How do GPs and patients experience Persistent Frequent Attendance in primary care? A qualitative study.

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ABSTRACT

Persistent frequent attendance in primary care in the UK can be seen as problematic for the health service as persistent frequent attenders (PFAs) take up a disproportionate amount of time and resources and impact on the clinical workload of GPs (General Practitioners) (Smits, 2009 & Smits, 2013). These patients can be frustrating and difficult for GPs to manage particularly when frequent attendance continues for longer periods of time (Lin et al 1991, Hanel et al 2009).

Research shows that only one in seven frequently attending patients continue to attend primary care so frequently for two years (Smits 2009, 2013). Therefore, it seems useful to focus on *persistent* Frequent attenders in primary care. In the UK, unlike long-term conditions that are typically managed by a multi-disciplinary team of GPs, nurses and other professionals, the management of PFAs in primary care has largely been the responsibility of GPs. Therefore, it is also important to understand how GPs experience managing the care of PFAs.

There is a lack of knowledge about PFAs and GPs experiences. A better understanding of their experiences might help us to improve service provision and management and ultimately improve patient well-being.

Aims and objectives

Aims

To better understand persistent frequent attendance, how PFAs perceive their life and healthcare use and to better understand how GPs perceive these patients and experience caring for them.

Objectives

- To carry out explorative interviews with PFAs in order to explore their experiences in relation to their health, their use of healthcare and their life experiences.
- To carry out explorative interviews with GPs to explore their experiences of caring for PFAs.
- To explore what the findings tell us about PFAs and their GPs. For example; do the participant's experiences tell us anything about their psychological or social needs.
- To discuss the findings in relation to the current literature and theories of Persistent Frequent attendance.

Findings

Twelve GPs and fifteen PFAs were interviewed about their experiences of PFA in primary care. Thematic analysis resulted in five main themes. The focus of Theme 1 is PFAs health and that they experience it as complex, worrying and poor. It is evident that complex poor health is a major reason for PFAs continued attendance with their GP. Theme 2 focuses on the importance of the GP and patient relationship and how experiencing trust, feelings of safety and continuity is valuable to PFAs but presents further challenges to the GP. Theme 3 focuses on how PFAs experience their mental and emotional health and their current circumstances. GPs seek to find and offer understanding with these issues but fail to know how best to move these patients on with limited resources and options. Theme 4 explains how PFAs negative experiences of other health services impacts on their health-seeking behaviour and may act as

a deterrent to them receiving mental health care out with primary care services. Theme 5 describes the impact managing the care of PFA patients has on the GP, leaving them feeling responsible and yet powerless to meet the needs of this patient group. Although GPs acknowledge the importance of managing PFA care, for them it engenders feelings of anxiety and responsibility in a situation in which they feel powerless to resolve or improve. An overarching theme throughout the data is the importance of attachment issues and how these need to be carefully considered with regards to the care of PFA patients.

Conclusion

The findings offer some clear insights into how GPs and patients experience persistent frequent attendance in primary care with overlaps in the two sets of data that support each other and provide a rounded account of the situation.

Overall, the way GPs and patients experience PFA can be frustrating for both parties and there is a need for more support for GPs in managing this care. PFA patients and their GPs may become locked into a relationship that, although supportive and offering high levels of care in terms of time and effort, is inadequate in meeting the PFAs complex needs. This situation can cause anxiety, impacts on their self-esteem and creates a feeling of hopelessness in GPs. Further research into the training needs of GPs and potential resources to meet the holistic care needs of PFAs is needed. Consideration of the impact of attachment issues seems like an important factor in developing interventions for PFA patients.

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CHAPTER 1- INTRODUCTION TO THE THESIS

Persistent frequent attendance in primary care in the UK can be seen as problematic for the health service as persistent frequent attenders (PFAs) take up a disproportionate amount of time and resources and impact on the clinical workload of GPs (Smits, 2009 & Smits 2013). These patients can be frustrating and difficult for GPs to manage particularly when frequent attendance continues for longer periods of time (Lin et al, 1991; Hanel et al, 2009).

The definition of PFAs used in this thesis study is patients who have had 30 or more face-to-face contacts with the GP in two years, excluding routine health monitoring such as international normalised ratio (INR) monitoring for patients taking warfarin. Initially, we tried to recruit the top 10% of FAs by age and gender as previously suggested (Howe, 2002) but the pilot practice found this too burdensome to operate. Therefore, we established the consultation rate that was within the top 10% of all face-to-face contacts with GPs in a pilot phase in practice A and then applied that rate in all five practices in the study. That rate was 15 face-to-face contacts with GPs per year so we set a cut-off of 30 or more face-to-face contacts with GP or practice nurse within the last 2 years.

Research shows that when followed up only one in seven frequently attending patients continue to attend primary care so frequently over 2 years (Smits, 2009 & Smits, 2013). Therefore, in this thesis the focus will be on *persistent* FAs in primary care (PFAs). In the UK, unlike long-term conditions that are typically managed by a multi-disciplinary team of GPs, nurses and other professionals, the management of PFAs in primary care has largely been the responsibility of GPs. Therefore, it is also important to understand how GPs experience managing the care of PFAs.

Research has shown that PFAs suffering from co-morbid and chronic physical and mental health problems including health anxiety and depression, are more likely to be from lower socio-economic groups, be isolated and at risk of unemployment due to their health. Research has found a correlation between difficult life events, traumatic childhoods, attachment issues, difficult health experiences and persistent frequent attendance (Springer, 2007, Chartier, 2007, Hotopf, 1999, Katon, 2001 and Craig, 1994).

Hanel et al, 2008 found that those patients who visited the GP most often had the largest degrees of impairment or were affected the most in their daily functioning because of depression, anxiety and somatoform disorders. Yet, despite their increased attendance there is little evidence that the increase in care improves the health of PFAs and helps them to cope better. A recent Swedish study (Strombom et al, 2019) found that health-related quality of life was compromised in Frequent Attenders and another study (Barnes et al, 2019) found increased attendance could also cause iatrogenic harm.

Persistent frequent attendance has been studied extensively using quantitative methods. The aim of this thesis is to gain a better understanding of persistent frequent attendance by taking a qualitative approach that will focus on how PFAs perceive their life and healthcare use and how GPs perceive and experience caring for them. This study uses established qualitative research techniques and a phenomological approach to analyse data from interviews with GPs and patients. The two different data sets (GP and PFA) are analysed separately to enable me to immerse myself in the two different experiences, of being cared for and providing care, so that I could gain a deep insight into both experiences and then compare them.

Within this, the analysis will explore whether the participants' experiences can tell us anything about the psychological or social needs of PFAs and how these are managed. The discussion chapter explores these findings in relation to current literature and theories of frequent attendance, using attachment theory as a potential theoretical framework for understanding PFA. The use of attachment theory to understand PFA has featured in research carried out by Wilkund-Gustin (2011) and Glaser (2006) who highlighted the role of attachment issues in contributing towards the needs of these patients. Bowlby (1973) developed attachment theory and proposed that individuals internalize earlier experiences with caregivers, forming enduring ideas about relationships that influence whether they perceive themselves as worthy of care (model of self) and whether others can be trusted to provide care (model of other). These ideas or cognitive schemas influence the kind of interactions that individuals have over the course of their life and how they view or interpret these interactions. Bartholomew and Horowitz (1991) developed a classification system based on attachment theory which can be used to explain how adults relate to others depending on their attachment style, developed in early childhood. It is thought that people have varying degrees of attachment styles that can be measured but tend to have a predominant attachment style that dictates how they relate to others. The four predominant categories include secure, preoccupied, dismissing and fearful.

Preoccupied attachment styles form as the result of caregiving during childhood that is inconsistently responsive. As a consequence, of this upbringing, these people are likely to be excessively vigilant of attachment relationships and emotionally dependent on others for approval. They

may have lower self-esteem and more subjective distress. Bartholomew suggested that attachment theory may impact on peoples' relationships with healthcare providers. Individuals with a negative self-model and preoccupied or fearful attachment styles may be more likely to report somatic symptoms as they have a greater disposition to focus on the negative. This corresponds with research suggesting that this negative view of self and your own health is correlated with more reporting of health issues even in the absence of evidence of disease. Individuals with preoccupied attachment tend to be overly dependent on others based on earlier inconsistent caregiving relationships and this, along with a tendency to report more somatic symptoms, may lead to them becoming high utilizers of health services and possibly dependent on their caregivers. Indeed, this has been found by Russo et al (1997) and Barsky et al (1979) and more recently by Taylor et al. (2011)

Taylor et al. (2011) carried out a study looking at insecure attachment and frequent attendance and found a significant relationship between frequent attendance and insecure attachment style, even after adjustment for sociodemographic characteristics, chronic physical illness and baseline function. Taylor et al. believe that pathological care seeking behaviour is linked to insecure attachment and that understanding this may help doctors to manage their frequently attending patients in a different way. Furthermore, they found that there was an even stronger relationship between insecure attachment and attendance in those patients who attributed their (unexplained) symptoms to having a physical cause. For those patients with co-morbid health issues, the picture seems to be even more complex. Taylor et al suggest for these patients they may experience

the symptoms of their chronic or comorbid health conditions as more troublesome. This theory may offer a plausible explanation for persistent frequent attendance and the results of this thesis will be examined with this in mind as a possible theoretical framework which can be applied to assist us with understanding PFAs.

It is hoped that this thesis will contribute towards a better understanding of PFAs and their care. This is important as this may help to reduce the impact that PFAs have on healthcare staff, decrease costs and improve the health outcomes and quality of life of those who frequently attend.

CHAPTER 2- NARRATIVE LITERATURE REVIEW

2.1 Method of Narrative Review

This narrative literature review aims to synthesise the available literature on frequent attendance and persistent frequent attendance in primary care focusing on qualitative literature but also including some background literature about the characteristics of these patients. By carrying out a narrative literature review I have clarified my understanding of the published literature in this field. I have identified the relevant literature, described, appraised and summarised it.

2.2 A note on terminology

In this review I have included literature pertaining to both Persistent Frequent Attenders (PFAs) and Frequent Attenders (FA's). The reason for including literature regarding both groups is as follows; although this thesis is focused on Persistent Frequent Attenders and the participants are Persistent Frequent Attenders (PFAs), the literature on Frequent Attenders is still relevant. The two groups share many similarities in terms of symptoms, behaviour and health. The main difference is the length the higher attendance rates continue for, I discuss this later. For the literature review and all references throughout the thesis, I use the same terminology to refer to the patients studied, as the authors whose papers I am discussing. Otherwise, PFA refers to the participants in my research study. I carried out this literature review by searching the relevant databases of OVID, ASSIA, BIOSIS, CINAHL, Web of Knowledge, Psychinfo and Google Scholar. I carried out this search using a keyword search using the search terms "frequent attenders" and "persistent frequent attenders", "primary care" and "general practice". I excluded papers that did not include a full text, were not available in English and did not refer to adults. In addition to the papers that came up in my search I also

include references I identified by manually searching through the references in cited texts.

I have tried to link-in my review with the aims of this thesis of understanding more about the lived experiences of Persistent Frequent Attenders in primary care and of their GPs. I focused on what we know about the lives of these patients. I aimed to critically evaluate the papers and explore the quality of the evidence presented. The results of this literature review highlight the gaps in our knowledge in this area. The papers have been organised into relevant themes and are presented by theme, for example, socio-demographics or qualitative research papers.

2.3 Frequent attendance and the UK general practice service

In order to describe frequent attendance and understand these patients it is useful to be familiar with the context in which they are attending. GPs in the UK see patients as part of the National Health Service (NHS). Established in 1948, the NHS was part of a post-war effort to improve the well-being of the general population regardless of individual wealth. An important point to acknowledge when considering PFA is that, with the creation of a universal health service freely available to everyone at point of need, there came no guidelines on how much patients can or should attend and this situation remains today. However, this service is stretched. The NHS is funded directly through taxation and in 2018-19; general practice was allocated an overall budget of 8.127 billion pounds, 7.1% share of the total NHS budget and a 0.2% decrease from the previous year (Bostock, 2018). The percentage of the NHS budget going into general practice has been reduced in the last decade resulting in the closure of surgeries, longer waiting times for appointments, a declining workforce, and further pressure on GPs. This also

means that it is less likely that patients will be able to see their "preferred" GP (General Practice in the UK, 2017).

The average member of the public sees a GP six times a year; double the number of visits from a decade ago (NHS Digital formerly the Health and Social Care Information Centre, 2019). These appointments are on average ten minutes long, during which time a GP may examine, diagnose, prescribe and make a referral for further treatment. Inconsistency of care and longer waiting times may in fact contribute to the problem of frequent attendance as these patients may become more anxious under these circumstances. Continuity of care is linked to improved quality and delivery of care (Dietrich et al, 1982, Pilottos, 1996 and Steven et al, 1998).

The British Medical Council's (BMC) General Practice Committee (GPC) is currently arguing for more to be done to support GPs, as they believe the service is struggling to work well in such circumstances. The BMC believes that without intervention General Practice is heading for systemic failure and consequently the continued likelihood of putting patients' lives at risk (Saving General Practice, 2017). Individual practices have taken some measures to try to manage their workloads differently to ease the burden. For example, traditionally, patients have been able to call their GP surgery and make an appointment to see their GP when they feel they need to but, more recently, telephone triage services have been introduced where a receptionist or nurse practitioner assesses the patient over the phone. The idea being that this might reduce consultation rates as the patient may see a nurse instead, obtain a prescription over the phone or be redirected to a pharmacist.

Reducing consultation rates is becoming increasingly important in a financially stretched and time pressured service. In order to create more resource and time efficient services it is important to understand why they are being used. PFAs are known to use services at a greater rate than average but there are still unanswered questions about why. It would be useful to understand more about how PFAs and GPs make sense of these attendance rates.

Neal's work (1998) found that FAs have an important effect on a GPs clinical workload. Neal recommended that further research was necessary to explain the behavior underpinning frequent attendance in order to identify appropriate management strategies; such strategies could have an important effect on clinical workload. Since then further work has been carried out and found that these patients can be frustrating and difficult for GPs to manage, particularly when frequent attendance continues for longer periods of time (Lin et al 1991; Hanel et al 2009).

As demand for the NHS in general and GPs services, specifically, continue to grow it is increasingly important to try to understand frequent attendance. In understanding more about frequently attending behaviour, we may be able to create a more appropriate care pathway whilst simultaneously reducing the demand they put on the health service.

2.4 The problem of ascertaining how much is too much in a free-at-the-point-of-use service.

Although their attendance is frequent, there are no guidelines for FAs, other patients or for GPs as to what is considered appropriate in terms of attendance rates. In other words, the patients are unlikely to know or feel that they are attending "too much" and there is no legitimate way for the GP to raise this issue

if they feel the patient is coming too often. There is also a duty of care whereby a GP is bound by their responsibility to see patients and to check their health status because at any point in time it can change, regardless of how many appointments they may have had.

In addition to there being no set guidelines as to what constitutes acceptable attendance at the GP surgery, there is also conflicting public health advice regarding seeing your GP. (This is certainly changing constantly since this thesis was originally written due to Coronavirus). There are poster campaigns and TV commercials warning the public to get a cough checked out if it persists for more than three weeks (Tell your Doctor/Be Clear on Cancer NHS ad campaign). Yet at other times, we are dissuaded from attending our GPs surgery; (Treat yourself better/ speak to your pharmacist first campaign). There are mixed messages given to the public about when and how much it is appropriate to attend the GPs surgery. So, although frequent attendance is considered problematic and experienced as stressful for the GP, there are no set guidelines on what is acceptable in terms of attendance rates and this creates an interesting and difficult tension because the problem presented is not necessarily seen as problematic by the patient.

2.5 Defining Frequent Attendance

FA is hard to define, because not only is it hard to know "how much is too much" but also due to the many different definitions of FAs. For example, Puri & Dimsdale (page 5, 2011) found that there were over 100 different definitions of FAs:

"The definition of a frequent attender or high utilizer varies greatly throughout the medical literature. While some studies simply focus on selecting the top utilizers by percent (ranging from 3–15%, there are over a hundred different definitions of Persistent FAs in various studies

Defining abnormal utilization must begin with defining how to measure general utilization, and then examining the impact of various definitions of abnormal utilization, particularly in somatoform disorders."

The ways in which normal and frequent rates of attendance are ascertained varies. Literature reviews on frequent attendance by Haroun, 2016, Puri and Dimsdale 2011 and Vedsted and Christensen, 2005, share a common sense of frustration at how difficult it is to compare and contrast studies of frequent attendance because of the lack of an accepted definition of what constitutes frequent attendance.

The group of patients referred to as Frequent Attenders is heterogeneous in terms of how they are defined. This makes it difficult to compare studies and to make sense of research findings in relation to each other. Vedsted & Christensen (2005) found no generally accepted definition of frequent attendance and warned that diversity in design, definitions and methods within research in this field should lead to caution in interpreting findings. For example, Haroun et al (2016) found that Randomised Controlled Trials on interventions with FAs were difficult to compare because the patient populations, interventions, comparators and outcome measures were so different.

Therefore, not only might it be difficult to manage the "problem" of frequent attendance because there is no set limit on attendance within the NHS but it is also difficult to define what is too much when so many different definitions are used to describe these patients within both the UK and elsewhere.

2.6 Predicting frequent attendance by looking at consultation patterns

Perhaps, in part, as a response to the wide variation in opinion on what constitutes a FA, some researchers have explored the relationship between consultation patterns and frequent attendance. The idea being that this might enable them to

predict which patients were "at risk" of continued or persistent frequent attendance and therefore be the most appropriate candidates for interventions. Several studies (e.g., Smits 2009, Jordan 2003, Andersson 2004, Hauswaldt et al 2013) have been carried out examining the consultation rates and patterns of attendance among FAs in an attempt to find "prediction rules". Researchers have set out to see if there is anything about the way in which people attend, for example short bursts of many appointments followed by pauses, to see whether these patterns are an indicator of whether a patient is likely to become a FA.

Jordan et al (2003) also emphasised the importance of previous consultation rates in predicting higher consultation rates in the future. Their medical record analysis suggested that reliable morbidity coding in general practice provides the best available basis for predicting future demand in primary care. Self-reported health status information was also useful additional information but not as strong a predictor as previous consultation rates. Andersson (2004) et al also set out to assess the extent to which frequent attendance is a persistent characteristic of a patient by repeat studies of attendance. They concluded that with the exception of a small group of mostly female patients, frequent attendance seemed not to be a persistent characteristic.

Smits (2009) was also interested in predicting consultation rates and set out to find a prediction rule, which could be used to predict and then select for intervention those patients most at risk of becoming long-term or Persistent FAs (PFAs). Smits did this using consultation rates readily available from GPs electronic medical records, in Dutch GP surgeries. They used the idea of "transient episodes of care", meaning episodes of care, which are relatively short- lived and may be related to problems that are resolved within a year. They concluded that among one year

FAs, six out of seven are transient FAs, so six of them would resume "normal" attendance rates after a short while. The rule developed performed modestly in selecting those more likely to become PFAs; their attendance must be in the top 10% for three years. They used bootstrapped multivariable logistic regression analysis to determine which predictors contained information on PFAs. This work by Smits is important because it could ascertain which patients might benefit from an intervention and which patients will return to normal levels of consultation after a situation such as a difficult life event has been dealt with or resolved, for example.

Hauswaldt et al (2013) sought to define frequent attendance based on contacts in a similar way. Although, Hauswaldt et al described their research as looking at "inter-contact intervals" (meaning the length of time between appointments) rather than episodes of care, both Hauswaldt and Smits are seeking to find meaning within the patterns of attendance rather than just the rates of attendance. Hauswaldt looked at inter-contact intervals of attendance at 123 general practices in Germany. They found that attendance follows what Hauswaldt calls a "disease logic" (so for example, a spurt of attendance may start with a symptom such as "stomach ache" and may be associated with ongoing appointments for a specific disease for example, irritable bowel syndrome). The work by Smits and Hauswaldt is useful in highlighting the importance of considering how illness might influence patterns of attendance. The research into predicting patterns of attendance suggests life events, previous high consultation rates of attendance and illness episodes are all factors that may lead to a patients' attendance becoming increasingly frequent.

In terms of the importance of managing frequent attendance for cost and quality of life or health reasons, it appears to make sense to identify those whose attendance will remain high beyond one year. As Westhead asserted (1985), *"it would*

be wrong to consider frequent surgery attenders as a homogenous group. Nevertheless, they constitute a special group in which is concentrated a wide range of common pathology." Page 340.

The literature on FAs highlights many complexities in how we define these patients and how we think about their service use. As illustrated, frequency and patterns of attendance have been examined by researchers to ascertain if these give us a greater understanding of this patient group but there remains much diversity in descriptions of this group. However, there seems to be some general agreement that focusing on how to care for PFAs rather than FAs is important because in the long term these patients are the most likely to cost more, suffer more and benefit from a greater understanding of them.

PFAs can be classified as the 1.6 percent of patients who frequently attend for three consecutive years or more. PFAs are responsible for about 8% of consultations and are known to have many somatic, psychiatric and social problems (Smits 2009). Koskela et al (2010) acknowledged and identified the difference between short-term FAs and PFAs and identified PFAs as those who attended eight or more times a year for three to four years.

2.7 Frequent attendance and age and gender.

Age and gender have been explored in relation to attendance rates as authors have wanted to ascertain the importance of these factors in influencing how much people attend. Bergh (2006) aimed to compare FAs within different age groups and in both sexes, within a stratified sample, according to characteristics and utilisation of care. Bergh concluded that FA's morbidity within different age groups is similar to controls but that there is also a higher consulting frequency for most medical problems and a significantly higher consumption of antibiotics.

Menchetti et al. (2006) looked at the association between depression and frequent attendance in a cohort retrospective sample of elderly primary care patients. They found a prevalence value of 22.4 per cent of frequent attendance among the elderly. Depression was associated with frequent attendance, even after controlling for physical illness and unexplained somatic complaints. The risk for being a frequent attender was more than two-fold in the elderly compared to non-elderly. Menchetti et al (2006) believe that depression plays a more important role in frequent attendance amongst the elderly than amongst the non-elderly.

Frequent attendance has been strongly associated in some studies (e.g., Sheehan, 2004) with female gender and older age, though other studies refute this (Branney, 2012), and overall there seems to be mixed evidence as to the importance of age and gender in the likelihood of being a FA. It is safer to conclude that in every adult age and gender group there are people who can be identified as attending frequently who share factors in common across the age and gender groups, such as features of their mental and physical health. Howe et al. (2002) recommend that PFAs are selected by identifying the top 3 per cent (in terms of attendance rates) of male patients below and above 45 years and the top 3 per cent of all female patients. They recommend this as a way of addressing the age and sex differences in consulting patterns. Luciano et al. (2010) suggest a consensus definition of persistent frequent attendance. They think the most fitting definition and the easiest to apply is that whereby the 10 per cent most Persistent FAs from each practice are stratified by age and sex.

These studies highlight the challenges of defining frequent attendance but overall it seems that although older age and female gender might have an impact on

increasing attendance rates, it is something that affects people across all ages and genders.

2.8 Frequent Attendance, location, geography and ethnicity

Frequent attendance has been linked to proximity to health centres (Savageu 2006). with immigrant status (Diaz et al 2014) and being of South Asian origin (Scaife et al 2000). These studies have found that people who have moved from their country of birth are more likely to frequently attend. Frequent attendance is studied internationally suggesting it is a global phenomenon. With work being carried out to better understand this patient group across the developed world including in Australia, the USA, Sweden, Denmark, Finland, Spain, the Netherlands and the UK. Despite the differences in definitions of frequent attendance as already described, there are also some similarities amongst these patients across cultural and geographical differences, such as the prominence of depression and anxiety, physical health co-morbidities and social isolation.

2.9 The relationship between social status and frequent attendance

Frequent Attendance is associated with lower socioeconomic groups (Karlsson 1999), lower social class (Jatic et al 2008, Scaife et al 2000), social isolation and poverty. This is perhaps not surprising considering the correlation between poor health and poverty, as outlined initially by the Marmot review; Fair Society Healthy Lives (2010). Since that initial review, life expectancy in the UK has actually fallen in the most deprived communities outside London for women and in some regions for men (Marmot et al, 2020)

Jyvasjarvi (1999) carried out a cross-sectional case study aiming to describe the proportion of FAs in a rural Finnish town. He defined FAs as those with eight or more visits to their GP in one year (Jyasjarvi 1999). He found that FAs were

generally poorer, less educated, more likely to be female, unemployed, claiming disability benefits and from lower-socio-economic groups.

Scaife et al. (2000) carried out secondary data analysis to determine the effect of a range of socioeconomic features on frequent attendance in general practice, from a large database of consultations using two definitions of frequent attendance. The first being, patients who had twelve or more appointments in a year and the second being patients who had six or more consultations for minor problems. They found socioeconomic factors to be important indicators of frequent attendance and state that frequent attendance is a complex process associated with many factors outside of the control of the GP. Social isolation and increasing poverty are the most important of these factors in increasing the chances of frequent attendance. Other social factors seen by Scaife et al (2000) as putting people at high risk are being unemployed, being a housewife, being a pensioner, and being divorced or separated with dependent children. Not surprisingly, this research highlights the link between social class and health.

Similarly, to Scaife et al (2000), work by Tegan Cruwys et al (2018) also found a link between unmet social needs and frequent attendance. Their work found that many of the factors associated with FAs such as interpersonal problems, divorce, poor mental and physical health and socioeconomic disadvantage such as unemployment and poverty are contributing factors towards social isolation. Cruwys et al argue that attending their GP surgery may be a mitigating factor used by FAs to counteract the social isolation they are facing.

Scaife et al (2000) argue that, along with the established understanding that frequent attendance is associated with physical and psychiatric morbidity; the issue is more complex and factors that go beyond the control, or even remit, of the GP. Social

inequalities are important issues to be considered, as care focused at a practice level can only have a limited impact if underlying social factors are left unaddressed. This echoes the findings of such reports as the 2020 Marmot review *10 years on w*hich emphasised the role social inequalities and austerity measures have in determining health inequalities. It is also possible that the recent global struggle to combat Coronavirus has increased feelings of social isolation and loneliness, particularly for individuals with co-morbidities that might make them more vulnerable, hence an increased need to shield themselves.

2.10 Education and Frequent Attendance

Lower educational status is associated with frequent attendance as found in studies by Ferrari et al, (2008) and Vedsted, (2005). Vedsted found that women without formal education were more likely to frequently attend. Lower educational achievement is often linked with the other factors associated with frequent attendance such as lower social class, poorer health and isolation. The substantial body of work describing the characteristics associated with frequent attendance suggests a correlation with lower socio-economic backgrounds and perhaps as a consequence of social deprivation, physical and mental health co-morbidities, lower educational attainment, social isolation and being single.

2.11 Physical health issues and frequent attendance

Alongside studies assessing the relationship between social factors and frequent attendance there are, unsurprisingly many studies assessing whether frequent attendance is related to specific physical health conditions, or disease.

Earlier work by Karlsson et al. (1997) profiled FAs into different clinical subgroups and named five different groups of patients: 1) those with physical illness; 2) those with clearly psychological illness; 3) those in the midst of a personal crisis; 4) those

who were chronic somatisers; and 5) those with multiple physical and other problems. (It is important to note that the word somatisers can be stigmatising and should be avoided. However, it was the term used in this study so it is important to include it here) FAs were defined in this study as those who had had eleven or more visits in the previous year. The authors concluded that the majority of patients were consulting for solely physical illness or symptoms and only a few of them were actually receiving treatment for psychological problems, suggesting an under-diagnosis or under-treatment of psychological or mental health issues.

Kersnik's (2001) Slovenian study found that frequently attending patients had a higher proportion of contact for malignant disease, mental disorders and gastro-intestinal disease. He found they are more likely to be referred to a specialist, less likely to receive a psychotropic drug and more likely to receive an antibiotic.

Van Steenkiste et al. (2010) found a relationship between higher BMI and increased attendance over a three-year study. Having a higher BMI increased attendance but they did not find that any other lifestyle factors, other than a sedentary lifestyle, were important in predicting frequent attendance. They recommended that using nurse practitioners to carry out lifestyle interventions might have an impact on rates of attendance. However, it seems like a rather simplistic solution to what studies have evidenced as a complex issue, where many social, physical, mental, societal and organisational factors may be at play. Obesity is a likely factor considering its link to many diseases, but combined evidence from other research suggests that it is only one of many possible issues PFAs are facing. A lifestyle intervention focused on reducing obesity alone is unlikely to be the complete solution.

The work of Foster et al. (2006) looked at the relationship between frequent attendance and disease, investigating whether frequent attendance was disease-

specific. They found that it is not restricted to specific morbidities but rather there is some aspect of frequent consultation that is a characteristic of individuals, regardless of the symptoms about which they consult. Therefore, there may be underlying or "hidden" reasons for frequent consulting, likely to be associated with a factor out with the patient's physical condition. Foster et al. did find some morbidities are more prominent than others. Stronger associations were seen between certain diseases, such as mental disorders, blood disorders, circulatory disorders, digestive, endocrine, and injury and poisoning. So there are some similarities here with Kersnik's (2001) study which also found mental disorders and gastro- intestinal disease as associated with higher attendance. They also found some variation between surgeries or general practices in the morbidities associated with frequent consultation. Overall, it can be concluded that there is more to frequent attendance than morbidity alone.

Stewart and O'Dowd (2002) carried out a medical record comparison of the consultation rates of regularly attending patients at one isolated rural practice in Ireland. They identified frequent attendance as those who attended 12 or more times within the study year. They stated that 56 per cent of these patients were described by their GPs as attending for clinically inexplicable reasons, or reasons for which they could not find a simple physiological explanation. Like others reporting research on frequent attendance, they associated frequent attendance with being female, mental disorders and higher levels of prescriptions for psychiatric medicine, they also found a greater association with chronic disease. However, it is questionable how generalisable these findings are, as they are from one small Irish practice.

Heywood (1988) aimed to characterise the attributes of frequent attenders and their use of services by carrying out a retrospective analysis of case notes. They referred to this patient group as VFA's or very frequent attenders. The mean frequency of visits to their GP amongst this group was 15 times a year. They found that 94 per cent of these patients had chronic health problems, as compared to only 39 per cent of the control group, aligning with Jyvasjarvi' (1999) and Kersnik (2001) findings. He also found that PFAs had five times the number of prescriptions and hospital referrals. Heywood (1988) states that the question of whether this is good GP containment of the problem or poor use of resources remains unanswered and The author suggests that, given the high levels of depression and low levels of well-being among this group, strategies to tackle these should be developed first.

Al-Kandari (2008) carried out a study of FAs in Kuwait and found that 5.8 per cent of the total number of patients at the study clinic were responsible for 19.2 per cent of all visits. They found a strong correlation between chronic illness and a high rate of attendance. In addition, socio-demographic factors, especially nationality, gender, age and job type were indicators of frequent attendance.

Kurpas et al. (2016) studied FAs with chronic respiratory disease and found that they were more likely to be FAs if they also had a poorer quality of life, which fits in with other work. The F. As in this study also had five or more prescriptions for medication and three or more chronic diseases. The study recommended that these patients might require more social support and monitoring of their clinical status.

In summary, all of the studies I have reviewed looking at the relationship between frequent attendance and physical health suggest that, rather than being attenders without physical illness, which FAs are sometimes seen as (i.e. 'the worried well'), they do have chronic illness and some have been diagnosed with long-term

physical health conditions as well as mental illness. There is also an association between frequent attendance and increased prescriptions and referrals (Heywood 1998). Although there isn't a simple set of specific conditions that predicts frequent attendance, it is important to acknowledge increased levels of physical illness identified in the research as this is likely to increase consultation for check-ups, medication reviews, referrals, investigations and symptoms. It offers some explanation for the frequency of attendance and may explain the necessity of these patients attending their general practice.

2.12 Symptoms associated with frequent attendance

Somatisation, or the concept of experiencing or communicating psychological distress in the form of physical symptoms, was first introduced by Willhelm Stekel in 1924 (Woolfolk and Allen 2006). The association between FA and somatisation disorder is complicated by the descriptions of these patients as presenting with a "mixed bag" of physical and mental health issues and co-morbidity.

As the previous section describes, there are chronic conditions associated with frequent attendance, yet, as the work by Foster et al (2006) suggests it is not specific to certain conditions. Therefore, although FA is associated with physical illness, mental illness and disease it is not specific to certain conditions and can be associated with many symptoms that are difficult to explain. Perhaps, in part, because of this FA and PFA has also become associated with the concept of somatisation.

Somatisation or somatic symptoms, hypochondriasis, Medically Unexplained Symptoms and bodily distress have all been associated with FAs and although considering these is not the focus of my thesis it is important to acknowledge that they are associated with frequent attendance in the literature. It is also important to

stress, that these terms are now sometimes seen as pejorative, offensive or stigmatising but nevertheless it is necessary to consider how they have been used in relation to frequent attendance.

Earlier work investigating somatic symptoms amongst F. As by Sensky et al. (1996) found that FAs generated significantly fewer normalising explanations (external or environmental reasons) for a series of common bodily sensations than the comparison group of people whose attendance rates were normal. Even though the two groups did not differ in their somatic attributions (symptoms). Sensky et al felt that this work might suggest that FAs may find it more difficult to cope with their symptoms or have an increased sensitivity or awareness of bodily sensations but without a means to explain them.

Tomenson (2012) set out to look at the relationship between somatisation, health anxiety and healthcare utilisation. Tomenson wanted to investigate whether somatisation and health anxiety were predictors of health care use, the research team randomly sampled 609 UK adults. The number of consultations in primary care were obtained from medical records for one year before and one year after the questionnaire assessment. They conclude that both increased health anxiety and number of somatic symptoms predict frequent medical consultations. They recommend a more complex model of predicting future health care use is needed than has been studied previously, one that includes measures of health anxiety, depression, physical health and demographic information.

Puri and Dimsdale (2011) carried out a literature review of healthcare utilisation and poor reassurance (patients being offered reassurance about their symptoms but found that their response in the long-term is poor, for example their anxiety returns). They found evidence to support a transient but poorly sustained response

to reassurance amongst patients with somatoform disorder. They also found evidence of over-utilisation, particularly in outpatient visits. Their review supports the idea that reassurance can contribute towards the creation of a cycle of reassurance seeking, where the patient seeks reassurance, is temporarily relieved and then their anxiety returns, leading to further reassurance seeking. The high number of outpatient visits could be connected to this need for further reassurance. Despite these findings, there was no association with dissatisfaction with the care they received. The authors conclude that it is difficult to ascertain what over-utilisation is, because there is a lack of agreed definition and also because it is difficult to research somatisation as a whole, as there are many sub-groups and patterns of care use could vary depending on what the patients are seeking.

Norton (2012) carried out a study of 1,060 patients from 46 family practices and found that, after adjusting for socioeconomic variables, patients with somatoform disorders were more likely to be FAs. He found somatoform disorder, and not physical health or chronic disease, to be the biggest driver behind frequent attendance. However, this is not in line with the results of many other studies that found FA to be associated with multi morbidity or co-morbidity.

Bergh et al (2005) found that consultations for injuries by FAs were considered medically appropriate. They did not think that chronic diseases explained the higher injury incidence among FAs. The mean attendance for injury consultations was the same for FAs with or without chronic disease. Bergh et al. (2005) believe that their findings may suggest that FAs are more vulnerable individuals, especially as their attendance for injuries was 7.2 times more common than the control group of normal attenders. However, consultation for injuries are likely to be a small proportion of their total consultations.

A systematic review of somatoform disorders and Medically Unexplained Symptoms in primary care by Haller et al. (2015, P.279) concluded that somatoform disorders and Medically Unexplained Symptoms are more common than generally assumed and that they are an important issue for primary care:

"Medically unexplained symptoms and somatoform disorders are often undiagnosed in primary care and therefore cannot be treated adequately. The associated costs therefore rise further independent of somatic and psychiatric comorbidities. The most recent estimates assume that 20% of primary care patients have somatoform disorders. Low-level evidence for the prevalence of subcategories of somatoform disorders and medically unexplained symptoms does not currently exist."

Work looking at the relationship between somatisation and frequent attendance does suggest these patients are often somatising or suffering with health anxiety. However, the explanations given for this are complex. For example, Aragones (2005) study, which suggests somatisation is associated with the under-detection of the underlying psychiatric process, ties in with the findings of other studies, which recommend we need to understand more about the connection between people's beliefs and life history and how they experience symptoms. There is also the concept that FAs do not necessarily have more symptoms or pain (Sensky 1996) but have fewer coping strategies for dealing with them but, again, the evidence for this is contradictory, with some studies suggesting this is not the case (Barsky, 1983). The relationship between somatisation, FA and the under-detection of depressive illness or anxiety is intriguing especially as we are generally less aware of the physical symptoms of mental illness. Gili and Luciano and others have explored these issues.

2.13 Mental Health and Frequent Attendance.

Gili and Luciano (2011) set out to compare mental health issues between people who were routine attenders and PFAs in primary care. The criteria they used to define PFAs was more than 12 appointments in a year. They compared scores from the two groups in sociodemographic and clinical data and then interviewed patients with a clinically significant score on depression or anxiety. They used schedules for clinical assessment in neuropsychiatry (SCAN). Their results showed that frequency of mental health issues differed significantly, with somatoform and affective disorders the most prevalent amongst PFAs. They conclude that the presence of depressive and somatoform disorders is the most powerful predictive factor for persistent frequent attendance. They also found that co-morbidity of physical and mental illness is an important factor, with a 42.1 per cent prevalence of mental disorders amongst PFAs. They conclude that PFAs have complex needs and that the GHQ-28 is a useful tool in predicting frequent attendance. This tool focuses on whether there are issues preventing normal functioning and assesses this in terms of somatic symptoms, anxiety, insomnia, social functioning and severe depression. Gili and Luciano (2011) recommend that further work should also consider the importance of environmental or external factors on health and functioning of FAs.

Like Gili and Luciano, Dowrick et al. (2000) also found that depressive symptoms were a major predictor of frequent attendance and recommend that clinical and research activity should therefore concentrate on the identification and management of psychological problems among PFAs in general practice.

The work of Jyvasjarvi et al. (1999) on PFAs and the concept of alexithymia (or having no words for feelings) found a significant association between frequent

attendance, hypochondriasis and psychological distress but did not find an association between frequent attendance and alexithymia. They observed that recognition of psychiatric disorders by GPs is poor and that somatisation makes diagnosis even more difficult, creating a vicious circle. He believes that these patients should remain within the care of their GP but that the challenge is for basic medical education and specialist training to be available to GPs so that they can improve recognition and adapt a patient centred approach. He recommends more research to evaluate alexithymia, hypochondriasis and psychological distress amongst PFAs, so like Gili and Luciano and Dowrick, the work of Jyvasjarvi also stresses the importance of psychological factors such as mental health on attendance.

Earlier work by Karlsson et al. (1994) found that PFAs are more distressed than other patients are but that their self-experienced need for psychiatric care was very low and did not differ from other patients' self-experienced need. GPs established that one third of PFAs suffered from mixed psychiatric and physical illness and over half from sub-clinical or clinical symptoms, the corresponding proportions for FAs being significantly lower. So again, Karlsson stresses the importance of understanding and treating the mental health of PFAs.

Later work by Donald (2011) ties in with Karlssons' work because, whereas Karlsson found PFAs to have very low self-experienced need for psychiatric care, Donald found that the more knowledge they had around managing their own health care including mental health care, the less likely they were to frequently attend. Donald (2011) carried out a population based sample-study of people with chronic disease from Queensland, Australia, and found that, as patients became more 'activated' they were less likely to frequently attend their main healthcare provider

for assistance with their chronic condition. 'Activation' describes the knowledge, skills and confidence a person has in managing their own health and care. They conclude that individual characteristics, such as patient activation and psychological functioning, as well as disease factors, contribute towards frequent attendance.

In addition to the research carried out around the impact of mental illness on frequent attending, Ford et al. (2004) found evidence that behavioural disorders, including addictive as well as depressive and anxiety disorders and high utilisation for primary health care services are related. They believe that behavioural disorders are an independent contribution to non-psychiatric health care utilisation.

Ronald et al. (2002) found that the following variables were associated with frequent attendance: prior consultation rate, past psychiatric history, ongoing social difficulties, current level of alcohol consumption, total psychiatric symptom score and total anxiety score. Together, these variables accounted for 41 per cent of the variance in consultation rates. Ronald and colleagues recommended that the detection and rigorous treatment of psychiatric disorders, the provision of social support and interventions for alcohol dependence as possible ways to reduce consultation by anxious and depressed patients in primary care. Conversely, other work suggests FAs are more likely to abstain from alcohol, although it is also the case that intervention studies aimed at PFA's may well exclude PFAs with alcohol dependence as a separate group. For example, Koskela (2010) found that alcohol abstinence was amongst the most influential predictive risk factors for frequent attendance.

Another study that suggested the importance of screening for mental illness amongst PFAs is Grabe's study (2009) which found that at 5-year follow-up, somatisation at baseline predicted an increase of inpatient and outpatient costs.

They recommended that simple and time-efficient screening procedures for mental disorders might help to identify subjects at risk for future healthcare utilisation and that 'standardised therapeutic interventions' should be evaluated in subjects at risk in primary care.

These studies show a body of evidence that FAs may suffer emotional distress and under-diagnosed mental illness, and that they may have an impaired ability to cope with adverse events or distress. There is also evidence here to suggest that this mental illness is often undetected or untreated, possibly in some cases because the circumstances within primary care are not conducive to a GP screening for recognising or treating these difficulties within a primary care setting. A criticism across these studies may be that that their recommendations for standardised screening and interventions fail to address the potential difficulty GPs may face in introducing the concept of a mental health element to the patient's care. Few studies have examined the implementation by GPs in their usual primary care clinics of mental health interventions with FA patients.

These studies create a picture of a patient group that is attending with a mixture of health problems, including mental health conditions, that are possibly not being adequately treated. The first line of treatment for depression or anxiety is usually anxiolytic or antidepressant medication but it seems possible that with such complex presentations, medication alone might not be enough to enable these patients to cope with their health status or manage their many symptoms. It would be useful to know more about how mental health is managed in this patient group.

2.14 Complexity, diagnosis and co-morbidities.

Several studies have emphasised the importance of complexity in relation to health and co-morbidities amongst FAs. Ferrari et al (2008) found that medical or psychiatric co-morbidity was more common amongst FAs than the control group, finding a median of four psychosomatic syndromes amongst FAs as compared to one in the control group. Ferrari et al suggest that this confirms a role for psychosomatic diagnosis criteria in revealing sub-threshold psychiatric comorbidity as predictive of a pattern of frequent attendance.

Jyvasjarvi (1999) found more chronic physical disease amongst FAs and concluded that FAs might be perceiving their health as poorer and therefore care seeking more for minor symptoms. In many ways this makes intuitive sense that the more unwell you are the more carefully you will monitor your health. Smucker (2001) carried out a qualitative analysis looking at why FAs visited outpatient clinics and found three main characteristics that included; biomedical complexity, psychosocial complexity and the degree of dissonance between the patient and the physician. Burton (2003) also found mental health disorders amongst patients repeatedly referred to hospital with Medically Unexplained Physical Symptoms. Burton recommended that improving the recognition and treatment of disorders such as depression, anxiety and panic has the potential to provide better and more appropriate and cost-effective care.

Robles and Gili (2009) also found a relationship between FAs and higher rates of physical, mental and social difficulties. Savague (2006) found chronic illness, depression and diabetes, A&E use and older age as factors associated with FA and suggested that applying a "chronic care model" may help manage the care of FAs.

The **Chronic Care Model** (CCM) is an organizational approach to caring for people with chronic disease in a primary care setting. The system is population-based and creates practical, supportive, evidence-based interactions between an informed, activated patient and a prepared, proactive practice team. Jatic (2008) also found that frequent attendance in primary care is characterised by poorer physical and mental health. Barsky (1986) and then later Karlsson (1999) found physical and mental health co-morbidities amongst FAs but also both noted somatic reasons were also often drivers of consultations.

Physical and mental health and co-morbidity and complexity are recurrent features associated with FAs. This is useful in understanding this patient group and in challenging the myth that they are the "worried well" or "malingerers" (Spence, 2016, Barsky and Kleman 1983). This perhaps also illustrates why it might be so challenging to unpick and explain bodily symptoms, when there is so much complexity in terms of what is happening physically and mentally for these patients.

2.15 Medication use and Frequent attendance

Pymont et al (2015) and Patel et al (2015) found an increased use of medication amongst FAs compared to those with normal attendance rates. Morris et al (2012) described normal attendance rates as up to 22 face-to-face contacts with GP or practice nurse over 2 years. This upper limit was based on a previous study of eight Nottinghamshire practices showing a median annual attendance of eight, interquartile range (IQR) (3–11) face-to-face consultations with GPs.

Considering the established correlation between frequent attending behaviour and increased physical and mental health co-morbidities, this might be expected. The association between frequent attendance and depression alone would suggest a higher use of medication amongst this patient group. Pymont et al's work (2015)

found that there was an increased use of all medication except for those used to aid memory, among FAs. The work of Patel et al. found that FAs had a median of five medications compared to the control group of people with normal attendance rates who had a median of one medication.

Medication use in itself could be seen as a contributing factor to attendance as people could be attending to have medication checks, to request a change in medication or to ask about side-effects and symptoms.

2.16 Frequent Attendance and wider service use

There have been many studies, which have observed the relationship between frequent attendance in primary care and the high utilisation of other services. Vedsted and Christensen (1999) found a strong association between PFAs in general practice and the use of Out of Hours Services such as Accident and Emergency. They found that the top ten percent of PFAs in normal working hours constituted 42% of the total out of hour attendance over the same time period. Similarly, Hildebrandt et al (2004) later found that frequent callers by telephone were a unique group of patients who were high utilisers of health services. They recommended better-targeted patient education and referral to other support services, believing that this might decrease the number of calls and the use of services, alternatively, frequent calls by telephone might be a substitute for other forms of care for this group.

Love and Burton (2005) set out to test their hypothesis that consultation patterns in primary care follow a power law distribution typical of a complex system. They found that consultation patterns in general practice show measurable properties of a complex system. They believe that the consistency of the distribution across different population groups suggests the attempts to manage consultation patterns

should focus on the whole system of patients rather than on individuals or subgroups of the patient population.

The link between FA and the use of other healthcare services could be explained in several ways. It is possible that their GP consultations have generated referrals on to specialist's services such as pain clinics, for example. Another explanation is that FAs are seeking care elsewhere as they are still requiring or needing further services in addition to those already being offered by the GP.

2.17 The cost implications of frequent attendance.

Smits (2014) work in Holland found a substantially increased cost of frequent attenders in primary care as compared with non-frequent attenders. Smits found that unadjusted mean 3-year expenditures were 5044 and 15824 Euros for non-FAs and three-year-FAs, respectively. After adjustment for all other included confounders, costs both in primary and specialist care remained substantially higher and increased with longer duration of frequent attendance. As compared to non-FAs, adjusted mean expenditures were 1723 and 5293 Euros higher for one-year and three-year FAs, respectively. Smits concluded that FAs of primary care give rise to substantial costs not only in primary, but also in specialist care, which cannot be explained simply by their multi-morbidity nor by how their GPs approach managing their care. Smits felt that the mechanisms behind this expenditure remain to be explained.

2.18 How is frequent attendance in primary care currently managed?

At the time of writing, there were no established national guidelines, care pathways or interventions to assist GPs in managing the care of PFAs in the UK. Few GPs have training in the management of functional somatic symptoms or PFAs (Reid et al 2001). Therefore, GPs are largely left to manage the care of these patients

alone. Some practices have ways of managing the care of PFAs and will discuss them in practice meetings and organise a care plan. Des Spence, a GP in Glasgow and former columnist for the British Medical Journal wrote in the BMJ in 2014 that frequent attenders deserve better care. Smits et al (2014) agreed with Spence but also recommended interventions should focus on those who had been persistently frequently attending for over one year. Spence's article initiated a debate with opinions that ranged from those agreeing with Spence that better treatment was required to others suggesting that charging for appointments was an appropriate solution. Attempts have been made to find and test interventions but so far, none have been integrated into practice.

2.19 Research using interventions to reduce attendance and improve health.

There have been several intervention studies that aimed to reduce frequent attendance whilst simultaneously improving the health of the participants.

Smits (2008) carried out a systematic literature review of interventions to address the care needs of PFAs in primary care. The purpose of Smits work was to determine which interventions were effective in influencing morbidity, quality of life and healthcare utilisation of PFAs in primary care. They found five primary care randomised controlled trials (RCTs) meeting their search criteria, three of which used frequent attendance to select patients at risk of distress, major depression and anxiety disorders. These RCTs then offered a psychological or psychiatric intervention to patients and focused on the undiagnosed psychiatric morbidity of PFAs. Two of the studies found more depression-free days and a better quality of life (QoL) after treating major depressive disorders in PFAs. No other RCT found any positive effect on morbidity or QoL. Two of the RCTs offered an intervention

aimed at reducing attendance, neither of which managed significantly to reduce attendance. Due to the difference in settings and the variation in methods of defining and selecting PFAs, a meta-analysis of the results was not possible. In conclusion, they felt that no study provided convincing evidence that an intervention improves QoL or morbidity of frequent attendance, nor did they think an intervention existed at the time, that was able to reduce attendance in this patient group.

Haroun (2016) also carried out a systematic review of interventions with PFAs but unlike Smits, Haroun focused only on RCTS. and found that there were 17 eligible RCTs carried out with this group but that within the studies diverse types of PFAs were targeted. Haroun found that there were many definitions of PFAs used which included those who were older, depressed, had general mental health issues, had MUS, were students, were 'distressed' or attended different numbers of times. The interventions offered also varied greatly but included health education, GP/nurse intervention, depression management programmes, psychiatric care, problem solving treatment, disclosure of emotional events, GP education about somatisation, multi-step interventions, acupuncture, mindfulness based CBT and brief educational programmes. Unsurprisingly, one of their main findings was that heterogeneity at the levels of intervention, study populations and outcome measures precluded combinations of results across the 17 RCTs of PFAs in primary care. However, they believe that a few of the trials stood out. Bellon et al (2008) for example, reported a modest reduction in consultation rates when trying an intervention that incorporated biopsychosocial, organisational and relational approaches to PFA care, which was delivered by GPs. Smith et al (2008), used multi-step patient centred methods and reported modest improvements in QoL and morbidity in PFAs with MUS. This review confirms the considerable

heterogeneity at the level of patients, interventions and outcome measures reported previously. The authors believe that it is important that studies of FAs and PFAs stratify for age and gender to avoid an over-representation of older women. Using the top ten per cent of attenders and stratifying for age and gender may allow future studies to be meaningfully compared but this in itself can be complicated at a practical level, working within busy general practices.

Haroun et al. (2016) offer several suggestions for future intervention work with this group and conclude that frequent attendance does not lend itself to a uniform approach or to simple interventional procedures. They suggest that stratification and differentiation according to patients' underlying conditions, adaptive selection and design of interventions, and professional staff's reflection of their own attitudes and involvement are important factors. In-depth analysis among GPs assessing a particular patients' reasons for frequent attendance and corresponding tailored actions may decrease consultations, they suggest. They also recommend more trials looking at MUS (Medically Unexplained Symptoms).

An early example of an intervention study for frequent attenders is from Katzelnick et al. (2000) who reported modest improvements in QoL and depression-free days using a depression management programme for PFAs but the effect on morbidity was not replicated in a recent trial. However, Matalon et al. (2002) carried out an intervention study that offered a short-term intervention to help participants cope with their symptoms, such as fatigue and showed some successful results. The mean number of symptoms per participant at recruitment was ten and they also had mental health issues, such as somatisation, anxiety and depression. The average costs of caring for these patients reduced with the intervention and led to modified illness behaviour and a decrease in the costs of medical interventions. The study

intervention consisted of biopsychosocial consultations, in which life history and medical symptoms were woven together into a new narrative.

Similarly, Bellon et al. (2008) carried out a randomised controlled trial of an intervention whereby GPs were trained to incorporate biopsychosocial, organisational and relational approaches to caring for PFAs. Their results were also effective in improving well-being and showed a reduction in consultations.

Adam et al. (2010) found that team care was an effective and feasible way of managing PFAs within a family medicine practice and could improve care. They carried out a case control study, the group receiving the intervention had their notes reviewed by a care team including physicians, nurses, psychologists and the centre's front desk manager. For one hour each week, the team met and reviewed the care status of a case patient. Then, the primary physician summarised options for improved care and recorded them in a care plan. The same physician then contacted the patient to schedule a free visit to discuss the care plan. The study was relatively small, with 32 participants, but the results were promising and showed team care to be feasible and to have the potential to reduce healthcare use and simultaneously improve the satisfaction levels and care of PFAs. The evidence supported the need for a biopsychosocial perspective and the inclusion of peer consultation in the management of these patients.

Prins et al. (2014) also carried out a study based in the Netherlands that found psychological treatment reduced healthcare utilisation in primary care and resulted in fewer consultations for psychological or social problems. They suggested that close collaboration between GPs and primary care psychologists seems important because the clients of psychologists are frequent attenders as well. treatment and short-term psychological interventions, worked well.

In a similar vein, work carried out by Van Ravestien (2014) illustrated that mindfulness based cognitive behavioural therapy (MCBT) can start a process of change in PFAs with MUS. They found that awareness and acceptance of painful symptoms and emotions are a key factor in this process. Changes in unhelpful behavioural patterns, increased self-care and self-compassion were also found to result from this process.

These interventions all suggest that there is some hope in providing additional help for PFAs and, perhaps, that those strategies which focus on a biopsychosocial intervention or are collaborative and individually tailored would work best. These type of interventions suggest a need for tackling those undertreated or under diagnosed mental health issues. The research illustrates that interventions that include talking therapies, an element of practical guidance such as CBT and a collaboration between GP, patient and therapist are promising, such as those described by Bellon et al (2008) The recurring theme of who to help and how to pinpoint the patient group, taking into account age and gender, is also an issue in designing interventions.

A gap in this research is work that explores and explains how these interventions are successfully implemented into practice and the process through which GP and patient go through in order to incorporate these interventions. It would be helpful to know more about how GPs manage consultations with PFA's and how they introduce these interventions. It would be useful to have more detail about how they overcome the challenges of introducing a new intervention. For example, it might be good for other GPs to know exactly how the GPs taking part in these studies went about identifying the important mental health and socio-economic factors that these patients were presenting with. Did the GPs gain a better

understanding of the patient's life story and how did they then suggest treatments to help tackle issues caused by these factors?

2.20 Mental health service use and frequent attendance.

Despite the frequency with which they attend the GPs surgery and that we know they are often treated for anxiety and depression, there is very little information in the existing literature about the care these patients receive for their mental health both within primary care and from mental health services. Frequent attenders consult general practices with medically appropriate problems such as injuries at the same rate as other patients of the same age and gender. Yet they also consult more often for other problems such as functional somatic symptoms (Bergh et al 2005) and mental disorders such as depressive and anxiety episodes (Baez 1998, Bellon et al 1999, Dowrick 2000, Kersnik, 2001, Ronald et al, 2002, Kapur 2004, Smith 2008, Ferrari 2008). There are many possible explanations for the lack of knowledge surrounding FAs and mental health services. It could be explained by an under detection of mental illness as Kersnik (2001) described. For example, it could be that FAs are not accepting/willing to accept a mental health element to their health and therefore do not access mental health services. It is possible that their mental health is treated with anti-anxiolytic or anti-depressant treatment and therefore contained within general practice rather than them being referred to mental health services. Alternatively, it could be simply that the link between these patients being FAs in primary care and recipients of mental health services hasn't been made.

2.21 The impact of frequent attendance on the individual and their social network.

Some studies have been carried out that explored how thought processes and experiences related to frequent attending impacted on the PFA patients. One UK study (Neal and Morley 2000) found that FAs have ground rules for attending and how the GPs role is viewed has an impact on how patients felt about their attendance. For example, some felt it was justified that they could speak to the GP as it was part of the GPs role to reassure, advise and support them. Other FAs in the study were less likely to consult if they felt that their GP saw them as a nuisance or judged them to be hypochondriacal. These responses suggest that being a FA might impact negatively on the patient if they see themselves as the recipient of judgement due to the number of times they attend. Sometimes participants feared consultation and would only consult if their fear of their symptoms outweighed their fear of consulting. The study also found that participants felt better about consulting if their family or friends corroborated and agreed with their decision to consult or if there were some positive outcomes that resulted from their attendance. For example, a quicker return to work after a bout of illness. Another qualitative study from the UK (Hodgson et al 2005) showed that patients saw their attendance sometimes in relation to an adverse life event or were simply unaware of the frequency with which they attended.

Karlsson (1995) found that frequent attenders were significantly more distressed than other patients in primary care. However, their self-experienced need (whether they felt they needed psychiatric care for themselves) was very low, meaning that they didn't feel they needed psychiatric care. The GPs estimated that over 1/3 of frequent attenders suffered from mixed (physical and psychiatric) illnesses and over

1/2 from subclinical or clinical psychiatric symptoms. The corresponding proportions for other non-frequently attending patients were significantly lower.

These studies give some insight into how PFAs think about their attendance, such as not wanting to feel judged for it, having an awareness that it might be due to a significant life event or feeling distressed. However, the research by Karlsson et al (2009) reveals that PFA's may have little understanding of their need for psychiatric care.

2.22 The Dr and patient relationship

Neal (1998) found that frequent attenders have an important effect on clinical workload and that between one in six and one in seven consultations are with the top three per cent of attenders. A further study by Neal (2001) also found this group to be high utilisers of other health services, such as out of hours' services.

Neal et al. (2000) also investigated consulting patterns of FAs with different GPs to see if there was any impact of the GP on consulting behaviour. Defining FA's as the most frequently attending 3 per cent of the practice population, this study found considerable variation in the numbers and proportions of consultations between individual GPs, with Frequent Attenders receiving more continuity of care than other patients. Neal believed his data highlighted three different categories of Frequent Attenders and looked at their attendance rates over 90 day periods, defining them as below;

1) *Regular' frequent attenders.* At least one consultation in every 90-day period, and no periods of 10 consultations over 90 days (a 'burst');
2) *'Burst/gap' frequent attenders.* At least one burst, and at least one period of no consultations over 90 days (a 'gap'); and

3) *Others'*. Not falling into one of the categories above.

This study was unable to establish why some GPs were more likely to see more PFAs and whether some GPs encouraged frequent attendance. Neal et al (2000) recommended that it is important to try to understand their types of PFAs and their attendance patterns further, as it may have important implications in the development of appropriate interventions for reducing problematic frequent attendance.

Neal's (2001) found that being diagnosed and being reassured had an effect on subsequent consulting patterns, paradoxically either increasing or decreasing the frequency of consulting. Neal also observed from this (2001) work that reassurance had an impact on the frequency of consulting, noting that relatively few people had their health anxiety improved by reassurance, but that some may have a transient benefit and others may become more anxious with reassurance. The feedback provided by GPs to patients on the appropriateness of consulting was perceived as being very powerful. Neal felt the results of this study illustrated that GPs tended to act very conservatively and sometimes defensively, and may prefer to see an individual too frequently rather than risk deterring them from consulting. This may be regarded as help-seeking behaviour on behalf of the patient, albeit inappropriately, and may account for the extent to which the GPs gave express permission to patients to come back. Neal felt that this is a powerful determinant of subsequent frequent attendance by that patient.

Neal (2001) concluded that the findings of this work had important implications for practice. The control that GPs have over the pattern of consulting and in addressing further help-seeking behaviour, by controlling medication reviews, repeat prescribing and review visits, may provide opportunities for developing

further intervention strategies. There was a clear perception that these patients believed that their own patterns of consulting were legitimate. From an outside perspective, Neal felt that the attendance was understandable, if not always rational, and was sometimes explicable by undiagnosed or established illness and sometimes supported/controlled by the GPs behaviour. Neal concluded that the time may have come to abandon the term "Frequent Attender" in favour of an alternative that betrays less attribution bias on behalf of the GP. Neal's qualitative work with frequent attenders (2000) is discussed later in the chapter and investigates further some of the issues raised by their quantitative work.

Little et al (2001) carried out research using pre-consultation questionnaires to assess the care needs of PFAs patients who attended five or more times in one year. They found that patients in primary care strongly desired a patient centred approach to care, with communication, partnership and health promotion seen as important aspects of patient centred care. Little et al recommended that doctors should be sensitive to high utilisers of care, as they may be particularly vulnerable psychosocially or to feeling unwell. This ties in with the work of Ring et al. (2003), who looked at the relationship of FAs or PFAs with Medically Unexplained Symptoms and suggested the importance of the GP in terms of offering person-centred care, making referrals and offering empathy or understanding for psychosocial needs.

Jiwa (2000) looked at whether providing GPs with detailed summaries of PFAs' problems would reduce consultation rates; the aim was to investigate the impact on consultation rates of providing a detailed and accessible summary of a patient's problems, including physical, social and psychological data, based on information already recorded in the patient's records. However, this failed to reduce

consultation rates and there is no information about whether there were any other benefits to this system. Moran et al. (2001) found that there was a disparity between a research rating of personality disorder and diagnostic ratings by GPs. GP ratings of personality disorder were strongly associated with adverse perceptions of patients' consulting behaviour. This paper perhaps highlights the importance of acknowledging that there is some negativity surrounding PFAs and/ or terms such as "personality disorder" and that this may influence practitioners' judgements about these patients.

Bellon and Asensio (2000) studied seventy-five physicians in primary health centres in Spain and asked them to describe their thoughts and emotions during interviews with FAs in order to find out more about the impact caring for FAs has on GPs.. They found that younger physicians were more positive and more likely to identify with the thought that 'this patient needs me'. They also found in this study that these consultations caused anxiety for physicians, in the sense that they were associated with greater workload, request for tests and out of hours' requests. The study found that GPs reported feelings of guilt at not being able to solve the patients' problems and at having a poor relationship with the patients. Sadness on the part of the GP was associated with the increased number of specialist referrals. Bellon and Asensio (2000) believe that the results of this study suggest that awareness and acceptance of their emotions may improve physician's emotional intelligence and physician-patient relationships.

Evidence around the importance of the GP-patient relationship for PFAs suggests that it is a significant relationship for both parties, provoking feelings of anxiety and of being needed by the GP, as well as guilt at not being able to solve the patient's problems. Some researchers, like Moran, suggest that PFAs are often

viewed negatively or with frustration by GPs such as the work of Carelli, 2002; O'Dowd 1988). Evidence suggests that reattribution (Morriss et al 2007) and reassurance (Salkovskis et al 2003) alone are not helpful methods of improving outcomes or reducing anxiety for these patients.

2.23 Qualitative studies from the patient's perspective.

In comparison to the numerous studies attempting to understand frequent attendance by medical record analysis, there are relatively few qualitative studies that examine frequent attendance from the point of view of the patient.

Neal's (2000) qualitative study of regular attendance found that patients' reasons for and patterns of attendance were complex. He found that the reasons underpinning each individual decision to consult were manifold and informed by their experience of symptoms and of consulting in the past. Neal also found that chronic physical and psychological illness had a major influence over attendance patterns. Neal observed that GPs were perceived to have power in the control of medication and over when (and if) the patient needed to return for a review. Neal also observed that individual reasons to consult 'aggregate' together and lead to more consulting. The study found themes of passivity and external control to be exhibited by some PFAs. They also found that the patients were very familiar with the process, making it easier for them to gain access to GPs in the future. The Health Belief Model (Becker, 1974) corroborates the positive influence of others, the severity of symptoms and past experience of illness. Neal (2000) describes patients as having a 'ground rule' or their own belief models regarding consulting that are similar to the 'wildcard factors' described in McDonald et al.'s (1996) work on reassurance. Neal believes that, although the model he developed in this study

has arisen from data from individuals with specific patterns of frequent attendance, it may have a more general application. Neal also felt that the results of his research work had similarities with Helman's folk belief model (1981), in that each individual patient develops a series of ground rules for consulting, often based on the need to have specific questions answered. Neal also observed a new and unexpected finding – that FA patients also had a framework for not consulting.

Salmon et al. (2004) carried out a qualitative study in which they examined whether patients presenting with unexplained symptoms presented any psychosocial cues when in consultation with their GP. Using inductive analysis, they looked at transcripts from consultations and found that common symptoms were abdominal complaints, pain in limbs, headaches, chest pain, dizziness, fatigue, skin problems and gynaecological or genitourinary symptoms. They presented between one and seven symptoms, of which at least one had lasted for three months or longer. The data analysis outlined how patients would present opportunities for psychosocial explanation or give explicit clues about emotional or social problems. The authors found that GPs either blocked or facilitated psychosocial opportunities, but that they generally closed up such discussion by proposing symptomatic intervention or follow-up. They found it to be rare that a GP would link psychosocial problems with the patients' symptoms and found only one example where a GP actually made the separation explicit. There were, however, a few examples where some GPs did incorporate emotional mechanisms into explanations and where patients themselves spontaneously attributed their symptoms to stress, 'nerves' or depression. The authors suggest a quantitative study to test the generalisability of the findings, going as far as to say that:

> *The responses that we observed were therefore unlikely to help patients. Moreover, some were counterproductive in responding to patients' cues for explanation by providing symptomatic treatments, investigations or referral, doctors effectively somatised these patients. (Page 175)*

In addition, a separate analysis of this data describes how ineffective explanation of symptoms exacerbated patients' presentation. A main point that they make is that a commonly held view of these patients is that they dismiss psychosocial explanations for their symptoms, but this evidence suggests otherwise. Their results imply that the patients' beliefs are more sophisticated than a dualistic explanation between physical and psychological factors. In fact, they think that somatisers[1] are a very similar group to psychologisers (socio-demographically, psychologically and medically) and that their psychological problems are easily uncovered.

Sandin-Vazquez (2010) carried out a qualitative study, which again emphasised the importance of psychosocial issues and the differences in patient characteristics, meaning that focusing on the psychosocial and looking at individual cases is more useful than trying to predict frequent attendance solely through the use of demographics.

Wilkund-Gustin (2011) carried out a qualitative study of PFAs using an inductive hermeneutic design. She identified PFAs and interviewed them, she then went on to analyse the interview data by means of a hermeneutic inquiry using three interpretative steps: naïve reading, structural analysis and critical reflection. Wilkund-Gustin (2011) found that PFAs are constantly striving to become healthier, to be of use and to please others. The patients do not attend until they

[1] It is important to note that the word somatisers can be offensive and stigmatising and should normally be avoided now.

experience suffering as unbearable. The patient experience however, is that health care staff do not understand their situation and that they then experience feelings of mistrust and rejection, which then further increase their suffering. The author recommends a more holistic approach to caring for PFAs in order to relieve suffering and, consequently, reduce attendance. An interesting aspect of this research is its focus on the patient's experience and how they describe suffering and relate it to existence, illness and caring. Wilkund-Gustin also highlights how the attender's image of themselves and their attendance informs their decision to attend and makes them vulnerable to rejection and even self-criticism. The author emphasises the need for these patients to be viewed as suffering, suggesting that, while individual symptoms may not be easy to comprehend, the important thing is to focus on the patient as an individual with a story who is suffering. The author suggests that attending to the person holistically, as a body and as a soul, is a significant and important factor in moving forward:

> *"The importance of responding to the human being as a whole, as an entity of body and soul, is also significant. This entity expresses the many dimensions in which the patient's needs and desires consist. The body is not without the soul and vice versa. Furthermore, it is the subjectiveness in this entity that determines how the world is comprehended. Thus, the suffering, behind the facade, in this context could be understood as incongruence between the entity of body and soul and the ability to take one's place in the world. The caregiver could then make a difference by seeing behind the facade, to comprehend the person "here-and-now" as he or she is. Doing so and accepting the person behind the facade could create the prerequisites for the patient to let go of the facade as well and to become reconciled with oneself." (page 219)*

A further paper by Wilkund-Gustin (2013) describes how she examined PFAs' perceptions of themselves and found a perception of 'not being good enough', a sense of not being taken seriously and that their own view of themselves was not reliable or trustworthy. In this paper, PFAs are described as 'coping on their own' because they create a façade to protect themselves, which hinders them in presenting their true self to others and underplays the extent of their suffering. This study emphasises that patients feel compelled to put on a brave face and that this increases their sense of isolation. The paper highlights the importance of this 'conception of being alone', the importance of social relations and attachment theory. The author concluded that it is important that healthcare staff listen to patients' stories, rather than simply examining their symptoms, stating that not doing this may result in interventions being suggested that conflict with the patient's conceptions about life and how it ought to be lived. Not feeling listened to could mean that they experience themselves as bigger failures than before and mistrust advice because they feel that the GP does not have the full story. Wilkund-Gustin' s analysis suggests that secondary control strategies are being used as a way of covering up a profound sense of shame, and that understanding these patients' core beliefs is crucial to understanding them. Wilkund-Gustin suggests that PFAs require strategies that facilitate coping with shame and fear of being abandoned if they fail. They suggest that CBT or group treatment would tackle the sense of isolation they feel, as well as offering practical help. This work suggests that some unique skills may be needed by the GP to allow these patients to feel safe and understood and override their sense of shame. Although this research offers hope for a solution which might be very beneficial to these patients it is difficult to envisage how this might happen within a routine GP appointment and some may argue it is beyond the remit of the GP.

These qualitative studies highlight frequent attendance from the patient's perspective and illustrate that although quantitative studies have provided a good understanding of PFAs in terms of co-morbidities and complexity, qualitative work is useful in creating a deeper understanding from the patient's perspectives. PFAs have ground rules for consulting or for abstaining from consulting, they are willing to discuss psychosocial issues but that perhaps a general practice consultation is not conducive to this. The work of Salmon et al (2004) and Wilkund-Gustin (2013) suggests some time and skills on behalf of the GP may be needed to enable the patient to feel comfortable enough to trust them and let down what Wilkund-Gustin describes as a "façade" to protect themselves.

2.24 How have models and theories been applied to explain PFAs and their experiences?

Researchers manifest a particular interest in whether there are psychosocial explanations for frequent attendance or ones rooted in childhood adversity (Kapur 2004), for example applying attachment theory (Bergh et al 2005) to understand frequent attendance. Other approaches may be embedded within a psychiatric model of illness using theories and terms such as hypochondriasis or somatisation, depression, anxiety or mental illness, such as the work of Gili et al (2011). Sociological explanations not only consider the role of illness but also other socio-economic factors that might drive attendance such as isolation, poverty and loneliness. For example, Cruwys et al (2018) work on FA and social isolation and Scaife's (2000) work on socio-economic factors and FA.

Illness behaviour theorists, psychiatrists and psychologists emphasise the importance of the manner in which patients experience and respond to illness and

symptoms. For example, health anxiety is given as an explanation for frequent attendance by Salkovskis (2003). The theory of Somatisation has also been used to explain PFA, by Jyvasjarvi et al (2001) and Burton (2003) to name but two examples.

According to illness behaviour theorists such as Zola (1973), Mechanic (1960) and Graham (1972) the decisions people make about whether or not to seek medical attention for bodily changes or 'new' symptoms is not straightforward and is dependent on the nature of the bodily symptoms, as well as personal, social and cultural factors relating to what is 'normal'. How people interpret these bodily changes is not fixed but can change over time and be revised. As well as the patient's experience of illness, symptoms and their life story, attendance also needs to be understood with reference to their relationship with caregivers such as GPs, with reference to how care is organised and wider cultural and social factors such as religious beliefs or attitudes towards mental health.

Braunack-Mayer (2009) states that, '*patients are able to rationalise their own help seeking and self-perceived anxiety about a health situation (for whatever mixture of reasons) is associated with immediate care-seeking behaviour'*. Furthermore, she states that '*the logic that they follow in deciding to seek help may not necessarily resonate with clinicians, since it will be shaped by more than the straightforward biomedical'. (page 478)*

Bergh et al. (2006) used a postal questionnaire to look at sense of coherence and life events amongst PFAs, as compared with normal attending controls. They observed that PFAs did not report more stressful life events nor less social support, but that they did have a weaker sense of coherence and, therefore, life events probably caused them more symptoms and diseases, influencing their consulting frequency. Sense of coherence is a health concept that measures an individual's

resources for coping with life stress. Early life events were not covered by the instrument, even though other work, such as that by Glaser (2006), suggests these might be important. Chronic disease and sickness/disability pension were the only two socio-demographic factors that were shown to have a significant effect on frequent attendance. Bergh et al. believe that these results suggest the need for a psychosocial view of these patients to be taken, as well as a biomedical one. The long-term effects of psychosocial factors on PFAs would be a useful issue to clarify in future surveys, Bergh et al. suggest. One hypothesis they offer is that PFAs are trying to create a relationship with their GP that is deeper than a professional one and that GPs are trying to avoid this. This may explain why these patients are sometimes described as 'heart sink' by GPs.

Glaser et al. (2006) looked at childhood trauma and emotional reactivity to daily life stress in adult PFAs. Their study looked at how 90 PFAs responded to stress and found that those with a history of childhood trauma reported significantly increased emotional reactivity to daily life stress, as reflected in an increase in negative affect (Emotional distress; Watson, Clark & Tellegen, 1988). This affect was significantly stronger for those participants who experienced trauma before the age of ten years old. The results of this study confirm that childhood trauma may have a long lasting and enduring effect on adult psychological functioning among PFAs, as exposed individuals continually react more strongly 'to small stressors occurring in the natural flow of everyday life'. The effects of trauma are, it seems, more detrimental the earlier the trauma occurs.

Matalon (2005) believes that the narrative approach or biographical life narrative technique is important in treating patients who are attending primary care and likely to have undiagnosed mental health problems because they are often somatised,

reporting physical symptoms. Using a case study example of an elderly frequent attender, Matalon described how deep listening to her life story and explanation of her symptoms was useful in helping the participant come to terms with, and make sense of, her life story and how she was therefore better able to contemplate the future.

Schilte et al. (2001) also looked at the importance of childhood adversity in somatisation in general practice and suggested that if GPs wanted to take a more active approach, they should take an interest in patients' childhoods and life stories, especially when patients are known to have chronic difficulties in relationships and genital-sexual symptoms.

In 2004, Kapur et al. wrote that few studies had considered the role of childhood experiences in adult health care use. They set out to examine the hypotheses that individuals frequently attending primary care have experienced childhood adversities and been exposed to illness (during childhood) more commonly than other patients, and that any association is independent of adult psychiatric disorder. Using a structured psychiatric interview and a semi-structured interview about childhood, they found that there was a strong association between childhood experiences and frequent attendance. They used multivariate analysis and reported that childhood illness exposures and reports of childhood adversity were each associated independently with adult consultation behaviour, even after results were adjusted to account for adult psychiatric disorder. They concluded that interventions for high users of healthcare might need to address childhood experiences of illness and adversity as well as adult psychiatric disorder. This was the first study to examine the effects of experience of both childhood illness and adversity on adult consultation behaviour. The results are consistent with previous

studies suggesting that childhood adversity is associated with increased healthcare use and childhood experience of illness with adult illness behaviour.

Kapur et al. (2004) looked at psychosocial and illness related predictors of consultation rates in primary care and concluded that childhood illness may influence consulting behaviour in adulthood by increasing the likelihood of chronic physical illness in adulthood. Another suggestion was that there is a link between physical symptoms in childhood and psychiatric illness in adulthood. Craig et al. (1993) suggest that somatic symptoms in childhood lessens the distress associated with neglect and so establishes a repertoire that involves somatic rather than emotional means of attracting care, and that this pattern of response persists into adulthood. In terms of childhood adversity, Craig et al (1993) felt that this may affect adult consultation behaviour by increasing their rate of psychiatric disorder, physical disease or health risk behaviours.

Taylor et al. (2000) propose a model in which aberrant early care leads to abnormal attachment styles in parental relationships that persist into adulthood and encourage medical help seeking. A further explanation that Kapur et al (2004) offer is that those individuals with a history of childhood adversity may interpret their symptoms in a more negative manner. These studies indicate that it may be useful for interventions aimed at high users of healthcare to address both of these needs; attachment styles and interpretation of symptoms. Other study findings lead to suggestions that the written disclosure of emotionally important events (including in childhood) reduces consultation rates (Pennebaker 1997). Promising alternative therapeutic approaches may include Cognitive Behaviour Therapy (CBT) symptom reattribution (reattribution is the process of attributing physical symptoms to an emotional cause) (Morriss et al. 1998) and psychodynamic interpersonal therapy

(Guthrie et al. 1999). A study carried out by Morriss et al. (2007) on reattribution for MUS concluded that practice-based training in reattribution did change doctor-patient communication but did not improve outcomes for patients with MUS. A study by Schilte (2001) also found that, although a disclosure intervention was well received by patients and doctors, it had no effect on the health of somatising patients in general practice. In contrast, Gidron (2002) also carried out a study using trauma disclosure but with the addition of guidance. Gidron believed that it could be beneficial if the patient was guided in a manner that enabled them to shift the mode of traumatic memories in a specific way. They hypothesised that PFAs who described past traumas in a guided manner would report fewer symptoms associated with somatisation than controls writing about casual topics. Their study could be criticised for not using a random sample of patients and also for not being able to examine, and therefore explain, the exact mechanisms by which the memories were shifted. However, the study does suggest some promise that writing about trauma in chronological order, labelling events and using insight to explain them could be beneficial in reducing symptoms.

Kapur et al. (2004) note that future research in this area is limited by the inaccurate measurement of childhood exposures, due to the obvious moral and ethical issues involved in prospective studies of childhood adversity in any form. However, prospective cohort studies could help to clarify whether childhood experiences of illness and adversity influence health care use in later life. Kapur recommends investigating possible mechanisms for the association between childhood exposures and adult illness behaviour, including measures of possible pathway variables, such as adult attachment, illness cognitions and somatic symptoms.

Katon (2001) wrote that stressful life events, anxiety, depressive disorders, childhood and adult trauma, and specifically, personality traits have all been found to be associated with multiple physical symptoms among primary care and medical speciality patients. His review highlights the relationship of a number of unidentified pathologies to childhood abuse. Similarly, a study carried out by Walker et al. (1999) showed the impact of childhood abuse and neglect on the health of adult women.

Hotopf et al. (1999) found that MUS appear to be related to prior poor experience of illness in the family, for example sudden unexpected illness or a poor experience of treatment. and previous unexplained symptoms in individuals. They wondered if this might reflect a learned process whereby illness experience leads to symptom monitoring. Their study was a large prospective study carried out over many years. A positive finding of their study was that physical disease in childhood was not associated with MUS in adulthood. Parental ill health was also a factor and the research suggests the need for a greater understanding of the developmental and genetic processes that lead to children with these childhood experiences becoming adults with MUS.

Chartier et al. (2007) also wanted to examine the relationship between childhood and adult healthcare utilisation. They did this by carrying out a large retrospective study in Canada where they examined the relationship between childhood abuse and adult healthcare utilisation. They found that there was an association between childhood abuse and higher use of urgent care services, but they suggest the lower use of GPs may be due to the transient lifestyles of these patients, meaning perhaps maybe they are less likely to be registered with or have a good relationship with a GP. Also they felt that there is a tendency among GPs to refer severely distressed

individuals to urgent care services more quickly. Explanations for why adult survivors of childhood abuse may have a greater need for healthcare use include that the impact of long term stressors, such as abuse, on changes in the child's developing nervous system, predispose them to ill health (Gunnar 2003); being exposed to unhealthy lifestyles; or developing unhealthy habits as coping mechanisms. Similarly, to Chartier et al, Springer et al. (2007) also found in a population-based cohort of middle-aged men and women, childhood physical abuse predicted worse mental and physical health decades after the abuse.

Craig et al. were also interested in how childhood experiences impacted on adult health and carried out two studies in South London (Craig et al. 1993 and 1994). These studies looked at the relationship between early life experiences and stressful life events. They carried out a two-year longitudinal study to identify patients in primary care with emotional disorders presenting with a recent onset of physical symptoms. They found that adult somatisation is best modelled, or can be predicted by, a parental lack of care, followed by childhood illness. In a further study of 184 interviewees, they found that 82 percent of people presenting with somatisation in primary care had experienced at least one event or difficulty in the 38 weeks before onset, leading them to conclude that somatisation in primary care was best regarded as a particularly common way of expressing emotional disorder. Craig et al. believe their study demonstrates that there are both general and specific associations between life event stressors and acute somatisation. The associations between a severe event or major difficulty in the recent past and the onset of an emotional disorder were observed across all subjects with a recent onset, regardless of how this was presented to their GP. Cultural factors, such as the acceptability of emotional suffering, and also the awareness patients have of their bodies, were seen as important considerations in whether patients consulted with their GP.

Secondary gain, perhaps in the form of receiving sympathy, was also seen as an important factor in patient's decisions to consult. Craig et al. also suggest that if a child has received more care or attention than usual during a period of illness then they may have developed unusual coping mechanisms in times of distress.

The studies by Springer, Chartier, Hotopf, Katon, Craig and colleagues all give evidence of a link between particularly difficult life events, traumatic experiences or childhood adversity and PFA. The research also suggests the importance of attachment theory as a possible explanation of why adults who did not always have secure attachments with their primary caregivers (because they were abusive or neglectful, or because they were ill), may be either distrustful of opening up to people or, conversely, may seek a 'connection' or the receipt of care in some form with a person they consider trustworthy, such as their GP.

An interesting study by Pymont and Butterworth (2015) found that consideration of any changes in an individual's circumstances, such as their finances or adverse life events, significantly improved the accuracy of predicting frequently attending status. In a similar vein, work by Saltini et al. (2004) looked at the strategies GPs use for making decisions regarding the attribution of emotional distress in primary care. They note that the detection of current emotional distress in primary care patients is vitally important and recommend that GPs should pay foremost and systematic attention to social problems and recent life events, especially of loss, and that these are more useful than looking at past patient records. Although much work focuses on past life events it seems logical to look at both past and current life events.

This evidence reinforces, along with other work, the premise that under-diagnosis of mental health challenges or emotional distress, including that which stems from

childhood and from trauma, including attachment issues, and unmet psychosocial needs are a significant factor in frequent attendance.

2.25 Gaps in knowledge and how this relates to the aims of this thesis.

This literature review describes what is known about frequent attendance in primary care. It highlights the difficulty in ascertaining how much is too much in terms of attendance, and of defining this patient group. It suggests that the patients we should focus treatment on are those most at risk of becoming persistent or long term FAs, which I refer to as PFAs. The literature explains that persistent frequent attendance is associated with physical and mental health co-morbidities, the under-detection and treatment of mental health issues and higher rates of medication use and wider service use. These patients are more likely to be from poorer socio-economic backgrounds, be single, socially isolated and have experienced difficult or traumatic lives from childhood. Yet we are still unsure about how all of these factors relate to continued frequent attendance and what it is PFAs are seeking from their appointments.

Understanding these patients by looking at their childhoods, socio-economic circumstances, life stories and how these relate to symptoms, health seeking behaviour and relationships with their GPs appear important. We know that these patients are expensive to the health service and can cause anxiety and stress for the GPs who are trying to manage their care, but still have limited understanding of how patients present within a consultation and how GPs respond.

Despite all the research carried out to profile these patients, to define their needs and suggest potential interventions, there seems to be a gap in knowledge regarding how psychosocial issues are discussed with these patients. We know little about how their mental health is cared for currently and how they make sense of their

attendance and experiences within general practice. The work of Wilkund-Gustin and Neal has begun to explore these issues and found that these patients have ground rules for consulting and are presenting themselves in a manner to protect themselves from a sense of failure, enabling them to continue to cope. Within this thesis, I am interested to know explore in detail how the mental health and psycho-social needs of these patients are currently understood, experienced and discussed. There is a gap in understanding about how these issues are currently managed within general practice and how this care, and the Dr patient relationship, is experienced by both GPs and patients.

2.26 Summary of narrative literature review.

It would be valuable to explore the extent to which GPs are aware of the current lives and life stories of PFA patients and what they do with that knowledge, how they make sense of it and whether they use this to inform and treat these patients. How do GPs feel about this group of complex patients and how do they manage their physical and mental healthcare? It would be helpful to see how patients view themselves, their lives, health and attendance. By understanding more about what happens during the consultation, what is discussed and what happens as a result of these discussions, we might increase our understanding of why these patients keep returning.

I aim to explore these issues by carrying out and analysing qualitative interviews with PFA patients. I will also analyse existing data resulting from interviews with their GPs. I will use semi-structured interviews to conduct an in-depth qualitative explorations of the patient's insights into their experiences of their health, seeking healthcare and their wider life experiences. I will examine the GP interview data to explore their perceptions of these patients and their experiences of caring for them.

It is hoped that by understanding more about how PFAs perceive their life and healthcare use and how GPs perceive these patients and experience caring for them, that we might understand more about gaps or barriers in providing effective care.

Chapter 3: RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction and overview of the research and design

The research process can be described as a journey (Moore, 2006) with several changes in direction. This is true of the current research and self –critical reflection on this journey was necessary to understand the study's origin, its direction and destination, as well as the personal and professional experiences gained through the journey. This is important as it helped to chart the research process aiding in the clarification and contextualisation of the emerging research. This research therefore arose by journeying through six interdependent stages as follows:

Stage1- Literature Review

Stage2- Self-criticality

Stage3-Reflective Data Collection- Patient Interviews and staff interviews.

Stage4- Familiarisation, description and understanding the data

Stage 5: Thematic Development.

Stage 6: Data analysis informed by an Interpretative approach.

3.2 Summary of methods.

I have used qualitative research methods to try and understand the experiences of PFAs and the GPs looking after them. I have also included baseline interview data that describes the clinical characteristics and health status of the participants, these data were collected as part of the wider (Regular Attenders) study by myself and a colleague (SP) and is useful in describing the participants' health. I describe the baseline data collection procedure and measures used in section 3.14, page 86. The participants came from a cross-section of GP practices selected by maximum variance sampling technique. For the qualitative semi-structured interviews, a guide was developed based on an initial literature review. Data collection continued until

saturation was reached and no new themes were arising. Data was organised and thematically analysed I chose this method because I am experienced at using it and understand how it is effective particularly in organising work that seeks to understand multiple perspectives, such as of patient and GP.. Interpretation of the data is informed by a phenomenological approach to data analysis which when carefully used can provide a powerful account of data that goes beyond description or reportage.

3.3 Background and Context 'The Regular Attenders Project' and how this thesis relates to it.

This thesis study was carried out alongside a wider study; 'The Regular Attenders Project'[2]. (See Appendix 10- Regular Attenders In Primary Care A Case Study Approach- Protocol 1.2) The objectives of that wider study included: to estimate the cost to the health service of regular attendance in primary care, to clinically characterise regular attenders, to compare them with 'normal' attenders and to determine the feasibility of providing a cognitive behavioural therapy based intervention and to explore how this was implemented. The duration of the study and data collections was from September 2010 until September 2013. The study was funded by the Collaboration for Leadership in Applied Healthcare Research, Nottingham Derby and Leicester (CLAHRC NDL) and was made up of 50 percent National Institute of Healthcare Research (NIHR) funding and 50 percent funding from NHS partners.

[2] To explain, 'Regular Attenders' is a different term used during the Regular Attenders project, so as not to cause offence to the participants but it refers to the same group of patients as referred to in this thesis as Persistent Frequent Attenders (PFA's).

The study used questionnaires, medical records, staff interviews and qualitative data to compare regularly attending and normally attending patients in primary care. It explored a variety of issues concerned with attendance, such as frequency of attendance, health anxiety, medication and emotional health. There was also an implementation analysis that used qualitative methods to look at how the research study and its findings was received in practice by GPs and practice staff. I was employed as a project manager and research associate on the wider study but carried out this PhD study independently. More information about the wider study can be found in the following papers; Morriss et al 2012, Patel et al, 2015 and Malins, 2016. The qualitative (PhD) aspect of the study (not the implementation analysis) was included to describe the experiences of people who regularly attend and to understand more about how GPs experience caring for these patients and how they manage the care of these patients (so we can understand how they perceive these patients and how they feel about caring for them).

3.4 The aim of this thesis study

The main aim of this study is to explore PFA and healthcare staffs' experiences and describe and try to understand them. This is done using interviews focusing on specific topics developed based from the literature review (see Chapter 1).

Research can be defined as the systematic study of a given topic in order to add to current knowledge (Theodorson and Theodorson, 1969). It requires the researcher to understand the interrelated components of research design that refer to the purpose of the research and the theory which surrounds it; as well as the development of suitable research questions, methods and sampling strategies (Robson, 2006). These, according to Robson provide the basis of a good research design. Consequently, this chapter describes and reflects upon the development of

the research design used within this study, whilst assessing the obstacles, justifications and rationale, which provide the foundation for the selected methodological approaches.

Previous research on this patient group highlights the importance of GP and patient relationships, the physical and mental health of the patients and their life stories. This thesis aims to investigate further how these issues are experienced and perceived. Taking a phenomenological stance, the use of qualitative methodology was determined to be the most appropriate methodological approach for this study. Phenomenology refers to the study of direct lived experience and is subjective in its understanding of the world (Smith et al, 2009). It is concerned with how subjects make sense of their everyday lives and the way they come to understand those experiences (Cohen et al, 2007, Smith et al, 2009). Qualitative methods can be seen as allowing little opportunity to generalise or replicate findings (Bryman, 2001). However, the subjective nature of human experience justifies the need to examine the perspectives of PFAs and the GPs that care for them. away from the reductionist confines of more positivist, qualitative methods (Robson, 2006). Moreover, previous literature related to PFAs suggests a need for further qualitative work to examine PFA from the patient and GP perspective (Neal 2000, Wilkund-Gustin 2011). The aim is to gain further insight and shed some light on some of the topics we know little about such as; how mental health issues are tackled within consultations, the impact on the GP, the concerns of the patients, how they view themselves and how they feel about their health and the care they receive. It would be useful to understand how the doctors and patients themselves view PFA.

3.5 Rationale and self-reflection on developing the research design and topics.

Although this research is nested within a wider study, I drove and designed the research within this thesis. My interest in the subject of mental illness and its relationship to physical well-being began with a need to understand, make sense of and reluctantly accept a diagnosis of recurrent depression, which began at the age of eleven.

As a Sociology undergraduate, I continued to try and understand and make sense of how my life story; growing up in a notorious inner city estate in working class Nottingham, being female, being aware of a sense of shame about the mental illness that ran through my family and other factors, may have impacted on me and my depressive illness.

As I began to make more sense of this as a young adult, I was drawn to working in social research and began my research career working with long term drug users in Glasgow. My career was interrupted as I faced a very difficult life event when at the age of 26 I experienced the illness and death of my first child. Amongst my grief, I was also spurred on by a need for knowledge and to understand more about how life experiences, especially those in relation to illness, loss and trauma, impact on physical and mental health, resilience and recovery.

I went on to work in the field of mental health and specifically, patient experience of suicidality and health anxiety. Despite the challenges of working in this field whilst continuing to suffer from chronic depression, I felt this work was important. Those with lived experiences are valuable contributors towards increasing our understanding about mental illness and treatments.

With the realisation that a lot of work is focused on describing patients, their symptoms, their medication use and how they complete standardised

questionnaires I was much more driven to understand how they themselves made sense of their illness and related it to their lives. I realised that for myself, understanding how life events have contributed and shaped my experiences of depression and illness had been healing to some degree and I wanted to explore the importance of life stories for these people too.

My experiences and career to date have therefore led me to choose to undertake this research which is set within a social constructionist theoretical position (Berger and Luckmann 1966), employing phenomenological philosophy. Social constructionism explains phenomena or experience in terms of their relation to the external world. It examines how meanings are placed on everyday experience as a social construct determined by human action, interaction and thought (Crotty 1998). Concepts surrounding the social construction of the world arose from postmodern thought and were highlighted by Berger and Luckmann in their book (1966) "The Social Construction of Reality". In addressing the ways in which social phenomena and social thought were constructed, Berger and Luckmann (argue that there are ways in which social groups make sense of their worlds (externalisation) is through the construction of their reality. This construction is developed through the objectification of constructs into socially real ideas, which is then internalised and understood by individuals through socialisation. These three "moments" Berger and Luckmann, (1966:78-79) state are *that "man and his social world interact with each other… Society is a human product. Society is an objective reality. Man is a social product."* As such, in applying this standpoint to the current research it is expected that factors in the social world of PFAs and their GPs will influence the ways in which their perceptions are constructed and internalised within the context of attendance in primary care and their health. Similarly, phenomenology, first introduced by German philosopher Edmund Husserl in the early 20th century seeks to examine

experience in terms of context in which it occurs (Berger and Luckmann, 1966), and in doing so encourages a person to identify essential qualities of that experience (Giorgi and Giorgi 2008; Smith et al 2009). Phenomenology encourages researchers not to start from the context that is being researched but to stay true to the original meaning of the data rather than reducing the data to a number of measurable and controllable variables (Giorgi and Giorgi 2008). It allows both the participants and the researchers to reflect, therefore developing their own personal meaning or "perception" related to that experience (Smith et al, 2009). Both constructivism and phenomenology are based on the concept of "intentionality" which explores the relatedness of human consciousness to an "object" (Crotty, 1998, Smith et al 2009). Intentionality is simply defined by Smith et al (2009:13) as *"the relationship between the process occurring in consciousness and the object of attention for that process…experience or consciousness is always consciousness of something- seeing is seeing of something, remembering is remembering of something, judging is judging of something."*

As such, the current research aims to understand PFAs and their GPs experiences (consciousness) of persistent frequent attendance (the object), resulting in their current perspectives or understanding related to their health and their attendance. This is based on the notion that their perceptions have been constructed through their experiences and their experiences constructed through the social world in which they exist. In order to understand the meanings that the patient and healthcare participants place on their experiences it is necessary to consult with them and embrace their personal narratives regarding their experiences. Moreover, this research goes further than just understanding what the perspectives of PFA patients and the healthcare staff caring for them are. It aims to give some control to the participants by enabling them to reflect on their own experiences and to speak up about the issues that affect them. It is important to remain aware that

attendance rates will not necessarily be perceived by them as an issue, it's the experiences of attending that the study is investigating.

In adopting a phenomenological position, a reflective and reflexive attitude is assumed by the researcher (Smith et al 2009). Thus reflection was carried out throughout the study using a research journal. This allowed for the appraisal of the research design, methodology, and analysis at all points throughout the data collection process. As a researcher, I was able to think reflexively about the position I assumed within the study, allowing for reflection and feedback about my own assumptions and the subjective nature of the investigation and its interpretation. I think this was particularly important considering that I was also a researcher working on the wider study and may have been influenced by that and by working in close contact with therapists treating some of the participants. In addition, I was careful to remain aware that my own experiences of mental illness may have made me overly sympathetic and familiar with the participants. Therefore, I was careful to keep a professional "distance" in terms of what I thought about the participants and how I related to them during interview.

Through journal keeping it was intended that personal beliefs and expectations would be identified so as not to impede on the meaning which the participants placed on their own experiences. Therefore, efforts were made to ensure that all interpretation of the data remained as close to the spoken word of participants rather than paraphrased interpretations based on the pre-existing knowledge, understanding and beliefs of myself as an academic researcher, person with recurrent depression and self-proclaimed advocate for the rights of people with enduring mental illness. In doing this, the research process was flexible, in order for the needs and opinions of the individual participants to shine through, making use of their language (rather than my own) and not over-analysing the data to reflect

the beliefs of myself or my colleagues. As a method of checking this, some of my interview transcripts were checked by two colleagues (SP and SB), firstly to look at my interview technique and secondly to check coding. My interview technique was seen as suitable by my colleagues and we were in agreement with most of the coding. Any discrepancies were discussed and reworded or reconsidered until one hundred percent agreement was reached regarding any differences in the transcripts.

3.6 Research Ethics

The premise that a patient's attendance being more than what is deemed 'normal' is one that some patients and GPs may struggle with. The patients themselves may not realise they attend primary care more frequently than other patients; others may realise they do attend frequently but believe it is their right to do so or, as often seems to be the case, that they need to continue doing so until they feel they have "got to the bottom" of what is bothering them. GPs themselves may feel the need for these patients to return because they themselves feel anxious that they haven't been able to, for example, adequately explain the patient's symptoms. Other patients may have different views. It is possible; therefore, that when this subject is broached with patients to engage them in the study there is a risk that it may cause offence. In order to minimise the risk of causing offence to the patient, the term 'regular attendance' rather than 'frequent attendance' was used in study documentation and when speaking to patients. This was decided on after consultation with the Institute of Mental Health's patient and participant representatives, who felt this was the most 'user friendly' term. With regard to the GP interviews it was felt important to present the research in a manner that would invite them to speak openly and honestly about the feelings working with PFA's

engendered in them. This was achieved by SB presenting the research and herself in a non-judgemental manner and stressing confidentiality.

This research was not initiated until the protocol, consent form, interview guides (Appendix 1, 2 and 3) and participant information sheets had received approval from the NRES Research Ethics Committee (REC Ref 11/EM/0392) and the National Health Service (NHS) Research and Development (R&D) departments, providing research governance to the participating NHS Primary Care Trusts. The study was conducted in accordance with the ethical principles that have their origin in the 2008 Declaration of Helsinki and the Department of Health Research Governance Framework for Health and Social Care.

3.7 Informed consent and participant information

The process for obtaining participant informed consent was carried out in accordance with REC guidance and Good Clinical Practice (GCP) requirements. The participant and I signed and dated the Consent Form before the person participated in the study. The participants received a copy of the signed and dated forms and the original was retained in the study records. A second copy was filed in the participant's medical notes.

The decision regarding participation in the study was entirely voluntary. I made sure to emphasise to the patient that consent regarding study participation may be withdrawn at any time, without penalty and without affecting the quality or quantity of their future medical care, or loss of benefits to which the participant is otherwise entitled.

3.8 Unique identity codes (UIC)

Each participant was assigned a study UIC for use on case report forms, study documents, transcripts, audio recordings and electronic patient records.

3.9 Case Report Forms

A database of case report forms for consented participants was kept. This was only accessible by password by myself or research colleagues working on the 'Regular Attenders Study'. This is the only place where identifiable participant data and UICs were kept, apart from on consent forms, which were kept locked in a filing cabinet.

Each Case Report Form included details of the participant including: name and address, telephone number, date the signed consent form was received, date of birth, GP practice at which they were registered or worked, usual GP and NHS number (for patients). Each participant was given a UIC, which reflected the surgery they were attached to and an individual number. For patient participants, these were allocated by the practice administrators after the initial database enquiry was carried out. All patient documentation was clearly marked with the patient's UIC and two identifiers: 1) date of birth and 2) initials. CRFs were treated as confidential documents and held securely in accordance with regulations.

3.10 Recruitment Logs

Separate recruitment logs were kept for patient participants and general practice staff participants. The recruitment log for participants included records of which GP practice the participant was recruited from and the date of their interview. All study documentation including audio recordings and transcripts were treated as confidential documents and held securely in accordance with regulations.

Transcripts had all identifiable information removed. Source documents were filed at the investigator's site (University of Nottingham) and included, but were not limited to, consent forms, study records, field notes, interview transcriptions and audio recordings. Source documents were available at all times for review by the

Chief Investigator and Sponsor's designee and for inspection by relevant regulatory authorities.

3.11 Data protection

Throughout the study, I endeavoured to protect the rights of the study's participants to privacy and informed consent, and adhered to the Data Protection Act, 1998. The data collection era for the study began in September 2012 and continued until September 2013. Participants' involvement ended with the final interview, which was carried out in September 2013.

3.12 Sampling and Data collection -Methodological Approaches

As this research is focused on allowing the PFAs and GPs to describe their own experiences, I wanted to ensure that the interviews felt more like a consultation (or co-production) and that I did not leave participants feeling disempowered. So I tried to design the interviews to enable the participants "telling" of their stories to be central, in line with work by Fitzgerald. (2016). My colleague (SP) who carried out the GP interviews and designed them shared the same approach. The methods for generating data encapsulated this approach by allowing the participants the opportunity and freedom to express their views within semi-structured interviews. The 15 PFA patients and the 12 GPs who participated in the qualitative interviews form a maximum variance sample, to ensure that the sample included participants of different age, gender and ethnic backgrounds and from different GP practices.

3.13 Selection and recruitment of practices

Five practices across Nottinghamshire were purposively selected to obtain a wide variation in existing organisation of care and socio-demographic contexts.

This provided a good sample of practices working under different conditions so that we could see how attendance impacted on staff and how the treatment of PFAs

may vary within different practices according to organisational, demographic and social factors. The practices are described in Table 1 and below.

Practices were approached by a letter from the Principal Investigator asking them to take part in the research study. All practice staff were then invited to take part in a semi-structured interview and were approached by SB (the implementation researcher) to be interviewed. The sample was a convenience sample in that that the staff took part if and when they had time to. The sample included younger and older GPs and as Table 1 shows, the practices were from across Nottinghamshire including rural and inner-city locations.

Table 1-Practice Profiles

	Practice A	**Practice B**	**Practice C**	**Practice D**	**Practice E**
Registered Patients	26977	11552	12915	14067	15325
No. of Sites	4	1	2	1	**1**
GPs	14	7	14	8	**6**
Deprivation decile*	4	6	9	5	**2**

*Based on Index of Multiple Deprivation (11):10 represents least deprived.

Practice A was selected because it prioritised access to care over continuity of GP care. For example, if a patient requested to be seen, they could be seen quickly but not necessarily by their named or 'usual' GP. This practice covered four sites in close proximity to a general hospital and served a deprived population.

Practice B was selected because it emphasised continuity of GP care, seeking to ensure that patients saw the same GP on each occasion. It served a more affluent population and was purpose built on the site of a hospital.

Practice C had some university links and served an affluent population on two sites, but was not close to a general hospital. It followed a policy of trying to meet patient preferences to see the GP of the patient's choice but suggested alternatives if appointments would be delayed.

Practice D prioritised same-day access to a GP, rather than continuity of care with the same GP if that meant waiting for longer. It had direct access to mental health professionals and welfare advice with financial problems at the practice. It served a deprived population within an ex-mining community and was not close to a general hospital.

Practice E was similar to practice C organisationally but served an inner-city ethnically diverse population in an area of high social deprivation.

3.14 Procedure and Measures used to capture the Clinical Characteristics of the PFA Participants

The wider study that this thesis was "nestled" within, included a case control study which aimed to look at measurable differences between PFA's and people with normal rates of attendance (NA's, see definition below) in primary care. This element of the study compared the mental and physical health characteristics and status of patients, to gain a greater understanding of the differences in health

between the two groups. I have used the baseline interview data of the 15 participants of this PhD study to give a more detailed picture of the PFA patients' health using clinical measures and patient records and because I carried out most of the data collection myself.

3.15 Procedure for baseline data collection

The participating practices identified PFA patients from their practice lists by an electronic search using study inclusion and exclusion criteria. All potential patients meeting the criteria were sent a letter from the practice that included a study invitation letter addressed from the GP practice, a participant information sheet and consent to contact form. Consenting participants were then contacted and a baseline interview was arranged and carried out at the participant's GP surgery in a consulting room either by myself or a research colleague (SP). The baseline interview included the use of the measures described below. Written and oral informed consent was obtained prior to the interview taking place. The interviews lasted up to one hour. We originally tried to recruit the top 10 percent of PFAs by age and gender but practice A found it too burdensome to carry out this search. Therefore, we established that the consultation rate that was within the top 10 percent of all face-to-face contacts with GPs per year and used these data to set a cut-off of 30 or more face-to-face contacts in the last two years. Recruitment of participants used the following inclusion and exclusion criteria; PFA had to be over 18 years of age, to have consented to take part and to have had thirty or more face to face contacts with their GP or practice nurse in the two years preceding the interview. Normal attendance is defined as people who have had between 6 and 22 face to face contacts with GPs or practice nurses in the preceding two years, including routine health checks (based on a study by Morriss et al 2009). Exclusion

criteria for PFAs were if their appointments were for routine health checks or if they were under 18 years old. The searches for potential participants had to be carried out by practice staff in order to protect patient anonymity. All potential PFAs were sent a letter which included a letter of invitation, a participant information sheet and a consent to contact form. The invitation was sent from the potential participant's GP. Following this, interested patients could contact the study team or GP practice in order to arrange an interview at time and place convenient to them. Recruitment was designed to impact as little as possible on practice staff and be efficient and effective. The research team worked with the practice administrators or in some cases, managers or GPs who led in mental health, to recruit patients. Where we were able to work closely with practice staff, recruitment was quicker. As the study progressed, the research team continued to work closely with practice staff to improve our understanding of how the different practices worked and ascertain how best we could assist them in engaging patients. Being flexible about where interviews were carried out was also very important when dealing with a patient group who, despite their regular attendance, might have felt anxious about being interviewed in a clinical environment by a person unknown to them. As a researcher I endeavoured to assist the participants to feel as comfortable and relaxed as possible in order to create the right atmosphere for an honest and open interview. When participants were interviewed at home it was mostly due to physical health issues.

The following four measures were used:

The Structured Clinical Interview for DSM-IV diagnoses (**SCID**) (First, 2002). The research version of this standardised psychiatric interview, was used to determine whether participants met the criteria for psychiatric disorder in the preceding two years. Training and supervision was given by a psychiatrist to ensure the SCID was

administered correctly. In addition to DSM-IV criteria, the abridged criteria for somatisation disorder were applied and an additional diagnosis of health anxiety disorder was created by replacing the criterion for specific disease conviction in the DSM-IV diagnosis of hypochondriasis with persistent worrying about acquiring a serious physical illness. Thus the criteria for health anxiety disorder together with hypochondriasis, are broadly in line with the DSM-V illness anxiety disorder.

HAI: The Health Anxiety Inventory Short Week Adapted (Salkovskis 2002) is a 14 item self-rated tool to measure health anxiety over the preceding week. A score of 18 or more identifies those whose health anxiety would be severe enough to be considered for a DSM-IV diagnosis of hypochondriasis if the concerns were related to conviction about a disease and they persisted for six months. A cut-off score of 15 indicates that people who are very health anxious but not severely enough to meet the criteria for a clinical diagnosis of hypochondriasis. Avoidance scores are calculated by asking respondents to rate their likelihood of avoiding ten health situations, for example, visiting someone in hospital; scores range from 0 would not avoid to 8 (always avoid it). Reassurance-seeking scores are calculated based on how often the individual seeks reassurances from a range of nine sources, with scores ranging from never (0) to daily (8). These scores indicate how much the patients might be seeking reassurance from others about their convictions about their health and are a part of the overall score.

EQ-5D- The EQ-5D-3L Euroqul (1990) is a descriptive system for health-related quality of life. The measure is self-completed and defines health states using five dimensions (mobility, self-care, usual activities, pain/discomfort, anxiety/depression), each with three levels of severity (no problems, some, moderate or extreme). In addition, respondents were asked to rate their health on

a visual analogue scale (VAS) ranging from 0-100 where a score of 0 indicates their worst and a score of 100 indicates their best imaginable health state. Using a valuation from a nationally representative sample, it is possible to attach preference weights to individual's responses. This enables the elicitation of a single index value on a scale anchored at 0 and 1, where 1 is full health and 0 is a health state of equivalent value to being dead. The higher the score, the better that participant sees their quality of life in relation to their health.

3.16 Physical health of PFA Participants

Details of long term conditions and medication use of all participants were obtained from electronic primary health care records extracted by practice staff. The research team, including myself, used a published classification site to accurately record this information (ICD-11- Online). In addition, attendance rates and body mass index (BMI) scores were extracted from primary care electronic medical records.

3.17 Reliability and validity of clinical characteristic data

The measures used have all been tested for reliability and validity. The HAI in an initial report by Salkovsis et al (2002) was found to demonstrate excellent psychometric properties and construct validity and was declared a reliable and valid measure of health anxiety as well as a brief screening instrument in the short form. The SCID has also been tested for use with several patient groups and found to be a reliable and valid measure of symptom severity dimensions of both current and lifetime psychopathology (Shankman 2018), Segal, 1994). The EQ-5D has also been tested and seen as a highly reliable, robust and easy to use form (Li 2019, Sonntag 2013). The retrieval of data from patient's medical records was carried out systematically by experienced practice staff and data given on attendance by patients was checked by myself against medical record data. Myself and my

colleague (SP) who conducted the baseline interviews were trained in using the measures by an experienced academic and clinical psychiatrist and we had completed formal training in research methods at the University of Nottingham. Our data entry was double-checked for accuracy by administrative staff at the University of Nottingham.

3.18 Interpretation and Analysis of the Qualitative Data

A phenomenological approach was taken for this research, which in its nature does not pertain to one specific analysis strategy (Smith et al 2009). Rather it is flexible, presenting an approach, which focuses analytic attention on the participants in an attempt to make sense of their experiences. As such, in analysing the data from this study, great attention is paid to understanding the meaning participants place on their own experiences of PFA. I was mostly approaching the data using an inductive approach. However, I had carried out a literature review but I have integrated the literature at the point of discussion not during data analysis. In addition to this, it was vital to not place my own interpretation on the participants' experiences. Therefore, throughout the analysis process every attempt was made to keep as close as possible to the spoken word of the participants from the transcription through to theme development. This was done through careful use of language ensuring that where possible the patient's own words are used. When further interpretation and structuring is required, this has been done within the context of the study and the process of data collection. In addition to this all interviews apart from one were recorded to aid with the description and analysis process.

Four stages were followed in the data analysis process, similar to the interpretive phenomenological processes outlined by Smith et al (2009). . I used four stages to analyse my data as outlined by Smith et al (2009) but used them flexibly.

Stage 1: Reflective data collection

Stage 2: Description of data.

Stage3: Understanding the Data.

Stage 4: Thematic Development.

Stage 1: Reflective data collection

Reflecting on the data directly after each interview allowed initial ideas about themes and key points to be drawn out and in the case of the first few interviews additional questions added to the topic guide. These included questions regarding how health impacts on self-care and any memorable consultations. Smith et al (2009:82) state that it is important for phenomenological researchers to enter a "phase of active engagement with the data" and through the research journal I felt I was able to reconnect with the participants and ensure that any contextual meaning was not lost in the analysis process.

Moreover, through the process of reflection it was determined that the GP data would be analysed separately from the patient data. Initially I had planned to look at the data together but as analysis was carried out it seemed more appropriate to look at them separately and then consider the data set as a whole later.

Stage 2: transcription of the data as described earlier.

Stage 3: Understanding the Data

To begin to understand and interpret the data in relation to the main research question and sub-themes, all transcripts were summarised. This involved reducing down the verbatim transcripts into more understandable narratives. The participants own words were used in the summaries and every effort was made to not paraphrase the responses. As such, summaries reported findings in an understandable and readable format, allowing findings to be fully understood. Notes were taken during this process about the potential themes and summaries

were grouped and read in terms of the practices that participants were from in order to see if there were any variations in the data by practice.

Stage 4: Thematic Development and analysis

Once the data had been accurately transcribed, summarised and understood, thematic analysis was undertaken. I organised the main themes and sub-themes that had emerged from the transcripts, the summaries of the transcripts and my journal. I used a five stage approach to data analysis:

1) Familiarising myself with the two separate sets of data, for example by transcribing, anonymising, initial reading and coding the data as described in stages 1-3 above.

2) Looking at the initial start codes in relation to the research question about experiences.

3) Developing these initial start codes into broader or overarching themes.

4) Refining and reviewing the themes for the separate sets of GP and patient data.

5) Looking at all the themes together considering potential interpretations of the data. Asking, how do the themes from the patient data and the GP data relate to each other and what might they tell us about the participant's experiences? And how does this data relate to existing theories and knowledge in this field and how might it be interpreted in relation to current understanding?

The following two chapters present the collection, analysis and the results of the data. Finally, the discussion chapter suggests ways in which we might understand

and attach meaning to the experiences of PFAs and the GPs who manage their care.

Chapter 4-DATA COLLECTION, ANALYSIS AND RESULTS OF THE GP INTERVIEWS

4.1 Data collection; The Interviews with GPs

The GP interviews were carried out by a colleague and senior Research Fellow (SB) who was employed on the Regular Attenders study (see Appendix 1). SB was carrying out the research specifically to look at implementation issues and the challenges of implementing a research intervention with this patient group. I was interested in how GPs and practice staff experienced caring for these patients. SB used a topic guide (Appendix 2) which includes questions on topics relating to PFA and their care, that we were both interested in. After GP practices were invited to take part in the study and had agreed, each individual GP was written to and invited to take part in a one to one implementation interview. GPs were interviewed as they responded and recruitment continued until data saturation was reached and no new themes arose during the interviews. Five of the GPs were female and seven were male.

Table 2 illustrates the number of interviews at each of the participating practices.

Table 2: GP participants from each practice

Practice A	**Practice B**	**Practice C**	**Practice D**	**Practice E**
4 GPs	2 GPs	2 GPs	2 GPs	2 GPs

Total: 12 GPs

4.2 Recruitment Procedure

GPs at practices participating in the study were provided with an invitation to take part, a study information sheet and were asked to nominate a day and to meet to be interviewed. Those who agreed were then asked to complete an informed consent form and were interviewed individually. Recruitment continued until data saturation was reached.

4.3 The GP Interviews

Interviews were audio-recorded, and then transcribed verbatim.

The interview guide focused on similar issues to the participant interviews in terms of memorable recent consultations, the types of issues PFAs might attend with and the GPs knowledge about the patients' history. GP interviews also focused on how the care of PFAs was managed in that practice, length of consultations, whether particular GPs tended to take care of PFAs and how the GPs felt about these patients and caring for them. As with the patient interviews, care was taken to protect the confidentiality and anonymity of the GPs. All data was anonymised and interviews were carried out in locations that enabled privacy.

Measures were taken to ensure that the GPs confidentiality was respected. Ensuring that people would not walk in on an interview by using 'engaged' signs.

During the interview, the topic guide was used only as an aide memoire to ensure all of the questions were covered. The interviews were conducted using a small digital recorder, after consent had been taken to record the interview. The recorder was placed out of the interviewee's direct line of vision to avoid them feeling self-conscious.

In most cases, the GP interviews lasted between 15 minutes to half an hour, one was cut short due to the GP being called to an emergency.

4.4 The topic guide for GP Interviews

After talking through the PIS and taking consent, SB began by asking GPs questions based on a topic guide (see Appendix 2)

- Topics covered included;
- Their overall aim with regards to managing the care of PFA's,
- communication with colleagues regarding the care of PFA's
- prescribing and PFA care
- How they feel morally regarding PFA's
- Managing secondary care referrals
- Managing the mental health care of PFAs
- External pressures (e.g. Primary Care organisations)
- Social care
- Gatekeeping by receptionists.
- GPs gatekeeping PFAs away from other services.

The benefit of this semi-structured qualitative interview style was that it did not force participants to choose from an accepted list of responses but, rather, provided them an opportunity to use their own words to describe their experiences. It gave SB the opportunity to highlight issues that began to look like they were important after the initial few interviews and explore these in more detail with later interviewees. So, for example, the issue of mental health service referrals began to look like an important one, so SB explored this with the GPs and I explored it with the participants, if relevant. This technique of analysing data as we were going along was very important in helping us to make the most of the interviews and to explore themes that were rising from the data as the research progressed.

The GP interviews were transcribed verbatim by a professional transcription service organised by the University of Nottingham, as part of the 'Regular Attenders' study. The transcripts were then checked against the recordings by myself, as the initial part of the coding process and also to check for anonymisation. After 12 GP interviews, it was felt that data saturation was reached and no new themes were arising.

4.5 The Analysis of the GP Interviews

This section describes the analysis of the GP interviews. The 12 GP interviews were analysed in accordance with the process described in section 3.13 Interpretation and Evaluation of Data and I will go into more detail here in order to describe the full process of what happened. Both myself and SB coded the interviews for reliability for the implementation analysis and this study. To check for reliability, we each took a sample of four interviews and coded them, we then compared our coding and discussed the themes until we reached 100% agreement.

. As I analysed the data I tried to remain aware of the research question of "how do GPs perceive PFA patients and experience caring for them?"

This phenomenological approach to data analysis meant thinking analytically about the experiences the GPs shared during interview, what their views were regarding issues around caring for PFAs and what this meant to them. Finally, I wanted to consider what we could potentially learn from these experiences.

Stage 1 involved familiarising and summarising the GP data. I did this by reading each individual transcript through one at a time. As I did this, I made notes about potential themes and thought about the views of the GPs. Each individual interview was then summarised. The summaries serve, as a reminder of the "whole story" of each transcript, so I could be mindful of this as well as the themes and codes it

could be broken down into. As Daher (2017) describes this is a useful tool in developing meaning from the themes and situating the experiences within the context of the informants' life and circumstances.

After the initial reading of each individual transcript I went on to generate initial codes by writing in the margins of each transcript when I identified a potential code (Stage 2). Once all the transcripts were coded, I systematically began to search for themes and organise the codes. In doing this, I considered how important each theme was, not merely by its frequency but also by considering the impact of the theme, asking myself, whether, why and how it was important. I then reviewed the themes, checking them against the transcripts and against each other, reorganising and streamlining them (Stage 4). See Appendix 5-Stage 4 of GP data analysis.

4.6 The use of an independent second coder

An independent researcher (EP) also carried out stages 2 to 4 of data analysis. EP used qualitative data analysis for her PhD thesis and was completely independent of this research and the University of Nottingham. EP analysed a sample of three GP transcripts without seeing any of my coding or development of themes. Once EP had carried out this work, we compared the codes and themes she had generated with mine and we reviewed the themes together. We agreed on the final themes and sub-themes. The reason for having a second-coder was to ensure that the data were coded and analysed rigorously and in line with the CoreQ-32 and CASP checklists for analysing qualitative data.

The final stage of GP data analysis was to present the themes and sub-themes to my supervisor (HB) for final discussion, refinement and organisation.

4.7 Results of the GP Qualitative data analysis

There were three main themes identified, with corresponding sub-themes (see **Table 3**). I will discuss each of the three main themes and sub-themes using direct quotes from the data. I will offer interpretations of the data and make suggestions about meanings. Within the discussion chapter I will integrate the findings with the research literature and discuss the findings from the two separate sets of data. In doing this, I have tried to stick as closely as possible to the data.

Table 3: Final Themes and sub-themes of the GP data.

Main Themes	Sub-themes
The relationship between GP and PFA	• Trying to understand who PFAs are. • Awareness that there is probably something "underlying", a story to tell. • Acknowledging the suffering of PFAs. • Offering continuity, trust and time • Containing frequent attendance within primary care.
The significance of the mental health of PFAs	• Being reluctant or unsure about having a conversation about mental health. • Trying to understand the relationship between mind and body. • The lack of options for the mental health care of PFAs. • Issues with prescribing anti-depressants.
The impact of managing the care of PFAs on GPs	• Self-esteem • Emotional cost & anxiety • Lack of skills/time/training.

4.8 Theme 1: The Relationship between GP and PFA

The significance of the relationship the GP had with their PFA patients was a main theme of the GP interviews. A pattern appeared in the data with regards to how the GPs approached their relationships with their PFA patients. GPs described the importance of developing a professional relationship with their PFA patients that was consistent, trusting and offered them time and continuity.

"We said look lets, 'I'll look after you, I'll do my best. I'll do my best' and so he, we've got that continuity, got that relationship now." GP5

In the quotes from GP5 and GP2 (below), the GPs seem to pledge to the patient to do their best to "look after them", build a relationship with them and offer them continuity, a listening ear and trust. These statements illustrate that these GPs are making a conscious effort to do their best by their PFA patients and feel that in order to do this they need to build a professional relationship of trust with the PFA patients.

"and so sort of, like, you know, you give them…you're empathetic and you build the relationship and they know that you will listen to them and if they do get some other thing you'll deal with it properly and that's my aim really." GP2

Building a trusting relationship with PFA patients comes across as very important to GPs because it allowed the GPs to get to know and understand these patients better and be able to relay to the patients that they could be trusted to take their healthcare seriously.

4.9 Trying to understand who PFAs are

The GPs felt it was important to have a relationship with PFA patients so that they could try to understand them, as GP6 describes:

"Because of course, part of the very nature of the regular attender-GP relationship is trying to understand the individual's context as much as take a more formalised, structured approach to disease." GP6

and

"First do no harm, primum non nocere, and, ummmm, listen. And part of what we do is listen, is to become involved in and try and understand someone's narrative...only by spending considerable time with these individuals can you understand what you need to know about their social context, their biography, than you're able to grasp in a ten-minute slot" GP6

Understanding their patients' narrative was seen as important by GPs because it helped them to appreciate the PFA patients' circumstances and to discover if there might be something happening in their life, a difficult phase, a bereavement or stress, for example, that might be causing them to attend more. As GP6 describes, this approach is about trying to understand the individual's context by taking a holistic approach, rather than by addressing the presenting set of symptoms alone. GP6 also stresses that this cannot be easily achieved within a ten-minute appointment slot and that it might be something that involves "spending considerable time".

4.10 Awareness that there is probably something "underlying"; a story to tell.

Building a relationship with PFA patients and trying to understand them seemed to be part of a process that GPs undertook in order to discover if there was something

underlying that the patients needed to talk about and "get off their chest" as GP10 describes.

"I mean how many times do you hear that, you know, people say just having the chance to tell their story, get it off their chest so to speak, you often get some clarity just from that don't you?" GP10

However, a barrier to understanding more about the patient's lives could be having to work through the presenting symptoms first, as GP2 describes in the quote below. Some PFA patients attended with many different or changing symptoms. The symptoms the PFA patients presented with, had to be carefully considered and examined. However, this need to manage symptoms was sometimes a barrier to trying to understand their patients and uncovering the "underlying" story, as GP2 explains he "might never get that far" because he is managing symptoms.

"I mean I think those ones where they find one symptom and then they go through a lot of investigations and then its negative; they come back with another symptom. In my experience, they are less common. I mean there will be people like that but generally the people I think of as frequent attenders they've got loads of symptoms. I mean I've sat with a woman and broken down every single symptom that day, there were 27 symptoms...first, and foremost have they got anything wrong with them? But there are people that are like her, I mean she might have a personality disorder or something but it's too, I mean, as I'd never get that far because I'm working through the presenting problem. I mean there are people who are obviously normal people in the sense that they haven't got a personality disorder for example who do get a lot of physical symptoms which they worry about but mostly I suspect there's something underlying their problems." GP2

The quotes from GPs given above, suggest that limited appointment lengths at GPs surgeries might mean that they do not have the time to go beyond discussing and investigating the presenting problem or symptoms and therefore it might be

difficult to find the opportunity to get a clearer picture of any other explanation for the increased frequency of attendance.

4.11 Acknowledging the suffering of PFAs

Acknowledging the suffering of PFA patients was important to some GPs who were keen to empathise with the suffering of their patients even if they were not confident that they always could help them or fully understood how they were feeling; as GP5 describes below. This quote illustrates an empathic approach to patient care and displays how much this GP knew about his patient's life story;

"But he always talks; he says, "I suffer". And if you look back, he was operated on by a surgeon who was struck off. I think he didn't have too many complications from his surgery but he has a bowel surgery and then I think he feels let down by the medical profession. He feels he generally suffers. He lost a daughter when she was a toddler to an asthma attack you know, which is tragic. And you know that only came out once when-cos he never mentioned that. So, I think here's someone who's really felt he's suffered all his life and he's really struggling. He just is suffering." GP5.

Although often GPs struggled to uncover the source of their PFA patients' increased attendance, they did acknowledge that although the cause may not always be clear, these people were suffering. Some GPs knew their patients well enough to be able to understand some of the reasons for their patients' emotional pain as described by GP5 above. In this extract the GP describes feeling empathy for his patient, he understands the tragic and difficult life events he has endured and is very pragmatic about the suffering of his patient. It is also possible that, as the GP infers, this patient has some anxiety around health having experienced several health-related traumatic events. For these GPs caring for PFAs means offering

them a trusting relationship where the PFA patient will feel listened to, understood and their suffering acknowledged.

4.12 Offering continuity, trust and time

The importance of having the time to invest in building up a relationship with PFA patients that offers trust and continuity was emphasised by the GPs. As GP8 states, at their practice, it was normal to encourage patients to have a "usual" GP who they were assigned to.

"And I would say we have a culture of continuity of care…and so I potentially say to patients you can see a different doctor, you know, once a week for three months but it's not good for you. It's not good for us. It's not satisfactory…therefore we assign you a usual GP." GP8

GP9 illustrates that at his practice, once they are aware of potential PFAs they will assign a "usual GP" or put safeguards in place to ensure continuity and reduce the potential for investigations and referrals to be duplicated.

"Our times not taken up too badly by the frequent attenders and if it is we spot it quickly and we put safeguards into place, so that we minimise this uncertainty for the patient by seeing different doctors who might start things at different stages and therefore duplicate work which in turn creates more attendance for follow up investigations that might have been done in the past, etcetera so in a sense I think yes we do have frequent attenders but we manage them in a different way." GP9

For these GPs, PFAs seeing different GPs would not be good for the patients, as this might create uncertainty and increase attendance rates. The importance they attach to continuity of care for PFAs is that it is better for the patients and for the GPs.

"I don't operate in a model of having "heart sink patients" so I don't have patients that I feel frustrated with because I'm always thinking, "Where am I going with this patient?" GP2

One GP interview (GP12) was different to the others as it was focused on what she perceived as a problematic situation with a PFA who ended up leaving the surgery. GP12 felt this patient left because she would not offer the same level or intensity of care as a former colleague. During her interview GP12 recounted how after a GP at her practice had moved, she "inherited" the care of his PFA patient for six months. The GP described this time as trying to address a high level of "doctor dependency". She spoke about how the patient had seen the same GP for many years and that this GP has offered her regular appointments to address her anxiety in relation to having had breast cancer twenty years before. GP12 expressed being cross with her colleague for allowing the situation to develop:

"I was a little bit cross with the doctor because he kind of colluded with this patient and allowed this to develop and actually didn't help her in that sense. Because he compounded her fear and anxiety by allowing her this attention." GP12

During the interview GP12 told how this experience had left her feeling that she had failed this patient as she wasn't able to manage her care. The patient left to go to the surgery where her previous GP had moved to. This account from GP12 offers an alternative perspective on the issue of giving time and continuity to PFAs. Perhaps illustrating that in some situations offering a relationship of continuity could in fact compound the patients fears or create "doctor dependency". These different GPs accounts could possibly be seen as illustrating the difficulty or problem of striking a balance between creating a relationship that offers the trust and continuity that allows a GP to understand their PFA patient and the risk of creating an unhealthy dependency.

GP12 saw herself as a GP who would offer PFAs time and she felt she attracted PFAs. It was hard for her because she didn't see herself as "good with mental

health" but she felt PFA patients kept coming back to her because of the time she gave them.

"I make people feel listened to even if I'm running an hour late…I don't know you're just thinking "No, their world will fall apart so I've got to deal with this person right now" and I think "I'm sorry let's just get on" and I try and work efficiently and quickly but I will deal with the problem but in a way I shoot myself in the foot because then people will keep coming back to me because I listen to them." GP12

GP12 feels it is important to deal with PFAs and give them time even if she feels she is running late. The extract above illustrates the sense of responsibility she feels towards her patients emphasised by her statement about how their world might be falling apart and she needs to deal with them. But she then goes on to say how, this might then mean they keep coming back to her. GP12's experiences with PFA patients, both her own and the one she "inherited" illustrate the potential challenges posed by offering time and continuity for PFA patients, and the complexity of this within the primary care system. For example, wanting to offer care and listen but not wanting to create or encourage "doctor dependency".

Despite differences in their narratives regarding their relationships with PFA patients, GPs emphasise their role and responsibility towards these patients and their attendance, whether they feel that they are moving them forward or worry that they are encouraging them to come back. For GPs, the relationship with their PFA patients seems to be very important but there are challenges and complexities for the GPs in managing this relationship.

4.13 Containing frequent attendance within primary care

Frequent attendance is not confined to general practice. Interestingly, in addition to seeing themselves as able to offer time and consistency to PFAs, GPs also seem

to feel it was part of their role and responsibility to contain the problem of PFA within primary care. Some PFA participants were accessing secondary care or presenting themselves at A&E, for example, due to concern over symptoms. In some cases, the PFAs were referred by GPs for investigations that were seen as part of a process of excluding potential causes of symptoms, and in other cases attendance was initiated by the patients requesting referrals to secondary care. Managing referrals, medication and iatrogenic harm were all issues discussed by GPs as part of their role in managing the care of PFA patients. The quotes below illustrate how GPs viewed part of their role as to contain frequent attendance within primary care and preventing A&E admissions or complicated secondary care referrals. GPs also describe how they struggle to negotiate and have the skills to persuade PFA patients that these further referrals are not always necessary.

"But sometimes you feel pushed down a path of investigating the problem, then investigating another problem, then investigating another problem, with the person asking you for a referral all the time to various specialists and you're obviously thinking, "this isn't the appropriate thing to do" and just having the skill to persuade them that it isn't necessary." GP10

Along with illustrating how much GPs feel pressured to investigate and refer PFA patients, GP10 is emphasising how there is a skill required here in persuading PFA patients that such referrals aren't necessary.

"That's right, yeah. We have to contain them in some way. Because if we don't do something it's when they start dialling for an ambulance every day and then we are in a bit more trouble." GP9

GP9 sees part of the containment of PFAs in primary care as discouraging them from calling an ambulance (above) but also feels that a part of their role is to prevent PFAs becoming over medicalised (below). I have used this rather long quote below as, when read in full, it illustrates the difficult balance several GPs

spoke about, of trying not to over-investigate the physical symptoms PFA's are presenting with but "keep them going" but that within this balancing act of caring for them and keeping them from secondary care referrals there is also the (sad) acknowledgement that it is not a solution. For GP 9, the fact that caring for PFA patients is aimed on keeping them from being over-investigated or over-medicalised is awful;

"…and that's my aim really, it's to stop them being over-investigated and over-medicalised, but yeah, really just to keep them going you know. And that's awful isn't it. It's not like a solution. But yeah, it's to, kind, of I mean, obviously, you don't want them to come every week or every month but to know they can come. And I suppose some of them do get a sense of something might be more sense of something more, more serious this time if you know what I mean.? I mean they must have a feeling that their symptoms have been as usual but now this is something different. That's what you hope anyway, they would recognise something. I mean, one patient that I was talking to just a minute, ago who's got lots of symptoms, she put herself in for an ECG recently and then she does this ECG, she's coming for the result of that ECG and I said "It was OK, why did you come? "well", she said I wasn't feeling very well that day and you sort of think well that's not very good but at least she only ended up having an ECG here and didn't go off to casualty or anything." GP9

GP4 (below) also talks about how having a regular slot with a GP might prevent a PFA calling for an ambulance or "cruising A&E".GP 4 is describing how one of their colleagues felt that seeing a PFA once a week regularly was a good option as it prevented the patient unnecessarily accessing other health services and didn't cost the NHS any more. So for them GP care was about containing frequent attendance.

"and if it wasn't him doing it, he was going to be phoning for an ambulance every other week, it was going to be cruising the A&Es, it was going to be something or other and he felt that really

it was the least bad option that he saw her once, in this case once a week for a regular slot because actually that doesn't cost the NHS anymore." GP4.

For GPs another reason for them developing a relationship with PFA patients was so that they were able to proactively plan to see them in the hope that this might prevent them from seeking appointments with other service providers such as A&E. Containing frequent attendance within primary care was seen as cost-saving and seemed to be viewed as a legitimate role of the GP.

4.14 Theme 2: The significance of the mental health of PFAs

The second main theme identified from the interviews was the significance of the mental health of PFAs, and the challenges this presented to GPs in managing the care of PFAs.

4.15 Being reluctant or unsure about having a conversation about mental health

A significant difficulty that GPs spoke about was being unsure of whether to, or how to, introduce the issue of mental health to PFA patients. As in GP4's account below, he feels that some PFA patients may not have the stamina and strength to face the painful process of tackling traumatic issues from the past. He describes how one PFA patient who experienced serial sexual abuse had tried to address these issues and "ended up in a bigger mess than before." The GP interprets this patient's experiences of attempting and failing to address past issues as leaving them now feeling that their health needs were "between me and my GP and I'm happy with the way things are."

"They don't want to risk the pain, if I can put it like that, of maybe going through the process of fixing it. They don't, the issues involved are painful, are deeply hardwired and they just don't want to be challenged on them because it's too hard. I can think of several groups of, of several patients

who would, there are big problems. They know they've got big problems but they just don't have the stamina, they don't have the, they don't feel they've got the strength to tackle them. You know I've got one patient who has, who'd had serial sexual abuse as a patient who has now has a very complicated presentation of epilepsy. How much of it is true seizures? How much is pseudo-seizures? She kind of knows where it's coming from. She knows but she's tried addressing it in the past and every time she's ended up in a bigger mess than before and now she doesn't want to go there any more…. So they end up thinking this is between me and my GP and I'm happy with the way things are." GP4

GP9 also describes a reluctance to raise the idea of CBT with his PFA patients because he feels he might risk alienating them, that they may disengage from him and "bristle". This GP feels that only very few PFA patients would be open to the idea of therapy or counselling such as CBT.

"I personally am uncomfortable bringing the idea of CBT up because when you even start to broach it you can see the patients picking up what you're thinking, err, along different lines and they do start to bristle, you know; start to disengage a bit if you're not careful. In very few cases, they might be open to it but that's unusual. I suppose it feels like you're walking a bit of a fine line in that, you know, you know where you should be going but you don't want to lose them." GP9

GP4 also takes a reluctant stance in terms of how far to push PFAs in terms of approaching a mental health aspect to their well-being. GP4 feels that delving into these issues could do a lot of damage and that some PFA patients may be managing to function and enjoy life because they have "boxed off" these issues (below).

"There is this popular concept that we're all better for getting it out of our systems. It's better to bring it all out and deal with it. Actually the more I talk to more experienced GPs I think that's wrong. I think sometimes obviously you can deal with these things at early stages and get them

addressed and move on, brilliant. But actually sometimes it's there and it's been buried, boxed off, compartmentalised and put away, no it's not ideal but really very little in life is ideal and if that means that they can get on in life and function in life and enjoy life again that may not be a bad thing. And having somebody like an enthusiastic new young vibrant GP who's keen to solve the world's problems getting involved and saying, no let's explore all of these issues, lets refer you to this and that and the other, can do a lot of damage. And I think that's something with a lot of these people it's probably true and I think we have to be quite careful how far we push them." GP4

These accounts regarding raising the issue of mental health with PFA patients illustrate that there can be a reluctance on the part of GPs to delve into these issues because they feel that there isn't necessarily a benefit to the patient. Sometimes GPs feel that introducing these issues might create more problems than it solves.

4.16 Trying to understand the relationship between mind and body

GPs found it a challenge to understand and convey to patients the relationship between physical and mental health, the connection between the PFA patients' physical symptoms and their mental or emotional well-being. GP1 states that people assume there is a physical reason for physical discomfort and GP5 states that there is a lack of awareness or unwillingness to acknowledge the psychological aspects.

"Yeah well the tendency is certainly…not necessarily because of fear or stigma but most people just presume I think that you've got physical discomfort there must be a physical reason. It's as much I think just not being aware that the mind can affect the body." GP1

"Well I think there's…people can't always acknowledge that it's not physical, it's psychological and I think that's probably the big thing." GP5

GP3 goes further by illustrating that it can be complex not only for the PFA patients but also for the GPs to untangle the intricate relationship between physical and mental health. In the example he gives on the relationship between stress and health, he describes how this can become messy and cyclical and difficult to comprehend or explain.

"So either physical problems lead to stress or vice versa and then it becomes so compounded it's hard to know what's what. One leads to the other very often, anyway and it becomes cyclical. People feel unwell for whatever…either because they are medically unwell or they're stressed and they don't realise it, they get stressed or more stressed about it, that brings its own set of problems and so it goes on. It's rather messy. There's not one I couldn't say there's a typical frequent attender because there isn't it's usually quite messy in that there's various things that bring people back again and again." GP3

GP3 also alludes to the cyclical nature of attendance and that there isn't a typical PFA. He is acknowledging that there are many reasons PFAs come back again and again and that there isn't a typical PFA. The multiple reasons presented for attending and the fact that there isn't a "type" Of PFA might also be seen as reasons that managing PFA care is so difficult to do.

4.17 The lack of options for the mental health care of PFAs

Along with a reluctance to raise issues of mental illness with PFAs and a perception that there is a lack of understanding amongst PFAs of the relationship between physical and mental health, there was also a third "barrier" that GPs reported regarding the mental health care of PFAs. This barrier was a lack of access to mental health care services. As GP9 describes below, their practice no longer has a counsellor and although they can refer patients to services through IAPT or Let's

Talk, he knows that the last patient who he referred had been waiting for a year, so there were gaps in service provision.

"We used to have a counsellor but she's now left. Now we've got access to IAPT which is short for improving access to psychological therapies, through a group called Let's Talk, erm so we have access through referral. Unfortunately, we've had recruiting issues locally and the last patient I referred when I looked, she's been on the waiting list for a year and not heard anything. So there's a gap there." GP9

Along with the risk of a long wait to receive mental health support, GP9 also feels that PFA patients might not want to see "strangers", implying here that they might not feel comfortable with risking disclosure of abuse or neglect with someone that they don't know or trust.

"Well and it's a huge risk isn't it, to disclose that you have been abused or neglected, or you weren't treated well as a little one or whatever. And it does seem that at least in part is part of the problem, they haven't wanted to get into seeing strangers." GP9,

Along with the difficulties GPs describe in terms of discussing mental health with PFAs and discerning the "messy" relationship between physical and mental health, the other issue they faced was in the lack of options for referral to mental health services. This was a recurring theme within the interviews and a source of frustration for GPs. They were frustrated with losing services, long-waiting times and also the thought of referring their patient on to "strangers".

It seems that even when GPs could overcome the barriers to discussing mental health issues and explain how mental and physical health connect, they faced a further barrier in that there was a shortage of mental health services to refer PFA patients on to.

4.18 Issues with prescribing anti-depressant medication

Related to the frustration GPs felt with the lack of options for referrals to mental health services, GPs also felt some reluctance about prescribing antidepressant medication to PFA patients. GP9 explained a predicament whereby a PFA patient might be suitable and willing to accept CBT but because services offering CBT are under-resourced, they may just end up taking anti-depressants alone as a treatment because they require help quickly and perhaps don't feel able to wait weeks until CBT is available. GP9 points out that the problem with this is that is a bit of a "sticking plaster" approach as the patient may well need the CBT in the future but they are opting for the medication as is it is more readily available.

"I feel like there could be a huge amount more done, you know, if you know they're going to wait months for assessment then and then a long time for the first appointment and these people are saying look I've got psychological difficulties I want help and you think they're suitable… it's so badly resourced. They're very good but I mean the resource like you know, it's like for us it's so frustrating because the NICE guidelines say you know CBT works as well as antidepressants. Well great but if you can't get it and then you start taking anti-depressants. And then they say, "Oh actually I feel a lot better, I don't think I'll go for that" and that's OK that's good in a way, because the resource is available to other people but in another way you think well that's a shame because probably they would have, they probably in the future they're going to need it." GP9

4.19 Theme 3- The impact of managing the care of PFAs on GPs

These interviews suggest that caring for PFA patients could have a negative impact on the GPs. As GP4 illustrates below, she felt it was not good for her self-esteem, as she was taking a "do what I think is best approach" as opposed to an evidence-informed one. She also refers to a lack of guidance or training on caring for PFAs within the curriculum for trainee Doctors, which several GPs mentioned.

There was a sense throughout all of the GP transcripts that the GPs were left to manage the care of PFA patients to the best of their abilities rather than by following an established care pathway.

"and it's not a particularly positive experience for a GP you know…it's not particularly good for your self-esteem but we, well I can't speak for anyone else but I do feel like I'm taking a "do what I think is best" approach rather than an evidence informed one." GP4

"I don't know whether it's on the curriculum for GP trainees. I can't remember seeing it." GP2

A further issue raised in terms of the impact of caring for PFAs on the GP was that it made GPs fearful or anxious that they might miss a sign or symptom of a serious disease or illness, as GP8 stated.

"And of course your fear is that you…well I reckon we're running the risk of missing something in her because you get to a point where you just dismiss everything because she's just here so often." GP8

There was also the example that GP9 gave of making a referral, as they couldn't listen to the patient anymore. This would appear to imply they were acting out of desperation rather than making a clinical decision that a referral was necessary.

"Oh I'll just refer you (for an investigation) because I can't listen to you anymore." GP9

GP5 found PFA patients to be complicated and frustrated, and in turn appears frustrated himself; he felt there wasn't anything he could do, or very little. He spoke about PFAs as being emotionally as well as financially costly.

"They're complicated and they're frustrated. That's where the frustration comes because I know that they're suffering and I can't, there isn't anything we can do, or there's very little that can be

done. I've tried everything I could think of, what is available. So they're costly but that's emotional as well as financial." GP5

The interviews highlighted how GPs sometimes experienced caring for PFA patients as stressful and having an emotional impact on them. The impact on them was described as affecting their self-esteem, causing anxiety and having an emotional cost. Some GPs fear they will miss something if they become complacent as described by GP8, at times they feel they have no other options and end up referring patients on. None of the GPs interviewed recalled receiving any training regarding PFA patients or knowing of a specific Care pathway.

4.20 Discussion of the GP data

Three main themes emerged from the GP interview data; the relationship between the GP and PFA, the significance of the mental health of the PFA and the impact of managing the care of PFA's on GPs.

The significance of the relationship between GP and PFA aligns with existing literature, for example the work of Neal (2000) and Little (2001) and Ring (2005). Neal highlighted the influence of the GP on the attendance of PFA's and the responsibility GPs had for providing continuity, reassurance and control over medications and referrals. The GP data presented in this study showed that offering continuity of care and trying to support PFA's were important strategies GPs used to manage the care of PFAs and that GPs were committed to trying to do their best for these patients.

The GPs interviewed had an awareness of the PFA's suffering and expressed empathy for the PFAs and acknowledged their attendance as understandable, even if they could not understand the rationale or "story" behind it. Neal made a similar observation in his work (Neal, 2000). The GPs I interviewed appreciated that it was

important to try and understand PFAs and offer to do their best to care for them. The GPs offered a patient centred approach, making referrals and offering empathy and understanding regarding the psychosocial care needs of PFA patients.

Bellon and Asencio (2000) described GPs caring for PFAs as having a feeling of *"this patient needs me"*. This certainly seemed to be echoed by the GPs in this study, who also felt anxiety regarding caring for these patients and a sense of responsibility to contain these patients within primary care. The GPs in this study did not appear to view their PFA patients negatively but acknowledged that these people were suffering even if they were unsure of the cause or the solution. We can see from these data that GPs were trying to understand and untangle the complex presentation of their PFA patients. This is in line with other studies (Ferrari et al 2008; Jyvasjarvi 1999, Roble and Gili 2009) that have highlighted the complexity of PFAs and how challenging it can be to unravel their various care needs.

It is perhaps unsurprising that mental health was a main theme within the GP interviews. Indeed, Gili and Luciano (2011) found a 42% prevalence of mental health disorders amongst PFA's as well as complications regarding co-morbidities. Jyvasjarvi (1999) suggested GPs required more training on mental health so that they could better recognise mental health conditions and offer a patient centred approach. Certainly, the data in this study illustrates that GPs were reluctant and unsure about having conversations with PFAs about mental health. This is interesting in light of the work by Karllson (1995) who found that PFA's had a low self-experienced need (i.e., they didn't think or know they needed) psychiatric care. Being unsure whether PFAs were aware that their mental health might be a contributing factor towards their attendance, and being uncertain how they would respond to a conversation regarding this, was an important issue for GPs. This

hesitancy was further compounded by the lack of treatment options available to them. Grabe (2009) also found that screening for mental health and treatment options in primary care are lacking.

The impact of caring for PFA patients was an important theme of this research. Caring for patients with complex needs when feeling ill-equipped in terms of skills/training and care-pathways, was frustrating for GPs. They felt a lot of responsibility and yet little power or control over the treatment options for these patients. This impacted on their self-esteem and was an emotional burden causing them anxiety. The impact felt by GPs due to caring for PFAs has been described before by Bellon and Ascencio (2000). Receiving more training to manage their care and having more timely options for referrals might help to ease the burden on GPs.

The economic and social problems PFAs were facing at the time of attendance were not raised as important issues by GPs, certainly not in the same way as understanding PFAs past histories or mental health were. This is in contrast to the literature on PFAs which highlights that factors such as being socially isolated, economic deprivation and being unemployed are associated with higher attendance rates (Karlsson 1999; Jatic et al 2008; Scaife et al 2000; Jyvasjarvi 1999). Steps to tackle these factors could also protect against poor mental health. It might be interesting to know more about how GPs feel about discussing the socio-economic situations of PFAs and making referrals for services to manage these. For example, do GPs see it as part of their role? This may be particularly interesting considering the rise in social prescribing, for example.

4.21 Summary of GP Data

Considering all of the GP data together, I wanted to also reflect on the tone or manner in which GPs spoke about PFA patients. Throughout the interviews, there is very little suggestion on the part of the GPs that they felt that the PFA patients act unreasonably or inappropriately in terms of their attendance in primary care. In fact, the GPs displayed empathy and a desire to understand and support these patients. They did, however, imply that PFA patients' attendance outside of primary care should be contained. This is interesting, perhaps also because in some ways, the GPs also imply that caring for PFA patients isn't a core part of what they should be doing, it is an additional aspect of their role that goes beyond managing the care of symptoms and disease.

There is a sense from the GP interviews that caring for PFA patients was about "doing their best", trying everything and treading a fine line in making judgements about whether or not to introduce the topic or mental health, or make a referral to secondary care. The overall picture that emerges from the GP data is that GPs find managing the care of PFA patients challenging, partly because of a lack of structure, guidelines or clear pathways and also due to the complexities of how the patients present in terms of symptoms. Managing PFA care seems to engender a deepened sense of responsibility in GPs that is routed in a lack of certainty that they are making the correct decisions or judgements regarding the care of these patients. The GPs feel they are doing their best but there is a definite sense that they feel this isn't enough or good enough and that they fear that some of what they do might be encouraging a cycle of recurrent attendance. All of this has an emotional impact on the GP, with some reporting that dealing with PFAs impacts on their self-esteem or making them feel anxious. The next chapter will present the PFA patient interview results.

CHAPTER 5: DATA COLLECTION, ANALYSIS AND RESULTS OF THE PFA INTERVIEWS

5.1 Introduction to the analysis and results of the PFA interviews

This chapter describes the clinical characteristics, interviews, data analysis and results of the fifteen PFA interviews. These were analysed in accordance with the process described in section 3.18 Interpretation and Evaluation of Data. I followed the stages as outlined for the thematic analysis of data, informed by phenomenology. I remained aware of the research aims to understand more about the experiences of PFAs with regards to their health and their healthcare and consider what the data might tell us about their psychological or social needs.

5.2 Recruitment of PFA participants.

The definition of PFAs used in this thesis study is patients who have had 30 or more face-to-face contacts with the GP in two years, excluding routine health monitoring such as international normalised ratio (INR) monitoring for patients taking warfarin. Initially, we tried to recruit the top 10% of FAs by age and gender as previously suggested (Howe, 2002) but the pilot practice found this too burdensome to operate. Therefore, we established the consultation rate that was within the top 10% of all face-to-face contacts with GPs in a pilot phase in practice A and then applied that rate in all five practices in the study. That rate was 15 face-to-face contacts with GPs per year so we set a cut-off of 30 or more face-to-face contacts with GP or practice nurse within the last 2 years

The participants were introduced to the study initially by their GP who gave them a letter of invitation and Participant Information Sheet during a consultation if it seemed appropriate and they met the inclusion and exclusion criteria described below. For data protection reasons, practice staff, rather than the research team,

selected PFAs from their practice lists. We established the consultation rate that was within the top 10% of all face-to-face contacts with GPs in a pilot phase in Practice A and then applied that rate in all five practices in the study. That rate was 15 face-to-face contacts with GPs per year so we set a cut-off of 30 or more face-to-face contacts with GP or practice nurse within the last 2 years. Participants were excluded by GPs in the practice if they had a diagnosis of a serious medical condition, acute life-threatening or catastrophically disabling physical illness, e.g. cancer, stroke or an acute serious mental illness such as schizophrenia, bipolar disorder, anorexia nervosa or dementia because these patients would not be referred for psychological treatment for Frequent Attendance in routine clinical practice. However, participants who had any of these conditions for longer than 2 years and were in remission or stable were included. Contacts for routine health care checks with nursing staff such as blood sugar or blood pressure monitoring, urine checks for drug misuse, routine blood tests, dressing changes or health promotion, e.g. smoking cessation, weight control, vaccination, were not included in the count of consultations nor were telephone contacts or contacts with staff other than GPs or practice nurses The GP introduced the study and asked them if they would consent to being approached to have the study explained to them in more detail. If they were in agreement they went on to have a baseline psychiatric interview and were offered the Cognitive Behavioural Therapy intervention treatment and asked whether they would like to take part in the qualitative study. The qualitative interviews took place at different points during the patients CBT treatment, depending on availability. All participants approached agreed to take part in a qualitative interview.

5.3 The Interview Guide

The interview guide for the PFA interviews (see Appendix 2) was developed and based on an initial literature review conducted by myself. The interview guides were carefully designed with the underlying aim of encouraging the participants to talk freely. Within the interviews, the following topics were explored:

- Recent experiences and perceptions or examples of consultations (including the reasons for consulting, symptoms and management of symptoms and any other issues)
- Memorable consultations
- Health problems/ reasons for attendance as perceived by the interviewee (GP or PFA)
- Times when consultation has increased
- Important life events
- How care is managed and organised for PFAs
- Challenges of care provision
- Is mental health care discussed and managed and if so how?
- How are these patients perceived and experienced by GPs?

The interview guides were reviewed by a public and patient representative and a practising GP, who gave feedback on the wording and length of the interviews. After that, the initial interview, questions were revised. This resulted in the inclusion of two questions about the support that the patients who took part in the intervention arm of the study received and what kind of issues they needed help with and whether this had any impact on them.

5.4 Data Collection; the interviews with PFAs

Measures were taken to ensure that the patient's confidentiality was respected whether the interviews were being carried out in the patient's home or the general practice. Ensuring that people would not walk in on an interview held at the practice was done with 'engaged' signs; if the interview was to take place in the patient's home, I checked with the patient beforehand that they would feel free to talk in confidence without interruption.

One participant was interviewed with her Mother present (PFA 1) She had asked if her Mum could be present and so I agreed.

Patient Information Sheets and confidentiality statements were read through with the patient before consent was taken and the participants questions were answered if they had any. It was explained that the interviews would be transcribed and anonymised and the patients gave their permission for their interview data to be used in future publications.

During the interview, the topic guide was used only as an aide memoire to ensure I had covered all of the questions. Fourteen of the interviews were conducted using a small audio digital recorder, after consent had been taken from the patients to record the interview. The recorder was placed out of the interviewee's direct line of vision to avoid them feeling self-conscious.

One participant declined to be recorded and therefore I took notes throughout the interview and still included this data as part of the study

The majority of interviews were carried out in GP surgeries in consulting rooms at times convenient to the interviewee. If the patient was unable to attend their GP surgery or preferred to be interviewed at home, I was able to do this, and followed the University of Nottingham's safety procedure for lone working. In most cases,

the interviews lasted for over an hour, but they ranged between twenty-four minutes and over two hours.

After talking through the PIS and taking consent, I began by asking about the patient's most recent attendance at their GP surgery using the interview guide (Appendix 2). Prompting with further questions about how they felt about their symptoms and whether they were worried. We would then go on to discuss the patient's history in terms of illness, whether anyone else was involved in his or her decision to attend and whether there was anything else, in addition to the main symptom, which they had planned to talk about.

I then enquired about any particular health problems or medication and whether the patient felt that they had consulted more in the previous two years than they normally would. Finally, I moved towards asking the patient about significant life events in the last two years and beyond. However, it should be stressed that I did not specifically ask about difficult, traumatic or "negative" life events.

The benefit of this semi-structured qualitative interview style was that it did not force participants to choose from an accepted list of responses but, rather, provided them an opportunity to use their own words to describe their experiences. It gave me the opportunity to highlight issues that began to look like they were important after the initial few interviews and explore these in more detail with later interviewees. So, for example, the issue of negative experiences of mental health services began to look like an important one, so I made a note to myself to enable and encourage the patients to talk about this further if necessary. This technique of analysing data as I was going along was very important in helping me to make the most of the interviews and to explore themes that were rising from the data as the research progressed.

All relevant information was recorded in field notes after each interview, once the participant had left. As Warren et al. (2003) and Kvale (1996) noted, I also observed that the unofficial talk time after the interview was slightly less formal and I was often asked for my opinion, both during and after the interviews, about the patients' health. Sometimes these questions were about medication and diagnosis. In these instances, I informed the patients that I was not a medical professional and could not offer advice or opinions on these matters. Although I felt positive about the fact that the participants felt relaxed and comfortable enough with me to answer these questions, I was aware, as Oakley refers to, the idea that there is – 'No intimacy without reciprocity' (Oakley 1981) and I worked hard to remain professional yet supportive.

After the debrief, on many occasions the participants thanked me and said that it had been good to talk about things and that they felt better, even if sometimes they had become upset retelling parts of their life stories. This 'cathartic' nature of the qualitative interview is not uncommon and is described by Collins (1998). The interview environment allowed me to deal with emotions safely, and I only once felt the need to seek further support for the participants' post-interview. I spoke to my supervisor a psychiatrist and along with the participant's GP we made a successful referral. This was in line with our ethics approvals and with the consent of the participant.

The initial two interviews were transcribed by myself, allowing me to get a feel for the data by immersing myself in it and enabling me to check the questions were working well. All the subsequent interviews were transcribed verbatim by a professional transcription service organised by the University of Nottingham, as part of the support for the PhD studentship. The transcripts were then checked against the recordings by myself, as the initial part of the coding process and also

to check for anonymisation. After 14 patient interviews, it was felt that, although data saturation was reached and no new themes were arising, it would be useful to include an interview with one more male patient and particularly one from an inner-city practice, so this was my final interview to ensure I had interviewed enough patients to satisfy my maximum variance sample.

5.5 Analysis of the PFA Interviews

The first stage of analysing the PFA interviews, involved familiarising and summarising the data. I did this by reading each individual transcript through one at a time. As I did this, I made notes about potential themes and thought about the views of the participants. Each individual interview was then summarised.

After the initial reading of each transcript I generated initial codes by writing in the margins of each transcript when I identified a potential code (Stage 2). Once all the transcripts were coded, I systematically began to search for themes and organise the codes (see Appendix 6- Stage 3 of PFA Data Analysis). In doing this, I considered how important each theme was, not merely by its frequency but also by considering the impact of the theme, asking myself whether, why and how it was important. I then reviewed the themes, checking them against the transcripts and against each other, reorganising and streamlining them (Stage 4). See Appendix 7- Stage 4 of PFA data analysis.

5.6 The use of an independent second coder

An independent researcher (EP) also carried out stages 2 to 4 of data analysis. EP used qualitative data analysis for her PhD thesis and was completely independent of this research and the University of Nottingham. EP analysed a sample of three PFA transcripts without seeing any of my coding or development of themes. Once EP had carried out this work, we compared the codes and themes she had generated

with mine and we reviewed the themes together. We agreed on the final themes and sub-themes- see Appendix 3. The reason for having a second-coder was to ensure that the data were coded and analysed rigorously and in line with the CoreQ-32 and CASP checklists for analysing qualitative data.

The final stage of PFA data analysis was to present the themes and sub-themes to my supervisor (HB) for final discussion, refinement and organisation.

5.7 The PFA Participants

The 15 PFA patients who participated in the qualitative interviews form a maximum variance sample, recruited to ensure that the sample included participants of different age, gender and ethnic backgrounds and from different GP practices. Participants were approached during the initial screening/baseline interview for the Regular Attenders study (See Appendix 1) by myself or asked later by the research therapist if they would be willing to participate in an interview. No one who was invited refused to participate in the interview.

I recruited a varied sample of patients in terms of ethnicity, employment status, gender, physicality, age and general practice. Although predominantly female and of middle age, the sample includes some younger patients and four male patients. In terms of ethnicity, most of the patients were White British and three of the 15 patients were from non-White-British backgrounds and were Eastern European, Pakistani and Jamaican. It was important to aim for diversity amongst the participants so that the data could reflect a wider range of experiences.

Eleven of the fifteen participants had been referred to mental health services in the two years prior to interview. Just under half were taking part in the study intervention of CBT treatment (See Appendix 10 and **Table 4**, page 133, column 7) at the time of interview. This intervention was offered as part of the wider study

that this thesis is a part of but the aims of this thesis are not to assess the efficacy of the CBT intervention but rather look at the PFAs experiences of attending prior to the intervention.

Four of the participants were married and the rest were widowed, divorced or single. In terms of employment or occupation, there was a mixture of occupations amongst the PFAs, including two retired patients, five patients who were in receipt of incapacity benefit, three full-time workers, four patients who both worked part-time and were carers for children and/or elderly or disabled partners. Two PFAs worked in what might be termed "alternative" medicine, as a holistic therapist and a "doula" (a mother's support during labour). The others worked in low or unskilled roles such as taxi driver and factory worker. The most highly qualified PFA participant was a retired nurse. The patients represented each of the practices taking part in the study and therefore came from a mixture of areas in Nottinghamshire, including inner city areas of high deprivation, middle class suburban areas and areas of more rural poverty, such as ex-mining communities (see **Table 1, page 85**).

Recruitment continued until data saturation was reached and I had interviewed a PFA from all five participating practices and across categories of age and gender categories.

5.8 The clinical characteristics of the PFA participants

A summary of the clinical characteristics of the PFA participants are presented here, with fuller details available in Appendices 7 and 8. The full results of the SCID interviews (See 3.14 Procedure and Measures used to capture the Clinical Characteristics of the PFA Participants page 86) with the fifteen participants can be seen in Appendix 8 and are summarised here. The interviews illustrate that the participants met the criteria for a wide range of psychiatric disorders in the two

years prior to interview. Eleven of the participants met the criteria for depression, with eight of these also meeting the criteria for dysthymia. Eleven of the participants were diagnosed with Somatoform disorders and ten with anxiety disorders. Four participants also suffered from Post-Traumatic Stress Disorder. Three participants met the criteria for Obsessive Compulsive Disorder, one for binge eating and one for body dysmorphia. The participants met the criteria for a mean (average) of six psychiatric disorders with the modal (most common) amount being seven. The results of these baseline SCID assessments illustrates the level of mental ill-health these participants were struggling with and also the complexity of their illness; most of them met the criteria for several serious mental health conditions, some of which alone would be very complicated and difficult to treat.

The HAI was introduced part way through the study so not all of the participants completed it. The results of the HAI (See 3.14 Procedure and Measures used to capture the Clinical Characteristics of the PFA Participants, page 86) illustrate that of the ten participants who did complete it, seven scored above 18, meaning that their scores were high enough that they would be considered to have hypochondriasis. Interestingly, the two participants who completed the baseline interview but did not meet the criteria for health anxiety, did meet the criteria for somatoform disorder.

The EQ-5D (See 3.14 Procedure and Measures used to capture the Clinical Characteristics of the PFA page 86) scores of the fifteen participants showed that the PFA participants reported their health status as poor with a mean score of 50, when 100 is optimal health. For all problems except for self-care, PFAs reported moderate problems.

Separate analysis of their medical records highlighted the poor physical health status of the fifteen participants. Practice staff retrieved their medical record data on medications, health diagnosis and attendance rates and this is recorded in Table 4. The participants had an average of 12 repeat prescriptions for medication each and six active physical problems. The most frequent long-term physical conditions with a well-defined pathophysiology included hypertension, asthma and diabetes. There were also less-well defined conditions, for example chronic pain and irritable bowel syndrome. Obviously, the PFA' were identified and selected for their high attendance rates but as Table 4 illustrates, for some participants the attendance rates were very high. For example, one participant had attended her GPs surgery 80 times in the preceding two years which equates to more than three visits per month. However, the modal number of visits in two years was 30, which was also the lowest number of visits. Five of the fifteen participants visited their GP 30 times in the preceding two years. The mean (average number of visits) in the preceding two years for the fifteen participants was 43.

The baseline data combined gives us a picture of how complex the clinical characteristics of the PFA patients are with co-morbid physical and mental health issues, high numbers of repeat prescriptions and health anxiety. It is understandable that these patients were in need of support from their GP and it is also very likely that their quality of life was diminished due to their health status.

Table 4: Description of socio-demographics of the Persistent Frequent Attender Participants

ID	Gender	Age	Ethnicity	Practice	No. of GP Appointments in last 2 years	Mental Health Service Referrals	Intervention study Treatment Status	Marital status	Occupation
1	F	46	White British	A	49	Counsellor	Post-treatment	Divorced	Carer for disabled daughter Incapacity benefit
2	F	25	White British	A	48	Psychiatry service	Assessment only	Single	Unemployed Single parent
3	F	40	Eastern European	C	34	Counsellor through work.	In treatment	Separated	F-T administrator Carer for partner
4	F	43	White British	C	30	Counsellor through GP	In treatment	Married	P-T holistic therapist
5	F	46	White British	C	62	Referral to "Let's talk wellbeing"	In treatment	Separated	P-T doula Carer for autistic son.
6	F	19	White British	C	63	CAMHS* and counsellor	Assessment only	Single	P-T cleaner
7	M	56	White British	A	42	Counsellor	In treatment	Married	F-T factory worker Carer for disabled wife
8	M	53	White British	A	37	Telephone counselling service	In treatment	Divorced	Full-time medical rep

ID	Gender	Age	Ethnicity	Practice	No. of GP Appointments in last 2 years	Mental Health Service Referrals	Intervention study Treatment Status	Marital status	Occupation
9	F	44	White British	A	80	Bereavement counselling	In treatment	Married	Incapacity benefit
10	M	43	White British	A	30	Art Therapy	Assessment only	Single	Incapacity benefit
11	F	62	White British	D	30	None	Pre-treatment	Married	Incapacity benefit
12	F	58	White British	D	30	None	Pre-treatment	Widow	Incapacity benefit
13	F	70	Caribbean British	E	43	CBT	Pre-treatment	Widow	Retired Nurse
14	M	33	Pakistani British	E	38	None	Refused	Single	Taxi Driver Carer
15	F	62	White British	F	30	CPN	In treatment	Divorced	Retired

*Child and Adolescent Mental Health Service.

5.9 Results of the PFA qualitative data analysis

There were three main themes identified, with corresponding sub-themes (see **Table 5**). I will discuss each of the three main themes and sub-themes using direct quotes from the data. I will offer interpretations of the data and make suggestions about meanings. In doing this, I have tried to stick as closely as possible to the data.

Table 5- Final Themes and sub-themes of PFA patient data

Main Themes	Sub-themes
How PFAs experience their health.	• Poor physical health and its relation to daily functioning, anxiety, fear and mental health. • Difficulties regarding medication. • Involvement of others in health decisions. The impact of health on caring and work responsibilities.
Experiences of health services and relationships with health professionals.	• Experiences of General Practitioner health care. • Experiences of mental health care.
Emotional or mental health	• The importance of life stories and feeling understood. • Current emotional state and perception of self.

5.10 Theme 1- How PFA's experience their health

As might be expected, an important theme for PFA patients, that came out of the data is how they experience their health. This theme has been broken down into sub-themes including; poor physical health and its relation to functioning, anxiety,

fear and mental health, medication, involvement of others and the impact of health on caring and work responsibilities.

5.11 Poor physical health and its relation to daily functioning anxiety, fear and mental health.

The PFAs interviewed experience their physical health as poor and impacting on their daily functioning. They also reported their physical health and symptoms as confusing with uncontrolled, unexplained, unexpected or undiagnosed aspects resulting in fear and worry. What they perceive as poor or worsening physical health seems to relate to an increase in anxiety due to symptoms and concerns about how these symptoms might impact on their lives. Some felt that they could not function well due to pain and symptoms, for example struggling with housework or sleep. They sought support from their GP in monitoring their health and symptoms.

"I have to go for regular checks because I've got that much wrong with me, they have to do me blood pressure and check me heart tablets" PFA5

PFA 11 Explained how she couldn't carry the shopping or complete her housework because of pain in her hands, explaining how her physical health impacts on her daily life;

"Yeah I can't pick anything heavy up because it hurts, can't hold nothing much. It's started to go to my feet now. So, erm, I know if I try to do anything now I have to, I can't do it you know, like finish it." PFA 11

PFA8 described a mixture of physical and mental health issues and how that impacted on him in terms of productivity and feeling lethargic;

"Physical, just being lethargic not feeling I could do things, concentrate, work productively, which has come to what I said earlier. Mentally, not being able to see thing clearly. Feeling anxious, depressed I suppose but never suicidal." PFA8

PFA 2 has a medical condition called Dariers disease which was usually treated with steroids and she described how it was getting worse during pregnancy because she couldn't take these medications, this seemed to be impacting on her mental health and she felt that her depression was worse too, she describes several aspects of here health as getting worse. PFA2 seemed to be describing how her physical symptoms were worsening and this was impacting on her mental health, causing her to feel depressed.

"Well, the Dariers has been much worse since pregnancy, I can't take any of the steroids 'n' that, you see. And the depression, that's been worse, and my knees..." PFA2

Patient PFA9 had a variety of health issues and pain, as described below, this resulted in her taking various medications including ones to help her sleep.

"I have an all year round allergy, they don't know to what. So I take, cetirizine all year around. I have asthma, so I have my inhalers; I have blood pressure, which is high, which is hereditary, and I take medication for that. Erm, with my back I have these patches but I also have two tablets that I take, what I call my night-night tablets; there are two I take, one is a muscle relaxant, erm, and the other one is, err... obviously for pain through the night so that I can sleep." PFA9.

PFAs relate their ill health and symptoms to their daily functioning and low mood. The accounts given by PFA patients illustrate that they perceive their physical health as very poor and sometimes they don't feel that they understand it, they describe how it impacts on their daily functioning and affects them in terms of daily tasks,

mood, sleep and at different times of the year and during specific times such as pregnancy. The accounts below illustrate health anxiety amongst these patients with them experiencing their symptoms as particularly worrying and creating fear because they are unsure why they are having them. Although symptoms and functioning differ from one participant to the next, there are similarities in the levels of distress and confusion around their health and symptoms. Not only are there symptoms affecting their functioning, such as their ability to sleep, concentrate, work, pick up shopping, as they described in the interviews they appear to be also suffering with their worry over their health. As PFA 10 (below) describes, she spends a lot of time worrying and so does her husband. There is also a sense of shame, embarrassment, of being a nuisance but her worries seem to override the embarrassment as she needs to "get it sorted" and seek some reassurance that if she becomes unwell it won't develop into something worse;

"I am embarrassed coming here because I feel as if I spend much of my time here and I feel as if I'm being a nuisance to them here but yeah I know in myself that I'm generally not up to par and it worries me and it worries my family, my husband is worried that if I start with my breathing it's going to develop into pneumonia if we don't get it sorted so he makes me come straight away." PFA10.

PFAs spoke about how they were afraid of illness, death or dying. For some, fear of illness and death was exacerbated by a physical condition or unexplained symptom that was causing them great concern. The 'unknown' or unexplained aspect of living with a health problem and the unanswered questions were causing the participants a lot of worry.

PFA 11 describes how, because the GP couldn't find an explanation for his symptoms, he had convinced himself it was cancer;

"I just, you get worried that it's something major, when you miss, when you're in this frame of mind, everything else has failed and so, at this stage, it's got to be cancer or something, at this stage, it's got to be something major, it's gotta be. And I, well, you just don't want to be told, do you?" PFA11.

PFA7 described how she got very upset when she had to visit a hospital and clearly articulated her fear of illness.

"I hate hospitals, I go with my job I go into hospitals all the time but that's with somebody else and one of the problems I had a few weeks ago my granddaughter got rushed into hospital. I was a wreck. We thought she'd got suspected meningitis but luckily me sister jumped in because I was a total wreck, I went to pieces and even the GP in A&E said you've got to get her out of here, she's a liability. I couldn't, I get diarrhoea when I get upset and I couldn't control that, I was a nervous wreck. I just think I've got a fear of erm, illness." PFA7

In the quote below PFA 4 describes how she looks for her own answers to her health worries on the computer because she feels that she is not getting the answers she needs and isn't being listened to;

"Because I'm constantly, that is my way of telling me, the computer, because I'm constantly looking for me own answers. So sometimes you look for your answers and you come up with something completely different. But it's because they're not giving me the answers. If I find one of the people I have a need to know something, but that, I mean that offence it was I think more of. I know when I'm not right. So, if I know I'm not right, it does my trolley in the fact that they're not listening." PFA4

PFA2 described how anxious she was about the physical symptoms she was experiencing;

"It is so extreme, not one part of my body that didn't ache or hurt. My lips felt numb, my eyes were funny, I had tests to see if I had had a stroke and they just said no its stress, I had really, really severe symptoms. I now feel like I wasted NHS resources. It's a cliché but I tried every kind of tablet, every kind of treatment. I seriously thought I was going to have a heart attack. I went to the hospital a couple of times. I blacked out, I couldn't breathe, I would just get off the bus on the way to work and go there."

PFA 2

These accounts of worry and anxiety over health and a fear of getting ill emphasise why PFA patients might be attending their GPs surgery for reassurance as well as for the necessary appointments needed to manage their physical health conditions. And as PFA4 illustrates, might "beg and beg and beg" until they feel like they get a referral, in this case, the referral didn't get her the answers she was seeking;

"So, I knew there was something wrong, but, again, I've had to beg and beg and beg and it's taken months. And the bloke's saying, 'I don't know'." PFA4

These interviews suggest several possibilities with regards to how PFA's perceive their own health. That these participants do have physical health issues which they experience as confusing and impact on their daily functioning. But also I think the interviews portray that living with these health issues is creating fear and anxiety in these PFA's. The participants' dialogues concerning their thought processes leading up to appointments or requests for referrals suggest that they have a "framework" for consulting whereby it is when their fear or anxiety over their symptoms outweighs any potential discomfort they may feel at seeking healthcare. It is also possible to see that there is an element of catastrophizing health worries, with patients fearing that their symptoms might result in, for example, pneumonia, a heart attack or cancer.

5.12 Difficulties regarding medication.

There are several examples within the interviews of times where PFAs felt the side-effects of their medications were affecting them, for example causing weight gain or sleepiness and there are also examples where the patients have rejected medications, in particular antidepressant medication. Participant PFA4 spoke about how she felt confused with regards to her medication;

"It was about the weight and the new tablets, painkillers I got because my old one was shocking and I forgot what it was supposed to do and because one is morphine based and the other one well is just like a strong pain killer. So I take both together and have to do that and I were a bit confused then." PFA4

Participant PFA6 talks about her sensitivity with medications and how she tried all sorts but now just takes it when she needs to.

"I am very sensitive to different types of medication and nothing seemed to suit me before, I just suffered with all the side-effects. None of it helped, I tried all sorts. Now I found ones that do suit me and I just take them as and when I need them now, not all the time not every day." PFA6

Both participants PFA1 and PFA2 (below) spoke about how they didn't feel medication, specifically anti-depressants were the answer to their problems and didn't want to take them. Their experiences with their GPs differed, PFA1 describes how she didn't feel the GP engaged with her but just offered her a prescription whereby PFA2 spoke about how she had long chats with her GP and that's what she needed;

"I was seeing GP X but he's gone now. I saw one GP a few weeks back, a new one but I don't like him… he didn't even look at me just the screen and my depression was really bad then. He prescribed me some antidepressants but I won't touch them." PFA1

PFA 2 describes a positive experience where she found she could talk to her GP without feeling patronised;

"I've been seeing GPs for many, many years. I have felt like they just stuffed tablets (antidepressants) down me and hoped for the best but that's not the answer. I am not normally a depressed type of person but everything was just getting on top of me, y'know, past, present and future and I couldn't cope any more. Wow I was in a very bad place and I had long chats with GP Y, she wasn't patronising or feeling sorry for me. I didn't want sympathy I just wanted someone to talk to." PFA2

Participant PFA6 spoke about how after a few sessions of counselling she was told that she wasn't able to have any more sessions as that was the available limit. She describes how she then reconsidered antidepressants out of a sense of desperation even though she didn't feel like she was a truly depressed person. Interestingly she describes how her GP sympathises with her, saying that she has been let down by the system;

"I went back and spoke to GP Z about it and she said, you have been let down by the system. I had all this stuff that I'd brought out and I didn't know what to do with it. Then they tried to get me onto this thing called mindful something but they said that I didn't qualify because I'd had these sessions with the counsellor. That's when I began to reconsider the antidepressants. I didn't feel like I was a truly depressed person, I am quite optimistic a lot of the time it was just that I'd got these things in the front of my mind again. PFA6

These examples convey a reluctance to take antidepressant medication and a sense of confusion around some other medications they have been prescribed. There is a feeling amongst some PFAs that handing over a prescription was the only option for GPs when they were not sure what they could or should offer them. The final quote above also illustrates that anti-depressant medication may be something PFAs as well as GPs will reconsider if they feel that there are little or no other options. Having someone to talk to, who gives them time is valued highly amongst some of these PFA patients. PFA6 illustrates why she felt antidepressants might not work, she felt that she wasn't depressed, more that there were issues that had come to the front of her mind again and were troubling her. For PFA patients' medications can be seen as a source of more worry and confusion and there is a sense that they would rather not take them. These results indicate that being prescribed medication can be perceived sometimes, as, perhaps an easy option for GPs, particularly in relation to antidepressant medication, being offered it seems to be seen as almost a way of dismissing their problems. Along with this feeling that antidepressant medication in particular isn't always the answer, participants also had concerns about medication side-effects.

This data illustrates that confusion regarding medications is one issue that PFAs are seeking support from their GP about which is perhaps to be expected considering the number of repeat prescriptions they were in receipt of.

5.13 Involvement of others in health decisions

Family members or friends have an impact on the PFAs' perception of their physical health and their decisions on whether or not to see the GP.

One participant was interviewed with her mother. Throughout the interview, her mother interjected to talk about how poorly the interviewee had been. saying, for

example *"it was really bad", "she needs to get back on those steroids*", *"You should have seen her last week she was at death's door."* (Mother of PFA1).

PFA 9 refers to what her husband wants in terms of her health, throughout the interview.

"Yes and that's what my husband wants, last year he wanted me to have a referral to a respiratory consultant but they didn't think that it was necessary for me, I've got my inhalers and they can keep it under control but my husband is now saying that I shouldn't have the winter, it's not fair to have a winter like I had last year and he wants me to ask GP X when I go back on the 4th if she can refer me to a respiratory consultant." PFA9

And then she explained how her daughter accompanied her to an appointment because the child was worried about her symptoms also. From the transcript, one can see that this appointment which seemed to be described as seeking reassurance for her daughters concerns, resulted in several referrals to secondary care and ended with the patient saying how healthy she was with regards to this particular issue.

"GP X asked (daughters name) how she was and she said she was worried about Mummy's feet and she said that Mummy's feet were especially, her left foot, goes discoloured, goes very grey and purple and loses its colour and erm, she was obviously very concerned about it because she mentioned it to GP X, I'd just not given it a second thought and err, she examined my feet…arranged for me to go and see a consultant and then a vascular consultant and ultrasounds… and obviously that then gave (child's name) confidence and put her mind at rest that something was being done and she was being listened to and it was nice and obviously GP X thought that, well she knows

(daughter name) and she was obviously concerned that if she had mentioned it rather than I'd mentioned it….I'm very healthy and my blood flow is brilliant yeah, I'm as good as a racehorse…" PFA9

In both of these examples, PFA9 describes how the GP referred her to consultants because of worries her partner and daughter had. This could be interpreted in a few ways. Firstly, it could be that anxiety around health does impact the whole family and not just the PFA. It is also possible that the PFA s may be encouraged to seek referrals or investigations because family members or partners wish them to. Another possibility is that the PFAs may feel that by informing the GP of family members concerns they gain a sort of leverage with which to request referrals or investigations (as with the example from PFA 9).

It is important to understand that family members can influence the healthcare seeking behaviour of PFAs and these findings suggest the wider family members' concerns might be a consideration when understanding PFAs experiences of health.

5.14 The impact of health on caring and work responsibilities

The relationship between physical health and the PFAs ability to work or carry out caring duties was an important topic. PFAs spoke about their need to see their GP for support with this. Support was given in the form of sick notes, guidance and letters of explanation. Five of the fifteen PFAs were no longer working due to their physical health. And two of the male interviewees were facing disciplinary action at work due to sickness absence and were seeking their GPs support with this.

"The Dr wrote on my sick note to limit me to forty hours a week and eight hours a day but the company just ignored that…I think they are trying to sack me; it's been going on since last June so I saw the Dr because it's... Just that I need more support from

work, they are letting me down I feel. They are putting me on jobs that are not suitable for me, cos other people don't want to do 'em so they've set up a rota so you've got to take it in turns going on these jobs." PFA7

PFA 7 describes how he saw the doctor because he wanted her help in getting more support from work with his back troubles and PFA 8 describes how he has been unable to work productively because of depression and is now concerned about being sacked.

"Because I've been unable to work productively, I've gone from being promoted to manager to being demoted from manager to actually being on a pathway of resignation or sacking which is how I see it at the moment." PFA 8

What we can learn from these interviews is that PFAs might seek support from their GPs when they feel that their health is impacting on their work and this is because they perceive that there are or will be serious repercussions from their poor health on their working status (ie; getting sacked or being unable to work well) therefore it makes sense that they will seek support to manage this.

One third of the PFAs were carers and during interview they spoke about how this impacted on their physical and mental health and vice versa. For example, participant PFA1 had been a carer for her disabled daughter for twenty years and had struggled to lift her in and out of bed for the first ten years. She attributed her back pain to this lifting. One of the interesting things that comes from this interview is that the participant describes her feelings about the invisibility of her illness and that people might not realise how much it affects her because they can't see it;

"Until she were 10 ½ I think it were I had carry her upstairs because her room was upstairs and nobody would think that wouldn't have an effect on my back you know and actually I think I'm not as bad as what possibly some people might have been you know so really I think it's a bit of a kick in the teeth from people because I think physically to look at I look alright and I think that's what does my head in." PFA 1

These interviews tell us that the physical and mental health of PFAs impacts on their ability to fulfil their roles at work and as carers. We can also see that being a carer can impact health as well. It seems important to PFAs that the impact of their health on their ability to work and the impact that caring has on their health is acknowledged and validated. There also could be detected in these interviews, a sense that they sometimes feel they are unfairly treated by employers or the benefits system, for example, because of their health. PFA 4 seems to be saying that, although she looks alright and she is carrying on and although "she's not as bad as she could be", she would still like her suffering to be acknowledged and validated.

The participants who were struggling to keep their jobs or fulfil their roles as carers due to their health seemed to feel threatened by the thought that they might be blamed in some way, they talked about feeling embarrassed or worried or even angry that people might not appreciate that their physical and emotional health was impacting on their ability to fulfil their roles. These emotional responses tied in with guilt, pride and shame could possibly be interpreted as reasons that PFAs might want to hide their feelings or find it difficult to engage in mental health treatment. This could be another barrier for them in seeking help regarding the impact of their health on their caring or working responsibilities.

5.15 Theme 2- Experiences of health services and relationships with health professionals.

PFA's spoke about how they experienced receiving healthcare in terms of the care that they received from their GP and also their experiences of care outside of general practice which was for their mental or emotional health.

5.16 Experiences of general practitioner healthcare

PFAs mostly describe their relationship with their GP positively when they had found a GP who they felt was offering them the care they felt they required. They valued continuity, support, time and trust and valued the GPs responding to their requests for referrals and checking things that they were worried about. These are the qualities that they see as providing them with the satisfactory care they feel they need. When PFAs had found what they perceived as a good GP this meant a lot to them and they wanted to be able to see them regularly. Finding a GP who was perceived as good with mental health issues was also important to PFA patients as PFA10 illustrates;

"I do see her quite regularly still, so, y'know 4-6 weekly or maybe a bit more some weeks so I do see her regularly cos she's so popular, she is really well up on mental health issues and she's the hardest one to see you know if you've not gorra appointment." PFA10

Consistency was valued highly by PFA patients who felt that receiving consistent care was a very important part of having a good GP, along with being able to trust the GP as PFA5 describes;

"So that's why it was good because I trust her (the GP) and I trust what she tells me because every time I go to the heart clinic I see a different Doctor and one'll say this and one'll say with the

condition you've got you shouldn't be doing that and then I'll see another one and they'll say oh no you can do that, that's fine. So you know, I do trust what she says now." PFA5

PFA patients like to see GPs who are willing to give them time. PFA2 compared her current GP favourably against previous GPs who she said made her feel guilty for asking for their support.

"Oh I seen her a lot over the last two years, my relationship with her is really good she's always been there for me, she understands me and she gives me plenty of time. The other Doctors before made me feel like I was in the wrong place, I felt guilty asking for their support." PFA2

Along with providing time in the form of longer consultations, PFAs also valued seeing GPs who would be willing to make referrals, where they had easy access to appointments and where they felt the GP understood them holistically, their life story and life circumstances;

"She knows that, she knows the ins and outs of everything with my life. Obviously I've had problems with me husband. We are sort of separated which is causing a problem because he has to come back here some weekends because obviously it's been with the house here, that's it and …GPs been absolutely brilliant saying "I don't know how you cope." PFA5

An interesting observation about this quote (above) by PFA5, is how important is it for her to receive validation of her suffering and her difficult life. Having this acknowledged by GPs is an important element of PFA's feeling well cared for. Having their feelings validated and "having a connection" with their GP, tied in with PFA's need for trust, time and understanding.

"It's very good I moved to that practice about seven years ago and for the past two years I have just been seeing GP X. I feel like we have connected and she understands me and vice versa, I understand her. So I've stuck with her… and she said to me that if I really needed to see her not

to wait and not to see anyone else. So we agreed I would just see her and if I needed to see her I had to just phone and explain the situation to reception and she would call me back." PFA4

"Yes I'm going to see GP D soon, I can talk to him but it's not the same as Dr N, we had a good relationship, we could have a laugh n that and he wasn't bothered about the time, he spent time with me and cheered you up, cracked a joke. Y'know." PFA 2

Many of the PFA participants spoke about their need for reassurance and needing an answer. Because they had these needs they sought GPs who would be willing and able to offer answers and manage the uncertainty that was causing them worry and anxiety. PFA1 below describes how she will persist until she gets an answer and feels listened to;

"and sort of in my mind I know I'm not going to tolerate, you know, when they tell me no. If I know myself that I'm not feeling 100% right and something is amiss, then I'll just keep harassing them until they do something. And I think I did say to the Doctor one day "you have made me suffer for a whole month because you didn't listen to what I'm saying and if you'd listened", I'm not saying they could have done anything because they couldn't do anything, there's nothing you could do but the point is I think the point because for that month not only having that pain and suffering but also your mind working overtime thinking. Am I cracking up? Am I, y'know?" PFA1

PFA1 is stressing here the importance of having her concerns validated and of feeling listened to. She acknowledges that the Doctor might not be able to do anything but for her the importance is knowing her concerns are being taken seriously because they are causing her to worry and wonder if she is "cracking up".

One patient spoke about how she didn't mind waiting for a response from the GP because she knew he was doing some research and it made her feel like he cared;

"He obviously didn't want to rush into anything because he asked me if he could read through my notes first and see what I've been on medication wise and do a bit of research kind of thing and then call me. He was really nice. He's not called back yet but that's OK I'm OK with waiting it's the fact that he wanted to do some research it made me feel like he cares." PFA4

The same patient spoke about how difficult the "not knowing" was and how having a plan really helped, this is useful as it shows that in terms of GP healthcare, one of the most valuable aspects for these PFA patients in helping them to cope with uncertainty, was having a plan in place.

"Yes it was the not knowing, the lack of a diagnosis or a treatment was the really difficult thing but the GP having a plan made me feel calmer, made all the difference." PFA4

These interviews give some useful insight into how PFAs perceive and experience what they view as good GP care. The PFAs acknowledge that they aren't always going to get an answer regarding their concerns or worries but they seem to be saying here that what helps them is to feel that their concerns are validated, that there is a plan in place and that they have been understood and heard. This would appear to give them peace of mind and help to make them feel calmer.

These interviews also reveal the aspects of care that the PFAs didn't find helpful. Negative experiences within general practice for PFAs was associated with feeling hurried or like the GP just wanted to give you a prescription;

"You can see them clock watching doctors when you've been in and they just want to push a prescription in your hand and get you on your way." PFA12

Unsatisfactory care was also associated with inconsistent care and feeling like the GPs weren't interested in them. A common complaint was not being looked in the eye during a consultation. Other issues that concerned PFAs were; when the GPs

changed frequently, surgeries being disorganised, unhelpful admin staff, discontinuity of care, lack of awareness of medical history, lack of medication reviews and being unable to change GP. In addition, having a past difficult experience such as a missed or misdiagnosis or disagreement with a GP about a diagnosis was problematic for PFA patients in enabling them to trust GPs or trust what they are told about their health.

A surprisingly common experience among participants was that of GPs leaving the practice without giving them any notice that this was going to happen. This happened in several of the GP practices leaving patients without the GP that they knew well.

"The most annoying thing is the fact that I thought when a Doctor left like my GP they were supposed to notify you that there's going to be a change at the practice, and oh your GPs leaving it's going to be this GP and you know or whatever. And every single one that's left like GP X, GP Y and GP Z not one of us has been told and I me n' all me and my kids are at this GPs me dad and everything and nobody knew that they were going." PFA11

Feeling that a new GP did not understand or know them was a difficult issue for PFAs to cope with. Starting from scratch, having to regain trust and perhaps tell someone new about your circumstances was difficult for PFAs. Several interviewees highlighted incidents where they had to see a new GP or a different one from normal and the consultation was uncomfortable.

"I was seeing Dr N but he's gone now. I saw one Dr a few weeks back, a new one but I don't like him…he didn't even look at me, just the screen and my depression was really bad then." PFA 2

Negative GP experiences were also related to the manner in which GPs spoke to PFAs regarding their mental health. When PFA patients felt that the GP could not look them in the eye when speaking about their mental health or introduced the idea of mental health in an abrupt or surprising manner this was difficult. leaving them feeling shocked and upset. For example, PFA XX felt very upset and surprised when the GP she saw told her that her problems were "all in her head", this left her feeling *"Oh my God he thinks I'm crazy"* (PFA 4). There were also examples of where patients recalled speaking to their GPs about their mental health and the language used in these exchanges was vague or old fashioned. It suggests that communicating about mental health might be difficult for some GPs and PFAs. This could be seen as missing a very good opportunity to speak to PFA's in a positive and reassuring manner regarding mental health and attempt to reduce any stigma they might feel about being "crazy" or bad with their "nerves". PFA 11 explained in interview that she thought she had a physical illness that was giving her a "swoosh" feeling but in fact her Doctor said that this was caused by her being bad with her "nerves", a perhaps outdated way of referring to feeling nervous or anxious.

"Erm, only that's I like I got that like swoosh feeling but it's not that at all, it's me nerves apparently, GP X said it's me nerves apparently." PFA11

Participant PFA4 described the time when she saw a different GP to her "usual" GP and he suggested that her physical symptoms had a psychological route. This was a shocking and difficult experience for her but retrospectively she realised it was helpful. She describes feeling embarrassed at the time but also reflects that she "probably needed it", she then went on to have CBT treatment. The manner in which the GP

advised her that it was a mental health issue comes across as quite blunt but looking back on the encounter PFA4 reflected that she didn't blame the GP. Although receiving this "news" from the GP was seen as the patient, with hindsight, as necessary, the way she described the encounter or experience does suggest that it could have been handled more sensitively and used as an opportunity to give the patient some more information about what was happening for her, The GP explained it by saying it was chemical, I am not sure how helpful this explanation would be. and it seems a missed opportunity to attempt to make someone feel comfortable (as opposed to embarrassed) about their mental health. However, as the patient states, she did feel she needed to receive this information.

"Yes I was soooo embarrassed I saw a different GP than usual, I went to see him and "I said I feel so ill what is wrong with me?" He said, we can't find anything wrong. He was quote abrupt with me and he just shrugged his shoulders and he said "I think it's something mental. He didn't look at me. I said "is it mental?" and he said, "yes there are chemicals in your brain and yours aren't working properly. They are causing you to feel like this "and I thought to myself "Oh my GOD, he thinks I'm crazy" Then I asked him about my daughter, I said "She behaves like this too, is she crazy as well?" I left the room and I felt like, it's my mind, I felt like I'm going crazy and at that point I accepted the CBT might be worth a try. I don't blame that GP or feel bad about what he said. I probably needed it, I needed to snap out of it." PFA4

This theme gives us some insight into how PFAs experience GPs and the qualities they associate with positive or negative appointments. In particular, I think it gives us some insights into how conversations about

mental health are handled. For the PFAs the qualities they associate with good care are consistency, trust, time, validation of feelings and having a plan. Having answers to worries appears to be less of an issue than having their feelings about their worries validated. The notion of the GP having a plan for their care also seems like a really important element of feeling cared for.

Conversations around mental health appear to sometimes be difficult. PFAs reported GPs telling them that the symptoms they were experiencing were their "nerves" or "something mental" which suggests some barriers in communication regarding mental health. This also suggests potentially lost opportunities for educating, informing and supporting PFAs about mental illness and perhaps, specifically its impact on physical health and symptoms.

5.17 Experiences of mental health care outside of general practice

Participants reported having negative encounters of mental health care outside of general practice. The problems PFAs reported include; feeling interrogated, finding it difficult to engage or trust a therapist, the therapy being stopped abruptly, the therapist appearing disinterested, asking inappropriate questions or not helping with the issues the PFA felt they needed help with. Of the fifteen PFA interviews, eleven had had some kind of referral or had self-referred to mental health services prior to being interviewed. These referrals included; counselling through work, telephone counselling, psychiatry Cognitive Behavioural Therapy and being seen by a Community Psychiatric Nurse.

PFA 8 had a referral for counselling for bereavement, he explained in the interview that he felt that he had never come to terms with the loss of his Mum when he was a six-year-old. He described to me how he stopped the counselling as it didn't address that issue and he felt there was too much paperwork;

"I went in (for counselling) because I felt that I lacked motivation, that I was suffering from loss issues. And that was what was supposed to be addressed by the telephone counselling service but I didn't think those issues were being addressed. They just kept sending me wads of forms to fill in. loads of forms, pamphlets, stuff to read." PFA 8

Several participants had had very negative experiences with mental health services ending abruptly, this extract from PFA10 illustrates it particularly well;

"I feel very vulnerable; it would have been better if I'd known beforehand (that the service was limited to 6 sessions) I need that extra support. I need it to be able to function. I've got children and I need to be able to get on with our life but the way it was left with the previous counsellor, she left me feeling exposed and in a mess really." PFA10

PFA10 was then reluctant to re-engage with counselling because she had felt vulnerable after her previous counselling ended. Often, services are designed to offer a limited number of sessions, but PFA10's story illustrates, that for some people it may take most of that time to get used to the process of therapy.

And then this lady who works in the [centre], not a therapist type, an administrator type thing, I'm guessing, calls me in front of everybody, like "xxx, can I have a word?",

sort of thing, and we just went into, y'know not private or anything like that, and she says yeah, y'know you've been here longer than you should have been really, y'know it's a 12 week re-enablement scheme…so, we think you're able to carry on, on your own now….like having the rug pulled out from you, sort of thing, because what was doing me really good was just taken away like that and I ended up and I still do, wish I'd never started in the first place because if I'd known about the hurt and disappointment I was going to feel losing that, I wouldn't have signed up for it. PFA10.

PFA10 describes how he would not have signed up for the art therapy course if he had known he was going to lose something that he felt was doing him so much good. He suffered from low self-esteem and social anxiety and had plucked up a lot of courage to go on the course. He benefitted from the social connection he was making, but then felt humiliated by the way his treatment was abruptly ended in front of a group of other people. Again, his overall experience was that he felt worse having gone on the course than he would have done if he had never started it. There is also a sense of sadness there too, that he found something that was doing him so much good and then he had to give it up, a sense of feeling teased almost, with the thought of what he could have had.

Other issues with mental health services included; feeling a lack of rapport with mental health staff, a lack of trust in the practitioner and feeling that the service on offer was not being that helpful. There were several examples of mental health care, in various forms that participants didn't find helpful. For example, PFA3 received counselling through work and found it patronising;

"It didn't work, they really made me feel patronised, it wasn't right so I went back to GP X and I told her how I was feeling and she said the anti-depressants weren't working and the chemicals don't work and she recommended the (CBT) study." PFA3

In the interviews there were also some rather surprising reports where the PFAs felt the therapists' approaches were 'horrid' or provoked anger in them.

"It felt horrid like being interrogated in a dimly lit room, I did two sessions and then I ran!" PFA4

"…I'm not a violent person but do you know every time I came out I wanted to punch him because he used to just sit with his eyes closed for the whole hour, n a corner. I'd be sat there on a chair and he put the chair like not behind a desk or anything as if I was in the middle of the room and then he would sit across with his eyes shut, waggling his leg. Never even acknowledged me and then he said, opened his eyes as if to say have finished now basically, bye." PFA5

The two examples are almost opposite in terms of the therapist's approach, one reports "feeling interrogated" and the other reports the therapist as sitting there not even acknowledging her. As well as these reports being surprising and concerning in terms of how the PFAs experienced this therapy, it is also interesting to see that the two very different approaches were both poorly received.

The accessibility and delivery of mental health services were described as not fitting in with PFAs practical needs. They found it difficult if they had to travel to see a therapist at a location other than their GPs surgery, sometimes because they were limited by their physical health conditions,

childcare responsibilities, or work commitments. PFA6 described her difficulty in finding the flexibility to fit in with therapy appointments due to caring for her grandchild and how she had to take her with her sometimes;

"and do you know I am not allowed to do anything for myself because when I first started the appointments with him (the therapist) … I thought, no I'm doing this for myself I need to go. So I took her with me. A couple of times I've been challenged where I can't go, there's been a problem but I've always, I mean I cancelled twice…" PFA 5

PFA5's account tells us that it might be challenging for these people with health problems, work and caring commitments to find suitable time to go to see a therapist.

PFA 8 was referred for telephone CBT but, not realising it was a telephone service, he turned up at the offices to speak to someone at the time organised to receive the phone call. He was then only able to speak to someone through a window grille and was told to phone to rearrange his appointment.

"Yes, because I actually turned up at the offices and they said no, we have to phone you, and I didn't realise it was just a phone conversation service and I went down there, they sent me away... I felt disappointed." PFA8

This implies a lack of understanding or clarity here about the nature of the counselling that PFA8 was offered. Understandably, this deterred him from following up with treatment. Another elderly PFA was given a DVD to watch as part of her treatment but could not watch it because she did not know how to operate her DVD player. She was also given a lot of

booklets to read but reported that she found it difficult to read them, possibly as her concentration was poor due to her depressed state. These accounts of mental health services being experienced as confusing or difficult to access tell us that maybe for PFA groups service delivery doesn't meet their needs in these formats.

PFA 8 recalls a confusing consultation with a psychiatrist where there was a lack of communication about what medication he was on and what treatment he should receive. This account suggests that there was a lack of continuity or shared information between primary care and the psychiatrist.

She [a psychiatrist] recommended that I should be on medication, that I should be having CBT therapy but I said I already am [on medication] and she got my records and it wasn't on, but she said show this record to your doctor… but GP X said she would put it on and she showed me the screen, but why the psychiatrist didn't know what I was on then I don't know!! PFA8

Another problem with mental health services that the PFAs reported was difficulty opening up to a therapist and trusting them. For example; PFA3 had had counselling before but it had taken her a while to open up and trust the therapist and then the service ended abruptly. This resulted in feeling reluctant to engage further in treatment even though she felt like she really wanted to find someone she could trust.

"Yes after I saw the counsellor for a little bit and I'd really started to open up a little bit not that much we didn't really click but none-the-less I'd started to go there and then it ended abruptly and I felt so low and shocked." PFA3

These accounts of mental health care from PFAs describe the difficulties they experienced in engaging with therapists, feeling a sense of control over the therapy in terms of lengths of treatments, appointment times and how services are delivered. These data tells us that PFAs have, for various reasons not found it easy to engage with mental health services. It might be that issues of trust or fear of being vulnerable also impact on how they engage with mental health services. There is also, for some PFAs a genuine sense of surprise that their health difficulties might also have a mental or emotional health aspect to them. It is important to know that it might be especially difficult for PFAs to engage with mental health services.

5.18 Theme 4- The importance of life stories and feeling understood.

At the end of the interviews PFAs were asked about significant life events **because increased attendance can often be associated with significant life events.** The question was phrased as; *"Finally, would you mind telling me about you and any significant events in your life, such as marriage, work, moving house?"* (See Appendix 2).

Often patients chose to delve quite far back and talk about events that occurred during childhood or earlier in adulthood, sometimes remarking that they have always wanted the opportunity to talk about some issues but never had the opportunity. The life stories shared included sad memories from childhood; some involved traumatic memories of illness, abuse, neglect or loss in the form of the death of close family members. Some PFAs spoke about events during adulthood including divorce or death. PFA13 spoke at length about the death of her son who had died of an undiagnosed heart condition in his 30s, fifteen years previously.

PFA13 felt isolated and lonely as her physical health was poor and her son was her only close relative.

"It hurts so much sometimes. If only he could come back and tell me that he's alright." PFA13

Other participants spoke about witnessing deaths in a manner that was unexpected or traumatic. For example, one patient recalled the death of her younger brother whilst she was in the room (aged 5) and the life-long feelings of guilt she felt about this. One adult male patient talked about his mother dying of cancer when he was six, he went on to talk about his fear of getting cancer, another patient spoke about his father having a heart attack on his twenty-first birthday, and a third spoke about the time he had dedicated to caring for his disabled younger sister.

In this interview, PFA5 described her experience of witnessing her grandfather dying from cancer and how she feels this has impacted on her, making her health-anxious;

"...after that obviously I'd got this fear. Me grandad was dying of cancer and I can remember sitting on the end of his bed and there's the district nurse there and I can actually remember the words they're saying. "Oh, she'll be ok." I was trying to get off this bed, but I was too little. It was a great big massive wooden bed. And he was throwing up in to this orange bowl; I can still remember it all and I was trying to get up of the bed and me mum had said I can't remember her saying it, but she said "Oh, you know, will she be ok?' She says, "Oh no, she's a child, she won't remember it." I can remember all of that." PFA5

Traumatic experiences related to death or illness seemed to be at the forefront of the PFA patients minds and for some like PFA5, they did relate some of this past suffering to their current fears around health and illness. Some of the PFA interviewees shared experiences of abuse and neglect. For example, PFA4 experienced abuse and trauma as a child, including witnessing the death of a younger sibling and subsequently being made to feel responsible for this but never feeling that there was a chance to talk about these issues during her life.

"I think it definitely makes the pain much more bearable, you know (talking about it). If I feel better in myself, I cope better with the pain. My whole life I have always wanted to talk to someone about what has gone on, about my childhood, but I've never had that trust, never felt able to do it." PFA4

The question about significant life events at the end of the interview, was interpreted by some PFA participants as a chance to disclose emotional issues that they felt they needed help with. There seemed to be a cathartic effect on the PFAs of disclosing difficult past events, giving them a chance to summarise their life story and reflect about how they were feeling emotionally. The disclosure of difficult past life events during these interviews could be interpreted as the PFAs having a need to tell their story or seek help with an emotional issue that they were struggling to cope with or manage.

5.19 Current emotional states and perceptions of self

PFAs spoke about feeling embarrassed about their attendance at the GPs surgery, feeling like they had taken up too much of their GPs time or

feeling like they were embarrassing to their families. The invisibility of their illness was something that was mentioned a few times by PFAs.

"with something like back pain, that's invisible there's nothing to remind them and people can be a little bit cruel. Every day is a battle." PFA7

Another way in which their health impacted on PFAs was to make them feel like a spectator in life, like they weren't fully able to participate in activities with other family members;

"I just seem to be a spectator in life though, not participating in things. I took my grandson go-karting, I would have loved to have a go but it's not worth the risk." PFA7

Being unable to take part in activities with children and grandchildren was especially upsetting for PFAs.

"If she wants to go horse riding, if she wants to go ice skating, if she wants to go to theme parks and go on the rides I can go there and I can be there and watch but he can do the things with her." PFA9

PFA 9 felt self-conscious that she used a stick to walk with. She explains how her husband reassures her that it's OK and they are doing the right thing for them;

"we get out of the car and straight away he's got my stick n sometimes I look at him and say, d'ya mind walking with me a bit? At our age we shouldn't be walking with sticks nor with crutches and things… do you get embarrassed? And he says no its absolutely fine whatever makes your life more comfortable and whatever you can achieve and I don't have a problem with it and I don't care what other people think or how they look at us. We do the right thing for us." PFA9

In terms of the quality of life of PFA patients it seems that their health is preventing them from being fully able to engage in activities and enjoy their lives and their families. It seems also like their health impacts on their sense of self, causing shame, humiliation, embarrassment or a feeling of being an outsider or a spectator in life.

5.20 Discussion of the PFA data

The main themes to emerge from the PFA data describe how these patients experience their health, health services, their relationships with health professionals, and their own emotional or mental health.

How PFAs experience their health, was, as expected, an important theme to arise from both the qualitative and quantitative data. The studies reviewed in the literature that looked at the relationship between frequent attenders and physical health (Karlson et al, 1997, Kersnik 2001, Foster, 2006, Stewart & O'Dowd, 2002, Heywood 1988, Al-Kandari 2008, Kurpas 2016 and Heywood,1998) suggested that, rather than being attenders without physical illness i.e.; the worried well, frequent attenders do have chronic illness, long-term physical health conditions as well as mental illness. The clinical characteristics of our participants confirmed this.

Poor physical health and its relation to daily functioning, anxiety, fear and mental health were all themes arising from the data and are not surprising considering the literature around complexity, diagnosis and co-morbidities in PFAs (Ferrari (2008), Jyasjarvi 1999, Burton (2003), Robles and Gili 2009 and Savague 2006). Again, high use of medication amongst PFAs is not an unexpected finding and is in accordance with what we already know from the literature (Pymont et al 2015, Patel et al (2015). What this data adds, perhaps, is more understanding around the difficulties PFAs

face regarding managing medication and their feelings regarding taking psychiatric medications such as antidepressants.

Like other studies, the PFAs in this study also relied on family members and others to support them in making decisions regarding their health. This is similar to the findings of Neal and Morley (2000) who also found that PFAs felt better about consulting if their families or friends corroborated and agreed with their decision to consult or if there were some positive outcomes that resulted from their decision to consult, for example with regards to support with work issues.

The PFAs in this study, sought support from their GPs regarding work issues and caring responsibilities, they also sought and, mostly, found continuity of care from supportive GPs who gave them the time and understanding they required. This is similar to findings by Neal (2000) who also found that continuity of GP care was important to PFAs and also that the behaviour of the GP may also support or deter PFAs from attending. Like the patients in Little et al.'s study (2001) the patients in this study also strongly desired a patient centred approach and communication was an important issue. An interesting and positive finding from this study is how much value and appreciation the patients had when they found a GP who they felt they could trust.

Although it is well recognised that PFA patients may be experiencing mental health issues (Gili & Luciano 2011, Dowrick 2000, Jyasjarvi 1999) and it is also well-recognised that they may have a low self-experienced need for support with their mental health (Karlsson et al 1994), one of the most original and interesting findings from this data is how difficult the PFAs had found being diagnosed with a mental health condition but also how negatively they had experienced mental health services. This is a worrying finding, particularly as work like that of Donald

(2011) suggests that access to good information around mental health and good care for mental health reduced attendance. The data from this research adds to what we already know about PFAs and their mental health in highlighting how important it is for these patients to feel understood and have their "stories" acknowledged and heard. This finding suggests that more needs to be done to help GPs and PFAs find ways of communicating about mental health. These results also suggest that referral pathways that result in timely and appropriate, helpful support are needed.

As in the qualitative research by Salmon et al (2004) it seems with this group of PFAs that their psychological problems may be easily uncovered with the right approach. Wilkund- Gustin found, in her work that if PFAs do not feel understood or experience feelings or mistrust or rejection, their suffering is increased. A similar phenomenon was experienced by the PFA patients interviewed for this study who's negative experiences of mental health services may have impacted on their willingness to re-engage with similar services.

This research also found that experiences of childhood neglect, trauma and abandonment were prevalent amongst PFAs and suggests, as did Bergh et al (2005) that applying attachment theory to understanding PFAs might be useful in therapeutic settings. Understanding the current socio-economic, factors impacting on PFAs such as work stress and caring responsibilities is also highlighted by the findings in this thesis as well as in work by Cruwys et al (2018) and Scaife (2000).

The overall findings of the PFA data confirm much of what is already known in the literature regarding the need for a holistic and patient centred approach to the care of PFA patients and in addition highlights the need for better mental health services to tackle the specific co-morbid and complex needs of this patient group

and to take into account the impact attachment issues might have on how these patients receive advice and support for their mental health.

5.21 Summary of the PFA data

It is evident that PFA patients are struggling to understand and manage their physical and mental health co-morbidities and are seeking the support of health services, specifically GPs with this struggle. The participant interviews illustrate a high level of anxiety regarding symptoms and that uncertainty leads to them to worry and become and fearful of illness. The quality of life of these participants is impaired by their poor overall health, with uncertainty over medications and symptoms, exacerbating their anxiety and contributing to a lack of well-being and impacting on daily functioning. Having a positive relationship with a GP is described as a comfort and support in the challenges that PFA patients faced and they valued feeling understood by their GPs. PFAs were grateful for the support of their GP when they felt that they had found a GP who offered them trust, consistent care, time and understanding.

Most of the participants had received some form of support from mental health services but this was in the most part, experienced negatively, with interviewees reporting a lack of trust in therapists and doubt about the usefulness of the services. An important aspect to receiving care for PFA patients was the extent to which they felt they could trust the caregiver and how much autonomy they had over when the therapeutic relationship would end. So for some PFA's the experience of receiving treatment might have been positive but the ending or perceived abrupt ending of treatment, left them with a negative view of the experience.

For some participants, being unwell or having experienced certain difficult life events meant that they felt ashamed, feared humiliation or perceived themselves as a nuisance or felt that they were a spectator in life not being fully able to join in with things.

The next chapter discusses the findings of the GP and PFA data together and in relation to what we currently know about PFA.

Chapter 6: DISCUSSION

6.1 Introduction to Discussion

Phenomenological approaches have been criticised for merely offering a first order analysis (Larkin et al. 2006) but this thesis goes beyond that and attempts to interpret these findings. This study, like many qualitative studies provides an intensive and detailed analysis of a small number of participants. The first aim of the data analysis was to step inside and describe what it is like for these patients and their GPs. Providing a coherent, third-person and psychologically informed description of the participants' views (Larkin 2006). The second aim is to develop a more overtly interpretative analysis of the data, positioning the initial description in relation to the wider social, cultural and theoretical context. So for example positioning the data in relation to general practice in the UK, sociological views of health and illness, attachment theory and the GP and patient relationship.

In this chapter I bring together and discuss the two sets of data, integrating the results and discussing any parallels between the two data sets. Where the same themes occur in the two sets of data, for example the significance of mental health or the GP/Patient relationship, I have collapsed them into one theme. I also discuss these themes in relation to the attendant literature in order to answer the original question posed, of *how do GPs and PFAs experience persistent frequent attendance in primary care?* Finally, I summarise the findings and suggest some conclusions and implications that can be made and make some suggestions about possible future research, strengths and limitations of this study and a reflexive statement.

The main themes to arise from the data are;

Theme 1- How PFAs experience their health

Theme 2- GP and PFA relationship

Theme 3-The emotional and mental health of PFAs

Theme 4- PFAs experiences of health services

Theme 5-The impact of managing the care of PFAs on GPs

6.2 Theme 1- How PFAs experience their health.

The poor physical health status of the fifteen participants is illustrated by their clinical characteristics and their qualitative interview responses. We can see they are in receipt of high numbers of prescriptions, meet the criteria for multiple physical and mental health diagnosis and have high attendance rates. The participants had an average of 12 repeat prescriptions for medication and six active physical problems each. The most frequent long-term physical conditions with a well-defined pathophysiology included hypertension, asthma and diabetes. There were also less well-defined conditions, for example, chronic pain and irritable bowel syndrome. It is reassuring (in terms of the representativeness of the sample) to see that the health and social status of the PFAs in this study was as expected from the literature review. The PFA patients presented at their GP surgery with a combination of physical and mental health co-morbidities and varying symptoms and worries about their health. Kersnik (2001), Foster et al, (2006), Heywood (1988), Al-Kandari (2008), Karlsson et al (1997) and Kurpas (2016) all found that frequent attendance was associated with chronic illness. Physical and mental health co-morbidities and chronic illness have been associated with frequent attendance by Robles and Gili (2009), Savageau (2006), Smucker (2001) Burton (2003) Jatic (2008), Karlsson (1999), Barsky (1986) and Jyvasjarvi (1999). However, data from the present study adds to what we already know by describing more about *how* PFAs experience their health. This qualitative data highlights how the PFA patients struggle with daily functioning and completing household tasks due to pain and

illness, the difficulties they had regarding medication, how they involved family members in decisions around their health and the impact it had on caring and work responsibilities. The qualitative data and the baseline clinical data combined give us a picture of how difficult the PFAs are finding it to function with their co-morbid health conditions.

At the time of interview, the participants were in receipt of an average of twelve repeat prescriptions. They also reported confusion about their medications. Eight of the PFA patients were in receipt of a repeat prescription for antidepressant medication. However, one patient had said during interview that she wouldn't take them and several of the other participants spoke about not wanting to take antidepressant medication. Therefore, it is unclear whether or not the patients were all adhering to these prescriptions. Using antidepressant medication as a way of managing depressive symptoms in PFA patients was spoken about in this study by GPs, but several PFAs were disparaging of GPs who would offer them a prescription of antidepressant medication and "not look them in the eye". Some GPs and patients did not see antidepressant medication as an appropriate long term solution to the mental health suffering of PFA patients but it seems that sometimes it was the only available option.

Medication use in general was problematic for some PFA patients with them reporting confusion over their medications and their side-effects. Pymont et al (2011) found an increase in use of all medications in PFAs but data in this study suggests a reluctance to take some medications and some confusion around medication use. The participants in this study were in receipt of a wide range of repeat prescriptions suggesting a need for greater monitoring of prescribing in this patient group.

Five of the PFA participants that took part in this study were in receipt of incapacity benefit and two were at risk of redundancy due to ill health. Reho et al (2018) carried out a longitudinal study of PFAs' and FAs' sickness leave and found that both groups had longer duration of sick leave than non-FAs for the duration of the study. They suggested that both occasional and persistent FAs should be identified in primary care settings and offered rehabilitation to avoid becoming unemployed due to sickness.

The results of this thesis suggest that support with work-related issues for PFAs are very important and might alleviate the stress or concern they feel regarding the impact of their health on their ability to function at work. There is also a sense, from the PFA interview transcripts, that shame is attached to feelings of not being able to productively work and this sense of shame might impede their willingness to ask for help. Being unwilling to ask for help may feed into the antidepressants/depression cyclical nature of attendance, therefore it seems very important to make it easy for PFAs to access and request support in a way that enables them to feel dignified and continue working. Discussions regarding mental health may be avoided by GPs and patients, creating a barrier for patients receiving more support to remain in work.

The other PFAs were retired or unemployed, in low-skilled or lower-waged work, some were socially isolated, divorced or separated and at risk of poverty due to relying on benefits or low wages. Four of the participants were carers for sick or disabled dependents. The association between PFA and lower economic groups was found in work by Karlsson (1999), with lower social and economic status by Jatic (2008), and with social isolation and poverty by Scaife (2000). The socio-demographic status of the participants of this study reiterates that PFAs may be

lacking in the social support needed to assist them in managing their poor health and socioeconomic disadvantages. This is similar to the findings of work by Cruwys et al (2018) who felt that attendance might be a mitigating factor used by PFAs to counteract the social isolation they are facing. These findings also highlight the economic burden of poor health due to its impact on PFAs' ability to work.

6.3 Theme 2- The GP and PFA relationship

Theme 2 is about the importance of the relationship between the GP and PFA. The manner in which the GP and PFA patients related to each other was a significant topic for both, who saw the value of time, trust and consistency in their interactions.

PFA patients in this study described the qualities that they sought in a GP as including; the ability to give them time, being trustworthy, giving them consistency and understanding them. Trust was a very important quality that PFA patients sought in their GPs. GPs were aware of how important this was and were invested in giving their time consistently and proactively to build up a trusting relationship with the PFA patients. The PFA patients valued GPs who they connected with and who understood them. These are likely the qualities that PFA patients would seek in a therapeutic relationship or rather, not having these qualities may deter them from entering into a "therapeutic alliance". For GPs, it was a challenge to provide this kind of supportive relationship within the limits of a primary care setting and acceptable appointment lengths. In terms of getting to know the pasts of patients, GPs may have some idea of mitigating life events but be unsure of the wisdom or practical usefulness of talking about these issues. GPs generally spoke about their PFA patients with kindness and acknowledged their suffering.

There are some clues in this data as to why trust is such an important factor for PFA patients when it comes to seeking care for both their physical and mental health. The PFA participants in this research shared stories about their childhoods or past traumas including abuse and neglect. The data also indicates that some of the PFA patients may have fearful or insecure attachment styles and be seeking approval or reassurance from their GPs. The results of this study confirm that the attachment styles of PFA patients might be worth considering when looking at their treatment needs. For GPs managing their care it was problematic to balance the need to create a relationship and offer some continuity to the PFA patients with the equally pressing need to avoid "Doctor dependency". Chew-Graham, May and Roland (2004) suggest there may be harmful consequences in elevating the doctor-patient relationship to be a primary goal of general practice consultation. The central argument of their work was that GPs may feel increasingly powerless to resolve such problems as chronic illness and incapacity in the community. Furthermore, they argue that GPs may find themselves colluding with patterns of illness behaviour that might maintain rather than resolve, incapacity. In other words, GPs ended up colluding with the patients in a relationship where "*no exit point is in sight, and the consultation is the focus of work to contain the expression of symptoms, rather than relieve or palliate their effects, the doctor is frustrated and the doctor-patient relationship itself has the potential to become chronic."* (Chew-Graham 2004, page 54) Like the GPs in Chew-Graham's study (2004) GPs in this study also articulated feeling that they focused on their relationship with PFA patients and yet had limited management options and resources for referral.

The results of this study highlight the difficulties faced by GPs in managing trust and attachment issues in their relationships with PFA patients. These findings

highlight that feeling secure and safe in their relationships with caregivers is important to PFAs yet also presents a challenge to GPs in managing this professionally and within the confines of the primary care system.

Findings suggest that PFAs are concerned with understanding and managing their symptoms, functioning, medication and co-morbid health needs. The data also tells us that having their concerns about their health validated and taken seriously was important to PFAs and alleviated their worries. GPs understood the importance of this but were cautious regarding reassurance and dependency. Feeling like the GP had a plan in place and that they would consider their needs and get back to them worked well; they didn't always feel they needed an answer so much as needing to feel they had been taken seriously, this is useful to know, particularly in relation to symptoms, as explaining symptoms and being concerned about them, engendered anxiety in GPs also.

There is an established connection between frequent attendance and experiencing many, varied or concerning symptoms. Various explanations have been given for the amount of symptoms presented, such as a lower ability to cope or manage symptoms (Sensky 1996), an under-detection of the underlying psychiatric process (Aragones 2005) and complex health with a prevalence of somatoform and affective disorders (Gili and Luciano, 2011). The findings of the present research do concur with earlier research with regards to the relationship between experiencing many symptoms and increased attendance for PFAs. Managing presenting symptoms was a barrier identified by GPs in moving patients forward as it, took up time and prevented GPs from exploring other options with patients. These findings suggest that PFAs seek support from their GPs specifically in relation to medications, symptoms, managing chronic conditions and concerns

about daily functioning. They also seek and receive support from their GPs with psychosocial issues, some of which are a direct consequence of their physical health (for example the impact it has on their ability to work), others seem more related to past trauma or current difficult life events.

6.4 Theme 3-The Emotional and mental health of PFAs

Managing the emotional and mental health of PFA patients was experienced as challenging for GPs. Some of the GPs interviewed avoided discussions about mental health and others offered support or "counselling". Wilkund-Gustin (2011) emphasises the importance of seeing PFA patients holistically and knowing or understanding them. However, findings from this thesis also suggest this does present challenges for the GPs when they are unsure what to do with this knowledge and it can leave the GP feeling powerless yet responsible, not knowing how to manage this information in moving these patients forward and avoiding inappropriate dependency.

The PFA patients interviewed spoke about how they had endured difficult life events, some of these events were related to a particularly bad illness experience and some were non-health related life events. It seems that, for some, these past experiences may still be impacting on the patient's mental health. Some reported current life stress such as divorce, caring responsibilities, benefit assessments or the threat of redundancy. The existing literature on PFA participants in primary care highlights the role that traumatic life events might have on PFAs. For example, the work by Schilte (2001) on childhood trauma, the work by Glaser et al (2006) and Wilkund-Gustin (2011) about the need to consider life stories in relation to the treatment of PFAs and the work of Matalon (2005) which looked at the role of a narrative approach to the treatment of PFAs.

During interview, GPs spoke about the likelihood of there being an additional reason for the PFAs' attendance rates, such as difficult life events. The patients often talked about difficult life events during interview also but they didn't always make a connection between the event and their attendance at the GPs surgery.

What is interesting is that the GPs were aware that there was likely an underlying story or issue that the PFA patient was struggling with and that it was likely to be impacting on their health and healthcare seeking behaviour. But, in many cases, the GPs were unwilling or very cautious about opening up a conversation with PFA patients about this. Sometimes this was because they did not want to risk alienating or upsetting their patients, feeling these discussions might be unhelpful. at other times it was purely because of a lack of time. Talking to PFAs about receiving a referral for help from elsewhere to support them to cope with difficult events, wasn't always seen as possible or useful by GPs. GPs reported being reluctant to broach these topics as they felt it might be better not to open up these issues because of the lack of resources, time and skills to deal with them and the need to maintain the trust of their patient. There are some similarities here with the work by Salmon (2004) that suggested that GPs may close down discussions regarding the psychosocial needs of PFAs. The reasons GPs gave for not always pursuing these conversations were valid and understandable but nevertheless suggests that the psychosocial needs of PFAs may not be being met because of barriers to having a conversation about these issues. As suggested in the work by Chew-Graham et al (2004) the GPs felt unwilling or powerless to challenge PFA patients by introducing potentially difficult topics and risking damaging their relationship with the PFA patients.

My literature review found little recent research regarding how psychosocial issues are discussed with these patients within primary care. Karlsson et al (1997) discovered that there was an under-diagnosis and under-treatment of psychological problems amongst PFAs. Kersnik (2001) also found an under-detection of mental health in PFAs. Dowrick et al (1996) carried out a study looking at the biopsychosocial model of general practice. They explored the extent to which GPs' views about the acceptable boundaries of their work were consistent with a biopsychosocial model. Their results suggested that GPs appeared to hold the view that a bio(psycho)model rather than a biopsychosocial model of care was appropriate. For the GPs who took part in this study, it seems that even if they were attempting to work to a biopsychosocial view of care, there were barriers to delivering this care.

Some PFA patients felt there was stigma attached to receiving a diagnosis of a mental health problem. When PFA patients talked about receiving psychological and general health care, issues of trust and concerns over the control they have over the treatment were important. For example, opening up to therapists, or taking part in a therapeutic service/environment and receiving good treatment and the treatment lasting long enough for them to feel better and function well again were really important issues for the PFA patients. Again this resonates with Wilkund-Gustin's (2011) findings. There were examples within the data of PFAs experiencing mental health services as poor and GPs reporting inadequate service provision. PFAs reported times when services ended abruptly and left them struggling to cope.

Although I did not set out to explore this specific issue of the relationship between attachment style of PFAs and their experiences of mental health services, the

findings from this data and the literature review, suggest that these issues may be particularly significant. Maybe future research could consider the link between PFA and insecure attachment style, vulnerability and suffering with regards to mental health care needs.

The PFA patients in this study expressed a need to feel they could trust their caregiver (both GP's and other healthcare providers) and this might be incompatible with how current service provision is designed. Many mental health services are designed so that people self-refer for an assessment which normally results in 4-6 sessions of treatment. For example, IAPT or Trent Psychological Service in Nottingham both adhere to this model. It seems likely that for PFA patients who have had high GP attendance for over two years, have complex healthcare needs, high health anxiety, mental distress and issues around trust and attachment, current services may not meet their specific needs.

There is some evidence in this data that GPs have an influence over PFA by "containing" patients from accessing secondary care and by being reluctant or unable to refer them to mental health services. There is evidence here that supports Neal's work (2000) that GPs have considerable control over PFAs' help-seeking behaviour. Ring (2003) also outlined the importance of the GP in making referrals and offering empathy and understanding to PFAs with regards to their psychosocial needs. Some GPs in this study felt that they were "not good" with mental health but that PFA patients came to see them because they offered them time and support. The results of this study confirm the difficulties PFA patients and GPs have with regards to managing mental health care and that these barriers may contribute towards the GP and PFA being stuck in a cycle. This might not

necessarily help the PFA to get better in terms of health and quality of life and may leave the GP feeling powerless yet responsible.

An important finding of this study is that addressing the psychosocial or mental health needs of PFAs may require a special and careful approach that takes into account psychological, social and personality factors such as attachment issues, trust, shame and stigma regarding mental health. The data in this thesis informs us that PFAs might find it difficult to "open up" about mental health issues unless the conditions feel right for them and might struggle to confide in people who they are not familiar with. The PFAs experiences of mental health also suggest that practical issues such as access and time might impact on whether PFAs engage in treatment. For example, can they physically access services easily and is service provision flexible enough to fit in with the demands of work, childcare or caring responsibilities?

6.5 Theme 4- PFAs experiences of health services

As well as reporting current poor physical health, the PFA patients in this study described some traumatic health related events, misdiagnosis or late diagnosis of illness. These events, some of which happened to them and some to their loved ones, may have left them distrustful of healthcare services and fearful of other similar events. It is possible that these past experiences influence PFAs decisions about whether or not to consult. The health belief model (Becker, 1974) corroborates the possible influence of others, severity of symptoms and past experiences of health in peoples' decisions about consulting. The patients in this study who had a traumatic past experience of health may perceive themselves as at higher risk of illness and that may inform their care seeking behaviour. Catastrophic thinking may also have encouraged health seeking behaviour in these patients.

Hunter et al. (2013) found that patients draw on previous experiences of services and practitioners when choosing how to respond to illness exacerbations. Applying the theory of recursivity and candidacy to PFAs in primary care, like Hunter et al. (2013), might shed some light on why PFAs chose to return to the "safety" of their GP. Traumatic health experiences may be influencing PFAs to choose GP care over other options as they experience their GP as someone they can trust and depend on for reassurance, investigations and referrals. This is an important finding as it reinforces previous work that stresses the important impact previous health encounters can have and suggests that this might need to be taken into account when planning the care of PFAs.

Aragones (2005) and Gili and Luciano (2011), found that psychiatric illnesses and somatic symptoms appear under-treated, under-diagnosed and complicated by chronic disease in PFA patients. As found by the work of Dowrick (2000) this sample displayed depressive symptoms and like Karlsson (1994) they also seemed very distressed even though their self-experienced need (whether they felt they needed) psychiatric care may be low. In the case of this sample, they might avoid thinking about their emotional or mental health due to shame or stigma associated with mental illness or unhelpful past experiences of mental health services. This suggests that discussions regarding mental health need to be managed particularly sensitively and perhaps with some emphasis on normalising experiencing mental illness in order to reduce the stigma or shame people might feel about receiving support with their mental health.

The findings presented in this thesis describe the barriers that GPs and PFA patients face in terms of discussing mental health and obtaining appropriate and effective referrals to mental health services. This supports the current

understanding that PFAs struggle with their mental health (Gili and Luciano 2011, Dowrick, 2000, Jyasjarvi, 1999, Karlsson, 1994, Donald, 2011 and Grabe 2009) and illustrates that they are not receiving adequate care to recover from, manage or improve their quality of life with regards to mental health.

Eleven of the fifteen participants had received some form of mental health support out with general practice, in the previous two years. They reported negatively about the mental health services they had received, often reporting issues with accessing services and when they did manage to access them, the treatment was cut off too soon or the ending of a programme of treatment was handled poorly or not communicated in advance to the patients.

Wilkund-Gustin (2011) found that PFAs can experience feelings of mistrust and rejection if they don't feel understood and that this can increase their suffering. There was very similar data in this study especially in relation to PFAs not feeling validated or taken seriously, feeling vulnerable or that their sense of self is under scrutiny because, for example they are struggling at work or using a walking stick. Like the participants in Wilkund-Gustin's (2011) work, the PFAs in this study, struggled if their sense of being capable and coping was threatened.

The PFA patients talked about how anxious they were about their health and some spoke about being afraid of hospitals, of dying and of receiving a diagnosis of an illness such as cancer. This is in line with the work by Puri and Dimsdale (2011) and Tomenson (2012) who found correlations between increased healthcare use, health anxiety and somatisation. What is interesting about the qualitative results of this study in relation to health anxiety is that they explain more about the complex presentation of symptoms and how this complex presentation of symptoms can make it challenging for GPs to unpick and explain a patient's health status and how

this uncertainty contributes towards the patient's health anxiety. The GPs interviewed found it a challenge to balance requests for referrals and investigations with a "wait and see approach" and the GPs' own fears of missing a serious illness. It was difficult for GPs to give the PFA patients the answers they were seeking about the reasons for their symptoms. Although the participants in this study (both GPs and PFAs) didn't necessarily use the terms "somatisation" or "health anxiety" there was evidence of the patients being concerned and confused about their symptoms and of them worrying about their health. GPs lacked ways to explain the psychological aspects of health or introduce the concept of a mental health component to symptoms and illness, in a manner that was acceptable to patients.

There was a distinct difference between the PFAs and the GPs in terms of understanding of health anxiety, as might be expected. The GPs spoke about health anxiety and were aware that some of their PFA patients had health anxiety whereas the PFA patients spoke about their "worries" or "being bothered by" or "a need to know" and appeared often very confused about their symptoms. The prevalence of health anxiety amongst these patients is not unexpected but it is useful to know more about the difficulties GPs and patients experience because of it, and how difficult it was for them to discuss it. This suggests a gap in understanding regarding health anxiety and difficulty in broaching this subject may be made harder by a sense of confusion, stigma or shame that exists around mental illness. It might still be seen as more acceptable to have a physical illness to PFA patients. The experiences of GPs in this study illustrate the challenge of managing health anxiety in primary care.

Another reason for not discussing mental health with PFA patients might be related to GPs finding it difficult to find the right words or language. Talking about mental

health was sometimes deemed as risking alienating the patient if the GP thought it could cause offence. There were examples in the data where this had happened, illustrating GPs were rightly cautious. Interviews with both GPs and PFAs illustrated difficulties with finding the right language with which to talk about mental health, one GP summed this up by stating he felt he resorted to "jiggery pokery" when talking about mental health.

6.6 Theme 5- The impact of managing the care of PFAs on GPs

The GPs interviewed spoke about how they were doing their best to manage the care of PFA patients without the existence of a structured care pathway or any training. The impact of this on the GPs meant that they often found it challenging and it could impact on their self-esteem and cause them anxiety. Like the GPs in Bellon and Sensio's study (2000) GPs in this study felt anxious about caring for PFAs. They felt that they would benefit from a more formal or informed approach to PFA care. Little (2001) suggested a sensitive patient centred approach to PFA care and the GPs in this study certainly seemed to be trying to offer this. An interesting result of the PFA participant interviews was that having their worries validated, being able to trust their GP and there being 'a plan in place' were valued highly even when reassurance was not possible in the form of explanations for symptoms.

One of the main causes of anxiety that the GPs spoke about concerning PFA patients was that of missing a diagnosis. In addition to this anxiety, having PFA patients also led to GPs having to manage greater workloads and balance requests for referrals and investigations. Caring for PFAs could impact on GPs own self-esteem and cause them to feel sad or frustrated at what they described as a lack of options for providing adequate care. It was challenging for GPs to try to understand

and meet the PFAs holistic needs in addition to managing symptoms, medication and requests for referrals.

The results highlight how GPs resorted to a model of care that was focused on providing continuity, time and trust to the PFA patients and on "keeping them going" or maintaining the relationship. GPs described how they sometimes avoided discussions about mental health or difficult past lives because they were unsure that this could help the patient currently and even feared that attempting to deal with these issues might be destabilising or have a negative impact on the patients daily functioning. This is similar to what Salmon et al (2004) found, regarding GPs blocking psychosocial opportunities and closing up such discussions. The findings from this thesis suggest that sometimes the reason this is being done is because GPs fear a lack of solutions (for example a shortage of referral options) or believe that these discussions might perhaps leave the patients feeling worse.

Trying to unravel complicated presentations of health and associated anxiety and attempting to understand if there was anything in the patient's life that was impacting on their health was a challenge for GPs within the confines of general practice. Relying on their personal skills to manage PFA care and to keep the relationship of trust going had an impact on GPs, causing them to worry and become frustrated, it also impacted on their self-esteem as professionals. Without a structured care pathway or guidance to follow, GPs described becoming stuck in a cycle where they saw themselves as managing to maintain the care of the PFA patients but perhaps lacking the necessary means to really move them forward in terms of the patients well-being. There are examples in the data of instances where this led to a situation of dependency and reassurance seeking which led to frequent consultation. Overall, caring for PFA patients engendered a great sense of

responsibility in GPs but a responsibility which they felt they were in many ways powerless to manage well.

6.7 Conclusion- How do GPs and patients experience Persistent Frequent Attendance in Primary Care?

The findings of this thesis offer some clear insights into how GPs and patients experience persistent frequent attendance in primary care with overlaps in the two sets of data that support each other and provide a rounded account of the situation.

Theme 1 illustrates how PFAs experience their health as complex, worrying and poor. It is evident that complex poor health is a major reason for PFAs continued attendance with their GP. Theme 2 focuses on the importance of the GP/ patient relationship and how factors such as experiencing trust, feelings of safety and continuity encourage these patients to see their GP and the challenges this presents to the GP. Theme 3 illustrates that PFAs seek understanding with regards to their mental and emotional health and current circumstances, GPs seek to find and offer this understanding but fail to know how best to move these patients on with limited resources and options. Theme 4 explains how PFAs negative experiences of other health services impacts on their health-seeking behaviour and may act as a deterrent to them receiving mental health care out with primary care services. Theme 5 describes the impact managing the care of PFA patients has on the GP, leaving them feeling responsible and yet powerless to meet the needs of this patient group. Although GPs acknowledge the importance of managing PFA care, for them it engenders feelings of anxiety and responsibility in a situation in which they feel powerless to resolve or improve. An overarching theme throughout the data is the

importance of attachment issues and how these need to be carefully considered with regards to the care of PFA patients.

Overall, it can be seen that the way GPs and patients experience PFA can be frustrating for both parties and there is a need for more support for GPs in managing this care. The data in this thesis does give some clues as to what aspects of holistic care would be needed for successful interventions or training to improve the options for GPs who manage PFA care.

6.8 Implications for further research and care

Taking into account the specific needs of PFAs might help with service design and delivery and help to move them forwards in terms of their health-related quality of life and mental health and well-being.

The patients themselves seemed to feel that in order to receive the care they needed in terms of time, trust, continuity, referrals and investigations, they needed to find a GP that they could develop a relationship with and rely on to consistently provide this care. GPs seemed to have a good understanding of the PFA patients' needs in this sense and some GPs saw themselves as willing to give extra time to support PFA patients. The most common strategy GPs employed to manage the care of these patients was to try and investigate and exclude, if possible, physical causes of worry, make referrals if necessary and offer time and support, empathy and a listening ear. The GPs might try to introduce the idea of the possibility of a mental health route to some of the patients but were often hesitant to do this. The data in this thesis suggests GP training in how to create open dialogues regarding mental health might be very useful in managing the care of PFA patients. In many ways, what both the GPs and the PFA patients have described is a situation where they have become "locked in" to a relationship, a cycle of investigation, referral and

prescribing that is difficult to find their way out of. GPs felt they were largely left to their own devices in terms of managing the care of PFA patients. They did not receive any training specifically on how to care for PFA patients and they didn't feel that there were appropriate services in existence to refer these patients on to for support with their mental health. Although some practices discussed these patients regularly at practice meetings, GPs largely felt it was their responsibility to manage the care of PFA patients alone. This meant relying on their personal skills and handling demands for reassurance, investigations or "counselling". Even though they were aware that these might not always be the most helpful in terms of reducing PFA and avoiding doctor dependency. Along with wanting to successfully manage PFA patient care, GPs also saw themselves as responsible for keeping PFA patients from using out-of-hours services such as A&E.

These findings suggest there is a gap in training for GPs in the care of PFA patients and that they would benefit from some training, perhaps specifically with regards to how to talk to PFA patients about the issues that worry or confuse them or that they might benefit from knowing more about. For example; the stigma around mental health, understanding the physical effects of mental illness, coping with health anxiety or managing co-morbidities. It also might be useful for GPs to have more guidance in how they manage their relationship with PFA patients, for example with regard to issues of attachment and dependency, referral and investigation requests and managing symptoms.

6.9 Implications and conclusions

This thesis has explored the experiences of PFA from the perspectives of both GPs and patients and highlights the challenges and barriers to providing healthcare that addresses the complex needs of these patients. The findings, like that from other

studies, show that PFA patients have co-morbid health issues and that they feel vulnerable, stressed and suffer with their health and worries.

What these findings add to current knowledge about PFA and GPs is detail on how challenging it is to manage the care of PFAs, specifically holistic care and their mental health care. Being unable to move forward and improve their quality of life leaves both PFAs and their GPs with feelings of anxiety, frustration and being "stuck".

GPs reported barriers to discussing psychosocial needs and making successful referrals to mental health services. PFA patients reported difficult experiences of mental health services and a need for a trusting relationship with caregivers. PFA patients value GPs who are able to offer a consistent relationship of trust to PFAs and a plan of how they will care for them. However, for GPs this is challenging and it has an impact on how they feel about their professional practice. GPs could benefit from more support with managing the care of PFA patients in terms of training and guidance on managing the psychosocial aspects of PFA care. The findings reveal a great emphasis on the importance of the GP and patient relationship and the advantages of this relationship in "containing" the PFAs within primary care services, offering them continuity, consistency and trust. However, as Chew-Graham et al (2004) suggest, GPs find forming a therapeutic relationship with PFAs and managing their mental health care needs can result in them feeling powerless to move PFAs forward. Not only do GPs find caring for PFAs a challenge but they also struggle to avoid creating a situation of doctor dependency and may in fact be sustaining health anxiety by offering reassurance.

6.10 Future Research

It would be interesting and useful to carry out more work looking at how PFAs feel about mental health and mental health services. Including a consideration of whether PFAs experience these services negatively due to issues of candidacy and recursivity, negative past health experiences, lack of trust or stigma and shame about mental health. It might be helpful to know if these issues are important or is it simply that these services are ill equipped to deal with such complex presentations of co-morbid health.

It might be interesting to consider whether the GP-patient relationship could be used to inform and prepare PFA patients for treatment by a service especially designed to treat them holistically.

Future research exploring the training needs of GPs with regards to PFA patients might be useful, as would studies looking at care pathways and therapeutic interventions for PFAs. The results of this study tell us more about the qualities PFAs value in healthcare providers and again, it might be useful to explore if this is reasonable and whether these expectations or needs might be better managed and met elsewhere. GPs might feel better supported and less anxious about managing PFA care if they received some specific training and if they felt there were more appropriate referral pathways. It would also be good to interview families as well about their experiences of PFA because some of the PFA patients described how their family members were involved in their decisions over their healthcare.

6.11 Covid-19

Since this research was carried out, the provision of healthcare has been impacted dramatically due to responding to the Covid-19 pandemic. Without a doubt, this

will have impacted on how easily accessible GP and secondary care services have been. In addition to changes around healthcare provision, people who already struggle with co-morbid health issues and anxiety around their health will have had to face the threat of Covid-19 and the uncertainty around constantly-changing healthcare advice. In addition to this people in the UK are facing increased unemployment, and redundancy rates, loneliness and isolation. It is difficult to predict how this might have impacted on PFA patients and their care but many of the aspects of healthcare that have been highlighted in this study as valuable to PFA's, such as the importance of accessing mental health care in a flexible manner or the importance of a consistent relationship with healthcare providers such as GPs, will have been impacted upon by Covid-19. The impact of Covid-19 on vulnerable groups such as PFA's should be (and hopefully is) being researched.

7. STRENGTHS AND LIMITATIONS OF THIS STUDY

A strength of this study is that it uses data from both GPs and patients so we can understand PFA from both of their perspectives. Another strength is that it provides qualitative data in a field that is lacking in qualitative research. Qualitative studies can give us a more in-depth understanding of human experience. Another strength of this study is that it gives a rounded view of the situation by exploring it from the position of the giver and the recipient of care.

Another potential limitation is that the GP interviews were not carried out by myself and were primarily carried out to look at the implementation of a wider study, this may have impacted on the content of the interviews.

The sample of PFA patients were part of a wider study (See Appendix 1) which does present the possibility that, having already had a screening interview that

explored their health, they had had a chance to reflect and this might have led them to reframe how they saw their health. A positive aspect to this however, is that having had a chance for reflection they may have been able to articulate their thoughts and feelings more clearly.

Social desirability factors may also have had an influence on how the PFA participants and the GPs described each other and other issues during interview to me. Especially considering some of the interviews were held at the GPs surgery this might have impacted on how positively the PFAs reported their relationship with their GPs. GPs might have been reluctant to describe their patients negatively as they might feel that this would impact on how the interviewer (SB) would view them, the GP. However, we tried to minimise this by ensuring confidentiality and emphasising a non-judgemental stance.

8. REFLEXIVE STATEMENT

Fischer (2009) and Day (2012) highlight the importance of reflexivity and bracketing during qualitative research. In this statement I have reflected back on my conduct throughout this research work and thought about how my experiences may have impacted on my interpretations of the data. I believe I remained professional during the interviews with PFA patients and adhered to the protocol (Appendix 1) for interviewing PFA patients. I also believe I tried very hard to be aware of my own position in relationship to the themes arising in interview, both during interview and during data analysis.

I did seek support of my then supervisor (RM) if I felt concerned about the answers a participant gave during interview. I only felt the need to do this once

and this was with the express permission of the participant. This conversation with RM was supportive for me because I felt reassured that the patient would get a referral for help with the issue she had confided in me about.

I do believe that my background will undoubtedly have had an impact on how I approached this study. I feel I may have more empathy and compassion for the PFA patients because of my own life experiences. These included my firstborn child dying of an undiagnosed heart condition and my daughter having Turners Syndrome and how these events can impact on many aspects of health and my own experiences of depression and anxiety. During most of my re-write of this thesis my father was in hospital due to dementia and being a double amputee, writing this and caring for him was a great challenge and I empathise greatly with the carers interviewed for this thesis (although I wasn't a carer at the time I interviewed them). Being from a working class background I can also relate to the socio-demographic issues that faced these PFAs, in particular problems with poverty and benefits. I have spent months applying for my father's Personal Independence Payment to be reinstated. This was stopped as he was seen as "fit to work" even though he was a double amputee with diabetes.

Sometimes I feel a sense of shame at the messiness of my life and perhaps also a sense of indignation, that it is understandable if I am having a bad time because of all the things that have happened and I can sense, I think that some of the PFA patients maybe felt some of these feelings too.

The lack of social care and referral pathways described by the GPs I can empathise with, as a user of mental health services I have myself had to wait for referrals and struggled to connect with therapists. Finally, I also took some time off work with stress during the rewrite of this thesis and am now facing the end

of my employment contract so understand the impact stress and poor health can have on your ability to work.

Having worked with GPs and with consultants in a children's hospital I am well aware of the challenges they facing in providing a holistic approach to care. I am also aware of the shortages we are facing in social care at this time and how that impacts on health care professional's options for referral and support.

My life has been quite "messy" and I think sometimes we try as researchers to make sense of and tidy up the messiness in our data, to clean, organise and interpret the often sad and raw emotions that are within the data. I have tried not to minimise this and to truly represent the informants, both GPs and PFAs in my analysis. However, I think my personal experiences possibly meant I had a deeper understanding or was affected more by the issues being presented. I was incredibly moved by the interview with a woman whose son had died from an undiagnosed condition. I could relate to her grief and sorrow about the loss of her son. I could understand that her back story was deeply tragic and sad and that grief for a son can be disabling and lonely.

I am not sure I would have set out to write a PhD thesis had I known in advance of the health struggles my dependents were to have during this time and as I try to complete this, my biggest reflection is on the difficulty of overcoming these barriers to achieve personal goals and the sense of shame you feel if you cannot function well enough to carry out daily tasks let alone meet those goals. I hope that I have managed to portray the lives of the PFA patients and GPs in a truthful and compassionate manner and describe their strengths as individuals in trying to overcome their struggles.

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Appendix 1: Qualitative Interview Guide PFA Participants

Could we start off by talking about the last time you went to see your Doctor?

a) When was this?

   What was the reason for this visit? If for a minor or ongoing issue, then prompt for previous appointment.

b) How long had/have you felt unwell for? What were/are your symptoms? (Ongoing health problem/new. Prompt for severity of symptoms and how many days of symptoms before consulting.)

c) Is there anything that particularly worries you about your symptoms?? (Symptom /that it was a sign of something else/ health anxiety??)

d) At what point did you decide to see your GP? Did you talk to anyone else about whether or not to see the GP? (E.g. partner etc.)?

e) Was there anything in addition to this (main symptom) that you wanted to speak to your GP about? If so what was it?

f) What response did you get from your GP regarding your symptoms? (Prompt for diagnosis/referrals/investigations/medication/follow-up appointments etc.)

g) Did your GP offer you any advice?

h) Was this what you were expecting?/was it helpful?

i) Is there anything significant you can remember about the time of your last visit? (Prompt with life events/ worries etc.)

j) Was it a Doctor that you usually see? (explore continuity) How important is it for you which Dr you see? Did you get an appointment when you wanted it?

k) What is your relationship with your GP like? (Prompt for how well understood they feel?)

1. **Are there any other times when you have seen your GP recently that you would like to tell me about?**

   Prompt for memorable consultations and use same Qs as 1).

2. **Have you got any particular health problems that you tend to see your GP about (regularly)?**

How is this dealt with? Prompt for diagnosis/referrals/investigations/medication/follow-up appointments etc.)

Repeat medications? How long have they been on them for and how much of these do you take (per day)? How do they feel about taking this?

How do your health problems affect your ability to look after yourself...do everyday tasks, do the things you like to do etc.?

3. **Have there been any periods of time in the last two years when you have felt the need to consult with the Dr more than you usually would?**

   If so, why, what for, what happened? Response?

Finally, would you mind telling me about you and any significant events in your life, such as marriage, work, moving house etc.?

In the last two years...and beyond.

Prompt with-

- Social networks-friends-relatives-people live with-
- Hobbies, community, church/religion, exercise (attitudes twds health)
- Life events/trauma
- Illness diagnosis
- Occupation
- Education
- Relationships-support-loneliness-home/family life
- Childhood
- Life events/trauma
-

Prompt with impact on health/would they talk to GP about these things/other sources of support?

What kinds of issues have you had help with? What kind of impact has this had on you? (Prompt with any change in physical/mental health/symptoms?)

Appendix 2: Topic guide for GP interviews

Lines of inquiry for future interviews – specific to *organisation of care*:

- Decision making:
    - **What is the overall aim with RA's?**
    - Commonly, a discretionary one-to-one (rather than a strategic practice wide) approach is taken to managing RAs – why?
    - How has this come to be the case?
    - What informs GPs' decision making where RAs are concerned?
    - Are there RA patients where they have or have had a strategic plan for their care? Please give an example or examples. How well is this strategic plan being followed? What has helped or hindered this?
    - How did GPs arrive at the default 'cycle of referral' approach to RAs?
        - What were they trained to do? e.g. medical school, early clinical posts, RCGP curriculum, training or experience in practice, other formal training or informal approaches, articles
        - If they were not trained for the role, what has influenced their approach to this problem and what training or other experience prepared them for the role?
    - How do GPs rationalise 'keeping hold of' patients with MUS over a long period?
- Communication / consultation:
    - What opportunities are there for peer discussion / consultation in relation to RAs? What opportunities are there to discuss any clinical cases? What is helpful or unhelpful about this? What encourages or prevents you from peer discussion? Are there opportunities to do this with professionals outside the practice? Who might be helpful to discuss these cases with?
    - What is the remit for practice meetings?
    - Who attends practice meetings?
    - How do GPs record their interactions with RAs with MUS? What info do they include in their notes? Why? Who are notes written for?
    - How do GPs interact with other practice staff such as nurses, reception staff in relation to RAs?
    - Do you have any specific strategies for managing some of these RA patients. Please give an example.
- Prescribing
    - What is GPs' aim when deciding to prescribe medication to RAs? What about symptoms relieving medication e.g. relieve pain where source is unclear or hypnotic (sleeping) drugs? Is there ever a role for opiates? What about the role for antidepressants?

- Legitimacy / deservingness / moral neutrality:
    - How legitimate (deserving of empathy / being taken seriously) are RAs? Why?
    - Is frequent attendance with MUS wrong or justified? Is it a legitimate use of GPs' time? In whose view?
    - What motivates the GP to continue to care for these patients?
    - For RAs who receive community care and social support, how fair is that? Why?
    - How comfortable are GPs with signing medical certificates / benefit claim forms for RAs on an ongoing basis? Why?
    - How do GPs think of patients who have suboptimal mental health? Does a mental health diagnosis cloud one's objectivity when that patient presents with a physical complaint? Does it affect their management?
- Referral to secondary care
    - For what / at what point would a GP refer to secondary care? Why?
    - What degree of uncertainty are GPs willing to live with? Why?
    - What information do GPs provide in their referral letters? Is the patient's history of having MUS noted? Why?
    - What do GPs ask for in their referral letters? Why?
    - Under what circumstances might urgent or out of hours care might be used for RA? Is your approach to this any different from other patients? If so how?
- External mental health services
    - How do GPs talk to patients about mental health / mental health services? What language do GPs use?
    - How do GPs learn how to talk about mental health with patients?
        - What did their training in relation to talking about mental health involve?
    - How readily are GPs able to refer patients to mental health services?
    - How adequate are mental health services perceived to be?
    - Do GPs need to employ any 'tricks' (e.g. consultation 'coaching') to get patients accepted by mental health services?
- External pressure
    - Are GPs under any pressure from their primary care organisation to manage RAs in a particular way? From whom and how does this affect you or the practice?
    - Are there any recent changes to this?
    - Are there any other external pressures on GPs in relation to RA?

- Are there any new opportunities for help with caring for people with RA? For example secondary care providers, alternative or private care.
    - Social care
        - How do GPs use social care / support for RAs?

    - What has been the impact of the withdrawal of funding for social care in relation to RAs? Why?
- Effect of RAs on GPs' morale / capacity to 'care'
    - Previous interviews/research suggests RAs with MUS can be 'wearing' – how do GPs deal with this?
    - Is it possible to remain fully empathetic in this context?
        - If not, what 'safety nets' are in place?

In addition - Further exploration of:

- Receptionists' 'triaging'/'gate-keeping' behaviour – how did they come to adopt that role?
- GPs as 'keepers' or 'deflectors' – how did this stance / position evolve?
- In light of findings about what RAs see as a good GP – what do GPs think patients want from a GP?
- If the opportunity arises to interview a GP about a specific case, what are their attitudes and aims in terms of managing these patients?

Appendix 3: Stage 3 of Thematic analysis of patient data

ID	Theme
GP1	Heart sink patients No one can help them MUS is a good term Investigate, exclude, go from there. No training Asking them to come back in a month Dr shopping Consistency-1 Dr Difficulty of introducing idea of mental health Appointment lengths are too short. Not wanting to spend too long. PFAs expectations of double appointments Needing reassurance Usefulness of CBT Insight is helpful to patients with health anxiety. Worry of missing something with PFAs Not sticking to planned appointments. Pressure not to refer PFA is a phase PFA due to boredom or loneliness, social issues Some GPs go down the alternative therapies route Internet can make worries worse Consultant referrals can make it worse. Lack of u/s of how mind and body affect each other. Not wanting to miss something. GP is not a counsellor. In- house therapy would be good. Lots of reasons why people persistently frequently attend. There is no answer

ID	Theme
GP2	They all end up getting something/ don't want to miss something. Finding a physical health issue legitimatise the attendance. Dr shopping Use of antidepressant meds Pain clinic referrals Some people are never ready to hear what you are saying because they are anxious. Patients with lots of symptoms Faxing daily Containing the problem from A&E Accepting MUS or not Difficulty in addressing mental health as so many symptoms PFAs-personality disorders. Underlying problem Not wanting to bring up trauma as nowhere to deal with it. Difficult for Drs to manage mental health Need for trust and familiarity Under-resourced services. Use of anti-depressants due to lack of services Can just offer the relationship/be there for them. Cycle of referrals and investigations. Refer when you can't bear to listen anymore. Most Drs are empathic. Discuss PFAs as a practice. Offer consistency Unknown whether in GP training. No care pathway or plan. Multiple meds. Difficulty reducing and managing meds. Some people aren't ready to change/accept a mental health diagnosis are resigned to their MUS.
GP3	Importance of safety, relationship and familiarity. Fear of missing something. Seeking referrals Complexity of physical and mental health It's a Phase Imp of intro idea of mental health early. Impact on GP Some Drs have a flair for PFA Time Not expensive financially for GPs to maintain PFAs.

ID	Theme
GP4	Risk of disengaging patients if intro idea of mental health Complexity over whether or not to refer Referral can exacerbate anxiety Frustration of Dr Counselling can be seen as just another stranger. Imp of trust. Not a lot else to do but keep them stable-contain them Do what I think best approach rather than an evidence informed one-Good quote.
GP5	People can't always accept it's not physical People want repeated blood tests because they are worried about symptoms People don't understand the symptoms are caused by stress. Stress impacts on whether or not you trust someone. Some people just need encouragement and understanding. Some people will be better by the time an appointment for therapy comes along.
GP6	Trying to understand the individual Approach PFA by listening and doing no harm Spend time trying to understand PFAs Continuity Cycle of referral and investigate

ID	Theme
GP7	Usual Dr System Can identify PFAs more easily with the usual Dr system. We have fewer PFAs because we are motivated to deal with them so they don't come back We contain PFAs Cost saving Some PFAs are happy as they are don't want to delve into the past Damage limitation Difficult to help some PFAs Iatrogenic harm Importance of continuity of care. Social aspect of PFA Challenges of PFAs with special needs. Mental and physical co-morbidities of PFAs Habitual PFA Lots of issues/symptoms. Phases and reoccurring PFA A "type" who can't cope. Medicalisation of life is a cause of PFA GP is a support system. GPs have to take PFAs seriously, they trust that GP will take them seriously. Some PFAs don't want to change Trauma and CSA is so deeply ingrained that some people don't want to change. Death during childhood. The danger of delving into issues. Opening up issues.

ID	Theme
GP8	Understanding PFA is key to medicine Everyone has a psychological component to their physical disease. It's frustrating as there are limited resources Challenging- GPs job is to try to understand and move them fwd. and offer solutions. Need to get to a point where you can intro the psychological Unique culture of continuity of care Imp of continuity Imp of the narrative, of understanding the PFAs narrative. How does the body, pain work? Medicine can help PFAs Explanations can help PFAs The relationship and offering continuity can help. Drs taking patient seriously and knowing them as a person is vital. Setting boundaries to time giving is important. Cannot give patient the reassurance they are seeking Can offer support Loneliness affects older and isolated PFAs Health anxiety is passed down from parent to child Are gender diffs in PFA Diff reasons for PFA, work, childhood trauma or attachment issues, chronic fatigue. Waiting for counselling or CBT, need for liaison psych Lots of suffering throughout a PFAs life Mental health is not just depression or anxiety Need for more reflective time for GPs PFAs are suffering Cost is emotional as well as financial Drs discuss PFAs together as group. Secretaries are helpful in assisting Drs with cont. of care, One patient one Dr works better.

ID	Theme
GP9	Continuity Not referring PFAs to secondary care Introducing the idea of the psychological A gap in psychological support. Readiness to accept a psychological element or not-having to be careful about it. Cycles of investigations and referrals. Having to investigate in case there is something. How it gets resolved sometimes. Just needing a chat A standby approach on how to deal with these patients would help. Usual Dr approach Managing meds One PFA lots of meds Daily meetings Frequency/pattern of appointments is important too-phases.
GP10	Dr shopping Importance of experience Unsure of what is in training regarding PFAs Patient being bounced back from mental health services Childhood attachment issues Importance of telling story Cost effectiveness of psychotherapy Inappropriate referrals Benefit of therapy Collaboration would be helpful Investigations and cycle Drs uncertainty, might get something like cancer Most people end up getting something. Need for training/guidelines Medicine as a dark art/magic/runes?! Part shaman/part GP Don't want to miss something. Dr dependency Imp of listening Knowing when to introduce the psychological Explaining MUS Mind-body connections Usefulness of psychotherapy Stigma regarding mental illness MUS Some Drs better suited to managing PFAs

ID	Theme
GP11	Doesn't have PFAs because of how he manages care Is a medical model GP? Different styles of GPs Exploring the psychological Problem of referrals and anxiety Having CBT to hand would be helpful Waiting times and lack of access to mental health care Dr dependency
GP12	Gives an example of Dr dependency Frustration Cross with colleague for colluding with patient Recognising that colleague's reassurance was compounding patient's anxiety Patients preference for female Dr Patient requiring reassurance very frequently after having had cancer
GP13	PFAs are poor copers Problem of time - ten minute slots Gathering info from patient and hypothesising about what the problem is. Some patients don't want to get better A vested interest in being unwell-illness as a coping mechanism Referrals Usual Dr system Might be good to have a system (register) for monitoring PFAs on practice site and alerting each other Would be good to meet to discuss them-but I don't think they currently do. Dr dependency Sometimes difficult to realise that they are PFAs Asking PFAs why do you go Lots of variations in why people PFA Some worry over minor things, come repeatedly-anxiety Employment issues Pressures on people Stress needing a sick note to have some space/a breather Resources and money Trainees and the need to be aware of the impact of psychological illness on physical illness and that sort of thing. RGCP (the college) focus on holistic care

Appendix 4: Stage 4 of GP data analysis

Main themes	Sub-themes and codes
It is of importance to GPs to know and understand who PFAs are.	They have an underlying story (trauma, childhood) Describing them (MUS, heatsink etc.) They have symptoms The relationship between Dr and patient Continuity Social reasons (work, stress, isolation, divorce) Suffering of PFAs How much time to give them? (Difficulty in knowing them in short appointments.) Importance of trust Role of anxiety
They experience confusion and frustration at a lack of training/resources/options for care/answers/solutions.	Shortage of Mental health resources Cycle of referrals/investigations Containing the problem (keeping them away from urgent care) Lack of training/formal guidelines Difficulties with medications Managing patients expectations/is there an answer??

Main themes	**Sub-themes and codes**
Caring for PFAs can have a negative impact on the GP	Frustration Stress Anxiety over missing something Uncertainty (a general theme)
Additional themes	Mental health-how to talk about it, whether to talk about it. Difficulties with language, jiggery pokery. IS it the Drs role? (Medical or social model of medicine. Financial implications of PFA It's a passing phase Some people don't want to get better Iatrogenic harm Doctor dependency They all get something in the end. The relationship between the mind and the body.

Appendix 5: Stage 3 Analysis of patient data

Main Themes	**Sub-themes**
How PFA's experience their health	Poor physical health and its relationship to daily functioning, anxiety, fear and mental health. Difficulties regarding medication. Involvement of others in health decisions. Impact on caring and work responsibilities.
Experiences of health services and relationships with health professionals.	Experiences of general practice healthcare Experiences of mental healthcare.
Emotional/mental health	The importance of life stories and feeling understood. Emotional pain and trauma and difficult experiences they'd had. Current emotional state and perception of self as a nuisance.
Additional and/or overarching Themes	The Epiphany experience- the realisation that they needed mental health care. Co-morbidity and complexity. Poor Quality of life

Appendix 6: Stage 4 of PFA Data Analysis (open coding)

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Appendix 7: Medications and Diagnosis of PFA Participants.

Redacted for this version

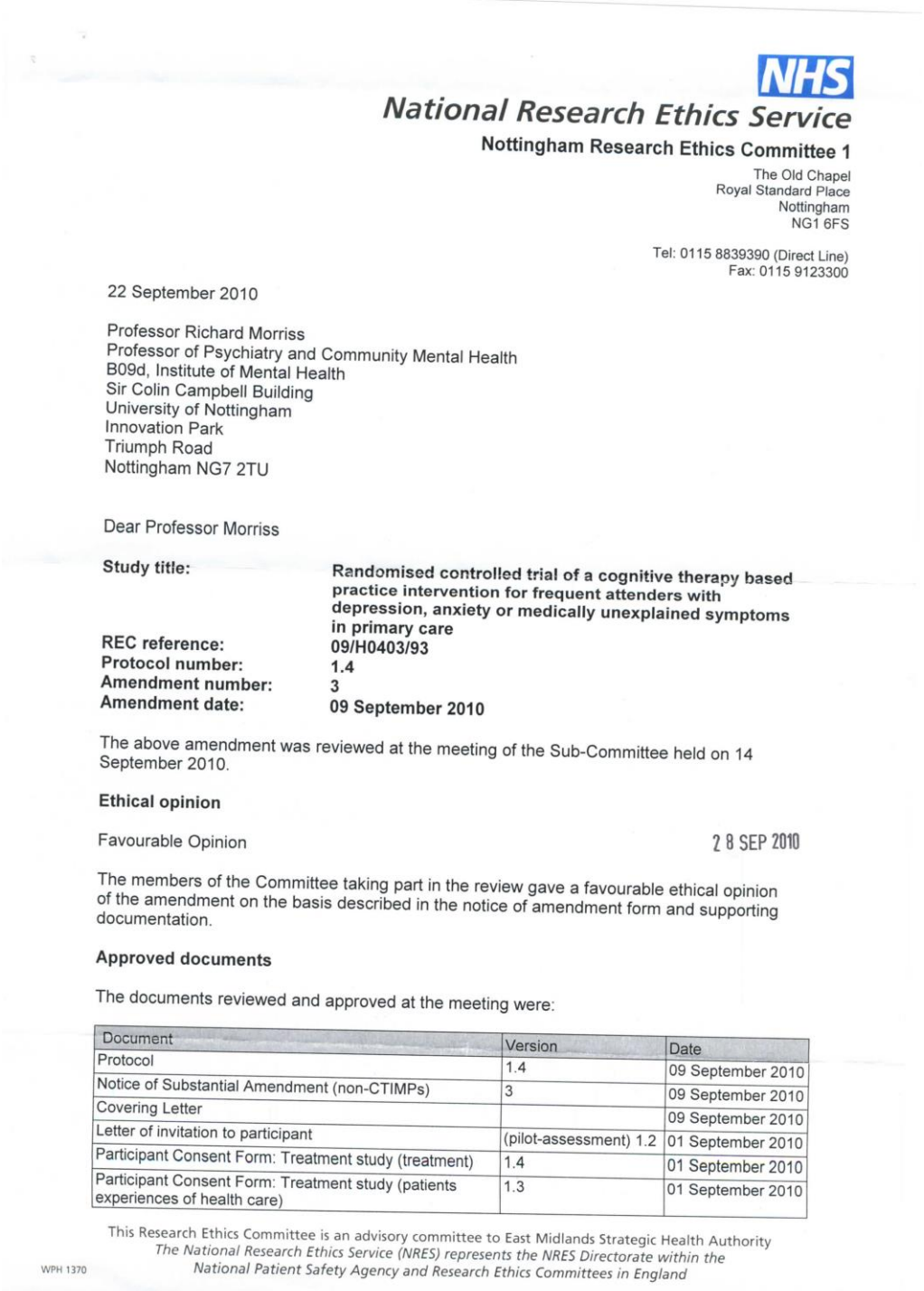
ID	Active Problems from medical records	N	Repeat medications	N
				9
				4
				4
				11
				19
				9
				5
				3
				16
				2
				6
				6
				4
				7
				12

Appendix 8: PFA SCID and HAI Scores.

ID	Mental health Disorders Diagnosis criteria met from DSMIV	HAI
PFA1	(7)Depression, Dysthymia, panic, specific phobia, Generalised Anxiety, Abridged somatoform, multi-somatoform ,	23
PFA2	(3)Depression, dysthymia., Binge eating	-
PFA3	(6)Depression, Dysthymia, anxiety, Post Traumatic Stress, somatoform, Generalised Anxiety.	35
PFA4	(7) Depression, dysthymia, panic, obsessive compulsive, generalised anxiety abridged and multi-somatoform.	20
PFA5	(8) Depression, dysthymia, generalised anxiety, abridged and multiform somatoform, hypochondriasis, body dysmorphic, health anxiety.	-
PFA6	(10) Depression, panic, social phobia, specific phobia, obsessive compulsive, Post traumatic Stress, Generalised Anxiety, Somatisation, abridged and multiform somatoform	24
PFA7	(9) Depression, panic, social phobia, specific phobia, post-traumatic stress, Generalised Anxiety, Somatoform, Abridged somatoform, multi somatoform	23
PFA8	(7) Depression, dysthymia, social phobia, generalised anxiety, somatoform, hypochondriasis, health anxiety.	-
PFA9	(3) Depression, Panic, generalised anxiety.	20
PFA10	(1) obsessive compulsive disorder	-
PFA11	(6) Depression, dysthymia, panic, social phobia, obsessive compulsive, generalised anxiety	-
PFA12	(3) Abridged and multi somatoform, somatisation.	9
PFA13	(5) Dysthymia, generalised anxiety, somatisation, abridged and multi-somatoform.	12
PFA14	(6)Depression, Dysthymia, specific phobia, post-traumatic stress, abridged and multiform somatoform	16
PFA15	(2) Abridged and multiform somatoform	18

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Appendix 9- Ethics Approval



NHS
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Nottingham Research Ethics Committee 1

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22 September 2010

Professor Richard Morriss
Professor of Psychiatry and Community Mental Health
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Sir Colin Campbell Building
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Nottingham NG7 2TU

Dear Professor Morriss

Study title: **Randomised controlled trial of a cognitive therapy based practice intervention for frequent attenders with depression, anxiety or medically unexplained symptoms in primary care**
REC reference: **09/H0403/93**
Protocol number: **1.4**
Amendment number: **3**
Amendment date: **09 September 2010**

The above amendment was reviewed at the meeting of the Sub-Committee held on 14 September 2010.

Ethical opinion

Favourable Opinion 28 SEP 2010

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

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol	1.4	09 September 2010
Notice of Substantial Amendment (non-CTIMPs)	3	09 September 2010
Covering Letter		09 September 2010
Letter of invitation to participant	(pilot-assessment) 1.2	01 September 2010
Participant Consent Form: Treatment study (treatment)	1.4	01 September 2010
Participant Consent Form: Treatment study (patients experiences of health care)	1.3	01 September 2010

This Research Ethics Committee is an advisory committee to East Midlands Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

WPH 1370

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Appendix 10: Regular Attenders Study Protocol

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Appendix 10-Protocol

Regular Attenders in Primary Care: A Case Study Approach

Version 1.2

06-12-2011Short title:	Regular Attenders project: protocol version 1.1
REC reference:	11/EM/0392
Trial Sponsor:	University of Nottingham
Funding Source:	The CLAHRC is a dual funded programme made up of 50% NIHR funding and 50% funding from NHS partners

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Professor Ruth McDonald, Professor of Healthcare Innovation and Learning, CLAHRC NDL, University of Nottingham

SYNOPSIS

Title	Regular attenders in primary care: A case study approach
Acronym	RA Study
Short title	Regular attenders project: protocol version 1.2

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Chief Investigator	Professor Richard Morriss
Objectives	1. To estimate the cost to the health service of regular attendance in primary care. 2. To clinically characterise people with regular attendance in primary care compared to normal attendance and to examine the pattern and chronicity of regular attendance, creating a typology of regular attenders. 3. To explore motivations, reasons for regular attendance in primary care and patient experience of consultation. 4. To determine the feasibility and acceptability of providing organised care within the practice enhanced by a cognitive behaviour therapy formulation and treatment package provided by cognitive behaviour therapists when required for regular attenders in primary care with depression, anxiety and medically unexplained symptoms in primary care. 5. To explore the utility of implementation analysis and organisational learning for enhancing the care of frequent attenders in primary care.
Study Configuration	Multi-centre
Setting	Primary care
Number of participants	**Case control study of clinical characteristics and economics:** 100 regular attenders [baseline interview and medical record analysis] 100 normal attenders [baseline interview and medical record analysis] **Motivation for regular attendance and patient experience:** 15 regular attenders **Cognitive behavior therapy intervention.** 50 regular attenders **Implementation analysis**

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	30 primary care staff (around 15 GPs, 5 practice nurses, 10 reception administration and managerial staff in the five practices)
Eligibility criteria	**Regular attenders:** • The patients are aged over 18, and have had 30 or more face to face GP appointments in the last 2 years.. • They give oral and written informed consent to participate in the study. **Normal attenders:** • Attended between 6 and 22 times in the last two years • Aged over 18 years • Given oral and written informed consent to participate in the study.
Description of interventions	**Case control study of clinical characteristics and economics:** 1) Baseline interviews with 100 regularly attending patients and 100 non-regularly attending patients. 2) Economic analysis of the records of 100 regularly attending patients with 100 non-regularly attending patients. **Qualitative study of reasons for regular attendance and patient experience:** • Qualitative interviews with 15 regularly attending patients. **Cognitive behaviour therapy intervention:** • Cognitive behaviour therapy delivered by qualified experienced therapists for 50 regular attending patients with depression, anxiety or medically unexplained symptoms. **Implementation analysis:** • Interviews with 30 practice staff members, observation of practice meetings in relation to this topic and documentary analysis of practice and trust policies.
Duration of study	4 years – study will complete no later than 30 September 2013

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ABBREVIATIONS

A&E	Accident and Emergency
BMI	Body Mass Index
CBT	Cognitive Behaviour Therapy
CEAC	Cost Effectiveness Acceptability Curves
CI	Chief Investigator
CLAHRC	Collaborations for Leadership in Applied Health Research and Care
CSIP	Care Services Improvement Partnership
CSRI	Client Service Receipt Inventory
DMC	Data Monitoring Committee
DoH	Department of Health
ESR	Erythrocyte Sedimentation Rate
GCP	Good Clinical Practice
GLM	Generalised Linear Model
GP	General Practitioner
HAI	Health Anxiety Inventory
IAPT	Improving Access to Psychological Therapies
INR	International Normalised Ratio
MRC	Mental Component Scores
MUS	Medically Unexplained Symptoms
NHS	National Health Service
NICE	National Institute for Clinical Excellent
NMAR	Not Missing At Random
QALY	Quality Adjusted Life Year
QoF	Quality and Outcomes Framework
PCT	Primary Care Trust
RCT	Randomised Controlled Trial
REC	Research Ethics Committee
R&D	Research and Development
SCID	Structured Clinical Interview for DSM-IV
UIC	Unique Identifying Code

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Appendix 1: Gantt chart 0

Appendix 2: Cognitive behaviour formulation for frequent consulting and its underlying health problems .....

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BACKGROUND FROM LITERATURE AND REVIEW OF PRELIMINARY FINDINGS

The regular attender's project, (09/H0403/93); a Randomised Controlled trial of a cognitive therapy based practice intervention for frequent attendees with depression, anxiety or medically unexplained symptoms in primary care has been running for twelve months. After a six month delay and then six months running our pilot, it became evident that the study was not ready for a trial as originally proposed.This project is a follow-on to that as we feel there are clearly additional important factors about the patients and organisation of their care that were inadequately understood. Patient recruitment into treatment was poor (only two and a half percent of potentially available cases). Assumptions made in the original design of the study from the literature, and previous research by the authors using samples of patients with medically unexplained symptoms (MUS) recruited from the waiting room, were not sustained. At an individual patient level, changes are not made after a brief course of treatment but require a sustained strategic approach led by the GP (Bellon et al, 2008) that may be informed and supported by a theoretical frame work such as cognitive behaviour therapy (Escobar et al, 2007). Changes in primary care practice designed to increase access to services and patient choice may have also compromised continuity of care except in the case of a few specified conditions such as diabetes. Furthermore, to make any sustained impact on the problem, it is likely that a multimodal approach to the problem will be needed that will require additional initial funding, re-organisation of care within practices, and training and support of existing and possibly additional staff to potentially improve the quality of life for the patient, reduce the cost of the problem and free up access to resources for other patients. To understand exactly what is required to address this problem and whether it is even cost effective to address it requires a more in depth understanding of the nature of the problem and its costs. Such a study needs to go beyond previous research into broad diagnostic categories and other forms of description to the level of formulating treatment plans, the identification of specific training needs in staff and the organisation of care within practices that might be required. We now propose to address the main issues below that have arisen throughout the pilot phase.

- Economic cost and patterns of care over 10 years.
- Clinical characteristics (typology).
- Drivers behind attendance and barriers to some potentially important aspects of care e.g. to address suspected mental health and social problems.

The research team is led by Professor Richard Morriss, study Chief Investigator (CI), and a team of Collaborations for Leadership in Applied Health Research and Care (CLAHRC) staff providing expertise, time and support including health economists, health policy specialists and general practitioners. The core team now consists of one full-time research associate, one part-time research associate, one part-time Cognitive Behaviour Therapist, one research clinical psychologist and an implementation researcher; to which will be added a second part-time cognitive behaviour therapist and further administrative support.

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Please note that the research literature uses the term "frequent attenders" which has a variety of definitions from study to study. We use this term in the literature review. However, a panel of service users that we recruited to review study documents in this study found the term "frequent attender" to be offensive as it implies a criticism of the patient when there are no rules or guides as to how many appointments a patient should have with their GP. The term may be seen as pejorative and blaming the patient by some patients who do not realise that they attend much more than other people of the same age and gender (Neal et al, 2000b; Hodgson et al, 2005; Dwamena et al, 2009; Peters et al, 2009). Instead the service user panel recommended a more neutral term "regular attender", which we have given a more precise meaning of attendance with the GP on 30 or more occasions over two years, excluding routine monitoring, the top ten per cent of attenders in our pilot work (Smits et al, 2009) . Therefore we will use the term regular attender throughout the protocol and on all study documents, including patient information sheets and consent forms, except in the literature review/background to the study where for the sake of accuracy we use the terms that the authors used (frequent attendance).

Features of frequent attendance: definition, use of services and economic cost

In primary care, the top three per cent of attenders account for fifteen per cent of all consultations (Neal et al, 1998), while patients who were in the top ten percent of attendance for two consecutive years (two per cent of a practice list) account for eleven percent of all consultations (Smits et al, 2009). A definition of frequent attendance that is restricted to the top 10 per cent of attenders in primary care is discriminative in terms of patient characteristics compared to broader definitions (Luciano et al, 2010). Frequent attenders consume five times as many prescriptions and hospital contacts compared to less frequent attenders (Heywood et al, 1998). Attendance rates vary with age and gender, with higher rates for females of all ages than males, and higher rates from males over 45 years than males under 45 years of age (Howe et al, 2002). Only one in seven frequent attenders (top ten per cent of attenders age and gender adjusted) over one year continue to be frequent attenders over the next year, but frequent attendance over two years usually persists for a further year (Smits et al, 2009). Frequent attendance is more common in some practices than others and from doctor to doctor, but most frequent attenders consult all doctors in the practice so a practice based initiative is required to limit frequent attendance (Neal et al, 2000a). Frequent attenders consult practices with medically appropriate problems such as injuries at the same rate as other patients of the same age and gender but they consult much more for other problems such as MUS (Bergh et al, 2005).

There are no formal economic studies of the problem of frequent attendance in primary care using primary data collection in the United Kingdom (UK). In a study based on two American primary care practices that was then extrapolated to the national United States health service, patients with somatoform disorders (MUS with or without depressive or anxiety disorders) were estimated to cost the United States health service $256 billion per year (Barsky et al, 2005). Using this data and some data on the prevalence of somatoform disorders

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and their use of health services from a variety of studies with a range of different case definitions and resource use data, the Sainsbury's Centre for Mental Health estimated that patients with both mental health and physical health problems including MUS may be in the region of eight billion pounds per year (DoH, 2008a) because of the frequency of health care use in this group of patients. However, this figure does not relate specifically to the problem of frequent attendance in primary care, but a group of patients with MUS who account for the majority but not the entirety of frequent attenders and it is not based on primary data collection in the UK health care system. A better understanding of the costs of frequent attender patients is required to understand the scope of the problem and how much resource would be worth spending on the problem to improve outcomes for patients and release resources for other patients. The costs of health care use among frequent attenders may be considerable. In the pilot phase of this study using data from 58 patients, the majority of patients consistently utilised primary and secondary care services at a higher than expected rate over a ten year period, and the increased resource use seemed to be related to life events in the last twelve month period.

Patient characteristics

Patients who frequently attend tend to share a number of common socio-demographic characteristics, health problems and psychological characteristics. Frequent attenders are more likely to live alone, be single, separated or divorced, unemployed or on a disability pension, to be less well educated, from lower social classes, or to be of South Asian origin and being born outside the country they now reside (Heywood et al, 1998; Scaife et al, 2000; Kersnik et al, 2001; Vedsted and Olesen, 2005; Ferrari et al, 2008; Luciano et al, 2010). In terms of health problems, they are likely to suffer from a range of different chronic physical health problems, together with mental health disorders such as depressive disorders or anxiety disorders, as well as functional somatic syndromes and MUS (Heywood et al, 1998;Baez et al, 1998; Bellon et al, 1999; Dowrick et al, 2000; Kersnik et al, 2001; Ronalds et al, 2002; Wyke et al, 2003; Kapur et al, 2004; Smith et al, 2005; Ferrari et al, 2008; Luciano et al, 2010). Around 60 per cent of frequent attenders have depressive and/ or anxiety disorders (Smith et al, 2005) and one third of frequent attenders have functional somatic syndromes or MUS (Jyvasjarvi et al, 2001).

There is a considerable overlap between frequent attendance and the presence of a depressive disorder, an anxiety disorder or MUS, with many patients having more than one of these conditions at the same time (Barsky et al, 2005). Furthermore many patients with depressive disorders or anxiety disorders develop MUS over time and vice versa (Skapinakis et al, 2004). Furthermore, frequent attendance, the number of somatic symptoms and sleep problems are associated with a 12 fold increase in the likelihood of new onset functional somatic syndromes such as chronic widespread pain in the following year (McBeth et al, 2001; Gupta et al, 2007). Additional negative life events (particularly conflicts and losses) substantially increased the likelihood of long-term sick leave or disability pension among frequent attenders compared to normal attenders (Bergh et al, 2007). Therefore,

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psychological interventions that promote coping with conflict and losses may reduce the economic burden to society as well as relieve distress. Psychological characteristics of frequent attenders include a history of childhood abuse or neglect and a history of childhood illness exposure (in self or members of family) (Kapur et al, 2004), and compared to other attenders, less sense of coherence but no more life events (Bergh et al, 2006), and greater health anxiety and hypochondriacal beliefs (Vedsted et al, 2001; Jyvasjarvi et al, 2001).

Despite the above descriptive information, none of the information provides enough understanding of the motivation for frequent attendance nor offers sufficient clinical insight to develop therapeutic interventions for this group because the vast majority of these patients have entrenched health seeking behaviour and a variety of inter-related physical, emotional, lifestyle and social problems that are related to this health seeking behaviour.. Most studies define frequent attendance over only one year and given that in six out of seven patients (Smits et al, 2009), frequent attendance spontaneously returns to normal after one year, it is possible that previous studies are not informative in relation to patients who persist in their frequent attendance over two or more years.

What are the reasons for frequent attendance?

Qualitative studies throw some light on the function that frequent consultation with the general practitioner (GP) serves for the patient who is a frequent attender. Neal et al (2000b) showed that frequent attenders had a set of idiosyncratic ground rules for consultation that depended on: 1. the perception of the patient of the GP's role e.g. frequent attendance was justified because the GP was employed to talk to, reassure, help and advise; 2. The nature of the relationship with the GP and what the GP thinks of them e.g. they are less likely to consult so frequently if they thought the GP considered them to be a nuisance or hypochondriacal; 3. Their current perception of their symptoms and problems in the light of past experience and knowledge of the natural history of their symptoms – if the natural history of the symptom was understood then the decision and timing of consultation was easier to decide upon; 4. Health anxiety where the fear of consulting outweighs the fear of not consulting; 5. Passivity and external locus of control – the patient believes that their consulting behaviour and ability to control some of their symptoms was beyond their control; 6. Mental health problem such as depression increase consultation behaviour; 7. The decision to consult was corroborated by family and friends; 8. The decision to consult might have desirable outcomes e.g. quicker return to work; 9. Familiarity with the processes for gaining access to the GP. The frequency of consultation was much more likely to be increased if several of these factors were present together and less likely to occur if symptoms came under control, if they consulted elsewhere e.g. chiropractor or if there were changes in life circumstances.

In a second qualitative study carried out in Liverpool (Hodgson et al, 2005), two patterns of consultation were discerned: a larger group who were unaware just how frequently they had attended and a second group who related their frequent attendance to a particular crisis in their life that would pass. In general, patients who frequently attended viewed the GP as a

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respected authority figure who is the most appropriate figure to consult for distinctive and extensive physical symptoms that the patient perceived to require medical care and reassurance. They often described a relatively high number of physical sensations that were difficult for them to endure and required reassurance from their family doctor. Despite holding the doctor in high esteem, most frequently attending patients expressed some dissatisfaction with their treatment, typically in relation to the lack of understanding of their problems by the GP, the lack of an explanation for their problems that they could endorse and the progress made in achieving a resolution of their problems. Most reported obstacles in the health system to obtaining an appointment with the GP but all were confident of obtaining a consultation if they required it. This second study therefore confirms certain findings from Neal et al (2000b), namely that the GP was the most appropriate person to consult, frequently attending patients had high health anxiety, some dissatisfaction with the outcome of consultation because their needs had not been addressed, and familiarity with the health system to such an extent that they would find their way round logistical barriers put in their way. Simply diverting care from the GP would not be effective in improving clinical outcome or even reducing attendance with health professionals.

In a third qualitative study of frequent attenders with MUS from the US (Dwamena et al, 2009), three groups of patients were identified: 1. Patients who had psychological insight into the psychological causes of MUS but the psychological insights had neither reduced the intensity of their symptoms or the use of the GP; 2. A group of patients with little psychological insight and capacity to help themselves who had vague symptoms and a strong sense of entitlement to be excluded from normal social roles; 3. A group of patients with high health anxiety and concern that a diagnosis may have been missed who tended to be dissatisfied with their health care and focussed on their symptoms. The second group might be characterised as having alexithymia, high passivity and low sense of coherence. In all three groups, an approach targeted at improving the patient's mental health would not necessarily reduce the frequency of consultation. All three studies lend support to the clinical assumption in the present study, that in order to be effective clinically and economically, both the patient's mental health needs and their association with consultation need to be addressed.

Health anxiety and somatisation

From a theoretical perspective, the most common explanation for the increased health seeking behaviour that marks frequent attendance is that patients are seeking reassurance about health and have developed health anxiety (Salkovskis, 1989; Lucock et al, 1997; Salkovskis et al, 2002; Barsky and Ahern, 2004; Greeven et al, 2007). Health anxiety will physiologically increase muscle tension through the body that might be experienced as pain, result in prolonged increases in the release of cortisol and other stress-related symptoms that might explain the presence of fatigue, and lead to both sympathetic and parasympathetic overactivity resulting in symptoms such as palpitations, breathlessness, faintness and diarrhoea. The anxiety including these physical symptoms would normally habituate and lessen over time if these symptoms are not given greater importance through such activities

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as help seeking from doctors. However, unless doctors explain and normalise the presence of these symptoms, lack of clarity in communication, lack of trust in the person delivering health care advice, and investment in their importance through investigations, referrals and prescriptions is likely to maintain or increase the health anxiety (Salmon et al, 2006; Salmon , 2007). Health anxiety is often present even when there are underlying physical health problems, particularly when there has been adverse previous experience of health care.

Somatisation refers to the physical presentation of mental health problems or an emphasis on the physical health problems but neglect of its psychosocial consequences. It seems to be associated with negative views about mental health, emotional and social issues as being a sign of moral weakness and something that should be dealt with outside health services. The function of somatisation is therefore blame avoidance and is more common in people who come from families that hold similar views and personal experience involving violation of trust in authority e.g. abuse and not being believed or being helped with abuse (Goldberg and Bridges, 1988; Garcia-Campayo et al, 1996; Kirmayer et al, 1996; Salmon et al, 1999; Arnold et al, 2004).

In the CBT treatment part of the pilot study seven out of eight cases of regular attenders had both high health anxiety and somatisation. The CBT formulation not only recognises the presence of these phenomena but seeks to explain why these features arose, why they are still present and how these are related to higher rates of health care seeking behaviour than expected, underlying health problems and their social context. There are a range of specific management actions that arise from this once the formulation has been made. By giving a theoretical and developmental explanation for why otherwise inexplicable and extreme consulting behaviour arises, then at the very least a more understanding and empathic response is likely to be generated by GPs to these patients (Dowrick et al, 2008). However, it should also develop a strategic management plan over the short and medium term. What is yet to be understood until this project is completed is how such a formulation is best communicated to the GP, the rest of the primary care team and the patient, and how any action plans can be supported and developed in a sustainable way e.g. through training of the practice team, internal supervision and support within the practice for this type of work with an emotionally challenging group of patients with complex problems, and what external support needs to be provided e.g. supervision, incentives to do this work.

Therefore in the pilot study we have evidence of a set of relevant theoretical constructs to frequent attendance and a methodology for further investigating the problem from a therapeutic perspective. However, there is a need to investigate a larger group of regular attenders, and to examine their representativeness in terms of other regular attenders and how they contrast to normal attenders in terms of severity of health anxiety and the presence of somatoform disorder.

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Intervention studies

Until recently there was conflicting evidence whether interventions for frequent attenders were effective in terms of reducing healthcare utilisation over the following year, possibly because of the high rate of spontaneous improvement in frequency of consultation among people who frequently attended over one year (Smits et al, 2008). However, recent trials show evidence of improvement in mental health outcomes and cost effectiveness in patients who were defined as frequent attenders over two years with depressive episodes (Katzelnick et al, 2000; Simon et al, 2001) or frequent attenders over two years with MUS (Smith et al, 2006). These interventions employed a stepped care intervention involving patient education, antidepressant treatment, monitoring of adherence to medication or nurse delivered antidepressant medication, reduction of analgesics, anxiety management and rehabilitation respectively.

The simplest effective intervention with frequent attenders with somatoform disorders has been the psychiatric consultation letter (Smith et al, 1986). Care within the practice is organised so one GP initiates a programme of care for the patient. The GP gives a longer appointment than usual, taking a thorough history and physical examination, followed by any investigations that the GP thinks are clinically indicated. The GP then arranges to see the patient again to review these results. The GP explains that the patient has a problem with "somatisation" where the patient has an excessive focus on the body and becomes worried when there are changes in the body. The GP offers to see the patient on a frequent basis for a period of time to check that this is the case and to gain the trust of the patient. However, the GP tells the patient that he will not carry out more investigations unless new symptoms develop and a physical examination indicates that further investigation is clinically warranted. After a period of four to six weeks, the number of appointments is decreased to monthly then two monthly with the same GP. The practice organises care so all requests for urgent appointments or to see other GPs are discussed with the lead GP and are strongly discouraged unless there is an urgent clinical indication. Randomised controlled trials (RCTs) of this intervention has reduced health care utilization and increased physical function in patients who frequently attended with somatization but has not improved mental health, social function outcomes or the perception that they remain unwell (Smith et al, 1986; Dickinson et al, 2003). However, this intervention is not appropriate for frequent attenders with depressive or anxiety disorders because the underlying depression or anxiety is not treated.

Another approach that has been proposed is the frequent attendance status consultation where the patient and their GP would have a 30 minute consultation (the GP is paid additionally for this extra consultation) with the patient (Vedsted et al, 2002). GPs do not recommend such a consultation for patients with two or more physical health conditions, and an exceptionally poor or good relationship with the patient. They would be likely to recommend such a consultation for patients with a mental health problem such as depression and anxiety, high health anxiety or health concern, MUS and one or more social problems. GPs would recommend approximately 25 per cent of the patients for such a consultation and

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approximately 80 per cent of patients offered such a consultation stated they would accept it (Vedsted et al, 2002). There is no evidence concerning the clinical or cost effectiveness of such an intervention but such research shows that both GPs and patients who frequently attend primary care perceive the approach to be of some value (Vedsted et al, 2002). In particular, GPs saw the value of the approach to be largely confined to frequently attending patients with depression, anxiety and MUS.

Bellon et al (2008) reported that an intensive training course for GPs lasting 15 hours reduced the frequency of consultation over one year in a sample of 209 patients in Spain. The intervention formulated a hypothesis for each patient's frequent attendance on organisation of care, doctor-patient relationship, social and cultural, and health problem grounds. However, previous work by the authors (Morriss et al, 1999; Appleby et al, 2000; Morriss et al, 2007) indicates that such a long course of training is unlikely to be acceptable to the vast majority of working British GPs so this approach is unlikely to be feasible in British primary care.

So far, no intervention study with frequent attenders over two years has explored the use of a cognitive behaviour therapy (CBT) formulation of the patient's physical and mental health and its relationship to frequent consultation behaviour. Such a CBT formulation based treatment may be effective if the whole practice, including the GP that the patient prefers to consult, is involved. Qualitative studies by Neal et al (2000b), Hodgson et al (2005) and Dwamena et al (2009) indicate that the reasons for high consultation rates can be formulated in the context of their mental health problems, coping strategies and access to practice and other health professionals. The RCT performed by Bellon et al (2008) establishes the value of individually formulating the reasons for frequent attendance. As well as depression and anxiety for which CBT is well-established (NICE, 2004), CBT based on a formulation is effective symptomatically and functionally for health anxiety and hypochondriasis (Barsky and Ahern, 2004; Greeven et al, 2007), and for MUS (Escobar et al, 2007). Therefore a formulation of the reasons for frequent consultation based on CBT principles in addition to stepped care, the use of antidepressants and the use of CBT for depression, anxiety, health anxiety or MUS has the potential to reduce the frequency of consultation in primary and secondary care and to improve underlying mental health problems and function.

Unfortunately recruitment to the CBT intervention in the pilot study has been poor although in the eight cases where recruitment has taken place, the formulation has been seen to be valuable by GPs. Perhaps unsurprisingly some of the mental health problems of frequent attenders are quite entrenched and a medium to long-term perspective on management based on the formulation may be an appropriate direction to follow. However, the literature is clear that interventions for somatisation associated with frequent attendance require continuity of care, clear communication and organisation of care within the practice so that most consultations are with a small number of practice staff, ideally predominantly one GP.

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Policy and implementation of care

Continuity of care and its organisation through independently contracted GPs acting as a primary care gatekeeper has been a stable and defining feature of British primary care for many years (Ustun and Sartorius, 1995; Lewis and Dixon, 2005). However, since the 1990s, there has been a greater emphasis on increasing access to primary care and its provision both within traditional primary care practices e.g. salaried partners, greater number and roles of primary care nurses, appointments arranged online, and outside e.g. NHS Direct, Walk-in centres, commuter surgeries (Chapman et al, 2004; Lewis and Dixon, 2005; King's Fund, 2011). Coupled with this in England there have been increasing market based reforms e.g. Payment by Results (Department of Health, 2002), which have encouraged secondary care to strive to increase health care activity with little independent monitoring to check the appropriateness of this activity (Rosen et al, 2006) and few low cost community developed alternatives (Evans et al, 2005). The sum of these developments is that it is increasingly difficult for primary care to provide continuity of care and the organisation of care, which seem to be an important element of management of frequent attendance associated with MUS and related health anxiety. The increasing range, accessibility and activity of primary and secondary care services pose greater problems than previously in consistency of therapeutic approach and clarity of communication, given that differences in communication about clinical matters tends to heighten health anxiety (Salkovskis, 1989; Lucock et al, 1997). Increased health anxiety might in turn lead to further help seeking from health care services and increased attendance in primary and secondary care, a vicious cycle (Salkovskis, 1989).

Recent NHS investment in Improving Access to Psychological Therapies (IAPT) (DoH, 2008b) has provided greater access in primary care to National Institute for Clinical Excellence (NICE) guideline recommended psychological treatments such as CBT for patients with depression and anxiety. The most recent guidance from the Department of Health (DoH) has extended IAPT treatment to MUS and the management of psychological morbidity accompanying long-term physical illness in primary care (DoH, 2008). The assumption has been that psychological treatment could pay for itself by returning people back to work and preventing people from requiring specialist secondary care services (Layard, 2006). However, people with MUS, particularly those who frequently attend primary care services, may be unwilling to consult health professionals offering psychological treatment of other forms of mental health care (Arnold et al, 2004), a finding born out in the pilot work in this study. Therefore the assumptions about the potential savings to be made out of developments such as IAPT may not be realised.

More recently, there has been a growing recognition that primary care practices vary widely in the nature and standard of health care provided (Lewis and Dixon, 2005; King's Fund, 2011). Not only are these issues apparent within practices in the same area, they are also evident by examining the considerable variation in almost every health indicator when examined at a Primary Care Trust (PCT) or local authority area level (Rightcare, 2010). It is possible that practices are particularly likely to show divergent practices in health care provision for

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patients with complex health problems and those who frequently attend primary care. Such differences in organisational, clinical, training and economic aspects of care are worth examining to clarify what aspects of care are likely to increase or decrease such variation in the standard of care. Furthermore there are further changes planned by the Government to the commissioning of secondary care services that will impact on primary care practice emphasising greater integration of care. The precise legislation and how it will impact on frequent attendance in primary care and the time scales for such changes are as yet unclear.

STUDY OBJECTIVES AND PURPOSE OF REVISED PROJECT PLAN

PRIMARY OBJECTIVE

To use a mixed methods case study approach to gain a better understanding of the needs of regular attenders in primary care.

SECONDARY OBJECTIVES

- To estimate the cost to the health service of regular attendance in primary care and to examine the pattern and chronicity of persistent regular attendance.
- To clinically characterise people with regular attendance in primary care compared to normal attendance.
- To explore reasons for regular attendance in primary care and patient experiences of consultation.
- To determine the feasibility of providing organised care within the practice enhanced by a cognitive behaviour therapy formulation and treatment package provided by cognitive behaviour therapists when required for regular attenders in primary care with depression, anxiety and medically unexplained symptoms in primary care.
- To explore the utility of implementation analysis and organisational learning for enhancing the care of regular attenders in primary.

The design of the study is outlined in figure 1.

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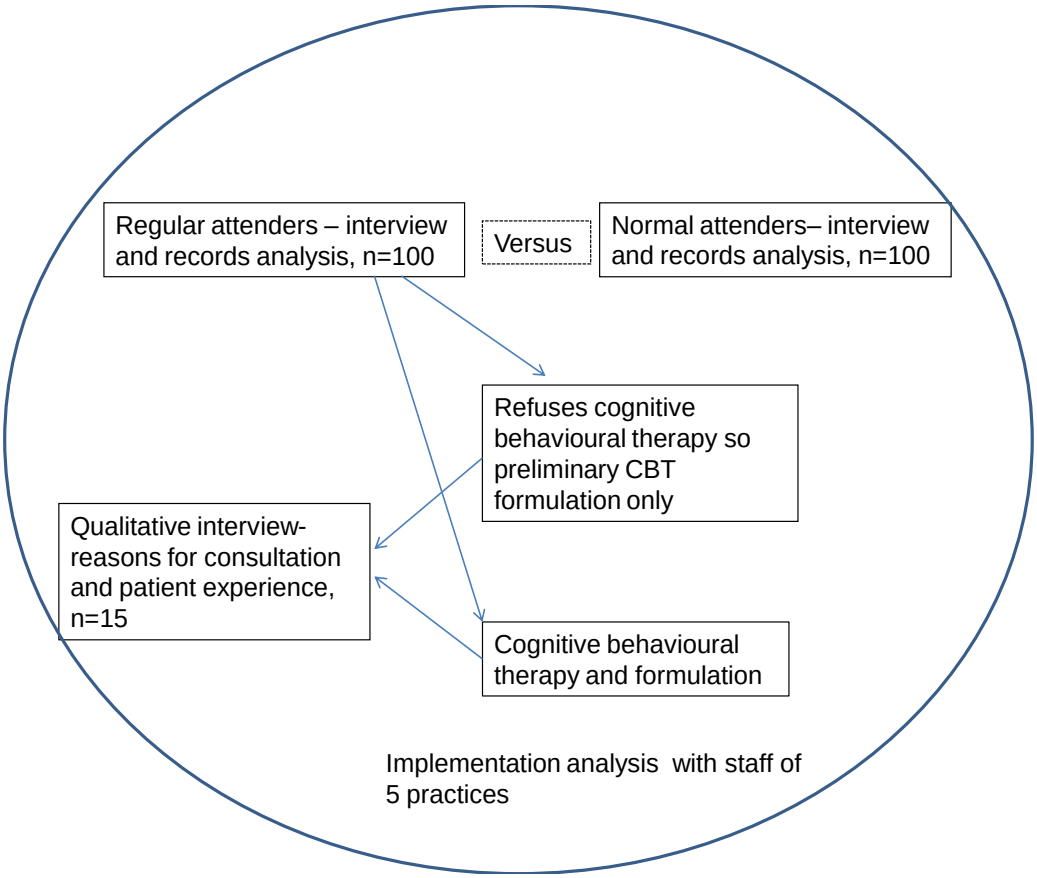


Figure 1. Design of the study.

A case control design is being adopted to compare the clinical characteristics and patterns of health care use over a ten year period of approximately 100 patients who are regular attenders (30 or more face to face attendances with GPs over two years) with 100 patients who are normal attenders matched for age, gender and practice. A maximum variance sample drawn from the regular attenders group will explore drivers, barriers and experiences of health care attendance in primary and secondary care settings from the patient's perspective. An extended pilot study of the cognitive behaviour therapy and formulation is required to understand the feasibility and acceptability of this approach in a patient with a diversity of problems of patients with regular attendance with depression, anxiety and medically unexplained symptoms (95% of regular attenders have these mental health problems together with one or more physical health problem from our initial analysis of cases). The implementation analysis will help to understand the approaches of practices to the organisation of care for these patients within the practice given that research has shown the benefit of an organised approach to the care of regular attenders in primary care.

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STUDY MANAGEMENT

The Chief Investigator Professor Richard Morriss will have overall responsibility for the conduct of the research. The CLAHRC Manager (Head of Programmes) of Nottinghamshire Healthcare Trust will have overall responsibility for financial monitoring and reporting.

The trial will be monitored by an independent and external CLAHRC Scientific Committee. In addition a Study Management Group will be established and will include co-investigators, the research staff employed to work on the study, service users, local NHS commissioners and CLAHRC managers. The study management group will review study progress, adherence to the protocol, standard operating procedures, quality assurance, research governance and financial management. It will meet quarterly for the duration of the project. Regular monthly minuted meetings between the PI and the researchers employed on the study will also take place.

At the end of the study data will be archived by the University of Nottingham and kept for the period of time required by the employer of the Chief Investigator.

DURATION OF THE STUDY AND PARTICIPANT INVOLVEMENT

Duration of the study

The study will commence in December 2011 (following ethics and R&D approvals) and is expected to continue until September 2013. Participants' involvement with the study will end with the baseline interview or qualitative interview The study will be considered complete in March 2013 and although write up and analysis will be continuous, this will allow a six month period of final write up and analysis when participant involvement is complete.

RECRUITMENT, STUDY REGIMEN & METHODS OF ANALYSIS

1. Case control study of clinical characteristics and economic study of regular attenders and normal attenders

Inclusion criteria-
Regular Attenders

- 30 or more face to face contacts with GP or practice nurse within the last 2 years
- aged over 18 years old,
- consented to take part in the study.

Normal Attenders

- **aged over 18 years old**

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- between 6 and 22 face to face contacts with GPs or practice nurses over 2 years including routine health care checks. A previous study of 828 consecutive attenders using the same electronic record systems in eight Nottinghamshire and Derbyshire practices show that the middle 68 per cent of consulters averaged between 3 and 11 face to face consultations with the GP per year.

- consented to take part in the study.

Exclusion criteria

Regular Attenders

- Contacts cannot include routine health care checks e.g. international normalised ratio (INR) monitoring, blood pressure monitoring, changes of dressings.

- Patients aged less than 18 years are excluded.

Normal Attenders

- Patients under 18

- Patients who have had below 6 or above 22 appointments in the last 2 years.

Recruitment

Regular attenders will be identified from four or five practices in the CLAHRC region of Nottinghamshire, Derbyshire and Lincolnshire and each is matched by age, gender and practice to a normal attender to control for practice and socio-demographic characteristics. Approximately 100 regular attenders and 100 normal attenders will be recruited. Pilot work in three practices shows that 30-40% of regular attenders will agree to be interviewed but previous work suggests that a higher proportion of normal attenders will agree to be interviewed. The representativeness of the selected regular attenders will be compared to the overall sample of regular attenders in the four or five practices and the overall list in terms of age and gender among patients aged 18 years or over.

Study regimen

All eligible patients will be invited to have a baseline interview (see below). To meet the requirements of the Data Protection Act, the identification of patients who meet the inclusion/ exclusion criteria from the electronic record will have to be performed by a member of the practice team via a database search. Practice staff will send eligible patients a study pack containing an invitation letter (on practice letterhead) inviting them to take part in the study, an information sheet, describing the study, a 'consent to contact' form and a stamped addressed envelope. If patients are interested in finding out more about the study and speaking to a researcher, they are asked to return the 'consent to contact form' to the study researcher in the stamped addressed envelope provided. The consent form will also ask

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the patient's permission for the researcher to access their anonymised medical records even if they do not wish to be interviewed. The researcher will then telephone the patient to discuss the study further, answer any queries they may have, and if verbal consent is given, arrange a time for interview.. One reminder letter (on practice letterhead) will be posted by practice staff to eligible participants who did not respond to the initial invite. In some instances where the GP feels the patient may be suitable for the study but the patient has not responded to invitations to take part, the GP may approach the patient directly and make an appointment to see them and using a form of words developed by the GP, research team and a service-user, explain the study.

Measures and procedure

Each regular attender and matched normal attender will be interviewed by two members of the researcher team. This will take place either at their general practice or at home. The purpose of this interview is to explore the presence or absence of psychiatric disorder including depressive disorder, anxiety disorder and somatoform disorder (American Psychiatric Association, 1994) using a structured psychiatric interview (SCID-1) (First et al, 1997), the presence and degree of severity of health anxiety over the last week (Salkovskis et al, 2002), quality of life on the EQ5D (EuroQol Group, 1990), and information on health and social care, work and benefits using the Client Receipt Service Inventory (CSRI) (Beecham and Knapp, 2001), see Table 1.

SCID	SCID-1 for DSM-IV (Structured Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders)(First et al, 1997)
CSRI	CSRI Client Services Receipt Inventory (Beecham and Knapp 2001)
EQ5D	EQ5D Standardised instrument for use as a health measurement (Euroqol group 1990)
HAI Short Week	Health Anxiety Inventory (HAI, a 18 item self-rated measure of health anxiety, Salkovskis et.al, 2002)

Table 1 Baseline interview

In addition, information on active physical health problems currently and in the last two years, body mass index (BMI), smoking and alcohol consumption, and exercise will be extracted from practice records. Practice records will be used to examine the pattern of primary and secondary care use over the previous ten years in both the regular attenders and the normal attenders. In theory, increased health care use may follow life events and life difficulties in the preceding six to twelve months among patients with regular attendance related to somatisation (Hennigsen et al, 2007).

We will also examine the accuracy of recall by patients over the previous three months compared to health care contacts recorded in the primary care record by comparing the percentage agreement between the number of contacts with members of the practice

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recalled between the regular attenders and normal attenders. The number of contacts with the core primary care team in the practice is likely to be accurately recorded in the patient's practice electronic record. There is some evidence that regular attenders may not accurately recall health care contacts and do not realise how frequently they are attending (Peters et al, 2009; Dwamena et al, 2009).

Statistical analysis in case control study

Burton et al (2011) showed that 93 (48%) of patients with medically unexplained symptoms diagnosed by secondary care physicians on two or more occasions and referred at least three times in the last five years had depressive and anxiety disorder compared to 38 (25%) patients only referred only once to secondary care in the previous five years (odds ratio 2.6 (95% confidence intervals 1.6, 4.1). These groups seem broadly similar to the regular attenders and normal attenders in the current study. A sample size of 100 regular attenders and 100 normal attenders should have 90% power to show a difference at the 5 per cent level of significance on two tailed testing. Such sample size may not be large enough for concrete inferences, in particular for some multivariate analyses proposed below, any descriptive statistics from this study should provide information for future planning of in depth research and randomised controlled trials.

The regular attender and normal attender groups will be compared on the prevalence of mental disorder (depressive disorder, anxiety disorder, somatoform disorder, overall prevalence of mental disorder), mean number of active physical health problems, distribution of severity of health anxiety, proportion of obesity on BMI, mean scores on smoking, alcohol consumption and exercise, and utility related quality of life on the Euroqol EQ5D.

Univariate analysis to test differences between the two groups will be performed using t-test for group means or geometric means if logarithm transformation is required for variables with skewed distribution. Chi-squared test will be used for group differences in categorical variables. To examine agreement in some key information of service use between patient recalls and primary care records, we shall use non parametric correlation analysis which includes Spearmen's rank correlation coefficient, Kendall tau, and Kappa coefficient for different outcome measures where it is appreciated.

Multivariate regression analyses will be conducted to identify factors significantly associated with frequency of primary care contacts by regular and normal attenders separately. Factors identified for each group will provide information for qualitative study as well as typology study. Important variables (either statistically significant or clinically important) for each group of patients will be used in a discriminant analysis which could further select a list of variables that best reflect different characteristics of the two groups and separate them in principle of a maximum distance. In regression analysis we will use generalised linear model (GLM) so that different dependent variables will be analysed in different type of model, i.e. linear regression for continuous variables, logistic for binary and multinomial for categorical variables. To examine possible relationship between number of primary care contacts and life events recorded in multiple episodes over time, we shall use a two-level bivariate regression

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model. In the analysis, patient is level 2 unit and episode time level 1 unit. Both number of life events and number of primary care contacts will be the dependent variables. Both variables will be fitted in the model simultaneously so that their correlation coefficient could be estimated within patient. A level 2 variance will be estimated to take into account variability of the variables between patients. Difference in the degree of correlation between the case and control groups will be examined and tested in the model. Adjusting for confounding will be considered in the model whenever it is necessary.

The SPSS package will be used for descriptive, univariate and discriminate analyses. The MLwiN will be used for GLM models as well as multilevel models analyses.

Health economics in case-control study

The study provides a unique opportunity to examine the health care costs longitudinally of this group of patients compared to a normal distribution of patients. The health and resource patterns for regular attenders have not before been compared to the resource cost for a normal population. This work will give a real opportunity to establish the true cost to society of a regularly attending group of patients. Whilst health economics does not generally consider burden of illness studies to be a good use of time unless we know the true resource costs of this group of patients, we cannot establish the likely willingness to pay for an intervention that may reduce the costs incurred by these regularly attending patients. Logically any intervention that costs less than the current annual treatment cost for regular attenders will at least probabilistically be potentially cost effective.

We will examine health and social care costs over the preceding 10 years and subsequent 12 months from baseline assessment from primary care records in both the regular attenders and normal attenders who have consented to the study. For each preceding year over the last 10 years, information will be collected on the number of contacts and missed appointments with the GP (at surgery, home or telephone contacts), practice nurse, community nurses, counsellors, physiotherapists, occupational therapists, social workers, community workers, NHS Direct, drop-in centres and home help, prescriptions, investigations, secondary care in-patient and out-patient care, and emergency care. Practice based primary care information is likely to be more accurately recorded than contacts that happened outside the practice. .Using a method recently developed by experts at the University of Nottingham, we will be able to extract detailed and accurate information. Secondary care data will also be obtained. Full and complete anonymised data sets of ten year medical records will be processed using a replicable method of electronic data collection that has been developed specifically to answer a number of health and economic and clinically important questions. In addition this data will provide us with a detailed insight into patients resource use in primary as well as secondary care. We will be able to check the data retrieved electronically with the data collected from the CSRI and therefore check the degree to which care outside the practice may be underestimated. Similarly the analysis of reporting of contacts with primary care at interview compared to the primary care record will explore whether or not regular attenders are underreporting health contacts compared to normal attenders. We will explore the effect any under-reporting by regular attenders may have had on health and social care costs.

We will ascertain health, social and personal costs using the CSRI (Beecham and Knapp, 2001) and also quality of life and cost utility on the EQ5D (EuroQol Group, 1990) over the three months preceding baseline interview in both the regular attender and normal attender

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control groups. Services measured will include secondary care mental and physical care, primary care, accident and emergency and other out of hours or direct access services such as NHS Direct, NHS walk-in centres, services provided by councils, other social care agencies, voluntary agencies and complementary therapy. In addition, inputs provided from family members as a result of the patient's health problems will be recorded and the amount of time off work by the patient and any carer due to ill health will be recorded and costs attached. Other costs include out-of-pocket expenses (such as travel to seek healthcare), expenditure on 'over-the-counter' medicines, the extent of informal care (for children or the house) and any other costs (such as informal care, heating from being at home when off work and costs to carers). Data on social security payments will also be collected. Prescribing data will be obtained from primary care patient records and patient interview. Nationally applicable unit costs (Curtis, 2007) will then be combined with the service use data to generate service costs for primary care. Medication costs will be obtained from the British National Formulary, and hospital based costs will be obtained from NHS reference costs/ PBR (payment by results). Costs of time off work will be calculated from the patient's own account of their salary and normal expectations of overtime and informal care to the patient will be calculated at the commercial rate that a carer would have normally expected to be earning at that time. Cost data will be combined with utility weighted health-related quality of life data as recorded by the EQ-5D.

2. Motivation for regular attendance and patient experience.

A central hypothesis of the study is that most regular attendance is initiated by the patient in response to a perceived health problem and that health care seeking is a motivated behaviour that serves a function of high psychological importance to that individual and is shaped also by the experience of health care seeking. Our pilot study CBT case series of eight regular attenders confirms that uncertain and unclear communication by health professionals, and consultations with health professionals that do not address the regular attender's main health concerns, are likely to increase health anxiety and result in further help care seeking. However, the representativeness of the participants who took part in the CBT case series suggests the need for a specific qualitative study involving maximum variance sampling of patient characteristics.

Recruitment

A sample of approximately 12 to 15 regular attending patients will be selected for individual qualitative interviews based on age, gender, ethnicity, practice, employment status, marital status, consultations primarily in primary care, emergency care and secondary care, high and low health anxiety, presence and absence of somatoform disorder, presence or absence of depressive disorder, presence or absence of panic disorder, presence or absence of more than one active physical health problem. Sampling will allow participants to meet more than one of these selection criteria. The exact number of participants will depend on the representation in this sampling frame and saturation of themes as they emerge. This purposive sample will be selected from the 100 regularly attending patients that have

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originally completed a consent to contact form and been recruited to the study. Selected participants will be invited to take part in the qualitative interview by the study researcher who will send them an invitation letter, information sheet and reply slip, along with a stamped addresses envelope. Upon receipt of the reply slip, the researcher will contact the participant, answer any questions they may have, and if verbal consent is given, a time and place for the interview to take place will be arranged. This might be at the participant's home or at their general practice. Separate written consent for this part of the study will be sought.

Study regimen

The interviews will be carried out by an experienced qualitative interviewer in an unhurried manner in a private and quiet venue such as the patient's home or GP surgery. The interviews will be semi-structured according to a topic guide, audio recorded, transcribed and analysed thematically using constant comparison. Catalytic validity will be achieved by using a reference group of researchers from a range of different backgrounds (academic GP, sociology, business school, psychiatry) so that the emerging data can be critically examined and the topic guide is refined according to the emerging thematic analysis. Recruitment of participants to interview will halt when fifteen patients have been interviewed or when a saturation of themes has been achieved.

This perspective of considering health care seeking as a motivated behaviour that serves a function of high psychological importance to that individual and is shaped also by the experience of health care seeking has rarely been applied before. Therefore there is value in understanding temporally the process of the evolution of the symptoms that lead to a consultation and what processes are involved in the decision to seek a consultation. How do these differ from when a person did not seek a consultation for a set of symptoms? If they did seek a consultation what were they seeking from the consultation and were those wishes met? How do consultations that meet their needs differ from those that do not? How does the decision to consult primary care and responses from primary care differ if it at all from the decision to consult secondary care or alternative providers? How does the existence of physical co-morbidities such as asthma, diabetes or obesity further complicate the consultation process?

3. Cognitive behaviour therapy intervention study.

Inclusion criteria

- Meets inclusion/exclusion criteria for case control study and completed the baseline assessment
- The presence at baseline of a current minor or major depressive disorder, anxiety disorder or somatoform disorder according to DSM_IV criteria (American Psychiatric Association, 1994) and established by standardised psychiatric interview (SCID).
- They give oral and written informed consent to participate in the cognitive behaviour therapy intervention part of the study.

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Exclusion criteria

Patients are excluded if:

- they have a potentially life threatening or disabling physical health condition that requires urgent treatment;
- they have a mental health condition that is associated with a risk to their own life or to others;
- they are already receiving specialist mental health intervention, including psychological treatment as part of specialist medical care e.g. pain clinic;
- they suffer from schizophrenia, bipolar disorder, eating disorders, substance use disorders (abuse and dependence), dementia or delirium that all require a specialist mental health team approach
- they are unable to communicate fluently in English (since CBT requires cultural and linguistic fluency and the concepts underlying CBT for regular attendance have not been formally assessed in other languages and cultures – we are addressing this in another research project application).

Piloting the intervention and its uptake

A case series of around 50 eligible patients will be recruited to refine the intervention, explore its acceptability, feasibility and how take up of the intervention and the research assessment can be maximised. Given the complexity of the patient problems that we have encountered an extensive pilot is required to understand the diversity of presentation and complexity of the health problems and behaviour underlying regular attendance. Eligible patients will be approached by the research team once they have completed their baseline assessment and will be separately consented for the treatment part of the study. The possibility of taking part in the intervention study will be discussed in the consent procedure for the baseline part of the study but the research team will be very clear that participants can take part in the other assessments of the study but are under no obligation at all to take part in the CBT intervention part of the study unless they wish to. A period of at least 24 hours will be given between the completion of the baseline assessment and completion of the consent procedure to the treatment part of the study to give time to the participant to consider fully if they wish to take part in the treatment part of the study.

As well as the specific formulation of the cases by the nurse with the GP that the patient prefers to see (supervised by the Chief Investigator and academic GP), training the practice to act upon the formulation and the organisation of the care of the patient within the practice will be explored. The implementation analysis outlined below will be used to refine the intervention so that it addresses potential barriers to its uptake, delivery and effectiveness.

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Measures

Unlike traditional RCTs that favour a small number of clinical outcomes, service delivery studies of complex interventions require multiple outcomes because services are interested in a range of equally important outcomes (Medical Research Council, 2008).

Primary outcomes

1. Change in the mental health component summary score of the 36-item self-rated SF-36 version 2 measure (Ware et al, 2000) from baseline to 6 and 12 months. The mental health component summary score is calculated from the following four scales of the SF-36- mental health, role emotional, social functioning and vitality.

Secondary outcomes

1. Proportion who achieve a 4 point change in the mental health component summary score (regarded as clinically significant change, Smith et al, 2006) of the 36-item self-rated SF-36 versi*on 2 measure (Ware* et al, 2000) from baseline to 6 and 12 months.

2. Change in depression on the nine item PHQ-9 (Kroenke et al, 2001) from baseline to 6 and 12 months.

3. Change in anxiety on the seven item GAD-7 (Spitzer et al, 2006) from baseline to 6 and 12 months.

4. Change in health anxiety on the 18 item Health Anxiety Inventory (Salkovskis et al, 2002) measure from baseline to 6 and 12 months.

5. Change in somatic symptoms as assessed by the PHQ-15 (Kroenke et al, 2002) from baseline to 6 and 12 months.

6. Change in physical health component summary of the 36-item self-rated SF-36 version 2 measure (Ware et al, 2000) from baseline to 6 and 12 months.

7. Patient satisfaction on a five item measure (met needs, help with problems, amount of time, overall satisfaction, want same treatment again) (Scott et al, 1992) from baseline to 6 and 12 months.

8. Change in the EQ5D from baseline to 6 and 12 months

9. Economic analysis (see below).

10. Patient-doctor relationship (van der Feltz Cornelis et al, 2004) from baseline to 6 and 12 months.

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11. Two measures of cognitive process, the rumination scale (Treynor et al, 2003) and the tendency to avoid thinking about painful emotional experiences (Hayes et al, 2004) from baseline to 6 and 12 months.

The treatment outcome measures booklet will initially be given to the treatment patient by the therapist during the assessment phase of the study, to take away and return by post. The six and twelve month follow-up booklets will be posted out by the research team. In the pilot phase this has been acceptable to patients and booklets have been returned completed.

CBT formulation and treatment (appendix 2).

The cognitive behaviour formulation and treatment will be delivered by qualified mental health professionals (nursing and clinical psychology), who hold British Association for Behavioural Cognitive Psychotherapy and/or British Psychological Society qualifications for the practice of cognitive behaviour therapy and experience of working independently with patients with problems of depression, anxiety and medically unexplained symptoms in the context of physical health problems. The therapists will be at band 7 level commensurate with being an experienced CBT therapist able to work independently in terms of delivering treatment but under supervision. The CBT therapist formulates the reasons for the regular consulting and how these relate to the underlying physical and mental health problems of the patient in consultation with the lead GP. The formulation will require at least one to two appointments with the CBT therapist, sometimes longer if there are particularly sensitive issues that the participant gradually divulges. The CBT therapist then plans further management of the patient with the lead GP according to the formulation but it may involve antidepressant prescribing, a reduction of symptomatic prescribing e.g. opiate painkillers, hypnotic drugs to induce sleep, CBT for depression, anxiety, health anxiety or functional somatic syndromes, organisation of care within the practice (Smith et al, 1986), and other strategies to promote coping other than frequent consultation with health professionals.

Further management of the regular attending patient will be divided between the lead GP, the CBT therapist and possibly other members of the practice team depending on the nature of the intervention identified in the formulation and the needs of the frequently attending patient. If the regular attending patient does not require CBT, then the regular attending patient will only see the lead GP and other members of the practice team as required in the management plan. The formulation will be shared with other practice staff e.g. at the practice meeting and arrangements for review of treatment progress will be made at one month between the lead GP and the CBT therapist (and involving other members of the practice team as required).

If the patient refuses to participate in the CBT intervention part of the study, then consent is obtained for the CBT therapist to discuss a preliminary formulation of the reasons for regular

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attending and how these relate to underlying physical and mental health problems of the patient with the lead GP, using information provided by the GP, the baseline assessments and review of medical notes from their consultations with the patient and from the rest of the practice. The CBT therapists will be supervised by RM and an academic GP. Once treatment has been completed, usually within 6 months, the CBT therapist and lead GP will summarise the treatment plan that the patient received as part of the experimental intervention.

Analysis

Primary analysis will be by intention to treat using two-sided significance tests. The primary analysis will focus on the 6 month outcomes using the mental health scale of the SF-36 and other clinical outcomes with a random practice effect. We will examine time point and time*treatment interaction effects in a secondary analysis to determine whether there is a linear or quadratic response profile over time. Multiple imputation will be used to handle missing data with a sensitivity analysis employed for NMAR (not missing at random). The only inferences that can be drawn are in relation to potential for clinical utility, feasibility and acceptability (patient satisfaction and doctor-patient relationship).

Health economics

We will ascertain health, social and personal costs and examine the potential for cost utility and cost effectiveness from health and social care, and societal perspectives. The aim is estimation in relation to NICE thresholds for cost effectiveness rather than significance testing (Medical Research Council, 2008). Although there is no control group, we will have detailed data on the patterns of health care use in this patient group over the preceding 10 years that can be used to model outcomes.Services measured will include secondary care mental and physical care, primary care, accident and emergency and other out of hours or direct access services such as NHS Direct, NHS walk-in centres, services provided by councils, other social care agencies, voluntary agencies and complementary therapy. In addition, inputs provided from family members as a result of the patient's health problems will be recorded and the amount of time off work by the patient and any carer due to ill health will be recorded and costs attached. Other costs include out-of-pocket expenses (such as travel to seek healthcare), expenditure on 'over-the-counter' medicines, the extent of informal care (for children or the house) and any other costs (such as informal care, heating from being at home when off work and costs to carers). Data on social security payments will also be collected. Prescribing data will be obtained from primary care patient records and patient interview. Nationally applicable unit costs (Curtis, 2010) will then be combined with the service use data to generate service costs for primary care. Medication costs will be obtained from the British National Formulary, and hospital based costs will be obtained from NHS reference costs/ PBR (payment by results). The cost of the specialist intervention can be calculated with the help of briefly completed, structured diaries showing time spent by the different members of the team in delivering the intervention together with these unit health costs. Costs of time off work will be calculated from the patient's own account of their salary and normal expectations of overtime and informal care to the patient will be calculated at the commercial

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rate that a carer would have normally expected to be earning at that time. An alternative approach would be to use a market rate for informal care. All costs and outcome will be collected at baseline,6 and 12 months.

Cost data will be combined with utility weighted health-related quality of life data as recorded by the EQ-5D If the costs of the new intervention are higher than treatment as usual but there is a greater improvement in outcome, then incremental cost effectiveness ratios will be generated. Cost-effectiveness acceptability curves (CEACs) will be generated to explore the likelihood that the intervention is more cost effective for each unit of reduction in mental health problems as measured by an appropriate measure of effect and utility. The net benefit method (Stinnett and Mullahy, 1998) will be used to construct the CEAC where net benefit (NB) = (λ*E)-SC (λ =monetary value that society places on one unit reduction in mental health problems, E= reduction in mental health problems between baseline and 6 and 12 months, and SC = service costs) and a range of values for λ are assumed. Cost data and cost effectiveness data are frequently skewed and as a result economic evaluation can be misleading if average costs are skewed by extreme outliers. In this event, the distribution of the data will be examined by employing generalised linear modelling. Missing economic data will be handled in the same way as missing outcome data in the statistical analysis. Sensitivity analyses, based on key assumptions that emerge from the analysis of contextual factors, knock on effects on other staff and patients, will explore these effects on costs and therefore cost utility and cost effectiveness. Results will be expressed as a net cost/QALY gained to the end of the trial to determine whether the intervention potentially meets the NICE threshold for cost effectiveness.

4. Implementation analysis

The implementation analysis will provide important information on the intervention in relation to knock on or unanticipated effects on staff and patients (including other staff and other patients), the barriers and drivers to the organisation and delivery of care, the effect of the intervention on wider patient behaviour and demand on health service resources, and how these barriers might be addressed.

This aspect to the research will be carried out by experienced organisational studies research fellows employed by the CLAHRC's implementation theme over the course of the wider clinical research project. It will involve three interrelated approaches to data collection, to be undertaken across the pilot practice and then three practices taking part in the main study. The five practices will be purposefully selected from Nottinghamshire and/or Derbyshire to represent different population characteristics and organisation of care such as an inner city practices with wide ethnic diversity, deprived former mining area with little ethnic diversity, more affluent services, practices close to district general hospitals or further away, organisation of care in the practice that strongly promotes continuity of care (i.e. see the same doctor as far as possible) versus rapidity of access to care (i.e. see the doctor that is most quickly available); practices that have staff offering psychological treatments in the

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practice already versus those that do not. Thus the implementation of management for regular attenders will be examined in different populations, different GP practices,and different levels of specialist knowledge and access to psychological treatment.

The implementation analysis will collect data on both the new intervention and the care pathway prior to the introduction of the intervention so that an understanding can be obtained of how the new intervention affects the usual care pathway.

Documentary analysis

Key documents relating to the implementation, delivery and ongoing commissioning of the project will be analysed to provide evidence of the challenges and facilitators faced in the implementation of the project, and of the way in which concerns about clinical efficacy, cost and organisational change are addressed in outputs from the project. This will include an analysis at the start of the project of key documents from the national to the local level (existing guidance on IAPT and provision of psychological treatment in primary care, documents produced by commissioners on service-level agreements with providers around service design, interventions, any available minutes from PCTs and provider trusts, any guidelines produced for practitioners by professional associations such as Royal Colleges) which will provide important contextual information on the field, national policy and (the variety of) local approaches to implementation.

Interviews

Interviews will be carried out with key stakeholders involved with the commissioning, management and delivery of care for regularly attending patients. These interviews will address issues relating to the uptake of the new approach to care, the barriers faced by this, and the role of various factors at the levels of policy, organisation, profession and the individual in the way in which care is delivered (an overview of interview topics is given below). Exact numbers and identities of interviewees are difficult to determine in advance, since they will depend on the nature of the network of actors involved in the commissioning, management and delivery of the new approach. However, we would expect to interview various individuals involved in delivering, managing and implementing the new approach to care in the intervention arm of the trial, including GPs, other practice staff, nurses delivering CBT, as well as those involved in the management of these groups, and service commissioners. Relevant individuals to be approached for interview will be identified in consultation with the project lead in the first instance, with some 'snowball sampling' of further relevant stakeholders to follow as necessary, partly informed by the social network analysis (see below). The implementation analysis will aim to interview approximately 30 staff over the fivepractices (approximately 15 GPs, 5 practice nurses and 10 reception, administration and managerial staff from practices including some staff involved in new service commissioning arrangements). thus permitting a nuanced analysis of processes in each of the fivepractices and permitting inter-site comparison. Subject to their agreement, some of these individuals may be re-interviewed towards the end of the research, to discuss issues raised in their initial interviews further, and to reflect on changes in the field that have subsequently taken place.

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Observation

Researchers from the implementation theme will attend meetings towards the beginning and end of the projects, in order to contextualise the understanding developed through interviews and to apprehend more directly the challenges and facilitators to the implementation of the project. Where possible, these will include meetings at various organisational levels, from those between teams of practitioners (e.g. within general practices) to those between commissioners and service managers. Since the regularity with which such meetings are held will vary with locality, exact numbers are difficult to predict at this stage, and may include more in some sites than others. However, we would hope to attend at least two to four meetings in each of five selected practices, as well as further meetings at other organisational levels.

In addition to these three approaches, to be carried out by implementation theme research fellows, those staff participating in the research as interviewees will also be invited to keep reflective diaries on the issues they face in putting guidance into practice, and to gather their own ideas about the kinds of changes (organisational and other) that might mitigate the difficulties posed by obstacles to implementation.

Factors at various analytical levels will be addressed through these different facets of the implementation research, from the macro-level impact of government policy down to individual-level interests and preferences. Staff interviews will cover questions of leadership, the management of knowledge, the role of social capital, the reconfiguration of roles within the workforce required by the implementation of the project, the way in which policy influences behaviour, and the degree to which evidence influences practice. Similar themes will form the focus of attention in the observational and documentary analysis work, providing several complementary perspectives on the way in which these issues obstruct or facilitate the realisation of this kind of change in service provision. Analysis of these datasets will be carried out according to qualitative research principles and using a computer-aided qualitative data analysis programme, such as NVivo, with data analysed in terms of individual biographies, site-level characteristics, and across sites to produce an understanding that is sensitive to context whilst also integrative and comparative in nature. The analysis of the implementation issues in each site will be illuminated and enhanced by the analysis of each other site (Eisenhardt, 1989; Yin, 1999). In this understanding, the use of complementary research approaches permits the enrichment of understanding of the issues being studied, rather than acting purely as a means of triangulation, so that competing or conflicting data from different sources are a matter for explanation rather than resolution. Data analysis will be led by one of the research fellows in the implementation theme, overseen by the theme lead and theme manager / senior research fellow, both of whom have extensive experience of health-related qualitative social-scientific research relating to the uptake of new ways of working (e.g. Currie *et al.*, 2008; Martin *et al.*, in press).

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EXPECTED DURATION OF PARTICIPANT PARTICIPATION

Participants who take part in the baseline interview for the case control study can expect to be involved in the study for approximately two hours, which includes time to read and respond to the study invitation, arrange a suitable time for the baseline interview, give consent, and be interviewed by a researcher.

Participants taking part in the qualitative interviews, either for the qualitative study or the implementation study, can expect to be involved for approximately one and half hours which includes around an hour for the interview and further time for reading the study documentation, giving consent and conversations with the researcher about the study.

PARTICIPANT WITHDRAWAL

Participants may withdraw from the study at any time. The participants will be made aware that this will not affect their future care. Participants will be made aware (via the information sheet and consent form) that should they withdraw, data collected to date cannot be erased and may still be used in the final analysis.

INFORMED CONSENT

All participants will provide written informed consent. The Consent Form will be signed and dated by the participant before they enter the study. The study researcher will explain the details of the study and provide a Participant Information Sheet, ensuring that the participant has sufficient time to consider participating or not. The study researcher will answer any questions that the participant has concerning study participation.

Informed consent will be collected from each participant before they undergo any interventions related to the study. One copy of this will be kept by the participant, one will be kept by the Investigator, and a third will be retained in the patient's medical records.

Should there be any subsequent amendment to the final protocol, which might affect a participant's participation in the study, continuing consent will be obtained using an amended Consent Form which will be signed by the participant.

COMPLIANCE

Participants will be expected to comply with the following study requirements in order to remain in the study.

1) Participants must try whenever possible to stick to arranged interview/ meetings. Research staff will take into account patient's circumstances and try to rearrange or accommodate when possible. However, patients who consistently fail to stick to arrangements will be unable to continue with the study. Two missed appointments without prior notice will be unacceptable.

2) Practices will be unable to continue with the study if they are unable or refuse to carry out the anonymised search of medical records, to communicate regularly with

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research staff or to supply information they have agreed to, as laid out in the study protocol.

CRITERIA FOR TERMINATING THE STUDY

In the event that the study should be stopped for any reason, unused study materials would be archived as described below.

ADVERSE EVENTS

The occurrence of adverse events as a result of participation within this study is not expected and no adverse event data will be collected.

ETHICAL AND REGULATORY ASPECTS

Ethical considerations

Some primary care patients may not realise they attend primary care more frequently than other patients; others may realise they do attend frequently but it is their right to attend frequently. Other patients may have a different view. It is possible therefore that when this subject is broached with patients to engage them in the study there is a risk that it may cause offence. In order to minimise the risk of causing offence to the patient, the term 'regular attendance' rather than 'frequent attendance' will be used in study documentation and when speaking to them in order to engage them in the project and throughout the study.

It is very unlikely that a participant will make a criminal disclosure during the course of the study. If a patient were to disclose something we would follow the procedures in line with the University's professional code of conduct and our Standard Operating Procedure, as set out below;

> If the participant makes a disclosure to a member of the research staff that reveals that the participant is in immediate or serious risk of danger to his/her own life or that of another person, the member of staff may break confidentiality in accordance with the Human Rights Act 1998 Article 8 (2) set out below.
>
> Article 8
> RIGHT TO RESPECT FOR PRIVATE AND FAMILY LIFE
>
> 1. Everyone has the right to respect for his private and family life, his home and his correspondence.
>
> 2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic wellbeing of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

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Ethics committee and regulatory approvals

The study will not be initiated before the protocol, consent forms and participant information sheets have received approval from the NRES Research Ethics Committee, and the National Health Service (NHS) Research and Development (R&D) departments providing research governance to the participating NHS Primary Care Trusts. Should a protocol amendment be made that requires NRES Research Ethics Committee approval, the changes in the protocol will not be instituted until the amendment and revised informed consent forms and study information leaflets have been reviewed and received approval from the NRES Research Ethics Committee and R&D departments. Minor protocol amendments for logistical or administrative purposes only, may be implemented immediately and the NRES Research Ethics Committee and R&D departments informed in writing.

The study will be conducted in accordance with the ethical principles that have their origin in the 2008 Declaration of Helsinki and the Department of Health Research Governance Framework for Health and Social Care.

Informed consent and participant information

The process for obtaining participant informed consent will be in accordance with the REC guidance, and Good Clinical Practice (GCP) and any other regulatory requirements that might be introduced. The investigator or their nominee and the participant shall both sign and date the Consent Form before the person can participate in the study. The participant will receive a copy of the signed and dated forms and the original will be retained in the study records. A second copy will be filed in the participant's medical notes.

The decision regarding participation in the study is entirely voluntary. The investigator or their nominee shall emphasize to them that consent regarding study participation may be withdrawn at any time without penalty or affecting the quality or quantity of their future medical care, or loss of benefits to which the participant is otherwise entitled. No study-specific interventions will be done before informed consent has been obtained.

The investigator will inform the participant of any relevant information that becomes available during the course of the study, and will discuss with them, whether they wish to continue with the study. If applicable they will be asked to sign revised consent forms.

If the consent form is amended during the study, the investigator shall follow all applicable regulatory requirements pertaining to approval of the amended consent form by the REC and use of the amended form (including for ongoing participants).

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RECORDS

Unique identity codes (UIC)

Each participant will be assigned a study UIC for use on case report forms, study documents, transcripts, audio recordings and elect*ronic patient records.*

Case Report Forms

A database of case report forms for consented patients will be kept. This will only be accessible by password by the research team. This is the only place where identifiable patient data and UICs will be kept in one place apart from on patient consent forms which will be kept locked in a filing cabinet only accessible to members of the research team.

Each patients Case Report Form will include details of the patient including; name and address, telephone number, date signed consent form was received, date of birth, GP practice at which they are registered, usual GP and NHS number. Each patient will be given a UIC which reflects the surgery they are attached to and an individual number. These will be allocated by the practice administrators after the initial database enquiry has been carried out.

All patient documentation including medical records, consent forms and questionnaires will have clearly marked on them the patients UIC and two identifiers, 1) Date of Birth and 2) initials.

CRFs will be carried out by the research associates on receipt of consent to contact forms from patients. Access to these forms will be strictly limited to the research team and the project manager will carry out checks once a month to ensure this procedure is being adhered to.

CRFs will be treated as confidential documents and held securely in accordance with regulations. The investigator will make a separate confidential record of the participant's name, date of birth, local hospital number or NHS number, and Participant Study Number, to permit identification of all participants enrolled in the study, in case additional follow-up is required.

CRFs shall be restricted to those personnel approved by the Chief or local Investigator and recorded as such in the study records.'

All paper forms shall be filled in using black ballpoint pen. Errors shall be lined out but not obliterated by using correction fluid and the correction inserted, initialled and dated.

The Chief or local Investigator shall sign a declaration ensuring accuracy of data recorded in the CRF.

Recruitment Logs

There will be separate participant recruitment logs for patient participants and general practice staff participants. The recruitment log for participants will include records of which GP practice the participant was recruited from, date of baseline interview, whether baseline interview was achieved, whether the participant has been selected for the case formulation study, dates of meetings with the therapist for case formulation, whether case formulation has been concluded, and whether they would like to receive study results when available.

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A staff recruitment log will record date of interview with the researcher, whether the interview was achieved, and whether they would like to receive study results when available.

Questionnaires and interviewer notes

All study documentation such as SCID and CSRI interview questionnaires, interviewer notes will be treated as confidential documents and held securely in accordance with regulations. Access to documentation shall be restricted to those personnel approved by the Chief Investigator or his nominee.

Interviews

Where interviews are conducted at patients' homes, a system for researcher safety will be in place, designed to meet the requirements of the University of Nottingham guidelines for fieldwork. Researchers undertaking off-site visits will choose a designated safety person (who may be a member of the study team, a researcher colleague or an administrator) and provide them with a completed form which contains details of the name of interviewee and address where the interview is to take place. The form will be placed in a sealed envelope and the researcher will write the expected interview start and finish times on the envelope as well as a time when they will call their safety person to confirm their safety. A system will be in place for contacting the researcher if they do not call at the expected time. All researchers have study mobile phones.

Interview recordings and transcripts

Audio recordings of qualitative interviews and transcripts will be treated as confidential documents and held securely in accordance with regulations. Audio recordings will be kept on a secure University of Nottingham computer server with access restricted to those members of the study team with permissions to access them. Transcripts will have all identifiable information removed before being made available to other members of the study team. Transcripts will be only be identifiable with a UIC once anonymised.

Source documents

Source documents shall be filed at the investigator's site and may include but are not limited to, consent forms, study records, field notes, interview transcriptions and audio recordings. Only study staff shall have access to study documentation other than the regulatory requirements listed below.

Direct access to source data / documents

Source documents shall be made available at all times for review by the Chief Investigator, Sponsor's designee and inspection by relevant regulatory authorities.

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Data protection

All study staff and investigators will endeavour to protect the rights of the study's participants to privacy and informed consent, and will adhere to the Data Protection Act, 1998. The researcher will only collect the minimum required information for the purposes of the study as described here. Paper records will be held securely, in a locked room, in a locked cupboard or cabinet. Access to the information will be limited to the researchers and investigators and any relevant regulatory authorities. Computer held data will be held securely and password protected. All data will be stored on a secure network server. Access will be restricted by user identifiers and passwords. Electronic data will be backed up daily.

Information about the study in the participant's medical records will be treated confidentially in the same way as all other confidential medical information.

QUALITY ASSURANCE & AUDIT

Insurance and indemnity

Insurance and indemnity for study participants and study staff is covered within the NHS Indemnity Arrangements for clinical negligence claims in the NHS, issued under cover of HSG (96)48. There are no special compensation arrangements, but study participants may have recourse through the NHS complaints procedures.

The University of Nottingham as research Sponsor indemnifies its staff and research protocols with public liability insurance. The University of Nottingham has taken out an insurance policy to provide indemnity in the event of a successful litigious claim for proven non-negligent harm.

Study conduct

Study conduct will be subject to audit for inclusion of essential documents; permissions to conduct the study; CVs of study staff and training received; standard operating procedures; financial oversight and budgetary compliance; consent procedures and study information leaflets; adherence to procedures defined in the protocol or standard operating procedures and accountability of study materials.

Study data

Monitoring of study data shall include confirmation of informed consent; source data verification; data storage and data transfer procedures; local quality control checks and procedures, back-up and disaster recovery of any local databases and validation of data manipulation. The Programme Manager shall carry out monitoring of study data as an ongoing activity and produce an annual report. The lead researcher at Nottingham will check the data quality assurance procedures at each site annually.

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Capture of the data on the study database will be checked by inspection against the source data. Where corrections are required these will carry a full audit trail and justification.

Study data and evidence of monitoring and systems audits will be made available for inspection by the approving NRES REC, the relevant Trust R&D dept and a representative of the Sponsor organisation as required.

Record retention and archiving

In compliance with the ICH/GCP guidelines, regulations and in accordance with the University of Nottingham's Research Code of Conduct, the Chief Investigator will maintain all records and documents regarding the conduct of the study. These will be retained for at least 7 years or for longer if required. If the responsible investigator is no longer able to maintain the study records, a second person will be nominated to take over this responsibility.

The study documents held by the Chief Investigator on behalf of the Sponsor shall be finally archived at secure archive facilities at the University of Nottingham. This archive shall include all study databases and associated meta-data encryption codes.

Discontinuation of the trial by the sponsor

The Sponsor reserves the right to discontinue this study at any time for failure to meet expected enrolment goals, for safety or any other administrative reasons. The Sponsor shall take advice as appropriate in making this decision.

Statement of confidentiality

Individual participant medical or personal information obtained as a result of this study are considered confidential and disclosure to third parties is prohibited with the exceptions noted above. Participant confidentiality will be further ensured by utilising identification code numbers to correspond to treatment data in the computer files.

Such medical information may be given to the participant's medical team and all appropriate medical personnel responsible for the participant's welfare.

Data generated as a result of this study will be available for inspection on request by the participating physicians, the University of Nottingham representatives, the REC, local R&D Departments and the regulatory authorities.

PUBLICATION AND DISSEMINATION POLICY

The study will publish its baseline assessment so that commissioners, service providers and service users are informed concerning current local practice and later the final results of the study once the results are collected. The results will be publicised through the extensive arrangements for dissemination locally within the CLAHRC (through road shows, websites, annual conferences and through diffusion fellows carrying out academic detailing) as well as publication in peer reviewed journals, local, national and international scientific conferences.

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In addition, to facilitate organisational learning, the diffusion fellows will present the findings of the study, including the implementation analysis, to the practices and the managers at Trust directorate and board level. The findings will also be presented to the commissioners of these services.

USER AND PUBLIC INVOLVEMENT

The research design has been devised in agreement with the CLAHRC POPULOS panel, a group of service users and carers which includes mental health service users from Nottinghamshire Healthcare NHS Trust. Additionally, two users of mental health services have commented and informed the developed of the participant information sheets and consent forms which will be used in the study.

STUDY FINANCES

Funding source

The CLAHRC Nottinghamshire, Derbyshire and Lincolnshire, the programme to which this study belongs, is a dual funded programme made up of 50% NIHR funding and 50% funding from NHS partners.

Financial management

The main study contract is between NIHR and Nottinghamshire Healthcare NHS Trust who hold the study grant income. The Primary Care Programme Manager will manage study finances and provide appropriate updates for the CLAHRC Board and Managers.

Participant stipends and payments

Participants will be offered a £20 High Street Voucher for their participation in the research; this includes participants in the case control study and the qualitative study. Participants who complete the treatment outcome booklet will receive a £20 High Street voucher each time they complete the booklet. We will offer reasonable travel expenses to participants in the case formulation study for visits in excess of usual care. The £20 voucher is intended as a 'thank you' for the participant giving up their time in recognition of the fact that the study does not directly benefit them. The small amount and form of payment has been chosen so that it is not an incentive to take part or a means of coercing people into taking part.

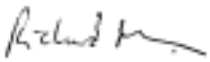
Each of the four general practices will receive appropriate service support costs for being involved in the research. The amount will be based on levels offered by the Primary Care Research Network (PCRN). It is the policy of many NHS Trusts to give recognition to service users for time given up by them to take part in duties that do not directly benefit them in some other way such as participation on Trust committees. The payment is in keeping with such Trust policies.

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SIGNATURE PAGES

Signatories to Protocol:

Chief Investigator: Professor Richard Morriss

Signature: 

Date: 5th March 2012

Study Statistician: Professor Min Yang



Signature:

Date: 5th March 2012

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Appendix 1: Gantt chart

Regular Attenders Gannt Chart

Project dates; December 2011 to September 2013



Ethics approval for protocol 1.1

Practices A,B & C

Send invite letters to eligible participants until target achieved

Baseline interviews

Qualitative study interviews

Agree with practice on matching participants

10 year medical collection and analysis- all participants

Practice feedback

Practices D & E

Recruit and sign agreement with practice

R & D Approvals

Database Searches and refinement

Send invite letters to eligible participants until target achieved

Baseline interviews

Qualitative study interviews

Agree with practice on matching participants

10 year medical collection and analysis- all participants

Practice feedback

Ongoing progress/case study review

Analysis of qualitative study

Analysis of medical records-data collection

Analysis of medical records- data extraction

Analysis of medical records-write-up

Write up of CSRI, EQ5-D, SCID & HAI short week comparisons

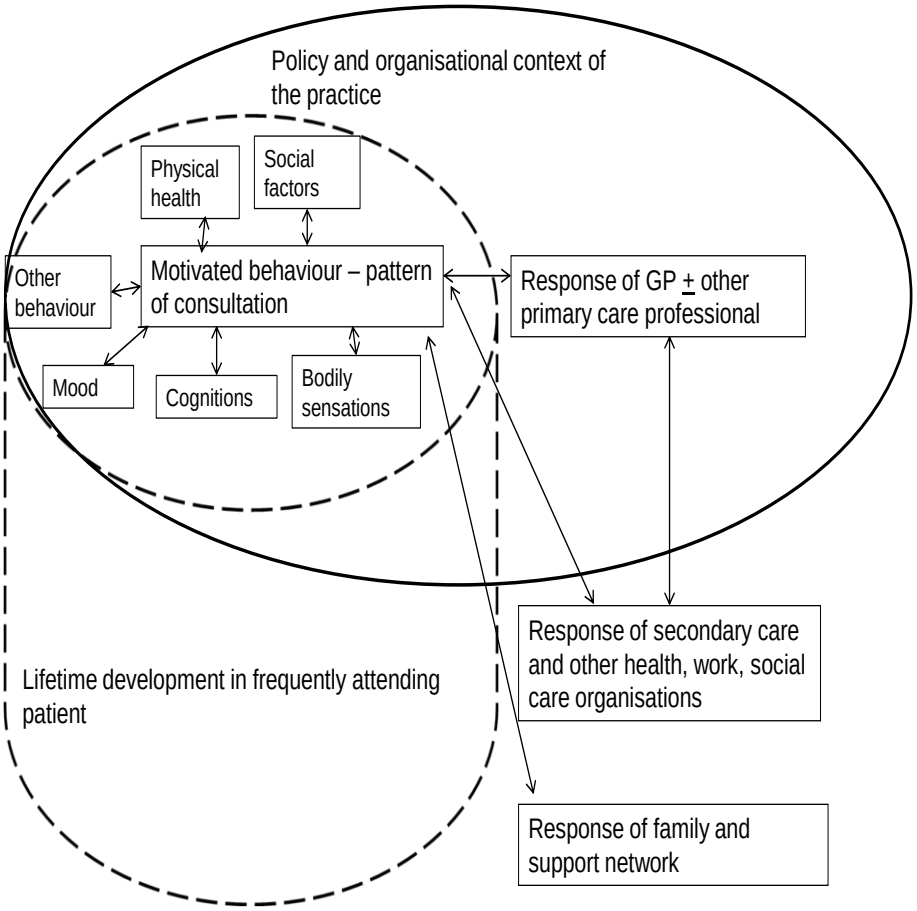
Write up qualitative study

Write up implementation study

Write up findings from CBT/Case formulation

Dissemination

Bids for further funding for RCT.



Appendix 2. Cognitive behaviour therapy formulation and treatment for regular attenders