understood. For patient A this was about health professionals not checking with follow up investigations to see if the symptoms had been responsive to treatment, leaving him uncertain if the problem he was referring to had been treated. Patient D in contrast spoke of the reverse problem, of feeling that time had been wasted going for X-rays and that the same diagnosis could have come from the blood test that confirmed it for the doctor:

> *"She did this blood test and the results came back within a*
> *week – 'ah yes it's this', then a week later…in the space of*
> *two weeks it took to find out what it were, the pain had gone.*
> *Whereas it took 4 months going through the x-ray process."*
> *(45)*

For patient D, she perceived it as the doctor being just as keen to find out what was happening and stated it was the Doctor who had "kept on sending me for X-rays to find out". This difference in views might reflect the difference in perceived interest in understanding the symptoms and also patient D may not have held the same level of concern about the symptoms being indicative of cancer.

4.8 Theme 5: The experience of the system

Theme 5 refers to the patient experience of the system that surrounds both themselves and their GP. This was discussed at a local level, with the difficulties of getting an appointment, as well as the wider context of the practice being in a pressured and underfunded NHS. Within this theme, the sub issues identified were to do with the duration of the appointment- *your 10 minute slot* and how both the process of getting an appointment as well as the actual 10 minute consultation was perceived as impacting not only on themselves and what they felt able to share but also the GP's ability to explain. Patients also spoke of the issue of the consistent inconstancies they saw in their symptom management. Sub-theme (*In) consistency* details the issues highlighted around not being able to see the same doctor, not knowing if you can see a doctor, being unable to continue with certain management options on the NHS. Lastly, patients spoke of what contributed to their perception that time had been made for their symptoms in the consultation. Details are provided on the responses that patient's valued receiving from their GP are provided in the sub theme *when time is 'made'.*

4.8.1 Sub-theme: Your 10-minute slot

Patients expressed empathy at the pressures they could see that GPs were working under. Patient A stated that "It's not them-bless them- I don't blame them as a person, it's just the situation that they are in", recognising that the 10 minutes slot he describes being 'put in' was a symptom of the system around both him and his GP. Patient B comments on the changes she has observed over time, stating that GPs no longer have the time that they use to have to explain things. For patient B, her particular concern was the difficulty of getting the 10 minute slot with the GP. She spoke of the dread she felt at waking up in pain and having to go through the "rigmarole" of getting an appointment, as well as being "frightened" that she would not be believed.

Similarly, patient C also found the process of getting an appointment difficult. For her, the barrier was not feeling comfortable speaking to a receptionist about the nature of her symptoms to get an appointment. She also found it difficult to speak on the telephone consultations that would be done with a GP to review her medication. She explains the impact that this has on her:

> *"It's just so difficult to get an appointment and getting to*
> *speak to a GP that I just don't and do it myself." (18)*

Whilst the appointment system may help to reduce the number of unnecessary appointments, it would seem for patient C that it colludes with her beliefs and concerns about being a bother and trying to manage it herself. Moreover, when she does get an appointment she finds it hard to "fit everything in" to the consultation, which increases the chances that symptoms don't get attended to in the way that she hopes, for example with the pain she reported in her legs that did not get followed up as "it was mentioned alongside something else". Patient E shares similar concerns, however interestingly comes from the perspective of the health professional, empathising with the GPs for needing to "cram everything in" to that window, recognising that the 10 minute consultation window was as much of a problem for the patient as it was for the health professional.

4.8.2 Sub-theme: (In) consistency

A shared theme among the patient's interviews was the difficulties experienced and anticipated at getting an appointment with the same GP. Patient A stated that "you never see the same GP" and this had become the norm that he had just become "accepting of". He placed this in the wider context of the pressured system, aware that this was not just his experience but one felt by other people that he knew of also. Patient B and E spoke of the difficulties of calling up on the day for your appointment, which may mean you do not see your preferred GP. Patient B described seeing someone who was not her "proper Doctor" and that they had spoken to her about the possibility of her symptoms being Multiple Sclerosis, but states, "We never heard nothing else about that" in the consultations that followed with other GPs, leaving the uncertainty of the diagnosis with her. In addition to the uncertainty of getting an appointment with a preferred GP, patient E also mentioned the uncertainty of being able to get an appointment when you called. Overall she perceived the changes to the local appointment system at the practice as doing "damage" to the relationship with your doctor.

Patient C spoke of the difficulties she had getting an appointment, citing that the practice' move towards telephone consultations, as opposed to face to face consultations was not something she was used to, nor did she use it enough to get used to it. She stated "it was always a different one" that she would speak to and that her actual GP she hadn't seen for a long time. As highlighted already in *the sub-theme 'Not being seen (as just a patient, a robot, or a number)'*, patient C finds

it hard to share how she feels on telephone consultations and instead choses to manage her medication herself rather than speak to her GP on the phone.

Patient D's focus was on the need to be able to access a management option long enough to feel the benefit of it. She had experienced three acupuncture sessions that had helped, but she could only have three sessions on the NHS before she would need to go back and be referred by her GP or go privately. She chose not to because it would take too long. She states:

> *"Three sessions is not enough… if you've got to stop for a couple of months whilst the appointment comes through again all of the system, you think 'well I've not really benefitted because we are starting again from the beginning'…You sort of get used to it and then it's gone."* (35)

In contrast to the dominant perspective that seeing a different GP was a barrier to getting the care you wanted, Patient F spoke of his concerns that seeing the same GP would limit his exposure to finding new treatments. He stated:

> *"I've seen different doctors, that's one problem is when I have to only see one doctor….I call the surgery in the morning they decide… I would like to see another GP to hear alternative…"* (14)

It would seem that although this is an alternative position to those held by other patients interviewed, a similarity amongst all is about having the choice of who to see, whether that be the same or different GP- rather than have this allocated to you when making your appointment.

4.8.3 Sub-theme: When time is 'made'

The main issue that patients highlighted as important to their consultation, was having interest shown and that this could be conveyed in the exploratory questions asked or explanations given by the GP. Patient A felt that there needed to be a difference in the consultation approach taken when the condition had "issues going on" rather than less complex conditions. He felt for the former, there needed to be more time to enable an explanation to be given, which would help to foster some

trust that the doctors were able to make sense of his symptoms.   At its most extreme, patient B describes an occasion where she had gone to her GP extremely distressed, but not felt there was time for her to be able to talk "as there were other patients in the waiting room", and made an attempt to take her life. Although this is a rare response, it does highlight how people's perceptions of care fluctuate in response to not only the GPs actual response but also the person's own level of distress and environmental influences that may heighten certain perceptions. In contrast to this, patient B also spoke of the importance to her that one doctor had taken the time to hear her despite it having been a consultation for her step son, stating "They asked…they explained …they made time for me". It would seem that patient B had not expected the GP to respond to her request, and that in doing so, all be it briefly, the GPs approach left patient B feeling cared for.

Patient C found that being asked at the start of the consultation what she thought her symptoms might be or if she was worried about anything in particular, helped her to leave the consultation feeling reassured. She valued GPs talking her through what they thought it could be and reasons why they did not think it was anything "sinister". Patient D also talked about the importance of the questions that the GPs asked, and how this encouraged involvement:

> *"The doctors have been really supportive.... They will ask*
> *you as well –we think you've got this, but what would you*
> *rather us do to help?" (47)*

Patient D spoke of seeing a change in the approach GPs take with their patients and that a "modern twist" has been brought in with new GPs –"…they are actually consulting me and seeing what I would like". She contrasted this with the experience she has had of being told what she must and should not do by GPs, which she stated would result in her agreeing with things she did not really agree with just so as she could "get out as quick as I could", but then would think "oh shit afterwards" at what she had agreed to. In regards to her experiences now, she states:

> *"I don't get that 'oh shit' thought at all, because they involve*
> *you and don't like dictate to you that you will have this done*
> *or you will have that done. They put you more at ease you*

know…I was worried about this but I'm not now because
they've explained this." (50)

How the explanation is presented is also important. Patient A stated that his experience of only being given a leaflet from the hospital about his condition, had left him with unanswered questions that he had not been able to discuss. He fears that this is what will happen more widely across services without more funding for the NHS. This experience is in contrast to patient D who similarly was given information by her GP to consider at the point of her diagnosis, but that time was also given afterwards to discuss the information that she had read.   This might also be representing a difference between clinical approaches taken in primary and secondary care services.

CHAPTER FIVE: GP RESULTS

This chapter will begin by providing context for the GP interview data collected and pen portraits for each of the GP participants. The main and subthemes from the participant's data will be presented in a table and supplemented further by rich description of the themes presented. Illustrative extracts will be provided throughout, with direct comparisons being made between participants reported experiences of working with and managing MUS.

5.1 GP participants

Four General Practitioners (GPs) were recruited from the 9 GPs that were approached with the study at the South Yorkshire practice. As there was enough GP interest in the study to retain the study focus at that practice, recruitment was not opened up to the Academic GPs at the University of Leeds. The recruited participants ranged between 35-65years of age. All had a variety of clinical interests and duration of clinical practice varied between 8-32 years, as indicated in Table 5.

Table 5*: GPs demographic and clinical interest information*

Participant	Age	Gender	Ethnicity	Clinical Interest	Retired (Y/ N)	Number of years clinical practice
GP A	*35*	*Female*	*White-British*	*Education, Mental health, family planning*	*No*	*8 years*
GP B	*58*	*Female*	*White-British*	*Paediatric health, learning disability*	*No*	*28 years*
GP C	*62*	*Male*	*White-British*	*Mental health*	*Yes*	*30 years*
GP D	*65*	*Male*	*White-British*	*Education, Diabetes / chronic conditions*	*Yes*	*32 years*

5.2 GP pen portraits

Similar to the pen portraits completed for the patient sample, these pen portraits aimed to put the individual accounts from the GPs into a wider context of their diverse range of experiences.

5.2.1 GP A

GP A had been practicing for 8 years as a GP at the city practice. Similar to the other GPs interviewed, she saw that the biomedical model was a framework that did not meet the needs of all patients, and she incorporated approaches from other fields to inform a holistic, person centred approach. She feels that her involvement with the university and medical student training has also had a focus on broadening her perspective on understanding illness, and has influenced her clinical practice. A common thread throughout the interview was the value that this doctor placed on establishing collaborative working practice between her and the patient, and also between her and colleagues. She found that this 'partnership' working, not only with patients but also staff took the pressure off of her to 'have all the answers', a pressure that came from the expectation of patients at times and also an internal pressure to be able to 'cure', which had lessened over her career. Despite this, there was an uncertainty to what extent patients saw 'talking' as a management option and would use the examination to help reaffirm what was being said. It was noticed that more management options were outlined in this interview, with the GP focusing more than any other interview on the issue of overprescribing of opiates and role of both prescribed and complimentary medication for this patient group.

This GP seemed to carry the frustrations of her patients and showed a lot of empathy for her patients in how she spoke about her experiences. She was instrumental in developing the current research project, and similar to the other GPs interviewed, welcomed any additional guidance that could be provided on ways to manage MUS at the practice. It was noted that in comparisons to the other GP interviewed, this GP spoke less about the direct impact on herself as a GP in managing this patient group and less about the chronic nature of the symptoms.

5.2.2 GP B

GP B had been practicing for 28 years as a GP at the city practice. She perceived her general practice work as containing a large number of people with MUS-roughly 1/3 of the patients she would see in a surgery, and many of her 'regular' patients she would see would also be considered to have MUS. The interview focused a lot on the consultation techniques this GP used to convey to the patient that they were being heard, providing containment with a negotiated agenda at the start of the conversation and conveying to her patient that they had permission to come back and access care without symptoms.

She recalled how the focus during her own medical training was to achieve a diagnosis by the end of the history taking, and although she recognised that training had changed, she felt it may heighten a doctors' frustration when working with a group of patients that don't lend themselves to this. Other challenges of working with this patient group that were mentioned in this interview were the paradox of seeing the importance of developing the relationship with the patient and knowing what was 'normal' for them, but not working in a system that enables it, which left this GP at times feeling frustrated, exhausted and questioning what her function was with managing such symptoms.

This interview was the only one which specifically talked about the cuts to social care and how although practical support was often the area that was perceived as making the biggest difference to her patients, the unclear referrals pathways and variability in availability made it difficult for people to access or referrals to be made.   She came across as a GP that placed great emphasis on nurturing the relationships she had with her patients and had more traditional views and experience of the GP being embedded within the community and being able to link patients in to relevant community projects. Similarly to GP A, there was a sense of not knowing if something was the right thing to do with understanding and managing such symptoms, but going with what felt right and what made sense in the context of the patient's range of life experiences.   She spoke of the importance of learning about things through training and valuing learning, but also recognising that the pressures on clinical time made it hard to apply any thoughts about what might work in clinical practice.

5.2.3 GP C

GP C had been practicing for 30 years as a GP at the city practice, before retiring two years ago. In addition to general medicine, he identified that he was also interested in social and psychiatric health, explaining that he started his career covering a list of patients with "classic psychiatric" problems, and over time moved into more "psychologically based problems", which he felt medically unexplained symptoms came under. He reflected a lot on the changes that he had seen in the area and in turn the diverse patient population that the practice served, as well as the changes seen in the health care system from continuity of care to a split up system of care with many points that the patient could now enter.

Compared to the other GPs he spoke more about the challenges of diagnosis, particularly with seeing patients over a long duration and the increase

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risk of disease pathology being missed or overshadowed by MUS. For him there was particular concern that missing something reinforced the existing distrust that he perceived the general public to have towards the medical profession, as well as the patient's own beliefs that really they have got a serious problem that is not being attended to properly. In addition this interview also focused more on how system protocols perpetuate the problem, and the need but also difficulty of working to isolate the 'problem' with different levels of the system. There was a clear interest in the local and wider system that operated around the patient and GP, providing reflection on how the move towards increasing service accessibility challenges the traditional model of care. He came across as a GP that placed great emphasis on understanding how the system influenced the narrative that his patients came with about their symptoms, and spoke of the importance of working with the system- which included partnership working with colleagues across levels of the system and also where possible with the patient and their family.

5.2.4 GP D

GP D had been practicing for 32 years as a GP at the city practice, before retiring a year ago. His identified clinical interests were in medical education and also diabetes, but stated that he had also thought a lot about the difficulties of managing medically unexplained symptoms. For GP D, the difficulty of general practice did not come from diagnosing, but holding the uncertainty around a patients symptoms and trying to maintain the patient-GP relationship. He spoke of the ability to achieve both as fluctuating according to the backdrop of pressures GPs have to work under. He spoke openly about his curiosity declining with the repeat exposure to 'self-limiting' illnesses over a long career, which he believed had prompted his retirement. Unlike other GP interviewees he also raised the issue of general practice potentially being an isolating experience for a GP, with little contact with others, outside of seeing patients. For him it was important that time to connect with colleagues was built in to the day, and he spoke fondly of the daily coffee break that would happen, with colleagues supporting one another if they were running behind, to ensure there was an opportunity in the day for all to come together.

This was one of the shorter interviews, which despite sharing the breadth of the themes that were raised in other interviews, may have lacked the depth and deeper exploration of the issues raised. He came across as a GP that held a lot of compassion not only for his patients but also the team he worked with and recognised the importance of staff connection with one and another.

5.3 Results from the GP Interviews:

Data from all four GP interviews were included in the analysis. The five main themes were based broadly around the conceptual framework of clinical decision making, and consisted of: symptom beliefs and expectations, diagnosing the health problem, managing the symptoms, professional preferences, and the experience of the system as a GP. The conceptual framework used to analysis the GP data was the same as the conceptual framework applied to the patient data, so as to aid comparison and contrast between the participant groups. The contribution of each participant to each theme and subtheme is indicated in Table 6. The main themes and the subthemes that were found to contribute to them will now be outlined.

Table 6: *GP themes and subthemes and frequency of utterances by GP*

Themes /*Subthemes*	GP A	GP B	GP C	GP D
	Frequency of Utterances			
SYMPTOM BELIEFS AND EXPECTATIONS	**14**	**34**	**33**	**14**
Symptoms will be complex and chronic	*1*	*12*	*11*	*2*
Facing the brick wall and rolling a stone up hill forever after	*4*	*12*	*13*	*5*
It is real, but what I think is going to help is more with your mood	*6*	*5*	*5*	*5*
The uncertainty of getting through the barriers	*3*	*5*	*4*	*2*
DIAGNOSING THE HEALTH PROBLEM	**13**	**18**	**14**	**12**
Culturing Curiosity	*2*	*8*	*3*	*4*
Negotiating different frameworks	*6*	*8*	*10*	*5*
The weird and wonderful sounding [medical] names	*5*	*2*	*1*	*3*
MANAGING THE SYMPTOMS	**23**	**12**	**11**	**13**
Reducing additional risk	*10*	*3*	*3*	*5*
Maintaining the relationship: knowing the person and giving permission to access care	*2*	*4*	*2*	*5*
Providing a credible alternative narrative	*11*	*5*	*6*	*3*
PROFESSIONAL PREFERENCES	**23**	**9**	**9**	**11**
Holding the uncertainty	*6*	*2*	*2*	*4*
Openness, honesty and understanding	*7*	*6*	*5*	*4*
Tackling the problem together	*10*	*1*	*2*	*3*
THE EXPERIENCE OF THE SYSTEM AS A GP	**18**	**14**	**18**	**13**
The priority of access over consistency	*9*	*6*	*11*	*7*
Finding protection against the pressures	*6*	*6*	*2*	*2*
Needing more time and resources	*3*	*2*	*5*	*4*

5.4 Theme 1: Symptom beliefs and expectations

Theme 1 refers to GPs general perceptions of the medically unexplained symptoms that their patients present with. A dominant belief was that the physical symptoms

reported by the patient would be made up of psychosocial factors that patients would not necessarily connect with their symptoms. GPs expected that the main focus of their work would be concerned with supporting patients to make and accept this connection. However, the extent to which these could be thought of as the 'cause' for medically unexplained symptoms varied among the GPs interviewed and is detailed in the sub-theme *'It is real, but what I think is going to help is more with your mood'*. Also highlighted are GPs perceptions that the symptoms are often going to be complex both in understanding and how they are managed, and that these symptoms were likely to exist for the duration of their relationship with the patient. Implications of such are discussed further in the sub theme '*Symptoms will be chronic and complex'*. The impact of managing such complex and chronic symptoms are also discussed in relation to the pressures GPs reported as coming from the patient, their own internal pressure and the system around both patient and GP, and are outlined further in the sub theme '*Facing the brick wall and rolling a stone uphill forever after'.* Numerous barriers that GPs were trying to find ways to overcome were identified in the sub theme '*The uncertainty of getting through the barriers',* and details are provided on the different perceptions and approaches taken to managing such barriers in the consultation.

5.4.1 Sub-theme: Symptoms will be complex and chronic
GPs spoke of a number of factors that contributed to making medically unexplainable symptoms a clinically complex area to manage. Firstly, such symptoms were recognised as not fitting within the biomedical framework of having a symptom underpinned by a disease. GP A talks about their own level of comfort with thinking outside of this framework to understand what the patient is presenting with.   Similarly GP B shows this level of comfort too, stating that she spends time "unravelling" the symptom to expose and address the psychosocial issues that she often finds are associated with the physical symptom. GP C reflects on the difficulty of being able to do this, stating "…the difficulty is then that you have to sift out the different symptoms and where they fall". For GP C, this appeared to be where they fell in relation to being either psychological or physical in nature, as well as distinguishing the medically unexplained symptoms that could also be co-existing with "real" physical symptoms.

Patients with MUS, who the GP participants were able to recall readily in the interviews, appeared to be individuals who regularly attended with symptoms that were hard to objectively measure, and who would present for help but did not

enable GPs to give it. In addition, GP B perceived there to be a difference in which patients were likely to give gifts to their GP stating "not many of our patients give gifts but, so it's interesting that these patients do". For her the function of the gift buying was a complex range of factors that she hypothesised could be as simple as a thank you after having seen them for many years, but for others she feels it could also be a " 'don't let me go, carry on making sure you do everything you can for me'". From what GP B describes, the gift buying itself then becomes a 'symptom' of the underlying issues for some of the individuals she sees.

In contrast, GP D spoke of 'clues' in the physical symptoms patients reported that may suggest it is likely that initial test results will come back as normal:

> *"Your common problems –chronic pain, recurring*
> *headaches, recurrent abdominal pain, [and] fatigue erm with*
> *people who have also got- I know from the life*
> *circumstances -that they have got other problems." (2)*

Despite such clues, the area of MUS is further complicated by patients potentially presenting to health services with acute exacerbations of chronic problems. GP C explains that problems arise when the patient presents in different parts of the system and neither the patient nor treating clinician may make the connection that the current presentation is related to a chronic condition, which then triggers a further cycle of investigations. Conversely, examples were also provided from GPs of the concerns that a long-term rapport could also reduce their ability to detect new symptoms. This rapport often came after many years of seeing patients as part of their management of their symptoms.

GPs described working with their patients over a long period of time, and tried to develop a good rapport that at its best enabled the process of improvement to be seen in symptoms or functioning, and at its worst has brought increasing fear that a symptom will be overlooked. GP B spoke of seeing one patient for nearly 20 years and that it had become "quite hard to see her fresh each time". GP C also speaks of the difficulty of remaining open and alert to new symptoms, particularly when the patient's initial symptoms have been considered as medically unexplained:

> *"You start wondering towards the end of your career which*
> *one of them is going to develop something else and you are*

> *going to –in inverted comma'-'ignore it' because it's part of*
> *their picture of their MUS." (19)*

Overall, such accounts highlight the complex balance that GP's are trying to establish in MUS management. GPs need to make sure that they do not disregard their core biomedical framework to treat new or existing disease pathology but also be open to exploring alternatives, and although a well-established rapport can have the benefit of knowing what is usual for your patient, caution is needed that an existing understanding of the symptoms does not over shadow new ones.

5.4.2 Sub-theme: Facing the brick wall and rolling a stone uphill forever after

GPs spoke of the exhaustion and often frustration that often went with managing complex patients with medically unexplained symptoms. One direction of frustration was at the system, which at times felt like disjointed care was being provided at the cost to both the NHS and the patient. GP C spoke of the impact that unnecessary procedures had on the understanding he was trying to develop with his patient and had meant "going several stages back" in their understanding. GP D in contrast stated that his frustration was at the system not recognising and appreciating the work being done with the type of patients that "you are never going to get a physical answer for"- where you are unable to objectively measure symptom outcomes. That systems that are concerned with looking for certainty in this patient group only maintains the problem, which he compares to being "like rolling a stone up a hill forever after".

One area of frustration that was described by the GP participants was the feeling of being "stuck" and under pressure to move the conversations on in the consultation. Both GP's who were currently practicing (GP A and B) spoke of the frustrations that could come with not feeling able to move the conversation about the symptoms on for the patient. For GP A the obstacles to this were cultural and language barriers that made it hard for explanations to "land", as well as the experience of a more extreme example whereby the patient continues to push against the time constraints of the appointment, which meant that this became the issue that was eventually attended to. GP B described a similar example of a patient who had become stuck in the search for an answer for his pain and was not open to discussing the management options being suggested. She states:

"He was stuck with the fact that we were missing something still…therefore when we said there wasn't any other management to offer apart from physiotherapy and analgesia, he couldn't get pass the fact that he felt something was being missed." (12)

This extract suggests that part of the 'stuckness' that was arising may have been due to this patient wanting to find a treatment and fix from his pain, rather than management options that could improve functionality. GP B found that this left her feeling "exhausted" after the consultation and questioning what her role was in his care, as she felt she had not been able to "give him anything" as he had not given her the opportunity to speak. GP C suggests that where it has not been possible to match the patients' health beliefs to his own, then one mutually agreed end point might be to stop seeing each other, stating "it's time for both of you to move on, they [the patient] need a fresh start."

Both GP C and D referred to their being an internal pressure to get their symptom understanding 'right', which came from a place of concern that a misdiagnosis could undermine the trust, not only of themselves but the wider medical profession. For GP D, he outlined the pressure that he feels "comes both ways", not only coming from the patient with their expectation that you will be able to label the symptoms and draw them together, but also the internal pressure felt as a GP to be able to do this and wondering 'have I missed something?'.

5.4.3 Sub-theme: It is real, but what I think is going to help is more with your mood

Participants varied in the extent to which they would consider psychosocial variables to be the cause of medically unexplainable symptoms, but did appear to agree that psychosocial factors were involved and without question felt it was appropriate the person was seeking support. GP D explains that regardless of a cause being identified it did not make a person any less justified in seeking help, stating that where symptoms were having a "big impact" on their lives and making a person "miserable" was enough justification to be seeking medical help.

A key area that GPs felt to be important in the MUS consultation was supporting the patient to make the connection between their physical symptoms and the impact of past or current significant life events. Although GP B perceived that trauma was likely to be associated with such problems, she cautioned that she

would be "reluctant to suggest to them that this is the whole picture", alluding to the inaccuracies of suggesting a linearity between the experience of trauma and physical symptoms as an inevitable response, without taking in to account other mediating and protective factors. GP C echoes this in his view that complex problems such as MUS need to be put in to the "entire context" of the person's situation as opposed to a very "brief context" for more simple problems.

Patients were thought not to make connections between their physical symptoms and psychosocial context, which GP participants attributed to being either a protective psychological defence or that cultural factors did not permit people to talk openly about how they felt. GP C states:

> *"…women in different cultures have different freedoms to express themselves… and frequently for both men and for women there are parts of the story that we are either unconsciously or consciously suppressing" (12)*

Similarly, GP D held the belief that generally speaking where a patient is using a non-European framework to make sense of their symptoms, it would not allow for physical symptoms to be due to psychosocial causes. In general he perceived that even though many will come with terrible psychosocial trauma "*they can't make the link between that and the physical symptoms*", however did acknowledge that this may also be effected by the education levels of a person and that where people are more educated there may be a more 'sophisticated' understanding of the mind and body.

That said, GPs spoke of the importance of helping patients to accept the link between mind and body in the explanations they would provide to the patient. Both GP A and D made references to a model of reattribution, which GP D described as a process of "*shifting the agenda from physical symptom to psychosocial context that the patient is in, and getting them to make the link between those things*". Rather then it be the GP providing the explanation, GP A and D explain that patients are encouraged to do this themselves, as GP A states "it *always sticks much better than if you plant an explanation on their plate."* This description of "*planting the explanation on their plate*" suggests an acknowledgement that although the GP may feel like they are giving the patient something, it will only be meaningful if the patient is ready to receive what is 'put on their plate' and can integrate it in to their existing beliefs about the symptoms. Both GP A and C stated

that only once this connection has been made by the patient would the option of psychological support be introduced. GP A reflects that learning how to approach the option of psychological support for the individual is something that has come over time and finding the language to use to reduce any inference made by the patient that she is saying they are making up their symptoms.

5.4.4 Sub-theme: The uncertainty of getting through the barriers
The GP participants spoke of the factors that contributed to their uncertainty of being able to overcome the barriers they encountered with some patients who had MUS, as well as what they have found helpful.

GP A described a frustrating situation where she had been unable to develop a working partnership with a patient who was consistently turning up late for appointments. She had managed this by speaking honestly to the patient about the difficulty she was experiencing establishing a partnership, but instead of opening up the conversation as hoped and exploring the barriers together, the patient had responded negatively and the relationship broke down. For GP A, although the approach had not gone as she had hoped, it was important for her to try and challenge the general perception that she felt was held by other GPs stating:

> *"I am aware that some Doctors might [think] 'nothing we do*
> *is going to make them better' and can take a short shrift*
> *type of approach to them, and I do get a bit annoyed with*
> *that because it doesn't help the patient and just moves the*
> *problem on to someone else." (96)*

GP B also showed a similar determination to try and overcome the barriers that presented in her consultations. In the absence of not knowing what else to do with one patient who had not responded to her attempts to focus the consultation, she reflected on what she needed to *feel* more able to contain the patient. She spoke of using a double appointment to provide a 10-minute consultation, building in time for "self-protection" for herself. This GP wanted to make it clear that not telling the patient that they had a double appointment was "unusual", and that she would "pick and choose" what she shares with the patient based on her understanding of them and their need. It would seem that for this GP, she thought about what she needed to be able to maintain her energy and commitment of hearing the patient and finding other options to overcome the moments when her

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"most effective ways of getting to the heart of the matter" were not working for the patient.

Both GP C and D spoke of the difficulty of being able to help a patient once a cycle of investigations had begun. The help that was being referred to, was as GP D said being able to "produce a different narrative" for the patient, that could help position them away from referrals and investigations. He spoke of this being particularly difficult when a patient's illness framework varied considerably from the Westernized framework of illness that he held, stating that "it's almost like a personality change that you've got to effect".

Overall there seems to be variation in the collective opinion of who is responsible for overcoming the barriers experienced in the consultation, from a joint approach whereby both GP and patient construct a way forward together, to one where the GP feels the weight of responsibility for finding a new way to overcome the challenges.

5.5 Theme 2: Diagnosing the health problem

Theme 2 refers to the process of building an understanding of the presenting issue, which is shared between the GP and their patient. In the sub-theme *'Culturing curiosity',* GPs spoke of the various ways they tried to broaden their own understanding of symptoms that challenged conventional medicine, curious to find the context that may help explain the symptoms. The effect of time and clinical exposure to similar symptom presentations is also considered in relation to what effect this might have on understanding the problem.

The challenges that the GPs described of developing an understanding that was shared between both them and their patient is described in the sub-theme *'Negotiating different frameworks'.* The main presenting focus for GPs was wanting to make sure that their patient felt heard, and details are provided within this sub-theme on the various approaches that they used and the barriers and facilitators experienced. In addition, GP's spoke of the function of the labels that cluster together medically unexplained symptoms and how it could create understanding for some patients and not others. Further details on the individual variation seen in patient receptiveness of functional labels is outlined in the sub-theme '*The weird and wonderful sounding [medical] names…',* along with consideration of what role such labels have for the GP working in a medical system.

5.5.1 Sub-theme: Culturing curiosity

Retaining curiosity about the symptoms that were being brought in to the consultation seemed to be an important factor for the GPs interviewed. GP A described seeing how on some occasions the medical model was *"not serving the patients well"*, which had encouraged her to explore other disciplines to see what other approaches could be taken.

Similarly, GP B also spoke of "drawing on everything" to help build up an understanding of the presenting issue, but for her the "everything" was in relation to exploring life circumstances of the patient to inform the approach taken. For her, the indication that she needed to take this approach was when she felt she and the patient were getting "stuck", she states:

> *"I'm not going to unpick everyone's past in a 10minute consultation when everything seems to be going alright, it's when you feel like you are getting stuck and when you feel like they are presenting stuff that you are not explaining … your agenda is different from theirs and something needs to happen… "(52)*

From this extract, it would seem that she would open up the consultation focus more, when the focus began to feel too narrow for both her and the patient to move together.

GP C also speaks of the importance of putting the issue in the context of the person's life story and belief system and that this can often give clues early on to "*which direction the symptoms are heading in*". For him, he describes this as being "*the single most important thing in any consultation*", yet that it can become overlooked in the pressure of work to get an "end result". Although this pressure for GP C is unclear where it is coming from for him, GP B perceives that there is a preference in the medical profession to be able to say what it is and be able to talk with greater certainty about what the patient might experience, which at worst could risk misdiagnosis.

In addition to such pressure making it difficult to keep the person in context, GP D states that this becomes easier with time and experience, but that beyond a certain time point it can also become harder. He reflects on some of his reasons for retirement:

> *"Your skill improves over a period of time and then there is certainly the evidence that GPs in my age group get less good at it and are more likely to make mistakes-they get inured-they see so much minor self-limiting illness that they get complacent-that's why I retired really."(22)*

The extract illustrates how curiosity and confidence both increase with experience, but that familiarity of particular symptoms built up over many years may make it harder to retain the curiosity that contributes to being truly able to hear the person as well as their symptoms.

5.5.2 Sub-theme: Negotiating different frameworks

GPs spoke of various ways they tried to manage the differences they perceived as occurring between their beliefs about the symptoms and their patients'. The main concern for the GPs appeared to be about making sure their patient felt heard. GP A stated that difficulties occur when patients get fixated on one type of framework or possibly feel "*threatened*" by a biomedical approach and decide to reject what is being suggested. She suggests that maintaining the dialogue between herself and the patient is needed to be able to move things forward, and tries to be "*open minded*" to the way a patient maybe making sense of their symptoms, even if she does not necessarily agree, stating "*if you dismiss them out of hand then you're not giving the patient a good service.*" However, she described being "*stuck in a rut*" if there was no willingness on the patient's part to also keep the dialogue open. For GP C, where differences were noted between his understanding and his patients, it was about trying to "*tease out*" what needed to happen to match his patient's symptom beliefs against his, which did not always work for clients who did not share a European understanding of health and illness. He reflected for one patient that the explanation he had provided for her symptoms had not been that helpful, which he reasoned was because of her "*deep seated beliefs*" that meant she turned back to her own beliefs, rather than take on "*a very European based belief set*".

Both GP A and D spoke of using the model of reattribution to support patients to open up their focus of symptom understanding from the physical to psychosocial causes. However, GP A states that one of the difficulties of doing so is finding an event that the patients are equally able to identify with:

> *"…quite often it can be quite hard to find a reason for it and*
> *then that explanation just does not wash-'well I don't feel*
> *stressed', and even to point out… you get 'yes, but I I don't*
> *feel stressed', and then that tent will fall flat."(71)*

Where patients had physical health symptoms that co-existed with medically unexplainable symptoms, this also added an extra layer of complexity. GP C spoke of trying to delineate these problems from each other where possible, and provide reassurance by building an explanation based on the physical health checks he would do in response to the patients' concerns. Remaining open to reviewing the current understanding of long term medically unexplained symptoms and displaying this to the patient was also perceived as important. GP B describes the subtlety of the signs that cued her in to re-taking and listening again to one particular patient's history:

> *"Normally she smiles at me and she pats my hand and says*
> *thank you doctor, and it was different this time…" (56)*

For this GP it had been important that her patient, who did not speak English, was able to convey her dissatisfaction and see that it would be heard and understood. In this instance the barrier of language was overcome by attending to the nonverbal communication occurring between this GP and her patient, and that an understanding of each other had been built over time.

5.5.3 Sub-theme: The weird and wonderful sounding [medical] names…

There were various views about the function of the terminology that gets used in reference to medically unexplained symptoms, and how the terms varied over time and context. Generally, the participants questioned the extent to which labels ascribed to medically unexplainable symptoms were done so to support patient understanding of their symptoms or were reflective of the pressures felt in the health system to provide a diagnosis. Both GP A and C made references to this being a distinctive group of patients that has been recognised across different specialities, with many different 'headings'. However, GP A questions the helpfulness of the language used to refer to such symptoms, not only questioning this for the patient but also the GP who is supporting with symptoms management:

"I don't think it serves the patient or us particularly well, because it is making something sound very medical, when what they are saying actually is there is nothing medical here."(39)

GP A felt that a decision had to be made about whether giving a label to otherwise medically unexplainable symptoms would help people to understand, or if this was going to reinforce already entrenched illness behaviour in the patient. For her, she perceived this to be a tension that also existed for the commonly used terms in primary care, such as ME or fibromyalgia, whereby it was helpful to some patients but by no means all. Similarly, GP D also spoke of the individual variation seen with 'fibromyalgia' and how for some it had been an acceptable label that had been enough to help manage their symptoms, but for others, particularly where there was co-existing anxiety or depression, it heightened their distress, perceiving the inference to be that it was 'all in their head'.

Not being able to provide a diagnosis went against the traditional medical model that most of the GPs participating in the study had experienced in their training. GP C states that the model she had been "*brought up with*" came with the expectation that diagnosis could be given at the end of taking a medical history, which medically unexplainable symptoms challenged. This was similar view to GP D who also shared that he perceived the role of the GP to be about being able to "*Label the symptoms, draw them together and label it*", and that if you couldn't then this became difficult trying to create an explanation that could move the patient away from referrals and investigations.

5.6 Theme 3: Managing the symptoms

Theme 3 refers to how GPs respond to patients whose symptoms are medically unexplained. As there is no disease pathology to treat for these symptoms, GPs spoke in terms of how they supported patients to manage their symptoms. Getting to a point of management, rather than treatment, came from GPs providing an explanation that the patient could identify with and was reassured by. As detailed in the sub-theme *reducing additional risk,* a key issue was the duty of care to not harm patients, which GP's identified as having for their patients and took steps to inform patient's decisions about taking complimentary medicine, monitoring and intervening with opiate use, preventing unnecessary investigations, and seeking

further support and opinion from colleagues to verify their own understanding of the complex symptoms. Having a good working relationship with patients was deemed as one of the most important aspects for understanding and being able to manage the symptoms. In the sub theme *'maintaining the relationship: knowing the person and giving permission to access care',* the barriers and facilitators to maintain the relationship are discussed in relation to the patient and the system of care that they are in.   GPs spoke of needing to provide an alternative explanation that could reassure patients about their symptoms and show that these symptoms were being taken seriously. The role of the examination, referring internally within the practice for second opinion and referring for psychological review are all detailed the sub-theme '*providing a credible alternative narrative*' . In addition, not only is this discussed from the position of the GP providing the credible explanation, but also the GPs response when this comes from the patient.

5.6.1 Sub-theme: reducing additional risk

The central issue was the duty of care that GPs held for their patients, with GPs reporting various stages in the management of medically unexplained symptoms for additional harm to occur. One aspect was regarding complimentary medicine and the limited evidence base for the range of management options patients were seeking, as well as the lack of evidence base in general for treatments that help to manage MUS. Although GP A could appreciate the value that complimentary medicine could have, particularly in encouraging a holistic approach to be taken, she also felt it could be "dangerous" if the patient pursued this at the exclusion of other areas, or without considering the risks.

GP A describes managing this uncertainty by providing patients with the information she has, stating:

> *"I will give you all the information and at the end of the day it*
> *is your choice...if they've got capacity then it's their right to*
> *make what we may see as bad choices, and you just have*
> *to say well I've given you all the information and what you*
> *decide is up to you." (12)*

It would seem that this was about supporting the patient to make an informed choice with the information available, and that in times of uncertainty it was important that the decision came from the patient.

Similarly, in addition to the risks of patients only pursuing an alternative therapy route, GP A also spoke of the risk of patients solely pursuing medication, particularly opiates and the associated risk of addiction. She described the position that she took with discussing management problems as consisting of "*I don't want to cause you more problems*". GP A also recognised that it was not necessarily patients that were always asking for medication, rather it might also be GP's responding to the pressure to "*do something*" to end the consultation. She states:

> "*It is the easiest thing to do, to write a script. Much harder to
> just listen and avoid the temptation to write scripts out,
> because that's erm [it] gets them out the door but doesn't
> solve the problem.*" (90)

For GP B, C and D the concern was the risk of repeating an unhelpful cycle of investigations, and balancing this against the other risk of missing new disease pathology. GP D described that part of his job was to "*protect the patient from really intrusive, painful, sometimes dangerous investigations*". Both GP B and D spoke of trying to manage this in the explanation that was given about the symptoms, whilst also trying to listen for new symptoms that the patient might describe. For GP D he spoke of incorporating the results from the preliminary tests that were done, and the medical history collected to build an argument that could position the symptoms within a psychosocial context and contain the problem within primary care. He describes taking a direct approach with the patient about what he thinks the problem is related to:

> "*You know this is what I think is happening, we've done
> these investigations and they are all absolutely clear, I note
> that you've had this very difficult time recently…*" (16)

Reducing risk to patients was not the only consideration, but also reducing the risk of additional stress amongst GPs. As detailed in the theme "*the experience of the system*", GP D highlights his perception of general practice being an isolating experience at times, and that it was important to build in time to de-stress with colleagues. In reference to managing the complex nature of MUS, he states that he values "*sharing the load*" with his colleagues, getting advice and second opinions from them, which helped to provide a "*fresh look*" at otherwise chronic symptoms,

and that doing so also was about "*reassuring the doctor that their judgements are okay*".

5.6.2 Sub-theme: maintaining the relationship: knowing the person and giving permission to access care

The doctor-patient relationship was a key factor that GPs identified in enabling them to understand how best to help the patient manage their symptoms. Similar to what other GPs described as 'having enough context' for the symptoms, GP A also states that before you have a "*deep understanding*" of how the patient makes sense of their symptoms, then you are unlikely to get anywhere with discussing management options.   For GP A, this made it difficult for her to be able to say what management options she would be considering exploring with the patient, stating "*I think it depends on the person I have in front of me*", with management options being guided by what the patient's preferences are.

For GP B, the familiarity that comes with seeing an individual over a long period of time, creates a sense of knowing what to expect from each other in the relationship. Being able to see patients regularly and agreeing to see them in a few weeks' time to see how they were getting on, was commented on as being a helpful approach by both GP B and D. For GP B this approach helped her to build an understanding with the patient over a long period of time, without the focus of the consultation having to be on new symptoms:

> "…it's quite useful to say that I will see you in whatever the time interval feels correct and then therefore they don't have to actually present with a set of symptoms to get that appointment and you can build on –you're not sort of trying to manage a new set of symptoms, but you can build on where you got to at the last appointment." (69)

This extract also begins to highlight the system challenges that the GPs are working against to manage the medically unexplained symptoms that patients have. That alongside an implicit message that the system may give of 'you need symptoms to access care', GPs are trying to give explicit messages that give people the permission to come back and develop the understanding needed for the management of their symptoms.

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Challenges to developing the relationship and in turn understanding, are not just limited to system issues, but also the patient's ability to take up the care offered. All GPs spoke of the frustrations of having a patient who would continue to request further medical opinions or resist the support offered, and how this could invite a rejecting or critical response from the GP. For GP D , he acknowledges that "*it is so easy to reject these people*", and tries to counter this by conveying that he takes what they are saying seriously, and from a place of concern offers to see them regularly to build an understanding and monitor the symptoms.

5.6.3 Sub-theme: Providing a credible alternative narrative

One of the issues highlighted as being important to the consultation, was trying to build a credible alternative understanding of the symptoms, which showed that the patients symptoms were being taken seriously. GPs described various ways they would try to develop this with their patient, without necessarily referring the patients for further investigations. For GP A the role of the physical examination was central in this and she perceived it as having other functions then just being away to gather information. Her perception of the process of examining a patient was that this helped to show the patient they were being listened to and taken seriously, and that the tangible nature of the "*laying on of hands*" conveyed a feeling of being cared for. Similar to GP C and D, it was another way to help build the evidence to support their explanation. However, she goes on to say that it helps to demonstrate her skills as a doctor stating:

> "…I think a lot of patients don't see talking as any sort of treatment, or don't attribute the same weight of talking to a professional. Sometimes I have to elevate my status a bit by doing the examination thing…" (75)

Here, there is an assumption that talking treatments are not perceived as an active form of management by patients, which contributed to this GP finding a way to "*elevate*" her status, being seen as doing something, so that she can be heard. Where she is struggling and getting resistance, then she will make the decision to refer to the pain clinic to access a psychological review of the symptoms by the psychiatrist there. She recognises that the patient may not take this option up, but for her it's about trying all the options "*before I give up*". For GP D, although he would refer on if progress was not happening with developing a symptom

understanding the patient could identify with, he would refer to another colleague within the practice to review the patients symptoms. He describes that the process of normalising the symptoms is much harder than diagnosing:

> *"…the most difficult bit of general practice, it's not making diagnosis, its actually convincing the patent that what they have got does not require investigation and it is in the normal range…somehow changing the narrative that the patient goes out with… that they've got a more positive narrative to explain the symptoms." (20)*

Although the alternative explanation for the symptoms is predominately spoken about from the position of it coming from the GP, patients who experience new symptoms whilst receiving long term support for their medically unexplainable symptoms, may also present their GP with an alternative explanation for their new symptoms. GP B spoke of the importance of showing the patient that as a health professional you are prepared to change your own narrative around their symptoms, or will say if you are unsure of the cause of their symptoms. She feels that this type of approach should be encouraged in junior doctors and that they get experience at taking the uncertain position in the consultation and doing so in a way that does not leave a patient feeling "*completely vulnerable*".   That it is not just about the patient being prepared to change their narrative, but also the GP.

5.7 Theme 4: Professional preferences

Theme 4 refers to the values that GPs apply to their clinical practice. The need for approaching their work with acceptance of what they were and were not able to do or explain, is discussed in the sub-theme '*holding the uncertainty'*. Within this sub-theme details are provided not only on the effects of time and experience on being able to establish this position in their work, but also the effect that patient' expectation has on this.

The importance of having openness, honesty and holding compassion for the patient and their symptoms were also important qualities that GPs tried to foster in their work. All GPs were open to considering a mixture of frameworks help them and support the patient to understand their presenting problem. The barriers and facilitators of taking an honest and open approach and how they sit alongside the

value of compassion are discussed in the sub-theme '*honesty, openness and compassion'*. Collaborating with others, which included both patients and other healthcare professionals, was also perceived as being important to the GPs interviewed. Issues of language ability, readiness for active involvement and academic ability were all factors that were discussed as barriers to patient collaboration. Further details of this, as well as the function of partnership working with other colleagues is discussed in the sub-theme '*Tackling the problem together'*.

5.7.1 Sub-theme: Holding the uncertainty

One of the issues discussed as being important to the GPs in their professional practice centred on the process of developing acceptance that they will not be able to explain and cure every patient that they see, and that this was not reflective of their professional ability.   GP A describes this as being a 'tough' realisation stating:

> *"I think you go into to medicine thinking naively that you are*
> *going to round curing lots of people and that's not the case*
> *in general practice… I'm at peace with that and figured that*
> *at a while ago, that my role is not often about getting people*
> *better erm… so it is tough." (53)*

This extract suggests the professional struggle and frustration of wanting to cure the problems people present with, but not being able to and questioning what your role is then about.   For GP A she states that "*with a bit of maturity and experience*" she now sees that she does not have to be the person who comes up with the answers all the time, and is happy to take a more advisory role for the patient.

Similarly for GP B, she refers to being more at ease with saying when she is unable to explain something and instead has found it helpful to focus on improving functionality for the person. She describes that since "*getting better at not worrying about having a diagnosis*", she is more able to manage the patient's anxiety and is in "*a better place to explain*" how she reached her understanding of the symptoms.

There was also recognition amongst GPs that to hold on to this position of uncertainty also meant needing to manage the patient expectation that as a GP you will be all knowing and able to cure everything. GP C refers to the situation of having patients ask him 'well how do you know it is not this?', whereby he acknowledges that he cannot know for sure because "*I am not God!*". GP D

perceives that "*holding that uncertainty is the essence of general practice*", and that patients with MUS are the most difficult part of being able to hold this. For him he feels that GPs have to have resilience to be able to cope with the pressures that this brings, which includes managing the "*unspoken scenario*" that if you have got it wrong as a doctor then the patient will sue.

5.7.2 Sub-theme: Honesty, openness and compassion

GPs identified three qualities that were important to uphold in the approach that they took with their patients- honesty, openness and compassion for the person's symptoms were all described as being central to the approaches taken. All GPs described themselves as using a biopsychosocial approach to understand the symptoms, adapting how much they attributed the cause to biological, psychological or social factors as they got to know the patient and their symptoms. GP C states that it was important to come to the consultation with an open mind, reasoning that "*0% to 100% of people's symptoms might relate to social and psychological factors*".   GPs described various ways they displayed openness in their approach with the patient, ranging from being open about the discomfort they may have with certain management options and discussing with them their reasons for this, as well as being open to hearing the new symptoms patients bring or the patient's own ideas for symptom management. GP D also spoke of the factors that he perceived as compromising how open GPs could be in the consultation, particularly if this meant saying something that was not in agreement with the patient:

> *"…everything gets in the way of the frank conversation-*
> *time, the discomfort of doing it, the skill needed to do it, the*
> *patients resistance, the patient getting angry-it's*
> *everything!.." (17)*

This extract highlights the struggle of wanting to be open and honest, but being unsure how to do this in a compassionate and understanding way. GP A also suggests this unease, describing how her approach of being honest and open with the patient about her discomfort at repeated prescribing of analgesics "might not be patient centred", however she reasons "[if] I am doing a good thing for the patient then I don't really mind". In this respect GP A perceives that patient centeredness is not about agreeing with the patient, but acting with the patient's best interests in mind and showing it is coming from a position of concern.

Being honest and self-reflective of your own practice was also highlighted by GP A and B. For GP A the cue for reflective practice was if patients kept on coming back and being curious as to what this might be indicating in regards to how well you've understood the problem. One perception was that health professionals may come across as dismissive in their approach due to not being transparent about their own uncertainty of how best to understand the problem. GP B states:

> *"I don't think professionals are always very good at being honest about our own thoughts about what is going on, so we sometimes use terms or seem dismissive because we have not explained something in our own minds fully, but we've done the tests that exclude the serious stuff…" (70)*

This extract might also be associated with the level of acceptance that GPs have of not having the answers, as detailed in the previous subtheme *holding the uncertainty,* whereby some GPs may feel that it is acceptable to say that they don't fully understand, whilst some might assume they have to have it clear in their own minds before they can provide an explanation. Overall, considering the interviews collectively, GPs wanted the patient to leave the consultation feeling that their symptoms have been heard through the concern and interest shown and that they as health professionals could be trusted to act in their patients' best interests through the openness and honesty they have shown in their clinical approach.

5.7.3 Sub-theme: Tackling the problem together

Partnership working was a factor perceived as being important for the GPs interviewed. However, GPs varied in the extent to which they spoke about this in relation to encouraging active involvement of the patient, or active involvement of other staff and clinical teams. GP A had a particular strong focus on promoting active engagement in the consultation. She states that the importance of being "patient centred" was taught on training, however it was not until she realised later in her career that she did not have to have all the answers could she be "*truly collaborative*". She states:

> *"I'm more comfortable saying to patients that we don't have all the answers and let's try and figure this out together. I think what works quite well is the patient alongside you, and*

> *that 'this is a complicated problem that needs tackling*
>
> *together really'…"(60-61)*

For this GP, it is about acknowledging the complexity of the issue and doing so in a way that not only empowers the patient to take on an active role, but also recognising the preferences that the patient may have.

For other GPs the focus was more on trying to maintain the relationship in general and trying to create an explanation that patients could "*take on board and understand*" (GP C). The academic ability to understand levels and quality of evidence, the language and cultural barriers that limit communication and readiness to take on an active role in the relationship were all cited by the GPS as barriers that limited patient collaboration. GP D describes the impact of the language barrier on building a collaborative relationship

> *"…all the tricks that one uses to build rapport and*
>
> *relationship- you've lost those, because communication is*
>
> *so poor. It's like going to France and having a conversation*
>
> *with a French person there would be no humour, no*
>
> *literature illusions, no political illusions –it would be 'can I*
>
> *have a cup of coffee' –very transactional..." (25)*

GP A shares a similar experience of needing to be more "*blunt*" in her approach where there is a language barrier, and where she perceives people to be drug seeking.

Working in collaboration with other colleagues was also highlighted as an important factor for GPs. Firstly, this provide the function of establishing consistency with patients that "*dot around*" (GP A). GP D describes the importance of giving a "*good background*" in the referrals that he makes, to encourage receiving health professionals to "*step back and talk to the patient*" so that a unified narrative can be established. A second function of working in partnership with other healthcare professionals, was the support that could be accessed to think about alternative ways to approach the problem. For GP B, and in regards to accessing support for managing patients with MUS, she perceived that it was particularly helpful to talk to colleagues "*who have a specific interest in mental health*".

5.8 Theme 5: The experience of the system

Theme 5 refers to the views that GPs have on the healthcare system they work in and the way in which these impact on the management of patients with medically unexplained symptoms. GPs reported the system pressures to increase accessibility in healthcare, but that the challenge was to do so without compromising delivery of consistent care for patients in primary care. In the sub theme '*The priority of access over consistency'* the issue of acute presentations 'overwhelming' the daily case load of GPs was raised, with concern that this was impacting on them having time for the management of chronic symptoms. Despite this, GPs who were currently practicing at the surgery suggested ways in which a consistent approach for all patients was being kept in the approach of the practice. Difficulties maintaining consistency with other parts of the system were also raised, which included navigating around the different service protocols and risk thresholds of certain symptoms. The issue of needing space to be able to withstand not only the system pressures, but also the pressures that come with managing complex symptoms was also raised by GPs and is outlined in the sub theme 'F*inding protection against the pressures'.* Concerns were also raised that although the amount of resources that MUS patients require can vary, that it initially requires a significantly greater amount of time than what is readily available to GPs to be able to build the relationship and develop understanding. This is described further in the sub theme '*Needing more time and resources'.*

5.8.1 Sub-theme: The priority of access over consistency
Views on the delivery of healthcare were discussed in relation to both primary and secondary care, with the central issues being around the role of increased access and consistency in care.

  Primary care level
  The perception amongst the GPs interviewed was that the national push to increase accessibility of healthcare for patients, could compromise the need that their complex and chronic patients had for a consistent approach to be provided in primary care. In regards to MUS management, GP C describes how traditional approaches of managing MUS by the same doctor seeing the patient and building an understanding of the symptoms had become increasingly difficult with the "*outside pressures*" placed on primary care. For him, he perceived this as a move towards seeing the GP role as providing "*items of care rather than as personal care*". GP D held a similar perception, stating that he felt the management of

chronic conditions was limited by what he describes as being "*completely overwhelmed"* with needing to be available to see acute problems in primary care. He also referred to the wider changes he had seen over time in the level of risk that was considered to be acceptable, stating that at the start of his career "*many conditions would not be investigated as they are now".*

In contrast, although GP A and B also acknowledged the difficulties, there was also a pragmatism that accessibility did need to increase for patients at the practice and that the issue was how to make sure that this was done in a way that supported consistency. GP B felt that increasing healthcare accessibility may help to manage some of the fear that may come with having symptoms that cannot be medically unexplained, stating:

> *"I think also if you are scared by your symptoms, which is*
> *very understandable if you don't know -nobody knows quite*
> *where they are coming from ….[then] lack of access to*
> *healthcare can be worrying." (68)*

Here, for this GP there is concern that the difficulties that patients with MUS experience getting an appointment might heighten the fear that they have not only about their symptoms being serious but that they are also on their own managing them.   GP B also raised the importance of social care to provide the practical and social support that she felt patients with MUS needed, particularly where medically speaking nothing more could be done. For this GP her frustration was at the inconsistency of the services that she perceived as making a difference to her patients, stating that *"it's a forever changing picture",* in reference to which third sector services continue to be funded. She describes it as a being a "*big let-down"* for both herself and the patient, after having reached a psychosocial understanding of the symptoms, but feeling unclear about how best to guide the patient towards the support that they've just identified as necessary. Similar to GP C and D, she also talks about the importance of delivering personal care, and the need to find a way to keep the consistency for patients as they move between health and social care.

Secondary care level

Establishing good communication between primary and secondary care services was identified as an important factor that helped GPs to provide

consistency of care for their MUS patients. GPs described taking active steps to support with the containing of the symptoms within primary care by placing notes that could quickly alert other parts of the system of the management approach currently being taken, or clearly stating their understanding of the problem in the background information for any referral letters they made. For some GPs, patient were not routinely copied in to the letters that would be written, however GP D states that patients could request to see a copy and that he wrote it "*with the understanding that the patient may see it*". GPs also described how the process of ensuring consistency when a patient is under the care of a specialist could create more work, particularly trying to negotiate the differences in healthcare protocols.

GP A described an occasion where communication had not been satisfactory between primary and secondary care, which had resulted in her patient having unnecessary surgery. She describes:

> *"I had rung A&E when I found out she had gone in and said*
> *she was well known to me and has MUS- I really don't think*
> *this is appendicitis, and I was quite, I was dismissed really*
> *and by that point the decision had already been made…"*
> *(37)*

She felt that the difference in how this persons symptoms were understood may have reflected the greater extent to which the biomedical model gets used in specialist services compared to primary care. This view was also shared by GP D, who perceived that secondary care was about finding "*certainty*" and that they would "*investigate until they get an answer*".

In contrast, GP C described an occasion where communication between different parts of the system had been effective. This was for a patient who was currently experiencing non cardiac chest pains, but whose past medical history of having an isolated cardiac event, would trigger a rapid response. He described the agreements needed to be established not only with the patient, but also the different parts of the system to be able to contain the problem.

> *"They [ambulance team] were part of the problem, because*
> *with their protocol, with chest pain you have to immediately*
> *transport and that was one of the biggest barriers to try and*
> *come to negotiation and if they did take her to hospital, then*

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> *the next part of the agreement was –clear on the A&E*
> *records, that this was someone who was not needing*
> *medical investigations…" (34)*

This extract highlights that whilst this GP recognises that certain protocols are in place to protect the patient, that they also need to be considered in the context of the patient so that unintentional cost to patient and NHS are not incurred.

5.8.2 Sub-theme: Finding protection against the pressures

Various views were put forwarded on how GPs withstood the pressure, not only of general practice but also of seeing patients with complex care needs. For GP A there was concern that under the time pressures, prescribing had become a method of quickly showing the patient that they have done something, which ends consultation. She states that rather than have the time to be able to hear what the patient need actually is, the GP might act based on an inaccurate assumption of *"what do we think the patient think is going on, [and] what do they want".* She made reference to the observed "*cultural aspect*" of opiate prescribing having increased within primary care, and her suspicions that this reflected in part the time pressures that GPs face. She states:

> *"…everyone that you speak to is having a tough time of it,*
> *that time pressure to be everything all the time is probably*
> *leading to that increase in prescribing and loss of continuity*
> *is harder now to keep continuity with our patients." (91)*

This extract suggests that there is another concern, which is that prescribing is not only going up but that monitoring of such medication becomes harder with the loss of continuity. GP A also suggested that another way GPs might try to manage the pressure of general practice might be to "*give a short shrift*" approach or refer patients on to other colleagues if they are perceived as "*too burdensome*" or "*emotionally draining*".

The GPs interview shared the view that space was needed to help themselves process challenging consultations. For GP A she stated that having the space to reflect on the "*bad experiences*" during the study interview had been cathartic, and enabled her to look at these experiences that "*weigh in on the back of your mind*" holding compassion for herself at having done her best even if it did not

have the outcome that she had hoped for. For GP B she had started to build this time in to the appointment slots that she offered, providing extra time for patients where needed, but also recognising there were patients where she would need this "*space to manage*" for herself. She had also experienced how useful it was to spend time going through patient notes, and spotting any patterns in repeated investigations, stating "*you can sometimes stop an unhelpful cycle of assessments by just stepping back.*" For GP D, having space was about having time away from paperwork and patients to connect with colleagues at some point in the day. He comments on the importance of the practice coffee break:

> "*I think building some time in to your day where you've got the opportunity to just discuss patients or de-stress is important…the coffee breaks got later and later but we all met up for that –a really key and crucial thing at our practice.*" (23)

5.8.3 Sub-theme: Needing more time and resources

GPs gave various reasons for needing more time and resources for the work they were doing with patients with MUS. Firstly, it was recognised that building up the initial relationship and understanding was something that could only come with time. GP C makes the distinction between the "*simple problem*" needing a brief context for it to be understood, compared to the complexity of MUS that required a more holistic understanding being formed. Instead, GP A describes the current approach as being "*piecemeal*", where patients are seen recurrently to build up the understanding. She feels that if there was extra time then the consultation could take on more meaning to the patient. With GP A there seems to be a professional frustration at seeing what the patient needs, but not being able to provide it:

> "*Just think, spend 30 minutes with them or an hour with them and [you would] probably would get to the bottom of it….but we don't have that luxury unfortunately.*" (84).

However, it is also recognised that not all patients with MUS would require the extra time. GP B states that where she already has a well-established relationship with a patient with MUS, then they don't always require the full amount of time, which differs from the initial appointments stating "*often [they] take a lot*

more than 10 minutes".   Time can become further pressured with the language barriers that GP C describes, where time is needed to enable translation and navigate cultural differences.   From what GPs describe they are identifying that appointment times are having to be tailored more to the presenting needs of the patient, and that extra time is particularly needed in developing an initial understanding or where language barriers are present. For GP D, there was a frustration and concern that although time was needed to be able to manage MUS patients and prevent costs to other parts the system, that without recompense for this type of work it was placing additional strain on an already pressured environment. He states:

> *"There is no credit for any preventative work... that sort of*
> *work is just not noted in the targets… there is no resource*
> *recognition… which basically means you are killing yourself*
> *because you don't have an extra nurse, an extra doctor to*
> *do the work." (14)*

Here, it would seem that GP D is describing an over stretched service that still continues to be pushed, without staff having the extra resource that they need to be able to manage it.

CHAPTER SIX: THE CONCEPTUAL MAP

A conceptual map was created, comparing, contrasting and combining the results from the patient and GP interviews, to build an overall understanding of the experience of managing medically unexplained symptoms more broadly.   Figure 9 shows the conceptual map developed from the data, and shows how patients and GPs manage MUS separately outside of the consultation, as well as how they manage it within the consultation space. Three conceptual themes emerged from GP and patient interviews- *understanding of the symptom(s), the emotion response, the validating relationship,* with one further conceptual theme present for patient interviews- *deciding what gets shared in the consultation.*

Similarity was seen in how patients and GPs both saw the symptoms as being part of a complex problem that had many possible layers to it. Divergence was found in whether psychosocial factors were considered to be secondary or primary to the pain symptoms patients reported. Predominantly patients spoke of psychological factors being secondary to the pain, although over time some patients had begun to wonder if it was a symptom of something "deep" within. In contrast, GPs perceived pain to be secondary to psychosocial factors, with the focus of the intervention being concerned with supporting people to develop a biopsychosocial understanding. There was evidence of there being a shared frustration, which came about from the patients experience of trying to access help for their symptoms in a pressured service and the GPs frustration at trying to provide person centred care without the resources to meet the level of need and demand. Both tried to manage the uncertainty of the symptoms through seeking support within the healthcare system- GPs focusing more at eliciting this at primary care level amongst colleagues, whereas patients spoke more about accessing this both at primary and secondary care level. In addition, patients also continued the search for understanding and management options outside of the consultation, which at times impacted on the level of adherence to the medical advice provided. Developing a validating relationship was important in the management of the medically unexplainable symptoms for both patient and GP. For patients this had the function of legitimising their level of suffering, and a space where their needs could be understood. For GPs the relationship was central to developing an understanding of the symptoms, as well as enabling risk management not only of the symptoms but the management options being used.

6.1 Patient and lead GP feedback

All 6 patient participants were sent a summary of the themes and a copy of the conceptual map, to help assess the credibility of the results of the study. For the purpose of feedback and for respect for confidentiality, GP themes and concepts were removed from the conceptual diagram sent to the patient participant group. Only 1 patient replied to the email invitation of reviewing and replying with their feedback. Patient A replied stating the following:

> *"Thank you for the summary and I appreciate you took the time to get back to myself. I do not think I wish to add anything to what you have written, You have captured the situation well I feel from the notes I read.*
> *Kindest Regards …"*

Participants conveyed a strong sense of the importance of being understood in their interviews. Although not all felt comfortable in 'speaking up', the majority interviewed displayed a level of persistence in order to be understood. As such, I wondered if the lack of response to my approach for feedback was reflective of participants viewing the content as satisfactory, and that if there were enough concern then this would have motivated a response.

The GP leading on the study at the practice was also sent a summary of the themes and a copy of the conceptual map. The copy of the conceptual map contained both GP and patient accounts, to provide feedback to the GP on the consultation experience of both patients and GPs at the practice.   The feedback from this GP was that this also "chimed" with their experience of clinical practice. In addition they also added their thoughts about how the results could inform changes to clinical practice, which was an additional source of data that was used to inform the discussion of the results.

The next section will now discuss how the conceptual themes outlined and the participant feedback are situated within the wider literature, along with consideration of the possible structures to support with patient and GP collaboration in Medically Unexplained Symptom management.

Problem coping response

Seeking information and medication outside of the consultation (*online, overseas, real time symptom monitoring*)

Stopping and swapping medication

Symptom Management

Building the biopsychosocial understanding, pain clinic, IAPT, physiotherapy, acupuncture, analgesics*

Past health care experiences

Responses of others

Other health problems (past / or current)

Perceived symptom control

Symptom intensity and impact

Professional values / training

Past experiences of managing MUS

Consult stage

Support from colleagues

Length of experience

Giving subjective opinion and feeling

Seeking social support not just medication

Multiple interpretations of symptoms (body-mind connection)

Referral confusion

Searching for objectivity and fact (mind-body connection)

Risk management (monitoring symptoms and medication)

Building the relationship (pre-emptive appointments)

Containing the problem (normalising and reframing)

Wanting to understand the symptoms

Establishing a validating relationship

PATIENT

GP

More time

Providing options

Establishing Consistency

Not enough time to explain

Difficulty saying how you feel on the phone /getting seen / expecting rejection

Getting use to a GP/ management option and then it changes

Feeling the push towards episodes of care rather than personal care-difficulties monitoring medication

Unclear referral pathway for social support

Fear

Fear

HealthCare System

Increasing access to meet the demand, 10-min appointments, disjointed services, reducing unplanned hospital admissions, and the acute focus over chronic.

Emotion Response

(*Seeks help at A&E, requests to see another Doctor*)

Emotion Response

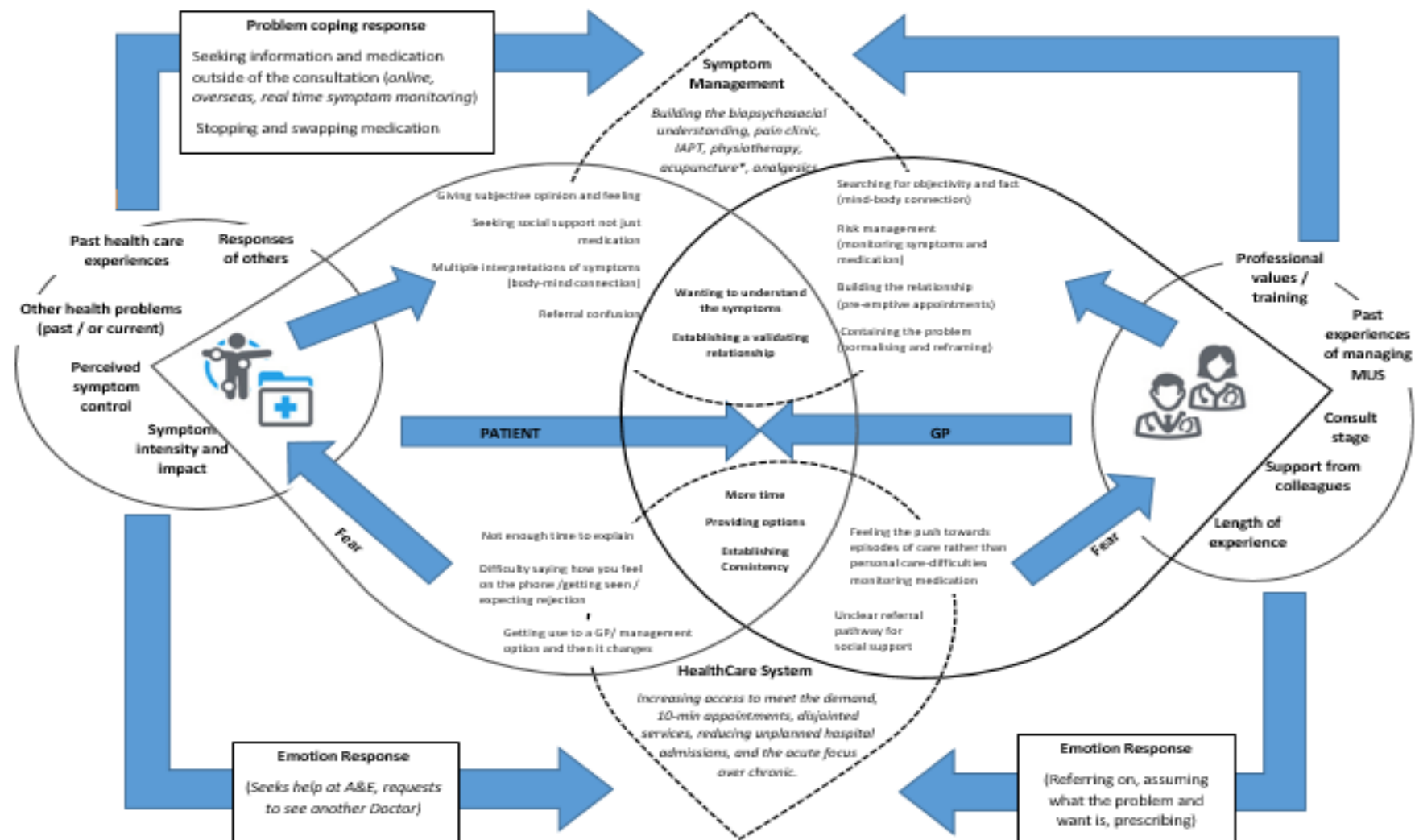(*Referring on, assuming what the problem and want is, prescribing*)

Figure 9: *Conceptual map of how GPs and Patients understand and manage MUS*

CHAPTER SEVEN: DISCUSSION

The aim of the study was to explore how patients and GPs understand long term symptoms with complex causes and their management, by addressing the following research questions:

- How are long term symptoms with complex causes understood and managed by patients and GPs?
- What way does their understandings overlap and diverge?
- How are differences in understandings negotiated?
- How can this inform shared decision making interventions to manage long term symptoms with complex causes more effectively in practice?

This chapter will provide a summary of the results in relation to the aim and study questions outlined, as well as consideration of the strength and limitations of the methodology, and what the clinical and research implications are of this study.

7.1 Summary of findings

This study provides two perspectives-patient and GP, on one shared experience- the MUS consultation at a South Yorkshire practice . This study contributes to the existing literature on primary care management of MUS, by focusing on the process between patient and GP in the consultation and what factors challenge and facilitate the development of a shared symptom and management understanding. The results suggest that both patients and GPs are trying to solve the problem of explaining and managing the medically unexplainable to the best of their ability, with the resources they have available. However, gaps are evident in both the management approaches used between patient and GP and the information that gets shared in the consultation. Both patients and GPs spoke of the importance of the relationship in the management of MUS symptoms, with patients valuing not feeling on their own managing their 'strange' symptoms, whilst GPs recognised the importance of being able to provide symptom validation and ongoing monitoring of the risk of new symptoms developing or changes in symptoms occurring. The results from the study suggest that an important aspect to consider in the development of future interventions to manage MUS will be to

focus on increasing what information is brought in to the consultation space. The implications being that prior to utilizing interventions that facilitate patient symptom understanding, that alternative methods may need to be used to open up the shared space between patient and their GP in order to assess a patients symptom understanding and need. The facilitators and barriers to patient-GP communication will be discussed in relation to the research questions raised initially in the study, with discussion of how the results fit within the literature already considered in chapter one and other relevant areas that have not yet been discussed.

7.1.1 How are long term symptoms with complex causes understood and managed by patients?

Understanding of the symptom(s)

All patients reported that chronic pain was the main symptom they experienced, with all but two diagnosed with a chronic pain syndrome that as yet has no identifiable cause-Fibromyalgia. Patients spoke of a process of trying to decide what normal pain for their own body was and initially wondered if this was reflective of age, or the cumulative effect of working in physically demanding jobs. Such normalisation of the problems would see patients try and self-manage the pain with over the counter pain relief, rather than see their GP.   These findings are similar to other studies that have considered how age affects a person's cognitive appraisals of their pain, whereby attributions for mild and chronic pain differ between young adults who associate this as being a symptom and older adults (60 years plus) who showed an increased likelihood to attribute this to the aging process (Prohaska & Leventhal et al., 1985; Hofland, 1992). That said, the age range of this study sample was between 44 -62 years of age, providing evidence contrary to Prohaska & Leventhal et al., that some middle aged people may also attribute their pain to growing older, all be it only when it is not severe and enduring pain. However, considering this study finding in regards to the self-regulation model of illness (Leventhal et al., 1984), it is possible that participants' experience of pain may have been influenced by other social determinants. For example the environment around them and the conversations with family and friends who may talk about their own aches and pains of growing older, or suggest it as an explanation to the individual who mentions they are in pain.

As predicted by the self-regulation model, when patients in this study initially attributed pain to the normal process of ageing, their coping response was to self-

manage. However when the pain persisted despite attempts to soothe and the intensity increased, patient participants then reported perceiving the pain as a potential symptom of disease in need of investigating, where additional resources were needed to what they already had. Appraising the pain as a symptom brought with it concern, which in addition to seeking help from their Doctor, for some it also brought with it a cognitive response of comparing themselves to other people that they knew with similar symptoms, and the beliefs that their symptoms might be a life limiting, or threatening disease such as cancer. For others they went back through their family history to see if there was mental health or physical health problems that could account for the symptoms. The process described by the patients interviewed seemed to followed a similar three stage process that has been outlined in how patients generally decide to access medical treatment- firstly noticing and labelling them as physical symptoms, secondly searching for causes and making symptom attributions based on past direct or indirect experiences of the symptoms, and thirdly deciding that the benefits of accepting treatment out way the cost (Safer et al., 1979). This suggests that the process of help seeking in medically unexplainable symptoms is similar to other medically explainable health conditions.

The emotion response

This study found that some patients reported less frequent attendance once they had a functional diagnosis they could identify with and which provided them with an understanding of how to manage the symptoms, with one patient stating that she knew best what worked for her own body. Excessive worry continued for patients who although had a functional diagnosis, were unable to identify with it in a meaningful way, and would repeatedly present at either the hospital or see different GPs at the practice. The exception to this was one participant who despite not identifying with the functional label, had found an alternative active coping strategy to manage his worry- faith.

The role of catastrophizing and its effects on pain severity, emotional and functional responses is well documented (Sullivan, Bishop, and Pivik, 1995; Campbell, Quartana and Buenover et al., 2010). What is less clear is to what extent catastrophic thoughts are primary or secondary to the pain experiences, and overlap with other pre-existing cognitive and emotional processes. One participant shared that without having a scan to verify that she did not have cancer, it exacerbated her fear of "you never really know if you are dying or not". Although she spoke of the depression as something that came after the pain, it was clear

from what she described that the onset of her pain coincided with the emotional pain from the loss of a significant relationship and that she had not been able to give herself the permission to grieve. It is likely that the catastrophic beliefs this participant held were a complex interaction of both her suspended grief, and the impact that the pain behaviours were having on her life. In addition, there is some suggestion that catastrophizing could be a learnt way to communicate level of need and support from friends and family (Sullivan, Thorn, Haythornthwaite et al.,2001). For this participant, whose identity was built on being a "strong" person and not being upset, this had the effect of eliciting her partners support, who would take her to appointments and reassure her that they would find the money to go get a private scan.

The validating relationship

Symptom fear was not the only motivator to see the GP, but also 'kinship' and hope were also factors. For patients who described this as being a motivator for them seeking GP support, there was a hope that the consultation would be a space that they could feel heard and understood, in a way that they were unable to get outside the consultation space. One patient described how her professional role of being a nurse meant that everyone expected her to be 'nursey nurse' 24-hours a day. She felt that when she went to see her GP, that they could 'see through my eyes' the struggles she was experiencing. This seems to be in reference to a sharing of the caring professional identity, which could deepen the empathetic connection and sense of relatedness for the situation of being in the caring profession, but also not being immune from needing care for yourself. The psychological need of relatedness, described as a "feeling of being respected, understood, and cared for by others" (Ng et al., 2012), has been identified as one of the two social factors that contribute to personal wellbeing (Deci and Ryan, 2000), as well as with reported patient satisfaction with healthcare services (Waters et al., 2016). It would seem that for this participant, the anticipated relatedness based on past experiences of healthcare contributed to her motivation to seek help from her doctor.

Reasoning about what gets shared in the consultation

Even when patients did go to their GP for management of their symptoms, there was also evidence of managing their symptoms outside the consultation via health forums, switching medication for alternative therapies and actively monitoring

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what impact if any, their mood had on the amount of pain they were in. Despite how involved patients were with their symptom management, none of the patients felt that in general they would bring such information in to the consultation. One of the reasons cited for not approaching their doctor with the information they were reading, or decisions to alter medication, were due to the past experiences of paternalistic care- not necessarily by the GP, but recalling a care hierarchy growing up or from experience of working in health care settings, and being unsure to what extent their opinion would be welcomed "I am mindful that I am the one approaching them for help". For others there was recognition that it was not an 'evidence-based' management option they were trying, and did not want to bother a busy GP with it. Perceived difficulties in getting a face to face appointment was also preventing one participant from saying how she felt about taking medication, stating that the impersonal nature of the telephone consultation, meant she found it difficult to open up to the consulting GP on the phone, and similar to participants not wanting to be a 'bother', did not want to be perceived as 'being silly' if she were to share her concerns. This suggests that for these patients there was an overall awareness of the pressures of the healthcare service, and that this, along with any internalized stigma regarding illness legitimacy in the absences of an identifiable cause, may have exacerbated existing beliefs about their overall worthiness for care. This lends support to the findings reported in other studies that have explored MUS patients experiences of primary care, whereby patients have highlighted the importance of non-verbal communication, amount of GP transparency about the limits of their knowledge, and perceived empathy from the GP to challenge perceptions that they are being seen as an 'inconvenience' by their GP (Houwen et al., 2017). In addition, where studies have suggested that patients may not feel comfortable talking to their GP about psychological health (Peters et al., 2009; Branch, 2000), this study would suggest that there may be a mutual colluding of not discussing co-existing mental health problems between patient and GP, with one participant stating that he believed GPs don't want to share what they are really thinking, as they are worried that patients will have a "breakdown". This perception reflects some of the findings of a study exploring patient and health professionals experience of discussing co-existing depression with management of long term physical health conditions, where concerns were expressed by GPs that making reference to someone's "depression" might come across as "intrusive" and would be avoided if the patient was perceived to be at risk of disengaging or too overwhelmed in managing their physical health condition (Coventry et al., 2011).

7.1.2 How are long term symptoms with complex causes understood and managed by GPs?

Understanding of the symptom(s)

For GPs, how they understood medically unexplained symptoms was based on past clinical experience and drawing on practice based evidence of the clinical markers that over the years had become suggestive that the symptoms were likely to be medically unexplained. This process of using probability reasoning to quickly build an idea of the nature of the symptoms supports the finding that such 'rules of thumb' strategies are used by health professionals to help with quick decision making and risk assessing (Andre, Borgquist & Molstad, 2003). Although this did not prevent tests from happening, it did seem to enable some GPs to make their rationale clear for why the routine tests were being done, and managing the patient concern and expectation that disease pathology would be found.

GPs expected that such symptoms would be complex in nature, and that it was important to keep the patient and their symptoms in a broad context. The amount of context that would be needed was dependant on the perceived complexity of the problem, with one GP stating that complex problems would need to be put into the "entire" context of the patient's life story, compared to simple problems that need a "brief" context to be able to understand. This position seemed to be influenced by the model of reattribution (Dorwick, Gask & Hughes et al., 2008), which both retired and current GPs made references to being a helpful model to 'work to', with one GP recalling that they had attended training a while ago at the practice on this model. Despite it being considered a helpful approach to take, it was also acknowledged that the difficulty came when the explanation could not be hung on a psychosocial factor that the patient could identify with, and that then, as one GP described "the tent goes flat". There was a perception that whilst a biopsychosocial framework was held by themselves, that the patient often came in with a biomedical understanding and would require support to make the connection between the psychosocial context and the physical symptom, placing pressure on them to search for medical certainty.

The emotion response

The internal pressure to be able to 'fix' was also identified by GPs in the study, and how tolerating uncertainty and not 'buying into' the public perception of the 'all knowing' expert, came with the right amount of both personal and

professional experience. GP's commented on being comfortable and "at peace" with the uncertainty, and recognised that in being able to manage their own anxiety, they were in a better position to think about what was going on for the patient.

Whilst there is evidence to suggest that tolerating the uncertainty of less 'concrete' problems is a widely shared challenge amongst Trainee GPs (Stone, 2013; Stone et al., 2014; Howman et al., 2016), there was evidence in this study that towards the later career stages there is also reduced confidence in the ability to assess symptoms due to a combination of the changes in the amount of risk tolerated in the healthcare system, as well as general over exposure to what one GP referred to as "self-limiting" symptoms. GPs then sought support from outside the consultation to reflect on the challenges of the consultation, doing so either on their own or with colleagues, or referring the patient on to other colleagues within primary care.

The validating relationship

Maintaining the therapeutic relationship was also identified by GPs as being a central part of MUS management. This enabled the gradual development of an understanding about the symptoms, which had to occur over many consultations due to demands on appointments, managing acute presentations, and the language and cultural barriers experienced with many of the patients with MUS. Although GPs identified that the long relationships they held with their MUS patients helped to provide a firm level of understanding of the symptoms, it was also recognised that this came with the risk of missing something with not being able to see the patient's symptoms "fresh" each time.

This suggests a dilemma for continuity of care, which has also been shown to occur in another study exploring the value of personal continuity for GPs, with suggestions that this dilemma could be managed by moving towards providing continuity of care at practice level rather than individual (Ridd, Shaw & Salisbury, 2006).

7.1.3 What are the areas of divergence and convergence in patient and GP symptom understanding and management?

In relation to how GP and patients both perceived symptom management, a similarity was seen in that both were searching for a way to make sense of the symptoms and fill in the gaps in their understanding. However, both patients and GPs raised the issue of needing more time in the consultation to be able to develop

a meaningful understanding, with patients reporting that the quality of the explanation that the GP was able to provide was used to indicate the extent to which they had been heard by their GP and enabled subsequent trust to be built in the relationship. Being able to provide and receive a range of options for managing the symptoms was also shared by GP and patients. Both shared the frustrations of the management limitations through lack of evidence-base, as well as the vague direction that could be provided if the symptom understanding and management was for psychosocial support. One GP described how the fixed term contracts for third sector services made it difficult to establish a partnership and confidence in what she was 'prescribing'. The lack of therapeutic direction with managing MUS has previously been cited as a shared concern by both patient and GP (Atkins et al., 2013), whereby patients interviewed about their experiences of MUS management reported that they felt "abandoned" by their GP, when diagnostic results came back clear and conversations began about potential co-existing stressors. Similarly, GPs in the Atkins et al. study also reported they at times felt unable to discuss 'psychosomatic' symptoms with patients anticipating this would be met with anger from their patients and would try and disguise their belief by using nonspecific phrases, such as 'stress-related' symptoms. The study suggested that GPs and MUS patients were silenced, stressed and working in their own silo to understand the symptoms.

To some extent this was evident in the current study. The study found a shared expectation between GP and patient, that the 'other' in the relationship would be using a different explanatory model to understand and manage the symptoms. For GPs this was the expectation that patients would predominately hold a biomedical understanding of their symptoms. Whilst for some patients this was evident, and the treatment goal was to fix, there were also patients who spoke of it being their GP on a search for answers and looking for a 'cure' for their symptoms. Contrary to research having found that chronic pain patients and GPs held different frameworks for understanding, with patients using biomedical and GPs using biopsychosocial understandings (Allegretti et al., 2010), there was evidence in this study that there was much variation in how patients made sense of their symptoms, with both biomedical and biopsychosocial models being used. Contextual factors from both outside and inside the consultation are likely to contribute to the variation seen, for example three patients worked within the care profession and spoke in relation to symptoms being managed rather than cured. Also, the extent to which health professionals had spoken to them about their

symptoms from a biopsychosocial perspective may have varied in relation to GPs perceptions about which patients would be able and ready to enter in to this form of conversation.

The findings from this study support existing research that have suggested that patients have a complex understanding of their MUS symptoms (Peters et al., 2009; Liden, Bjork-Bramberg & Svensson, 2015). This lends support to the argument that although GPs report that patients are unlikely to make the link between bio-psycho-social factors themselves, that this might be reflecting not necessarily limitations in patients' understanding, but their uncertainty about deciding what is relevant and how to talk about these issues with their GP. Factors such as the transient nature of internal and external experiences, cultural issues around talking about psychosocial issues (Coventry et al., 2011), as well as logistical barriers of appointment (Murray et al.,2016), have all been reported as barriers to good consultation communication.

The difference between the results in this study and Allegretti et al's paired interview study between MUS patients and GPs, may also be highlighting another important factor that influences the extent to which patients pursue a biomedical explanation and treatment for unexplained symptoms- the role of privatised healthcare and the extent to which patients can afford to pursue it.

7.1.4 How are differences in understandings negotiated?

Patients varied in the extent to which they felt able to spontaneously say or question their GP if they were concerned or disagreed about something. For some, they found it helpful when their GP began the consultation by asking them questions that helped them to share what concerns they had about the symptoms, giving them the permission to question. Signposting and providing of information was also welcomed by patients from their GPs, although it was important that there was enough time that this could be discussed together in the consultation.

Where patients had not felt there had been a mutual exchange of information, there was evidence of resistance to medical opinion and seeking consultation with another GP or going to the hospital. GPs also commented on this stating that at times the dialogue between patient and GP would become 'stuck', with 'both of us facing a brick wall' - unable to move beyond a particular narrative in the consultation.   GPs spoke honestly about occasions when differences in understanding had not been possible to resolve and that the agreement reached

was to bring the relationship to a close.   One GP spoke of the importance of accessing the health beliefs of the patient and using this to work out what needed to occur to move the patient's beliefs closer to their own. Although there was also evidence that some GPs tried to co-construct an understanding with their patients about the symptoms and management options, there is also evidence to suggest some support for research that has previously found that where patients present with complex presentations, either the patient or GPs agenda gets prioritised, rather than shared (Sinnott and McHugh et al., 2013).   That said, it is important to recognise that a number of contextual factors will be impacting on how GP and patient approach patient involvement. This study found that although patients did favour the move towards patient involvement in their care, it was also recognised that the amount of involvement they wanted in the consultation fluctuated and at times they felt it was more appropriate that the GP took the lead. This was attributed to the nature of the consult, and the acute nature of their symptoms. This highlights the temporal nature of patient involvement and the dynamic assessments that GPs are having to make regarding the appropriate approach to take.

7.1.5 How can this inform shared decision making interventions to manage MUS more effectively in practice?

As outlined in chapter one, Shared Decision Making (SDM) has been described as a way to help promote patient involvement in decisions made about their health (Coulter & Collins, 2011), in a way that recognises both the preferences, values and knowledge that the patient brings, as well as the clinical expertise and knowledge regarding risk benefits of treatment or management options that the health professional brings (Ahmad et al., 2014).   Both patients and GPs in this study showed a similar anxiety regarding the risk of the medically unexplained symptoms either being, transforming or overshadowing something life threatening, and that both managed this anxiety outside of the consultation. Although this was helpful when GPs spoke to colleagues for their own support and suggestions, patients found it confusing if a referral was made that did not fit with their own understanding of their symptoms or style of coping, with one participant stating that she did not know how the exercises in the pain management programme applied to her when she did not believe she had any control over the pain.   Evidence suggests that where patients show low active coping response (taking active steps to make changes) and high passive coping response (look towards factors outside of them for control) there is an increased risk of non-

compliance with referrals for exercise-based rehabilitation programmes (Ferrari and Louw, 2011), as well as reduced perception of being able to control the symptoms (Baastrup et al., 2016), and increased severity of depression (Mercado et al., 2000). This suggests that having space in the consultation to assess and discuss potential barriers to management options may support identifying patients in need of additional support before they are able to access self-management options for their symptoms.

Use of Patient Reported Outcome Measures (PROMS) has been reported as one way of helping to open up the conversation between patient and health professionals and provide information that can be considered together to help inform decisions made about health care through use of generic or disease specific PROMS (Black, 2013). Although use of PROMS in a primary care setting is not routine for chronic health conditions, a self-management screening tool has been developed and validated on a Netherlands sample of primary care patients with chronic health conditions, which measures self-efficacy, anxiety and depression, locus of control and social support, and assess preferences for mode of delivering support (groups, computer, willingness to self-monitor) (Eikelenboom et al., 2015). Whilst this screening tool did not include patients with MUS in the sample, it does provide an example of how the identification of barriers to management of long term conditions or symptoms could be a potential way of providing the permission that patients appeared to need to discuss different aspects of their health (mental and physical) with their GPs, and a way for GPs to safely approach the conversation of mental health and discuss risk issues. This suggestion certainly fitted with the study feedback that was received From the GP, who suggested that introducing a triage system, whereby screening patients particularly for self-efficacy may help to determine the level of resource allocation needed.

However, although use of PROMs in MUS management may have the additional benefit of evidencing need for resource to commissioners, the cultural diversity seen within a practice population would limit the extent to which standardised measures could be used, where validation of existing measures are unlikely to be representative of the cultural and clinical diversity seen with patients with MUS. Other methods supporting generic shared decision making may be better suited to the unique needs of a practice, for example brief decision aids and option grids that could provide a visual representation of the risk and benefits of deciding between continuing with a focus on disease pathology whereby

investigations and treatments are pursue. Alternatively, a focus on quality of life and symptom management approach, as well as thinking about the congruency of their response to their symptoms with doing what is important to them in their lives (Ahmad et al., 2014).

7.2 Evaluation of method

The overall credibility of the results, will now be outlined alongside the strengths and limitations of the design used. The trustworthiness of the results will be considered against the extent to which procedures recommended by Chiovitti & Piran (2003) were followed, which include *letting participants guide the inquiry process*, *checking the theoretical construction generated against participants meanings of the phenomenon, using participants actual words in the conceptual framework, and clarifying researcher bias.*

7.2.1 Quality

Interview questions were developed with support both a GP and patient consulting on the study. In addition, the topic guides were used to provide a loose structure to the interviews, and enabled flexibility in how and in what order the topics were discussed. Data from the interviews as they were completed also informed the gradual refining of the interview questions. This was to add greater exploration of topics that had not necessarily been captured in the initial broader questions that had been asked.

Pen portraits were also provided to help orientate the reader to the particular context of each of the participants. The process of developing the conceptual map was an iterative process of going back to the results and the transcripts to ensure that the words used were not being taken out of context. The lead study GP and patients were provided with a copy of the conceptual map and given the opportunity to verify the concepts generated. The feedback gained from both a GP and patient participant helped to confirm the representativeness of the results. In addition, the feedback from the GP on local developments primary care, helped to inform thinking about the clinical implications and recommendations from the study.

Themes generated have remained close to the actual words used by participants. Although the conceptual map by its very nature moves towards more abstract concepts to support with the situating of results in to the broader context, participants own words have been used as much as possible, and extracts from the

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original data has been provided alongside the interpretations made for the readers to make their own assessment of credibility of the themes.

The multiple process of going through ethics required providing clear detail and justification for the study procedures and methods of data collection. In addition the method used creates a transparent approach to how the process of moving from codes to categories was generated. The coding matrices used also had notes in red, to make it clear when interpretations moved away from the data and reflected researcher observations in patterns of meaning or assumptions regarding underlining themes in what the participant was reporting. All matrices used in the analysis are provided in the additional supplementary information provided. Reflection was encouraged in supervision, and areas for potential bias were clearly stated at the start of the study for the reader to make their own appraisal of the extent of researcher bias.

Quality checks of the data collected was verified through data triangulation between patient and GP interviews.   Supervision was also used to ensure quality of both the categories and the constructs being generated.

7.2.2 Strengths

The study has contributed to the literature exploring medically unexplained symptoms from the perspective of GPs and patients, by placing a greater focus on the processes involved in managing the medical uncertainty between GP and patient in the consultation. Research that has highlighted the challenges of MUS management in primary care have predominately focused at the individual level of the GP and patient rather than the partnership and interaction between patient and the GP. Subsequent interventions have also been at the individual level, with it recognised that the variability seen in success may reflect the challenge being positioned with the GP rather than as a joint challenge that is shared and influenced by the patient and what they decided to share in the consultation (Peters et al., 2009). The results from this study indicate how two perspectives of one shared experience – managing MUS in primary care- overlap and diverge between GPs and patients at one practice, and has enabled a closer focus on what's important to GP and patient in a MUS consultation, the individual and system challenges that impact on this, and the possible areas to build on. This may help to provide a broader context of the reported challenges of managing MUS in primary care and

the processes involved for GPs in developing a shared understanding of such symptoms and management options.

Another strength of the study was the qualitative method used to collect and analyse the data. Use of a qualitative approach enabled the diversity to be seen in the views of the study participants, capturing the complex nature of MUS and consultation behaviours in a way that other quantitative approaches have been unable to capture (Van der Weijen et al., 2003; old Hartman et al., 2013). In addition, using framework analysis added to the transparency of the process of moving through the different levels of data abstraction. Although complete replication of the study results is not possible by the nature of qualitative methods (Seale, 1999), the use of coding matrices added to the explicit outlining of the procedures that led to the conclusions.

Lastly, the inclusion criteria used in the study was kept broad to limit the amount of researcher influence on how GPs were defining MUS in their practice, as well as 'frequent attender' status within the practice. This provided face validity to the process of identifying eligible patients during the recruitment phase, and avoided imposing arbitrary criteria that GPs at the practice might not have identified with as being relevant to managing this patient group. GPs were reminded that 'frequent attender' status could include people who have MUS symptoms satisfactorily controlled or otherwise. This enabled variation to be seen in the views collected from patient participants.

7.2.3 Limitations

The current study has several limitations. The context of the study was at one primary care practice; therefore caution should be taken generalising to other primary care sites, and further research would be needed to consider applicability to secondary care, where this next tier in the healthcare system may come with different expectations and logistical challenges to the consultation. In general, the results did show some similarities in reported patient and GP experiences from other primary care studies that had occurred both within and outside of the UK, which would suggest that there are general challenges that are experienced in managing symptoms that do not have a medically explanation, regardless of the context. In addition, it was noted that the final sample consisted of mainly patients with a functional diagnosis of fibromyalgia, which may limit generalisability to nonspecific forms of MUS. That said, commonalities were seen in this study

between participants who had a diagnosis and those that did not, which may suggest that the shared feature between the participants was the important aspect- that they were all managing symptoms without an objective medical cause.

The process of needing to opt in to the study, may have also introduce an under representation of views, with it reported that people who respond are more likely to be higher in literacy, education and motivation (Barker, Pistrang and Elliott, 2002, p. 116). This may have meant that the views represented in this study are from participants who are motivated to be involved in their care and can create a more complex account of their symptoms. Interestingly, although the list of eligible patients was not shared with me, it was reported that the potential participants identified as eligible had a range of MUS labels, which predominately included 'medically unexplained symptoms' and 'unexplained symptoms continued' rather than 'fibromyalgia'. One possible explanation for the increased response from patients with fibromyalgia, might be that all information sheets sent to participants included my name and that I was a trainee clinical psychologist. It is possible that people who were more willing to take part were more open to exploring the role of the mind on the body, which may also reflect that many of the patients who had a diagnosis of fibromyalgia were involved with the pain management clinic where this was being discussed. However, the results of this current study did indicate diversity in how participants both made sense of their symptoms, as well as variation in the extent to which they thought they should be involved in their symptom management.

Recruitment of GPs also included current and retired GPs at the practice, which may have introduced views that were not representative of current practice or memory recall bias. That said, GPs had spent the majority of their career at the practice and had retired within the last 2 years, with one GP commenting that this was a group of patients that you do not easily forget. GPs that were no longer practicing shared that they did not mind speaking openly and frankly about the challenges they experienced, due to no longer working in the profession, which may have helped to reduce any potential effects of social desirability that limited what GPs felt able to share.

Lastly the qualitative method used has the limitation of not being representative beyond the sample of participants in the study. In addition, the study results will invariably be affected by my own embeddedness within the research process, whereby the rapport I built with participants, how I posed questions and

which areas I decided to probe further in to, will contribute to the conclusions that have been made in this study. Although precautions were taken to add wider reflection, for example reviewing themes and constructs in supervision, as well as inviting feedback from participants, further research may want to use a questionnaire survey design to test how representative the themes are in the wider MUS population. This might enable comparisons to be made between primary and secondary care, as well as reducing the impact that the researcher might have on the data collected.

7.3 Clinical implications and directions for future research

One of the clinical implications for supporting the management of MUS in primary care, is to try and bring what is happening outside of the consultation for the patient, in to the consultation for shared discussion. Not only might this help to support with management consistency, but also is a way to monitor symptoms and manage risk of new symptoms and medication. The study highlighted the potential increased risk of patients altering medication or stopping without clinical guidance or awareness, whereby unused medication remained available, with some patients at their lowest points also reporting active thoughts of suicide. In addition there is the concern that patients are also substituting other medicines for ones they can access on line, which are not regulated and are being taken in combination with other medication. This comes with cost implications to the NHS, of prescribing medication that is not being used, as well as increased risk of unplanned admissions to hospital.

The second clinical implication is to the importance of encouraging patients to see self-management as an active intervention that does not have to come at the end of a series of investigations where no treatment has been identified. Patients spoke of the frustrations that came with not having the knowledge to manage their symptoms without first getting a diagnosis. Although GPs spoke of the need to rule out serious disease pathology, and the importance of placing the symptoms in to the wider context of the person's life, there could be an argument made that another important aspect is to provide an alternative narrative to the discourse that GPs acknowledge as having dominated medicine, and one that the patient has become to expect from their own past experiences, which is that intervention is only possible once a diagnoses is in place. Patients have spoken about the importance of having access to information about their symptoms and being signposted to

credible sources that can provide this, as well as the value for some of self-monitoring mood on symptoms, attending for regular physical health checks, and finding ways to increase access to social support. In this respect, it may be helpful to emphasise self-management as something that can start immediately, rather than something that comes at the end of trying everything else and only once a comprehensive understanding is in place. That self-management is not instead of investigations, but in addition to the preliminary investigations that would routinely be completed. The clinical guidelines for the management of nonspecific pain conditions is currently under development, and may assist with how management options are discussed between patient and GP (NICE guideline: Chronic pain, 2018).

A third clinical implication is that although many patients could identify that psychosocial factors were associated with their symptoms, they were not sure that they were caused by them. Similarly, GPs recognised that although a model of attribution was helpful, it did not work for all patients that didn't identify with the 'stressors' being identified, leaving the dialogue feeling stuck. An alternative approach was suggested in a pilot trial of a primary care 'symptom clinic' (Burton et al., 2012), which focused on developing explanations that were positioned within the medical framework that some patients were coming to the clinic with. The focus was on meeting the patient where they were in their understanding about the symptoms and opening the dialogue up enough for psychological factors to be discussed as factors that were likely to be associated with the physical symptoms, rather than the cause of the symptoms (Burton et al.,). This was reported to be an acceptable approach to the majority of patients involved in the trial, with eight out of the eleven patients reporting that they felt helped by approach taken, and that the time and the explanations were particularly valued, however there were three patients who had remained sceptical about the approach and that this was still a method of attributing physical symptoms to psychological causes. Unfortunately no data was provided on any observed differences between patients that identified with the approach and those that didn't. Overall, it would seem that this approach would help to leave the direction of the relationship between mind and body open for the patient to decide on, which maybe in contrast to the Attribution model that positions the physical symptom with psychosocial causes.

This study suggests that having an intervention that can support with the building of the shared part of the consultation between patient and GP may help to

reduce the risk that comes with management external to the consultation. Patients reported that it was important to them to feel in control of their symptoms, and that having a tailored approach that could demonstrate they had been taken seriously and had been heard was an important aspect in the management of their MUS.

This also seemed congruent with what the GPs in the study reported of wanting to find ways to establish a partnership in how symptoms were understood and managed. Incorporating psychosocial measures in to routine clinical practice may also helped to supplement information in the consultation as well as facilitate a shared discussion about factors that are feared by GPs as being heard by MUS patients as "it's all in your head". Feedback from a GP participant was that there may be potential to introduce a triaging system for patients, whereby screening patients for self-efficacy may help to determine the level of resource allocation needed. In addition, it was felt that using measures to triage may also help to reduce clinician 'burnout', by providing GPs with feedback about the additional needs that a patient may have. It was suggested that initially this could be trialled using the local move in primary care to use the 'Patient Activation Measure' (PAM) in care planning, as a measure of self-efficacy that is not disease specific and may hold relevance for patients with complex symptoms. Patients that scored low on self-efficacy would then alert the GP that a more bespoke approach was needed.

7.3.1 Directions for future research

Suggestions for future research in to this area may include increasing the representativeness of the results by using the results from both GP and patient interviews to develop a questionnaire that can be widely disseminated to other GPs at both urban and rural practices and patients with a wider range of MUS, which focuses on the illness (or symptom) perceptions that people have, the management options considered and the experience of shared decision making in MUS management. Collecting data on the type and number of MUS symptoms that patients have, for example using the Patient Health Questionnaire-15 (PHQ-15), and the intensity of their most prevalent symptom might also help to capture to what extent acute and chronic symptoms impact on considered management options and involvement.   That said, it may be that investigating the additional value and acceptability of introducing either PROMS or a general shared decision making aid could be trialled using a mixed methods approach in primary care MUS consultations. This could compare treatment as usual with consultations that have used explicit frameworks of SDM. The effect of using SDM on increasing perceived

symptom control and use of self-management options, and reducing symptom fear and avoidance in patients managing MUS could be considered through measuring anxiety, self-efficacy, and including a measure of coping styles to explore the extent to which this impacts on how people respond. In addition, interviews could be completed with a sub group of patients and GPs regarding their experience of using a SDM approach in the consultation and how this contrasted with times when they had not used this approach. It is hypothesised that compared to consultations where SDM has not been used, that patients will report an increase on social factors that have been associated with personal wellbeing and patient satisfaction with services; increased feeling of competency to get involved in decisions made about their symptom management and an increased amount of felt relatedness between themselves and the GP (Deci and Ryan, 2000; Waters et al., 2016).

This appeared to be the experience reported by one participant, who shared that participating in research was important to her and that having received an initial approach from her GP to take part in this study was likened to taking "two tramadol". In this respect, the participant was pleased that their GP had given them the opportunity to get involved in a project that they felt had relevance to their symptoms and was congruent with what they valued. Despite the concerns raised in ethics about the possibility of damaging the patient-GP relationship, it would seem that for this participant, being approached by their GP with the study potentially strengthened rather than threatened the therapeutic alliance and was akin to pain relief. As such further research about the patients experience of GPs approaching them with research and comparing this against patients with MUS experience of this, may help to assess if being given the option to take part in research has additional value for people with symptoms that are not medically explained.

7.3.2 Plans for Dissemination

Although the research findings have been shared with the GP consulting on the study, it is anticipated that the study results and recommendations will be presented to all staff at the South Yorkshire practice. The study will also be considered for wider dissemination through publication and conferences.

7.4 Conclusions

The study explored patient and GP experiences of understanding and managing medically unexplained symptoms, comparing and contrasting interviews with patients (n = 6) and GPs at their practice (n =4). The study found that GPs viewed the patient-GP relationship as central to developing symptom understanding and providing support to patients that have symptoms that are medically unexplainable. The importance of being able to professionally tolerate the uncertainty that came with the symptoms was highlighted by GPs, both for their own wellbeing and that of their patients. The role of the pressured working environment, the healthcare movement towards preventative intervention and fear of litigation, were identified factors that made this approach difficult to always maintain, but was buffered by the support of colleagues and the working alliance held with the patient. Whilst patients also reported anxiety around their medically unexplainable symptoms, they showed evidence of having built an incomplete but multi-layered understanding of their symptoms through actively seeking understanding and management options both within and outside of the consultation. However, patients recognised this information was not always shared in the consultation, due to lack of time during the consultation as well as concerns about how their contribution would be perceived by the GP. The results highlight a potential gap between patient and GP approaches to symptom management, as well as identifying a shared belief that the relationship between patient and GP is valued in the management of MUS. The clinical implications outlined provide potential ways to open up the shared dialogue between patient and GP, so that a balance can be established between the patient's understanding and preferences and their GP's clinical experience and knowledge of risk management.

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APPENDICES

Appendix 1: Ethics Approval

1.1 First page of the REC letter confirming favourable opinion

NHS
Health Research Authority

Yorkshire & The Humber - Leeds East Research Ethics Committee

Jarrow Business Centre
Rolling Mill Road
Jarrow
NE32 3DT

Telephone: 0207 104 8081

> **Please note:** This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

23 January 2018

Miss Natalie Salimi
Level 10, Worsley Building
Clarendon Way
LS2 9NL

Dear Miss Salimi

Study title:	Managing long term symtpoms with complex causes in Primary Care: A Survey of Patient and General Practitioner Experiences
REC reference:	17/YH/0412
IRAS project ID:	226107

Thank you for your letter of 12th January, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation

A Research Ethics Committee established by the Health Research Authority

1.2 First page of Research and Development approval/ local CCG assurance

Sheffield Health and Social Care NHS
NHS Foundation Trust

Medical Directorate
Research Development Unit
Fulwood House
Old Fulwood Road
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S10 3TH

Tel: 0114 2718804
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RDU Reference: **226107** (please quote this number of all correspondence)

05 February 2018

Miss Natalie Salimi
Level 10, Worsley Building
Clarendon Way
LS2 9NL

Dear Miss Salimi

Re: **Managing long term symtpoms with complex causes in Primary Care: A Survey of Patient and General Practitioner Experiences**
Sponsor: **University of Leeds**
IRAS project ID: 226107
REC reference: 17/YH/0412

The Research Development Unit at Sheffield Health and Social Care NHS Foundation Trust are writing on behalf of NHS Sheffield CCG to acknowledge that we have been notified of this study. The RDU in conjunction with the CCG has reviewed the above study to provide an assurance that the appropriate HRA approval is in place and have no objections for the study to be undertaken within Sheffield Primary Care.

Please note that this letter is confirmation of assurance only. Capability and capacity to participate in this study must be received from each individual primary care practice / independent contractor (including GPs, Pharmacists, Dentists and Opticians) based on their review of the studies statement of activities. A copy of this letter should be presented to each practice you wish to conduct your study in, in order to aid this process.

Documents reviewed:

- 17 SW 0242 Ltr- Unfavourable Opinion- 24.10.17.pdf
- 17-YH-0285 Unfavourable Opinion 12.09.17.pdf
- 17-YH-0412 226107 Provisional Opinion 15.12.2017.pdf
- 226107 17.YH.0412 Favourable Opinion on receipt of further information.pdf
- Bekker_CV_2017_short_grant_Application.docx
- Confirmation of Liability Insurance Letter 2017 18.pdf

226107 SCCG assurance letter

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Appendix 2: Practice covering letter to patient's

[INSERT PRACTICE LOGO/ LETTER HEADER]

[N&A]
[Date]

Dear xxxxxxxx

We are writing to provide you with the option of taking part in a research study that XXXXXX Surgery is currently involved in.

Together with the University of Leeds, the surgery is helping to further understand patient and GP experiences in managing long-term complex symptoms.

Further information about the study and how you can get involved can be found in the enclosed study information sheet. Before you decide whether or not you wish to take part, please read this information and talk about your decision to take part with others.

Contact details for members of the study team can be found at the bottom of the information sheet provided, and they are happy to be contacted with any questions that you may have about the study.

Thank you for taking the time to read this information,

Yours sincerely

Appendix 3: Study Information and consent forms

3.1 Patient study information sheet

Leeds Institute of Health Sciences
FACULTY OF MEDICINE AND HEALTH

UNIVERSITY OF LEEDS

PARTICIPANT INFORMATION SHEET

MANAGING PEOPLE'S LONG-TERM SYMPTOMS WITH COMPLEX CAUSES IN PRIMARY CARE: A SURVEY OF PATIENT AND GENERAL PRACTITIONER EXPERIENCES.
[REC reference 17/YH0412]

What is the purpose of this study?
You are being invited to take part in a research study that your GP practice is involved in. This study is about patient and GPs experience of managing long term symptoms that have unknown medical causes. Such symptoms are sometimes referred to as 'Medically Unexplained Symptoms' (MUS) or 'functional syndromes/symptoms' (FS). Before you decide whether or not you wish to take part, please read this information. Do ask if there is anything that is not clear, and please talk about your decision to take part with others if you wish.

Why have I been chosen?
You have been invited as you have been seen by a GP at the practice for symptoms that have lasted longer than 3 months and do not fit a disease specific explanation. We are interested in people's experiences of having these symptoms and the management of them. We want to talk to 8-10 people, which will include patients and GPs.

What does taking part in the study involve?
Taking part in the research would mean taking part in an interview about your experiences of your condition. This would be a 30-60 minute recorded phone call with Natalie (lead researcher), who would arrange a convenient time to call you. In the interview you would be asked to provide information about your age, gender, ethnicity, and your experience of MUS / FS- particularly what you feel has been helpful or unhelpful in managing it. The topics discussed will be guided by what you feel comfortable sharing. At the end of the interview, you would be asked if you would like to receive a summary of the initial findings for your review and feedback. This would be an A4 summary with an optional comments section for your feedback, which could be returned in a provided pre-paid envelope. All feedback would be anonymised and included in the write up of the study.

Has Ethics / NHS approval been granted for this study?
Yes [REC reference 17/YH0412, 23/01/2018], and the study also has NHS Sheffield CCG assurance [05/02/2018].

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Do I have to take part?
No - involvement in this study is entirely voluntary. Declining the study will not affect the care you receive from your GP in any way. Your GP will not be informed of your decision to take part in the study or if you decide not to. Even if you decide to take part, you are still free to withdraw at any time without giving a reason. However, anonymised data collected will be retained unless asked for removal from discussion. Participants requesting to withdraw after completing the study will have one week from their interview date to do so, after which data will be integrated into the analysis and it will be no longer possible to remove the data.

What are the possible disadvantages for me taking part?
In discussing some of the topics, we may cover sensitive issues that you find difficult thinking and talking about. If you feel uncomfortable at any stage, the interview can be paused or even stopped at your request. Only share what you are happy to do so, and decline to answer any questions that make you feel uncomfortable.

What are the possible benefits for me taking part?
The benefits in taking part in this study is that you are contributing to furthering understanding on how MUS / FS is experienced by patients with MUS. Implications for quality improvement may also encourage a local review of the current management of MUS / FS in primary care.

Will my taking part in the study be kept confidential?
Research data collected will be anonymized and kept securely and separately from participant identifiable data. All information collected as part of this research will be stored securely using locked filing cabinets, encrypted software, and secure IT systems in the University of Leeds. Only members of the research team and authorised persons from the University of Leeds who are involved in organising the research may have access to your information. The audio recordings will be transcribed by a University of Leeds approved transcriber who is accustomed to transcribing sensitive recordings, and who has read and signed a transcriber confidentiality statement. Data from your interview will not be shared directly with your GP, nor will you be identifiable at write up. The only exception to confidentiality will be if you disclose something to the researchers that cause them to have concerns about your safety, or the safety of anybody else. We will make every effort to let you know if this is the case.

Anonymised quotes may be included in the findings; your name or the practice details will not be included anywhere in any published findings. You will be given a participant identification label (e.g. Patient A) to protect your identity.

What will happen to the data from the research study?
Results of the study will be submitted as part of Doctorate in Clinical Psychology and may be disseminated at conferences and in peer reviewed journal articles. Your anonymity will be preserved at all times.

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Data collected during the course of the project might be used for additional or subsequent research.   In accordance with the Data Protection Act (1998), anonymised data from the study will be securely archived for 3 years after the end of the study, after which it will be destroyed confidentially. All personally identifiable information will be destroyed confidentially at the University of Leeds after the study has ended.

How can I find out more information or express my interest in the study?

Please complete both the consent form and the contact details form enclosed. These can be returned in the free post envelope provided. Once received, you will be contacted by the lead researcher- Natalie- to discuss any questions you may have about taking part and a suitable date and time will be arranged with you for the study interview. Alternatively, if you have questions about the study and wish to speak to someone from the study team, you can contact Natalie directly on:

> Natalie Salimi (Trainee Clinical Psychologist)
> E-mail: umnsa@leeds.ac.uk
> Telephone: 0113 343 2734

How can I share any study concerns or complaints that I may have?

If you have any concerns about this project and do not wish to contact the lead researcher but would like to speak to another member of the research team, you may contact:

> Dr Gary Latchford (Clinical Psychologist)
> E-mail: g.latchford@leeds.ac.uk
> Telephone: 0113 343 2734

If you would like to raise a complaint and do not wish to contact a member of the research team, you may prefer to contact:

> Clare Skinner (Faculty Head of Research Support)
> E-mail: governance-ethics@leeds.ac.uk
> Telephone: 0113 3434897

MANY THANKS FOR TAKING THE TIME TO READ THIS INFORMATION SHEET.

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3.1.1 Patient consent form

**Leeds Institute of
Health Sciences**
FACULTY OF MEDICINE AND HEALTH

UNIVERSITY OF LEEDS

MANAGING PEOPLE'S LONG-TERM SYMPTOMS, WITH COMPLEX CAUSES
IN PRIMARY CARE: A SURVEY OF PATIENT AND GENERAL PRACTITIONER
EXPERIENCES.

Please initial or
tick each box

Statement of Informed Consent

I .... understand that I have agreed to be interviewed
about my experience of living with my long term symptoms as part of a study exploring
the understanding and management of Medically Unexplained / Functional
Symptoms.

□

I have received a copy of the project information sheet (version 9, 19/12/2017) and
have been given an opportunity to ask questions about my participation in the study.

□

I understand that my participation in the study is entirely voluntary, and that if I wish to
withdraw from the study at any time I may do so at any point, and that I do not have to
give my reasons for doing so.

□

I understand that if I wish to withdraw from the study that anonymised data collected
will be retained unless asked for removal from discussion. That to remove data I must
notify the lead researcher no later than <u>one week</u> after the interview, and that after this
time point the data will be integrated into the analysis and it will be no longer possible
to remove the data.

□

I understand that the telephone interview will be recorded and an anonymised
transcript of the discussions will be produced. Anonymised data will be kept and
included in analysis. Parts of the transcripts may appear anonymously in the written
report and may be used for teaching, training and secondary analysis.

□

I understand that the information collected about me will be used to support other
research in the future, and may be shared anonymously with other researchers.

□

I have read and understood this information and consent to take part in the study.

□

Signed .... (Participant)   Date...................

Signed.. (Researcher)   Date...................

3.2 GP study information

Leeds Institute of Health Sciences
FACULTY OF MEDICINE AND HEALTH

UNIVERSITY OF LEEDS

PARTICIPANT INFORMATION SHEET

MANAGING PEOPLE'S LONG-TERM SYMPTOMS WITH COMPLEX CAUSES IN PRIMARY CARE: A SURVEY OF PATIENT AND GENERAL PRACTITIONER EXPERIENCES.

[REC reference 17/YH0412]

What is the purpose of this study?

You are being invited to take part in a research study that the GP practice is involved in. This study is about patient and GPs experience of managing long term symptoms that have unknown medical causes. Such symptoms are sometimes referred to as 'Medically Unexplained Symptoms' (MUS) or 'functional syndromes/symptoms' (FS). Before you decide whether or not you wish to take part, please read this information. Do ask if there is anything that is not clear, and please talk about your decision to take part with others if you wish.

Why have I been chosen?

You have been invited as you are a GP at the practice who may see patients with physical symptoms that have lasted longer than 3 months and do not fit a disease specific explanation. We are interested in people's experiences of having these symptoms and the management of them. We want to talk to 8-10 people, which will include patients and GPs.

What does taking part in the study involve?

There are two levels of involvement with the study- patient identification only or identification and interview. Initial involvement would require you to review your caseload for patients who in your opinion are frequent attenders with MUS / FS- this might include people who attend frequently but who have well controlled management of MUS , as well as patients with MUS / FS that do not have well controlled symptoms. Patients would then opt in following a practice mail out of study information. If you decided that you did not want to take part in the GP interviews, then your involvement in the study would end there.

Further involvement with the study would consist of taking part in an interview about your experiences of managing MUS / FS, reflecting on your general clinical experience

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of MUS. This would be in a 20-30 minute recorded phone call with Natalie (lead researcher), who would arrange a convenient time to call you. The interview would be on your experience of MUS /FS and what you feel has been helpful or unhelpful in managing it. The topics discussed will be guided by what you feel comfortable sharing. At the end of your interview, you would be asked if you would like to receive a summary of the initial findings for your review and feedback. This would be an A4 summary with an optional comments section for your feedback, which could be returned in a provided pre-paid envelope. All feedback would be anonymised and included in the write up of the study.

Has Ethics / NHS approval been granted for this study?

Yes [REC reference 17/YH0412, 23/01/2018], and the study also has NHS Sheffield CCG assurance [05/02/2018].

Do I have to take part?

No-involvement in this study is entirely voluntary. Declining the study will not affect the practice, nor your patient's involvement in the study if you declined further involvement. Even if you decide to take part, you are still free to withdraw at any time without giving a reason. However, anonymised data collected will be retained unless asked for removal from discussion. Participants requesting to withdraw after completing the study will have one week from their interview date to do so, after which data will be integrated into the analysis and it will be no longer possible to remove the data.

What are the possible disadvantages for me taking part?

In discussing some of the topics, we may cover sensitive issues that you find difficult thinking and talking about. If you feel uncomfortable at any stage, the interview can be paused or even stopped at your request. Only share what you are happy to do so, and decline to answer any questions that make you feel uncomfortable.

What are the possible benefits for me taking part?

The benefits in taking part in this study is that the interview provides opportunity for practice based reflection. Implications for quality improvement may also encourage a local review of the current management of MUS / FS in primary care.

Will my taking part in the study be kept confidential?

Research data collected will be anonymized and kept securely and separately from participant identifiable data. Information collected as part of this research will be stored securely using locked filing cabinets, encrypted software, and secure IT systems in the University of Leeds. Only members of the research team and authorised persons from the University of Leeds who are involved in organising the research may have access to your information. The audio recordings will be transcribed by a University of Leeds approved transcriber who is accustomed to transcribing sensitive recordings, and who has read and signed a transcriber confidentiality statement. The only exception to confidentiality will be if you disclose something to the researcher that cause them to have concerns about your safety, or

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the safety of anybody else. We will make every effort to let you know if this is the case.

Anonymised quotes may be included in the findings; your name or the practice details will not be included anywhere in any published findings. You will be given a participant identification label (e.g.'GP.A') to protect your identity.

What will happen to the data from the research study?

Results of the study will be submitted as part of Doctorate in Clinical Psychology and may be disseminated at conferences and in peer reviewed journal articles, with any embargoed information removed. Your anonymity will be preserved at all times.

Data collected during the course of the project might be used for additional or subsequent research. In accordance with the Data Protection Act (1998), anonymised data from the study will be securely archived for 3 years after the end of the study, after which it will be destroyed confidentially. All personally identifiable information will be destroyed confidentially at the University of Leeds after the study has ended.

How can I find out more information or express my interest in the study?

Please complete the consent form attached and / or contact Natalie directly on the details provided below.

Natalie Salimi (Trainee Clinical Psychologist)

E-mail: umnsa@leeds.ac.uk

Telephone: 0113 343 2734

How can I share any study concerns or complaints that I may have?

If you have any concerns about this project and do not wish to contact the lead researcher but would like to speak to another member of the research team, you may contact:

Dr Gary Latchford (Clinical Psychologist)

E-mail: g.latchford@leeds.ac.uk

Telephone: 0113 343 2734

If you would like to raise a complaint and do not wish to contact a member of the research team, you may prefer to contact:

Clare Skinner (Faculty Head of Research Support)

E-mail: governance-ethics@leeds.ac.uk

Telephone: 0113 3434897

MANY THANKS FOR TAKING THE TIME TO READ THIS INFORMATION SHEET.

3

3.2.1 GP consent form

**Leeds Institute of
Health Sciences**
FACULTY OF MEDICINE AND HEALTH

UNIVERSITY OF LEEDS

MANAGING LONG-TERM SYMPTOMS, WITH COMPLEX CAUSES IN
PRIMARY CARE: A SURVEY OF PATIENT AND GENERAL PRACTITIONER
EXPERIENCES.

Please initial or
tick each box

Statement of Informed Consent

I .... understand that I have agreed to identify potential participants
only / identify potential participants and be interviewed about my experience of
working with Medically Unexplained / Functional Symptoms as part of this study.

☐

I have received a copy of the project information sheet (version 7, 01/11/17) and have
been given an opportunity to ask questions about my participation in the study.

☐

I understand that my participation in the study is entirely voluntary, and that if I wish to
withdraw from the study at any time I may do so at any point, and that I do not have to
give my reasons for doing so.

☐

[For GP interviews only] I understand that if I wish to withdraw from the study that
anonymised data collected will be retained unless asked for removal from discussion.
That to remove data I must notify the lead researcher no later than one week after the
interview, and that after this time point the data will be integrated into the analysis and
it will be no longer possible to remove the data.

☐

*[For GP interviews only]*I understand that the telephone interview will be recorded and
an anonymised transcript of the discussions will be produced. Anonymised data will
be kept and included in analysis. Parts of the transcripts may appear anonymously in
the written report and may be used for teaching, training and secondary analysis.

☐

*[For GP interviews only]*I understand that the information collected about me will be
used to support other research in the future, and may be shared anonymously with
other researchers.

☐

I have read and understood this information and consent to take part in the study.

☐

Signed .... (Participant)   Date...................

Signed....................................... (Researcher)   Date...................

Appendix 4: Contact details form

4.1 Patient contact details form

Managing long-term symptoms, with complex causes in primary care: a survey of patient and general practitioner experiences

Contact form

Name: ....

Telephone numbers:

Home: ....

Mobile: ....

Email address :

....

Preferred method of contact: Home phone ☐ Mobile ☐ Email ☐

Preferred day and time of contact ....am/pm

Please include this with your consent form in the freepost envelope provided.

Thank you.

4.2 GP contact details form

UNIVERSITY OF LEEDS

Managing long-term symptoms, with complex causes in primary care: a survey of patient and general practitioner experiences

Consent to contact form

Name: ....

Telephone numbers:

Work: ....

Mobile: ....

Email address:

....

Preferred method of contact: Work phone ☐ Mobile ☐ Email ☐

Preferred day and time of contact ....am/pm

Please include this with your consent form in the freepost envelope provided, or contact Natalie directly to express your interest in the study at:

umnsa@leeds.ac.uk

Thank you.

Appendix 5: Supplementary information to Leeds East REC from study GP

Dear colleagues,

Many thanks for your comments and recommendations on the above study. I wish to respond as a member of the study design team and as a GP partner in the practice where we hope the research is to take place. The practice chosen has been selected for its high number of patients meeting the criteria for medically unexplained physical symptoms. A recent search has shown this group of patients makes up around 3% of the practice list size (close to 300 patients). Given that the study design has been changed and is now no longer using a dyad model, it is difficult to understand the board's concerns about a breakdown in the GP - patient relationship. Whilst GPs in the practice will play an active role in excluding unsuitable patients, given the high number of patients who meet the inclusion criteria I feel it is unlikely that sample quotes will be directly attributable to any particular individuals and therefore unlikely that there will be a resultant break down in relationship. Perhaps I am misunderstanding where this concern arises from, and if so, please could more information be provided in order that we can provide a suitable response.

The GPs in the chosen practice are invested in the study as we feel this group of patients forms a large part of our workload. Given the paucity of evidence about the best way to manage patients with medically unexplained physical symptoms, and given that the majority of these patients (at our practice at any rate) are dealt with in the primary care setting, we welcome further investigation into this area by the study team.

I hope the board can reconsider its recommendations to perform the study in a different GP practice for the above reasons.

Dr
GP
'
University of Leeds.

Appendix 6: Example section of coding index / frameworks

DEFINING THE HEALTH PROBLEM: MAKING THE INVISIBLE VISBLE	2.1	2.2	2.3	2.4	NOTES
Participant Letter., Gender, Age, Occupation Status,	Searching for answers	The responses of others	Clumping symptoms and labelling them	Life before and during the symptoms	
PartA, Male, 52, part-time support worker, Fibromyalgia since 2012, depression 1996, diverticulitis since 2017 *Has a functional label, doesn't identify with it*	I saw my Doctor about elbow pain, and she said it could be fibromyalgia, but I never had a definitive...er.. (2) Erm, not a great deal to be honest...it still is not now! [Laughter]...there is nothing clear on it really (5). I did a pain management course because erm...well, even those guys, they wasn't erm clear when you questioned them (8) when I've looked on the computer as	Some people say that you will and you can er go like in to remission (9). I put a claim in and they said you need to see a specialist, and they confirmed that is what it was (4+2.2). I think the best person I've seen was the NHS physiotherapist, they really sort of talked to me about it. From their perception it wasn't about it being invisible and saying what it was and wasn't.(24). I suppose it made me think about what I don't want to think (28).	Sometimes I even question if it's fibromyalgia or is it just that they don't know what is going on (10). is it fibromyalgia, because yes I have this joint pain, but have they just labelled me to give me tablets to shut me up- so that's my thoughts on it, but I'm not a GP (10).	I had a car accident 2013, which exaggerated it and made it a lot worse. (3) up until I was..er..er..their.. Late twenties..28/ 29, I always did very physical work, so my body had quite a battering – whether that be the steel works or building (35). I was a heavy drinker before Islam and heavy smoker-60 cigarettes a day, and two or three bottles of wine in one night. I wasn't going out, as brought my daughter up on my own and looking back I was just doing it to have a good night's sleep. That	*Definitive answers needed for insurance companies and further fuels search- they imply what is 'normal' for condition and triggers further comparisons and confusion about what it is for patient A.* *Friends search for definitive answers, but respond with acceptance that the doctors don't know.* *Overall perception that GPs are expected to cure and that the GP may also share this perception even if*

1

SYMPTOM BELIEFS AND EXPECTATIONS (GP)	2.1	2.2	2.3	2.4
Participant Letter., Gender, Age, Duration as GP, Clinical Interest	The brick wall and rolling a stone uphill forever after [The impact]	It is real, but I think what is going to help you is actually more with your mood...	The uncertainty of getting through the barriers	Symptoms will be complex and chronic
Interview Transcript: GP A, 38 year old female, white-British, GP since 2010, mental health lead and clinical interests in family planning.	I had rang A&E when I found out she had gone in and said she was well known to me and has MUS, I really don't think this is appendicitis and I was quite, I was dismissed really... I knew the patient and they weren't really prepared to listen to what I was saying. (37) [*Frustration at not being listened to by the system. labelling it as a symptom-difficulty between systems?]* Again the main challenge I think is when there is a language barrier and a cultural barrier, because again you just lose all that nuance in the consultation, people can feel less well understood and sometimes you can just feel as	"So clearly some problems will lend themselves to a more biomedical, medically focused approach-and I think it is important to not lose that, but yeah, I think particularly when it comes to medically unexplained symptoms and where we are not finding or think pathology is there, I think there are other frameworks are possibly more helpful." (4) "for example chronic pain and past trauma, I would talk about that past trauma, the bodies response to that, chronic stress that can cause pain or if we are going to talk about low mood, we know for example that low mood can really exacerbate pain, so **yes you are feeling**	It is hard to know if its bits of translation or cultural barrier or what, but I've had that experience of trying to get through that barrier, going over the explanation over and over again and feeling like I'm not getting anywhere..." (50) "I have had a situation where not only was I struggling to develop a partnership but there were a lot of barriers from the patient, she had a lot of issues actually , a lot of mental health problems, that she was not willing to acknowledge, but then expected and was also turning up late for appointments and I ended up having to be quite challenging with her and saying	"If its solely described with the biomedical model, yes you would be under that misapprehension, that every symptom has a disease causing it and erm, and that there should be some kind of explanation, or if not cure for that problem. But like I say, and I'm not wholly fixated on that, erm Theory, biomedical model, I do think it's much more complex than that and I'm comfortable with that actually."(56)

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