Exploring the delays to diagnosis of endometriosis in the United Kingdom: a qualitative study

By

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Abstract

In the United Kingdom, the average time to diagnosis of endometriosis, a common gynaecological condition, is 7.5 years. The aim of this qualitative doctoral study was to explore, in two phases, the reasons for the delay to diagnosis of endometriosis from the perspectives of both patients and healthcare professionals. In phase 1, fifteen women with confirmed endometriosis participated in individual, semi-structured interviews, and a conceptual description was generated using constructivist grounded theory. Further analysis resulted in a novel, substantive theory; this describes how the main concern of women with undiagnosed endometriosis is coping with a fracturing life, which they address through a process of making sense. The way in which a woman seeks to make sense depends upon the context of refusal, disbelief or belief arising from her interactions with others. Across each context, the grounded theory identifies how women's individual experiences influence health-seeking behaviours and the subsequent delays to diagnosis.

The findings from phase 1 informed the design of phase 2, where focus groups with fifteen healthcare professionals were conducted to explore delays to diagnosis of endometriosis. The data were analysed using reflexive thematic analysis. Three main themes evolved: (1) endometriosis is peppered with discrimination, (2) invisible women and the invisible line for referral, and (3) visibility in a context of belief: rendering the woman visible. A key finding that connected both phases was the way in which clinicians rendered women invisible and how women recognised and responded to this.

This study provides a unique understanding of the health-seeking behaviours of women with undiagnosed endometriosis and develops a multivariate theory to explain the delays to diagnosis. This original contribution can be used to alleviate structural discrimination and encourage collaboration within and among professional bodies and patient groups to facilitate referral and diagnosis.

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Motivation for this PhD

I am currently a Specialty Registrar in obstetrics and gynaecology. At a very early stage of my career, I have taken three years out of my training programme as a Clinical Research Fellow to conduct this PhD project. I have often wondered what it must be like to conduct a PhD project; now I know exactly what this experience entails!

In my current role, I see women with suspected endometriosis or confirmed endometriosis on a weekly basis. Through conducting these clinics, I have listened to the personal stories of many women on their diagnostic journey. At times, I have been left feeling surprised and shocked about the convoluted and often complex journey some of these women have experienced. I therefore felt compelled to change this, even if this initial change is on a local level.

The clinical environment can often be a very busy and chaotic environment. Therefore, taking time to conduct this PhD project has allowed me to engage with patients on various levels, as a researcher, medical doctor and lay person. This has been a transformative journey related to both understanding myself as a researcher and doctor, as well as how I can better support patients with endometriosis.

Conference presentations

Oral presentations

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Karavadra, B. 2020. Exploring the delays to diagnosis of endometriosis. 36th virtual Annual Meeting of the European Society of Human Reproduction and Embryology, 7th July.

Poster presentation

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Lay summary

Endometriosis is a common gynaecological condition that affects women. It happens when the tissue that normally lines the womb is found elsewhere in the body. The most common places include the ovaries, fallopian tubes and pelvis. Tissue that lines the womb usually causes vaginal bleeding as part of the monthly menstrual cycle. The bleeding that occurs during the monthly cycle exits the body via the vagina; however, when this bleeding occurs in other parts of the body, the blood cannot leave the body. Some women do not experience any symptoms from this but in other women it can have a devastating effect. Some of the symptoms of endometriosis include long-term pelvic pain, heavy vaginal bleeding and problems with fertility. When endometriosis is suspected, a doctor will try to diagnose it through a combination of taking a medical history, examining the patient and performing a scan of the pelvis. The best way to diagnose endometriosis is by having keyhole surgery to look inside the pelvis and taking a sample of tissue suspected to be endometriosis. This tissue is sent to a laboratory to be observed under a microscope for confirmation.

The aim of this study was to explore women's experiences of being diagnosed with endometriosis. In the United Kingdom, we know that that a diagnosis of endometriosis takes 7.5 years on average. To explore women's experiences of being diagnosed with endometriosis, fifteen women were individually interviewed. The findings were analysed using grounded theory (a method involving the simultaneous collection and analysis of data) to develop a model. Fifteen healthcare professionals then participated in three separate focus groups and these findings from these were analysed to identify common themes and patterns in the data.

Women with endometriosis discussed the negative impact of their symptoms on their quality of life and how this influenced the way in which they recognised abnormal symptoms and subsequently coped with unexplained symptoms. They also discussed their experiences with healthcare professionals and how these experiences affected the way in which they sought help. These factors had an influence on the time taken to diagnose endometriosis. Healthcare professionals discussed their experiences of the medical consultation, the way in which another person in the consultation affected the diagnostic process, and the preconceived judgements healthcare professionals made about a patient with endometriosis. These factors also contributed to the time taken to diagnose endometriosis.

There are many reasons for the delay to diagnosis from both a patient and healthcare professional perspective. The findings from this study could be used to inform healthcare professionals’ personal understanding of delays to diagnosis as well as aid in the development of tools/algorithms to facilitate referral and diagnosis of endometriosis.

PART 1 – INTRODUCTION AND SCOPING REVIEW

Chapter 1 – Background to the study

1.1 Introduction

This chapter will present the context of the study and describe the background relating to endometriosis as a gynaecological condition. This will be followed by a summary of the overall thesis structure.

1.1.1 Context of the study

Endometriosis is a common gynaecological condition wherein endometrial stromal cells are found outside the endometrium (Giudice and Kao, 2004). The most common locations for endometriosis to be develop include the ovaries, fallopian tubes and pelvis (Nisolle and Donnez, 1997). Endometriosis can also develop within the gastrointestinal tract and the urological system, resulting in dyschezia (difficulty in passing stool), blood in the stool, haematuria, and difficulties with urinating (Nisolle and Donnez, 1997). It is a gynaecological condition that can significantly impact women's physical and psychological health and social aspects of their lives (Karavadra, 2019).

There are often delays to diagnosis of endometriosis. In the UK, it takes on average 7.5 years to diagnose the condition (NICE, 2017; Bullo, 2019; Agarwal et al, 2019) but can often take far longer (APPG October 2020 report). There is still very little known about the aetiology of endometriosis or why it takes so long to diagnose. In 2017, the National Institute of Clinical Excellence (NICE) published guidelines on the diagnosis and management of endometriosis and made extensive reference to the timeframe involved in diagnosing women with endometriosis. There was specific mention of the following research priorities within this document:

- 'What are the most effective ways of educating healthcare professionals throughout the healthcare system resulting in reduced time to diagnosis and improved treatment and care of women with endometriosis?'

- ‘How can the diagnosis of endometriosis be improved?’
- ‘What is the most effective way of managing the emotional and/or psychological and/or fatigue impact of living with endometriosis (including medical, nonmedical, and self-management methods)?’

A timely diagnosis for any medical condition is important for several reasons. In general, a diagnosis allows the patient to understand and rationalise their symptoms and subsequently enables them to obtain the respective treatment. In the case of endometriosis, a diagnosis enables appropriate treatment (medical or surgical) to be considered and therefore have a positive impact on the health-related quality of life. Endometriosis is associated with infertility, and a cohort study by Moss et al (2021) found that if endometriosis was diagnosed in women prior to undergoing artificial reproductive techniques, then they were more likely to conceive. Their findings also suggested that in-vitro fertilisation may be more effective in achieving a live birth, compared with intrauterine insemination, in women with endometriosis (Moss et al, 2021). Collectively, there are clearly several reasons as to why an early diagnosis of endometriosis is important.

Craddock and Mynors-Wallis (2014) explain that a diagnosis alone is not enough, but it should be used in a wider context to create a management plan in psychiatry. A diagnosis is also important as it enables patients and healthcare professionals to communicate more effectively through a common language (Craddock and Owen, 2010). A diagnosis enables patients to legitimise their symptoms and subsequently have a medical explanation for them (Craddock and Owen, 2010). In psychiatry, a diagnosis may enable individuals to 'make sense of being different' (Craddock and Mynors-Wallis, 2014, p.94). Finally, a diagnosis enables individuals to make informed decisions about their healthcare, whether this involves an intervention or not (Craddock & Mynors-Wallis, 2014).

Delay to diagnosis is linked to several factors, which can be considered from a patient, clinician and medical system perspective (Ballard, Lowton and Wright, 2006). For example, the interval between patient awareness that they have a ‘problem’ to presenting to the clinician is a complex process. This thesis will focus on the diagnosis experiences of women with endometriosis, as well as the understanding of the healthcare professionals involved in the diagnosis pathway, to gain deeper insights into the factors influencing delays to diagnosis.

Two years after starting this PhD, the All-Party Parliamentary Group (APPG) on endometriosis launched an enquiry into delays to diagnosis, the findings of which were discussed in parliament (APPG October 2020 report). The main findings were that delays to diagnosis continue, with an average of 8 years from symptom onset to diagnosis. In addition, of the 10,000 participants who completed the APPG survey online, 58% of them visited their GP more than ten times prior to receiving a formal diagnosis, 21% saw a hospital doctor more than ten times and 53% visited the accident and emergency (A&E) department (APPG October 2020 report). As a result, in 2020, the government introduced the teaching of menstrual wellbeing for all pupils in primary and secondary schools in England (Endometriosis UK).

Education is an important aspect in raising awareness of what are ‘normal’ and ‘abnormal’ symptoms and subsequently facilitating the recognition of endometriosis as an illness. Over recent years, the awareness of endometriosis has increased among the general public, possibly due in part to celebrities sharing their experiences in the media. The APPG report, combined with increased public awareness, has placed endometriosis on the radar. However, education alone is unlikely to reduce delays in diagnosis, so it is likely that a combination of factors will influence diagnosis; therefore, there is a need to explore this more deeply.

It is important to acknowledge that wider, unanticipated factors can have an impact on the diagnosis of endometriosis. In December 2019, the World Health Organization (WHO) declared COVID-19 to be a global public health emergency. This had a major impact on the way in which medical and surgical care is delivered. Of particular relevance to this thesis was that routine and non-cancer-related gynaecological surgery was postponed for some time during the pandemic, and this impacted on the waiting list for those with suspected endometriosis (Ball et al, 2021). The impact of the COVID-19 pandemic on the diagnosis of endometriosis has not been captured in this thesis, as the data were collected earlier.

The delay to diagnosis of disease and illness is a wider issue in healthcare. To understand the delay to diagnosis, it is important to appreciate the different stages involved in reaching a diagnosis. There does not appear to be standard definition for what is considered a delay to diagnosis in patients with suspected endometriosis. However, exploring more widely, Richards, Morren and Pioro (2020) define delay to diagnosis of amyotrophic lateral sclerosis as the mean or median timeframe from when a patient reported their symptom(s) to when a formal diagnosis is reached by the clinician. In contrast, Ukwenya et al (2008) discuss the delay to diagnosis based on four main stages: patient delay, healthcare professional delay, healthcare system delay and, subsequently, treatment delay. The three main stages discussed by Olesen, Hansen and Vedsted (2009) include symptom recognition to presentation to the healthcare professional, the point from presentation to a healthcare professional to ordering the respective medical tests, and finally the point at which an investigation has been ordered and the respective treatment has commenced. There is clearly significant variation in the definition of delay to diagnosis for different medical conditions.

An early diagnosis of any medical condition, whether it be considered benign or malignant, is important for several reasons. For instance, in general, if cancer is diagnosed at the later stages of the disease process, the overall survival rate and respective clinical outcomes are poor (Richards, 2009). Haroon, Gallagher and Fitzerald (2015) compared patient-reported outcome measures as well as clinical data between patients who saw a rheumatologist early in the disease process versus those who experienced a delay in diagnosis. They found that patients who experienced a delay in review by a rheumatologist of even 6 months experienced poorer long-term physical outcomes compared with those who were reviewed earlier.

It is important to differentiate between a *delay* in diagnosis and how it relates to a *late* diagnosis. It is also important to understand that there is an overlap between what is considered a delay in diagnosis and a late diagnosis. There are limited studies exploring the difference between the two; however, Wilton et al (2019) explain that a late diagnosis can occur due to patients presenting to a clinician late in the disease process. In their study with HIV patients, Wilton et al (2018) found that a late diagnosis was more likely to occur in heterosexual men and in those participants who were from Africa and the Caribbean. It is important to understand that if a patient presents 'late' to a clinician, this may not necessarily be due to the patient avoiding the healthcare system. For instance, in the case of lung cancer, patients may not necessarily display the signs and symptoms of the underlying pathology that cause them to seek medical help until the disease has reached an advanced stage (Corner et al, 2005).

1.1.2 Researcher background and positionality

As a specialist trainee in obstetrics and gynaecology in the United Kingdom, I took three years out of this programme to embark on a PhD as a clinical research fellow in endometriosis. During my fellowship, I regularly encountered patients with either suspected or confirmed endometriosis in both the clinical and operative setting. It was during this time and through my clinical training that I gained insights that the delay to diagnosis of endometriosis was a problem.

Through my clinical encounters in secondary care, it became clear that a considerable proportion of women diagnosed with endometriosis expressed grievances about how long it had taken for them to receive a formal diagnosis of endometriosis. My philosophical assumption is based on the experiences of many women, who cited a complex range of psychosocial factors as well as dissatisfaction with an apparent lack of knowledge, understanding and interest they encountered in general practice. It was this insight that initially sparked my interest in exploring women's experiences of being diagnosed with endometriosis. To further inform and supplement women's experiences, I was also interested in exploring healthcare professionals' perceptions about diagnosing endometriosis. I considered that if I was able to obtain insights into why delays to diagnosis were occurring and provide an understandable framework or model to help explain how these factors influence the process of diagnosis, then I could use this information to raise awareness among patients and healthcare professionals (to reduce delays to diagnosis) and potentially change healthcare practice.

1.1.3 Why is a timely diagnosis of endometriosis important?

A diagnosis enables a woman to receive the most appropriate treatment for endometriosis, whether this be medical or surgical; a number of studies have found that hormonal treatment in particular is associated with a greater improvement in health-related quality of life outcomes (Souza et al, 2011; Tripoli et al, 2011). For those women who are considered to have deep infiltrative disease, their treatment will be in a specialised centre that offers advanced endometriosis surgery. In addition, a diagnosis offers women the opportunity to seek tailored psychological support from professionals, patient groups (e.g., the charity Endometriosis UK) and endometriosis nurse specialists; it has been found that patients with endometriosis have high rates of anxiety and depression (Sepulcri and Amaral, 2009). A diagnosis of endometriosis legitimises women's symptoms and allows them to seek the respective support for their condition, whether this be professionally via medical practitioners or through their employer for work-based adjustments (Ballard, Lowton and Wright, 2006). In addition, a diagnosis allows women to have a common language in which they can express the impact of their symptoms to other people, and therefore find ways of coping with them (Ballard, Lowton and Wright, 2006).

Endometriosis impacts women's quality of life in various ways and has been well described in the literature. Gallagher et al (2018) performed a longitudinal study involving 567 participants and found that adolescents with endometriosis had worse physical and mental component scores compared with controls; therefore, the quality of life in these individuals was worse (Gallagher et al 2018). In addition, the longer the time to diagnosis, the more significant the impact of endometriosis on quality of life (Gallagher et al, 2018).

A thematic analysis by Roomaney and Kagee (2016) involving 25 participants with endometriosis in South Africa identified categories capturing the quality-of-life impact that endometriosis has on women. They found that endometriosis not only had a negative impact on work productivity with subsequent financial implications but also on physical, psychological and sexual function (Roomaney and Kagee, 2016). More specifically, women felt impaired in performing daily activities that were taken for granted, experienced isolation and hopelessness, and experienced painful sexual intercourse, which resulted in relationship tensions (Roomaney and Kagee, 2016). Awareness of the way in which endometriosis symptoms impact on women can deepen understanding of why they seek medical help or not. Primary research has consistently shown that work-related productivity and employment is also negatively impacted for those women with endometriosis (Nnoaham et al, 2011; Hansen et al, 2013; Moradi et al, 2014); again, a diagnosis enables women to negotiate any particular workplace adaptations with their employer as necessary.

The influence endometriosis has on psychological health has been well documented in the literature. A grounded theory study by Hallstam et al (2018) in Sweden explored 16 women's experiences of living with endometriosis. In this study, three categories (women with painful endometriosis, dependence on others and a ruined life) and one core category (living with painful endometriosis) emerged (Hallstam et al, 2018). They concluded that healthcare professionals should be more mindful of the grief that is associated with living with this condition and find ways of supporting women through this. Hallstam et al (2018) also found that their participants described how some healthcare professionals were 'neglectful' and as such caused diagnostic delays. The authors did not elaborate on what was considered 'neglectful', but it is assumed to have a negative impact. However, further research is required as to how 'neglectful' behaviour by clinicians might influence delays in diagnosis. Culley et al (2013) conducted a critical narrative synthesis of 42 research articles (all study types) and through thematic analysis found that women experienced uncertainty and delay in the diagnosis of endometriosis, and that endometriosis has a considerable impact on women's social and psychological lives.

The impact of endometriosis on female identity has been briefly discussed in the existing literature. Manderson et al (2008) provided insights into the 'complexity of help seeking' and how 'the ways in which ideas of gender informed by women's embodiment but also their reporting of symptoms, influence their interaction with health professions'. In addition, Facchin et al (2018) conducted a grounded theory study to explore the impact of endometriosis on women's psychological health. They found that some women described their experiences with healthcare professionals as being 'treated like they were insane' or 'crazy' (Facchin et al, 2018). The core category from this Italian study was 'disruption', and this permeated women's lives to the extent it influenced their female identity. To ensure women with endometriosis have the most appropriate psychological support, both of these studies highlighted the importance of clinicians being aware of how endometriosis can impact a woman's identity and female embodiment.

Subfertility or infertility related to endometriosis can have an influence on a woman's self-identity. Riazi et al (2014) found through their interview study with patients and healthcare professionals that endometriosis-related infertility impacted on female identity, while dyspareunia affected a woman's perception of her femininity. This is an important finding, as the issue of female identity and femininity in association with endometriosis may be perceived differently in different cultures and may therefore impact women's lives in different ways. In addition, Aerts et al (2018) found that women with endometriosis experienced greater sexual dysfunction in comparison with women who did not have endometriosis. Lukic et al (2016) followed up 67 women who had surgery for endometriosis and found that there was an improvement in their sexual function 6 months after surgery, reinforcing the importance of an early and timely diagnosis.

The lack of awareness of endometriosis among healthcare professionals is still a problem at this time and can lead to the normalisation of symptoms. Through 15 individual interviews with women who have endometriosis, a thematic and content analysis by Denny (2004) found that even when diagnosed with the condition, women felt their symptoms were normalised by healthcare professionals. As a result, this had a negative influence on their personal relationships, employment and sexual health (Denny, 2004). Researchers have attempted to increase awareness of endometriosis-related symptoms, particularly in the adolescent population. Geysenbergh et al (2017) created a six-item questionnaire to be used with adolescent patients who are suspected to have endometriosis, with items including 'age of menarche, cycle duration, dysmenorrhea, pain descriptors, dyschezia and urinary symptoms'. These items in themselves point to multiple factors influencing the diagnosis of endometriosis.

A woman's age can influence whether she chooses to seek medical help. Among the adolescent population, endometriosis has been described as a 'hidden, progressive and severe disease', and women in this group also face diagnostic delays (Brosens et al, 2013). Divasta et al (2018) conducted a cross-sectional study involving 360 participants with endometriosis and 207 controls, all of whom were under the age of 25 years. They found that members of the adolescent population were more likely to seek help due to pain impacting their quality of life, as opposed to pelvic pain in general or concerns about fertility. This suggests that there are important differences in health-seeking behaviours between the adolescent and adult female populations. Matsuzaki et al (2006) suggested that if painful symptoms develop during the adolescent period, then these individuals are more likely to experience a delay in diagnosis as they may delay presentation to the clinician. No further explanation was provided by the authors as to why this may be the case.

The ways in which endometriosis disrupts the quality of life in the adolescent population can be markedly different to those of the adult population. Zannoni et al (2014) conducted a questionnaire-based cross-sectional study involving 250 adolescents to investigate the prevalence of dysmenorrhoea in adolescents (not confirmed to have endometriosis) and factors that may predict endometriosis. They found that absenteeism from school or work and the impact of symptoms on sexual function were two potential predictors of endometriosis and recommended that schools increase the awareness of endometriosis through education Zannoni et al (2014).

Powell (2014) made it very clear that the clinical approach to an adolescent patient presenting with chronic pain should be carefully considered. Powell (2014) stated that adolescents have specific considerations that must be taken into account, including the potential embarrassment they may experience during a medical history or examination, as well as concerns they may have about confidentiality. In addition, if an adolescent patient is commenced on medical treatment for chronic pelvic pain and does not notice an improvement in their symptoms, then this individual should be investigated further for endometriosis (Attaran and Gidwani, 2003; Yang et al, 2012). These are important factors that require further exploration to help understand the delay to diagnosis.

The existing evidence clearly indicates that women's healthcare experiences of endometriosis diagnosis are important. Grundstrom et al (2017) interviewed nine women with endometriosis to gain insights into their healthcare experiences. They described their findings as 'the double-edged experience of healthcare encounters', as women felt there was a 'constructive' and a 'destructive' element to their encounters due to women feeling a sense of 'ignorance' from healthcare professionals as well as feeling 'acknowledged and confirmed' Although this study provided insights into how some women feel when seeking help from healthcare professionals, the findings cannot be directly related to adolescent females and younger women as the age of the participants ranged from 23 to 55 years. Further work is required to explore how these complex interactions with healthcare professionals affect the health-seeking behaviour of women with endometriosis.

1.1.4 What is the current gap in the literature?

There is an extensive body of literature exploring the experiences of women living with endometriosis. However, very few studies have looked at the experiences of women who specifically perceive a delay to diagnosis. There are also very few studies that have explored the health-seeking behaviours of women with suspected endometriosis, or the coping strategies adopted by these women prior to diagnosis. Therefore, this qualitative study aims to explore these factors in detail. The average time to diagnosis of 7.5 years in the UK (Husby, Haugen and Moen, 2003) is an unacceptable length of time and, during this period, women experience a significant disruption to their quality of life. Affirming national government pressure to reduce the diagnosis time, the current 2017 National Institute of Clinical Excellence guidelines on the diagnosis and management of endometriosis (NICE, 2017) recommend that further research is conducted to explore the reasons for such delays.

Exploring the wider context of this PhD, at present, there are no validated, patient reported screening tools that can predict endometriosis or prompt clinicians to refer patients with suspected endometriosis to a specialist gynaecologist. There are currently a number of quality-of-life assessment tools for endometriosis, including non-specific instruments such as the Short Form-36 tool (De Graaff et al, 2013) and the WHO quality of life tool (Sepulcri and Amaral, 2009), as well as those very specific to endometriosis, such as the Endometriosis Health Profile-30 (Jones et al, 2001). These tools are undoubtedly extremely valuable and allow the impact of endometriosis to be assessed; however, they can only be applied once a patient has received a diagnosis of endometriosis. While there are resources on the Endometriosis UK website to help patients with suspected endometriosis (symptom diary and menstrual wellbeing kit for General Practitioners), these resources have not been validated, and they primarily focus on symptoms only. Endometriosis is a complex condition and requires a multidimensional approach when it is first suspected. It is therefore hoped that the qualitative findings from this thesis can be used to develop such a tool in the future, to increase the awareness of endometriosis among both patients and healthcare professionals in the primary care setting.

1.1.5 What is the aim of this thesis?

This thesis will focus on the experiences of women diagnosed with endometriosis and the understanding of the healthcare professionals tasked with providing the diagnosis in order to achieve timely treatment and management. The findings will enable the process of 'diagnosis' to be explored in detail. This will include, but not be limited to, the following questions. What makes women with endometriosis recognise that there is a problem? How do women with suspected endometriosis interpret their symptoms? What makes women with suspected endometriosis seek help?

1.1.6 What will this thesis not focus on?

Endometriosis is a complex condition, and there are many factors that can influence the process of diagnosing endometriosis. Although very important, this thesis will not focus on the surgical or biomarker predictors of endometriosis. While the findings from this study will prove useful in developing a non-invasive tool in the future to increase awareness of endometriosis among the public and healthcare professionals, the focus of this study is not to develop the actual tool. Finally, the thesis will not explore the experiences of endometriosis diagnosis among women aged less than 16 years.

1.2 Background to endometriosis

This section is not intended to be exhaustive but to provide a brief overview of the prevalence, aetiology, pathophysiology, clinical diagnosis and management of endometriosis.

1.2.1 Prevalence

It is difficult to estimate the exact prevalence of endometriosis based on age; however, the overall prevalence of endometriosis varies between 10% and 15% (Giudice and Kao, 2004). Among women who have chronic pelvic pain, it has been estimated that the prevalence of endometriosis is between 24% and 40% (Whitaker et al, 2016; Mowers et al, 2016).

1.2.2 Incidence

In a study by Eisenberg et al (2018), the annual incidence of endometriosis was shown to be 7.2 per 10,000 women aged between 15 and 55 years.

1.2.3 Aetiology of endometriosis

The exact cause of endometriosis remains unknown (Burney and Giudice, 2012). However, several theories have been postulated and these are outlined next.

Retrograde menstruation theory

The retrograde menstruation theory states that during the menstrual cycle each month, blood flows back from the uterus into the pelvis via the fallopian tubes, causing endometrial cells to implant within the pelvis; this is often referred to as 'seeding' (Sampson, 1927). These cells are then stimulated by oestrogen and behave as if they were located in the endometrium, resulting in bleeding within the pelvis and subsequent symptoms of pain. While this theory is the most widely accepted, it does not explain why endometriosis occurs at more distant sites (Dhesi and Morelli, 2015).

Metaplasia theory

During foetal development, the Mullerian duct forms from the coelomic epithelium (Gruenwald, 1942). The coelomic epithelium is involved in the development of the pelvic peritoneum and surface of the ovaries (Gruenwald, 1942). Generically, metaplasia refers to one cell type changing to another (Gruenwald, 1942). In the case of endometriosis, it is suggested that cells on the visceral and parietal peritoneum transform to become endometrial cells via metaplasia (Gruenwald, 1942).

Lymphatic and vascular spread

Occasionally, endometriosis can be found in distant sites, including the lungs and nose (Jubanyik and Comite 1997). To explain this, it has been suggested that endometrial cells have spread from the uterus to these sites via the lymphatic or blood systems (Jubanyik and Comite, 1997).

Immunological explanation

It has been suggested that women with endometriosis have larger macrophages in their peritoneal fluid in comparison to women who do not have endometriosis (Oosterlynck et al, 1991). It is also postulated that women who do not have endometriosis have macrophages that predominantly comprise monocytes as a subtype (Oosterlynck et al, 1991). This theory further suggests that there is reduced clearance of endometrial cells and, as a result, there is a reduction in the number of natural killer cells (Lebovic, Mueller and Taylor, 2001). The production of various cytokines and growth factors will result in endometrial cells proliferating and evoking an inflammatory response (Lebovic, Mueller and Taylor, 2001).

Genetic link

Several studies have suggested that the development of endometriosis may have a familial predisposition (Hansen and Eyster, 2010). The incidence of endometriosis is increased by five to seven times if there is a family history of the condition (Hansen and Eyster, 2010).

1.2.4 Pathophysiology of endometriosis

Most commonly, endometriosis occurs within the pelvis, in areas including the ovaries, the peritoneum of the pelvic side walls, the bladder, bowel and ligaments (Vercellini et al, 2007). It is important to note that the invasiveness of the disease can be superficial or deep and that the number of lesions does not correlate with symptom severity (Vercellini et al, 2007). The lesions can vary from superficial small spots to deeply invading nodules. The colour of these lesions can be variable, including brown, black, red and white. Endometriosis that develops on the ovary is described as an ovarian endometrioma (Khan et al, 2014).

Histologically, features of endometriosis include ectopic endometrial glands, while old haemorrhages can be seen due to macrophages containing haemosiderin (Khan et al, 2014). The pain that occurs in relation to endometriosis is due to increased levels of prostaglandins, of which prostaglandin E2 and F2-alpha are the most common (Zorbas, Economopoulos and Vlahos, 2015). The increased levels of prostaglandin E3 cause increased levels of oestrogen (Rafique and Decherney, 2017). Importantly, it is this supply of oestrogen that enables foci of endometriosis to develop. Prostaglandin-E2 levels are also high in concentration within the endometrium, and this is another source of oestrogen (Rafique and Decherney, 2017). Further sources of oestrogen are the ovary and peripheral adipose tissue (Rafique and Decherney, 2017).

1.2.5 Clinical diagnosis

Symptoms

The clinical symptoms of endometriosis are extremely variable (Bulletti et al, 2010). Approximately 20-25% of women with endometriosis will be completely asymptomatic (Bulletti et al, 2010). The most common symptoms include pelvic pain that is linked with the menstrual cycle, as well as problems with fertility (Bulletti et al, 2010). Changes in the menstrual cycle with regards to its regularity is also a feature, as is pain during sexual intercourse (Schrager, Falleroni and Edgoose, 2013). Women may also present with nonspecific symptoms, such as urological or gastroenterological dysfunction, as well as nausea and vomiting (Schrager, Falleroni and Edgoose, 2013). Gastroenterological symptoms include abdominal pain, bloating, dyschezia and rectal bleeding (Schrager, Falleroni and Edgoose, 2013). Urological symptoms include increased urinary frequency and haematuria (Schrager, Falleroni and Edgoose, 2013).

Signs

Clinical signs on examination include generalised abdominal tenderness (Riazi et al, 2015). Digital vaginal examination may reveal nodularity on the uterosacral ligaments, a fixed uterus or tenderness in the adnexa (Riazi et al, 2015). Occasionally, a speculum examination may reveal endometriosis over the cervix or vagina (Riazi et al, 2015). Importantly, the clinical examination may be unremarkable.

1.2.6 Investigations

Imaging

Ultrasound of the pelvis is often the initial test that is conducted (Bourgioti et al, 2017). It can help to identify any ovarian cysts or other pelvic abnormalities such as fibroids (Bourgioti et al, 2017. An ultrasound can also help differentiate between a simple cyst and an endometrioma (Bourgioti et al, 2017) A magnetic resonance imaging (MRI) scan of the pelvis can be performed to assess endometriosis in more detail (Bourgioti et al, 2017. This imaging modality is often used to help plan more extensive surgery if there is bowel or bladder involvement. It is important to note that ultrasound and MRI can produce normal findings, but endometriosis may still be seen upon laparoscopy (Bourgioti et al, 2017; NICE, 2017).

Definitive diagnosis

The ‘gold standard’ test to confirm endometriosis involves a diagnostic laparoscopy (NICE, 2017). The aim of this procedure is to visualise the pelvis in a systematic manner to identify areas of endometriosis. If endometriosis is seen or suspected, then samples of tissue can be excised for confirmatory histological examination (NICE, 2017). Photographs of the pelvis are often taken for the patient’s medical records.

1.2.7 Management

Treatment options include management of pain, hormonal treatment and surgical options; at present, these recommendations are based on the NICE (2017) guidance on the diagnosis and management of endometriosis.

The different medical treatments that are offered to patients with either suspected or confirmed endometriosis include hormonal therapy in primary care and analgesia and hormonal treatment in secondary care.

Analgesia

Several types of analgesia are recommended as part of symptom control (NICE, 2017). Based on the WHO pain ladder, simple analgesics such as paracetamol are considered first and quite often, combined with non-steroidal anti-inflammatory drugs (NICE, 2017). Other types of analgesia can include opioids.

Hormonal treatment in primary care

Hormonal treatment can include the combined oral contraceptive pill, progesterone-only pill or the Mirena coil (NICE, 2017). A systematic review by Jensen, Schlaff and Gordon (2018) found that the use of combined hormonal contraceptives resulted in a significant reduction in pain that was attributed to endometriosis. If there is no improvement in pain, or if the hormonal treatments are not tolerated or are contraindicated, it is recommended that the patient be referred to a gynaecology (or a paediatric and adolescent gynaecology) service (NICE, 2017).

Gonadotrophin releasing hormone (GnRH) agonists

This group of drugs can be prescribed by the consultant gynaecologist. Examples of GnRH agonists include leuprolide acetate (Lupron), given as an intramuscular injection once a month, and goserelin acetate (Zoladex), which is administered subcutaneously monthly (Rafique and Decherney, 2017). Essentially, these drugs work by inhibiting ovarian function and therefore temporarily placing the patient in a state of menopause by inhibiting the levels of oestrogen production by the ovary (Rafique and Decherney, 2017). GnRH analogues can cause levels of follicle stimulating hormone (FSH) and luteinising hormone (LH) to be released; however, over time, the drug impacts the GnRH receptors in the pituitary gland and supresses the hypothalamic–pituitary–ovarian axis (Rafique and Decherney, 2017). Consequently, the ovaries are unable to produce oestrogen at the levels they were prior to the administration of this drug, resulting in anovulation (Rafique and Decherney, 2017). The woman will then be in a state of 'medical menopause' whereby she may experience symptoms of hypoestrogenism (Rafique and Decherney, 2017). This significant reduction in oestrogen levels can result in the regression of endometriotic nodules (Rafique and Decherney, 2017).

It is very important to mention that by creating this state of menopause, women are at increased risk of osteoporosis and should be offered treatment to reduce this risk. This treatment is often in the form of hormone replacement therapy, an example of which is tibolone. If a trial with GnRH agonists is successful, it implies that surgically removing the ovaries will improve a patient’s symptoms; as such, this may then be the next step in the clinical plan (Rafique and Decherney, 2017).

Surgical treatment

The type of surgical treatment will depend on the extent and severity of endometriosis. It is recommended that surgery is conducted laparoscopically in the first instance (NICE, 2017).

Diagnostic laparoscopy and minor surgical treatment for endometriosis

In cases of suspected endometriosis, a diagnostic laparoscopy will often be performed. If there is minor endometriosis, i.e., endometriosis that is superficial and affects the peritoneum only, then this will be treated during the laparoscopy, either by ablation or excision (NICE, 2017). If there is more extensive endometriosis, then the diagnostic procedure will be used to help plan future surgery (NICE, 2017).

Surgical treatment of an endometrioma

If an endometrioma ('chocolate cyst') is present, then the aim of surgery will be to remove this but also conserve as much ovarian tissue as possible (NICE, 2017). The capsule of the cyst will be gently dissected away from the ovary (Luisi, Stefan and Santulli, 2013). It is important to conserve as much ovarian tissue as possible, otherwise there is a risk that the patient will undergo a surgical menopause and therefore require hormone replacement therapy (Luisi, Stefan and Santulli, 2013).

Total abdominal hysterectomy with conservation of one or both ovaries

In those women who do not wish to consider future fertility and have other co-existing conditions, such as adenomyosis (endometriosis affecting the muscle wall of the uterus), a total abdominal hysterectomy with conservation of one or both ovaries may the most appropriate form of surgery (NICE, 2017). The aim of this surgery is to eliminate the risk of retrograde menstruation by removing the uterus. The ovaries are conserved to ensure the woman does not transition to a state of premature menopause.

Treatment of endometriosis involving the bowel or bladder

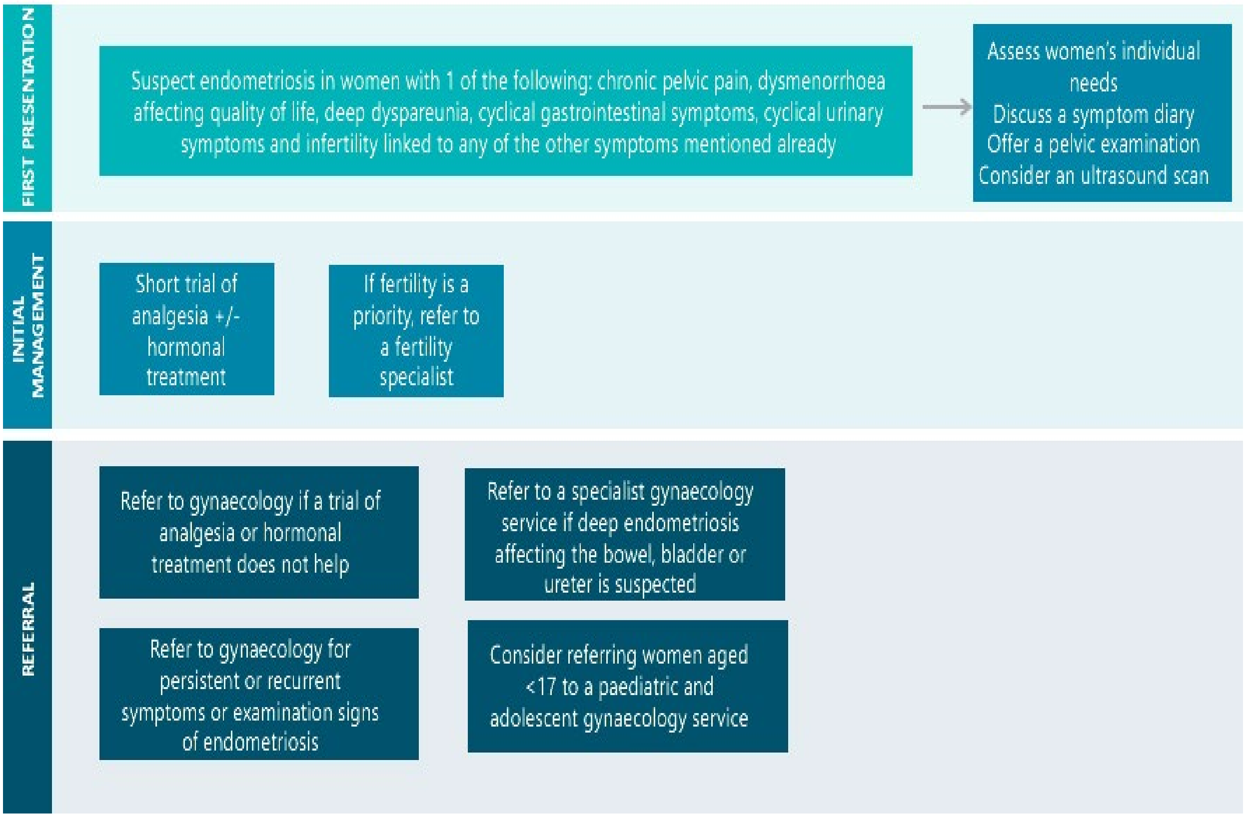
The medical and surgical management of women with bowel or bladder endometriosis will be unique to each individual and will encompass a multidisciplinary approach involving colorectal surgeons and urologists. Endometriosis involving the bowel, bladder or other organs is often considered to be deep infiltrating disease (Abrao et al, 2015).

1.2.8 The British Society for Gynaecological Endoscopy Centre (BSGE Centre)

While there are general gynaecological services in the UK, there are also specialist centres accredited to perform surgery for cases where endometriosis is advanced and involves the para-rectal space (Byrne et al, 2021). These centres are known as BSGE centres (Byrne et al, 2021). Each centre must be accredited through its caseload, its multidisciplinary approach, and the way in which its cases are audited (Byrne et al, 2021). The NICE (2017) guidance makes clear when patients should be referred to a BSGE centre as opposed to a general gynaecologist.

Figure 1 is a summary, adapted from the NICE (2017) guidance on the diagnosis and management of endometriosis, highlighting the endometriosis diagnosis and management pathway.

Figure 1. A diagram adapted from the 2017 NICE guidance to show the diagnosis and management pathway for endometriosis in the primary care setting.



Suspect endometriosis in women with 1 of the following: chronic pelvic pain, dysmenorrhoea affecting quality of life, deep dyspareunia, cyclical gastrointestinal symptoms, cyclical urinary symptoms and infertility linked to any of the other symptoms mentioned already

Assess women's individual needs
Discuss a symptom diary
Offer a pelvic examination
Consider an ultrasound scan

Short trial of analgesia +/- hormonal treatment

If fertility is a priority, refer to a fertility specialist

Refer to gynaecology if a trial of analgesia or hormonal treatment does not help

Refer to a specialist gynaecology service if deep endometriosis affecting the bowel, bladder or ureter is suspected

Refer to gynaecology for persistent or recurrent symptoms or examination signs of endometriosis

Consider referring women aged <17 to a paediatric and adolescent gynaecology service

1.2.9 Overview of the thesis structure

This PhD thesis explores the diagnosis experiences of women with confirmed endometriosis (phase one); in phase two, these findings are supplemented with the experiences of healthcare professionals. The conceptualisation and overall design of the research is organised in four main parts, as follows:

PART 1 (Introduction and scoping review)

Chapter 1: Introduction. This chapter provides a contextual backdrop to the study and an overview of endometriosis.

Chapter 2: Scoping review. A review of the current literature, focussing on the reasons for the delays in the diagnosis of endometriosis.

PART 2 (Methodology, methods and data analysis process)

Chapter 3: Methodology. This chapter explores the philosophical assumptions that underpin the research and examines the constructivist grounded theory and reflexive thematic analysis approaches.

Chapter 4: Methods. This chapter describes the study design, including recruitment, sampling, data collection, ethical considerations and methodological rigour. The chapter focuses on both phases of the study, the first being the grounded theory phase, the second being the equally important healthcare professional phase.

Chapter 5: Data analysis. This chapter provides a detailed account of the data analysis process for the data generated by participants with endometriosis (grounded theory) and the data generated by healthcare professionals (reflexive thematic analysis).

PART 3 (Study findings from participants with endometriosis, the grounded theory, and from healthcare professionals using reflexive thematic analysis)

Chapter 6: Conceptual findings (participants with endometriosis). This chapter presents and explores the four main categories that were derived from the semi-structured interviews with women diagnosed with endometriosis (phase one)

Chapter 7: The grounded theory. This chapter presents and explains the constructivist grounded theory, developed from the findings in chapter 6, to explain the delay to diagnosis of endometriosis.

Chapter 8: Findings (healthcare professionals). In this chapter, the findings from three focus groups with separate healthcare professionals are presented in the form of a reflexive thematic analysis (phase two).

Chapter 9: Providing the whole picture: Linking both phases of the study. This chapter draws together the findings from both phases of the study.

PART 4 (Discussion, conclusion and reflexivity)

Chapter 10: Discussion. This chapter critically interprets the findings from the research conducted for this PhD in the context of the existing literature and considers the strengths and limitations of the thesis. The implications for future practice and research are also discussed.

Chapter 11: Reflexivity. This chapter provides a reflexive account of the researcher's reflections on themself and the research process.

Chapter 12: Conclusion.

Chapter 2 – A scoping review to explore the delays to diagnosis of endometriosis

2.1 Introduction

The aim of this scoping review is to explore the current literature surrounding the delays to diagnosis of endometriosis. This chapter will start with the justification for conducting a scoping review and why it was carried out prior to data collection, especially considering that a grounded theory methodology underpins the first phase of the study. It will then go on to detail the literature search strategy and the design and findings of the scoping review. The chapter concludes with the aim and objectives of this doctoral study.

2.3 The literature review in the context of a grounded theory approach

This PhD thesis incorporates a grounded theory (GT) approach; in the context of GT approaches, a justification for a literature review is important. Bryant and Charmaz (2007, p.19) state that 'ever since the publication of *The Discovery of Grounded Theory*, concerns have arisen regarding how students and researchers should approach and use the existing literature relevant to their research topic'. It is important to note that there is no debate as to whether a literature review should be conducted, but as to *when* it should be performed (McGhee, Marland and Atkinson, 2007). This consideration stems from Glaser and Strauss's (1967, p. 37) *The Discovery of Grounded Theory*, where they state that, at first, 'the literature of theory and facts on the area under study should be ignored'. They felt this was important as it would allow categories and themes to emerge from the collected data, rather than be 'contaminated' with existing literature and theories (Glaser and Strauss, 1967). As a result, they recommend that once a grounded theory is complete, only then should the researcher engage with the wider literature (Glaser and Strauss, 1967). However, Charmaz (2006) explains that the existing literature can be explored prior to commencing the grounded theory study, provided the researcher accounts for this through the process of reflexivity.

Exploring the issue of conducting a literature review from the opposite stance, McGhee, Marland and Atkinson (2007) state that performing the review prior to commencing the study can have its merits. It would mean that the researcher will have a clear rationale for the study, as well as being confident that the work is not a duplication, allowing originality to be demonstrated in one's work. In addition, the researcher will gain insights into preconceptions that they may have about the phenomenon of interest (Maijala, Paavilainen and Astedt-Kurk, 2003). Coffey and Atkinson (1996, p. 157) make an important point, that 'the open-mindedness of the researcher should not be mistaken for the empty mindedness of the researcher who is not adequately steeped in the research traditions of a discipline. It is, after all, not very clever to rediscover the wheel, and the student or researcher who is ignorant of the relevant literature is always in danger of doing the equivalent'. Importantly, Cutcliffe (2000, p1418) states that 'no potential researcher is an empty vessel, a person with no history or background'. One way to acknowledge that a researcher has preconceived ideas, whether it is from the literature or from experience, is through the process of reflexivity. McGhee, Marland and Atkinson (2007, p. 335) describe reflexivity as 'an awareness of the ways in which the researcher as an individual with a particular social identity and background has an impact on the research process'.

After reading the reports of other GT studies and papers exploring the debates surrounding the timing of the scoping review, I decided to conduct my scoping review prior to conducting each of the study phases of this PhD. Through a continued process of reflexivity and memo writing, I was able to gain awareness of my own preconceptions. I engaged with studies exploring the impact of endometriosis on women's lives, as well as emerging literature on the reasons for delay to diagnosis. I also read extensively about GT and used it to underpin the design of the first phase involving participants with endometriosis. It was through this process that I was able to gain a deeper understanding into some of the unmet issues surrounding delays to diagnosis of endometriosis and ultimately refine my research question. It allowed me to appreciate and respect the work of other scholars in the field and gain insights into the 'literature gaps', which enabled me to justify my PhD proposal at my probationary review meeting.

2.3.1 Rationale for a scoping review

Scoping reviews are very different from traditional systematic reviews (Pham et al, 2014), in that their aim is 'to map rapidly the key concepts underpinning a research area and the main sources and types of evidence available' (Mays, Roberts and Popay, 2001, p. 194). A systematic review focuses on a very specific research question, while a scoping review is broad in both its question and exploration of the literature (Munn et al, 2018). The aim of the literature review in this doctoral study was to gain broad insights into the existing reasons for the delay to diagnosis of endometriosis, prior to conducting the grounded theory phase of the study.

Grounded theorists advocate that the researcher should have minimal preconceptions about the study area prior to conducting a study and how engagement with the existing literature connected to the research area can influence this (Charmaz, 2006). After much thought, a scoping review was thus conducted to gain insights into the existing literature that explores the reasons for the delays to diagnosis of endometriosis, prior to the data collection process. A scoping review enabled me to strike a balance in gaining the required background information on the delays to diagnosis, but also allowing me to be reflexive on how these findings may influence the research process.

A scoping review is also particularly useful when the field of interest has not been extensively explored previously (Pham et al, 2014), as was the case in this research area. A broad search was performed without research design limitations, allowing a wide range of evidence to be identified and used to inform the research focus of this study. A scoping review was also useful as no definition exists as to what constitutes a delay to diagnosis and therefore enabled this to be explored further within the literature (Munn et al, 2018). The rationale for the timing of the scoping review in relation to the research process was discussed at length earlier in this chapter.

2.3.2 Qualitative or quantitative enquiry – justification of the scoping review structure

To understand and capture the problem of diagnostic delay, both qualitative and quantitative research studies need to be explored. Qualitative studies provide an understanding of the problem from a patient perspective, while quantitative studies provide numerical data, often saturated from surveys and questionnaires involving a larger number of participants, to gain more generalisable insights. The review findings will be explored using the structure of themes rather than chronology of paper publication to allow key insights relating to the diagnosis of endometriosis to be demonstrated.

Qualitative research involves an interpretative approach (Charmaz, 2006). It aims to interpret meaning in depth and can be used to develop theories. It is not about testing a particular hypothesis; it is more about developing a greater understanding of a particular phenomenon (Charmaz, 2006). For this reason, qualitative research is considered to provide potentially more valuable insights into understanding the existing reasons for the delays to diagnosis. Qualitative research is increasingly being used in medical research as it enables the patient perspective to be considered when exploring individual experiences of care or when developing a patient service.

2.3.3 Scoping review framework

This scoping review is based on the original methodological framework proposed by Arksey and O'Malley (2005), which was further developed by Levac, Colquhoun and O’Brien (2010). In the case of this research, this involved the following:

1. **Developing a research question.** It is important to be clear about the reason for conducting the scoping review in relation to the research question.

2. **Identifying relevant studies.** A team with the relevant expertise in research methodology should be involved. For the purposes of this PhD, oversight was provided by two supervisors with a background in qualitative research.
3. **Selecting studies for inclusion.** This was an iterative process that involved modification of the search strategy as necessary to ensure all relevant studies were included. It is normally recommended that two researchers separately select studies for inclusion; however, for the purposes of my PhD this was not appropriate.
4. **Charting the data.** A data collection chart should be developed, and the authors suggest content analysis for the data analysis process. A summary of all the included studies is provided in this chapter in a tabular form.
5. **Collating and reporting the data.** This stage is performed in three separate phases: (1) numerically and thematically analyse the data, (2) report the findings according to the research questions, and (3) discuss the findings in more detail and in relation to the scoping review question.
6. **Consultation**. This is an optional stage and involves presenting the findings to a stakeholder group. It is important to have a clear objective for this consultation. For this research, this stage was conducted; further information is provided within this chapter.

2.3.4 The scoping review question

This scoping review is centred around the York Methodology developed by Arksey and O’Malley (2005). Based on this methodology, the different stages of the review will include identifying the research question, identifying the relevant studies, selecting studies, charting the data and reporting a summary of the results (Arksey and O’Malley, 2005).

The aim of the scoping review was to explore the existing evidence base concerning the delays to diagnosis of endometriosis. As a result of my supervisory meetings and wider reading, this broad aim was further refined to include the following objective:

- *What are the reasons for the delays to diagnosis of endometriosis?*

2.3.5 Search strategy

The search strategy was conducted for research published up to October 2018. The literature search was performed using a combination of synonyms, phrase searching, truncation, wildcard searching and linking of terms (Kable, Pich and Maslin-Prothero, 2012). A subject-heading search was used in addition to keyword searching. Figure 2 shows details of the search strategy.

There are many tools available for designing a review question and search strategy; PICO (Population, phenomenon of Interest, Comparator and Outcome) and SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) are two commonly used tools (Cooke, Smith and Booth, 2012). As Cooke, Smith and Booth (2012) note, the PICO method is more suitable for quantitative than qualitative research questions. For instance, the 'comparator' component of PICO may not necessarily be relevant for qualitative research (Cooke, Smith and Booth, 2012). In this review, the SPIDER tool was used (Cooke, Smith and Booth, 2012).

Figure 2. Search strategy: endometriosis diagnosis and delay.

SPIDER Strategy	**Search Terms**
Sample	(i)endometriosis* or endometrioma* (ii)*adult OR *adolescent OR *teenager
Phenomenon of interest	delay* OR diagnos* OR discover* OR detect* OR recogni* OR wait* OR defer*
Design	observ* OR questionnaire* OR “interview* OR “survey* OR “focus group* OR case stud* OR cohort* OR “cross-section*
Evaluation	experience* OR view* OR perception* OR impact* OR perspective* OR effect*
Research type	“mixed method*” OR qualitative* OR quantitative*

2.3.6 Information sources

The MEDLINE, EMBASE, CINAHL, PsycINFO and the Cochrane databases were searched for studies published up until November 2018. Ethical approval was not required for this scoping review. No authors needed to be contacted for further information. MEDLINE is one of the largest databases and was therefore included as a bibliographic source. PubMed was also searched because it contained PubMedCentral papers that are yet to undergo indexing with Medical Subject Heading (MeSH) terms and, as such, were not available on Medline. These articles are often ‘ahead of print’. PsycINFO is a database that contains literature covering a wide a range of areas including psychology and psychiatry; this database contained literature that was not available via Medline. EMBASE is mainly a biomedical database; however, it provided access to some journals that were not included in Medline. The Cochrane Library provides systematic review literature relating to healthcare interventions and their effectiveness; this was particularly important in the context of delays to diagnosis of endometriosis. CINAHL (Current Index to Nursing & Allied Health Literature) provides access to research conducted by nurses and allied healthcare professionals.

2.3.7 Study eligibility

The inclusion and exclusion criteria for studies in the scoping review were as follows.

Inclusion criteria

- Studies exploring women's or healthcare professionals' experiences of endometriosis diagnosis. As the diagnosis process involves both groups, it was important to explore studies that involved them both.
- Endometriosis of any severity was included. Studies included endometriosis that was described as 'superficial' and/or 'deep', in addition to endometriosis affecting the pelvis, bowel or bladder. Studies that included women with endometriosis that was described as 'extra-peritoneal' were also included (for instance, affecting the lung). As discussed in chapter one, the extent of endometriosis does not necessarily correlate with the severity of symptoms; therefore, articles involving participants with endometriosis of any severity were considered eligible.
- Studies published anywhere in the world. Endometriosis is a common gynaecological condition, thus research from anywhere in the world regarding experiences of diagnosis is important.
- Available in the English language.
- Studies involving participants of any age. Endometriosis can affect any female of reproductive age, so it is important to capture experiences of diagnosis at any age.
- No restriction in the timeframe of research. This allowed the reviewer to capture how literature exploring the area of delayed diagnosis has evolved over time.

- Studies of any research design. All study designs, including randomised controlled trials, as well as observational, prospective and retrospective studies were included. Qualitative and quantitative studies, as well as single- and multi-centre studies, were included in the review. This enabled as many studies as possible to be included.
- The article must have been published through a peer-reviewed process to ensure rigour and be available as a full copy for review.

Exclusion criteria

- Studies exploring pelvic pain in women who do not have endometriosis. The review was only concerned with women who have endometriosis, and while other studies involving women who do not have endometriosis might be useful for the discussion section, they are not relevant to this review.
- Studies not written in the English language. Translating studies into English can be a complex process; therefore, due to time and funding constraints, only studies written in English were included.
- Studies using quantitative methods for diagnosing endometriosis (such as blood biomarkers, urinary biomarkers or imaging techniques). This scoping review was solely focussed on the delays to diagnosis as opposed to the ways in which endometriosis can be diagnosed once it is clinically suspected. While it is useful to have an awareness of studies investigating different diagnostic methods, it is not relevant to the aim of this scoping review.

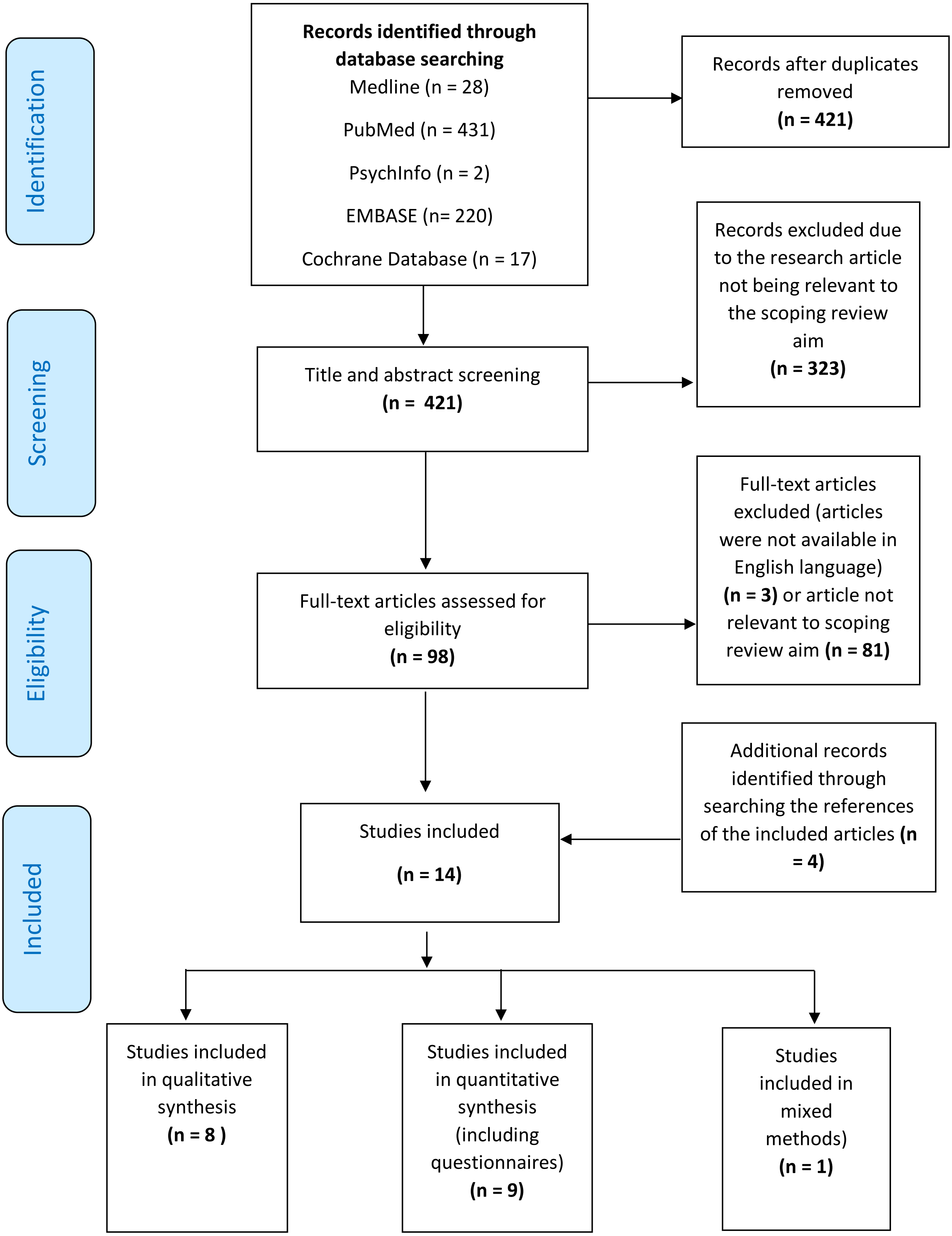
2.3.8 Literature screening

A two-stage method was used to screen all studies using the eligibility criteria. To ensure rigour, the planned search strategy was checked by my primary supervisor at the time. Stage one included screening the title and abstract of all citations identified by the search strategy. Stage two involved screening the full text of all papers that appeared to meet the eligibility criteria during stage one, plus those for which it was not possible to ascertain eligibility at stage one. Further literature was sought by searching for grey literature using the British Library Ethos website and hand-searching the reference sections of those articles already selected. Details of all selected publications were recorded in a Microsoft Excel file, and the data extracted from the studies were stored in a Microsoft Word file. There were no discrepancies between the two researchers in terms of which studies to include or exclude.

2.4 Search results

Figure 3 shows an overview of the search results from all the databases in the form of a PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram (Moher et al, 2009).

Figure 3. PRISMA flow chart showing the process of identifying relevant studies (Moher et al, 2009).



2.4.1 Data extraction

The scoping review was conducted based on the PRISMA statement criteria (Liberati, 2009), and data extraction was conducted on the selected studies. A Microsoft Excel spreadsheet was used to record the following information from each study: author details, year of publication, study title, aim(s), methods, findings, and conclusions (this is represented in Table 1).

Table 1. Studies exploring the delay to diagnosis of endometriosis (18 research articles).

Article	Title	Study aim	Method	Findings	Study conclusions
1. Seear, 2009 (Australia)	The etiquette of endometriosis: Stigmatisation, menstrual concealment, and the diagnostic delay.	• To explore the diagnostic delay of endometriosis in 20 Australian women.	• Qualitative • Semi-structured interviews and thematic analysis.	• Women may be reluctant in divulging to their doctor details about their menstruation in fear that they may be stigmatised.	• Women 'actively conceal their menstrual irregularities through practices of the 'menstrual etiquette'.
2. Grundstrom et al, 2016 (Sweden)	'A challenge'- healthcare professional' experiences when meeting women with symptoms that might indicate endometriosis.	• To explore healthcare professionals' experiences of diagnosing women with endometriosis, with 10 gynaecologists, 6 GPs and 9 midwives.	• Qualitative. • Interview study involving content analysis.	• What was considered 'normal' regarding 'menstrual pain' varied among healthcare professionals.	• Symptoms are sometimes 'camouflaged' as 'normal' menstruation pain.
3. Zanden and Nap, 2016 (Netherlands)	Knowledge of, and treatment strategies for, endometriosis among general practitioners.	• To explore the awareness and knowledge base of endometriosis among 101 GPs.	• Quantitative. • Questionnaire based.	• On average it took 65.7 months to diagnose endometriosis (39.1 months due to patient delay and 26.6 months due to medical practitioner delay).	• General practitioners do not always recognise the symptoms of endometriosis. • Awareness of endometriosis among healthcare professionals needs to be improved.

4. Staal, Zandan and Nap, 2016 (Netherlands)	Diagnostic delay of endometriosis in the Netherlands.	- To explore the time taken to diagnose endometriosis and its potential causes; a Dutch study with 139 participants.	- Qualitative. - Telephone interviews.	- The median time to diagnosis was 4 years; of which patients contributed 7 months, 35 months GP's and 5 months via gynaecologists.	- Women whose symptoms started at a 'young age' and those who were using contraceptive or analgesia had a greater delay to diagnosis.
5. Riazi et al, 2014 (Iran)	Patients' and physicians' descriptions of occurrence and diagnosis of endometriosis: a qualitative study from Iran.	- To explore the perceptions of endometriosis among 12 women with endometriosis and 6 gynaecologists.	- Qualitative. - Semi-structured interviews. - Content analysis.	- Content analysis: findings show there was disruption to daily life, effects on physical health and women struggling with 'the role of femininity'.	- A non-invasive method of diagnosing endometriosis is required. - Physicians 'ignoring complaints or normalising them' can lead to delays. - Short-term pain relief can mask symptoms and lead to delay in diagnosis.
6. Hudelist et al, 2012 (Austria and Germany)	Diagnostic delay for endometriosis in Austria and Germany- causes and possible consequences.	- To explore the diagnostic delay time for endometriosis and the reasons for such delays in 171 women with endometriosis.	- Quantitative. - Cross-sectional study.	- The median time from the onset of symptoms to diagnosis was 10.4 years.	- Reasons for delay to diagnosis: normalisation of dysmenorrhoea by patients and women not talking about menstruation during adolescence.

					- Public awareness programmes need to be created.
7. Zanden et al, 2018 (Netherlands)	Gynaecologists' view on diagnostic delay and care performance in endometriosis in the Netherlands.	- Exploring gynaecologists' views on delays. - 67 hospitals participated.	- Quantitative. - Questionnaire based.	- Main reasons for delayed diagnosis related to 'lack of knowledge and awareness of endometriosis' in patients and healthcare professionals.	- Improve awareness among patients and healthcare professionals.
8. Denny and Mann, 2008 (United Kingdom)	Endometriosis and the primary care consultation.	- To explore women's experiences of endometriosis diagnosis - 30 participants with endometriosis recruited.	- Qualitative. - Semi-structured interviews with thematic analysis.	- Half of the participants described a 'negative experience' with their GP regarding their diagnosis.	- The 'perceived attitudes' of GPs towards women presenting with suspected endometriosis can be further improved. This could include 'sensitive history taking'.
9. Pugsley and Ballard, 2007 (United Kingdom)	Management of endometriosis in general practice: the pathway to diagnosis.	- To examine women's experiences of endometriosis at the point of symptom onset to diagnosis in a sample of 101 women.	- Quantitative. - Primary care records from four general practices in south-east England were retrospectively analysed for 101	- One third of women had seen a GP six times or more prior to diagnosis. - 39% of women were referred to two or	- Average time to diagnosis was 9 years. - More awareness of how GPs interpret women's experiences

			women with diagnosed endometriosis. - General descriptive analysis.	more gynaecologists prior to a diagnosis.	and symptoms is needed.
10. Ballard, Lowton and Wright, 2006 (United Kingdom)	What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis.	- To explore the delays to diagnosis of endometriosis and its impact on 32 women.	- Qualitative. - Semi-structured interviews. - Thematic analysis.	- Delays were due to patients and healthcare professionals. Often due to normalising symptoms and the masking of symptoms through hormonal treatments.	- A diagnosis allowed women to have a ‘language in which to discuss their condition’. - Significant impact due to delays in the diagnosis.
11. Husby, Haugen and Moen, 2003 (Netherlands)	Diagnostic delay in women with pain and endometriosis.	- To explore the time between symptom onset and confirmation of diagnosis of endometriosis in 261 women.	- Quantitative. - Questionnaire-based study.	- Statistical analysis (Mann-Whitney U test and Kruskal-Wallis test). - Median delay to diagnosis was 5 years.	- Awareness of endometriosis symptoms needs to improve.
12. Arruda et al, 2003 (Brazil)	Time elapsed from onset of symptoms to diagnosis of endometriosis in a cohort study of Brazilian women.	- To assess the time period between symptom presentation and diagnosis of endometriosis.	- Mixed methods study. - Interview-based.	- Quantitative statistical analysis (median, interquartile range, the non-parametric Wilcoxon test and p-value).	- Delays potentially due to clinicians not understanding the symptoms of ‘painful menstruation’ as pathological.

		- ‘To identify factors associated with diagnostic delay’ in 200 Brazilian women with endometriosis.		- The median time to diagnosis from symptom onset was 7 years. - The younger the age of symptom onset, the greater the delay.	- Adolescents ‘might be less convincing and persuasive when reporting symptoms’.
13. Hadfield et al, 1996 (United Kingdom and United States of America)	Delay in the diagnosis of endometriosis: a survey of women from the USA and the UK.	- To investigate the time between pain symptom onset and diagnosis of endometriosis surgically in 218 women with endometriosis in the UK and USA.	- Quantitative. - Postal questionnaire.	- Statistical analysis (two-tailed t-test). - The delay to diagnosis in women from the USA was 11.73 +/- 9.05 years and 7.96 +/-7.92 years for UK women.	- Further work is required to minimise the delays to diagnosis.
14. Soliman, Fuldeore and Snabes, 2017 (United States of America)	Factors associated with time to endometriosis diagnosis in the United States.	- To determine the delay to diagnosis time and factors influencing this in 638 women with endometriosis.	- Quantitative. - Questionnaire-based.	- Mean time to diagnosis was 4.4 years.	- To improve endometriosis-related symptom awareness among patients and clinicians
15. Nnoaham et al, 2011 (United Kingdom)	Impact of endometriosis on quality of life and work productivity: a multicentre study across ten countries.	- To explore the impact of endometriosis on quality of life and productivity in employment in 1418 women.	- Quantitative. - Cross-sectional study throughout 10 countries.	- The average time to diagnosis was 6.7 years, and this was predominantly in primary care.	- Diagnostic delay is a problem, particularly in primary care. - There needs to be greater awareness among clinicians for

				• Women on average, lost up to 10.8 hours in work productivity per week, and as such, this had an impact on their finances.	them to suspect endometriosis as a differential diagnosis.
16. Denny, 2009 (United Kingdom)	I never know from one day to another how I will feel: pain and uncertainty in women with endometriosis.	• To explore the experiences of living with endometriosis in 30 women with endometriosis.	• Qualitative. • Semi-structured interviews.	• Narrative analysis. • The way in which pain is interpreted by women and healthcare professionals' results in uncertainty.	• The way in which uncertainty is interpreted by both patients and healthcare professionals is important as part of the diagnosis process.
17. Fauconnier et al, 2013 (France)	Comparison of patient- and physician-based descriptions of symptoms of endometriosis: a qualitative study.	• Comparing the descriptions of endometriosis symptoms by patients with those to that of clinicians, with 41 endometriosis participants and 9 gynaecologists.	• Qualitative. • Interviews (separately with both groups of participants).	• Colaizzi's method was used to analyse the data. • Similar pain-related symptoms were described by both groups of participants, but there was variation in the way they interpreted these symptoms.	• There is variation in which the symptoms of endometriosis are interpreted by patients and healthcare professionals.

18. Ballweg, 2004 (United States of America)	• Impact of endometriosis on women's health: comparative historical data show that the earlier the onset, the more severe the disease. [Review]	• A research registry from the 1980s of 3020 cases was compared with a registry created in 1998 (4000 cases) to explore the way endometriosis is diagnosed and treated.	• Quantitative.	• Comparing the two registries, it was found that the age at which the first symptoms developed before the age of 15 increased from 15% to 38%. • In addition to pain, other symptoms include bloating, fatigue, exhaustion, and dizziness. • 47% of women had seen a doctor five times or more prior to receiving a diagnosis.	• Delay to diagnosis continues to be a problem. • On average, the time from symptom onset to diagnosis was 9.2 years.

2.4.2 Summary of the included study methodologies

Once the studies were selected and included for review, each research article was read in detail to obtain a global overview of the study's aims, objectives, methods, findings, and discussion. Unlike systematic reviews, the aim of a scoping review is not to provide a synthesis of the findings, but to summarise and map out the literature (Pham et al, 2014).

The included studies varied in terms of their underlying methodology and included the following:

Eight studies were qualitative: Seear (2009), Grundstrom et al (2016), Staal, Zandan and Nap (2016), Riazi et al (2014), Denny and Mann (2008), Ballard, Lowton and Wright (2006), Denny (2009) and Fauconnier et al (2013). Nine studies were quantitative: Zanden and Nap (2016), Hudelist et al (2012), Zanden et al (2018), Pugsley and Ballard (2007), Husby, Haugen and Moen (2003), Hadfield et al (1996), Soliman, Fuldeore and Snabes (2017), Nnoaham et al (2017) and Ballweg (2004). One study employed mixed methods: Arruda et al (2003).

The aim of a scoping review is not to critically appraise the literature (Pham et al, 2014). However, here I do consider the strengths, limitations and applicability of the included studies as part of the findings in this chapter. As a result, there is no separate section with a methodological critique of the included studies.

There is a variety of critical appraisal tools available to assist with a scoping review. Due to the heterogeneity in the study methodologies adopted by the included studies, different research appraisal tools were used. For qualitative research studies, the Critical Appraisal Skills Programme (CASP) checklist was used, while for quantitative studies, the respective reporting guidelines were selected from the CASP website.

There was a wide variation in the research designs employed by the included studies, which is discussed further in section four, where the findings are mapped. Due to the inclusion of both qualitative and quantitative studies, it was impossible to make comparisons between the different sampling methods used. However, all the qualitative studies made clear reference to the sampling strategy they employed, compared to the quantitative studies that involved a questionnaire design. In addition, where appropriate, all studies declared that the relevant ethical approval had been obtained. Many of the questionnaire-based studies did not validate their questionnaire and, if they did, there was often inadequate detail about how this was done. In addition, none of the questionnaire-based studies included patient or public involvement in their development.

Most of the quantitative studies were questionnaire-based and mainly analysed by a thematic analysis approach. Some of the quantitative studies were analysed using statistical methods and yielded numerical data relating to the delays to diagnosis.

2.4.3 Charting the data and the process of data analysis

The findings from each of the included studies were analysed through the process of thematic analysis (Braun and Clarke, 2006). This method involves exploring the data for patterns and eventually assigning codes to organise these patterns into themes. Thematic analysis is used for research questions that are contextual, diagnostic, evaluative or strategic (Ritchie and Spencer, 2002). In this case, the question of exploring the delays to diagnosis fitted within the ‘contextual’ and ‘diagnostic’ areas. The contextual element fitted because the scoping review was concerned with exploring women’s and healthcare professionals’ experiences of either living with endometriosis or diagnosing it, and the diagnostic element fitted with the exploration of the delays to diagnosis of endometriosis and why they occurred.

The process of thematic analysis was conducted using NVivo software (version 12.1) (Bazely and Jackson, 2014) to collate, store and organise the data into codes and respective themes. This was important as it allowed a large amount of data to be stored and organised, which in turn allowed the existing literature surrounding the delays to diagnosis of endometriosis to be summarised.

Thematic analysis is commonly used in scoping reviews because the process allows key ideas to be summarised in a structured way while using a rigorous method (Braun and Clarke, 2006). Thematic analysis involves identifying and describing themes from data (Braun and Clarke, 2006). There is a limited number of studies that have explored the area of delay to diagnosis, with the literature concerning delays to diagnosis often forming part of wider studies. By using thematic analysis, it was possible to concentrate specifically on the delays to diagnosis. In addition, the review included both qualitative and quantitative studies, so the use of thematic analysis made collating findings from these studies manageable. Once the data had been collated in a tabular form, codes were developed based on the literature, and these were then arranged into appropriate broader categories.

2.5 Findings of the scoping review

The review broadly captured the delays to diagnosis based on two emerging themes: healthcare professional factors and patient factors. Figures 4 and 5 show a pictorial representation of the main themes from the scoping review. This section begins with a short synopsis of the current literature, exploring the time taken to diagnose endometriosis, followed by the findings of the scoping review in relation to delays to diagnosis.

Diagnostic delay has been reported in several studies; at present, the delay to diagnosis time in the UK is 7.5 years from the initial onset of symptoms (NICE, 2017). Arruda et al (2003) conducted interviews in a cohort study of 200 Brazilian women with surgically confirmed endometriosis to explore the time taken from symptom onset to diagnosis. They reported a median time to diagnosis of 7 years (Arruda et al, 2003). They also found that the median delay to diagnosis was 12.1 and 3.3 years in women aged less than 19 years and women aged more than 30 years, respectively (Arruda et al, 2003). The authors explain this disparity in delay between the two age groups as being due to adolescents not divulging their symptoms and being ‘less persuasive’; however, no further explanations for this were discussed.

The time to diagnosis of endometriosis appears to vary elsewhere in the world. Hudelist et al (2012) conducted a questionnaire-based, cross-sectional study with endometriosis patients in Austria and Germany between 2010 and 2012 to assess the delay to diagnosis time and the possible reasons for this. They found that the median time to diagnosis from the onset of symptoms was 10.4 years (Hudelist et al, 2012). The authors noted that the normalisation of dysmenorrhoea by patients was a major contributor to this delay, as well as misdiagnosis (namely pelvic inflammatory disease and psychosexual illness) by clinicians (Hudelist et al 2012). The authors briefly explain that when the participants' mothers viewed menstruation to be a 'negative event' then this resulted in women with suspected endometriosis also not discussing their menstrual symptoms. However, the study does not provide any further descriptive or contextual insights into this potential reason for the delay to diagnosis.

Nnoaham et al (2011) conducted a cross-sectional, multicentre study involving 1418 women aged 18 to 45 years who were due to have a laparoscopy for endometriosis-related pain to explore the impact of the condition on their quality of life and work productivity. Between August 2008 and January 2010, participants completed a 67-item questionnaire about their symptoms and the impact on their health-related quality of life, and the authors found that the average time to diagnosis was 6.7 years (Nnoaham et al, 2011). While they found that work productivity was reduced by 10.8 hours per week in each woman with endometriosis, the delay to diagnosis was greater in those women who presented with multiple symptoms, such as dysmenorrhoea and dyspareunia (Nnoaham et al, 2011). However, the authors do not elaborate on why this was the case. A postal survey-based study conducted by Hadfield et al (1996) aimed to explore the timeframe between the onset of endometriosis-related pain and a surgical diagnosis of endometriosis in 218 women with the condition in the UK and USA. They found that the delay to diagnosis was greater in women from the USA compared with the delay among the UK women, but they were unable to explain this difference. However, the authors did note that the participants were recruited through self-help groups, and it is therefore possible that the recruited women may have been more likely to have had negative experiences in relation to their diagnosis.

Figure 4. A flow chart summarising the reasons for the delay to diagnosis due to healthcare professional-related factors (theme 1).

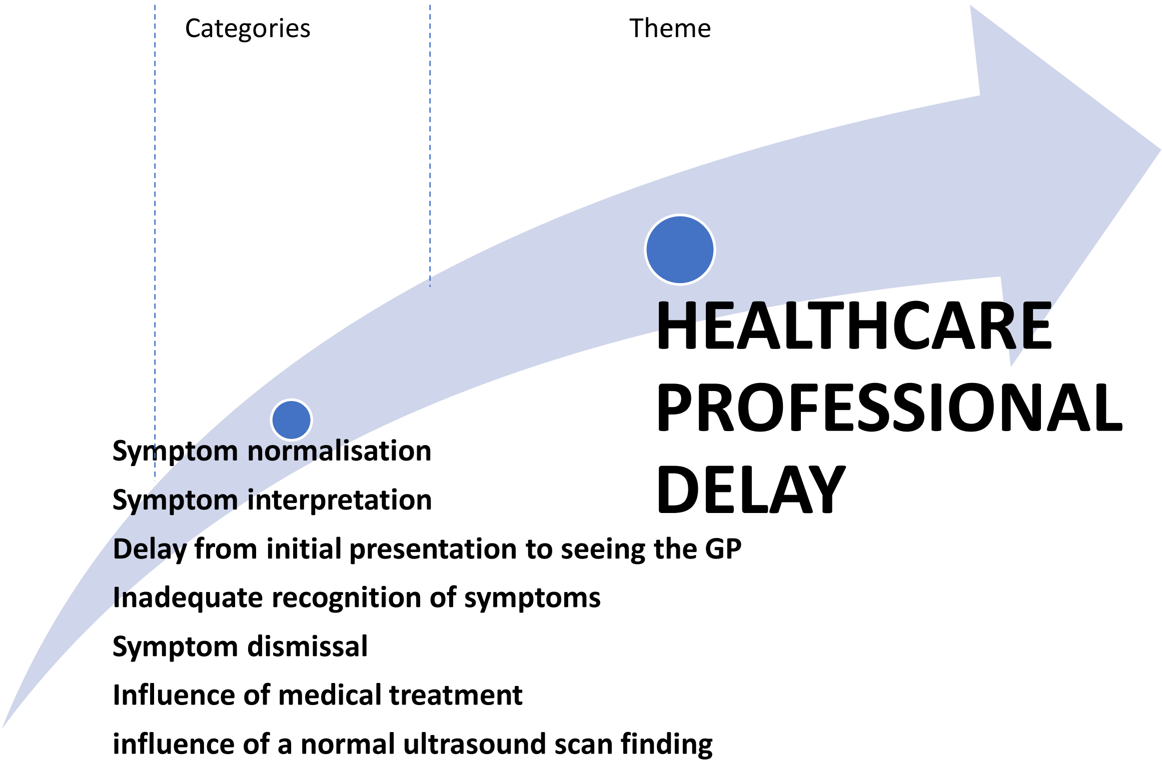
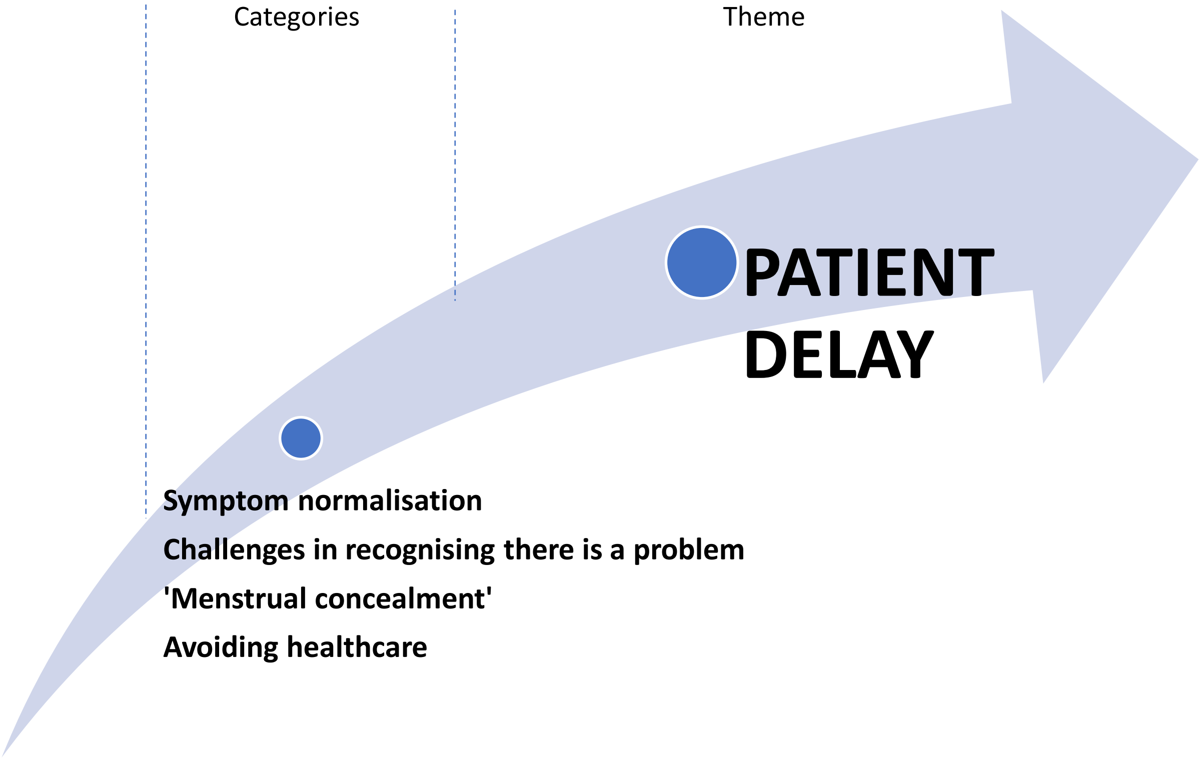


Figure 5. A flow chart summarising the reasons for delay to diagnosis due to patient-related factors (theme 2).



Each of the themes will now be discussed separately.

2.5.1 Theme 1: Healthcare professional-related delay to diagnosis

The reasons for the delays to diagnosis of endometriosis due to healthcare professionals highlighted by the evidence from this review include symptom normalisation, challenges in interpreting the symptoms of suspected endometriosis, delays from the initial presentation of symptoms to seeing a GP, inadequate recognition of symptoms, symptom dismissal, the influence of medical treatment and the influence of a normal pelvic ultrasound (Figure 4). Each of these will now be discussed in further detail.

Symptom normalisation

Symptom normalisation by doctors in the primary care setting was observed in a number of studies. The included studies identify that normalisation of symptoms can occur in one of two ways: 1) challenges in symptom recognition and interpretation and 2) a lack of awareness among healthcare professionals. Seear (2009) conducted a qualitative semi-structured interview-based study with 20 Australian women with endometriosis aged between 24 and 55 years. It was discovered that primary care clinicians found it difficult to differentiate between normal and abnormal symptoms related to menstruation and, as a result, endometriosis symptoms were normalised (Seear, 2009). This finding is further supported by a qualitative study involving semi-structured interviews conducted by Denny and Mann (2008), who explored the primary care experiences of 30 women aged between 19 and 44 years with confirmed endometriosis in the UK and found that symptom normalisation by GPs resulted in a delay to diagnosis. They also found that the average time from a woman presenting to her GP to diagnosis was 5.65 years (Denny and Mann, 2008). Both studies provide useful insights into the normalisation of symptoms being a problem in primary care, although they do not explore in-depth how and why this occurs. It is also important to note that none of the studies in this scoping review explain what a clinician perceived to be a 'normal symptom' and what made them perceive a symptom to be abnormal.

There appear to be challenges in the way clinicians understand and interpret the signs and symptoms of endometriosis. Grundstrom et al (2016) conducted a qualitative study aimed at exploring the clinical experiences of ten gynaecologists, six GPs and nine midwives in Sweden who encounter women with suspected endometriosis. Using semi-structured interviews, they reported that healthcare professionals stated that it was challenging to distinguish symptoms that were considered normal for a menstrual cycle from symptoms related to endometriosis (Grundstrom et al, 2016).

Challenges in symptom interpretation

Healthcare professionals appear to interpret some symptoms that are suggestive of endometriosis differently to the way these symptoms are interpreted by patients. For example, in a qualitative study, Fauconnier et al (2013) aimed to compare any differences in the interpretation of endometriosis-related symptoms between 41 women with endometriosis and 9 gynaecologists in France. The participants with endometriosis underwent an interview with a clinician to describe their symptoms of endometriosis and these were analysed by a psychologist using an adapted version of Colaizzi's method (Fauconnier et al, 2013). In addition, the nine gynaecologists were interviewed in a second phase of the study; however, the authors do not make clear how the interviews were conducted or how the findings from this group were obtained. They found that, in general, both groups of participants employed similar descriptions for endometriosis-related symptoms; however, there was variation between these groups' descriptions of severe pelvic pain, dysmenorrhoea and dyspareunia (Fauconnier et al, 2013), in that the healthcare professionals provided incomplete descriptions. The authors highlight that some participants did not undergo any specific investigations to rule out other pathologies (Fauconnier et al, 2013); therefore, it was not clear whether the participants underwent an actual diagnostic laparoscopy to confirm endometriosis. This study very importantly highlights that the symptomatology for suspected endometriosis can vary among patients and healthcare professionals in terms of description and perception. It is vital that this difference is explored further, using a qualitative approach to understand the ways in which women with suspected endometriosis interpret their symptoms and subsequently communicate this with their clinician. A qualitative approach will also allow exploration of how clinicians recognise and interpret symptoms suggestive of endometriosis. This is an important part of understanding the delay to diagnosis of endometriosis.

Delay following initial presentation to the GP

Zandan and Nap (2016) aimed to explore the knowledge of endometriosis among 101 Dutch GPs in a unvalidated questionnaire-based study. They found through their statistical analysis that it took on average 65.7 months from the initial presentation to a GP for the GPs to arrive at a formal diagnosis of endometriosis. They also found that 87 out of the 101 GPs said they would like to receive further education about endometriosis. The delay to diagnosis in this study clearly represents a long time and indicates that there are healthcare professional- and healthcare system-related factors that contribute to the delay to diagnosis; both require further exploration (Zandan and Nap, 2016). While this finding from a Dutch study is very useful, because it is based outside the UK, variations in healthcare systems mean that the findings must be interpreted with caution when considering this within the context of the UK healthcare system.

The type of clinician also appears to have an influence on the delay to diagnosis time. Staal, Zanden and Nap (2016) aimed to explore the delay to diagnosis time of endometriosis in the Netherlands and the factors that influence this delay via questionnaire-based interviews conducted over the telephone with 139 women. They found a 35-month delay in general practice and a 5-month delay once women were referred to a gynaecologist for an opinion (Staal, Zanden and Nap, 2016). They also found that the delay was greatest among those individuals who were younger at the time their symptoms began and, among those individuals, those who used analgesia and the oral contraceptive pill (Staal, Zanden and Nap, 2016). These findings support those of Arruda et al (2003), discussed earlier in this chapter.

The included studies also identify a delay to diagnosis in the time between a woman realising she has symptoms and seeking medical help. Hudelist et al (2012) aimed to explore the delay to diagnosis time of endometriosis and the causes for this delay through a 26-item cross-sectional questionnaire-based study of 171 women with endometriosis, conducted in Austria and Germany between 2010 and 2012. They found that the median time from the onset of symptoms to diagnosis was 10.4 years; this included 2.3 years from symptom onset to seeking help (Hudelist et al 2012). In addition, they found that for those patients who primarily presented with pelvic pain, the delay to diagnosis was 10.5 years, compared with 9.8 years for those with fertility-related concerns (Hudelist et al, 2012). This study is useful in that it provides specific time points in relation to delays to diagnosis; however, the study also aimed to explore the reasons for the delays to diagnosis. Unfortunately, the quantitative nature of the study has not allowed for these reasons to be explored in depth and so does not provide the reader with any further, specific information as to *why* there were delays to diagnosis at the various time points. Neither do the authors discuss whether women themselves recognised their symptoms as endometriosis-related or simply as abnormal. If women perceived that their symptoms were suggestive of endometriosis from the very moment they recognised their symptoms were abnormal, then this may have reduced the delay to diagnosis time. Further exploration is required to understand the perceptions of women with suspected endometriosis prior to diagnosis and their respective health-seeking behaviours.

It appears that those women presenting with fertility related concerns experience the least delay to diagnosis time. Pugsley and Ballard (2007) analysed the primary care records of 101 women with confirmed endometriosis in south-east England. Their aim was not to specifically explore the reasons for the delay to diagnosis of endometriosis but to investigate the pathway that these women underwent prior to diagnosis. Based on this retrospective observational study, they found that those women who primarily presented with issues concerning fertility or dyspareunia experienced a shorter delay to diagnosis (median time to diagnosis of 2.4 years for those with major dyspareunia and 1.5 years for those with fertility concerns compared with 3.2 years for women presenting with pelvic pain), as they were referred to secondary care (Pugsley and Ballard, 2007). This implies that there may be certain signs and symptoms that GPs consider to be more associated with endometriosis and make them more likely to refer a woman to secondary care.

A questionnaire-based study involving 261 women in Norway with surgically confirmed endometriosis aimed to explore any differences in the delay to diagnosis time between individuals who were members of an endometriosis patient group versus those who were not (Husby, Haugen and Moen, 2003). While they found no statistically significant difference in the delay time between the two groups, they did find that there was a median delay to diagnosis of 3 months from the point at which a woman recognised her symptoms and consulted a medical professional and a median delay of 3 years from the point of consulting a doctor to receiving a surgically confirmed diagnosis (Husby, Haugen and Moen, 2003). Husby, Haugen and Moen (2003) conclude that the diagnostic delay was primarily due to clinicians; however, the purely quantitative nature of their study does not allow the reasons for this to be explored.

Inadequate recognition of endometriosis-related symptoms

The lack of awareness of endometriosis-related symptoms among GPs has been documented in a number of included studies (Denny and Mann, 2008; Zanden and Nap, 2016). When a woman presents to a clinician (usually their GP), the usual process would involve the woman detailing her symptoms within a 10-minute consultation in the UK. The literature search in this review provided insights into how clinicians struggle to recognise that 'there is a problem' in the first instance, despite women mentioning symptoms of potential endometriosis to them. This itself contributed to delays in diagnosis.

The way in which GPs interpret symptoms of endometriosis must be improved. Pugsley and Ballard (2007) and Zanden and Nap (2016) found that GPs did not necessarily recognise the symptoms of endometriosis, especially if the symptoms were other than 'dysmenorrhoea' and 'cyclical'. This finding highlights the need to explore what GPs consider to be 'normal' and what they consider to be abnormal. An understanding of GPs' perspectives in relation to the interpretation of symptoms will provide insights into how GPs can be best supported to understand patients presenting with suspected endometriosis and subsequently lead to improvements in the delay to diagnosis from a primary care perspective.

The knowledge gap among GPs with regards to endometriosis symptoms is another reason for the delay to diagnosis. Zanden et al (2018) conducted a questionnaire-based study between May and July 2016 involving 67 gynaecologists in the Netherlands to assess whether they were adhering to the ESHRE (European Society of Human Reproduction and Embryology) guidelines on the management of endometriosis and explored reasons for the delay to diagnosis. They confirmed the original findings of Zanden and Nap (2016), that the delay to diagnosis due to GPs arose because of issues with knowledge gaps and challenges in recognising endometriosis. While both Zanden and Nap (2016) and Zanden et al (2018) provide quantitative analyses of their questionnaire-based studies, their findings still lack the coherent and exploratory discussion that the complex topic of delay to diagnosis warrants. An in-depth and robust qualitative approach is required to further explore this area. The questionnaire created by Zanden et al (2018) was based on the ESHRE guidelines on the diagnosis and management of endometriosis and so the findings may not be generalisable to the UK, where the NICE (2017) guidance has been developed for the diagnosis and management of endometriosis. It should also be noted that this study was based solely on the views of Dutch gynaecologists, who work in a very different healthcare system to the UK. As a result, the findings from this study should be interpreted with this in mind when considering healthcare system factors in relation to the delay to diagnosis in the UK.

The qualitative study by Grundstrom et al (2016) described earlier in this chapter provides valuable insights into how primary care clinicians are less likely than gynaecologists to identify endometriosis as a potential diagnosis. However, this Swedish based study also included midwives among the interviewees. In the UK, it is very unlikely that a midwife would be involved in the care of those individuals before they are diagnosed with endometriosis and so the findings from this group of healthcare professionals must be applied with caution in the UK.

Another reason for the delay to diagnosis in primary care highlighted in this review was due to women being misdiagnosed with another condition instead of endometriosis. Denny and Mann (2008) claim that due to the lack of awareness of endometriosis symptoms and GPs' reluctance to accept such symptoms as gynaecological, diagnoses of irritable bowel syndrome are often made instead. These findings are echoed in a qualitative study by Riazi et al (2014), who aimed to explore the experiences of patients and clinicians with regards to endometriosis diagnosis through individual interviews with six gynaecologists and twelve women with endometriosis. They found that women with endometriosis may present with non-specific pain-related symptoms and therefore making it challenging for clinicians to recognise endometriosis as a diagnosis. Hadfield et al (1996) used postal questionnaires to explore the delay to diagnosis of endometriosis in the UK and USA. Although this data collection method limits the ability to collect in depth data, they received 218 replies and found that women do not always immediately disclose their symptoms to a healthcare professional and, once they do, the clinician may find it challenging to differentiate between endometriosis and other causes of pelvic pain. These findings could have been developed further to explore why this was the case; however, the use of a postal questionnaire will of course have limited the opportunity to do this. It is evident from the existing literature that recognising endometriosis-related symptoms is a challenge for clinicians, specifically GPs.

Symptom dismissal

Studies included in this review suggest that women with suspected endometriosis are not taken seriously by their GP. Denny and Mann (2008) performed semi-structured interviews with 30 endometriosis participants and found that delays to diagnosis in primary care were perceived by these women to be due to their symptoms of endometriosis not being taken seriously by their GP. In addition, these researchers found that many women repeatedly presented to their GP; the reasons for these recurrent presentations included the fact their symptoms were affecting their employment or fertility (Denny and Mann, 2008). This study builds on the findings of other included studies, which do not discuss delay to diagnosis and do not explore the health-seeking behaviours of women with suspected endometriosis.

Influence of medical treatment

Some studies have explored the impact of hormonal treatment on the delay to diagnosis of endometriosis (Ballard, Lowton and Wright, 2006; Pugsley and Ballard 2007). Ballard, Lowton and Wright (2006) conducted an interview study involving 32 women with suspected endometriosis (of whom 28 were later diagnosed with endometriosis) and found that the use of the oral contraceptive pill meant that some women did not seek medical attention, as their symptoms were supressed. However, over time, and once their symptoms no longer responded to hormonal treatment, these women re-sought medical attention, and this delayed their referral to secondary care. This finding is supported by Riazi et al (2014) who found that women using analgesia or hormonal treatment for non-specific symptoms experienced the greatest delay to diagnosis of endometriosis. This finding only occurred in one study; however, it nevertheless implies that while these initial treatments may help with symptom management, they may also delay a woman being referred to secondary care for a definitive diagnosis of endometriosis.

Normal ultrasound findings

When women were referred for an ultrasound assessment, if the finding was reported to be negative, this appeared to reassure GPs that endometriosis had been ruled out (Ballard, Lowton and Wright, 2006). Based on the literature described in chapter one, however, it is clear that endometriosis affecting the pelvis cannot always be seen on an ultrasound scan; therefore, a negative ultrasound result does not rule out the possibility of endometriosis. This again highlights a knowledge gap amongst primary care clinicians and requires further exploration.

It is evident that there are multiple clinician-related factors that contribute to a delay in diagnosis of endometriosis. The dominant factors contributing to these delays appear to include symptom normalisation, challenges in the interpretation of symptoms, inadequate recognition of endometriosis symptoms and symptom dismissal. The influence of medical treatment and the false reassurance of a normal ultrasound scan can also add to the delay to diagnosis.

2.5.2 Theme 2: patient-related delay

The delays to diagnosis of endometriosis as a result of patient-related factors include symptom normalisation, ‘menstrual concealment’ and choosing to avoid healthcare (Figure 5). Each of these will now be discussed in further detail.

Delay from symptom onset to presenting to a GP

There appears to be a delay in women with suspected endometriosis presenting to their GP. In a study, by Nnoaham et al (2011), 1486 participants across ten countries completed a questionnaire. This study did not specifically explore why there were delays to diagnosis, but the findings allude to some important reasons for why this is the case. These include the fact that women who had a higher body mass index were more likely to experience a delay in diagnosis due to challenges during their clinical examination. These are important areas that require further consideration and exploration. What is not clear from this study, however, is whether the delays outlined were due to patient factors only.

Ballweg (2004) compared two research registries, one from the 1980s and one from 1998, to further explore delay to diagnosis further. It was found that the earlier the symptoms presented in a patient (in terms of their age), the greater the time taken to diagnose endometriosis. In addition, it was found that 47% of women had seen a doctor five times or more prior to a diagnosis (Ballweg, 2004). Occasionally, women have to seek medical attention on multiple occasions prior to a diagnosis. This is further supported by Soliman, Fuldeore and Snabes (2006), who administered a cross-sectional survey to women with confirmed or suspected endometriosis in the USA. They found that respondents aged less than 18 years experienced the longest time from the point of having a consultation to a diagnosis (mean 34.5 months); this compared with a mean delay to diagnosis of 12.4 months for respondents aged 40 to 49 years. Again, this finding highlights that adolescent patients with suspected endometriosis encounter a greater delay to diagnosis time compared with adults.

Symptom normalisation

Symptom normalisation by patients has been observed in some studies (Seaar 2009, Hudelist et al, 2012). For those women who normalised their symptoms, Hudelist et al (2012) found that there was on average an 11.3-year delay to diagnosis, compared with a delay of 8.5 years for those who did not normalise their symptoms. However, this questionnaire-based study does not explore reasons why this may be the case. Seaar (2009) argues that women themselves actually contribute towards a delay in diagnosis of endometriosis when they do not disclose their menstrual-related symptoms because they fear they will be stigmatised. She also identifies that participants often normalised their symptoms in response to other family members normalising them (Sear, 2009).

In normalising their symptoms, some women begin to cope with them and therefore delay health seeking behaviour. Ballard, Lowton and Wright (2006, p. 1298,) found that ‘women did not want to appear weak and unable to cope with what they thought was normal'. As a result, women developed different coping strategies whereby they relied on analgesia and withdrew from socialising with others or taking part in activities (Ballard, Lowton and Wright, 2006). It is important to understand more about how women cope with their symptoms and how this influences their health-seeking behaviour prior to diagnosis, to gain further insights into the patient-related factors contributing to a delay in diagnosis.

Riazi et al (2014) conclude that women with endometriosis experience pain-related symptoms in different ways. These symptoms may be interpreted as non-specific and therefore women may adapt to or cope with them prior to seeking help (Riazi et al, 2014). Their findings raise the question whether pain symptomatology in women with endometriosis should be evaluated differently than how it is currently assessed by healthcare professionals during medical consultations. The findings also highlight that women with suspected endometriosis need help to explore their pain symptomatology more accurately during a medical consultation.

'Menstrual concealment'

Women appear to conceal discussion of menstruation for fear that they will be judged by other people (whether this be by a romantic partner, a family member or a work colleague) (Seaar, 2009). Seaar (2009) identifies that perceived stigmatisation can be due to 'being judged' by colleagues in an employment setting, resulting in embarrassment (Sear, 2009). The current literature does not explain whether the 'menstrual concealment' described by Seaar (2009) occurs gradually over time, or if there are factors that can positively or negatively influence this perception. An understanding of this phenomenon is important for both women and clinicians, as it can then be recognised by both and discussed in an open context (i.e., during a medical consultation).

In an interview-based questionnaire study conducted by Arruda et al (2003), it was found that younger women waited for a longer time before seeking help from a doctor for menstrual-related symptoms. The authors postulate that the adolescent population may feel uncomfortable when discussing symptoms related to menstruation and may also be ‘less convincing’ compared with older women (Arruda et al, 2003). This is further explored to some extent among the non-adolescent population by Ballard, Lowton and Wright (2006), who found that the women in their interview cohort did not disclose pain symptoms to their friends or family due to feeling embarrassed, and therefore women were not able to compare their symptoms to those of others.

Avoiding healthcare

Women with suspected endometriosis may initially avoid healthcare prior to seeking help from a clinician. A 56-item questionnaire-based study was conducted in the Netherlands by Zanden et al (2018) to explore gynaecologists’ views on the delay to diagnosis of endometriosis. They found that patient-related factors in association with a delayed diagnosis were, according to the gynaecologists, due to ‘avoidance of healthcare’ (Zanden et al, 2018, p. 766). The authors do not elaborate on how and why individuals avoided healthcare in the first instance. While it is encouraging to see that the development of their questionnaire was based on an expert panel of clinicians, thus providing methodological rigour, unfortunately the authors have omitted to include any patient representation as part of this panel. In addition, the authors do not explain the process of item generation or how face validity was achieved.

2.6 Definition of ‘delay to diagnosis’

At present, there is no formally accepted definition of the term ‘delay’ in relation to the diagnosis of endometriosis. There does not appear to be a clear consensus on what constitutes a delay to diagnosis, either as a definition or in terms of the time scale. This of course makes it difficult to compare the reported delay to diagnosis times among the different studies. Different studies use this term in different ways; therefore, comparing data from such studies is challenging. At present, there is also no specified target timeframe for endometriosis diagnosis from the time of a patient’s initial presentation to a healthcare professional, adding further ambiguity to what constitutes delay.

There are very few research articles that have offered a definition for what is considered to be a delay to diagnosis of endometriosis. In their questionnaire-based survey, Zanden and Nap (2016) suggested that a delay to diagnosis was considered from the ‘start of symptoms until diagnosis’. If all studies offered a definition for what is considered to be a delay to diagnosis, then much more robust comparisons of data between studies could be carried out. Pugsley and Ballard (2007) make the point that although there are delays to diagnosis of endometriosis, the delays may also reflect times during which the patient has been symptomatically well.

2.7 The consultation stage

While Arksey and O'Malley (2005) state that the consultation stage with stakeholders is optional, it is recommended by Levac et al (2010). This stage proved particularly important in the design of the scoping review carried out as part of this research. In February 2018, a stakeholder meeting was held at the Royal College of Obstetricians and Gynaecologists in London, and members of this panel included one representative each from the Royal College of General Practitioners, the Royal College of Obstetricians and Gynaecologists, and the British Society of Gynaecological Endoscopy. Two consultant gynaecologists and a registrar in gynaecology were also present, along with the Chief Executive of the charity, Endometriosis UK. An in-depth discussion took place about the pressing issue of delay to diagnosis of endometriosis and the most suitable way to explore this further. The most prominent message from this stage was that delay to diagnosis of endometriosis is clearly a problem, and research is urgently required to gain new insights into this issue. They also identified that primary care clinicians must be further supported to facilitate the process of suspecting endometriosis and referring patients to secondary care in a timely manner. This was deemed important considering the waiting time to see a gynaecologist.

The initial consultation stage did not include any lay members of the public. However, to help understand the problem of delay to diagnosis of endometriosis further, lay members of the public who had been diagnosed with endometriosis were invited to a tertiary hospital in the East of England to take part in further discussions. These individuals were all members of the charity Endometriosis UK, and this consultation occurred during a meeting organised by them. The views expressed at this stage once again highlighted how important the issue of delays to diagnosis of endometriosis are to this group of women.

2.8 The gaps in the existing literature base

Making comparisons among the studies included in this scoping review has been a challenge; this has been due to the varying clinical symptoms documented in the studies, the different research methods adopted, and the fact that some studies did not document how the included participants were diagnosed with endometriosis. Quite often, the studies did not offer a definition for the delay to diagnosis, therefore making it difficult to compare the delay to diagnosis times between different studies. The most notable deficiency in the research exploring the delays to diagnosis in the current literature base is the lack of studies exploring the delays to diagnosis from the moment an individual recognises ‘abnormal symptoms’ to the point they attend a primary care consultation. This is a clear gap in the literature and requires further exploration. Based on this scoping review, there appear to be differing viewpoints between patients and healthcare professionals as to what is considered ‘normal’ menstruation. While this insight is important, and has been described in a number of studies, none of the studies go further to explain what each party considers normal and why. This may be a crucial factor to explore further to help understand delays to diagnosis.

2.9 Summary

This scoping review has found several key findings. At present, there is no universal definition for what constitutes ‘delay to diagnosis of endometriosis’; for instance, is it from the moment a symptom is recognised as a problem by the patient or from the moment the woman presents to a healthcare professional? It is very important to explore this further as part of this PhD, as this will enable more insights into the delay to diagnosis. All of the studies that included the term ‘delay’ as part of their research used different definitions for it; therefore, comparing findings from these studies was challenging. This variation in the definition of delay to diagnosis can have a major impact on the treatment women receive as well as any onward referrals to a gynaecologist.

Although the review has identified a number of studies exploring delay to diagnosis, there are very few studies exploring health-seeking behaviours and coping strategies used by women with suspected endometriosis who are eventually formally diagnosed with this condition. There are also limited studies that have specifically explored what happens when a patient first recognises an abnormal symptom suggestive of endometriosis to the moment they present to their clinician. This is an important area to explore further in this PhD thesis.

The search findings identified a combination of qualitative and quantitative studies. While it is encouraging to see different methods employed to explore the area of delayed diagnosis further, there remains scope for more qualitative research. For instance, a number of studies make reference to healthcare professionals not engaging with women who have either confirmed or suspected endometriosis; however, only a handful of these studies actually explain how this engagement process can be improved. It is also apparent that the current literature base is primarily evidenced from the use of questionnaires. While this technique provides rapid and accessible data, the area of endometriosis diagnosis and delays requires a more refined and investigative approach involving qualitative methodology. The majority of the included studies have not validated the questionnaires they used or, if they have, the authors provide insufficient detail with regards to face validity or item generation.

While the included quantitative studies identified that the delay to diagnosis of endometriosis is a problem, they did not provide any insights into the nature and meaning of the problem; a qualitative methodology is therefore more appropriate to explore these issues further.

The exploration of the delays to diagnosis of endometriosis is an overlooked, underappreciated and under-researched area that requires further work to understand health-seeking behaviours, women's experiences of diagnosis and their delays to diagnosis. This PhD thesis aims to address this knowledge gap. There are clearly limitations in the literature in terms of understanding the complex interplay among the factors that influence women's experiences of diagnosis and healthcare professionals' communication and decision-making. More in-depth qualitative work is required to explore these aspects further. Therefore, there is a need for a theoretical model or framework to help understand how these factors work together to influence the process of diagnosis. Increased understanding about the reasons for the delay to diagnosis would help to provide women with suspected endometriosis a voice and enable individual clinicians to evaluate their own practice in the planning and delivery of primary care services for these women. Based on the scoping review findings, this understanding is most likely to develop from a research study that involves both women with endometriosis and healthcare professionals that diagnose the condition.

Following the scoping review, the aim and objectives of this PhD thesis are as follows:

Aim: To understand delay to diagnosis in women who have endometriosis.

Objectives:

1. To explore and understand the experiences of women who have been diagnosed with endometriosis (phase one).
2. To develop a theory to explain how factors that influence delay to diagnosis in women with endometriosis can impact on the process of diagnosis (phase one).
3. To explore and understand healthcare professionals' perspectives on women's experiences of diagnosis of endometriosis to deepen our understanding of the healthcare context and factors influencing health professionals' decision-making (phase two).

The following chapter will describe and discuss the theoretical framework underpinning the study.

PART 2 – METHODOLOGY, METHODS AND DATA ANALYSIS PROCESS

Chapter 3 – Methodology

3.1 Introduction

The overall aim of this thesis is to understand delay to diagnosis through the experiences of women with endometriosis and healthcare professionals. The scoping review described in chapter two has provided a background to the thesis and a justification for conducting this research study. The review demonstrates that there is a clear gap in understanding the causes of and pathways to delays to diagnosis of endometriosis.

This chapter will consider the most appropriate methodological approach to address the aim and objectives of the study, for both phases of the study. It will describe and justify the theoretical framework for the study in terms of the philosophical assumptions, both ontologically and epistemologically. This will be followed by an exploration and discussion of grounded theory (GT), in particular constructivist grounded theory (CGT), considered the most appropriate methodological approach to address objectives one and two of the study. This chapter will also consider a general interpretive approach as a suitable methodology for addressing the third study objective.

3.2 Qualitative or quantitative?

Chapter two has provided insights into the current literature base exploring the impact endometriosis as an illness has on women's lives, as well as their experiences of delay to diagnosis. While this scoping review provided a background to the problem of diagnostic delay, it is important to appreciate that the included studies are mainly quantitative. While quantitative studies provide very useful information about the problem of delay, this approach is not able to answer the 'why' question of the problem. Importantly, although a considerable amount of literature has highlighted that delay to diagnosis is a problem, the question as to why this delay is continuing to occur still requires further exploration. A qualitative exploration of women's experiences of endometriosis diagnosis will provide in-depth insights into this area, and therefore offer greater understanding of the factors influencing women's experiences, as well as why and how these factors may lead to delays in diagnosis. This will add to the existing research by offering new insights into and understanding of the delays to diagnosis of endometriosis. Uniquely, this thesis explores delay to diagnosis from the perspective both of women with endometriosis and healthcare professionals who are involved in the diagnosis process in one study.

The choice of whether to adopt a quantitative or qualitative approach depends on the research question (aim and objectives), but also on the researcher's own position about how they view the world and the assumptions they believe to be true about it. Therefore, the following section will provide insights into the methodological decisions that underpin this PhD study.

3.3 Qualitative approach

A qualitative approach was chosen to address the research aim, as this would allow women's experiences of being diagnosed with endometriosis to be explored in great depth through an inductive approach, as opposed to testing a specific hypothesis using a positivist approach (Merriam, 2002). Hammarberg, Kirkman and de Lacey (2016, p. 498) state that qualitative research is used to investigate 'beliefs, attitudes and concepts of normative behaviour' as well as 'to understand a condition, experience or event from a personal perspective' (Hammarberg, Kirkman and de Lacey, 2016, p. 499). While a quantitative approach would have allowed for some aspects of women's experiences of diagnosis to be captured, maybe through a patient-reported outcome measure or quality of life tool, it would not have allowed for the depth and breadth of exploration required to achieve the objectives of this study. There is limited literature exploring the experiences of diagnosis in women with endometriosis who have experienced a delay or the context of those experiences; therefore, a qualitative approach is useful in exploring the complex behavioural and social processes that influence the health-seeking behaviours of women with suspected endometriosis. Check and Schutt (2012) state that the aim of qualitative research is to obtain a rich description of the world and this ethos is in keeping with the aim and objectives of this research.

3.4 Philosophical assumptions

Before starting any research, it is important for a researcher to be aware of her or his own assumptions and how these may influence the research. Each researcher will bring his or her own assumptions based on their personal and professional background (Patton, 2018). Having this knowledge and understanding of these philosophical assumptions will help influence the way in which the study is conducted (Birks and Mills, 2015). These assumptions can be explored from three philosophical positions: ontology, epistemology and methodology. Ontology refers to 'the study of being' (Crotty, 1998, p. 10), epistemology to 'the nature of knowledge' (Cohen et al, 2007, p. 7), while methodology refers to 'the lens in which research is conducted' (Crotty, 1998. p. 3). It is important to appreciate that all three of these terms are interrelated. This study is grounded in a relativist ontological position, an interpretivist epistemological position and a grounded theory methodology.

3.4.1 Ontology

Through my assumption that experiences and perceptions that individuals hold are subjective and that the way in which individuals create meaning about their healthcare experiences is unique, I have taken a relativist ontology, whereby I consider individuals to have multiple realities, and that each individual will view the world in ways that will be similar and in ways that will be different (Levers, 2013). Crotty (1998, p. 43) states that 'we need to remind ourselves here that it is human beings who have constructed it as a tree, given it the name, and attributed to it the associations we make with trees'. The description of this object (i.e., a tree) has been constructed by people through their interaction with themselves and with the world (Scotland, 2012). Research methodologies appropriate to relativism include grounded theory, phenomenology (exploring experiences without letting preconceived ideas influence this), hermeneutics (exploring different meanings in language) and ethnography (studying a particular cultural group over a particular timeframe) (Scotland, 2012).

3.4.2 Epistemology

One assumption that I held at the beginning of this study was that the way in which women and healthcare professionals alike ascribed meaning to their experiences in a clinical context would have an influence on the time taken to diagnose endometriosis. While the process of diagnosing an individual with endometriosis can be seen as a process involving a medical history, performing an examination and requesting investigations, it can also be seen through a more interpretive lens to include the way women with suspected endometriosis and their healthcare professionals make sense of the diagnosis process.

Phase 1 of the study is underpinned by a constructivist epistemological stance, and this lens will have an influence on the way in which the study is designed (chapter 4, methods). The epistemological approach in this study seeks to capture the individual accounts of women with endometriosis and therefore, as Silverman (2005) points out, the epistemology will be subjective. Broadly, there are two main epistemological assumptions described by scholars, namely positivism and interpretivism; the latter is also known as constructivism (Goldkhul, 2012).

Positivists view the nature of reality as objective, whereas constructivists view reality as comprising multiple realities (Park, Konge and Artino, 2020). Positivists consider that there is only an objective way to view the world and, as such, this is guided by logical processes (Park, Konge and Artino, 2020). Positivism is based on the natural sciences model and therefore is more in keeping with quantitative research (Park, Konge and Artino, 2020). Topping (2006) explains that because positivism is based on objectivity, the process of data collection should not be conducted through philosophical assumptions, but through measured methods. Aliyu et al (2014, p. 81) explain that ‘a positivist investigator has an idea or notion that the universe or world conforms to permanent and unchanging laws and rules of causation and happenings’. A positivist approach often uses quantitative analysis and laboratory-based methods to obtain research data (Olesen, 1994). Frequently, the approach to research is deductive and involves the testing of a hypothesis (Silverman, 2005); therefore, the analysis of data often involves statistical tests, enabling the findings to be generalised to different population groups (Scotland, 2012). While a positivist approach has many advantages, it does not allow the potential social processes contributing to women's experiences of being diagnosed with endometriosis to be explored in depth or allow the 'why' aspect in such a study to be explored. The aim of this study is not to generalise the findings to all women who have endometriosis, but to explore different phenomena that are grounded in the recruited cohort of participants.

The opposing epistemological paradigm to positivism is constructivism (Young and Collin, 2004). While there are merits to performing quantitative research, its limitations became more apparent in the 1970s and an awareness of constructivism began to emerge further (Young and Collin, 2004). For the constructivist researcher, the meaning of something is not discovered, it is constructed (Young and Collin, 2004). Qualitative research allows the constructivist to explore participant accounts further using various methods of data collection (semi-structured interviews, for example), but also through an inductive approach (Silverman, 2005). The research objective and aims of this PhD require me as the researcher to engage and interact with participants during the interviews and data analysis process and to analyse their experiences in depth to construct deeper interpretations. A constructivist epistemology is considered the most appropriate to achieve this goal.

Constructivists view the world through a subjective rather than an objective lens and are thus interested in the way an individual makes sense of the world (constructivism) or the way a group of individuals make sense of the world (constructionism) (Young and Collin, 2004). Constructivism stems from earlier research conducted in the field of psychology (Piaget and Inhelder, 1969; Vygotsky, 1978). The assumption that underlies the constructivist approach is that individuals experience a phenomenon from their own unique perspective (Honebein, 1996). Constructivism assumes that reality is constructed (Charmaz, 2006, p.187), whereas social constructionism assumes that 'people create social reality(ies) through individual and collective actions' (Charmaz, 2006, p.189). It is important to note that researchers view constructivism through various lenses. For instance, Piaget and

Inhelder, 1969 explain that the process of construction is highly personal to each individual. However, Bruner (1990) explained that the way in which people construct knowledge is through the social relationships they form; therefore, constructivism enables the complex factors that influence delays to diagnosis of endometriosis to be explored.

Adom, Yeboah and Ankrah (2016) explain that as the constructivist paradigm aims to understand phenomena by exploring how individuals construct meaning through their experiences of those phenomena, it provides a foundational perspective that can help to direct and support several qualitative research methodologies. In addition, the researcher will co-construct meaning from the participants' perspectives as well as their own (Adom, Yeboah and Ankrah (2016). This is an important aspect of this PhD study.

3.5 Methodologies considered

Three constructivist methodologies were considered as potentially suitable for this study: phenomenology, narrative analysis and grounded theory.

3.5.1 Phenomenology

Phenomenology is a qualitative research methodology that focuses on the pre-reflective lived experience of a particular phenomenon (Smith, 2004). It explores how people make sense of these experiences and how they relate to them (Smith, 2004). The two main threads of phenomenology include descriptive phenomenology, developed by Husserl, and hermeneutic phenomenology, developed by Heidegger (Laverty, 2003). As a key objective of this research was to develop a theoretical model to help explain the complex process of diagnosis and the respective factors that influence this, phenomenology was not considered to be the most appropriate choice.

3.5.2 Narrative analysis

Narrative analysis involves a collection of approaches whereby a researcher explores the 'stories' (narratives) of individuals and tries to understand the meaning within these narrative experiences (Reissman, 2007). Through this approach, the researcher can understand the meaning people place on their experiences (Bryman, 2016). Participants are encouraged to recall a story or narrative of their experiences (Reissman, 2007). The researcher pays close attention to the way in which the narrative is described by the participant, the order in which events are discussed and the language used, to understand the meaning (Reissman, 2007). These stories focus on how people's experiences have influenced their identity and social world (Stephens and Breheny, 2012). This could be appropriate methodology to address the research aim and objectives because it would allow in-depth exploration of women's accounts of being diagnosed with endometriosis; however, it would not allow the generation of a model that integrates the factors that influence the delays to diagnosis.

3.5.3 Grounded theory

Grounded theory is an approach that allows a theory to be developed at the same time as data are being collected and analysed (Glaser and Strauss, 1967). It is particularly useful for exploring social processes and how these impact on the behaviour of individuals (Crooks, 2001). Based on the scoping review findings, to understand women's experiences of being diagnosed with endometriosis, complex social processes may need to be explored and uncovered. Grounded theory was the approach that was considered the most appropriate to achieve this and will now be discussed in detail.

3.6 Grounded theory (GT)

To address the research aim and objectives, a GT approach was adopted to explore and understand how women with endometriosis make sense of their diagnosis and to use their perspectives to identify an underlying theoretical framework, representing the factors that influence the process of diagnosis and how they connect to each other. While the philosophical basis of GT will be discussed in this section, the specific aspects of GT in relation to the study procedures will be explored in the methods chapter (chapter 4). GT is not only a methodology but also a method, as the approach ensures data saturation and the development of a theoretical framework (Charmaz, 2006). As far as I am aware, there is one grounded theory study exploring women's experiences of endometriosis in the UK (Facchin et al, 2018) and one grounded theory study exploring GPs experiences of diagnosing endometriosis in the Netherlands (van der Zanden et al, 2020).

Grounded theory was initially developed in 1967 by Barney Glaser and Anselm Strauss in their book 'Awareness of Dying' in 1965 (Charmaz, 2006). It was developed at a time when positivist researchers were dominant in society (Charmaz, 2006). The basis of GT was developed by Glaser and Strauss as they explored the experiences of dying among individuals who were terminally ill (Charmaz, 2006). They explored a way of developing theories from the collected data by using inductive methods, rather than deductive methods that would test a prior hypothesis (Charmaz, 2006). It was through their book that Glaser and Strauss (1967) were able to argue for the importance of simultaneously collecting and analysing data, as well as highlight the methodological rigour that qualitative research can possess. Since 1967, there have been a number of 'revisions' to the original grounded theory in terms of how the methodology is used. In 1990, Strauss and Corbin joined forces to write a book called 'Basics of Qualitative Research: Grounded Theory Procedures and Techniques' (Charmaz, 2006). In 1992, Glaser and Strauss had a disagreement, which led to Glaser publishing the book 'Emergence vs Forcing: Basics of Grounded Theory Analysis' (Charmaz, 2006). In Glaser's opinion, Strauss and Corbin's version of GT did not involve the development of a theory that was grounded in the collected data (Charmaz, 2006). Glaser considered that the research question in a study emerges in the early parts of the study, whereas Strauss and Corbin described the research question as a statement and the actual phenomenon will emerge later (Charmaz, 2006). Corbin also criticised the way in which Glaser and Strauss coded their collected data (Charmaz, 2006). She felt that the coding process did not consider preconceptions that a researcher may have based on their personal experiences (Charmaz, 2006). For this thesis, it is proposed that an explanatory theory can be generated using GT, making it the most appropriate approach for this work.

GT involves 'progressive identification and integration of categories of meaning from the data' (Willig, 2008, p.35). As a method, it provides insights into how these categories are linked with each other (Willig, 2008). As a theory, it allows a phenomenon to be explored in depth (Willig, 2008). The foundations of GT are based on the following principles (Glaser and Strauss, 1967), with further details on how these have been applied in this research provided in chapter 5 (data analysis).

1. **Avoid conducting a literature review** until the findings from the study have been analysed. This is to ensure that the researcher does not have any preconceived ideas that may influence the study. Here, however, to identify the gaps in the existing evidence base, a scoping review was conducted prior to commencing the study, and a justification for this is provided in chapter two.
2. **It is a constant-comparison method,** whereby data are collected and analysed simultaneously. The data analysis is performed when the researcher explores similarities and differences in the findings. This involves comparisons between transcripts, between codes, and between codes and categories (Charmaz, 2006).
3. **Memo writing** enables the researcher to note down in a research diary any thoughts about the collected data, participants' emotions or any immediate reflections.
4. **Theoretical sampling:** once categories have been developed; theoretical sampling allows for any 'emerging themes' to be tested with new

participants. This process allows the meaning of themes to be further explored and refined (Charmaz, 2006).

5. **Theoretical saturation:** this is reached when the properties characterising each category are exhausted (Charmaz, 2006). It is important to be aware that this stage is subjective and most likely intuitive. Therefore, the recognition of the moment of theoretical saturation will vary among researchers.
6. **Theoretical sensitivity:** this is a concept that concerns the researcher's ability to have insights into the research area and make connections within and between the data at an abstract level.

For this research, a GT approach was chosen for several reasons. First, as Glaser and Strauss (1967) have discussed previously, a GT approach aims to explore individuals' experiences and has a major focus on the social and psychological factors that influence such experiences. This is important for this study involving participants with endometriosis because, based on my own clinical experience and interactions with such patients, their experiences of being diagnosed are often complex and the impact of their symptoms on their quality of life is multifaceted. Second, GT aims to develop a theory based on encounters with people who have experienced a particular phenomenon (Strauss and Corbin, 1998) and, as such, the methodological principles underlying this were in keeping with my own epistemological beliefs. Third, while other qualitative methodologies refer to the role of reflexivity, GT specifically emphasises the role of the researcher and the influence of her or his interaction with participants in co-creating meaning (Charmaz, 2006). This was important, as it allowed me to recognise my own frames of reference and manage these during the research process. Finally, each participant will have placed their own meaning on their experience of being diagnosed with endometriosis, based on their interactions with society (e.g., healthcare professionals, partners, friends), and GT enables such interactions to be explored dynamically, as well as exploring the impact of these interactions on women's experiences.

3.7 Constructivist grounded theory (CGT)

CGT was developed by Charmaz (2006, p. 187), who described grounded theory as:

'a method of conducting qualitative research that focuses on creating conceptual frameworks or theories through building inductive analysis from the data. Hence, the analytical theories are directly "grounded" in the data' (Charmaz, 2006, p. 187).

Dey (2004) explains that there are different ways in which GT can be viewed from a methodological perspective. Each view has a different epistemological foundation and therefore the researcher must make a deliberate decision as to which view to incorporate in his or her study. The following section will discuss and justify why the CGT approach proposed by Charmaz (2000, 2003, 2006) was adopted for this study.

As Charmaz (2008, p. 397) points out, GT takes into account not only the way the research is conducted but also the 'analytical method of producing it'. The CGT approach reflects the underlying assumption that researchers will create categories from the data they collected (Charmaz, 2008, p. 402). CGT researchers also view the actual process of research itself as a 'social construction'; therefore, researchers are also actively involved in their research (Charmaz, 2008, p. 403), mindful of the way the research study is being conducted, and, if necessary, make changes in the way data are being collected or analysed (Charmaz, 2008, p. 403). This involves being attentive to any 'emerging information' as the study progresses and exploring it accordingly (Charmaz, 2008, p 403).

The process of gathering data, making sense of the data (through coding), writing memos, theoretical sampling, saturation, and sorting, eventually lead to the development of a theory (Charmaz, 2006). In Charmaz's GT, the researcher's position within the research is accounted for much more explicitly, unlike the version of GT proposed by Glaser and Strauss. Charmaz (2008) states that in her version of GT, she accounts for the researcher's position much more explicitly within the research, unlike Glaser and Strauss. Charmaz's approach also assumes that the theory that evolves from the collected data is *constructed* rather than discovered (Charmaz, 2006). This contrasts with Glaser and Strauss, who assume that the researcher and the participant are independent of each other (Charmaz, 2006). Charmaz makes it very clear that the theory generated using her methodology is a subjective rather than an objective interpretation of the studied phenomenon (Charmaz, 2006). In addition, Charmaz can elaborate on and eloquently explain the methodological underpinnings of GT compared with the position of Glaser and Strauss (1967), whose focus is on the methods rather than the underlying philosophical assumptions (Birks and Mills, 2015, p. 5).

The question of conducting a literature review prior to starting the data collection process has also been an important area of consideration for grounded theorists. Charmaz supports the approach where researchers conduct a scoping review prior to data collection and explains that the researcher should account for this through the process of reflexivity (Charmaz, 2006). In contrast, Glaser (1998, 2005, 2009) does not support this position and advises against it. In my case, due to the practicalities of writing a PhD proposal in the first instance for my university and for the purposes of ethical approval, this was not possible. However, by employing reflexivity throughout the research process, I was able to recognise, acknowledge and account for my role as a researcher; this is discussed further in chapter 11 (reflexivity). In addition, to ensure the originality of my PhD project and identify gaps in the literature, it was important to perform a literature review in the first instance. Charmaz's (2006) focus on the role of the researcher in co-constructing meaning enables the researcher to explicitly recognise and account for their own position in the research, and this was another reason for selecting this methodological paradigm to address my research aim.

CGT assumes that knowledge is constructed, rather than simply discovered (Charmaz, 2006); a CGT approach enabled me to clearly acknowledge any assumptions I held from my clinical experience as a doctor and from the initial scoping review I conducted. CGT allows researchers to explore how people place meaning within their world (Charmaz, 2006). Most importantly, the CGT approach also allows the researcher to answer the 'why' question when exploring the experiences of women with endometriosis (Charmaz, 2008), offering the participants autonomy and the freedom to discuss in depth their experiences. Finally, using a CGT approach will allow the findings from this PhD study to be applied in the context of the National Health Service (NHS) in the UK, which is particularly important when relating the findings to the wider context and making clinical and research recommendations.

3.8 Symbolic interactionism (SI)

In CGT, there are specific connections between how people make sense of their experiences and symbolic interactionism (Carter and Fuller, 2015). Symbolic interactionism is a theoretical perspective drawn from the work of the American philosopher, George Herbert Mead, first published in 1934 (Dennis and Smith, 2015). It is based on the epistemological concept that 'individuals use language and significant symbols in their communication with others' (Carter and Fuller, 2015, p. 932). Thus, this PhD thesis is based on symbolic interactionism.

Carter and Fuller (2015) state that symbolic interactionism enables insights to be gained as to how people make sense of the world through repeated actions. The assumption underlying symbolic interactionism is that the interactions individuals have with society are essentially constructivist as symbolic interactionism focuses on the meaning of the interaction itself (a construct). Carter and Fuller (2015) summarise symbolic interactionism (shown in italics) as being underpinned by four assumptions, which will be considered here in the context of this study:

'(1) individuals act based on the meaning's objects have for them Blumer, 1969'. The scoping review in chapter two found that women with endometriosis had varying perceptions of what they considered worthy of seeking medical help. For instance, women with a family history of 'heavy periods' often normalised their symptoms, as this was not considered to be abnormal.

(2) 'interaction occurs within a particular social and cultural context in which physical and social objects (persons), as well as situations, must be defined or categorized based on individual meanings' Blumer, 1969. It is evident from the scoping review

that women's perceptions of what was considered to be 'normal' menstruation were influenced by their encounters with healthcare professionals. It was also clear that adolescent individuals with suspected endometriosis encountered the greatest delays to diagnosis, and one reason for this was the dismissal or normalisation of their symptoms by healthcare professionals. These interactions impacted on future health-seeking behaviours.

(3) 'meanings emerge from interactions with other individuals and with society' Blumer, 1969. The scoping review found that one of the reasons women normalised their symptoms of endometriosis was because of their symptoms being normalised by *other individuals (family, partner, friends, healthcare professionals)*. Symbolic interactionism will enable further exploration of this finding.

(4) 'meanings are continuously created and recreated through interpreting processes during interaction with others' (Blumer, 1969). The aim of this PhD is to explore the healthcare experiences of women with endometriosis, and therefore this aspect of symbolic interactionism is in keeping with the findings of the scoping review. To explore the deeper reasons for the delay to diagnosis, it is important to explore the *interaction* between a woman with suspected endometriosis and her healthcare professional.

GT as a methodology was developed to explore society from the perspective of symbolic interactionism (Glaser and Strauss, 1967; Charmaz, 2006) and as such aligns well with the underlying philosophical assumptions of this study. Symbolic interactionism assumes that the way people behave depends on the way in which they interpret other people's behaviours (these behaviours are representative of 'symbols') and that these interpretations are shared within a culture (Flick, 2009). In this instance, from the scoping review, women's health-seeking behaviour was seen to be influenced by their interactions with others. GT is also appropriate for areas of research that have not previously been explored in detail (Wilson and Hutchinson, 1991) and, as the scoping review in chapter 2 has highlighted, there is limited research in the area with which this thesis is concerned, therefore this approach is suitable for exploring women's experiences of endometriosis diagnosis in relation to delays. The CGT methodology is most closely aligned with the assumptions of symbolic interactionism (Jeon, 2004), and therefore it will enable women's experiences of diagnosis, and their interactions with others, to be explored in depth. This phase of the study is therefore that underpinned by a combination of the constructivist grounded theory, symbolic interactionism, and constructivism.

3.9 Phase 2: Healthcare professionals

The philosophical assumptions underpinning this phase of the study (objective 3) are the same as for objectives 1 and 2. However, it is important to briefly discuss why an interpretive approach is considered suitable for objective 3. As discussed in the scoping review in chapter one, delays to diagnosis for women with endometriosis are not only due to patient-related factors but also to healthcare professional-related factors. To capture this important influence, a third objective was added to this study to understand how clinicians interpret women's experiences and how this influences their clinical decision-making. To conduct this phase of the study, it was important to adopt a methodology that connected both phases of the study and explicitly enabled the study objective relating to healthcare professionals to be informed by CGT. Therefore, the methodology underpinning the study of healthcare professionals is also drawn from an interpretive approach.

While the data analysis method is discussed at length in chapter 5 (data analysis), it is important to briefly mention why reflexive thematic analysis (Braun and Clarke, 2006) was chosen and how it links with an interpretive approach. Prior to deciding on reflexive thematic analysis (RTA), other approaches, such as phenomenology, grounded theory, framework analysis and content analysis, were considered. The reasons for choosing RTA are four-fold. First, my underlying epistemological position was that of a qualitative and interpretive approach (as discussed earlier in this chapter); the way in which data are organised and interpreted through RTA is consistent with this. Second, healthcare professionals were provided with verbatim quotes from the grounded theory study, which again is underpinned by a constructivist approach, and therefore RTA was in line with this. Third, approaches such as framework analysis appeared reductionist, in the sense that a framework is developed from an initial focus group and this ‘rigid structure’ is then applied to the subsequent transcripts, even if there is no clear applicability (Gale et al, 2013). Content analysis was also considered as it adopts a similar approach in terms of generating codes and themes; however, its underlying epistemological assumption is more in keeping with positivism (Ryan and Bernard, 2000) and thus did not fit with the epistemology of this study. Finally, the research objective for the healthcare professional phase of the study is designed to focus on a central observation, i.e., the delay to diagnosis; an RTA approach will enable this to be explored and to complement the grounded theory findings from participants with endometriosis to answer the overarching research question.

As seen in the scoping review findings, the existing delays to diagnosis of endometriosis are underpinned by complex social processes. To explore this deserves a thorough, detailed and insightful enquiry; an interpretive approach will certainly facilitate this. To explore the experiences of healthcare professionals in relation to diagnosing endometriosis, an in-depth and interpretive approach is required. This approach will enable the assumptions and experiences of healthcare professionals to be explored further (Alharahsheh and Pius, 2020). An interpretive approach lends itself to interview-based research to capture individual experiences (Alharashsheh and Pius, 2020). Central to my thesis is the exploration of human experiences and the co-construction of meaning with participants. An interpretive approach will also allow me to be reflexive during this process.

3.10 Summary

CGT will be used as a methodology to address objectives one and two of this study and was specifically chosen over other methodological stances to enable the development of a theory. An interpretive approach was chosen for objective three, which allows the use of the CGT findings to inform a further stage of data collection, involving healthcare professionals.

Chapter 4 – Methods and data collection

4.1 Introduction

This chapter provides a discussion of the methods adopted to address each of the three study objectives. This is followed by an articulation of the ethical considerations, as well as the strategies used to enhance the methodological rigour underpinning both phases of the study. To recap, the three objectives of my PhD in relation to each of these phases are:

1. To explore and understand the experiences of women who have been diagnosed with endometriosis (phase one).
2. To develop a theory to explain how factors that influence delay to diagnosis in women with endometriosis can impact on the process of diagnosis (phase one).
3. To explore and understand healthcare professionals' perspectives on women's experiences of diagnosis of endometriosis to deepen our understanding of the healthcare context and factors influencing health professionals' decision-making (phase two).

4.2 Self-interview

Having identified interpretive methodologies as being the most appropriate with which to conduct this study, it was important to consider my own position and any assumptions I may hold that might influence the research process at the beginning. As a doctor in obstetrics and gynaecology, I have my own perspective on women's and healthcare professionals' experiences of endometriosis, which is likely to influence the research process. In co-constructing meaning, I am aware that my interpretation of the study findings will be based on two factors: (1) women's interpretation of their experiences and (2) my experiences as a clinician. To gain insights into my preconceptions of women's and healthcare professionals' experiences of diagnosing endometriosis, I was interviewed by an academic member of staff experienced in qualitative research, but with little knowledge of my PhD research (Appendix 1). This was a powerful and reflective exercise, which highlighted that I perceived healthcare professionals to be responsible for the delays to diagnosis and that women were victims of their actions. This insight was important for me to be mindful of when interviewing participants and co-constructing meaning with them. By recognising my own position and perspective, I was able to increase my self-awareness of the approach I took in designing and conducting the study. This therefore enabled me to understand more clearly how I may influence the research process and allowed me to more actively focus on the voices of women with endometriosis and healthcare professionals who participated in this research.

4.3 Phase 1: Exploring women's experiences of being diagnosed with endometriosis and identifying meaning

4.3.1 Study location

The research site for this study was a large NHS teaching hospital trust in the east of England, in the UK. This hospital is a tertiary referral centre and a BSGE-accredited endometriosis centre, where a group of gynaecologists have received specific training to manage complex and advanced endometriosis. This means that referrals presenting at clinics held at this site involve a combination of patients, with basic or complex surgical needs, who may also require input from a colorectal surgeon or a urologist. The accreditation of the endometriosis centre is re-evaluated every year.

In parallel to these clinics, a general gynaecologist will also see patients with endometriosis and treat them; these patients often have 'less complex' disease. The decision to choose this research site was straightforward, for two main reasons. First, as a regional hospital, there was access to patients with endometriosis of varying degrees of complexity. Second, it is my place of work and therefore, from a practical perspective, I had ready access to the facilities through the Research & Development (R&D) department.

4.3.2 Study sampling strategy

With grounded theory, the findings are analysed at the same time as interviews are conducted, until theoretical saturation is reached (Bowen, 2008). Theoretical saturation is the point at which the properties of a category or categories have been defined, and the relationship between these categories has been cemented (Morse, 2015). This is discussed in more detail in chapter 5 (data analysis).

4.3.3 Sample size

In view of this study being based on grounded theory, the sample size could not be pre-determined. However, although the exact number of participants for the sample size cannot be provided prior to the study, Braun and Clarke (2019b) argue that one must 'guestimate' a figure for practical reasons (to obtain ethical approval, for example) and then modify this number during the data analysis process. The interviews with women with endometriosis guided the sample size needed. Each interview generated more themes, and the interviews continued until theoretical saturation was reached. After conducting between eight and ten interviews, I was looking for theoretical saturation, but this did not occur. I therefore continued to interview participants. It was important for me to be aware that saturation was a perception and therefore a subjective process. Theoretical saturation does not simply refer to 'no new data', but actually refers to 'saturation in the analysis' of data (Charmaz, 2006). The data were collected and analysed simultaneously, with this aspect of the study taking 13 months to complete.

4.3.4 Sampling

Purposive sampling and theoretical sampling

All women who attended the gynaecology clinic and met the eligibility criteria were invited to be involved in this research study. Participants were initially recruited via purposive sampling at the gynaecology clinic at the research site. Purposive sampling involves identifying individuals with the phenomenon of interest (Palinkas et al, 2015), i.e., in this case women who had been diagnosed with endometriosis and met the eligibility criteria. As grounded theory involves the generation of a theory from sample data, theoretical sampling was also performed (Palinkas et al, 2015). This type of sampling is iterative and is used to develop a more detailed theoretical construct by interviewing participants about a particular phenomenon. Once the initial themes emerged, theoretical sampling (Conlon et al, 2020) was used to identify those individuals who specifically experienced a delay to diagnosis of endometriosis. This was achieved by asking participants if they perceived a delay in their diagnosis prior to recruitment Theoretical sampling is in keeping with a grounded theory approach as it enables emerging concepts to be explored in detail (Charmaz, 2006).

Snowball sampling

Many women who took part in the study also went on to tell other women with endometriosis about the study; therefore, snowball sampling (Dragan and Isaic-Maniu, 2013) was also part of the recruitment strategy. This type of sampling facilitates the participation of 'hidden populations' (Dragan and Isaic-Maniu, 2013), who may not have direct access to the gynaecology clinic. A limitation of this approach is that confidentiality may be breached through 'assumed commonality' (Dragan and Isaic-Maniu, 2013). For instance, participant X could say that participant Y may also be interested in the study and, in doing so, participant X may inadvertently disclose participant Y's diagnosis of endometriosis. However, if a participant mentioned another potential participant, they were asked not to disclose their details to the researcher directly, but to ask the potential recruit to make contact if they so wished, thus rendering this approach an acceptable risk.

4.3.5 Study inclusion and exclusion criteria

To be eligible for inclusion in this study, participants had to be female, aged 18 years or more (with no upper age limit) and have had a confirmed diagnosis of endometriosis via a diagnostic laparoscopy and subsequent histology. It was important to have a confirmed diagnosis through this method as it is the gold standard technique for diagnosing endometriosis (NICE, 2017). As discussed in the scoping review in chapter 2, there are other medical conditions, such as inflammatory bowel disease, that can mimic the symptoms of endometriosis;

therefore, a confirmed diagnosis was vital. Participants also had to have sufficient mental capacity to provide informed consent and engage in the research study. There was no restriction in terms of ethnicity, socio-economic group or geographical location within the UK. It was important to ensure that a diverse range of participants was recruited to the study; however, all participants who enquired about or participated in the study spoke and understood English. Women aged less than 18 years, who lacked mental capacity, or who experienced symptoms of endometriosis without a confirmed diagnosis were not eligible for the study.

4.3.6 Participant recruitment

The participant recruitment process included advertising the study and directly approaching participants who might be interested in being involved in the study.

Study advertisement

Posters were placed in the gynaecology outpatient department waiting room and toilets at the research site (Appendix 2). The posters advised interested individuals to contact a research nurse for further information. An information sheet with an outline of the study (Appendix 3) was given to potential participants along with a 'consent to contact' form (Appendix 4) and a participant invitation sheet (Appendix 5); individuals were given 14 days to read this and reflect on whether they wished to participate. If a woman wished to participate, she was invited back to the clinic to discuss the study with me, have any questions answered, read the consent form, and sign it if she was still interested. I was not involved in directly approaching participants prior to them expressing any interest in the study. This was important; as mentioned in the scoping review, healthcare professionals act as gatekeepers to service access, and therefore I did not want to influence women's perceptions of their medical care in relation to participating in this study.

4.3.6 Approaching participants

Once potential participants had been given the opportunity to read through the information leaflet, after 14 days I personally contacted them via telephone to see if they were still interested in partaking. I used this as an opportunity to answer any of their questions and reiterate that their participation was entirely voluntary and would not influence their clinical care (Manti and Licari, 2018). Women who agreed to participate were then sent a consent form in the post (Appendix 6), and an interview date was arranged at the research site. They were given at least 7 days to read the consent form prior to their interview.

Prior to conducting the interviews, I ensured that all participants had the mental capacity (based on the 2005 Mental Capacity Act) to make the decision to participate and had a clear understanding of the purposes of the research study and how the information they provided would be used. When participants arrived for their interview, they signed the consent form in my presence, and I answered any final questions they had.

4.4 Backgrounds of participants

Fifteen participants were recruited into the first phase of the study. Below is a summary of each participant's background and journey to their diagnosis of endometriosis. While it is important for me to provide these contextual details, it is also vital that I maintain ethical integrity by only providing sufficient details to the reader, to maintain the anonymity of participants. Each participant is ascribed a pseudonym.

Janet

Janet is a 22-year-old woman. Her journey from symptoms to diagnosis has spanned more than 2.5 years. Her symptoms became considerably worse at the age of 19 and she therefore 'pushed' to be seen by the relevant medical professionals. She received a multitude of differential diagnoses in addition to endometriosis. She provides extensive insights into her experiences with healthcare professionals; these predominantly relate to not being believed and the impact a 'hidden illness' can have on daily life.

Diana

Diana is a 23-year-old woman who has had a delay to diagnosis of more than five years. She described in very intricate details the challenges she faced while trying to 'convince' healthcare professionals to be referred to a gynaecologist. She spoke about her symptoms being normalised by various GPs. She experienced significant disruption to her daily life, including impacts on her GCSE examinations, being unable to play sports, and struggles with socialising with friends and family.

Gemma

Gemma, a 45-year-old woman, has seen many healthcare professionals over 23 years. Her delay to diagnosis was approximately 8 years. She described in fine detail what made her seek help from a doctor and the barriers she faced when seeking such help. Gemma described a prominent moment in her life that made her seek help, which was when she noticed her blood-stained mattress. This iconic moment for Gemma changed the way she perceived her symptoms. She is currently awaiting a hysterectomy.

Anna

Anna, a 22-year-old woman, has had 'abnormal' symptoms from a young age. She spoke about her struggles with endometriosis treatment whereby she did not tolerate the pill and did not like the idea of a Mirena coil. The thought of the Mirena coil made her feel ‘abnormal’, as she wanted to feel ‘normal’ by ‘having a bleed’. Anna provided great insights into the way healthcare professionals perceived her symptoms, even after being diagnosed with endometriosis. She provided a powerful account of how she felt various doctors in primary care and Accident & Emergency (A&E) perceived her ‘as an endometriosis patient’.

Harissa

Harissa, a 34-year-old woman, was diagnosed with endometriosis after 18 months from the time of initially presenting to her GP. She felt ‘dismissed’ by her GP on a number of occasions and eventually took her partner with her to see the consultant so she would be ‘believed’. She provided an interesting account of how her partner’s presence had an influence on her being referred to gynaecologist. Even after being diagnosed with endometriosis, Harissa struggled to assimilate the exact findings from her laparoscopy after being ‘debriefed’ by her consultant. She has had a number of medical treatments for endometriosis.

Umbola

Umbola, a 43-year-old woman, has had troublesome symptoms since her teenage years. She provided compelling insights into the 17-year delay she faced before eventually being diagnosed. She perceived differences in the care she received if she saw a male doctor compared with the care she received if she saw a female doctor. Umbola noted that, prior to her diagnosis, she felt the need to ‘comply with the GP advice’ to be believed, although she was eventually referred to gynaecologist. Umbola felt particularly dismissed by healthcare professionals when she was younger.

Barbara

Barbara, a 28-year-old woman, waited approximately 12 months to be diagnosed with endometriosis. She has experienced chronic pelvic pain since she was a child and was diagnosed with irritable bowel syndrome (IBS). However, it was after the birth of her third child that her symptoms of pain got worse. Barbara used various internet forums to seek support once she was diagnosed with endometriosis. She detailed the various doctors she came into contact with and the multitude of medical treatments that she tried. Interestingly, Barbara said that she did seek help from the GP on multiple occasions during her teenage years, but as she felt ‘dismissed’, she stopped going.

Faye

Faye is a 27-year-old, self-employed woman who has had a delay to diagnosis of 5 to 6 years since she first presented to her GP. She was on the pill since her early teenage years until she was diagnosed with hypertension. She explained there was a lot of miscommunication between the GP and gynaecologist. She explained that she received her diagnosis of endometriosis after having a laparoscopy for suspected appendicitis. Her symptoms had impacted her daily life to the point that she would sleep for up to 14 hours a day. She is currently awaiting more surgery.

Neha

Neha is a 23-year-old woman. Her journey to diagnosis began during childhood. She said she always had chronic pelvic pain, but no obvious cause was found. As she became older, her symptoms of heavy menstrual bleeding and worsening pain became debilitating. She had surgery to excise endometriosis and has felt considerably better since. However, her journey has certainly not been without its challenges.

Millie

Millie, a 40-year-old woman, first saw a gynaecologist at the age of 38. She explained that her symptoms had in fact been ongoing since childhood. Her symptoms were ‘unusual’ in the sense that she experienced bleeding from the umbilicus in addition to pelvic pain. Her experience in general with healthcare professionals was not positive; she highlighted how she felt dismissed and how her symptoms were normalised. She spoke about the coping strategies she employed over the years when dealing with chronic pelvic pain. Interestingly, she went on to describe how a formal diagnosis enabled her to cope with her symptoms in different and better ways.

Alma

Alma, a 22-year-old woman, experienced a delay to diagnosis of approximately 5 years. She spoke about her diagnostic journey in the UK and abroad. She went on to describe the support services she has used to engage with other women with endometriosis. One such support network was available online; interestingly, she discussed the advice women give each other so that they are believed by their GP. This advice included ‘how to dress’ and ‘how to behave’.

Bonnie

Bonnie, a 42-year-old woman, spoke about how her symptoms were essentially masked by ‘multiple pills’. She had taken Zoladex with limited positive effect. Later, she underwent surgery; unfortunately, this surgery did not have a significant impact on her symptoms. She found it surprising that doctors did not question why she was frequently presenting to them with worsening symptoms. Bonnie was extremely passionate about raising awareness of endometriosis.

Elisha

Elisha, a 28-year-old woman, provided an account of the symptoms she had experienced since the age of 18 and the impact they had on her education. She tried multiple hormonal treatments until she had to stop them due to being diagnosed with migraines. After this, she decided to ‘give her body a break’ and did not see a medical practitioner for five years. Prior to being diagnosed with endometriosis, Elisha was diagnosed with depression as well as irritable bowel syndrome.

Erika

Erika, a 32-year-old woman, described her journey to diagnosis after seeing multiple GPs. Interestingly, in common with other participants, Erika made comparisons between endometriosis and other medical conditions. These comparisons related not only to how other conditions are diagnosed but also how they are perceived by others. She described the influence that a GP ‘who listened’ had on her diagnostic journey.

Vivienne

Vivienne, a 33-year-old woman, described in extensive detail her symptoms, which started at the time of her menarche at age 14. She experienced medical care at two different hospitals, with contrasting stories. She went on to discuss how her symptoms worsened after the birth of her child and some of the challenges she faced in terms of being referred to gynaecology as a result. She is currently waiting for another laparoscopy to treat endometriosis.

4.5 Semi-structured interviews for data collection

The aim of grounded theory is not to test a specific hypothesis but to explore meaning; this meaning is co-constructed between the participant and the researcher (Charmaz, 2006). Therefore, the use of semi-structured interviews was appropriate and in line with the principles of grounded theory as a methodology (Charmaz, 2006).

Qualitative research studies often employ semi-structured interviews or focus groups as part of their methods (Hammarberg, Kirkman and de Lacey, 2016). Such approaches are a very useful way to gain insights into individuals’ experiences (Gill et al, 2008). Interviews are generally one to one between a participant and researcher and are ideal for obtaining qualitative data (Gill et al, 2008). There are various types of interviews, including structured, semi-structured and in-depth interviews (Gill et al, 2008). The questions asked in structured interviews are often closed, and these types of interviews are generally used more in quantitative studies (DiCicco-Bloom and Crabtree, 2006). Semi-structured interviews are very commonly used in health research and rely on a topic guide of themes and questions; however, there is some flexibility in this (DiCicco-Bloom and Crabtree, 2006). Finally, in-depth interviews are designed to explore a particular area in great detail and in an iterative manner (Ryan, Coughlan and Cronin, 2009).

According to the scoping review described in chapter 2, the diagnosis of endometriosis is often complex. Therefore, face-to-face, qualitative, semi-structured interviews with women with endometriosis were selected as the most appropriate way to explore this phenomenon. While the interviews could have been conducted online, for example via Skype, or over the telephone, it was anticipated that a face-to-face approach would allow social cues and non-verbal body language to be better appreciated (Smith, 2005). This would also facilitate more of a therapeutic relationship between the researcher and participant and enable data to be gathered and explored more effectively.

In an article by Potter and Hepburn (2005), they discuss the importance of not 'deleting the interviewer'. It was important for me as the researcher to appreciate that when representing and discussing the findings from the interviews, I must put them into context and not make it appear as if the participant has spontaneously had a conversation with themself. Potter and Hepburn (2005) also discuss the importance of viewing the interview as a conversation, by representing features such as pauses, pitch of voice and speed of speaking; these are important aspects of a transcript that signify the conversational nature of the interview (Potter and Hepburn 2005). Finally, to substantiate claims made based on the interviews, the researcher must clearly describe why participants are taking part in the study and what they understand about the research (Potter and Hepburn, 2005). In this research, participants with confirmed endometriosis were recruited and told that the aim of the research was to explore their experiences of being diagnosed with the condition.

Rapley (2001) argues that to analyse an interview transcript in the most meaningful and analytical way, the researcher must appreciate that any conversation is a collaboration between the researcher and participant. Having this awareness will enable fine details of the transcript to be discussed and brought to the forefront of the data analysis process. Another important consideration that Rapley (2001, p317) explores is the notion that the interviewer is a 'central and active participant in the interaction'. I was able to appreciate this and the conversational and collaborative nature of the interviews through the process of reflexivity. This subsequently enabled me to further understand my role within the research process and how my preconceptions about the subject area may influence it. This is discussed further in **chapter 11.**

Finally, Randall and Phoenix (2009) provide insights into the concept of truth and how this is influenced by a participant's memory over the course of time, the participant's perception and interpretation of a particular event, and also how truthful a participant actually wants to be with the researcher. The concept of truth was a powerful concept to understand and appreciate as part of my research process. Prior to commencing each interview, I explained to participants that if they were unsure of any details in their accounts, then it was important for them to let me know this.

4.6 Reflexivity in semi-structured interviews

When the participants were invited to attend an interview, there were a number of considerations to take into account prior to, during and after the interview.

4.6.1 Pre-interview

Prior to conducting an interview, it was important to check that I had extra copies of the consent forms and participant information sheets. I checked the room booking was still in place and that the audio recording equipment was working. I ensured that the position of the chairs was appropriate for an interview.

4.6.2 During the interview

At the start of each interview, I reminded the participant as to why they were there and the potential timeframe of the interview. I also introduced myself as a researcher and reiterated that all personal data would remain confidential. The semi-structured interviews took place in a clinic room in the gynaecology outpatient clinic or the Clinical Trials Research Unit at the research site. At the start of each interview, the participant consent form was discussed and signed, and any concerns were answered. The whole of each interview was audio recorded via a dictation device, and the interview data were transcribed verbatim immediately afterwards.

For the first interview, an endometriosis nurse specialist was also present in the room, with the participant's prior consent. She was able to give me feedback on my interview style; this enabled me to adapt my style as necessary. Ethical approval for this was obtained.

An interview topic guide was developed based the scoping review described in chapter two and used to guide the participants; however, the interviews mainly comprised a 'free-flow' process, and participants led the discussion (Appendix 7). The interview schedule formed more of a prompt for discussion, rather than a prescriptive list of questions. The schedule focussed on the journey to diagnosis and the way in which endometriosis affected women's lives. It was important to be aware that when using the guide, the participant did not feel 'talked at' and that the interview was more of a natural discussion. The interview commenced with a broad and general question: 'please can you take me through your journey of being diagnosed with endometriosis'?

As a clinician, it was important for me to not interrupt participants, to avoid 'medicalising' the discussion and to remain objective and neutral. My role was purely that of researcher, to listen and gain insights, and not as a clinician whose role was also to 'problem solve'. Verbal and nonverbal cues from participants were carefully looked for and acted upon, with further clarification of any discussion points requested as necessary.

Using verbal and non-verbal probing, I was able to explore women's thoughts in detail and ask further questions accordingly. Starting the interview with a broad question was a useful way of letting the participant talk freely. This technique is similar to the 'golden minute' used by a clinician during a clinical consultation, based on the Calgary–Cambridge communication skills model (McKelvey, 2010).

Interviews can be conducted either face-to-face, over the telephone or through video conferencing applications such as FaceTime and Skype. In this study, I chose a face-to-face approach as I felt this would facilitate a better researcher–participant rapport and potentially enable emotive topics to be discussed more sensitively, making full use of any non-verbal communication. However, I was aware that a face-to-face approach may limit who can participate and that not all those who wished to participate may be able to travel to the hospital. Although telephone interviews allow more participants to be recruited, they would make it more difficult to appreciate non-verbal cues and thus make it more challenging to build rapport. Tools such as Skype mean interviews can be held with participants throughout the world; however, if participants have a visual or hearing impairment or limited access to such tools, then this can be restrictive.

I was aware of my own agenda, and it was important for me to marry this sensitively with the participants' agenda(s). Non-verbally, I was attentive to my own body language and how this could affect the interview. Therefore, it was important for me to maintain eye contact and an open body posture. The use of pauses and allowing participants to speak was important in instilling confidence in them. It was important for me to be aware of not asking leading questions or 'loaded questions'.

The interviews were conducted in English. In total, fifteen participants were involved in this phase of the study, as data saturation was reached at this point. The interviews varied in length, from 60 to 190 minutes.

4.6.3 After the interview

The contents of the interview were briefly summarised verbally, and participants were thanked for their time and reassured that their data would remain anonymous. I ensured that any questions participants had about the study were answered and discussed how their input would be used in the thesis. All participants were offered the opportunity to receive a summary of the findings from the thesis. I also made field notes for my thesis, which included my general thoughts about the interview, participant behaviours or body language, and the highlighting of any specific quotes I considered important.

An important part of the data collection process was to debrief participants post-interview and provide them with a debrief sheet (Appendix 8). This sheet contained useful contact details for support services. At the end of the interview, participants were asked if they wanted to add anything else that we had not covered. They were also asked if they had any concerns or queries about the research that they would like to be addressed.

At the end of the interview, all participants who had parked in the hospital car park were given a reimbursement voucher for the parking charges. No other participant reimbursements were offered.

As a researcher, I also debriefed with my PhD supervisory team, especially after the first interview. This was an opportunity for me to engage in the process of reflexivity with regards to the content of the interviews and my interview style.

4.4 Phase 2: Exploring the experiences of healthcare professionals

The following section will discuss the process and procedures involved in phase two of the study, exploring healthcare professionals' experiences of caring for women with endometriosis. This phase of the study was designed to be conducted only after completion of the first phase, with the findings from phase one informing the interview guide for phase two.

4.4.1 Study location

The focus group of gynaecologists and nurses was conducted at the same research site as phase 1. The general practitioner (GP) focus group, however, was conducted at a primary care surgery. All interviews were also conducted at these respective locations, as they were the most convenient for the participants.

4.4.2 Study inclusion and exclusion criteria

The inclusion criteria included any healthcare professional who was a GP (including registrar grade), primary care nurse, endometriosis nurse specialist, general gynaecology nurse, or gynaecologist (including registrar grade). All participants were expected to be over the age of 18 years. Individuals could be from anywhere within the UK. All participating healthcare professionals were involved in the care of patients with endometriosis; the term 'care' was defined as 'anyone who is involved in diagnosing or treating a patient with suspected or confirmed endometriosis'. If participants were not able to understand and speak English language at a sufficient level to consent and participate in the interview, then they were not eligible for the study. Any participants who did not have sufficient mental capacity were also not eligible.

4.4.3 Sampling

Purposive sampling was used to obtain participants for the healthcare professional group (Palinkas et al, 2015). This ensured that a broad range of individuals within each occupation were selected. Snowball sampling (Naderifar, Goli and Ghaljaie, 2017) also formed part of the recruitment process of healthcare professionals, as this allowed more participants to be recruited.

4.4.4 Sample size

The sample size for healthcare professionals was pre-determined to be a total of fifteen individuals. Rabiee (2004) stated that there should not be more than ten participants in a focus group as this may result in challenges in managing the group. Therefore, to facilitate fruitful discussions, each focus group comprised five gynaecologists, five GPs and five nurses.

4.4.5 Participant recruitment

Advertisement

The healthcare professional phase of the study was advertised in the gynaecology outpatient clinic (Appendix 2) and via a local radio station. To maximise the recruitment of GPs and primary care nurses, the study was also advertised verbally at a regional teaching day for primary care clinicians.

4.4.6 Approaching participants

The recruitment poster in the gynaecology clinic directed potential participants to contact the researcher directly. The researcher contact details was also advertised at the regional teaching day for primary care clinicians. If they were interested, then a participant information leaflet (Appendix 9) was sent to them via email with a consent form (Appendix 10) for their review. Interested individuals were given two weeks to consider their participation. Table 2 provides an overview of the participant demographics from phase 2 of the study.

Table 2. Participant demographics from phase 2 of the study, involving healthcare professionals.

Healthcare professional	Age	Sex	Pseudonym	Ethnicity	Time since qualifying as a healthcare professional (years)
General Practitioner	58	Male	James	White British	26
General Practitioner	56	Male	Carl	White British	22
General Practitioner	34	Male	Richard	White British	8
General Practitioner Registrar	32	Female	Stella	White British	4
General Practitioner Registrar	28	Male	Kieron	Black African	4
Gynaecologist (Consultant)	53	Male	Gopal	Asian Indian	22
Gynaecologist (Consultant)	52	Male	Jordan	White British	16
Gynaecologist (Consultant)	39	Female	Mamta	Asian Indian	12
Gynaecology Registrar	37	Female	Holly	White British	8
Gynaecology Registrar	31	Female	Rebecca	White British	5
Nurse (Endometriosis Specialist)	55	Female	Lisa	White British	22
Nurse (Gynaecology Sonographer)	33	Female	Olivia	White British	8
Nurse (Hospital ward-based)	36	Female	Emma	White British	12
Nurse (Hospital ward-based)	28	Female	Charlotte	White British	7
Nurse (Primary Care)	42	Female	Priyanka	Asian Pakistani	16

4.4.7 Focus groups as a data collection method

Once all the interviews with women with endometriosis had been conducted, the healthcare professionals were interviewed. These participants were selected for inclusion based on their own interest expressed. The interview topic guide (Appendix 11) for healthcare professionals was purely informed by women's experiences of a delay to diagnosis of endometriosis revealed during phase one. By interviewing healthcare professionals, themes and issues raised by women who had experienced a delay to diagnosis were explored further through reflexive thematic analysis.

Focus groups were selected as the best data collection method with the healthcare professionals and to allow for the exploratory research objective to be addressed (Bolderston, 2012). Focus groups are increasingly used in healthcare research to generate data though facilitation (Breen, 2006; Tausch and Menold, 2016). This approach is often used to explore and understand meanings and processes (Breen, 2006) and allows narratives among participants to be explored in detail (Patton, 2018). Importantly, it is the interactions among participants in a focus group that enable insightful data to be generated (Patton, 2018). Focus groups provide an excellent platform for individuals to discuss their experiences of diagnosing women with endometriosis and encourage each other to explore each other's opinions (Kitzinger, 1995). My role as the researcher was to facilitate the discussions and interactions (Tausch and Menold, 2016). This co-construction of knowledge helped to obtain insights into the experiences of healthcare professionals who care for patients with suspected and confirmed endometriosis. The aim of using focus groups with healthcare professionals was to ensure participants were able to discuss their experiences in a social context that they were familiar with (Breen, 2006), i.e., with other healthcare professionals who worked in the same field of medicine.

Each focus group with the respective types of healthcare professionals was conducted separately to ensure power dynamics did not influence the interactions. In addition, each of the focus groups used the same semi-structured interview topic guide; this guide was developed based on the findings from phase 1. Selected quotes from endometriosis participants in phase one that were considered to be a pertinent part of the grounded theory helped to shape the focus group interview topic guide, which was used to explore healthcare professionals' subjective experiences of caring for patients with endometriosis. The development of the focus group interview topic guide was an iterative process, involving three revisions before a final version was selected for all the focus groups. These revisions were necessary because the interview topic guide was tested with two colleagues to ensure the language, flow and structure was appropriate, as recommended by McGrath, Palmgreen and Liljedahl (2019). The topic guide can be found in Appendix 11. During each focus group, I made brief notes on aspects of the discussion that I considered to be pertinent; these subsequently formed part of my initial memos.

Prior to the commencement of each focus group, all participant consent forms were checked to ensure they had been signed and it was also confirmed that the participants did not have any questions or concerns. When each focus group commenced, I introduced myself and asked each participant to introduce themselves and their role. This acted as a form of 'warm up' exercise. Each quote from the interview guide was presented to the group in the form of a PowerPoint slide and used to prompt discussion among the participants.

4.4.8 Reflexivity in the focus group interviews

While the use of focus groups in healthcare research has its merits, there are some considerations the researcher must be mindful of and subsequently account for. Probing participants is an important skill used to obtain more information about a particular area, and one must be clear to not confuse this with prompting (Guest et al, 2017). The regular use of summaries throughout the interview helped both me and the participants to gain perspectives on the ideas emerging from the interview.

Smithson (2000) encourages the researcher to think about how participants are using the focus group and what their motives are. In addition, Smithson (2000) discusses the importance of recognising 'dominant voices' and facilitating discussion between all participants in a focus group. Ground rules, such as respecting each other's opinions and not talking over each other, were also mentioned prior to the commencement of each focus group. Individuals were encouraged by me to discuss their thoughts by verbally probing any participants who were perceived to be quiet and asking them for their opinion. It was therefore important for me to pick up on any verbal or non-verbal cues that implied participants were not engaged. If there were concerns about participant engagement during the focus group, I negotiated around this by summarising key aspects of the discussion at various intervals and facilitated conversation by paraphrasing what participants had said and signposting them to the next quote of interest.

It was made clear that my role was purely as a facilitator and not as a doctor; this was to ensure there was some degree of neutrality between myself and the participants. Individuals within focus groups may be tempted to only discuss views that are considered to be normative (Smithson, 2000); the researcher should challenge such views. Therefore, it was important to give participants ‘permission’ to explore their views without feeling worried or judged; this was achieved by using sentences such as ‘Some women find X challenging. What was your experience of X?’ Neutralising a sensitive topic of discussion was also important to obtain more information about it.

Rabiee (2004) makes an important point about ensuring the different positions discussed by participants are analysed within the group context; she claims that it may be tempting, without necessarily realising it, to only analyse the individuals within a group. There were also practical aspects, discussed by Tausch and Menold (2016), that I needed to reflect on prior to the commencement of a focus group; these included the room size and temperature, the availability of refreshments, and ensuring that all participants were aware of the fire safety procedure. While this section has highlighted some of the considerations to be mindful of in relation to focus groups, overall, the use of focus groups encouraged group discussions among individuals and provided insights into healthcare professionals’ experiences of diagnosing endometriosis.

4.4.9 Transcribing the semi-structured interviews and focus group transcripts

For both phases of the study, each recording was transcribed verbatim into a Microsoft Word document immediately following each interview. Although this process took some time, it allowed me to capture details in the transcripts that another person may not have been able to. For instance, this included making a note of the way in which participants discussed their experiences based on the tone of voice. As Roberts (2015) states, it is these intricate details captured during the transcription process that will help with data analysis and interpretation.

This process of transcribing also enabled me to ‘connect’ with the data more personally, and this was an important part of becoming familiar with the data. It was anticipated that if any participants raised any safeguarding issues during the interview, then this would not be included in the transcript. I was also able to appreciate the non-verbal cues in more detail by transcribing the data myself. If there were particular non-verbal cues that a participant displayed, then I noted this down during the interview. Bailey (2008) makes it clear that the process of transcription is ‘an interpretative act rather than a simply technical procedure’.

It is important to note that all the data were transcribed verbatim; however, interruptions such as a participant answering their telephone mid-way through the interview were not included. Observations of non-verbal communication made during the interview were included, such as the manner in which something was expressed by a participant, their body language or their tone of voice. All participants were assigned a pseudonym on transcription to ensure anonymity (Moore, 2012).

For both phases, the use of computer-assisted data analysis software, such as NVivo (Bazeley and Jackson, 2014) , was considered for the management of qualitative data (Dalkin et al, 2020). However, I actively decided not to use such software. Having used NVivo for the scoping review, I personally found that manually organising the findings on ‘post-it notes’ to be more useful. I found that this helped me to ‘connect’ with the data in much more meaningful ways than I could using NVivo. The process was also more fun and engaging.

4.5 Ethical approval

Since the introduction of the Declaration of Helsinki, all research involving human participants requires appropriate ethical approval to be sought prior to its commencement (World Medical Association, 2008; Brown, Spiro and Quinton, 2020). In the UK, ethical approval for a research study must be obtained from a research ethics committee (Health Research Authority, HRA). Ethical approval (Appendix 12) for this research was obtained from the London–Surrey Borders Research Ethics Committee (reference 17/LO/1614). When this research protocol was initially conceived, I obtained ethical approval to explore the general impact of endometriosis on women in the UK. I attended an in-person meeting with the ethics committee and answered their queries. The panel members required me to make minor amendments to the participant information sheets and the consent forms. Three months after commencing the study (January 2018)), the focus of my thesis changed based on the initial two semi-structured interviews and new guidance released by NICE (NICE, 2017) on the diagnosis and management of endometriosis. This report specifically mentioned that the delay to diagnosis of endometriosis was a research priority and required further exploration. Therefore, a substantial amendment was submitted to the same ethics committee and received a favourable decision (March 2018) (Appendix 13). In the ethics application, I opted to include the figure of 'up to 20 women' and suggested that if saturation was not reached with this number, I would re-submit an updated application.

A second substantial amendment was made, but to the healthcare professional phase, following supervisory discussions in April 2019 (Appendix 14). This amendment made reference to the change from semi-structured interviews to focus groups with healthcare professionals from three different occupational groups: primary care nurses, GPs and gynaecologists. Many participants with endometriosis described the hierarchy issues they faced within the healthcare system; thus, it was felt that individual interviews may not be as fruitful as focus group discussions. This was also an opportunity for healthcare professionals within the same occupation to discuss their views on the experiences of women diagnosed with endometriosis. Each occupation was treated as a separate group, to avoid the influence of any power dynamics and allow individuals to speak freely about their thoughts. This substantial amendment was also influenced through my regular reflective practice and memo writing. It was through this process that I was able to have a ‘helicopter view’ of the project and make changes as needed. Reflexivity is discussed in more detail in chapter 11.

Prior to commencing recruitment, I obtained the relevant approval from the research site R&D department and from the University of East Anglia.

4.5.1 Specific ethical considerations

The primary aim of any ethics review is to ensure that all participants are, within reason, protected from harm (Garrard and Dawson, 2005). There were several ethical considerations that I needed to reflect on prior to commencing the study. Prior to applying for research ethics approval, I consulted several different sources, including the General Medical Council (GMC) Good Practice in Research document (GMC), UK Clinical Ethics Network (UKCEN), and local ethics policy documents from the University of East Anglia (UEA ethics). After further research, the ethical considerations were based on the Economic and Social Research Council (ESRC) ethics framework (ESRC, 2015). This framework was particularly useful because it was user friendly and clear to a novice social science researcher who had a limited background in qualitative research. The ESRC ethics framework is also specific to social science research, unlike others that focus on biomedical science research (ESRC, 2015).

The main research ethics principles underpinning the ESRC framework include (ESRC, 2015):

- Participants should take part voluntarily and without coercion,
- The benefits of conducting the research should outweigh the risks,
- Participants and those involved with the research should be fully informed about the study,
- Confidentiality should be respected,
- The research design should be transparent,

- If there is any conflict of interest, then this should be stated.

A discussion of the main ethical issues considered for both phases of the study is as follows.

Informed consent

Informed consent is underpinned by three main concepts, voluntarism, information disclosure and the ability to make a decision (Gupta, 2013). Voluntarism refers to individuals being able to make decisions free from coercion (Roberts, 2002). The participant should also receive appropriate information about the research study, in a form that is understandable by them, and have enough time to consider this to ensure adequate information disclosure (Gupta, 2013). Through the judicious application of these concepts, the participant is then able to make a fully informed decision whether to participate that is free from coercion. These principles were applied in this research study. It is important to note that a GT study is considered to be an evolving study, and therefore the exact nature of what participants will discuss is almost impossible to predict (Charmaz, 2006). It was made clear prior to commencing both phases of the study that, while a semi-structured interview guide would be adopted, participants may also discuss aspects of their experiences not directly associated with this. As this research was purely qualitative in nature, it was anticipated that participants might discuss aspects of their experiences that they may not have initially considered and therefore increased the importance of ensuring that the process of informed consent is an ongoing and dynamic process (Gupta, 2013).

Autonomy

The principle of autonomy was carefully considered as part of the process of obtaining informed consent (Owonikoko, 2013). Autonomy is an important ethical principle that underlies informed consent (Owonikoko, 2013). Participants should not feel any coercion to continue with a research study if they change their mind (Edwards, 2005). It was made clear to participants, both in the information leaflet and in person, that should they wish to withdraw their consent at any point during the study, this was possible. It was also explained that no reason was required for this withdrawal, and it would not impact on their clinical care in any way. As consent is an ongoing process, participants were frequently asked throughout the research process (when signing the consent form, at the start of the interview and during the interview) if they were comfortable continuing. This was particularly relevant if participants spoke about any sensitive or distressing experiences.

To do no harm

All research has the potential to cause harm to participants, whether this be physical or psychological, and therefore non-maleficence was taken into consideration (Omonzejele, 2005). In qualitative research, one must be particularly mindful about the psychological harm that may result from interviews. I was aware that participants might discuss aspects of their medical care that they were dissatisfied with. I was also vigilant with regards to the emotive nature of the research question and the nature of the disease itself; as a result, there was a possibility of participants discussing distressing events in relation to sexual function and/or a history of sexual abuse. Therefore, at the end of each interview, it was made very clear to participants that should they need to seek further support, they could do so from their GP or by calling the Endometriosis UK helpline.

None of the participants discussed any experiences in relation to sexual abuse. However, a few did become distressed (crying) during the interview when talking about their experiences. I offered to temporarily terminate the interview or, of course, give them the option to withdraw from the study entirely. I was also conscious of my verbal and non-verbal communication skills throughout the interviews. On the whole, most participants found it useful to partake in the study as it offered them an opportunity to discuss their experiences from a non-medical perspective. All of the women who participated were passionate about reducing the delay to diagnosis of endometriosis and therefore participants appeared to feel empowered.

At the start of each interview, it was explained to women that they may find themselves discussing aspects of their experiences that are upsetting, and if at any point they wanted to stop, this was of course possible. This ‘pre-warning’ was important as participants were made aware that they may discuss distressing aspects of their experiences and would have the option to stop if they felt it was appropriate.

Stahlke (2018) notes that it is also important for the researcher to be mindful about harm (emotional) that they may experience during the research process. To ensure that my emotional wellbeing was considered throughout the research process, I conducted no more than one interview in a single day and did not arrange any interviews for days on which I was also partaking in clinical activity. I used a reflexive journal to capture my thoughts and emotions, as well as verbally debriefing with my supervisory team as needed.

Confidentiality

Confidentiality is an important ethical and research governance requirement in any study (Kaiser, 2009). Participants were given assurances from the outset of the research via the information leaflet, the consent form and prior to the actual interview that their data would remain confidential. It was made transparent on the consent form that their anonymised data would be used for a PhD thesis, articles published in journals, and conference presentations. Discussing the issue of confidentiality from the very beginning of a research study is important to gain the trust of participants (Crow et al, 2006). The consent form also made specific reference to the safe storage of participants’ data in accordance with the Data Protection Act 2005 and subsequently the General Data Protection Regulation (2018) for a total period of five years. The data were stored on a computer at the research site and all transcripts were anonymised of any identifying features. All participants were ascribed a pseudonym. A physical copy of each signed consent form was stored in a locked cupboard in a secure room in the obstetrics and gynaecology department at the research site.

It was important for me to be mindful about the use of verbatim quotes during the data analysis and to ensure confidentiality was maintained. Kaiser (2009) discussed the importance of being aware of ‘contextual identifiers’ that relate to what people have said. For example, some participants mentioned the impact of their symptoms on their work life; therefore, I anonymised this accordingly in any data analysis or verbatim quote use. Parry and Mauthner (2004) explain that when a researcher attempts to anonymise such contextual information, there is a risk that the original meaning of the data may change significantly. I was careful during the research process to ensure this did not occur. If there were any issues, I discussed this with my supervisory team.

After obtaining the appropriate ethical approval, access was also gained to the participants’ hospital medical records. Participants should be informed of the reason if access to their medical records is required as part of a research study and to ensure they know that their medical records will only be used for a very specific purpose (Kass et al, 2003). The sole purpose of accessing patient medical records in this study was to ensure each participant in phase 1 had a laparoscopically and histologically confirmed diagnosis of endometriosis. No other aspects of their medical records were viewed, and this was made clear to the participants.

4.6 The influence of the researcher

As part of the informed consent process, it was important for me to consider my role as a clinician and researcher. As a doctor in obstetrics and gynaecology, I have experience of caring for patients with endometriosis and of course I had conducted the scoping review in relation to this PhD. Therefore, prior to commencing the study, I was interviewed by a qualitative researcher; this enabled me to gain insights into the preconceived ideas that I held about the research and about individuals who have endometriosis. This exercise highlighted the importance of not only being aware of one’s assumptions but also how they can be accounted for during the research process.

To avoid inadvertent coercion to participate in the study, potential participants for each phase were initially approached by the endometriosis nurse specialist to see if they would like to take part; in some cases, potential participants made the first enquiry after seeing the poster advertising the study. At this point, a participant information leaflet was sent to the potential participants' home addresses, and after two weeks I contacted them via telephone. This ensured that individuals had sufficient time to consider the information and think of any questions they may have. A recent study by Geddis-Regan, Exley and Taylor (2021) highlighted the challenges associated with being both a clinician and a researcher in the context of 'power' and its influence on study participants.

As the study progressed, I increasingly realised how much I was learning from the participants and that in fact they were the 'experts' in this research process, not me. My role as a researcher and clinician is discussed in more detail in chapter 11 (reflexivity).

4.7 Methodological rigour

Here, as with any research study, it is important to demonstrate methodological rigour. As with quantitative research, qualitative research is also bound by guidance to ensure methodological rigour. Lincoln and Guba (1986) state that research stemming from a constructivist perspective should have credibility, transferability, dependability and confirmability. This set of 'criteria' is useful both when critiquing qualitative research and when conducting qualitative research, to ensure its trustworthiness. The consolidated criteria for reporting qualitative research (COREQ) checklist was also used (Tong, Sainsbury and Craig, 2007).

4.7.1 Credibility

Credibility is achieved by having an awareness of one's own preconceived ideas; in my case, these came through my clinical experience as a doctor and through conducting the literature review. This PhD project aims to explore the experience of women with endometriosis. However, I am aware that as a doctor in obstetrics and gynaecology I will have my own opinions regarding the care provided to women with endometriosis; it is important to acknowledge and then bracket such thoughts. I have also kept a written journal of my reflections during the course of my PhD, as well as thoughts I experienced during the interviews. The constructivist approach in particular allows for this 'acknowledgement' and 'bracketing' (Charmaz, 2008). Fischer (2009) explains that bracketing involves the researcher being aware of and accountable for his or her own assumptions. Fischer (2009) also discusses that through evolving data analysis, the researcher may become more knowledgeable about a particular aspect of the research and will therefore need to take this into account when revisiting data during the iterative data interpretation process.

In qualitative research, the term 'reflexivity' is used to describe 'the effect of the whole-person-researcher on the research' (Attia and Edge, 2017). The process of reflexivity was conducted by writing through memos and engaging in regular reflection. These thoughts concerned my own views about diagnostic delays and the research methodology I had chosen, as well as my thoughts about what the participants were telling me during the interviews. It was important for me to realise that, as GT uses a constant-comparison method, my thoughts about the data may change over time and to acknowledge this when interpreting the findings from interviews with participants. These reflexive accounts are detailed in chapter 11.

To ensure that the theory generated is grounded in the study, I analysed the data as I collected it, created memos on my findings and used a 'constant-comparative' method. This is discussed in greater depth in chapter five, data analysis. In addition, the flexibility of GT meant that I could revisit earlier transcripts and reflect upon any findings from these through reflexive practice. Through this process, I was able to question any codes and themes that did not 'fit' with the theory. In addition, as I was collecting and analysing data simultaneously, I had an awareness of any 'deviant cases' or findings, i.e. participants' accounts that did not quite fit with findings from other participants (Anderson, 2010). It was important for me to acknowledge such findings and use them to further test, develop and substantiate my theory in phase one.

4.7.2 Dependability

Dependability refers to ensuring that the results from both phases of the study are reproducible, provided the same type of participants are involved (Forero et al, 2018). This was evidenced by having an audit trail of the different developments to the protocols and the respective ethical approvals. In addition, the data collection and data analysis processes are discussed at length (in chapter 5) to provide other researchers with clarity on how these were approached.

4.7.3 Confirmability

Confirmability refers to the extent that another researcher may be able to confirm the findings of a study (Forero, et al, 2018). This was achieved through the use of a research diary and the researcher engaging in the process of reflexivity. This process was iterative and occurred from the very moment I commenced my PhD. In particular, my thought processes about the conception, design and data analysis of both phases of the study were documented in my research diary.

4.7.4 Transferability

Grounded theory studies do not claim to make generalisations about their findings to a wider context, but they do make sound conclusions grounded in the findings relating to their study participants (Charmaz, 2006). Here, therefore, the concept of delay to diagnosis will be explored very specifically among a specific cohort of participants. The context of this study meant that participants were from the UK and had experience of the NHS, a system that is free of charge at the point of care. While generalisations of these findings to the wider endometriosis population cannot be made, the findings will be extremely useful to obtain insight into delays to diagnosis and how care for women suffering from endometriosis can be improved. It is not the findings per se that are generalisable but the concepts and thinking behind them that can be applied to women with endometriosis outside of this research cohort.

4.8 Summary

This chapter has provided an overview of the data collection processes used for both phases of the study and taken into account the relevant ethical considerations. The following chapter will discuss the data analysis processes used for both phases of the study.

Chapter 5 – Data analysis

5.1 Introduction

This chapter will focus on how the data were analysed, first using the constructivist grounded theory approach (Charmaz, 2006) for phase 1, involving participants with endometriosis, followed by reflexive thematic analysis (Braun and Clarke, 2006, Braun and Clarke, 2019b, Braun and Clarke, 2021) for phase 2, involving healthcare professionals.

5.2 The constructivist grounded theory approach

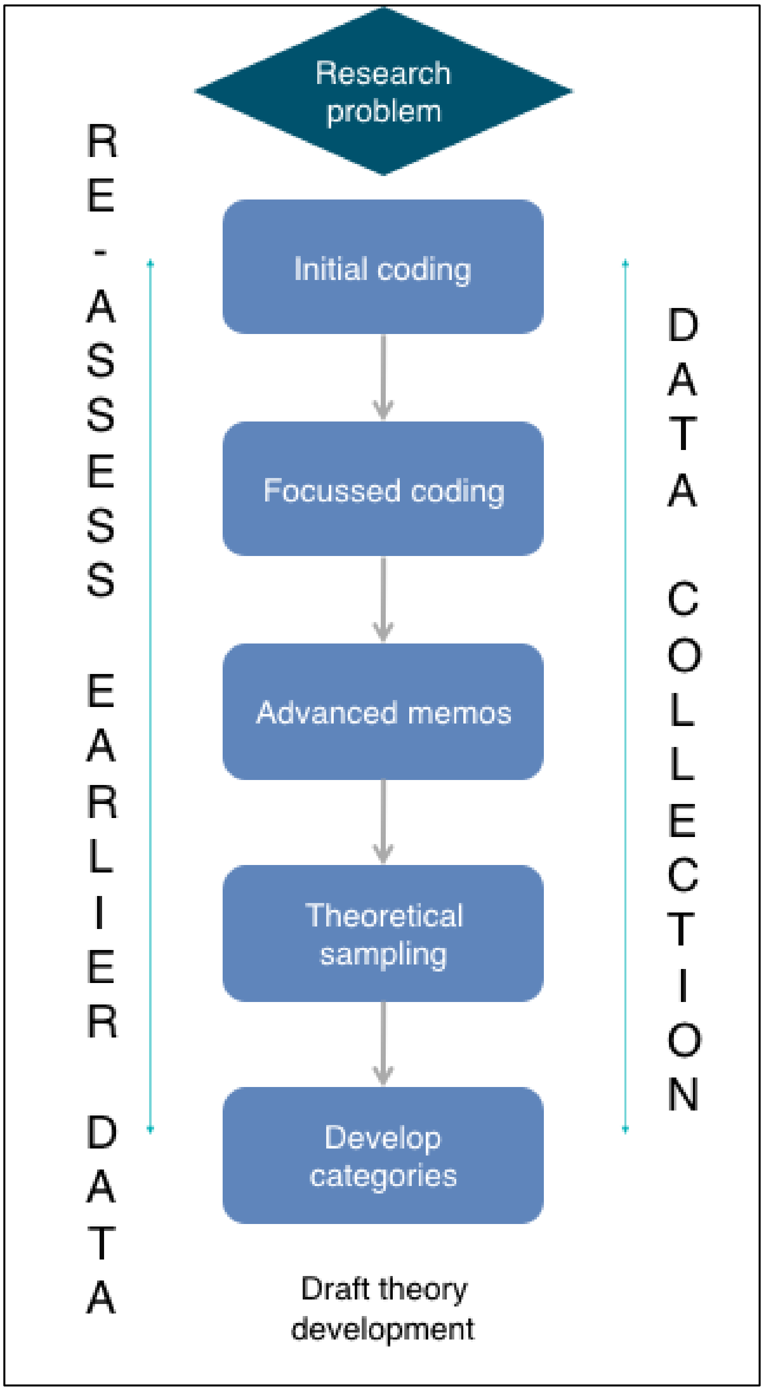
To develop a grounded theory, there are a number of key concepts that should be considered by the researcher; including the constant comparison technique, theoretical sampling and theoretical coding (Charmaz, 2006). Each of these is discussed in detail in this chapter.

5.4 Overview of the constructivist grounded theory process

As discussed by Charmaz (2006), there are different processes involved in developing a grounded theory. After each interview was conducted, it was transcribed verbatim within 24 hours. Following this, data analysis commenced; this involved initial coding, memo writing, constant comparison of data, focussed coding, theoretical sampling, developing categories and eventually writing a draft theory. Figure 6 shows a schematic overview of the overall process involved in generating a grounded theory, as depicted by Charmaz (2006, p.11). Each aspect of this process will now be discussed in detail.

It is important to note that while the data collection and analysis processes are described in a linear fashion, the actual process was in fact the opposite. There were multiple occasions when it was necessary for me to re-analyse the earlier transcripts, to solidify categories as well as ensure that I did not miss any emerging categories. In reality, the process was not as rigid as the flow chart may imply. In fact, the principles in the flow chart were applied dynamically. Throughout this chapter, the constructivist grounded theory process will be illustrated in tables and descriptively as suggested by Urquhart (2013).

Figure 6. A flowchart to show an adapted overview of the process involved in developing a theory, as envisaged by Charmaz (2006, p.11).



5.5 Constant comparison of data

Prior to discussing the coding process adopted, I will discuss the importance of the constant-comparison method that Charmaz (2006) advocates. To develop data into a theory, Charmaz (2006) encourages the adoption of the constant-comparison method; this involves comparing codes with codes, categories with categories and ultimately categories with higher-order analysis. She states that for a theory to remain grounded in the data, it is important to simultaneously collect and analyse the data (Charmaz, 2006). This was a particularly useful technique when interviewing women with endometriosis as it allowed me to explore different avenues and home in on areas of particular significance through theoretical sampling, as discussed in chapter four. The constant-comparison method ensured that I continually referred to my original data and made judgements based on those data only. It is important to note that the constant-comparison method was used throughout the research process, from initial coding to the generation of the substantive theory. Through this method, I was able to compare data within a transcript and between different transcripts; as such, an iterative approach to data analysis was adopted as per Charmaz (2006). The points at which the constant-comparison method was used throughout the research process will be highlighted in the relevant sections of this chapter.

5.6 Coding

Coding, first described by Glaser and Strauss (1967), is a process whereby data are summarised into short names (Charmaz, 2006). There are two parts to coding. The first is initial coding, where word by word and line by line aspects of a transcript are studied (Charmaz, 2006). The second is focussed coding, where the initial codes are further tested (Charmaz, 2006). Charmaz (2006, p. 42) states that codes can also be formed from the exact words that participants use; these are known as 'in-vivo codes' (Charmaz, 2006 p.42) and can have 'symbolic' meanings (Charmaz, 2006, p.55). The whole process of coding is underpinned by constant-comparison within the transcript and between transcripts (Charmaz, 2006). Overall, the process of coding involves sorting and selecting participants' data prior to analysing these data

(Charmaz, 2006). Importantly, the codes are generated from the actual data rather than any other prior resources the researcher may have engaged with; in this way, the coding process allows ‘actions and processes’ to be studied (Charmaz, 2006 p. 45).

5.6.1 Initial coding

Initial coding was performed as the first stage of data analysis. During this phase of coding, I went through each word in the transcript line by line to generate the initial codes. I was able to look for ‘action’ within the data (Charmaz, 2006, p.47). I was mindful to be aware of preconceived ideas that may influence this process of coding, and therefore reflexivity was particularly important at this stage. This process of reflexivity was achieved by writing memos; this is discussed in more detail later in this chapter. It was also important that I remained as open as possible to the ‘theoretical direction’ of the research (Glaser 1978 and Charmaz, 2006, p.46).

Charmaz (2006, p.48) explains that the initial codes should be ‘provisional, comparative and grounded in the data’. Charmaz (2006, p.49) also warns against using generic words, such as ‘experience’, gleaned from data to create codes, as such words will not necessarily add meaning to codes. To capture ‘action’ within the data, Charmaz (2012) advises the researcher to look for gerunds within the transcript. I actively did this throughout the coding process.

I was able to start the initial coding process word by word and line by line manually. I printed off a participant’s transcript and used a highlighter to note specific words on the transcript. This was an iterative process, as I was able to create the initial codes based on what I thought was happening in the verbatim text. I ensured that I used the words specifically mentioned by the participants, thereby allowing the participants’ voices to remain at the forefront of the coding process. While I completed this aspect of the analysis manually, I could equally have used data management software to do this (for instance NVivo; Bazeley and Jackson, 2014). However, by manually coding the transcripts, I felt more engaged with the findings, and I was able to code more freely, rather than through the computer screen, as another medium. As part of the initial coding process, I revisited the transcripts and audio recordings on multiple occasions. This was a useful way to ensure I was accurately capturing the meaning within the dataset. Figure 7 shows an example of the initial coding process for the first paragraph of the first transcript.

Figure 7. An example of initial coding for the first paragraph of the first transcript.

Transcript extract, verbatim	**Initial code**
So, you don't put two and two together at the time.	Difficulty connecting symptoms
I remember my mum and dad arguing saying that I can't not go to school because of period pains.	Impact on parents Fracturing relationships
I remember lying in bed thinking how painful my periods were and being sick with migraines.	Impact on self; questioning self
My mum and dad thinking I wanted a day off school.	Other people's perception of symptoms
I went on the pill at the age of 14 for heavy bleeding, which I think masked all my symptoms.	Medical treatment Masking of symptoms
Then I was about 19 when I started to have pain and bleeding all the time.	Change in symptoms-persistent
I only just started working on the ward and so didn't want to make a fuss.	Coping with symptoms
I then got investigated for all sorts, IBS, cysts etc by the GP.	Multiple symptoms
They said it could be a UTI or pelvic inflammatory disease.	Differential diagnosis
I think I had bled for 6 weeks non-stop and I knew that if I went to the doctors, then they will send me to the ward. *So, I went to the iCASH clinic instead! They scanned me there and said I probably had a miscarriage- even though I had a negative pregnancy test! I was only 19 and devastated!*	Perception of doctors Seeking help in alternative routes to GP

5.6.2 Focussed coding

Focussed coding was the second part of the coding process, and this was conducted over time as more data emerged through interviewing participants. It was during the focussed coding phase that I was able to look for further meaning within the text and relate this meaning to a particular context, as described by Glaser (1978), Strauss and Corbin (1998) and Charmaz (2006). Again, I revisited transcripts, and this allowed me to decide on which of the initial codes could be representative of potential categories (Charmaz, 2006). Categories are defined as 'groups' wherein 'events, processes and occurrences' that share similar characteristics are detailed (Charmaz, 2006). The categories are initially descriptive but, as the data collection and analysis proceed further, the categories become more analytical (Charmaz, 2006). Focussed coding offers the opportunity to compare the various initial codes assigned to the different interviews and look for further meaning (Charmaz, 2006). As Charmaz (2006) states, focussed coding allows for further direction to be sought in the data. It also offered another opportunity for me to explore any preconceived ideas that I may have had about the data. I was able to explore new categories within the dataset and compare them with the initial tentative categories (Charmaz, 2006).

Constant comparison of data at the same time as creating focussed codes and memo writing simultaneously enabled the initial codes to be refined and developed further (Charmaz, 2006). It was through this very process that categories were beginning to emerge with their respective concepts. As with any grounded theory study, there will be a core category that underpins the phenomenon of interest in the study. Figure 8 shows an example of how the focussed coding was carried out. At this stage, the categories were only tentative and further focussed coding was required. I presented the initial and focussed codes to my supervisory team, and we discussed them further. It was through this process, further interviews with participants, and the use of constant comparison that I was able to develop a more detailed and connected grounded theory.

Figure 8. An example of generating a focussed code ('comparing endometriosis to other medical conditions').

Interview data from the initial codes	Focussed code
Interview 1 *In comparison, if I had broken my leg and it was swollen and painful, then people can see this and therefore understand.* ***Interview 2*** *Some people get embarrassed to talk about it, but you won't be embarrassed talking about a broken hand- so why this! Maybe because its gynae problems and so people don't talk.* ***Interview 4*** *Oh, opiates and birth controls don't always work. It's as prevalent as diabetes and lots is being done about that! You have a broken arm, you can do something. Why is it different for endometriosis? It's not one glove fits all. It's very different for each woman.* *You can go get a solution for a broken arm, but why not this? People don't seem to give a crap about endometriosis. I even look at natural remedies in chemists, and there is nothing. It's not widely known.* *If someone had cancer, then they wouldn't be dismissed, would they? Some people can have endo but have no symptoms! How do you tackle an illness that presents with so much variation?*	Comparing endometriosis to other medical conditions

5.6.3 Axial coding

Charmaz (2006, p60) also discusses another type of coding, referred to as axial coding; it derives from the perspective of Strauss and Corbin (1998). Axial coding allows subcategories to be developed around an existing category (Charmaz, 2006). She describes it as a framework that researchers can use but at the same time, she appears to neither agree nor disagree with its use in the coding process (Charmaz, 2006). I did not use axial coding as I felt the initial coding and focussed coding enabled me to explore the data in meaningful ways as well as allowing fluidity in the coding process without feeling restricted to some degree by such a framework.

The process of coding was interactive with each participant because I was constantly reading and re-reading the transcripts (Charmaz, 2006). Charmaz (2006) makes the important point that although the researcher generates the codes from participant data, the researcher is actually constructing the codes from data. The researcher therefore chooses what she or he feels is important to include (Charmaz, 2006). It is particularly important to be aware of this during reflexivity and acknowledging such influences on the data analysis aspect of the study.

During the process of coding, I had to be mindful that my preconceptions as a doctor in particular may influence the development of codes. It was therefore important for me to follow the process of initial and focussed coding watchfully through careful questioning of the data as well as constant comparison. Even asking myself ‘is this really a code from the transcript?’ or ‘is this a code from my preconceived knowledge?’ is something that I did quite often.

5.7 Memo writing

Memo writing is an important aspect of qualitative research and was incorporated in this research study. Charmaz, (2006, p.72) describes memo writing as a ‘space and place for making comparisons between data and data, data and codes, codes of data and other codes, codes and category and category and concept’. I was able to document my thoughts not only on the content of the interview findings but also on how I conducted the interviews. I was able to keep a log of my general thoughts about the direction of the project, as well as reflect on the overall research process.

Memo writing is the process of analysing collected data in any way possible and is carried out throughout the research process (Charmaz, 2006). I interpreted memo writing as a method for visually capturing my thought processes. I noted down my thoughts about the way interviews were conducted as well as the findings from these interviews. Even during the interviews, I was able to note down phrases that a participant used and then expand on my thoughts following the interview. I found the process of memo writing extremely therapeutic as it gave me a sense of connectedness with each participant through words. As Charmaz (2006) explains, memo writing allows comparisons to be made between data in a multitude of ways, exploring similarities and differences. It was through this process that I was able to form categories and explore their respective properties from a truly analytical stance by exploring the conditions in which they occurred. The best part of writing memos was that it encouraged spontaneous free-flow writing.

I followed Charmaz's (2006) guidance when creating memos. This involved giving each memo a title, defining a category using codes and exploring the assumptions surrounding the categories. Charmaz (2006) explains that both early and advanced memos can be useful. Early memos focus on collecting codes and thinking about how more information about these codes can be collected in future interviews, in terms of processes (Charmaz, 2006). Advanced memos allow deeper analysis to occur in terms of comparing data between participants and comparing categories (Charmaz, 2006).

Charmaz (2006) states that memos can be written through the processes of clustering or freewriting. Clustering refers to creating a visual representation of the codes, while freewriting is literally writing freely without any restriction (Charmaz, 2006). I used a combination of both clustering and freewriting during the development of my memos. I found it particularly useful to start freewriting in the first instance, and as I developed my work towards advanced memos, I found it easier to connect my thoughts and ideas about categories using clustering diagrams.

As the memos developed, I was able to create categories from the codes. This aspect of writing memos was initially challenging; however, I used Charmaz's (2006, p.92) guide. Charmaz (2006, p92) advocates the following:

1. *'Define the category*
2. *Explicate the properties of the category*
3. *Specify the conditions under which the category arises, is maintained, and changes*
4. *Describe the consequences*
5. *Show how the category relates to other categories'*

I constantly revisited and re-revised memos throughout the entire research process. Figure 9 is an example of an early memo for illustrative purposes, and Figure 10 is an example of an advanced memo.

Figure 9. An example of an early memo after interviewing a participant.

Memo 1

My first ever memo! I have just completed my first interview. This was a real eye opener. The process took considerably longer than I had initially anticipated. The whole process felt quite emotionally exhausting. I now realise why it is important to maybe not do more than one interview a day. The participant provided me with so much information- more information that I ever thought was possible to gather! She described her experiences of living with endometriosis in meticulous detail. What struck me the most was the impact the illness had on her and her family. She provided great insight into her diagnostic journey and how she did not feel believed by healthcare professionals. I learned that living with endometriosis in her shoes was a challenge. She battled daily with symptoms and juggled the effect her symptoms had on her life with commitments- family, relationship, employment.

Figure 10. An example of an advanced memo.

During the interviews, a number of women have compared endometriosis to other medical conditions. Comparisons were made to signify the delay to diagnosis and how this delay may not occur if it was another medical condition. Comparison was often made with illnesses that are physically visible (such as a fractured bone) or conditions that would provoke an emotive reaction (cancer and mental health). Women described how other conditions received an element of sympathy compared to endometriosis. Interestingly, women provided insight into their experiences of being diagnosed with A&E and then being seen in A&E for acute symptoms. They detailed negative encounters with healthcare professionals and that they felt 'judged' and 'acopic' This is definitely worth exploring this further in the next set of interviews. Maybe their experiences in A&E could have an impact on health-seeking behaviours? I wonder if this could then in turn influence the delay to diagnosis?

5.8 Theoretical sampling and theoretical saturation

As discussed in chapter 4, Initial sampling involved interviewing women with endometriosis through purposive sampling, which was discussed in chapter four. However, after two interviews had been conducted, theoretical sampling was used. Theoretical sampling, as described by Charmaz (2006), is a strategy whereby categories are questioned, refined and then their properties are further developed. As I coded each interview script prior to interviewing the next participant, I was able to theoretically sample. Through developing codes, I was able to question the categories in terms of their properties. It was very evident that when I was in the earlier stages of coding and memo writing, the categories lacked depth and breadth. It was through questioning the data that I was able to theoretically sample and recruit participants that would enable me to develop, refine and enhance the initial tentative categories. It is clear from the literature that theoretical sampling does not represent an actual population, but it relates specifically to the development of theory (Charmaz and Henwood, 2017). It is the process of writing memos and reflection that facilitates the process of theoretical sampling. Charmaz (2006) describes theoretical sampling as emergent and, as such, the categories will continue to develop and evolve until theoretical saturation is reached.

Theoretical saturation refers to the point at which no new properties are generated for the chosen core categories (Charmaz, 2006). In grounded theory, data collection and analysis occur simultaneously, and these processes continue until theoretical saturation is reached (Charmaz, 2006). The notion that theoretical saturation has been reached is a subjective one, but it is important to appreciate that this stage is not reached by data saturation, but in fact through saturation in the data analysis. In this study, theoretical saturation was reached after interviewing fifteen participants.

5.9 Theoretical coding

Theoretical coding was the third stage of the coding process and involved refining the focussed codes into categories (Charmaz, 2006). This stage provides insights into and details of the complex interactions among different categories and, over time, leads to the development of the substantive theory. Table 3 shows an example to illustrate the process of theoretical coding for an initial category.

The process of theoretical coding was certainly dynamic, in that I was able to view the overall dataset with more conviction. I was able to gain a deeper understanding of the main concerns of participants with endometriosis and explore the categories that underpinned these concerns.

5.10 Theoretical sensitivity

Theoretical sensitivity is a key concept that forms part of the grounded theory process. It is defined by Charmaz (2006) as the ability to explore data at an abstract level and make connections within it. Importantly, theoretical sensitivity enables the researcher to consider his or her assumptions about the research area itself and, as such, encourages one to engage in the process of reflexivity. Engagement with theoretical sensitivity was important as it enabled me to make active decisions about which aspects of the data needed exploring further as part of the emerging theory and subsequently allowed the properties and dimensions of each category to be further developed (Charmaz, 2006).

Theoretical sensitivity informed my findings in several ways. I was able to engage with theoretical sensitivity in multiple ways and demonstrated this throughout the research process by initially undergoing a self-interview with another researcher to recognise, explore and acknowledge my underlying assumptions about endometriosis. My initial engagement with the wider literature that explored the delays to diagnosis of endometriosis meant that I was able to engage with subtle details that my participants told me during the interviews and could therefore further define and refine the grounded theory. In addition, through my reflexivity journal, I was able to reflect upon the research process prior to data collection, during data collection, following the interviews and during the data analysis stage. Throughout the process of coding and re-coding the data, and by using the constant-comparison method, I was able to further identify and engage with the abstract level of detail within the data. Finally, throughout the research process, by taking a reflexive approach to my preconceived ideas about endometriosis and the knowledge gained from the scoping review, I was able to further engage in theoretical sensitivity.

Table 3. An example showing the development of an initial category ('noticing something was not right').

Focussed codes	**Category**
'Odd pain' 'Feeling unusual' 'Starting to take time off work' 'Feeling tired all the time' 'Partner commenting on symptoms' 'Starting to miss out on dinner dates' 'Friends commenting on tiredness' 'Other people showing concern'	'Noticing something was not right'

5.11 The use of diagrams

The use of diagrams can be particularly helpful in testing emerging concepts during the development of a grounded theory (Buckley and Waring, 2013). Throughout the data analysis process, I used multiple diagrams as part of the constant-comparison process and when I generated the initial categories. Throughout the development of the substantive grounded theory, various diagrammatic representations of this were developed and refined over time.

5.12 Theoretical development

Once I had created and developed the initial categories, it was time to sort through them and explore their meaning in the wider context. Sorting involved going through the memos in order of their title and comparing the categories, as described by Charmaz (2006). I used a variety of post-it notes to help reshuffle the memos as needed. Clarke (2003, 2005) and Strauss (1998) suggest the use of diagrams to visualise the different categories and their subsequent links. I was able to use this process of sorting as part of the theoretical development (Appendix 15). The development of a substantive constructivist grounded theory was a lengthy process that took more than two years to complete. The theory was refined during this time until theoretical saturation was reached. The data analysis processes for phase 2 of the study, involving healthcare professionals, will now be discussed.

5.13 Reflexive thematic analysis

This section will discuss and explore the process of reflexive thematic analysis that was used to analyse the findings from healthcare professionals.

5.14 Phases of reflexive thematic analysis

While the process of reflexive thematic analysis (RTA) may appear linear when described on paper in this chapter, it is important to note that I moved ‘back and forth’ between the different phases. As Braun and Clarke (2006) explain, this type of analysis should be viewed as a ‘tool’ rather than a ‘rule’ to facilitate creative writing.

Prior to analysing the data using RTA, the data were transcribed. Throughout the process of data transcription, there is an element of subconscious data analysis, as I subconsciously but actively engaged with the data and their general meaning. Each focus group was audio recorded, and during the focus groups, field notes were made by me on any key points raised by participants as well as any specific emotions and actions they demonstrated. A reflexive diary containing my thoughts was also updated throughout the study. Once each focus group was complete, the recording was transcribed verbatim by me. Due to the flexible nature of Braun and Clarke’s (2006) RTA method, I had autonomy in how the data were transcribed.

While the transcription process may initially appear to be a ‘simple’ process of typing up what has been said during an interview, upon reviewing the wider literature it became apparent that there are many facets that one must consider as part of this process (Lapadat and Lindsay, 1999). The interplay between verbal and non-verbal behaviour during a discussion and the verbal tone with which words are communicated is known to be useful when exploring the interactions that take place during an interview (Bailey, 2008); this was explored during this study. In addition, Bailey (2008) discusses who should conduct the transcription process; in this instance, this was performed by the researcher who conducted the focus groups, as this enabled me to contextualise the findings to the research question and engage further with the data. Bailey (2008) also prompts the transcriber to consider how any linguistic variation among participants is reflected during the transcription process.

Here, to ensure clarity in interpretation, any literal phrases used by participants that may have impacted the interpretation of data were changed to standard English used in the UK.

While the process of transcription took some considerable time, it paid dividends as part of the analysis process, as it enabled me to become more familiar with the data. It is evident that the transcription process required me to make active decisions about the level of detail to include or exclude. This is an important consideration as part of the reflexivity process. The six phases of RTA (Braun and Clarke, 2019) and how they were adapted for the focus groups will now be discussed

5.14.1 Familiarisation

The aim of this phase is for the researcher to immerse themself in the data to gain familiarity with any key ideas and themes. Immersion is defined by Braun and Clarke (2006) as the re-reading of the transcripts and actively trying to make sense of the data. Therefore, this stage involved an initial listening to the audio recordings to make sense of them overall. Transcripts were read in detail at least twice to obtain a deeper understanding of the data (Ritchie and Lewis, 2003). Notes on initial ideas were made in the margin of each transcript during the familiarisation process to ensure key ideas were captured. The audio recordings were also revisited to ensure subtle details, such as the participants' verbal tone, was captured during the familiarisation process. In addition, field notes made during and after each focus group were read and reflected upon as part of the diary that was kept. As part of the familiarisation process, it was important to refer to the original aim and objectives of the study (Braun and Clarke, 2006) as this helped to further make sense of the transcripts. The advantage of both interviewing the participants and being involved in the RTA process was that it enabled me to further engage with the data. This stage enabled me to gain specific insights into healthcare professionals' experiences of caring for participants with suspected and confirmed endometriosis. This was essential to gain an understanding of the reasons for delays to diagnosis.

The familiarisation phase also enabled me to reflect on my own clinical experiences as well my own philosophical assumptions to help make sense of the data. This familiarisation process was carried out for each focus group and again for all of the focus groups combined.

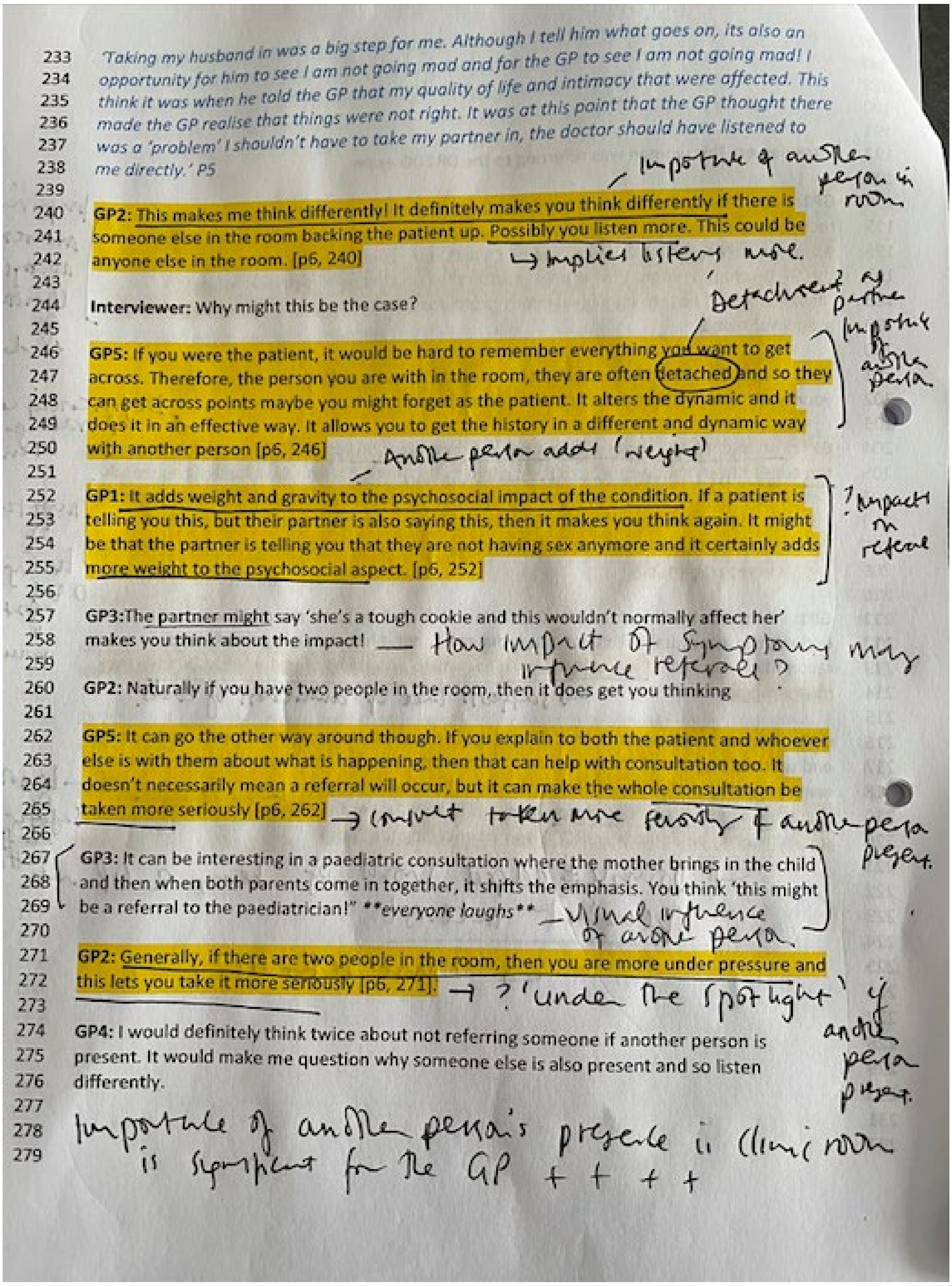
5.14.2 Generating initial codes

Initial codes are generated based on my thoughts from the familiarisation process. A code is defined as 'the most basic segment' of the data (Boyatzis, 1998, p63) and can be a semantic code (representing an obvious meaning) or a latent code (representing an underlying assumption) (Braun and Clarke, 2006). It is important to note that coding was carried out for participants' behaviours, emotions and values (Gale et al, 2013). The codes were initially generated from the GP focus group transcript and then from the nurse and gynaecologist focus group transcripts. It is important to acknowledge that the coding process of subsequent transcripts will be somewhat influenced by that of the previous transcripts; again, this offers an opportunity for reflexive practice.

As part of any qualitative data analysis, there is always the option of using computer-assisted qualitative data analysis software (CAQDAS). In this study, NVivo software (Bazeley and Jackson, 2014) was considered, but as only one researcher was involved in the data collection and analysis process, a manual paper-based approach was considered more appropriate. This also enabled me to engage more closely with the data. The coding process was initially performed with the use of coloured pens and highlighters and by writing in the margins of each transcript (see Figure 11). For ease of reading, the same example section of the coding has been provided in an electronic format (Figure 12). Braun and Clarke (2006) and Braun and Clarke (2012) make it clear that all transcripts should be assigned equal time for their review. If the present study had been conducted by a large research team then the use of NVivo may have been more appropriate, as it enables all team members to view data 'live' and work together more effectively. It was important for me to optimise my ability to engage with the data and having a full representation of the data, on paper and displayed on a large wall, facilitated this (see Figure 13 and Figure 14 for examples of this). The use of post-it notes stuck on a large wall enabled me to dynamically engage with the data, move the codes around the wall and begin to explore patterns within the data. This process was dynamic in that I was able to ‘stand back’ and view all of the initial codes on the wall and adjust the organisation of the codes.

As each transcript was re-read three times, it enabled further codes to be generated, and this was an iterative process. Braun and Clarke (2006) discuss that for each code, data from the entire transcript should be collated to represent that particular code. Through this process, the data are organised into ‘meaningful groups’ (Tuckett, 2005). The structure of the focus group interview guide was the same for all groups of healthcare professionals, and this guide was influenced by the verbatim quotes from the phase of the study involving endometriosis participants. In total, 109 initial codes were generated from the healthcare professional focus groups.

Figure 11. An example from a GP focus group transcript showing how the initial codes were generated.



'Taking my husband in was a big step for me. Although I tell him what goes on, its also an opportunity for him to see I am not going mad and for the GP to see I am not going mad! I think it was when he told the GP that my quality of life and intimacy that were affected. This made the GP realise that things were not right. It was at this point that the GP thought there was a 'problem' I shouldn't have to take my partner in, the doctor should have listened to me directly.' P5

Importance of another person in room

GP2: This makes me think differently! It definitely makes you think differently if there is someone else in the room backing the patient up. Possibly you listen more. This could be anyone else in the room. [p6, 240]

→ Implies listening more.

Interviewer: Why might this be the case?

Detachment of partner

GP5: If you were the patient, it would be hard to remember everything you want to get across. Therefore, the person you are with in the room, they are often detached and so they can get across points maybe you might forget as the patient. It alters the dynamic and it does it in an effective way. It allows you to get the history in a different and dynamic way with another person [p6, 246]

Importance of another person

Another person adds 'weight'

GP1: It adds weight and gravity to the psychosocial impact of the condition. If a patient is telling you this, but their partner is also saying this, then it makes you think again. It might be that the partner is telling you that they are not having sex anymore and it certainly adds more weight to the psychosocial aspect. [p6, 252]

? Impact on referral

GP3: The partner might say 'she's a tough cookie and this wouldn't normally affect her' makes you think about the impact! — How impact of symptoms may influence referral?

GP2: Naturally if you have two people in the room, then it does get you thinking

GP5: It can go the other way around though. If you explain to both the patient and whoever else is with them about what is happening, then that can help with consultation too. It doesn't necessarily mean a referral will occur, but it can make the whole consultation be taken more seriously [p6, 262] → Consult taken more seriously if another person present.

GP3: It can be interesting in a paediatric consultation where the mother brings in the child and then when both parents come in together, it shifts the emphasis. You think 'this might be a referral to the paediatrician!" ***everyone laughs*** — Visual influence of another person.

GP2: Generally, if there are two people in the room, then you are more under pressure and this lets you take it more seriously [p6, 271]. → ? 'under the spotlight' if another person present.

GP4: I would definitely think twice about not referring someone if another person is present. It would make me question why someone else is also present and so listen differently.

Importance of another person's presence in clinic room is significant for the GP + + + +

Figure 12. The various codes ascribed to a sample passage from the GP focus group transcript in electronic format for ease of reading.

Code

Role of patient advocate

Importance of ‘another’ in the room

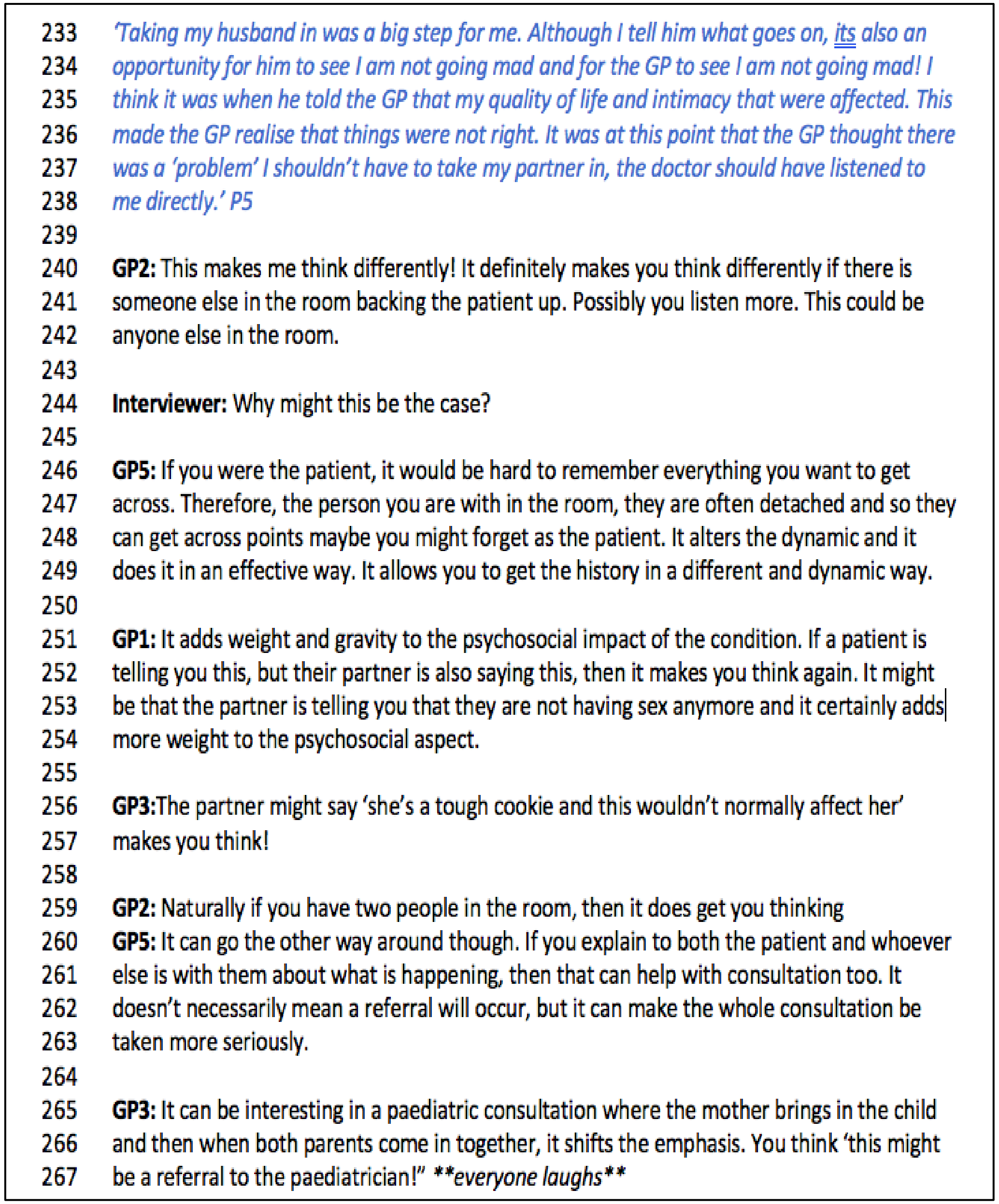
Importance of ‘another’- ‘detachment’

‘Another’ adding ‘weight’

Relating impact of symptom(s) to coping

Taken more seriously

Consultation dynamics



‘Taking my husband in was a big step for me. Although I tell him what goes on, its also an opportunity for him to see I am not going mad and for the GP to see I am not going mad! I think it was when he told the GP that my quality of life and intimacy that were affected. This made the GP realise that things were not right. It was at this point that the GP thought there was a ‘problem’ I shouldn’t have to take my partner in, the doctor should have listened to me directly.’ P5

GP2: This makes me think differently! It definitely makes you think differently if there is someone else in the room backing the patient up. Possibly you listen more. This could be anyone else in the room.

Interviewer: Why might this be the case?

GP5: If you were the patient, it would be hard to remember everything you want to get across. Therefore, the person you are with in the room, they are often detached and so they can get across points maybe you might forget as the patient. It alters the dynamic and it does it in an effective way. It allows you to get the history in a different and dynamic way.

GP1: It adds weight and gravity to the psychosocial impact of the condition. If a patient is telling you this, but their partner is also saying this, then it makes you think again. It might be that the partner is telling you that they are not having sex anymore and it certainly adds more weight to the psychosocial aspect.

GP3: The partner might say ‘she’s a tough cookie and this wouldn’t normally affect her’ makes you think!

GP2: Naturally if you have two people in the room, then it does get you thinking

GP5: It can go the other way around though. If you explain to both the patient and whoever else is with them about what is happening, then that can help with consultation too. It doesn’t necessarily mean a referral will occur, but it can make the whole consultation be taken more seriously.

GP3: It can be interesting in a paediatric consultation where the mother brings in the child and then when both parents come in together, it shifts the emphasis. You think ‘this might be a referral to the paediatrician!” ***everyone laughs***

Notes

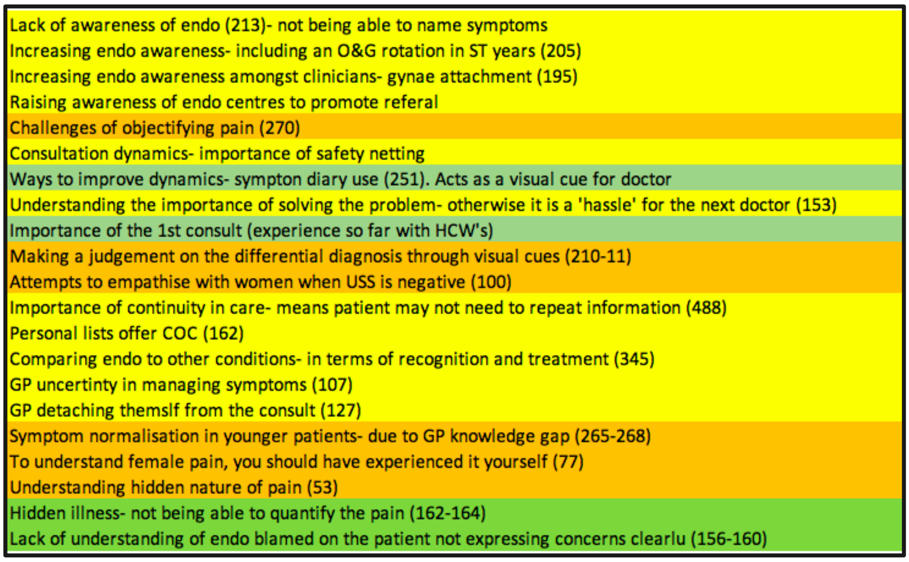
I wonder if bringing someone else into the consultation impacts on the power dynamics between a patient and clinician?

Double-edged sword as to why patients bring someone else into the consultation with them and how doctors perceive this

Does ‘another’ impact referral decision?

Figure 13. An example of the initial clusters of codes generated from the focus groups. A different colour post-it note was used for each group of healthcare professionals.

Figure 14. A small extract of the initial clusters of codes from Figure 13 is shown here for clarity. The numbers in brackets represent the line in the transcript.



Lack of awareness of endo (213)- not being able to name symptoms
Increasing endo awareness- including an O&G rotation in ST years (205)
Increasing endo awareness amongst clinicians- gynae attachment (195)
Raising awareness of endo centres to promote referal
Challenges of objectifying pain (270)
Consultation dynamics- importance of safety netting
Ways to improve dynamics- sympton diary use (251). Acts as a visual cue for doctor
Understanding the importance of solving the problem- otherwise it is a 'hassle' for the next doctor (153)
Importance of the 1st consult (experience so far with HCW's)
Making a judgement on the differential diagnosis through visual cues (210-11)
Attempts to empathise with women when USS is negative (100)
Importance of continuity in care- means patient may not need to repeat information (488)
Personal lists offer COC (162)
Comparing endo to other conditions- in terms of recognition and treatment (345)
GP uncertinty in managing symptoms (107)
GP detaching themslf from the consult (127)
Symptom normalisation in younger patients- due to GP knowledge gap (265-268)
To understand female pain, you should have experienced it yourself (77)
Understanding hidden nature of pain (53)
Hidden illness- not being able to quantify the pain (162-164)
Lack of understanding of endo blamed on the patient not expressing concerns clearlu (156-160)

5.14.3 Searching for themes

At this point, I had all of the initial codes generated from each of the three focus group transcripts. This phase focussed on exploring these codes and developing them further to search for patterns within them (Braun and Clarke, 2006 and Braun and Clarke, 2016). As Braun and Clarke (2006) explain, this stage focuses on generating broader themes based on these codes. Code names were written on post-it notes and arranged on a blank wall then, using a process of trial-and-error, initial themes were sought. An illustration of this is provided in Figure 13, whereby the initial themes are shown on pink post-it notes and the respective codes are arranged below them. The use of post-it notes enabled me to move back and forth between the data when developing wider themes. There were some codes that did not appear to fit within any particular theme so, as suggested by Braun and Clarke (2006), a 'miscellaneous' theme was also created. This process was a particularly interactive and enjoyable period of data analysis between me and the data as it enabled explorative thinking about the themes. This process also enabled me to be mindful of the central phenomenon within the data and how this is connected by the initially identified themes.

Table 4 shows an example of the initial themes.

Table 4. The initial themes.

Theme
• Lack of awareness of endometriosis; ‘the obvious is not so obvious’
• The consultation; a playground for all
• A desperate attempt to convince the doctor
• Facilitating a diagnosis
• An attempt to shut down the patient; normalisation as a form of HCPs coping
• The diagnosis
• The importance of a diagnosis- for patients and HCPs (‘because it comes back to you’)
• The challenges of diagnosing
• The influence of the ‘other’; a double-edged sword
• The moment of realisation; the bigger picture
• The threshold for referral to secondary care; an invisible line
• The endo patient; the unsaid
• We are all one, but are we?
• Improving diagnosis suggestions by HCPs
• Miscellaneous

5.14.4 Reviewing and refining the themes

This phase involves refining the themes and ensuring there is clarity and distinction between them (Braun and Clarke, 2006). Upon close examination and scrutiny, it may appear that some of the initial themes generated may be now combined or dismissed completely. As described by Braun and Clarke (2006), the themes were reviewed and refined at ‘two levels’: (1) reviewing the transcript extracts under each code and ensuring they fit within the particular theme and (2) the themes were explored within the wider dataset to ensure they were connected. Braun and Clarke (2006) suggest creating a map of the themes. It was through this mapping process that some of the initial codes were moved to a different theme, or an entirely new theme was generated. Some of the questions I asked myself during this phase involved whether the theme generated was an actual theme, whether the codes represented the actual theme and whether the themes were connected by a central idea (Braun and Clarke, 2006). Once again, the key to success in this phase was for me to remain modest and open to changing the themes or re-arranging the codes; without this insight, I would not have 'done the data justice'. This process took many hours of 'sitting in front of the wall' and thinking about how the different themes and respective codes were connected.

One aspect that I had not considered until this point was *when* to stop reviewing the themes. It became apparent that it was an intuitive and personal decision as to what was considered to be the 'end' of phase four. Table 5 shows further refinement of the themes.

Table 5. An example of further refinement of themes for phase 2 of the study.

Theme
1. Lack of awareness of endometriosis; 'the obvious is not so obvious'
2. The consultation; a playground for all • Facilitating a diagnosis • A desperate attempt to convince the doctor • An attempt to shut down the patient; normalisation as a form of HCP coping
3. The diagnosis • The importance of a diagnosis - for patients and HCPs ('because it comes back to you') • The challenges of diagnosing • The influence of the 'other'; a double-edged sword • The threshold for referral to secondary care; an invisible line
4. Judgement time • We are all one, but are we? • The endo patient; the unsaid • The moment of realisation; the bigger picture
5. Improving diagnosis suggestions by HCPs
6. Miscellaneous

5.14.5 Defining and naming the themes

The aim of this phase is to further shape the themes by defining and refining them (Braun and Clarke, 2006). Through this process, I explored the deeper meaning of each theme by reviewing the transcript data attached to each code under each theme (Braun and Clarke, 2006). I applied the themes to the context of the original research question and was able to explore the 'golden thread' that was positioned among the themes. Braun and Clarke (2006) explain that a 'story' should emerge for each theme, and this story should make a connection between each theme and with the overall phenomenon of interest. Each theme was given a description of what it essentially captured, and this was also reflected in the name of the theme (Braun and Clarke, 2006). Figure 15 shows an example of how the themes were further defined and refined, and Table 6 shows the final themes.

The initial theme of 'improving diagnosis; suggestions by healthcare professionals' was removed as a theme in itself, and its respective codes were combined with other themes. In addition, the theme, 'lack of awareness of endometriosis; the obvious is not so obvious' was added to 'the consultation; a playground for all' theme.

Figure 15. Further refinement of themes.

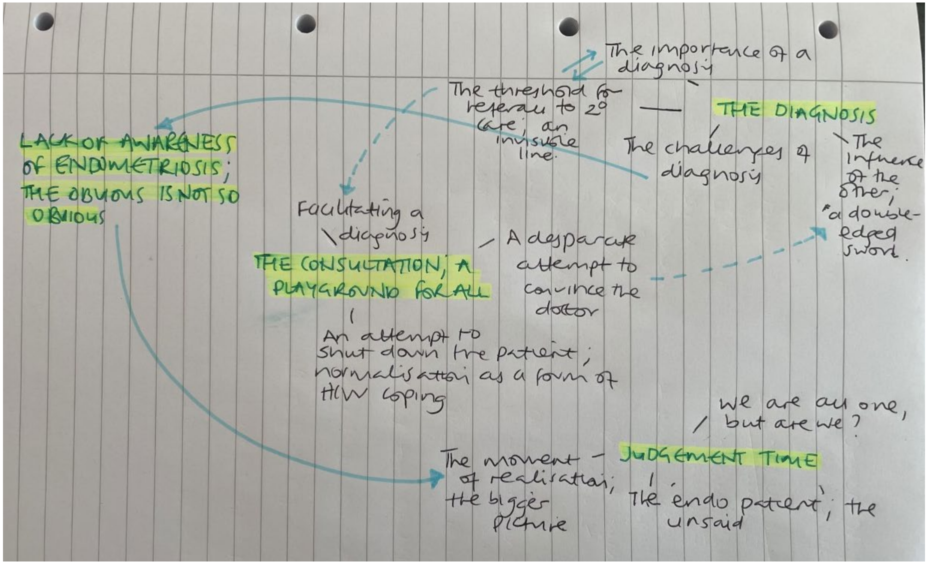


Table 6. The final themes

Theme
1. **Endometriosis is peppered with discrimination** • 'It's not me, it's other people': healthcare professionals' preconceived judgements of each other • The endo patient: the unsaid
2. **Invisible women and the invisible line for referral** • Invisible women and the significance of the other • The threshold for referral to secondary care; an invisible line • Attempting to push the women over the invisible line: facilitating diagnosis • Crossing the invisible line can be problematic: the challenges of diagnosing
3. **Visibility in a context of belief: rendering the woman visible** • The importance of a diagnosis: rendering visible and making sense • Rendering visible: realising the impact of disbelief

5.14.6 Creating the report

This final phase involves creating a report of the RTA and presenting this in a clear and coherent way (Braun and Clarke, 2006). This phase offers the opportunity to ensure that all the themes are connected and evidenced with the appropriate data from the focus group interviews (Braun and Clarke, 2006). The report should contain a rich analysis of the data and demonstrate a 'compelling' argument that clearly relates to the aim and objectives of the research question (Braun and Clarke, 2006). To gain a more detailed understanding of interpretative analysis, I read examples of published thematic analyses. The RTA, represented by three main themes, is presented in chapter 8.

The following chapter will present the findings from the interviews with participants with endometriosis.

PART 3 – PHASE 1 AND PHASE 2 FINDINGS

Chapter 6 – Conceptual findings from phase 1

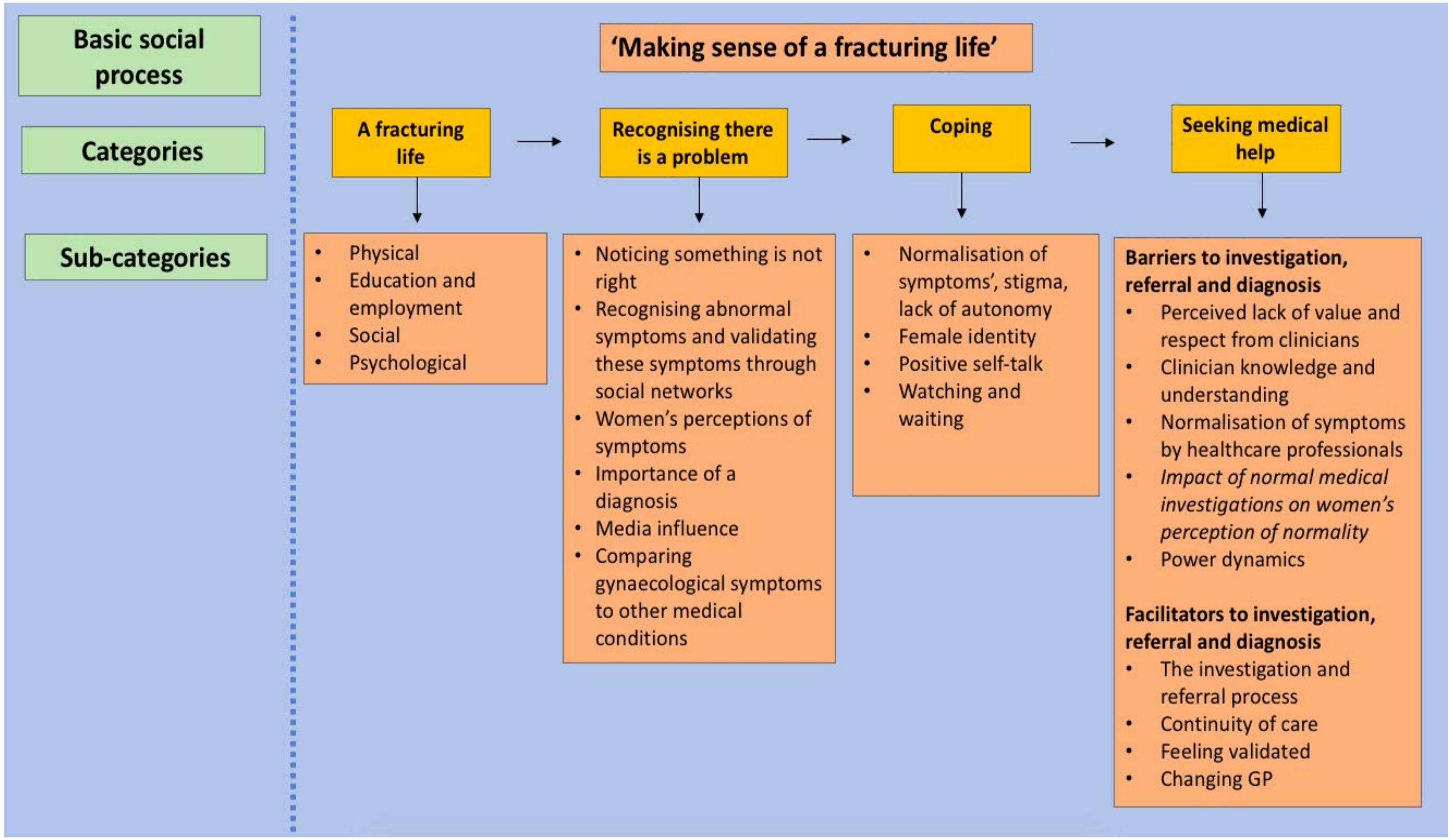
6.1 Introduction

The previous chapter detailed the method and process of data analysis I used, guided by constructivist grounded theory (Charmaz, 2006). This chapter provides a comprehensive, conceptual description of the findings from participants diagnosed with endometriosis and explores the four emergent categories that encompass the social process of ‘making sense of a fracturing life’. The four categories that underpin this social process include ‘a fracturing life’, ‘recognising there is a problem’, ‘coping with symptoms’ and ‘seeking medical help’. This is summarised in Figure 16.

A fracturing life relates to the way in which the symptoms of endometriosis severely and negatively impacted on the physical, psychological and social dimensions of the lives of women with undiagnosed endometriosis, disrupting their experiences of work and education and especially impacting on their close relationships with family and friends. It is important to understand how the way in which these women perceived their symptoms and how their symptoms impacted their daily lives in turn influenced when the women recognised their symptoms as abnormal, how they coped with the symptoms and when they sought help. Critically, their experiences of the illness itself and their attempts to understand their symptom(s) had a profound and negative psychological impact, especially with regards to their own female identity.

This chapter will begin by discussing the first of four categories, ‘a fracturing life’. I will use illustrations to demonstrate the sub-categories that contribute to each of the four categories.

Figure 16. A conceptual and descriptive summary of how women made sense of a fracturing life.



Basic social process

‘Making sense of a fracturing life’

Categories

A fracturing life → **Recognising there is a problem** → **Coping** → **Seeking medical help**

Sub-categories

A fracturing life

- Physical
- Education and employment
- Social
- Psychological

Recognising there is a problem

- Noticing something is not right
- Recognising abnormal symptoms and validating these symptoms through social networks
- Women’s perceptions of symptoms
- Importance of a diagnosis
- Media influence
- Comparing gynaecological symptoms to other medical conditions

Coping

- Normalisation of symptoms’, stigma, lack of autonomy
- Female identity
- Positive self-talk
- Watching and waiting

Seeking medical help

Barriers to investigation, referral and diagnosis

- Perceived lack of value and respect from clinicians
- Clinician knowledge and understanding
- Normalisation of symptoms by healthcare professionals
- *Impact of normal medical investigations on women’s perception of normality*
- Power dynamics

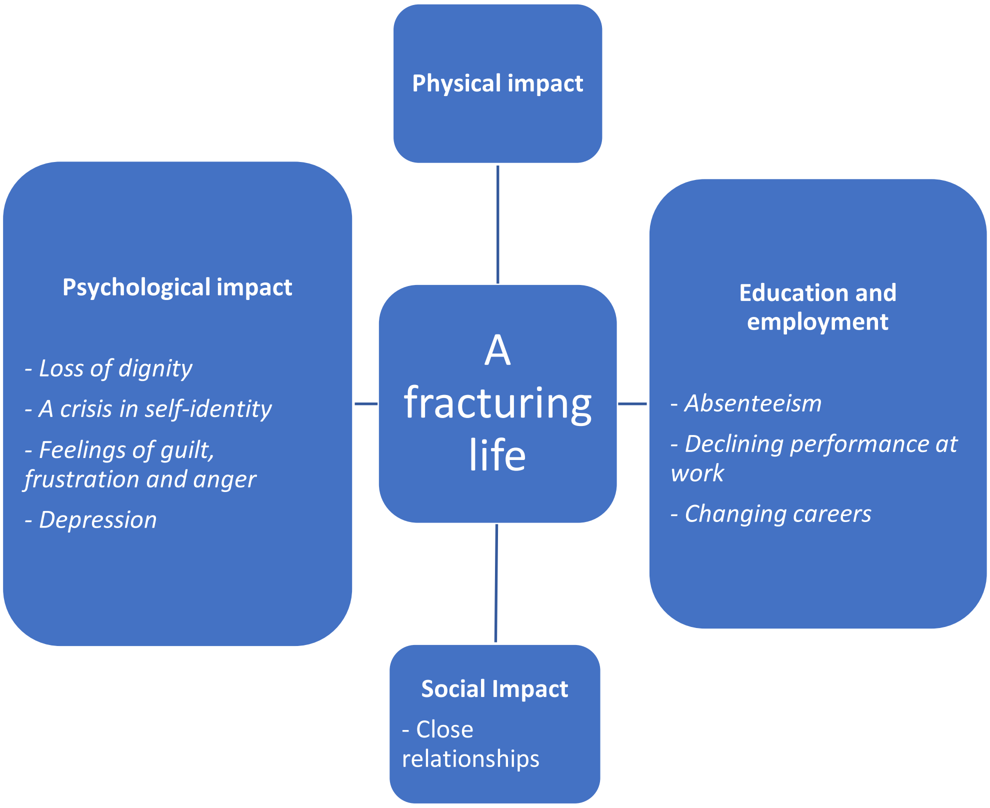
Facilitators to investigation, referral and diagnosis

- The investigation and referral process
- Continuity of care
- Feeling validated
- Changing GP

6.2 Category 1: A fracturing life

This section explores the four dimensions in which the women's lives fracture as a result of undiagnosed endometriosis, as illustrated in Figure 17. The dimensions include the physical impact, education and employment impact, social impact and psychological impact.

Figure 17. Category 1: a fracturing life.



6.2.1 Physical impact

The physical symptoms that women with undiagnosed endometriosis experienced included pain (abdominal, pelvic, back), vaginal bleeding, fatigue and nausea. The women experienced physical pain in different ways. Some experienced excruciating pain during their menstrual cycle, while others experienced pelvic pain at any time. Those women whose endometriosis affected their bowels complained of pelvic pain during defaecation or blood in the stool.

> *'I just knew there was something wrong with my bowels. I mean, I did have pain during my periods, but every time I emptied my bowels, without fail, the pain would be so bad and sometimes bleeding from the back passage. Like, so bad. It felt kinda stretchy pain. I even took laxatives, but that didn't help' (Neha).*

A number of women noted lower pelvic pain as the most common symptom, but some also discussed the debilitating back pain they experienced. The intensity and duration of pain varied, with some describing the pain as 'sharp' and 'crippling', while others experienced a 'dull ache'. Nearly all women experienced pain during sexual intercourse.

> *'My partner knew when sex was going to be difficult. I used to struggle so much during sex and knowing that this affected him, it hurt me emotionally too' (Diana).*

For some women, the timing of the pain was predictable and caused by an activity, e.g. defaecating or having sex.

> *'I remember, each time my husband tried to have sex with me, I just couldn't bear it. That burning horrible pain inside my tummy was just awful. I tried to let him in, but after a few minutes, I would usually have to stop because of the pain' (Millie).*

A predominant theme appeared to be the unpredictable nature of the pain and how this impacted across women's lives: for some, pain (especially back pain) appeared without warning, which the women found difficult to cope with.

> *'I could cope with the back pain. But what I struggled to cope with, was how the pain in my pelvis would just randomly appear with the back pain. I mean, I could be at work, in the bath, or on any holiday. It's just so shit' (Alma).*

For some, vaginal bleeding was the predominant symptom and it occurred either during their menstrual cycle or at random and apparently unrelated times.

> *'I just thought I was on my period all the time. It just didn't make sense. I just had to carry pads around all the time! It just gets so tiring and frustrating' (Alma).*

All participants discussed the non-specific symptoms associated with pain; fatigue, tiredness and nausea, which were experienced either intermittently or over weeks to years. The women explained that these symptoms impacted on their ability to physically participate in the activities of living, whether this be reduced tolerance for exercise or for physical work. Experiencing symptoms that appeared to be 'random' and seemingly unrelated to the gynaecological system led to some women feeling frustrated and confused.

> *'Nausea was one of the worst symptoms. I couldn't understand why I had it and so how am I supposed to explain that to the doctor? I just felt frustrated that I had lots of random symptoms' (Umbola).*

6.2.2 Education and employment

Women discussed the impact of their symptoms on education and employment, especially in relation to absenteeism, declining performance and changing careers.

Absenteeism

The women's physical symptoms led to them missing activities and taking protracted time off school or work due to pain and fatigue. Where symptoms of tiredness and pelvic pain related to a woman's menstrual cycle, taking time off became a pattern. Absenteeism was reflected in poorer grades and reports and in compromised social relationships with peers and colleagues.

> *'My grades really dropped in my mock GCSE exams. I just didn't know what was happening at school as I missed so much. It wasn't my fault, with the period pain, I just couldn't face it' (Neha).*

Declining performance at work

Several women stated that their employer had commented on their declining performance at work, either as a result of taking time off work due to sickness or because of taking frequent breaks at work due to the unpredictable onset and persistence of pain. These women described how, as a result of these comments from their employer, they felt under pressure to disclose and discuss intimate symptoms related to endometriosis with their employer.

> *'When I had to take lots of breaks at work, my boss eventually pulled me to a side and said I wasn't working hard like the others. He said that I couldn't keep taking random breaks at work. I just felt so terrible and felt under so much pressure to just tell him all the things I was going through. I didn't even know why I was having terrible pain like that. If I had a diagnosis, it would have made it easier to speak to him' (Millie).*

Changing careers

For some women, the unpredictability of their symptoms and an inability to manage them resulted in them being forced to change careers. For those regularly using analgesia to manage their pain, their cognitive and physical performance declined over time and in some cases led to them losing their job. There is a clear sense that having to leave work or change careers is out of these women's control.

> *'I just couldn't sit at the desk all day. I really enjoyed my part-time job, but, as time went on, the pain in my back and tummy just got worse. I was on so many regular painkillers that I felt really sleepy and low. I just didn't want to be there either. My boss said, "this can't carry on"'(Alma).*

6.2.3 Social impact

For many women, their physical ability to participate socially was compromised, and their social lives were disrupted to the point where they were no longer able to participate in social events with friends or family. The women realised that their wider social networks were fracturing around them, noticing changes in their relationships with friends, such as not being included in “texts” and not being invited to events. As Alma explains:

> *‘Sometimes, the pain was so bad that all I wanted to do was lie in bed with a hot water bottle. It just happened so many times and often when least expected. It would be sod’s law that I would have planned dinner with friends or a social with the girls. I just had to cancel so many times. Eventually, I think they gave up and would hardly invite me to things as they felt bad. If I knew what was causing everything, I would have told them, and I wouldn’t have been blocked out like this by them’ (Alma).*

Physical social activities were actively avoided because of worries about heavy menstrual bleeding showing and spoiling clothes. Some women stopped taking part in physical sports entirely, while others who felt under pressure to continue participated in their hobbies but would make an ‘excuse’ to leave early.

> *‘‘I love volleyball, but the bleeding just got to the point where I had to make an excuse to not go anymore. I used to dread it each time as I felt under pressure to think of a different excuse to leave early. Eventually, I just stopped going’ (Diana).*

Close relationships

The impact of the women’s physical symptoms on close personal relationships with partners, children and parents was discussed in detail. For many women, their symptoms impacted on their desire to be intimate and their ability to have penetrative sexual intercourse due to pain. Physical tiredness and anticipation of pain led to reduced libido. When couples thought about these challenges separately or together prior to having sex, it led to their relationship becoming more distant. For some, the sexual element of their relationship disappeared.

> *‘The physical side of my relationship has been non-existent for years. He’s scared of hurting me and I’m scared of it hurting. We eventually just stopped having sex. The worst part was both of us anticipating it would hurt’ (Bonnie).*

Over time, the tension caused by severe and unexplained symptoms resulted in separation and divorce for some women. In turn, this led to financial difficulties for some.

> *'He just couldn't take it anymore. My whole personality changed due to ongoing pain. I wasn't myself anymore. He eventually broke up with me and I was left with nothing' (Umbola).*

Some women removed themselves from their children so that they did not witness their mother's suffering. When a mother failed to engage with her child about her illness, this was seen to disrupt and damage the parent–child relationship. Similarly, physical symptoms forced some women to withdraw from other close relationships.

> *'I knew it was damaging for my son to see me in bed all the time. I got paranoid that he must think this is normal for a mum to be like this' (Umbola).*

6.2.4 Psychological impact

The physical symptoms, together with the impact of the women's experiences of their lives fracturing around them, had a detrimental impact on the women's mental wellbeing relating to loss of self-esteem, a crisis in self-identity and feelings of frustration, anger, guilt and depression.

These feelings had a cyclical and negative impact on all strands of the women's lives and especially on personal relationships with partners and family members.

> *'…my boyfriend would try and comfort me. The more he tried to comfort me and help me, the more worthless I felt. I know he was trying, but my pain was so bad that no one could do anything about it. I just felt like I lost every shred of dignity with him.' (Anna).*

Loss of dignity

Some women felt worthless and experienced a 'loss of dignity' due to what they considered to be embarrassing symptoms. Diana described the loss of dignity she experienced when her partner noticed blood-stained clothes in the washing basket.

It was this sense of loss of dignity that negatively affected these women's self-worth and had a profound effect on their autonomy.

> *'I just couldn't believe it. He commented on how much blood there was on my clothes in the washing basket. He didn't mean anything by it, but I felt all my dignity had collapsed in a heap. I just felt like shit. It just took away all control I had over my body' (Diana).*

A crisis in self-identity

Many women discussed the internal conflict they perceived within themselves due to the persistence of often confusing and unpredictable symptoms. When women did not understand their bodies, some perceived a dissociation between their mind and their body, which often led to confusion about what their symptoms meant and whether they were abnormal.

> *'I genuinely was confused with my body! The pain was just so unpredictable and bad. My mind was telling me that this will get better, but my physical body was telling me another. I hated that feeling. It was just so awful and disturbing' (Alma).*

Some women spoke of the fear of being a woman and requiring 'time off work for heavy bleeding and surgery' (Neha). Loss of career and under-performance at work also challenged a woman's identity and fundamentally undermined who she believed herself to be.

> *'My job is everything to me. It's bad to say, but it defines me, you know. Taking all that time off work for symptoms really made me question what my purpose in life was' (Neha).*

Umbola explained how she questioned her role as a mother when trying to cope with her symptoms.

> *'During a flare up, I would rest in bed and my son would see me. He always knew I wasn't feeling great and would ask me if I wanted any food or drink. It*

> *made me sad when he asked why I was always in bed. Is this what a mother is supposed to be like?' (Umbola).*

Feelings of guilt, frustration and anger

Guilt was commonly experienced by women who felt that they were failing those with whom they had a close relationship, while frustration and anger were commonly experienced emotions arising from ongoing unexplained symptoms. Frustration was born of not being able to understand why they have abnormal symptoms, whereas over time, some women experienced anger towards the ongoing nature of their pain. In turn, frustration and anger led to feelings of depression and low mood which subsequently impacted on the way women interacted socially.

> *'I just felt pure frustration that no one really got it. I would try and explain it, but as people can't see pain with their eyes, they just don't understand. The more I had to explain myself to people, especially at work, the angrier I got! At the same time, I would start crying as I just felt so depressed that no one understood what I was going through. When I felt at my lowest, I just didn't want to see anyone or do anything' (Anna).*

Depression

Depression and low mood arose from having unexplained and ongoing symptoms as well as feeling isolated from friends and family. Some women experienced depression as affecting their sleeping and eating patterns.

> *'The pain got me down so much that I just resigned myself to staying at home. What's the point in seeing all my other friends who are in happy relationships and don't have chronic pain like me. I didn't want to see others happy; I know that sounds bad. I felt so depressed that no one wanted to help me' (Vivienne).*

The lives of these women slowly fractured over time. Recognising this fracturing to be a problem also took time.

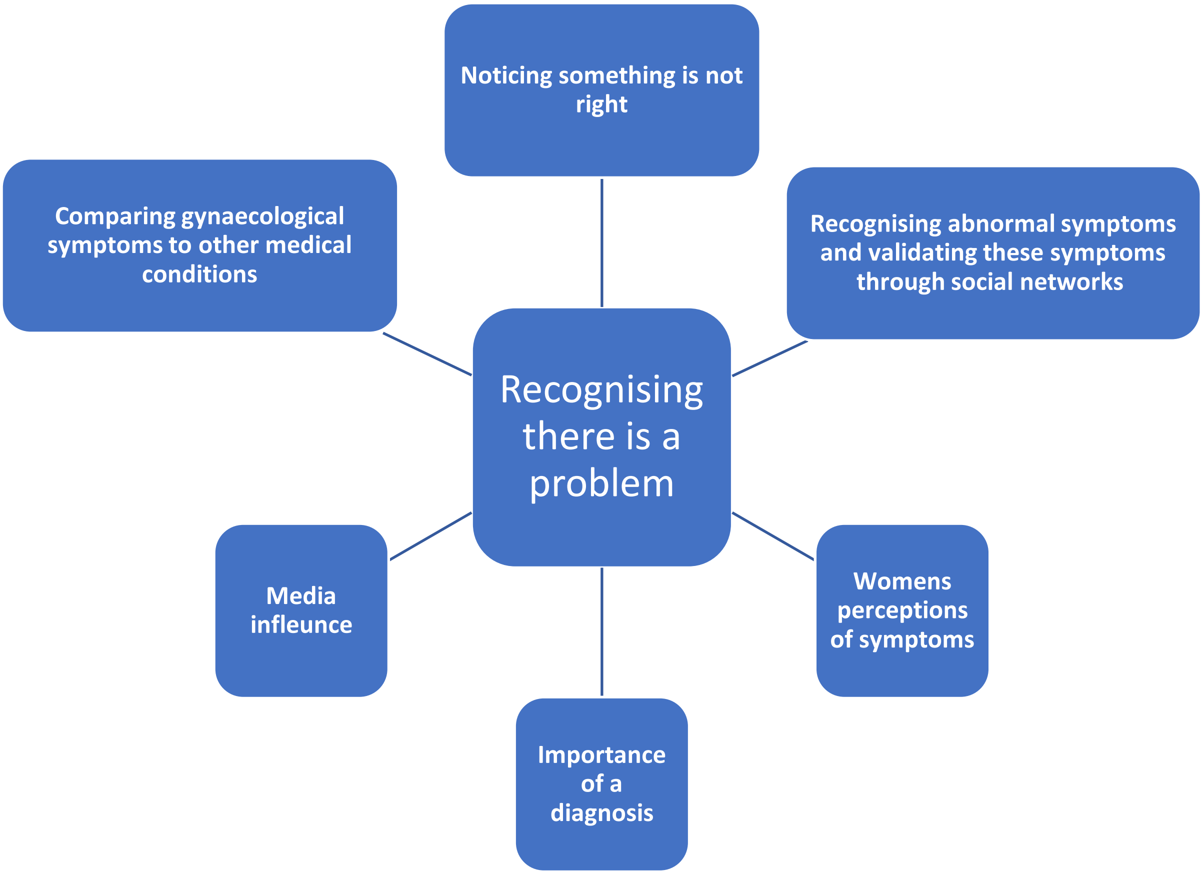
6.3 Category 2: Recognising there is a problem

As women's lives altered around and within them, they sought to make sense of what was going on, and all participants described in detail how and when they realised there was a 'problem'. Participants provided insights into the window between initially recognising the presence of symptoms, recognising them to be abnormal and then seeking help (medical or non-medical).

Subcategories underlying the 'recognising there is a problem' category are illustrated in Figure 18; these include:

1. **Noticing something is not right**
2. **Recognising abnormal symptoms and validating these symptoms through social networks**
3. **Women's perceptions of symptoms**
4. **Importance of a diagnosis**
5. **Media influence**
6. **Comparing gynaecological symptoms to other medical conditions**

Figure 18. Category 2: ‘recognising there is a problem’.



6.3.1 Noticing something is not right

Most participants realised that 'something was not right' with regards to their symptoms when they began to impact on their daily life. The three main ways in which women noticed this was through (1) self-recognition, (2) recognition by others, and (3) recognition as a result of a medical intervention. Awareness of symptoms did not necessarily lead to women seeking medical help.

Self-recognition

All women stated that it was the *persistence* of symptoms that triggered the recognition that their symptoms were abnormal. The symptoms most commonly reported by participants as being 'abnormal' included 'pelvic pain', 'disturbance in menstrual cycle', 'nausea', 'vaginal bleeding' and 'back pain'. Noticing that these symptoms also impacted negatively on their activities of daily living created a trigger moment. For some women, the trigger moment often involved the noticing of a 'layering' of symptoms. For example, Faye explained that she:

> *'… didn't realise the pain was abnormal until the bleeding started' (Faye).*

Some women compared their symptoms with those of other people around them and reflected on what would be considered normal or abnormal for women of their age. It also appears that the onset of symptoms at a younger age is an influencing factor for perceiving symptoms to be normal.

> *'My mum is obviously older than me, but she has so much energy! My lethargy and general tiredness made me realise that when I compared myself to mum, my symptoms were just not normal for my age. It's only when I really stared to think about it, that it dawned on me' (Elisha).*

Women appeared to recognise abnormality retrospectively rather than at the time, and all participants provided important insights into the moment they realised 'normal' was 'abnormal'.

> *'When the penny dropped, it was a weird feeling. I collapsed on my sofa and cried. Finally, I realised all this pain was just not normal. But it took me some time to understand this. Just knowing it wasn't normal made me feel better' (Barbara).*

Recognition through others

Some participants made sense of their symptoms and recognised them as abnormal when others drew attention to and commented on them.

> *'I just knew that the pain in my pelvis was not right. For me, it was when things started to go wrong at work and my employer commenting on how I was missing things. It made me realise that my lack of sleep and tiredness was affecting work. I just knew I had to get help' (Diana).*

Some participants explained how discussing their symptoms with other people made them realise there was a problem. Talking to female colleagues or friends and comparing experiences of menstruation was powerful and often acted as a trigger point for recognising symptoms to be abnormal.

> *'I spoke to my friend at work, and she was just so shocked at what I was going through. She was teary and couldn't understand why I put up with the symptoms. It was after this that I realised this was just wrong' (Bonnie).*

Diana knew from a young age that her symptoms were 'not right' after she spoke to other people about her periods and when she was unable to play hockey. The fact that she could not play hockey without pain was the trigger for her to see her GP.

> *'When I spoke to my friends, it made me realise their periods were so different from mine and that mine were abnormal. This is when I realised things were not right' (Diana).*

Recognising abnormal symptoms and validation through social networks

Some women drew attention to the importance for them of finding information about their symptoms on the internet. The women compared their symptoms with the information they found and also compared their symptoms with those reported by other women in online forums. The comparisons provided validation of their symptoms. The women also compared their negative experiences of the healthcare system. As Neha explains:

> *'Reading about other women's stories online made me feel brave and strong enough to fight my doctor for my problems. Lo and behold, I did have problems and started writing my own blog online about my journey' (Neha).*

Recognition through medical intervention

While the majority of participants realised there was a problem by the time they sought medical attention, some did not realise they had endometriosis until they received medical help for unrelated conditions.

> *'I had keyhole surgery for my appendix and the endometriosis was found through this operation. I had symptoms all along but because I was told by people that the pain was normal, I didn't think much of it. Only after my keyhole operation, I realised my symptoms were not normal' (Janet).*

6.3.2 Women's perceptions of their symptoms

The way in which women perceived and interpreted their symptoms pre-diagnosis had an influence on health-seeking behaviour. Participants explained that the perception of their symptoms changed over time as these symptoms began to impact on different aspects of their life.

Oscillating between 'normal' and abnormal'

Participants described feeling conflicted as they experienced phases of questioning the meaning of their symptoms, and women oscillated between believing and not believing their symptoms to be normal. Factors that appeared to influence this process of oscillation were if other people believed their symptoms, if they had a positive experience with their clinician, their level of education about menstrual wellbeing and their understanding of menstrual health. Experiencing a negative consultation with a clinician, whereby they were not listened to or believed, led women to perceive their symptoms to be normal. Participants' understanding about menstrual health from what they had been taught at school or by family members impacted their perceptions of whether their symptoms were normal or abnormal. In particular, those women who had received little or no education at school in relation to menstruation were more likely to normalise their symptoms, particularly their experiences of heavy menstrual bleeding and dyspareunia.

> *'Your mind plays tricks. I just didn't know what to believe. Even in one day this feeling can go either way! You are desperate to get an answer, but then the doctor tells you nothing is wrong. This was hard to deal with. I can't quite explain it, but I went through silly cycles of thinking all this is normal and then not normal' (Alma).*

Perception of risk

Some of the women spoke about the moment they felt threatened or 'at risk' from their symptoms. They defined a symptom as 'risky' if they considered it to be serious enough to seek medical help and if it began to impact their quality of life. If they believed that the symptom should be considered normal for their age and sex, then they considered their symptoms 'not risky'. However, their perceptions of risk changed if information they found online or received from family or friends contradicted their perception.

> *'I was always taught that women's periods are meant to be bad, and it wasn't easy to be a woman. But you get on. When my friend spoke to me about her symptoms and she was diagnosed with a polyp, it made me realise that my symptoms were not normal. I didn't judge my symptoms to be risky or anything' (Faye).*

Importance of a diagnosis

Women's medical health-seeking behaviour was also influenced by their perception of how much importance they placed on finding a diagnosis for their symptoms. By the time these women decided to seek help, they had placed some emphasis on the importance of obtaining a diagnosis, whatever this may be. A number of the women discussed how having a diagnosis influenced the way they were perceived by other people and the manner in which they were viewed by healthcare professionals when seeking help for ongoing symptoms. As Faye explains:

> *'People take you more seriously, I guess. The A&E doctor changed her attitude as soon as she saw I was on the waiting list for suspected endo. So, if you want to see a consultant again, they will actually refer you' (Faye).*

Some women explained that even having a suspected diagnosis of endometriosis meant that they could legitimately seek medical help for worsening symptoms. Having a formal diagnosis, however, offered women a sense of validation that their symptoms were worthy of receiving medical attention. This in turn encouraged women to seek medical help as they needed it.

> *'I guess it's the thought that you are not making it up. You genuinely start to believe that it's a bad period. Even when they suspected endo, I felt believed and so I knew I could go back to the GP if things got worse' (Faye).*

Media influence

Women spoke about how the media has had an influence on their perception of menstrual wellbeing. The language used to describe menstruation and menstrual hygiene products by the media appears to shape women's perceptions of what should be 'normal' or 'abnormal' in terms of menstruation. It also appears that the use of 'coded' language surrounding menstruation is not helpful, and this perception does not encourage women to seek help if there is a concern.

> *'Even in the media, the language used like 'time of the month' is just not right. It doesn't encourage women to talk about periods, does it? Being a woman or*

> *in a female body can be seen as shameful. It's called 'time of the month' in coded, complex language' (Alma).*

Comparing gynaecological symptoms to other medical conditions

In an attempt to make sense of and explain how they felt about their symptoms, many women compared their experience of endometriosis-related symptoms to other medical conditions, including diabetes, human immunodeficiency virus (HIV) infection, cancer, fractured bones and mental illness such as depression. This appeared to be for a number of reasons, including to highlight that other conditions are more understandable to the general public, are more socially acceptable and are less embarrassing to talk about. In addition, they felt that these conditions generated a greater degree of empathy and understanding. When a comparison was made with 'fractured bones', for example, women spoke about how other people were able to understand the pain better and realise that there is an actual medical problem.

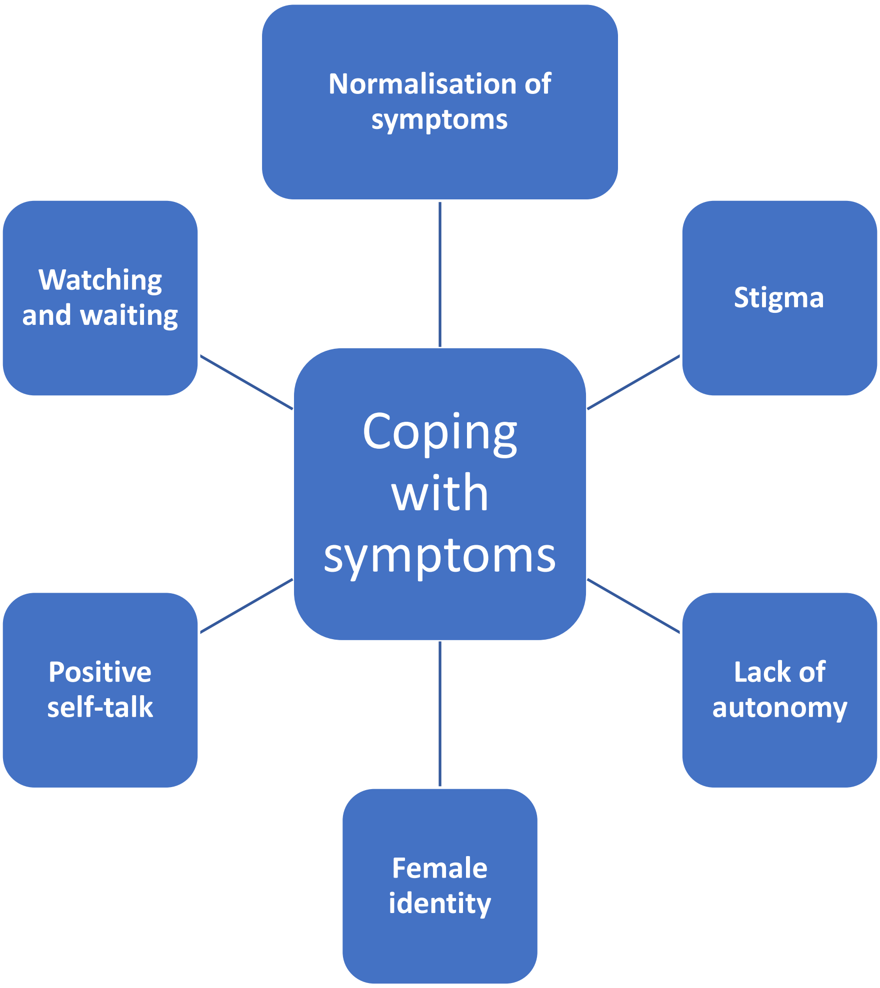
> *'If you have a broken leg, people can see your problem and tell you to have a day off. If you have a hidden illness like endometriosis, no one understands and think it's not a problem' (Umbola).*

While it is important to understand how women recognise they have a problem, this recognition does not always lead to seeking medical help. Instead, they cope with their symptoms in different ways.

6.4 Category 3: Coping with symptoms

Women oscillate between believing their symptoms as normal and abnormal. During this time, they cope. Figure 19 illustrates subcategories related to coping, including the 'normalisation of symptoms', stigma, lack of autonomy, female identity, 'positive self-talk', and 'watching and waiting'.

Figure 19. Category 3: 'coping with symptoms'.



6.4.1 Normalisation of symptoms

Every participant in the study discussed the 'normalisation' of their symptoms, either by themselves or others, during their diagnostic journey.

Self-normalisation

Participants diagnosed with endometriosis recognised how they had adjusted to their symptoms over time and how they had used self-normalisation as a coping strategy.

> *'After I got my diagnosis, I realised that all my symptoms were abnormal from the very beginning. I can't believe I had been kidding myself all along' (Faye).*

Self-normalising strategies therefore acted as a barrier to seeking medical attention, delaying the women's eventual diagnosis.

Some participants determined the difference between normality and abnormality by comparing their symptoms with their experience of their periods at a younger age, meaning that the comparator they used might already be abnormal. Vivienne stated that her first period was 'really heavy and painful' and so her definition of normality was based on this first experience. Vivienne suggests that when she was younger, she self-normalised her symptoms by attributing them to 'hormones' and did not suspect she might have a medical condition.

> *'It was my first period, and it was really heavy and painful. This is what normal was meant to be for me and so I just got on with it as best as I could. You don't think much of it I guess and put it down to hormones' (Vivienne).*

Anna, who had a protracted journey to diagnosis, questioned the definition of normality. She self-normalised her symptoms until they 'got persistent.' This raises the question, at what point does the patient's perception of normal become abnormal? Anna uses age as a marker of whether she should know what is normal or abnormal:

> *‘When you are young, you just don’t know what’s normal for your symptoms. When you are older, you listen to the news more, you are wiser, you speak up more. For me, abnormal was so much clearer the older I got’ (Anna).*

Normalisation by others

Women spoke about their symptoms being interpreted and normalised by others, especially by their mothers and school nurses. Some of the women explained that there is an expectation that pain during the menarche is normal and that the school nurse reinforced this point. Women appeared to place a lot of trust and importance in the school nurse, and therefore, if she said the symptoms were normal, then they assumed that this must be true

> *‘I felt everything was normal because no one said otherwise. When I spoke to the school nurse about it, she said it was normal for girls to get period pains. She sees this all the time with other girls, and I trusted her’ (Diana).*

Neha mentions that her perception of a normal period was that it is ‘supposed to be painful’, which was supported by what she had been taught at school. This suggests that education is an important factor in women’s normalisation of their own experiences. Umbola supports Neha’s point about menstruation education influencing her expectations of what was normal:

> *‘We only had brief teaching about women’s health in schools. Back then, it wasn’t really spoken about, but what I did know, I thought it was normal. Even my aunt mentioned that getting heavy periods was just a normal part of being a woman’ (Umbola).*

Mothers acted as a sounding board to discuss intimate and embarrassing symptoms at a young age. The role of the mother and her own experience of menstruation often impacts the daughter, with mothers normalising their daughters’ abnormal symptoms by claiming a ‘family history’ of gynaecological problems.

> *‘My mum always told me her periods were always painful. She said my period*

> *pain was normal and that all girls will go through heavy periods. She mentioned we always had bad periods in the family. Why would I question her, I trusted her' (Vivienne).*

The women accepted the normalisation of their symptoms by others until they were triggered to view their symptoms as abnormal and seek medical attention.

6.4.2 Stigma

Stigma was experienced by the women with undiagnosed endometriosis as 'feeling judged' and being 'made to feel abnormal' when discussing their symptoms with friends and family or with healthcare professionals. Stigma was discussed by participants in two contexts: (i) where perceived stigma stopped women from sharing their experiences with friends and family and led them to use a coping strategy to hide their experiences and (ii) where perceived stigma from medical professionals impacted on health-seeking behaviour. Stigmatised participants also discussed feeling depressed and having a low mood.

Stigma of discussing periods with others

A number of women described how they felt about talking about their menstrual cycle. Some women found it particularly difficult to talk to their partners about heavy periods, as they were worried about their partners' perceptions and whether discussing intimate details would affect their emotional or sexual relationship. As Bonnie and Elisha explain:

> *'I just couldn't believe it when my boyfriend asked me to stop talking about my period and said it was weird to talk about it. I told him as a woman I should be able to!' (Bonnie).*

> *'I remember telling my partner that my periods were getting so bad and heavy. He said that it's something I should talk to my female friends and that guys shouldn't be talking about it in detail as its embarrassing for him' (Elisha)*

Some women experienced stigma when discussing their menstrual cycle with their school nurse and described being made to feel ‘disgusting’ or ‘weird’. There also appeared to be shame and secrecy associated with the use of sanitary pads.

> *‘I learnt very quickly at age 11 that you can’t talk about periods. The school nurse tells you not to talk about them or doesn’t want to hear about it. The school nurse told me to keep sanitary pads in my bag but tells you not to tell anyone. She always changed the subject when I mentioned it. Girls didn’t even talk about periods at my school. When I learned about periods at school, I had already started mine’ (Alma).*

The hidden nature of managing menstrual symptoms is also discussed by Erika in terms of concealing tampons in the bathroom compared with how toilet rolls are stored. She discusses the ‘taboo’ associated with menstruation and how the world views menstruation as a topic. There appeared to be ‘body shaming’ among women if they discussed abnormal, menstrual-related symptoms with each other. This negative perception of menstruation causes embarrassment and may lead to either delayed health-seeking or withholding information during a medical consultation.

> *‘I feel it still is a taboo subject. I think women are so scared to open up because they are worried about criticism from other women. You know, we all body shame and compare each other’s bodies and live with our own. We don’t hide toilet rolls, but we hide our tampons in the bathroom, don’t we? It's because people get awkward, and this makes the woman embarrassed’ (Erika).*

6.4.3 Lack of autonomy during teenage years

Teenage women are less likely to have autonomy over the recognition and management of abnormal symptoms and are more likely to be controlled by their mother. Teenage women may therefore feel disempowered to take matters into their own hands. Many participants explained that, as they grew older, they developed more autonomy, gained a better understanding of menstrual wellbeing and questioned whether their symptoms were abnormal.

> *'I remember my mum putting me on the pill at 15 and telling me it will be okay. Only when I got older, I realised the pain just wasn't normal' (Millie).*

6.4.4 Female identity

Many women alluded to their role as females in society and what this meant for them with regards to seeking medical help. Some women explained that, as females, there is an expectation from society that they should cope with periods, and these women discussed how they complied with this expectation by coping and therefore not seeking help. As Faye explains:

> *'As a woman, I just got on with my life and didn't think much of my symptoms. I just thought it was a normal part of being a woman. Surely everyone has pain during periods and heavy periods' (Faye).*

This is important, as it suggests that Faye has associated her symptoms with being female and that social expectations of what it means to be female may be a factor used by participants to judge whether their symptoms will be perceived as a problem by others.

Women also described their perceptions of the gendered differences in the ways in which men and women are expected to seek help for medical concerns. Umbola explains:

> *'Women are always told to get on with things. I mean, periods are obviously normal. I think if men had weird symptoms, then maybe they would get help quicker than a woman. I really did just get on with life despite clearly having abnormal symptoms' (Umbola).*

One of the ways that women cope is by using positive self-talk.

6.4.5 Positive self-talk

Some participants self-talk to delude themselves that, while they may consider seeking medical help, 'everything will be okay'. Some women defined positive self-talk as replacing negative thoughts about their symptoms and focussing on other aspects of their health that are positive.

> *'The pain and nausea were there for so long. I just had to be positive and say to myself that everything will be ok' (Neha).*

For the time that positive self-talk outweighs the recognition of abnormal symptoms, this coping strategy delays diagnosis.

6.4.6 Watch and wait approach

Some participants discussed how, prior to seeking help, they used a 'watch and wait approach':

> *'But before I even went to see them [GP], I waited for so many months as I thought things would get better. I just thought it would go away' (Alma).*

Another participant, Anna, used this approach because she had encountered negative experiences with HCPs in the past, for other, unrelated concerns, which included not feeling listened to, being dismissed or not being taken seriously. She was concerned that this might happen again:

> *'When my skin problems were diagnosed, I had such an awful experience with the GP. I just thought my GP will be the same again and so I waited to see if the pain in my tummy would get better before seeing the GP' (Anna).*

Other coping strategies, used in tandem, were denial and avoidance, as participants watched and waited for symptom improvement.

> *'I knew there was something wrong. I kinda went into denial as I was so worried that it might be something sinister. Like cancer' (Janet).*

6.4.7 The 'mattress moment'

Women described how they doubted the validity of their symptoms, which were normalised both by themselves and by healthcare professionals. Gemma used coping strategies until the pivotal moment she realised that her symptoms were not normal. She described this as the *'mattress moment'*:

> *'We were about to carry it (a blood-soiled mattress) out of the house and my poor husband is so caring. We carried this mattress out of the house and the builders were there. The builders were our friends and I felt disgusted and embarrassed. I felt so disgusted. All this time I had doubted myself and the symptoms I was going through. It was only when I saw this mattress being carried out of the house that I realised how real my symptoms were as a woman. This is not a normal part of being a woman. This was my 'mattress moment'. I stopped going to the doctor for a while, but after this moment, I just had to go back.' (Gemma).*

As she discussed her thoughts, Gemma became teary as it brought back memories of this particular realisation. She explained how her initial experiences with her healthcare provider stopped her from seeking help after a few occasions. It was only after the 'mattress moment' that she re-initiated medical contact to seek a diagnosis.

Their equivalent of the powerful 'mattress moment' was also explored by other women, again inducing an emotional response. As Umbola and Alma explain:

> *'I just knew that when my son saw me in bed and asked why I was in bed all the time with pain, I knew it was time to get help' (Umbola).*
>
> *'My partner at the time just said to me that he understood our sex life will never get better. It made me realise that this was unfair on him. When he said that, it made me cry, but at least we spoke to each other that there was a problem here' (Alma).*

Women with undiagnosed endometriosis learn to cope with their symptoms prior to receiving medical help. They cope during the time of the delay resulting from their own self-normalising behaviour and the normalising behaviours of others. They endure while suffering the stigma created by the attitudes and behaviours of others. They fail to cope as their female identity is attacked and undermined. They are shocked by their equivalent of the mattress moment. They engage in positive self-talk as they watch and wait to see what happens. Once the women realised their symptoms were not normal, they began to question *why* their symptoms were occurring and persisting. The women began to reflect on their coping mechanisms and the advice that they may or may not have received from their HCP. They then seek medical help.

6.5 Category 4: Seeking medical help

The increasing disruption to the quality of the women's lives caused them to recognise that they needed to seek medical attention. However, the women's accounts of seeking medical help highlight that this was not a straightforward process (see Figure 20 and Figure 21) and that there were particular challenges with the initial clinical encounter that impacted on their experience of diagnosis. This category is subdivided into two: 1) barriers to investigation, referral and diagnosis and 2) facilitators to investigation, referral and diagnosis.

Figure 20. Category 4: seeking medical help (barriers to investigation, referral and diagnosis).

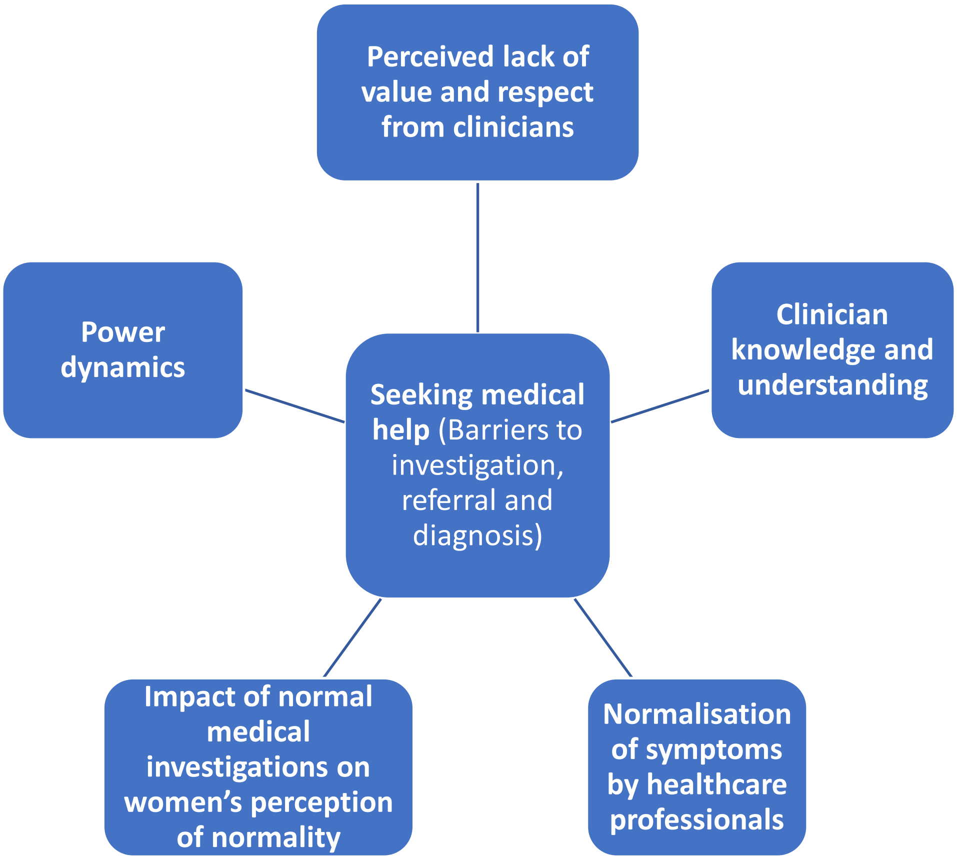


Figure 21. Category 4: seeking medical help (facilitators to investigation, referral and diagnosis).

6.5.1 Barriers to investigation, referral, and diagnosis

Perceived lack of value and respect from clinicians

The women's first ever consultation with an HCP appeared to be especially significant. Women who experienced a consultation with a clinician who lacked empathy, did not listen to or believe them, and who felt dismissed, were reluctant to seek help in the future. This inevitably caused a delay to diagnosis.

A lack of empathy was experienced by the women as their HCP not appreciating the severity of the impact of symptoms on their lives and in the failure of HCPs to display empathic non-verbal cues, such as maintaining eye contact and not interrupting them when they described their medical history.

> *'Each time I went to the GP, I just kinda felt fobbed off. They just didn't seem to care about me or my symptoms. I was telling him how awful I have been feeling and he didn't even look at me! It just puts you off going again I suppose' (Neha).*

All of the women who participated in this study perceived that they were not believed by their clinician at some stage of their diagnostic journey. This was most commonly seen in primary care, especially when the women first presented to an HCP. Some women described having to convince their GP that their symptoms were genuine, while others were explicitly told that their symptoms were related to other medical conditions, such as depression or anxiety, irritable bowel syndrome and urinary tract infection. As a result of not being believed, the women felt 'frustrated', which led to them feeling negative emotions towards their GP.

> *'I remember being seen as an emergency on the gynae ward and being told that I have a urine infection and that this is not an appropriate service. I'm sorry to get so emotional (starts crying). No one believes you and that's the most frustrating part. I just wanted validation of my symptoms that I wasn't going crazy. It just put me off going back to see anyone for such a long time for follow up' (Janet).*

The behaviour of HCPs during a consultation significantly impacted on the women's health-seeking behaviour, with HCPs not only suggesting that they did not believe the women but also making personal judgements about them.

> *'One day, I came to the hospital for an appointment, and I had so much bleeding all day and in pain. The doctor actually said to me 'you seem to be well composed! Are you faking the pain?' I then said to the doctor 'I cope with it quite well. Should I be crying instead? I just didn't feel believed. I actually walked out. Unsurprisingly, I didn't see him again obviously.' (Faye).*

It is clear that ‘not being listened to’ impacted on the way participants interacted with their HCP: for some, it influenced how much information was disclosed during a consultation; for others, it stopped them from going back to seek support; while some persevered until they felt listened to. The women also shed light on the unspoken thoughts participants experienced during their consultation. For example, none of the participants challenged their doctor about her or his body language, despite the significant impact this had on the way these women perceived their consultation.

A few women in the cohort thought they may have endometriosis prior to seeing their GP. If a woman mentioned endometriosis to her clinician, this was not always received positively. Some women explained how they perceived embarrassment from their GP if endometriosis was mentioned.

> *‘Yes, it’s that stigma around ‘women’s problems’. People say ‘its women’s problems’ and it’s all normalised. I feel that sometimes doctors don’t know what they are talking about. I told my GP I think I have endometriosis and he literally ignored it and said I had a urine infection. He kinda felt embarrassed that I even mentioned it’ (Harissa).*

Not acknowledging endometriosis as a potential differential diagnosis and not referring a patient to a gynaecology specialist is a source of frustration for those who consider a diagnosis important. This lack of acknowledgement by some HCPs may be a function of a lack of clinical knowledge.

Clinician knowledge and understanding

One of the diagnostic challenges arose when a GP did not include endometriosis as a differential diagnosis as part of their clinical work up. This was experienced by the women as ‘dismissal’, as ‘not (being) taken seriously’, ‘concerns about being undermined’ (Janet) and ‘being asked to get on with it’ (Alma). Dismissal by their GP led to feelings of anger towards their GP and, in some cases, to not returning to the GP for a further appointment despite persistent symptoms and no diagnosis.

Women often perceived that their clinician had his or her own agenda and that their concerns and expectations were not necessarily valued or sought.

> *‘My husband listened and knew I wasn’t very well. But, when I saw the locum GP, it was a case of “well, its women’s problems, everyone goes through it and you must be run down”. So, I thought it was the case for months on end’ (Harissa).*

Some of the women associated dismissal with GPs’ lack of awareness about both the symptoms of endometriosis and about specialist endometriosis centres and sought to inform their GPs about both. Barbara, for example, guided her GP through the entire referral process. In response to her dismissal, Elisha recorded her symptoms. She felt that her GP was distracted with their computer, and as such, was not processing verbal information very well.

> *‘I started writing down my symptoms and how I thought they linked to endometriosis. The GP then listened. If you physically show them a list of symptoms, then it gets taken a bit more seriously. Often the GP might be distracted by looking at the computer screen, but having a written list helps make it clear on what the problem is. Something objective’ (Elisha).*

The dismissive behaviour of GPs experienced by women not only caused women to stop seeking medical help for a time but on their return to the healthcare system it also impacted on their trust in HCPs in secondary care. As Alma explains:

> *‘Do I trust this guy to treat me? I was very apprehensive and so I had to vouch for myself and protect myself. It’s hard to trust another doctor when the others haven’t done much! But when he recognised how horrible these symptoms were, I kinda started to trust him’ (Alma).*

A number of women presented to the Accident and Emergency (A&E) department with unexplained symptoms prior to being diagnosed with endometriosis. All of the women who discussed their A&E experience described a negative experience, particularly in relation to a lack of awareness among A&E staff of endometriosis as a gynaecological condition. If there was any suggestion by the patient that the symptoms were related to endometriosis, A&E staff referred the patient back to their GP to investigate this, meaning that the opportunity for onward referral for a gynaecological opinion was lost.

> *'With all my pain attacks, I would ask them if endometriosis could be a cause. They just wouldn't listen and refer me back to my GP. One doctor even asked me what endometriosis was. I was shocked' (Diana).*

Normalisation of symptoms by healthcare professionals

All of the women discussed how HCPs in primary care normalised their symptoms from the very first consultation. The most common symptoms to be normalised included heavy menstrual bleeding, pelvic pain, frequent urination, nausea and back pain. Women responded to the process of normalisation by HCPs in one of three ways: (1) some questioned the legitimacy of their symptoms, (2) some normalised the symptoms themselves and (3) some started to withdraw from society. Ultimately, each of these responses led to a delay in women seeking medical attention

When their symptoms were normalised, some women questioned the legitimacy of their own symptoms. They ceased to believe in themselves and began to doubt their own bodies. Furthermore, they continued to cope with their symptoms and find ways of managing their symptoms, physically and emotionally. The impact on these women of questioning whether their symptoms were legitimate was long-lasting and affected their experiences of secondary as well as primary care:

> *'I thought I was faking it! They kept saying its normal. I nearly gave up. I genuinely thought I was making it up. Once I had the scan and we found the cysts, I knew I wasn't making it up' (Faye).*

When women questioned the legitimacy of their symptoms, it led to some of them questioning whether they were worthy of being helped. If women re-presented to their GP when feeling like this, they appeared to be testing whether the GP would continue to normalise their symptoms or whether the GP had a new perspective. If the GP continued to normalise their symptoms, then women delayed seeking further help. If the GP did not normalise their symptoms, then the women felt empowered to continue to seek help.

> *'So, yeah, I went back to the GP after they told me it's all normal. I thought to myself, will he tell me there's a problem this time? Or will he just say the same. I just knew it though, he said there wasn't anything wrong' (Faye).*

Umbola explains that her HCP validated her assessment that her symptoms were not legitimate and did not warrant medical attention.

> *'Even though the doctor said my pain was normal, I went back stupidly. And you know what? When I went to my GP, he proved my point. He just wanted me out and he said again there was nothing wrong' (Umbola).*

This validation negatively influenced Umbola's health-seeking behaviour.

The impact of symptom normalisation in primary care was witnessed by the gynaecologists. The majority of the women, while content with being referred to secondary care, were apprehensive about the consultation. They went into the first consultation feeling apprehensive about being believed and often questioned whether they were able to trust the doctor.

> *'I was happy to see the appointment with gynae. When I stepped into his room, I was so nervous and scared if he would believe me. I had been burnt before by the GP. I just wasn't sure if I could trust him and if he would normalise the pain too' (Barbara).*

Impact of normal medical investigations on women's perception of normality

A number of women struggled to comprehend why they were continuing to experience symptoms despite the medical investigations they were undergoing (blood tests, vaginal swabs, ultrasound scans etc.) being reportedly normal. If investigations returned a result that was 'normal', then clinicians were more likely to normalise the symptoms, causing a further delay to diagnosis.

> *'I was like, well why are all these test results coming back as normal. Before I went to the doctor, I went through a phase of believing it was normal and then abnormal. Mum made me think it was abnormal. After the scan came back normal, I thought my symptoms probably are just normal and there is nothing wrong. I then didn't see the doctor for a while' (Erika).*

Power dynamics

Cultural expectations and norms relating to the authority of doctors and the respect that is due led to the women holding preconceived ideas about HCPs and shaped their perception of the power disparity between them. As Alma explains:

> *'You are brought up to respect doctors. There is this power disparity between "them" and "you". When you are sat in that room and feeling helpless. It's like they have your life in their hands - it's very anxiety inducing.' (Alma).*

While some participants discussed how they perceived a disparity in 'power' with their clinician, for others this disparity remained implicit in their discussion of their experiences of diagnosis. Participants defined 'power' as the clinician, as opposed to the patient, 'being in control'. The jargon used by clinicians and the way in which they communicated medical facts made participants feel that the clinician had 'more power'. The negative impact of the clinician using medical jargon was exacerbated if women also felt unheard. The women wanted their clinician to explain any unfamiliar medical terminology, and when this did not occur, they perceived this as a power imbalance between them.

> *'The GP just kept throwing words at me and I had no clue what he was talking about. It really made me feel worthless. Clearly he wanted to be powerful' (Diana).*

Power disparity was particularly perceived by women when they felt the clinician did not listen to them and clearly had a fixed agenda. The women accepted that there will be two agendas during a consultation, that of the patient and that of the clinician. However, if women perceived that the clinician was not listening to them and if they did not incorporate the patient's agenda, then this was also seen as a power imbalance.

> *'Clearly when he (the GP) had his own agenda and didn't listen to me, it made me realise who was in control. It was clearly him' (Elisha).*

Women also experienced a GP's assertion of power as control of the referral process.

> *'The way he would just respond to everything I said kinda made me think he wasn't really listening. He had all the control - like I say, the power. It's like he knew that he was in control of referring me and no matter what I said, it wouldn't matter. I just changed surgeries. (Neha).*

If women experienced a power disparity during a consultation, they were more likely to re-evaluate whether they would disclose more information about their symptoms to the clinician *during* the consultation; they were also more likely to change GP or delay seeking further medical help.

> *'When I realised he was trying to be mighty and powerful, I just switched off. I deliberately didn't want to tell him anything. I just couldn't wait to get out the room and see a different GP' (Alma).*

In this instance the woman herself delays diagnosis as a result of experiencing disempowerment in her relationship with her GP.

6.6 Facilitating factors

6.6.1 Investigation and referral process

Once the women began to undergo investigations for the symptoms for which they had sought medical help, almost all of the women experienced further delays, which further impacted the timeframe to diagnosis. This included investigations initiated by the GP in primary care, as well as referrals to non-gynaecological specialists in secondary care due to the impact of endometriosis on other organs in the pelvis, such as the bowel and bladder. Additionally, almost all women felt that their GP treated the symptoms rather than seeking the actual cause of their symptoms.

> *‘My GP kept fobbing me off with different pills and pain management. We weren’t getting to the root cause of it’ (Barbara).*

Where it was explained to patients that treatment and tests followed a plan of action as part of the diagnostic work up, the women were more accepting of the pathway to diagnosis and generally had a more positive medical experience.

A number of women, however, spoke about the multiple visits and investigations instigated by their GP prior to being diagnosed with endometriosis, including numerous blood and urine tests. Some women were trialled on hormonal treatments, with a ‘watch and wait’ approach. Yet others had an ultrasound of their pelvis prior to being referred to gynaecology. Sometimes the wait for an ultrasound lasted many months and, if the results were reported to be normal, then the women with undiagnosed endometriosis were not necessarily referred to gynaecology at all. As Gemma and Elisha explain:

> *‘I have been backwards and forwards for past 23 years. It got to a point that I got anaemic, and the GP then finally referred me to the hospital’ (Gemma).*
>
> *‘Well, the whole journey was about 10 years! Ummmmm it must have been about 8?! I had so many tests that were normal. I had to fight to get referred to gynaecology’ (Elisha).*

A number of women spoke about the various differential diagnoses that were considered prior to receiving a formal diagnosis of endometriosis. The most common conditions suggested were irritable bowel syndrome, urinary tract infection and constipation. These differential diagnoses often involved being referred to various departments, such as the gastroenterology, general surgery or urology department, and each time the women were referred back to their GP when these specialties were unable to help, therefore adding considerably to the time taken to diagnose endometriosis.

> *'I have battled between specialties like urology and colorectal. Literally being batted from one specialty to another. I feel I spent a lot of time going from one department to another and back. Just because you have these* symptoms doesn't mean you don't have endo' (Janet).

Janet explains that being kept informed during the differential diagnosis stage would have enabled her to understand and cope better with her symptoms while waiting for further investigations.

> *'I then got investigated for all sorts, IBS, cysts etc. by the GP. They said it could be a UTI or pelvic inflammatory disease. Thing is, no one told me it could be all these things. If they had told me from the start that it will take time, then I would have been more understanding' (Janet).*

6.6.2 Facilitating factors in the process of diagnosis

The factors that facilitated the process of referral to gynaecology and subsequent diagnosis included continuity of care and feeling validated.

Continuity of care

Continuity of care was very important for these women, particularly in primary care, although this was often not the women's experience, with some seeing between three and eight GPs for their persistent symptoms. Although some women chose not to see the same doctor again, for those who perceived a particular doctor to be supportive, this continuity in care was found to be helpful and enabled them to engage further. Faye explained that having the same doctor meant her concerns were understood better by her GP. She says that doctors do not 'always write down everything you tell them' and that she felt more comfortable seeing the same doctor, as they may remember her. Having to repeat their clinical story over and over again with different HCPs is emotionally draining and it meant women having to repeatedly relive their experiences. In addition, having to repeat themselves made women feel as though they were not listened to. Therefore, a lack of continuity of care may be experienced by women as not feeling they are being listened to and may exacerbate the emotional impact of their condition due to having to repeatedly discuss their symptoms with different HCPs. Diana explains that:

> *'It was all about seeing the same GP and having continuity. Once we got to see the same GP, it was better, and I felt less vulnerable whilst waiting for a referral as I knew I could go back to them if I had any more problems' (Diana).*

Feeling validated

Perceiving that they were being listened to and believed by their GP made women feel validated and respected and supported their engagement with the diagnostic journey. Harissa explained that after she suggested a diagnosis of endometriosis, her GP listened to and supported her, helping her to prepare for the next stage in the referral process.

> *'When she (GP) explained the way referrals work, I understood better that this won't be an easy journey, but I was prepared eventually for this' (Harissa).*

Faye explained how her doctor made her feel 'validated' after he spoke to her about his anecdotal experience:

> *'When we spoke about his own anecdotal experience, it really made me feel believed. Like, validated? It was good. I was dismissed too many times before by others' (Faye).*

The use of a symptom diary was discussed by the women as additional evidence to help them to demonstrate the progression and persistence of their symptoms to their GP:

> *'I wanted my GP to know how bad my symptoms had got. I took my little diary in and showed him everything' (Vivienne).*

The evidence provided by symptom diaries helped validate the women.

Taking someone else into the clinical consultation

A number of women spoke about the importance of taking another person into the medical consultation with them and how it made them feel believed and, in turn, validated.

> *'Eventually, I had to take my husband in and then we both told her that there was nothing wrong in my head and that I had an actual problem. Taking my husband in was a big step for me. I think it was when he told the GP that my quality of life and intimacy that were affected. It was at this point that the GP thought there was a "problem"' (Harissa).*

It appears that taking 'someone else' into a medical consultation empowered women and helped them to make sense of the consultation, especially if they perceived it to be a 'negative' consultation. Taking someone else into the consultation also helped women to co-construct the meaning of their symptoms with their HCP.

Those women who experienced an imbalance in power dynamics and perceived that their clinicians had 'more control' over the diagnostic process also found it helpful to take another person with them into the consultation.

> *'When the GP didn't believe me, I was adamant to book another appointment and take my partner in with me. How dare he didn't believe me. He gave me the impression he was very powerful and that he knew my body better than me! My partner was ready to come with me and put a stop to that' (Umbola).*

Changing general practitioner

Several participants spoke about how they changed from one GP to another, either in the same practice or in a new one if they did not feel they were listened to or believed.

> *'I exhausted two older GPs in one practice. I would try different doctors in one practice. When I found a GP that was willing to listen, I would stick with them.*

> *I just kept hitting walls. When doctors came back to me "empty" then I would always go to a new doctor armed with my own research' (Alma).*

6.7 Summary

This chapter has focussed on women's experiences of being diagnosed with endometriosis. The women discussed the ways in which their lives fractured around them as they began to experience symptoms. They also discussed the ways in which they recognised abnormal symptoms and subsequently coped with them. The accounts of healthcare professionals provide insight into the way women perceived their clinical encounters. This chapter underpins the next chapter, which outlines the substantive grounded theory.

Chapter 7 – Making sense of a fracturing life: grounded theory

7.1 Introduction

The previous chapter discussed women’s experiences of being diagnosed with endometriosis and these experiences are represented as categories. This section connects the findings from the previous chapter and explores what it means for women with endometriosis to experience the slow fracturing of their lives as a result of the physical symptoms they are experiencing. As their lives alter around and within them, the women seek to make sense of what is going on. The way in which a woman seeks to make sense depends upon her current context (refusal, disbelief and belief). The substantive grounded theory described here is based on the findings from the previous chapter and offers an explanation for the delays to diagnosis of endometriosis. Each of the different contexts will now be discussed in detail. The core category is ‘making sense of a fracturing life’. The main concern of women with endometriosis is coping with a life that is fracturing around them and they address this concern through a process of ‘making sense’. The chapter will start by further discussing what it means for women to experience ‘a fracturing life’ and this will be followed a discussion of how women make sense of ‘a fracturing life’ through the different contexts.

7.2 A fracturing life

The physical and psychological symptoms experienced by women with endometriosis impact on every thread of their lives, influencing their experiences of work and education and particularly impacting on their close relationships with family and friends. Critically, their experiences of the illness itself and of their attempts to make sense of their symptoms have a profound and negative psychological impact, especially with regards to their own identity.

7.2.1 Physical impact

The physical symptoms that women with endometriosis experience include pain, vaginal bleeding and fatigue.

The women experience physical pain in different ways. Some experience excruciating pain during their menstrual cycle while others may experience pelvic pain at any time. Those women whose endometriosis affects their bowels complain of pelvic pain during defaecation.

> *'I just knew there was something wrong with my bowels. I mean, I did have pain during my periods, but every time I emptied my bowels, without fail, the pain would be so bad. Like, so bad. It felt kinda stretchy pain. I even took laxatives, but that didn't help' (Neha).*

The intensity and duration of pain varies, with some women describing the pain as 'sharp' and 'crippling' while others experience a 'dull ache'. Nearly all of the women said they experienced pain during sexual intercourse.

For some, vaginal bleeding is the predominant symptom.

> *'I just thought I was on my period all the time. It just didn't make sense. I just had to carry pads around all the time! It just gets so tiring and frustrating' (Alma).*

For most of the women, fatigue becomes an increasing problem, experienced intermittently or chronically.

> *'For me, the pain was bad. But, the tiredness was even worse. I would just fall asleep randomly! I just wouldn't feel refreshed. My energy tank just felt empty all the time' (Erika).*

For some the timing of the pain was predictable and caused by an activity, such as defaecating or having sex.

> *‘I remember, each time my husband tried to have sex with me, I just couldn’t bear it. That burning horrible pain inside my tummy was just awful. I tried to let him in, but after a few minutes, I would usually have to stop because of the pain’ (Millie).*

For others the pain can appear without warning.

> *‘I could cope with the pain. But, what I struggled to cope with, was how the pain in my pelvis would just randomly appear. I mean, I could be at work, in the bath, or on any holiday. It's just so shit’ (Alma)*

These symptoms impact across these women’s lives.

7.2.2 Education and work

The women’s physical symptoms lead to them missing activities and taking protracted time off school or work due to pain and fatigue. Where symptoms of tiredness and pelvic pain relate to a woman’s menstrual cycle, taking time off becomes a pattern. Absenteeism is reflected in poorer grades and reports and in compromised social relationships with peers and colleagues.

> *‘My grades really dropped in my mock GCSE exams. I just didn’t know what was happening at school as I missed so much. It wasn’t my fault, with the period pain, I just couldn’t face it’ (Neha).*

For some, the unpredictability of symptoms and an inability to manage them can cause them to choose to change their career. For those regularly using analgesia to manage their pain, cognitive and physical performance can decline over time and can lead to job loss.

> *‘I just couldn’t sit at the desk all day. I really enjoyed my part-time job, but, as time went on, the pain in my back and tummy just got worse. I was on so many regular painkillers that I felt really sleepy and low. I just didn’t want to be there either. My boss said this can’t carry on’(Alma).*

7.2.3 Social impact

For many women, their physical ability to participate socially is compromised: their social lives are disrupted to the point where they are no longer able to integrate with friends or family or engage in social activities such as meeting people for dinner.

> *'Sometimes, the pain was so bad that all I wanted to do was lie in bed with a hot water bottle. It just happened so many times and often when least expected. It would be sod's law that I would have planned dinner with friends or a social with the girls. I just had to cancel so many times. Eventually, I think they gave up and would hardly invite me to things as they felt bad' (Alma).*

Physical activities are actively avoided because of worries about heavy menstrual bleeding showing and spoiling clothes.

Close relationships

The impact of the women's physical symptoms on close personal relationships with partners, children and parents is invidious and cruel.

For many women, their symptoms impact on their desire to be intimate and their ability to have penetrative sexual intercourse, due to pain. Physical tiredness and anticipation of pain can cause reduced libido. Whether couples think about these challenges separately or together prior to having sex, this can lead to a couple's relationship becoming more distant. For some, the sexual element of the relationship disappears.

> *'The physical side of my relationship has been non-existent for years. He's scared of hurting me and I'm scared of it hurting. We eventually just stopped having sex' (Bonnie).*

Over time, the tension caused by severe symptoms can result in separation and divorce.

Some women remove themselves from their children so that the children do not witness their mother's suffering. Where a mother fails to engage with her child about her illness, this can disrupt and damage the parent–child relationship. Similarly, her physical symptoms can force a woman to withdraw from other close relationships.

> *'My mum and I used to be so close. We always did things together. But my pain started to get worse and my tiredness became unbearable. I was no longer able to see her all the time. She took this very personally and became angry towards me. I tried my best to see her, but it wasn't enough. One day, we had a really big argument and it's never been the same since. Sad really. I never meant for bad. She was my main support' (Diana).*

7.2.4 Psychological impact

The physical symptoms, together with the impacts of the women's experiences of their lives fracturing around them, have a detrimental impact on the women's mental wellbeing and relate to loss of self-esteem, a crisis in self-identity and feelings of frustration, anger, guilt and depression.

These feelings have a cyclical and negative impact on all strands of the women's lives and especially on personal relationships with partners and family members.

> *'… my boyfriend would try and comfort me. The more he tried to comfort me and help me, the more worthless I felt. I know he was trying, but my pain was so bad that no one could do anything about it. I just felt like I lost every shred of dignity with him.' (Anna).*

Loss of self-esteem

The women feel worthless and experience a 'loss of dignity'.

> *'I just can't progress in my life. The pain was just getting worse and worse before I even knew what it was all about. It really made me feel worthless and rubbish' (Diana).*

A crisis in self-identity

The women suffer an identity crisis: they are unable to be themselves and can, for example, suffer from ‘not being believed by your own body’.

> *I genuinely was confused with my body! The pain was just so unpredictable and bad. My mind was telling me that this will get better, but my physical body was telling me another. I hated that feeling. It was just so awful and disturbing’ (Alma).*

Some women speak of the fear of being a woman and requiring ‘time off work for heavy bleeding and surgery’. Loss of career and under-performance at work can challenge a woman’s identity, fundamentally undermining who she believes herself to be.

Feelings of guilt, frustration and anger

Guilt is commonly experienced by the women, who feel that they are failing those with whom they have a close relationship, while frustration and anger are commonly experienced emotions arising from ongoing unexplained symptoms. Frustration is born of not being able to understand why they have abnormal symptoms, whereas some women, over time, experience anger towards the ongoing nature of the pain.

In turn, frustration and anger lead to feelings of depression and low mood, which subsequently impact on the way women interact socially.

> *‘I just felt pure frustration that no one really got it. I would try and explain it, but as people can’t see pain with their eyes, they just don’t understand. The more I had to explain myself to people, especially at work, the angrier I got! At the same time, I would start crying as I just felt so depressed that no one understood what I was going through. When I felt at my lowest, I just didn’t want to see anyone or do anything’ (Anna).*

Depression

Depression and low mood arise from having unexplained and ongoing symptoms and also result from self-isolation from friends and family. Some women experience depression as affecting their sleeping and eating patterns.

> *'The pain got me down so much that I just resigned myself to staying at home. What's the point in seeing all my other friends who are in happy relationships and don't have chronic pain like me. I didn't want to see others happy; I know that sounds bad. I felt so depressed that no one wanted to help me' (Vivienne).*

This section has explored what it means for women with endometriosis to experience the slow fracturing of their lives because of the physical symptoms that they are experiencing. As their lives alter around and within them, the women seek to make sense of what is going on by exploring and investigating their symptoms. The way in which a woman seeks to make sense depends upon her current context.

7.3 Contexts

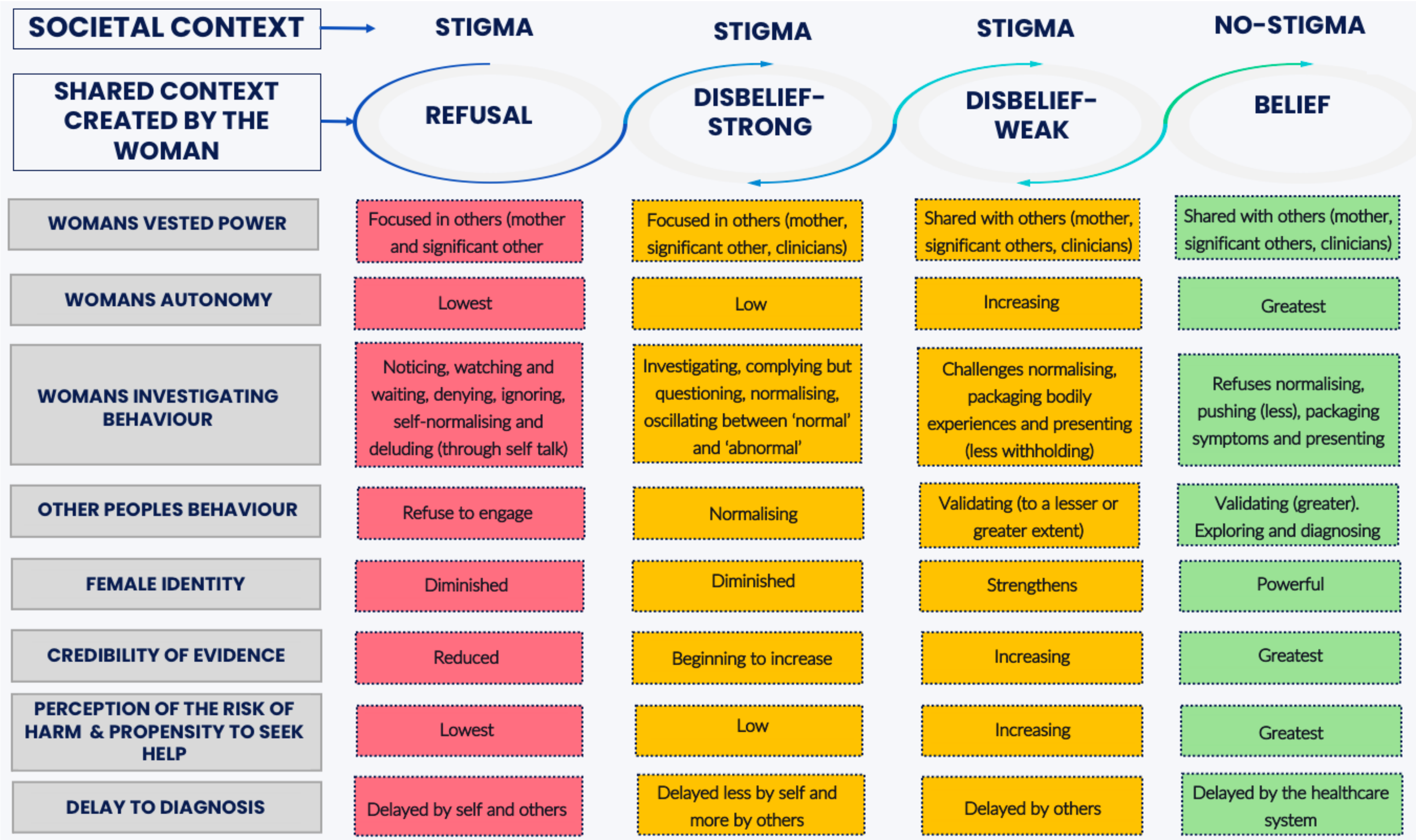
A context is created by two or more people (for example, the woman and her significant other, friend, or healthcare professional) and relates to the 'feeling in the air' between them. A woman's current context is influenced by a wider and more general taboo regarding discussion of menstrual matters and is likely to involve one of three contexts: refusal, disbelief (stronger and weaker) and belief. Figure 22 shows a diagrammatic representation of these different contexts.

Figure 22. Diagram of the different contexts in the grounded theory.

Across these different contexts, there is variation in the way (i) each woman perceives the credibility of her evidence of her symptoms, (ii) the way in which other people behave towards her and (iii) the power she vests in the ‘other’. Together, these factors impact on the way women seek the meaning of their symptoms, i.e. on the way a woman behaves in a particular context. This ultimately influences the time taken to diagnose endometriosis. Figure 23 shows the different contexts and their interacting factors.

Each woman cycles between different contexts, sometimes fluctuating back and forth through different contexts within a day, a month, a decade. As she cycles through contexts, her experiences within a context vary and often change the way she understands her symptoms, which in turn undermines or increases the credibility of her evidence to herself and others. She experiences a psychological loop: she enters a context with a degree of autonomy and – based on how she perceives the credibility of her evidence – her perception of the risk of harm from her symptoms. Her propensity to seek help varies with these two factors. As she seeks to make sense of her symptoms, her experiences within a context will stigmatise or validate her. The degree to which she is stigmatised or validated impacts on her identity as a woman and thus also on her autonomy. Each context will now be discussed in turn.

Figure 23. The grounded theory: Different contexts and their interacting factors.



SOCIETAL CONTEXT	STIGMA	STIGMA	STIGMA	NO-STIGMA
SHARED CONTEXT CREATED BY THE WOMAN	REFUSAL	DISBELIEF-STRONG	DISBELIEF-WEAK	BELIEF
WOMANS VESTED POWER	Focused in others (mother and significant other	Focused in others (mother, significant other, clinicians)	Shared with others (mother, significant others, clinicians)	Shared with others (mother, significant others, clinicians)
WOMANS AUTONOMY	Lowest	Low	Increasing	Greatest
WOMANS INVESTIGATING BEHAVIOUR	Noticing, watching and waiting, denying, ignoring, self-normalising and deluding (through self talk)	Investigating, complying but questioning, normalising, oscillating between ‘normal’ and ‘abnormal’	Challenges normalising, packaging bodily experiences and presenting (less withholding)	Refuses normalising, pushing (less), packaging symptoms and presenting
OTHER PEOPLES BEHAVIOUR	Refuse to engage	Normalising	Validating (to a lesser or greater extent)	Validating (greater). Exploring and diagnosing
FEMALE IDENTITY	Diminished	Diminished	Strengthens	Powerful
CREDIBILITY OF EVIDENCE	Reduced	Beginning to increase	Increasing	Greatest
PERCEPTION OF THE RISK OF HARM & PROPENSITY TO SEEK HELP	Lowest	Low	Increasing	Greatest
DELAY TO DIAGNOSIS	Delayed by self and others	Delayed less by self and more by others	Delayed by others	Delayed by the healthcare system

7.3.1 Context of refusal

In a refusal context, the power tends to be focussed in the ‘other’. In a social setting, this other may be the woman’s mother, partner or spouse, and this person refuses to engage with the woman, who has noticed that ‘something is not right’.

> *‘I just couldn’t believe it when my boyfriend asked me to stop talking about my period and said it was weird to talk about it’ (Bonnie).*

The woman notices a decline in her mental health and finds that she is curtailing her activities, perhaps being unable to continue swimming (Janet), running (Neha), playing hockey (Diana) or participating in physical education classes (Faye).

The woman seeks to explore the meaning of her bodily experiences; however, in the face of refusal, some women, concerned about how discussing their experiences might affect their emotional relationships, comply and do not push for engagement.

Feeling that the credibility of her evidence is weak, even as the bodily experiences persist, the woman normalises them and suspends any health-seeking behaviour. She adopts a ‘watch and wait’ approach.

> ‘*Before I even went to see them [GP], I waited for so many months as I thought things would get better’ (Alma).*

Some will withhold information from her ‘other’ as requested, denying and/or ignoring her symptoms and deluding herself as to their severity and their meaning.

> *‘I knew something was wrong… I was in a new relationship at the time and thought that the pain would get better. But it didn’t, genuinely, weeks turned into months and I thought, I can’t keep avoiding sex with my partner. I eventually went and saw the GP’ (Elisha).*

> *'I wanted it all to go away. I knew there was a problem. When the GP didn't believe me, I went into denial mode about my symptoms. I just blanked it out in my mind for a bit despite feeling so awful and in pain all the time' (Erika).*

In a refusal context, the woman's autonomy is low, her evaluation of her risk of harm from her bodily experiences is low and her propensity to seek help is low. Critically, her perception of the stigma arising from the other's refusal to engage causes her to experience a diminished female identity.

> *'I remember telling my partner that my periods were getting so bad and heavy. He said that it's something I should talk to my female friends and that guys shouldn't be talking about it in detail as it's embarrassing for him' (Elisha).*

For many women, an early assault on their female identity comes from the school nurse, some of whom refuse to engage:

> *'I learnt very quickly at age 11 that you can't talk about periods. The school nurse tells you not to talk about them or doesn't want to hear about it' (Alma).*

For some, the dismissive comments and the body language of the nurse stigmatise the women, leading them to feel 'disgusting' or 'weird'.

A woman may leave a refusal context when the credibility of her evidence is such that she recognises and accepts that there is a problem. In the face of her parents' persistent refusal to engage, one woman recognised her bodily experiences were abnormal when she overheard her parents argue about the amount of time she was taking off school as a result of her period pains. Their apparent acknowledgement of her symptoms raised the credibility of her evidence and validated her.

The delay to diagnosis of potential endometriosis in the refusal context is principally caused by the behaviours of others, encouraged by the compliance of women themselves.

It is very unlikely that once a woman leaves a refusal context that she will permit the context to revert back: she will move to either a context of belief or disbelief.

7.3.2 Context of strong disbelief

There are degrees of disbelief as to the abnormality of a woman's bodily experiences, ranging from strong disbelief to weaker disbelief. In a context of disbelief, the woman is actively noticing her bodily experiences and exploring their meaning for her.

In a social setting of strong disbelief, the power is again focussed in a significant other, such as a parent, partner or spouse. The woman is likely to be in the early stages of her illness and in seeking to make sense of what is happening to her she compares her bodily experiences. If she experienced pain during menarche, she will compare her current pain to her first pain and is likely to self-normalise the pain.

> **'***I don't know what normal has been because from the very first period I ever had was heavy and its always been really heavy, it's always been really, really painful, but I suppose in my teens I just put that down to what I expected of a period, it was supposed to be painful, it was supposed to be heavy, you know, that's what I thought was normal' (Vivienne).*

In making sense of her fracturing life, a woman investigates her symptoms, comparing and packaging them. She begins to see them as abnormal but, in the face of rebuttal by a powerful other, she oscillates, perceives her symptoms to be normal and suspends her sense-making activities. She watches and waits, ignoring and denying her symptoms and deluding herself as to the risk of harm from them. She complies with the expectations of the powerful other, withholds information and is diminished in the process.

Where symptoms relate to a woman's menstrual cycle, her mother is likely to normalise the woman's experiences, often citing a family history of gynaecological problems.

> *'I was told its women's problems and its normal. Gynae problems run in my family and so I always knew this was normal for me. My mum even told me they were normal for us all' (Millie).*

The school nurse is another who may dismiss the women's concerns of having heavy periods and normalise their symptoms.

> *'Even at school, my periods were so heavy and so painful. But the school nurse said they were fine. So then, I thought it was normal too. (Alma).*

These early interactions can have a profound effect on a woman. In the face of the normalising behaviours of powerful others, the woman oscillates between perceiving her experiences as normal and abnormal. Where she accepts her normalisation, she will suspend her investigations, cease comparing her bodily experiences and cease seeking help, sometimes for decades. Her autonomy remains low, but in making sense of her experiences the credibility of her evidence slightly increases.

She is likely to watch and wait and, in so doing, ignore, deny or delude herself as regards her symptoms. She withholds from further discussion of her symptoms.

Some women may seek out a different context in which to continue their sense-making activities and seek medical help. This, however, does not always change her context. In a structured healthcare environment of strong disbelief as to the abnormality of a woman's symptoms, the powerful other will also normalise the woman. This person could give the woman access to relief but instead is perceived to use his/her power to dismiss and/or resist the woman's attempts to gain appropriate medical help, which from the woman's perspective is a gynaecological referral. Instead, the clinician treats her symptoms.

Taking part in a medical consultation in a context of strong disbelief is a humiliating experience. The women experience being dismissed, feeling that they are not being taken seriously, that their concerns and expectations are not properly gathered, that they are unheard.

> *'So, yeah, I went to the GP and I felt so happy to get the appointment. He trampled all over my feeling and what I was telling him. No point even going as he made me feel shit. I was already dubious about going. He didn't even acknowledge how awful things were. I didn't go back for ages' (Faye).*

In the face of their symptoms being normalised as 'women's problems' and being told to 'get on with it', coupled with the embarrassment that can accompany disclosing gynaecological symptoms, the women are likely to withhold further sensitive and intimate information.

These women are also likely to accept the clinician's normalisation, make sense of their own symptoms by believing them to be normal and suspend their investigations.

> *'I saw a gynaecologist there and my family doctor - they both reassured me it's normal. When you have a professional like a doctor and someone close to you like your family telling you its normal, then what am I supposed to believe? Of course, I accepted this!' (Alma).*

Some healthcare professionals are prepared to treat the symptoms but resist a woman's efforts to gain a referral to a gynaecologist.

> *'A lot of GPs treats the symptoms rather than the actual cause. I know it's hard, but surely they can treat the symptoms and investigate you for why it's actually happening. Just starting the pill is not enough!' (Gemma).*

For those women who feel that the clinician wants to be 'in control' of the referral process, the disparity in 'power' with the clinician is unjust, leading to feelings of frustration and anger.

As a direct result of their experiences in a context of strong disbelief, a woman's mental equilibrium is challenged.

> *‘Your mind plays tricks. I just didn’t know what to believe. You are desperate to get an answer, but then the doctor tells you nothing is wrong. This was hard to deal with’ (Alma).*

Many women leave a consultation feeling judged and stigmatised. These experiences, and the misery created by her body not behaving the way it should, become part of her embodied identity: the associated shame, embarrassment and disgust becomes part of who she is.

> *‘Everyone has periods and I’m weak and pathetic because I can’t deal with them’ (Alma).*

As in the refusal context and as a result of being normalised, the woman’s sense of autonomy is low, her evaluation of her risk of harm from her symptoms is once again low and thus her propensity to seek any help is also low: she ceases efforts to make sense of what she is experiencing, believing her symptoms to be normal. Her perception of the stigma arising from the other’s disbelief causes her to experience a diminished female identity.

The delay to diagnosis is caused less by a woman herself and more by others.

Transitioning through a context of strong disbelief to a weak disbelief context

In response to experiencing a refusal and/or disbelief context, a woman may seek a context of belief in order to explore her symptoms. In the early stages of seeking to make sense of her bodily experiences, a woman may seek the help and support of other women, for example by joining endometriosis internet forums. Here, she will explore and compare her bodily experiences with the symptoms of others with diagnosed or suspected endometriosis.

> *’On the online forum, I noticed fatigue, bloating, heavy painful periods, hip pain, painful ovary pain and these were the main symptoms. It was just a link really. Everyone validates symptoms on there’ (Harissa).*

The recognition of her symptoms by others increases the credibility of her evidence and she oscillates from feeling that her symptoms are normal to believing them to be abnormal.

Simply by moving to a different room within a home a woman may transition from a context of belief as to the abnormality of her symptoms to a context of disbelief, experiencing a concomitant oscillation of her own beliefs.

Making sense over time

As her bodily experiences of endometriosis continue over time, a woman's perception of the credibility of her evidence regarding her symptoms increases and she has greater confidence that her symptoms are abnormal. She investigates more intentionally. She continues to compare her symptoms with those of other women with endometriosis and with other women with other medical conditions such as diabetes, HIV, cancer, fractured bones and mental health issues. Through her comparisons, she perceives that other conditions are more understandable to the general public, the source of pain more visible, the topic more socially acceptable and less embarrassing to talk about: empathy for sufferers of these illnesses flows more freely. For those with the largely hidden symptoms of endometriosis, empathy is withheld, and the woman feels a lack of validation of who she is and what she is suffering.

Nevertheless, as a woman's conviction grows, she is less likely to tolerate either a context of refusal or of strong disbelief. Thus, when returning to seek medical help women are less likely to accept the normalisation of their symptoms and are more likely to experience negative emotions towards their healthcare professionals as a result of their clinicians' disbelief. Encouraged by their experiences of belief contexts, these women will switch doctors until they find someone who is prepared to listen.

> *'I exhausted two older GPs in one practice. I would try different doctors in one practice. (Alma).*

When a woman finds a clinician who will listen, they prefer to maintain a continuity of context in the hope, but not expectation, that their concerns will be better understood.

> *'When I found a GP that was willing to listen, I would stick with them. I just kept hitting walls' (Alma).*

These women are triggered to explore and find, if not an open context of belief, then at least a context of weakened disbelief. They begin to challenge their medical professionals.

> *'When no one believes you, you really do have to be selfish and believe in yourself. I have never really believed in myself; even at school. But this time, I just had to remain positive and not give in. I just couldn't give in. My pain was so so bad that I had to find some way through this all.' (Diana).*

Over time and as a result of the validation that a woman receives in her open contexts of belief coupled with her continuing to experience life-changing symptoms, a woman's perception of risk of harm from her symptoms and her propensity to seek help increases and her identity as a woman strengthens.

> *'Reading about other women's stories online made me feel brave and strong enough to fight my doctor if I had any problems. Lo and behold, I did have problems and started writing my own blog online about my journey' (Neha).*

She develops greater confidence in the credibility of her evidence, and she achieves greater autonomy.

Increasing credibility of evidence

A woman may cycle through contexts of refusal and disbelief for a protracted period of time, oscillating between believing her symptoms to be normal or abnormal. For some there comes a moment of personal transition: 'the mattress moment'.

> *'We were about to carry it (*a blood-soiled mattress*) out of the house and my poor husband is so caring. We carried this mattress out of the house and the*

> *builders were there. The builders were our friends and I felt disgusted and embarrassed. I felt so disgusted. Have I done something wrong? Is this normal? Am I not using the right stuff? Is it because I haven't taken the tranexamic acid? You blame your body. In your mind, you are taking the advice you are supposed to take, but it's still not getting better. So yeah, that was unpleasant. All this time I had doubted myself and the symptoms I was going through. It was only when I saw this mattress being carried out of the house that I realised how real my symptoms were. This was my "mattress moment". I stopped going to the doctor for a while, but after this moment, I just had to go back.' (Gemma).*

The moment of personal transition often happens when a woman experiences a change in the influence of her symptoms on how she lives her life, as well as a worsening of her symptoms: she notices and challenges the fracturing of her life.

Corroborating evidence

To obtain medical help, an autonomous woman has to believe in the abnormality of her symptoms and have confidence in the credibility of her evidence in order to persuade her healthcare clinician to also have confidence in the abnormality of her symptoms. In some cases, she will ask another person to accompany her to a consultation to provide corroborating evidence.

> *'Eventually, I had to take my husband in and then we both told her that there was nothing wrong in my head and that I had an actual problem. Taking my husband in was a big step for me. I think it was when he told the GP that my quality of life and intimacy were affected. It was at this point that the GP thought there was a "problem"'' (Harissa).*

7.3.3. Context of weak disbelief

Challenging

When a woman feels more secure in her belief of the abnormality of her symptoms, she will begin to challenge the disbelief of powerful others and their normalisation or misdiagnosis of her symptoms. In medical consultations, she will question her healthcare professional and may change her GP. She begins to ‘push’. By pushing, the woman continues to compare and collate information about her symptoms, finding ways to package her symptoms, demonstrating their progression and persistence.

> *‘Maybe she understood actually what I was experiencing wasn’t normal as I took my symptom diary in. She was impressed with it’ (Vivienne).*

She also learns to present her ideas.

> *‘They must think, is it worth pushing this girl forward for referral at such a young age? I understand this and I’m sure they were doing it in my best interests, but it also meant I was left untreated. When doctors came back to me “empty” then I would always go to the doctor armed with my own research’ (Alma).*

She learns to weaponise her female identity towards the healthcare professional.

In a context of weak disbelief, the healthcare professional becomes more open to investigating the meaning of the woman’s symptoms with her. This simple change validates the woman to a degree. Medical practice, however, requires the healthcare professional to explore the possibilities of different diagnoses, including endometriosis. This can require the woman to be referred to specialities other than gynaecology. Where medical investigations return a result of ‘normal’ this can influence a woman’s perception such that she believes her symptoms to actually be normal and so suspends her sense-making activities.

> *‘I was like, well why are all these test results coming back as normal. Before I went to the doctor, I went through a phase of believing it was normal and then abnormal. Mum made me think it was abnormal. After the scan came back normal, I thought my symptoms probably are just normal and there is*

> *nothing wrong. I then didn't see the doctor for a while' (Erika).*

Most women therefore find it helpful if their GP explains that it is important to conduct more investigations to rule out other medical problems. As a result, the woman can feel a sense of validation that her symptoms are 'real' and 'worthy of being investigated further'.

> *'When she explained the way referral work, I understood better that this won't be an easy journey, but I was prepared eventually for this' (Harissa).*

However, where the work-up process towards a diagnosis is not properly explained to them, women can perceive these referrals as a form of disbelief.

> *'I then got investigated for all sorts, IBS, cysts etc by the GP. They said it could be a UTI or pelvic inflammatory disease. Thing is, no one told me it could be all these things. If they had told me from the start that it will take time, then I would have been more understanding' (Janet).*

In response to perceived disbelief, a woman may withhold information; this can sometimes compromise a consultation with another specialty that is not related to gynaecology.

In other cases, a clinician may recognise endometriosis as a potential differential diagnosis, confirming the woman's current oscillation towards perceiving her symptoms as abnormal and somewhat validating her identity. In this context, however, if the clinician declines to refer the woman to a gynaecologist, in the same moment that the clinician validates the woman, the clinician also uses their power to withhold medical help and instead stigmatises and diminishes the woman.

Where a woman cycles through specialties, leaving a context of weakened disbelief and entering a context of strong disbelief, there is a real risk that she may once more need to suspend her sense-making activities.

> *'With all my pain attacks, I would ask them if endometriosis could be a cause. They just wouldn't listen and [would] refer me back to my GP' (Diana).*

> *'One day, I came to the hospital for an appointment, and I had so much bleeding all day and in pain. The doctor actually said to me "you seem to be well composed! Are you faking the pain?" I then said to the doctor "I cope with it quite well. Should I be crying instead?" I just didn't feel believed. I actually walked out. Unsurprisingly, I didn't see him again obviously.' (Faye).*

Identity

In a context of weakened disbelief there remains a degree of disbelief on the part of the healthcare professional as to the abnormality of a woman's symptoms and the meaning of them. However, the validation afforded by a tentative exploration offered by a healthcare professional can positively influence her identity as a woman. Where the woman is encouraged by these experiences, she will continue to disclose intimate and hidden details about her symptoms.

As a result of her experiences in a context of weakened disbelief, a woman will have an increasing confidence in the abnormality of her symptoms, an increased perception of risk of harm from her unexplained symptoms and an increased propensity to seek medical help. While her identity has taken several hits, her sense of autonomy is stronger.

Transitioning from a context of weak disbelief to belief

Some women are catapulted into a context of belief:

> *'I had keyhole surgery for my appendix and the endometriosis was found through this operation' (Janet).*

This is not, however, the experience of most women. For most women, delay and yet more delay is built into the entire process of making sense of her symptoms and her fracturing life. Over time, the women learn to collate information and package their symptoms to better present them in structured communications with healthcare professionals. They begin to diagnose themselves with endometriosis and encourage their healthcare professional to facilitate this diagnosis through interventions or referral to secondary care. As they move from a context of weakened disbelief to structured openness and belief, however, the women may experience a range of psychological states.

7.3.4 Context of belief

As they enter a context of belief with their healthcare professionals, at best the women will feel autonomous, have made sense of their symptoms, have confidence in the credibility of their evidence and feel powerful as a woman: brooking no argument. Some, however, while still feeling stronger than they did, are exhausted by the weight of the opposition they have experienced in getting this far.

> *'I mean, even when the gynaecologist asked me how I was, I just burst into tears. It felt like someone actually believed me because they were asking me how I was feeling' (Umbola).*

All of the women in this context of belief exert greater power when seeking medical help than they have done previously.

Validating and complying

The differentiating factor in the belief context is that healthcare professionals explore the meaning of women's symptoms with them, recognising the symptoms to be abnormal.

When the women feel listened to, they also feel validated, so that they can challenge less and focus more on investigating and working with, or complying with, the healthcare system.

> *'He was like, we will tick off every box that we can tick off before we get you referred and so I really appreciate. It helped me to realise that this may take time to get an answer, but it's okay as I have the right support' (Erika).*

As part of the women's investigating behaviour, the women feel the need to push less. While continuing to package and present their symptoms, the women feel able to freely discuss their symptoms, without perceiving adverse judgement from their clinician, and are able to make collaborative decisions about their care.

Validation can result from something as simple as a clinician acknowledging a woman's challenging personal journey; looking through their GP records and acknowledging the duration of symptoms; discussing the impact that the unexplained symptoms are having on the woman's quality of life or on the woman's relationship with her partner; or guiding the woman through the diagnostic process to rule out different potential causes of her symptoms.

Complying means that the women will tolerate being made to cycle through specialists as potential diagnoses are ruled out.

> *'I have battled between specialties like urology and colorectal. Literally being batted from one specialty to another. I feel I spent a lot of time going from one department to another and back' (Janet).*

Credibility of evidence

A clinical encounter combined with medical results increases the credibility of women's evidence. A diagnosis provides the most powerful evidence of all of a woman's illness and persuades other health professionals to believe in the abnormality of the woman's symptoms. A diagnosis will facilitate the swift emergence of an open-belief context when seeking future medical help, for example during future trips to A&E or a GP.

> *'People take you more seriously. I guess, my doctors changed their attitude as soon as they saw on the hospital letter that they found endometriosis. So, if you want to see a consultant again, they will actually refer you' (Faye).*

A diagnosis is the most powerful validation of the woman.

Identity

In this context, the women perceive their identity as a female in a much more powerful way and find a trajectory for relief in their eventual referral and subsequent diagnosis. The outcome of the women's experience of an open-belief context is that the women's perception of risk is at its greatest, they perceive their symptoms as abnormal, and they subsequently experience the greatest propensity to seek medical help.

Their emerging identity as a woman has been grounded in the normalisation of 'shameful' and 'debilitatingly painful symptoms'; of being convinced they are 'faking it', and 'weak in not being able to cope with being a woman'; and in their lack of power in being able to secure timely relief embedded in who they know themselves to be. A turning point is found for some who feel 'touched and believed' when they understand that 'someone is going to help'.

7.4 Summary

The majority of the women begin experiencing abnormal symptoms during their teenage years, some from their very first period. Diagnosis commonly occurs when the women are mature. During the intervening years and sometimes decades, delay occurs for both structural and social reasons. Delay due to structural reasons occurs during the protracted time the medical system takes to work up to a diagnosis. It is the avoidable social delay, however, that is the most odious, causes the most damage and which occurs at the hands of powerful others who normalise the women: dismissing and resisting their efforts to make sense of what is going on in their fracturing lives, stigmatising them in the process and profoundly affecting their identity as a woman.

Chapter 8 – Healthcare professional findings, phase 2

8.1 Introduction

The previous chapter explored the experiences of diagnosis among participants with endometriosis and developed a substantive grounded theory. This chapter will focus on the qualitative findings generated in phase two of the study from data gathered through semi-structured focus groups with gynaecologists, GPs and nurses working across primary and secondary care. The interview schedule used verbatim quotes from participants diagnosed with endometriosis, taken from the grounded theory study, to ensure that the research focus remained on the voices of those diagnosed with endometriosis. These findings provide insight into the delays to diagnosis from the perspective of healthcare professionals. The interview guide containing the quotes presented to healthcare professionals can be found in Appendix 11.

The aim of this phase of the study was to explore healthcare professionals' experiences and perceptions of endometriosis diagnosis based on the accounts of women with endometriosis and is intended to complement the findings from the grounded theory.

The specific objectives of this phase of the study were as follows:

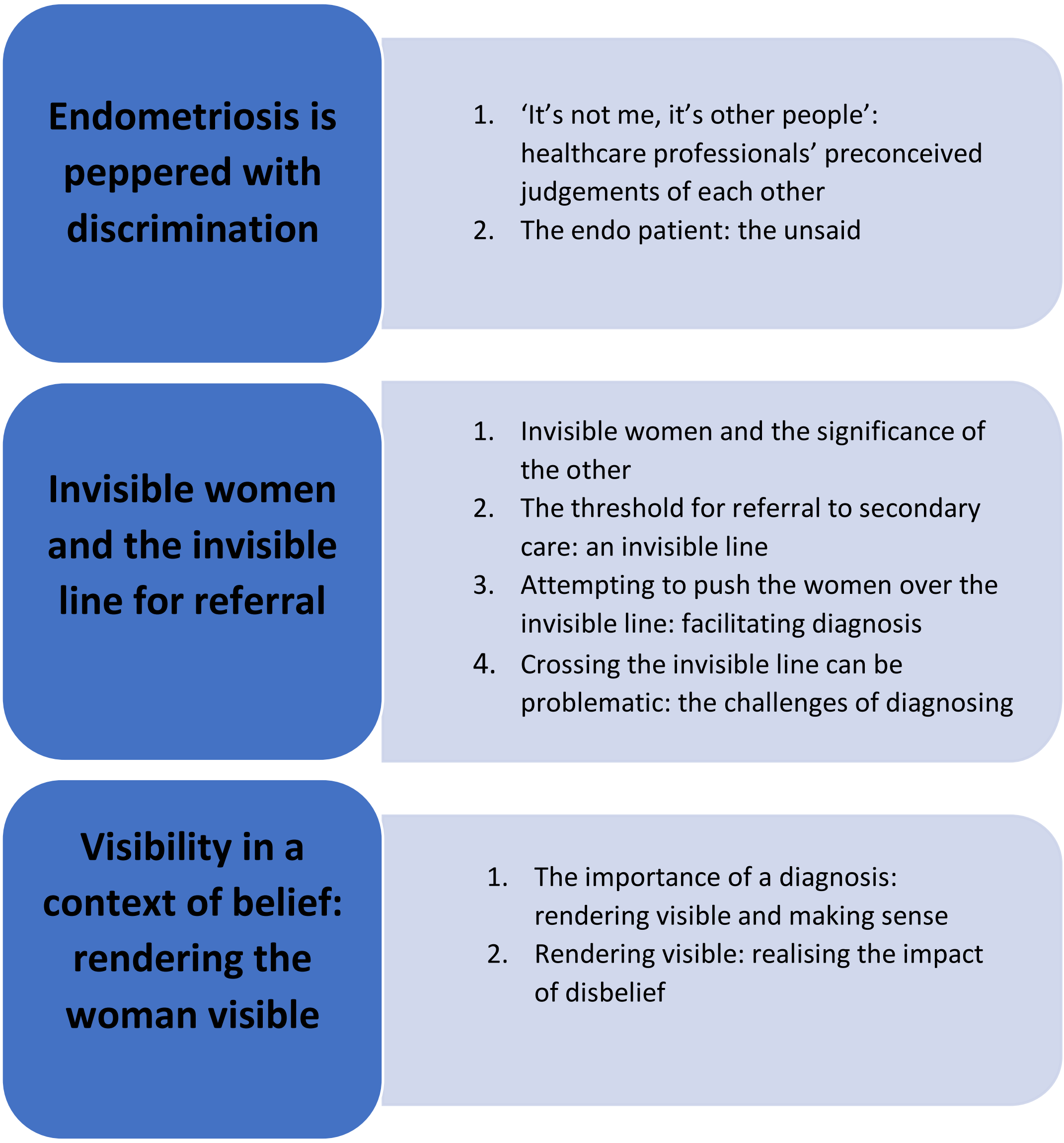
(1) To explore healthcare professionals' experiences of diagnosing endometriosis.
(2) To explore reasons for the delays to diagnosis from a healthcare professional perspective.

The findings generated from this phase were developed into three overall themes, and these were underpinned by a number of sub-themes. The three overall themes were:

1. **Endometriosis is peppered with discrimination**
2. **Invisible women and the invisible line for referral**
3. **Visibility in a context of belief: rendering the woman visible**

Figure 24 shows a summary of the themes and sub-themes from the healthcare professional focus groups.

Figure 24. A summary of the themes and sub-themes discussed by healthcare professionals.



Endometriosis is peppered with discrimination

1. ‘It’s not me, it’s other people’: healthcare professionals’ preconceived judgements of each other
2. The endo patient: the unsaid

Invisible women and the invisible line for referral

1. Invisible women and the significance of the other
2. The threshold for referral to secondary care: an invisible line
3. Attempting to push the women over the invisible line: facilitating diagnosis
4. Crossing the invisible line can be problematic: the challenges of diagnosing

Visibility in a context of belief: rendering the woman visible

1. The importance of a diagnosis: rendering visible and making sense
2. Rendering visible: realising the impact of disbelief

Each of these themes will now be discussed in detail.

8.2 Theme 1: Endometriosis is peppered with discrimination

Discrimination, as a form of judgement, is discussed from two perspectives in this section. First, healthcare professionals judge each other's clinical practice, and how this may influence the delay to diagnosis, but do not actually question their own role. Second, clinicians discriminate against patients with suspected or confirmed endometriosis. This discrimination is now discussed in further detail.

8.2.1 'It's not me, it's other people': healthcare professionals' preconceived judgements of each other

All healthcare professionals discussed their perceived judgements about each other's clinical practice and how this may influence women's healthcare experiences. On the whole, GPs were under the impression that gynaecologists are resistant to performing laparoscopies due to their workload. This perception led to GPs being less likely to refer a patient to secondary care in what would be considered a timely manner. In addition, while on the surface it may appear that the medical and nursing team presents a cohesive front in supporting patients to reach a diagnosis, the findings outlined below raise doubts about this, based on the various judgements passed by all healthcare professionals about each other.

> *'I think gynaecologists must be presented with so many women with the expectation that they need to have a laparoscopy. Therefore, they will try and treat the symptoms without having to do the invasive procedures.' (GP 2, Carl, line 43).*

One nurse speculates that patients may be under the impression that it is only the consultant who is able to help her reach a diagnosis. However, she explains that various healthcare professionals can 'add an important part'. This nurse's speculation implies that she perceives some form of hierarchy within the healthcare system.

> *'If women only think that the consultant is the only person that "knows best", then there is something very wrong here. Everyone can add an important part in a patient's journey – especially listening to someone's concerns and trying to understand their symptoms prior to a diagnosis of endometriosis.' (Nurse 1, Lisa, line 338).*

Olivia, a nurse sonographer, discusses the discrepancy in the reason for an ultrasound referral from the GP she often receives and the reason the patient gives. It appears that the initial medical history from the GP may not always hold true and, through further questioning of the patient, more detail is obtained by the secondary care practitioner. If an inadequate medical history is taken in the primary care setting, then endometriosis may not be suspected in a timely manner and this may influence the time taken to refer the patient to a gynaecologist or for any imaging procedures.

> *'Patients often say the pain is worse on their periods and when they open their bowel. However, the GP referral might say something very different! It might say "chronic pelvic pain, ?cyst" on the scan referral. This happens a lot from GPs.' (Nurse 2, Olivia, line 127).*

Emma, a nurse, perceived that GPs may want to be involved in the care of patients with suspected endometriosis in the community for longer than they should, and as such, contribute to the delayed diagnosis.

> *'Often, these very young women have to wait a long time because the GP might think they want to look after them in the community for longer.' (Nurse 3, Emma, line 91).*

The differences between a general gynaecologist and a gynaecologist specialised in endometriosis was discussed by the nurses in particular. They perceived that general gynaecologists will 'not want to get involved' and will want to refer the patient to an endometriosis specialist. If this perception holds true, then it may also explain in part the delay to diagnosis, as this process may naturally take some time.

> *'I wonder if the general gynaecologists are quite keen to get the patient to the endo specialist and so they don't want to get involved in their care too much?' (Nurse 2, Olivia, line 35).*

Gynaecologists also discussed how they perceived differences between general and specialist gynaecologists. Gopal, a general gynaecologist, discusses how patients who are referred from another hospital are 'often' unhappy with their care elsewhere. However, while he is critical of the care provided at other hospitals, he does not reflect on or elaborate how his care is different.

> *'I always seem to hear the same story from patients. Some GPs are either very good at following up on these patient concerns and some not. When I see referrals from another hospital, it is often because the patient is not happy with the team. There is definitely a difference between a general gynaecologist and one that is an endo specialist.' (Gynae 1, Gopal, line 31).*

All healthcare professionals provided insights into the ways in which they hindered a diagnosis. Gynaecologists provided insights into the challenges that GPs may face in primary care when first encountering patients with suspected endometriosis. One clinician discussed how a ten-minute appointment is a limited time period and speculated that this can impact on women's healthcare experiences.

> *'I understand that it's quite difficult to ascertain all the concerns in a 10-minute appointment. Maybe these patients need longer in the GP clinic?' (Gynae 3, Mamta, line 79).*

Mamta hints at structural discrimination that limits dissemination of knowledge to GPs in training and limits the time available to explore issues with women during a consultation. Structural discrimination may therefore cause delays in diagnosis in primary care. Mamta begins her first consultation by exploring the woman's medical experiences so far, based on her assumption that many women who present to her will have experienced a negative medical experience in primary care.

> *'However, when I see new patients in the clinic, we often start the consultation about their medical experiences so far. They will tell me that they haven't been listened to and dismissed. When you dig deeper, their symptoms have been affecting them for a long time.' (Gynae 3, Mamta, line 76).*

Healthcare professionals judge each other's clinical practice directly and indirectly. However, none of them discussed insights into their own practice and how they may also be involved in contributing towards women's healthcare experiences.

8.2.2 The endo patient: the unsaid

All healthcare professionals discussed the 'unsaid' preconceived judgements that they held about patients with endometriosis or suspected endometriosis. It appears that there is an 'inherent bias' against this group of women, through which they are invisibilised. Both quotes below, one from a GP and the other from a nurse, illustrate how a 'well-versed' woman with endometriosis can appear intimidating to them and, as a result, she is 'treated differently'. Both healthcare professionals interpret a woman's knowledge of endometriosis to be intimidating. This feeling of intimidation in the face of a woman's challenge may stem from a lack of competence on the healthcare professional's part or gaps in their medical or nursing knowledge.

> *'Endometriosis patients would get left in the corner and muttered about "Oh, she's back again!" I think there is some inherent bias among healthcare professionals, including gynae nurses, nurse specialists and trainee doctors, against endometriosis patients. This is because they are well-versed on their condition and well read. I think this can be scary and so get treated differently.' (GP 1, James, line 294).*

> *'They tend to be young and know a lot about their condition. This can be intimidating - they might have lots of questions that require specialist knowledge.' (Nurse 2, Olivia, line 49).*

A number of other judgements were made by healthcare professionals about women with endometriosis. Some view them as wanting an immediate solution to their symptoms or perceive them to require regular analgesia. These judgements influence how healthcare professionals behave towards these women.

> *'I think these patients are often looking for a quick fix diagnosis.' (Nurse 5, Priyanka, line 103).*

> *'The patient may require regular pain relief, and this can be always difficult to give at the exact time.' (Nurse 4, Charlotte, line 58).*

Some healthcare professionals, namely nurses, perceive women with endometriosis as 'complex': they form an image of the 'endo patient' regardless of whether these judgements hold true. Olivia admits that the combination of these patients having 'chronic pain' and requiring 'lots of medications' is frustrating for her. The very fact that Olivia has labelled her own preconceptions about women with endometriosis by using the term 'endo patient' is a judgement in itself.

> *'I think, maybe they are complicated. But I think we have this image of an "endo patient" that they might be complex? I mean, when I used to work on the ward, if they come in with chronic pain and longstanding, with lots of medications, it can be frustrating for us and the patient.' (Nurse 2, Olivia, line 46).*

> *'They are complex patients with complex needs. They need pain requirements. They are complex patients with complicated histories.' (Nurse 1, Lisa, line 43).*

The perception that women with endometriosis are complex may influence the way in which healthcare professionals interact with these women when they present to hospital. This is particularly important for a woman who has suspected endometriosis and is still awaiting a diagnosis.

8.3 Theme 2: Invisibility: invisible women and the invisible line for referral

Participants with endometriosis attending a medical consultation in a context of disbelief (from the grounded theory) felt that they were not listened to and not taken seriously when seeking help for their (subsequently confirmed) endometriosis. Women's symptoms are therefore normalised. This finding was presented to healthcare professionals for further exploration.

This theme of invisibility is encompassed by the following sub-themes:

- Invisible women and the significance of the other.
- The threshold for referral to secondary care: an invisible line.
- Clinicians attempt to cross the invisible line.
- Crossing the invisible line can be problematic: the challenges of diagnosing.

For various reasons, GPs seek to prioritise treating the women's symptoms within primary care rather than exploring the underlying cause. In their practice, they create a threshold for referral to secondary care, an 'invisible line' over which the women must cross. In their disengagement and initial refusal to refer these women, GPs normalise the women's symptoms and effectively render the women invisible to the secondary healthcare system.

> *'A lot of our patients are undemanding actually, and they often put up with the symptoms and pain.' (GP 2, Carl, line 68).*

The women challenge the normalisation of their symptoms by pushing, packaging and presenting their symptoms. This is seen by healthcare professionals (namely GPs) as desperately seeking to persuade them. A quote was presented to healthcare professionals from one participant, Alma, who said 'you want to look unwell enough to be believed, but not look good enough that you won't be believed'. Lisa, a nurse, interpreted this as symptom fabrication, but at the same time, she had the insight that the patient is attempting to convince the doctor about the legitimacy of her symptoms.

> *'At first, it may appear that the patient is fabricating her symptoms if she has to put on an act when seeing the GP, but at the same time, it shows how much of an impact her symptoms have had on her life. To feel too strongly about her appearance in front of the GP must be challenging. She is clearly trying her best to be believed and listened to. This is not right.' (Nurse 2, Lisa, line 225).*

8.3.1 Invisible women and the significance of the other

A woman who suspects she has endometriosis and who is unaccompanied in a consultation with a GP is often not taken seriously. Her invisible illness cannot be reliably measured using the clinical tools available in primary care. As a result of structural discrimination, GPs frequently lack the knowledge necessary to understand the psychosocial impact of the illness in women with suspected endometriosis and do not have the time to fully explore this within the time constraints of a consultation. As a result, the woman's symptoms may be treated within the primary care system, but they remain undiagnosed. Success for the GP invisibilises the women.

All healthcare professionals discussed the influence of a significant other in a consultation. The woman can be rendered visible by a significant other, usually a man, who 'adds weight and gravity' in terms of the impact of her symptoms on her quality of life. This implies that the GP (in this instance) is perceiving the credibility of the woman's evidence (medical history) as low. It also questions the way in which a woman is perceived in a medical consultation, compared with how a man is perceived. It is not enough for the woman to present by herself and be believed. As this GP explains:

> *'It adds weight and gravity to the psychosocial impact of the condition. If a patient is telling you this, but their partner is also saying this, then it makes you think again. It might be that the partner is telling you that they are not having sex anymore and it certainly adds more weight to the psychosocial aspect.' (GP 1, James, line 252).*

It is often the case that GPs pay more attention to a woman's concerns when others are present in the room.

> *'It definitely makes you think differently if there is someone else in the room backing the patient up. Possibly you listen more. This could be anyone else in the room.' (GP 2, Carl, line 240).*

With regards to a GP making a decision to refer a woman, some GPs tend to hear women more clearly through her significant other and this influences whether they refer her to secondary care.

> *'I would definitely think twice about not referring someone if another person is present. It would make me question why someone else is also present and so listen differently.' (GP 4, Stella, line 274).*

Gynaecologists and GPs tend to judge the credibility of women who they suspect to have endometriosis differently. The gynaecologist quoted below highlights that it is expected that a woman will bring another person to the consultation and that this is seen in a positive light.

> *'It's quite usual for a woman to bring a friend or her partner into the clinic with them. This is a really good thing. If the woman has not taken in everything we have discussed, then it's quite likely that the other person will have remembered.' (Gynae 3, Mamta, line 120).*

Where significant others accompany and support a woman during a consultation, GPs also perceived the contributions of others as helpful, particularly as a way of obtaining information about the impact of symptoms on the woman's quality of life. However, the GP in the following quote admits to how the consultation dynamic changes as a result of the presence of another person. He implies that another person is required to obtain a woman's medical history and that the woman alone is not recognised in providing this information. Once again, the GP does not question their own clinical practice with regards to how they obtain information from a woman if she is alone or why another person in the consultation is necessary for this.

> *'If you were the patient, it would be hard to remember everything you want to get across. Therefore, the person you are with in the room, they are often detached and so they can get across points maybe you might forget as the patient. It alters the dynamic and it does it in an effective way. It allows you to get the history in a different and dynamic way with another person.' (GP 5, Kieron, line 246).*

There appears to be more validity placed on the woman's presence if another person is also in the consultation room. This perception undermines the woman as an individual, takes away her autonomy and signifies that the clinician will only view the consultation 'more seriously' if a significant other is present. In most cases, the significant other was a male partner. One GP commented that:

> *'If you explain to both the patient and whoever else is with them about what is happening, then that can help with consultation too. It doesn't necessarily mean a referral will occur, but it can make the whole consultation be taken more seriously.' (GP 5, Kieron, line 262).*

However, other clinicians found the presence of another person intimidating.

> *'Generally, if there are two people in the room, then you are more under pressure, and this lets you take it more seriously.' (GP 2, Carl, line 271).*

Finally, the role of another person in a consultation was seen as a form of verification. The nurse below acknowledges that while someone may have chronic pain, the woman alone is not able to 'verify' this; however, the other person in a consultation is able to 'verify how unwell' the woman is. Again, this invisibilises the woman.

> *'Someone might say they have chronic pain and talk about the symptoms. However, the person who else is with them might be able to put the symptoms in context - they might be able to verify how unwell someone else is.' (Nurse 1, Lisa, line 151).*

Healthcare professionals appear to need to verify women's symptoms because they invisibilise these women in the first place. Through the simple expedient of accompanying a woman to a consultation, their significant other can render the woman visible to the primary care system and help her cross the invisible line of referral to secondary care by increasing the credibility of her evidence. This is discussed further in the next sub-theme.

8.3.2 The threshold for referral to secondary care: an invisible line

GPs in particular discussed the ways in which they managed patients with suspected endometriosis within the primary care setting. All healthcare professionals alluded to the point at which they believed patients should be referred to secondary care for further assessment. An important distinction to note is that gynaecologists and the women with endometriosis view being *diagnosed* as 'success', whereas GPs see success as 'treating and managing symptoms' within primary care.

> *'Maybe people need to be aware that you don't necessarily need the diagnosis to get the treatment in primary care.' (GP 5, Kieron, line 361).*

This creates an invisible line for when patients with suspected endometriosis are referred to secondary care.

As highlighted in the following quote, it was clear that GPs were trying to manage symptomatology in the community by persuading women with suspected endometriosis to use a Mirena coil or contraceptive pill.

> *'We try and persuade people to come and have it fitted as it genuinely works for so many people - not necessarily for endometriosis, but for symptoms.' (GP 2, Carl, line 416).*

These patients may not have necessarily been diagnosed with endometriosis and therefore GPs placed more emphasis on symptom management than achieving a formal diagnosis of these women's symptoms. This may explain why women are not referred to secondary care for a prolonged period of time.

> *‘If it is ordinary menorrhagia, then they might respond to the pill. So many young women come in aged 14 to 17 with menorrhagia and the pill transforms their lives.’ (GP 4, Stella, line 387).*

> *‘Yes, many 16-year-olds get on with Kyleena very well! They come back and tell me how much their lives are transformed. Even with the Mirena coil.’ (GP 2, Carl, line 390).*

GPs discussed their role in terms of managing conditions in a primary care context and wanting to have the autonomy to do that. One GP, quoted below, discusses how GPs are ‘not just secretaries’ and asserts his power as a GP. He places the onus on the patient to understand the way suspected endometriosis symptoms are managed in the community.

> *‘As GPs, we like to manage conditions in primary care and within our scope. We are not just secretaries that refer everything to a specialist. If we have tools at our disposal, then of course we will use them. Patients maybe need to see this differently and it boils down to us educating them about this. For example, I may tell the patient that “even if I was to send you to the gynaecologist, they may just do X or Y”.’ (GP 5, Kieron, line 98).*

In addition, another GP discusses how it is important to appreciate that they are able to manage patients appropriately in primary care. He emphasises that a large proportion of women with suspected endometriosis are managed within the community and that their symptoms ‘settle’. While symptom suppression is considered important from the GP’s perspective, it delays women from obtaining a formal diagnosis of endometriosis.

> *‘You might be surprised how many women will have symptoms that settle with what we do in primary care.’ (GP 3, Richard, line 65).*

Both GPs quoted above appear defensive about their role as doctors and both are focussed on symptom management as opposed to diagnosis. This view of success can make referral appear to be a failure and creates an invisible line over which some

GPs are reluctant to cross. The concept of 'failure' is used in this way by the GP quoted below.

> *'I would say maybe rule out the obvious things it could be in addition to endometriosis. From this point, it's failure of primary care management.' (GP 3, Richard, line 116).*

However, ruling out 'obvious things' to which a patient's symptoms could be attributed is an important moment at which women are considered for referral to secondary care. The realisation by a GP that treatment has failed may also result in the woman crossing the referral threshold.

> *'In primary care, we try and deal with what we can. Cases where the treatment has failed could be a threshold for referral to secondary care.' (GP 3, Richard, line 62).*

The need for 'specific guidance' on detecting those women who are more likely to have endometriosis is discussed as an important way of ensuring the threshold for referral is better understood and more transparent.

> *'Obviously, if there was specific guidance on spotting those women who are highly likely to have endometriosis, then yes it would save a lot of bother.' (GP 3, Richard, line 62).*

As discussed previously, clinicians placed great importance on the influence of another person being present during a consultation. They recognised that another person in the room raised the credibility of a woman's evidence, which can shift the woman over the invisible line to achieve a referral to secondary care.

> *'The partner might say "she's a tough cookie and this wouldn't normally affect her" makes you think about the impact!' (GP 3, Richard, line 257).*

In particular, GPs appear to have a different perception, compared with that of patients, of what they consider to be success in terms of treating the symptoms of suspected endometriosis. This may influence the way in which women perceive the healthcare they receive in primary care.

> *'Maybe the faith in the GP's ability to deal with these conditions can also play a part. Maybe if we are just treating the symptoms and not giving a firm diagnosis, then maybe this is influencing how women perceive what we say and do?' (GP5, Kieron, line 106).*

8.3.3 Attempting to push women over the invisible line: facilitating diagnosis

All of the healthcare professionals discussed ways in which a diagnosis of endometriosis can be facilitated. Primary care clinicians in particular discussed the use of a symptom diary that patients can 'take to their GP'. Although not explicitly stated, the GP in the example below implies that physical evidence of some form, other than the symptoms that a patient verbalises with their GP, is an important part of the consultation.

> *'If the Royal College of O&G or Endometriosis UK had a tool whereby women could have a period diary to write down their pain, dyspareunia, pain on opening their bowels, then this would be useful for women to take to their GP.' (GP 1, James, line 418).*

Some healthcare professionals also discussed a combined clinic involving a consultation with a gynaecologist, the collection of 'hard data about the woman's testable symptoms' (through medical imaging) and exploring information about the woman's bodily experiences. Some healthcare professionals were sceptical about this proposal, while some were more hopeful.

> *'A one-stop clinic sounds fantastic, but it's just about organising the practicalities. If there was a clinic whereby the woman can have a scan, see the gynaecologist and then have a plan made, then that would be great.' (Gynae 1, Gopal, line 207).*

> *'For a one-stop shop, it could work for post-menopausal clinic for example as it's less complicated. However, for endometriosis this is more complex due to the way its diagnosed, the way it impacts women. Combining investigations with consultations is very good, but not sure if it would work for endometriosis.' (Nurse 3, Emma, line 252).*

Endometriosis and the challenges in diagnosing it were compared with other medical conditions, with some clinicians recommending the use of a non-invasive test.

> *'I suppose diabetes is so much easier to diagnose compared to endometriosis. If there was a non-invasive test of diagnosing it, it would make it easier.' (Nurse 5, Priyanka, line 180).*

Healthcare professionals redirect patients to the appropriate support services when they are no longer in a position to help diagnose them. For instance, nurse 5 (quoted below), a nurse sonographer, attempts to empathise with a patient's lack of a diagnosis if their ultrasound scan result is negative. In those cases, she specifically advises the patient to 'ask for more investigations'. This implies that once a negative ultrasound scan has been reported, a GP is most likely to misinterpret this as being negative for endometriosis and normalise the patient's symptoms and be unlikely to perform any further exploratory investigations. This can be viewed as the 'normal–abnormal' aspect of diagnosing endometriosis.

> *'Even I get frustrated when I don't find anything on ultrasound. I hope this makes the woman feel listened to. I will tell the patient to contact the GP and ask for more investigations.' (Nurse 5, Priyanka, line 100).*

Continuity in care involving the same clinician was discussed as being an important factor in facilitating diagnosis, particularly in primary care. Being able to see the same GP is important for the patient and avoids the repeated collection of their medical history. If the patient is seeing a variety of GPs, then she may not necessarily disclose sensitive aspects of her medical history that may be important as part of the process of diagnosing endometriosis.

> *'Our surgery is great in the sense that it allows continuity of care - we have our own lists and so we see our own patients. I can completely see how not having continuity of care can have such a major influence on someone with suspected endometriosis. It's almost as if the patient has to restart the medical history again and has to go through so many intimate details with another clinician.' (GP 2, Carl, line 487).*

Clear medical documentation and 'forward planning' was important when facilitating a diagnosis of endometriosis. GPs in particular discuss why it is important to document a 'what to do next' plan in a woman's medical records should the original investigative path be unsuccessful. However, while this approach has its advantages, if the previous clinician has not suspected endometriosis in the first instance, then a subsequent clinician may not suspect this either and therefore delay referral to secondary care.

> *'I mean I saw a patient of one of my colleagues earlier in the week during my locum. The doctor had written a plan that specified what to do next should the original plan not work. So, I looked through and did exactly that!' (GP 3, Richard, line 172).*

Recognising and acknowledging the persistence of symptoms and the frequency with which a woman presents to her GP is an important consideration that was discussed by most of the healthcare professionals. The persistence of symptoms should act as a trigger point to question the underlying cause and is an important consideration when differentiating between 'normal and abnormal'. Once again, the success or failure of the clinician to suspect endometriosis is transferred back to the patient herself and the information she provides the clinician. The gynaecology registrar quoted below does not question her own practice of how she can better differentiate between normal and abnormal symptoms.

> *‘With endometriosis, I suppose a big part of what is normal and abnormal will depend on the patient’s history and maybe the persistence of symptoms or lack of improvement in symptoms?’ (Gynae Spr 4, Holly, line 244).*

GPs in particular discuss ways in which they attempt to empower women with symptoms persisting for a ‘long time’ by once again asking women to take charge of their symptoms and inform their doctor about symptoms that persist. The statement below implies that the persistence of unexplained symptoms is due to women themselves as they have ‘not said anything’ to the doctor.

> *‘I always find that I say to patients “why have you not said anything to your doctor? You do not have to put up with these symptoms for such a long time!”’ (GP3, Richard, line 117).*

In contrast, the gynaecologist quoted below shows insights into the complexities of diagnosing endometriosis but places the responsibility of ascertaining all the critical information from a woman’s medical history on the clinician themselves.

> *‘It really is a hidden illness. How can you quantify pain? How can you understand the sexual dysfunction? How can you understand the psychosocial impact it can have? It’s all a hidden mystery unless you ask.’ (Gynae Spr 5. Rebecca, Line 162).*

Finally, the importance of asking patients to re-return to the clinic should their symptoms not improve despite following the initially agreed management plan in primary care was discussed.

> *‘I think the key is to tell the patient to re-return if symptoms are not better.’ (GP 2, Carl, line 218).*

8.3.4 Crossing the invisible line can be problematic: the challenges of diagnosing

Diagnosing endometriosis is challenging, particularly for those healthcare professionals who lack knowledge competence (‘endo-competence’) in this area. Healthcare professionals tend to normalise women’s symptoms; either dismissing or treating them, rather than investigating them. In dismissing women's symptoms and denying the extent of endometriosis, healthcare professionals render these women invisible. See for example the response of GP1 (below), which was based on the following verbatim quote that was presented to them:

> *'Actually, should we start the investigations sooner? Like Urology, they've got the one-stop shop. You know the breast clinic have got the one-stop shop. It's one of them, could gynae do a one-stop shop to look for polycystic ovaries, to look for fibroids, you know all of the stuff that could be causing this other than endometriosis, because obviously I understand you can't do that. But could they look for more symptoms in a one-stop shop so they could be rule out sort of thing, so then you could look at different avenues.' Erika.*

> *'That's like using a sledgehammer to tap in a pin nail - i.e. we don't know what's going on with this woman and we need to get a diagnosis. This approach might be appropriate, but is it a practical and proportional way? Not necessarily.' (GP 1, James, line 395).*

Having a special interest in women's health as a GP is generally considered to be important from the focus group findings. However, these clinicians perceived a potential problem in that these GPs may increasingly refer women with vague gynaecological symptoms to gynaecology services. This would mean that women who do not have endometriosis would be blocking this valuable resource and denying other women who are more likely to have endometriosis the opportunity for a timely diagnosis.

> *'There is some evidence that GPs who have a special interest in women's health may end up referring more! They may know the rarities. Whether this is good or bad, you don't want your clinic full of people who may not have endometriosis.' (GP 2, Carl, line 216).*

Some investigative techniques can confuse the non-specialist. While a positive ultrasound scan that reveals abnormalities can be included as evidence and contribute to a diagnosis, a negative scan that reveals no issues does not preclude a diagnosis of endometriosis. Negative scans are often misunderstood by non-specialists and taken to mean that the patient does not have endometriosis. While the technical specialist, i.e. the sonographer, may be aware of this issue, the reporting system does not encourage them to alert non-specialists to this fact and this may therefore contribute to a delayed diagnosis.

> *'As a nurse sonographer, I am purely acting like a sonographer. If there are normal pelvic appearances, we unfortunately have to say its normal and no other information. Maybe we should say something like "scan difficult to do due to pain and so query other cause?"' (Nurse 1, Lisa, line 132).*

Some clinicians highlighted the limitations to their role. One nurse sonographer, for instance, discussed how she is not able to include her clinical opinion about whether endometriosis was a likely diagnosis in the absence of any abnormalities on an ultrasound scan. Although the nurse sonographer recognises the limitations of the ultrasound scan, she highlights the limitations of her role as she is unable to express her concerns that endometriosis may still be a likely diagnosis. In addition, she provides the insight that such patients are likely to be 'bounced back' as a result of symptom normalisation that subsequently leads to a delay in diagnosis.

> *'We just can't really put our own opinion on the report if its normal anatomically.' (Nurse 2, Olivia, line 129).*

> *'When I scan people, I sometimes think that this woman most probably has endometriosis. However, the ultrasound might be normal, but when you ask the woman more questions about symptoms, she has clear symptoms of endometriosis. As a nurse sonographer, I can't do anything with this information unfortunately. I can just write on the report: normal scan. Then you can see the patient getting bounced back.' (Nurse 2, Olivia, line 94).*

For the gynaecologist, the frustration of being unable to adequately measure and communicate the impact of the illness is evident. All healthcare professionals discussed endometriosis in terms of it being a 'hidden illness'.

> *'It really is a hidden illness. How can you quantify pain?! How can you understand the sexual dysfunction? How can you understand the psychosocial impact it can have? It's all a hidden mystery unless you ask.' (Gynae Spr 5, Rebecca, line 162).*

It was evident that the awareness of endometriosis as a disease and the way it is recognised and subsequently managed is limited among primary care physicians, partly as a result of medical knowledge gaps. The way in which the foundation year and GP training scheme is designed does not necessarily mean that trainees will have exposure to women's health as part of an obstetrics and gynaecology rotation.

> '*If you asked people [GPs] to name five symptoms of endometriosis, then they may struggle.' (GP 1, James, line 213).*

> '*And so, a load of trainees do not get specialty training in gynaecology. They can go straight through GPVTS training with no exposure at foundation level or GP training!' (GP 4, Stella, line 205).*

Another GP also provides insight into the disparity between women's perceptions and those of healthcare professionals with regard to the demands placed upon women in coping with their symptoms while engaging with primary care management.

> *'For the patient, this [waiting] might seem forever, but from the doctor's perspective, a few months may not be a long time. For the actual patient day in day out, with actual symptoms, the days and months may feel like a long time.' (GP2, Carl, line 54).*

It is therefore important that women with suspected endometriosis are provided with realistic expectations as to how long primary care management of their symptoms may take in the first instance.

8.4 Theme 3: Visibility in a context of belief: rendering the woman visible

Healthcare professionals had awareness that women with suspected endometriosis were being invisibilised; however, they also discussed ways in which they were able to visibilise them. This is underpinned by two sub-themes whereby clinicians first provide insights into the importance of a diagnosis of endometriosis and second appreciate the impact of the disbelief faced by women.

8.4.1 The importance of a diagnosis: rendering visible and making sense

All healthcare professionals discuss why having a formal diagnosis of endometriosis is important. A diagnosis is important in that it helps women to make sense of their bodily experiences and enables them to gain access to appropriate care. In addition, not having a labelled diagnosis for their symptoms can be frightening for women and generates uncertainty within them.

> *'Yes, without a diagnosis, you are just in limbo. You don't know if it is anything sinister like cancer or life-limiting. Whereas, when you have a diagnosis, everything is so much clear - you know the treatments, you know the symptoms, you know how serious it is or isn't.' (Nurse 2, Olivia, line 314).*

> *'If they have a confirmed diagnosis of endometriosis, then they have access to their gynaecologist, but otherwise, it's the GP or a pain specialist.' (GP 3, Richard, line 510).*

> *'Making sense of symptoms is important for women as it helps them to understand their illness better, cope with their symptoms better and subsequently gain the appropriate support.' (GP 1, James, line 473).*

In addition, having a diagnosis helps women to understand why they are experiencing their symptoms, and this in turn may influence the way in which they cope with these symptoms.

> *'Naturally, if you have a diagnosis, then coping with the respective symptoms may be easier. At least the patient is able to make some form of connection between the symptoms and is able to understand why they are happening. Without a diagnosis, there is a lot of uncertainty as to why certain symptoms are occurring.' (GP 1, James, line 473).*
>
> *'I mean, if someone doesn't have a diagnosis, but they continue to get symptoms, then I suppose it affects how they will cope. It probably means they find ways to cope with symptoms better and less likely to maybe contact a doctor about it?!' (Gynae 2, Jordan, line 282).*

For the non-endometriosis specialist, the absence of a diagnosis creates uncertainty about how to best support a woman who has unexplained symptoms. Healthcare professionals in this area are ill-equipped to recognise endometriosis and need a diagnosis to understand how best to support the women. For example, some women present to A&E due to a worsening of their symptoms and for acute analgesia. Having a diagnosis renders the women visible to A&E clinicians, which should enable them to understand how best to support these patients.

> *'Also, if the patient has been labelled with chronic pelvic pain, but without a diagnosis, then surely this has an influence on the perception of A&E clinicians towards these patients?' (Gynae Spr 4, Holly, line 335).*

Empathetic healthcare professionals also understood how a diagnosis influences a woman’s perception of herself and enables her to make sense of her bodily experiences.

> *‘It helps with the way you see yourself. It lets you put your symptoms in context. This must only be a good thing.’ (Nurse 1, Lisa, line 311).*

Having a diagnosis impacts how a healthcare professional perceives both the individual and her symptoms and therefore how they seek to help the woman. Having a diagnosis for endometriosis as opposed to a label of heavy menstrual bleeding (menorrhagia) is important for women with endometriosis, as the illness attributed to endometriosis appears to be taken more seriously. It seems that terms such as 'heavy menstrual bleeding’ are less likely to be taken seriously. In addition, while GPs recognise the importance of a diagnosis, they also explain that the correct ‘label’ must be attributed to women’s symptoms.

> *‘I think people want that label of endometriosis and that “I don’t just have heavy periods, but its linked to endometriosis”. I think there is a similar problem to bipolar disorder where people get a bit up and down with their mood. They want to be labelled as bipolar, but actually, they might have a personality disorder instead. As I say, some people want a label and unfortunately, that might not be the right label for them anyway. Maybe it goes back to the point that heavy periods might not be viewed seriously and so this is the reason why women want a label of endometriosis? Maybe people need to be aware that you don’t necessarily need the diagnosis to get the treatment in primary care.’ (GP 5, Kieron, line 361).*

8.4.2 Rendering visible: realising the impact of disbelief

During the focus groups some participants experienced a ‘eureka’ moment of realisation about the extent of the problems women with undiagnosed endometriosis encounter. This moment is powerful in appreciating how clinicians also perceive the experiences of women subsequently diagnosed with endometriosis. Gynaecologists in particular recognised the magnitude of the problems that women experience when they are not believed and are rendered invisible by GPs.

> *'This woman's experiences sound like they have been terrible with doctors. She really does want to be believed, doesn't she? I must admit, it's not often I feel lost for words, but right now, I really do.' (Gynae 3, Mamta, line 191).*

Part of the realisation concerns the impact on women of being disbelieved; the impact of healthcare experiences, whether positive or negative, will travel with these women in subsequent medical encounters. In the following instance, the gynaecologist has noticed 'defensive' behaviour towards them by some women when they present at an outpatient clinic. This defensive behaviour may be due to women not being believed in previous medical encounters.

> *'Clearly this poor woman has been severely affected by her experiences with the medical world. I can see why women would feel defensive when they see us in clinic.' (Gynae spr 5, Rebecca, line 181).*

Becoming aware of the way in which women seek further guidance about their symptoms, for example from online forums, was a moment of realisation for the gynaecologist quoted below.

> *'This particular woman really has thought about this, hasn't she? It sounds like an online platform is also very powerful - especially with women advising each other. I think this is a much bigger problem than we realise.' (Gynae 1, Gopal, line 177).*

The gynaecologist now understands that the 'problem' women with suspected endometriosis face in terms of being initially believed and subsequently diagnosed, is greater than they had anticipated.

When experiencing such a moment of realisation, one GP wonders:

> *'Do we need to support the less demanding patients more and tell them they don't need to put up with the symptoms?' (GP2, Carl, line 68).*

The implications of this GP's realisation are that in their future practice the prevailing context in a consultation with a woman with suspected endometriosis is more likely to be one of belief. In supporting less demanding, hidden patients, this GP may render them visible in the future.

Summary

The findings from this chapter are complemented by the findings from the grounded theory phase involving participants diagnosed with endometriosis. This chapter has provided insights into the reasons for the delay to diagnosis from a healthcare perspective. These insights can be considered to fall within one of the three following themes: endometriosis is peppered with discrimination, invisibility and visibility. In the next chapter, I will focus on a cohesive commentary that brings together the findings from both phases of the study.

Chapter 9 – The overarching chapter: connecting the voices from both phases of the study

9.1 Introduction

The grounded theory 'making sense of a fractured life' conceptualises the perspectives of women who experience a delay to diagnosis of endometriosis. To link the findings from phase 1 with those from the focus groups with healthcare professionals (HCPs) in phase 2, the data from the latter have been selectively coded to identify both existing and new concepts that relate to the women's concerns around making sense of their fractured lives.

The aim of the HCP phase of the study was to further build upon the grounded theory developed from the experiences of the participants with endometriosis and provide insights into the delays to diagnosis from another relevant perspective. As highlighted in the original scoping review in chapter 2 and the findings from this doctoral study, delays to diagnosis occur because of decisions made or actions taken (or not taken) by individuals from each of these groups. When conducting the focus groups with the HCPs, specifically selected verbatim quotes were presented to them to sample for key concepts generated from participants with endometriosis. The purpose of this was to generate additional data to augment the perspectives of women with endometriosis and gain vital insights into HCPs' experiences of diagnosing endometriosis. In this chapter, the combined findings from both phases of my research will be discussed, presented as an initial synopsis followed by a more detailed discussion of specific key points.

9.2 Initial synopsis

The journey for women with suspected endometriosis begins when they recognise a fracturing of their life because of abnormal bodily experiences. This fracturing subsequently leads these women to realise that 'there is a problem'. Some women normalise their symptoms and try to cope with them, while others seek medical help in an attempt to make sense of their abnormal bodily experiences.

When seeking help, particularly in primary care, it appears from the evidence gleaned during each phase of the study that there is a disparity in understanding between women with suspected endometriosis and their HCP. Some women perceive their symptoms as bodily experiences where ‘something is not right’, whereas a clinician will seek concrete signs and symptoms. To understand delays to diagnosis, we need to understand how women are packaging and presenting their symptoms; women should not be expected to provide ‘clear symptoms’. If women feel that their complaint(s) have not been taken seriously by their HCP, then they will seek other sources of information to make sense of their symptoms; these sources include their friends and family and online forums such as those operated by the charity Endometriosis UK.

During a medical consultation, both the woman who suspects she has endometriosis and the HCP react to and adapt to each other’s behaviour. As women reattend their GP’s practice on multiple occasions to seek medical help, they begin to adapt to the perceived behaviour(s) of their clinician. The clinician also adapts to their perception of the woman’s behaviour. For instance, if a woman perceives that she has been dismissed during a consultation, she may not return to seek further help. What is important to note is that neither the woman with suspected endometriosis nor the HCP openly discuss the impact each other is having on the medical consultation, but that they both indirectly adapt to each other’s behaviour. In some cases, a woman who suspects she has endometriosis may bring a significant other with her into the consultation. The influence and impact of this person differs for the woman and for the HCP. For the woman, the other person represents validation of her symptoms and therefore power. However, for the HCP, the significant other represents a threat, and as a result of their presence the HCP is more likely to visibilise the woman and consider referring her to the gynaecology department.

Symptom normalisation was a common occurrence, both among women with suspected endometriosis and HCPs. Women frequently normalised their bodily experiences (or symptoms) prior to seeking help; they also normalised their symptoms if they were assured by their HCP that their symptoms were ‘normal’. HCPs also normalised a woman’s symptoms, for example if they believed her symptoms were not worthy of further investigation, if the clinician lacked knowledge about endometriosis, or if the initial ultrasound investigation did not show any abnormality. This combination of normalisation by both the woman and her HCP is one of the factors that contributes to a delay in diagnosis. Importantly, symptom normalisation by either party had an impact on a woman’s self-identity; if she perceived that her symptoms were part of ‘being a woman’, then she continued to normalise them.

The GP is a powerful gatekeeper; one who normalises the symptoms of a woman who suspects she has endometriosis, at certain times refusing to refer her to gynaecology, and at other times commencing hormonal treatment to mask her symptoms. Despite their role as gatekeeper, some clinicians are unaware that BSGE centres exist. Even after receiving a referral, a woman may encounter a registrar or a consultant who may or may not suspect endometriosis. The clock continues to tick. When clinicians have a lack of suspicion of endometriosis as a potential differential diagnosis, this in turn influences the way in which the clinician communicates with their patient. Some women with suspected endometriosis are labelled as having ‘chronic pelvic pain’; this label can result in these women being discriminated against. As soon as a woman presents to A&E with chronic pelvic pain, they tend to be judged by HCPs, and this judgement can have a negative influence on the care provided, further delaying a diagnosis. As a result of these experiences, women lose faith in the healthcare system.

During a consultation, giving a woman the time to discuss the way in which her symptoms impact her life can be a powerful moment for her to collect her thoughts. This moment allows the patient and the HCP to connect and ‘speak the same language’. When a clinician empathises with a woman, for example by saying ‘I am so sorry you are going through that’, this can empower the woman and create a safe space between the two, facilitating further discussion. It is only after this powerful moment that the biomedical perspective should be sought, enabling more information to guide a diagnosis to be obtained. The approach to the style of communication adopted by HCPS must change; this will require cultural change. A referral to a gynaecology specialist is not the only answer to improving delays to diagnosis of endometriosis, but it is a start.

Endometriosis can have a major impact on a woman's intimate relationships. This means the condition often needs to be considered through the lens of a couple-centred approach. The impact of dyspareunia, for instance, influences a woman's identity as a female and her role as a woman. It can also have an impact on her partner.

Exploring the wider impact of a woman's symptoms, employers do not always understand the symptoms of endometriosis and so they ignore them or fail to take them into account. The children of women with endometriosis may notice changes in the way their mother behaves; this again can influence the way a woman perceives herself and can have an impact on her female identity.

Girls and young women are led to believe that painful periods are normal, by the school nurse, the education system, the media and HCPs. Young males lack an understanding of menstruation generally and the symptoms of endometriosis specifically; therefore, how can they be expected to support their female partner if she has suspected endometriosis, or encourage them to seek help? Endometriosis among adolescent females is an increasing problem; if girls lack knowledge of 'what is normal', they have no way of expressing their symptoms to their GP. As the GP also often lacks an understanding of adolescent endometriosis, they will normalise the young woman's symptoms. This can impact an adolescent female's identity.

The research findings presented in this thesis form a crucial and connecting part of the wider picture that is endometriosis and specifically the part of the iceberg that involves the delay to diagnosis of endometriosis.

9.3 Specific considerations from each phase of the study

The complementary and shared concepts between both phases of the study show that making sense of women's bodily experiences is a concern that is common to both HCPs and women with undiagnosed endometriosis. These concepts also point to where there is a clash of perspectives and meaning is obscured, resulting in a delay to diagnosis. Below, I will discuss the following concepts, which have emerged from each of the phases of the study:

- **Self-reflection**
- **Creating meaning: the difference between bodily experiences and symptoms**
- **The invisible line to referral to secondary care and the contradictory definitions of 'success'**
- **Structural discrimination and the flow of meaning**
- **Crossing the invisible line and being rendered visible**
- **Healthcare professionals' prejudices towards patients with endometriosis**

9.3.1 Self-reflection

Neither women with suspected endometriosis nor the HCPs belonging to the cohorts investigated here appeared to reflect on their own perspectives and behaviours and how they as individuals can influence the delay to diagnosis of endometriosis. For instance, there is an opportunity for women to challenge their normalisation (either by themselves or by others) earlier, which many neither perceive nor pursue. Similarly, HCPs are unaware of the challenges that women with undiagnosed endometriosis encounter when first experiencing the abnormal bodily experiences that prompt them to seek medical help. Some GPs are unaware of their lack of knowledge and therefore cannot challenge or improve their practice in relation to diagnosing endometriosis.

Both the women with suspected endometriosis and the HCPs blame other people with regards to the delays to diagnosis. Neither demonstrate insights into their own role and how they may have individually influenced the delay to diagnosis. For example, in phase 1, women discussed not being believed by their HCP and, as a result, felt this was the reason for the delay to diagnosis. However, none of the participants in phase 1 discussed directly how they also played a part in the delay to diagnosis (i.e. through not always presenting to their GP as soon as they recognised abnormal bodily experiences). In contrast, the HCPs tended to blame other HCPs for the delay to diagnosis, as opposed to questioning their own medical practice and its influence on the delays to diagnosis of endometriosis.

Both women with suspected endometriosis and HCPs seek to make sense of the women's bodily experiences but, to do this, they must be committed to actually understanding one another. Women with suspected endometriosis initially see their clinician on the basis that there is mutual trust between the two of them. When interacting with HCPs who are not familiar with endometriosis, women might benefit from recognising the normalising behaviours of others and learning how to present and package their symptoms in a way that they think their HCP will understand.

9.3.2 Creating meaning: the difference between bodily experiences and symptoms

Endometriosis is an invisible illness with mostly invisible signs and symptoms, many of which could be explained by other diagnoses. Both the HCPs and the women with endometriosis sought to make sense of what the women perceive to be bodily experiences and the HCPs regard as signs and symptoms. Bringing these perspectives together has provided additional insights that build on the findings from each of the phases. HCPs are taught to rely on measurable, hard data. Endometriosis presents largely as subtle, difficult to measure signs, including pain, fatigue or vaginal bleeding. Where, when and how pain is felt can indicate endometriosis but does not prove it. The current data collection instruments used in primary care are unable to capture the soft data relating to subtle signs and symptoms, and making sense of these signs and symptoms is problematic. What is important here is to understand that women with suspected endometriosis may not necessarily present with specific symptoms. They may in fact discuss abnormal bodily experiences, or the impact of these bodily experiences on their quality of life. Therefore, careful and meticulous medical history taking during a consultation is of key importance.

An important difference between the perspectives of women and those of HCPs is the way in which the bodily experiences and signs/symptoms are first presented during a medical consultation. Prior to seeking medical help, when women perceive that ‘something is not right’ they sometimes view this as an abnormal bodily experience and then either cope with this or seek medical attention. When they do eventually seek medical attention, there is a gulf between the perceptions of both patient and HCP, which manifests in the language they use to communicate and define the problem. Whereas women perceive the ‘something is not right’ moment as a bodily experience, HCPs seek to conceptualise the women’s explanation in terms of abstract signs and symptoms, which together must fit within a predefined category in a set of guidelines. The women’s bodily experiences, however, cannot always be expressed and measured as predefined signs and symptoms and therefore cannot easily be recognised and diagnosed. An important difference between the two populations is their different perceptions of the same phenomenon and the language they use to describe it: fundamental differences in the way the other communicates the problem obscures meaning and creates a context of disbelief between the two parties, delaying diagnosis.

9.3.3 The invisible line to referral to secondary care and the contradictory definitions of ‘success’

The invisible line to referral to secondary care and contradictory definitions of ‘success’ are two important and closely related differences identified in the two phases of the study. A clinical diagnosis relies on hard data obtained during a diagnostic procedure; for instance, during a laparoscopy, visible endometriosis is excised and sent for histological analysis. Consistent with the endometriosis guidelines produced by NICE (2017), GPs will engage in symptom management within the context of primary care, for example trying analgesia or hormonal treatment in the first instance.

The treatment received following a diagnosis, however, can be life-altering – for good or ill. While the NICE guidance includes a clear pathway for referral to secondary care, GPs describe a threshold, an **‘invisible line’,** that women with endometriosis must cross to be referred to secondary care. For some GPs this line is thicker, wider, and stronger. These GPs may perceive themselves to be protecting often very young women from irreversible outcomes (for example a hysterectomy or menopause-inducing hormone treatment). *Such GPs perceive success as treating the women within primary care: a diagnosis is not always necessary for them.* Symptom management options at a GP's disposal (for example, the oral contraceptive pill, the Mirena coil or analgesia) can sufficiently mask and mitigate the symptoms of endometriosis for some women who settle for this treatment. Such women are not referred to secondary care and therefore do not undergo a diagnostic laparoscopy to confirm endometriosis, nor do they need one.

For women with undiagnosed endometriosis whose condition is not sufficiently managed, the lack of a diagnosis – the lack of an explanation for their bodily experiences – is troubling. *For these women, success is a diagnosis that makes sense of what they are experiencing*. In refusing them a referral to secondary care or access to investigations (such as an ultrasound scan) that could identify their illness, the GP is perceived to be normalising their symptoms and resisting referral. These contradictory perspectives as to what constitutes success create a meaning gap and cause dissonance: the women are dissatisfied and feel ignored, unheard and rendered invisible. The women subsequently normalise their symptoms, leading to a delay in diagnosis.

9.3.4 Structural discrimination and the flow of meaning

Structural conditions, for example, regulations, policies, guidelines and healthcare systems, will shape the behaviours of both patients and HCPs. Within the NHS, structural conditions can intentionally or unintentionally discriminate against some groups of patients. The HCPs noted that there is structural discrimination against women with undiagnosed endometriosis, reflected in the lack of sufficient training for relevant clinicians and the lack of time during primary care consultations in which to investigate a woman's issues and concerns. Given the very different ways in which women and HCPs perceive women's bodily experiences, the time required to reconcile these perspectives and create shared meaning is often more than the time that is allocated during a medical consultation. Both the lack of training and the lack of time during a consultation contribute to delays in diagnosis of endometriosis.

Structural conditions will therefore impact on the flow of meaning between a woman and her HCP. The flow of meaning is an important new concept. Meaning flows in the following ways: between patient and clinician, between clinician and clinician, and between the result of an investigation to clinician. The usefulness of the meaning conveyed depends on the endometriosis-competence of each person involved. In the most egregious cases, a GP gives a woman's evidence of endometriosis no credence, orders an ultrasound scan to investigate a different problem, and therefore the investigation is for the wrong problem and returns a negative result. The nurse recognises endometriosis, but protocols and templates deny him or her the opportunity to communicate that recognition. The GP misinterprets the 'negative ultrasound scan' result, and the woman is normalised, dismissed and rendered invisible. The compromised meaning that flows within the healthcare service thwarts the woman's need to make sense of her symptoms and delays her diagnosis. The role played by the flow of meaning (accurate and inaccurate) as generated through the diagnostic system is a new concept for women with undiagnosed endometriosis and suggests a potentially fruitful area for future research.

9.3.5 Crossing the invisible line and being rendered visible

For a woman with undiagnosed endometriosis, making sense of her bodily experiences requires a diagnosis, which in turn means that she has to cross the invisible line. To do this she must manage her subtle signs of illness, dressing and acting in such a way as to convey her unwellness to an HCP in a credible way. She will package and present her symptoms to maximise her credibility. For some GPs, making a referral to secondary care represents a personal failure, i.e. failure to manage a patient's symptoms in the community. In such cases, only when a woman can demonstrate that the management of her symptoms in primary care is failing, by providing her GP with what they perceive to be credible evidence, will that GP refer her to a specialist.

If a woman on her own fails to convince her GP or non-specialist gynaecologist to refer her to specialist care, she may bring a significant other to a future consultation. This significant other verifies the subtle signs that she presents and brings an additional perspective about the impact of the illness on the woman and perhaps also on their personal relationship. GPs and non-endometriosis specialists pay special attention to this supporting evidence, and this extra credence often pushes the woman over the line. The woman is rendered visible through the influence of another person (usually a male individual) or through the result of an investigation that is reported to be abnormal.

Interestingly, neither the women with suspected endometriosis nor the HCPs discussed the concept of invisibility with each other during consultations. They both, however, recognised the impact of invisibility, but in different ways and thus different responses. For some women with undiagnosed endometriosis in a context of disbelief in a consultation, this will halt the diagnostic process, as they accept being rendered invisible, while for others, it will delay diagnosis.

9.3.6 Healthcare professionals' prejudices towards patients with endometriosis

In phase 1, women with endometriosis provided extensive insights into how they perceived feeling judged by HCPs. They discussed feeling stigmatised during their repeated medical consultations. This finding is corroborated by the HCP phase of the study, whereby clinicians openly discussed their prejudices about 'the endometriosis' patient. This finding provides an insight into why there may be delays to diagnosis due to HCPs failing to adequately engage with these women's concerns.

9.4 An overview of the links between the two studies

The two phases of this study integrate and completement each other, contributing to our understanding of the delays to diagnosis experienced by women with endometriosis; this is a problem that is recognised by both parties.

What comes across very strongly from the HCP phase of the study is that both the healthcare process and the HCPs themselves render women with endometriosis both invisible and visible. Primary care renders the women invisible, while secondary care renders them visible. Women with suspected endometriosis recognised this invisibility when primary care clinicians either dismissed their symptoms or did not believe them. The hidden challenge for the invisible woman seeking to make sense of her experiences is to cross the invisible line and obtain a referral. To achieve this, she must render herself visible to the referring clinician by raising the credibility of her evidence. Often, she does this by bringing a significant other into the medical consultation. While this was clearly apparent from the women's data, the importance of the contribution of a significant other was understated but also highlighted by the HCPs in phase 2 of the study. HCPs explicitly described how the influence of another person during a medical consultation altered the dynamic of the interaction, and therefore they were more likely to refer the patient to secondary care for further assessment.

The following chapter will discuss the findings from both phases of the study in relation to the wider literature, to explore the reasons for the delays to diagnosis of endometriosis.

PART 4 – DISCUSSION, REFLEXIVITY AND CONCLUSION

Chapter 10 – Discussion

10.1 Introduction

An explorative approach will reveal the unexpected. What is unexpected in this study are the fundamental impacts on female identity. These impacts are caused (i) by women's bodily experiences due to the disease endometriosis; (ii) by the women themselves, who discount and normalise their experiences; (iii) by significant others, who ignore and normalise the women's bodily experiences; and (iv) by healthcare professionals (HCPs), who invisibilise women during their healthcare encounters. These influences combine to diminish a woman's female identity, which in turn affects how she makes sense of her fracturing life and encourages her to use coping strategies, which slow the pace of sense-making and influence and inhibit healthcare seeking behaviours. A diminished female identity thus directly contributes towards a delay in diagnosis.

As well as playing an indirect role in delaying diagnosis through undermining women with undiagnosed endometriosis, HCPs can also directly delay diagnosis: they may intentionally and directly delay diagnosis by seeking to treat women in primary healthcare or unintentionally delay diagnosis by ordering inappropriate tests and misinterpreting the results. The design of the healthcare system and in particular the way in which some clinicians navigate through the differential diagnosis process can also delay diagnosis.

The grounded theory in this study provides an explanatory framework demonstrating that the main concern of women during the often protracted period prior to being diagnosed with endometriosis was making sense of a fracturing life. The way in which the women who participated engage in sense-making is heavily impacted by the prevailing context of **refusal**, **disbelief** or **belief.** These three contexts are created in the moment by the actions and interactions between the women and significant others, friends, strangers and/or HCPs and are shaped by the perceived power dynamics operating within each encounter. The contexts of refusal and dis-belief are both heavily influenced by the social constructs of menstruation and the impact of taboo associated with this. In the face of the constraining behaviours of others, the women's experiences within and transitions between the three contexts and their journey through the process of diagnosis depends on a number of key influencing factors. These include their perception of their female identity; their investigative behaviours (especially: ignoring, normalising and coping); and their perception of the risk of harm and consequent propensity to seek help (both non-medical and medical).

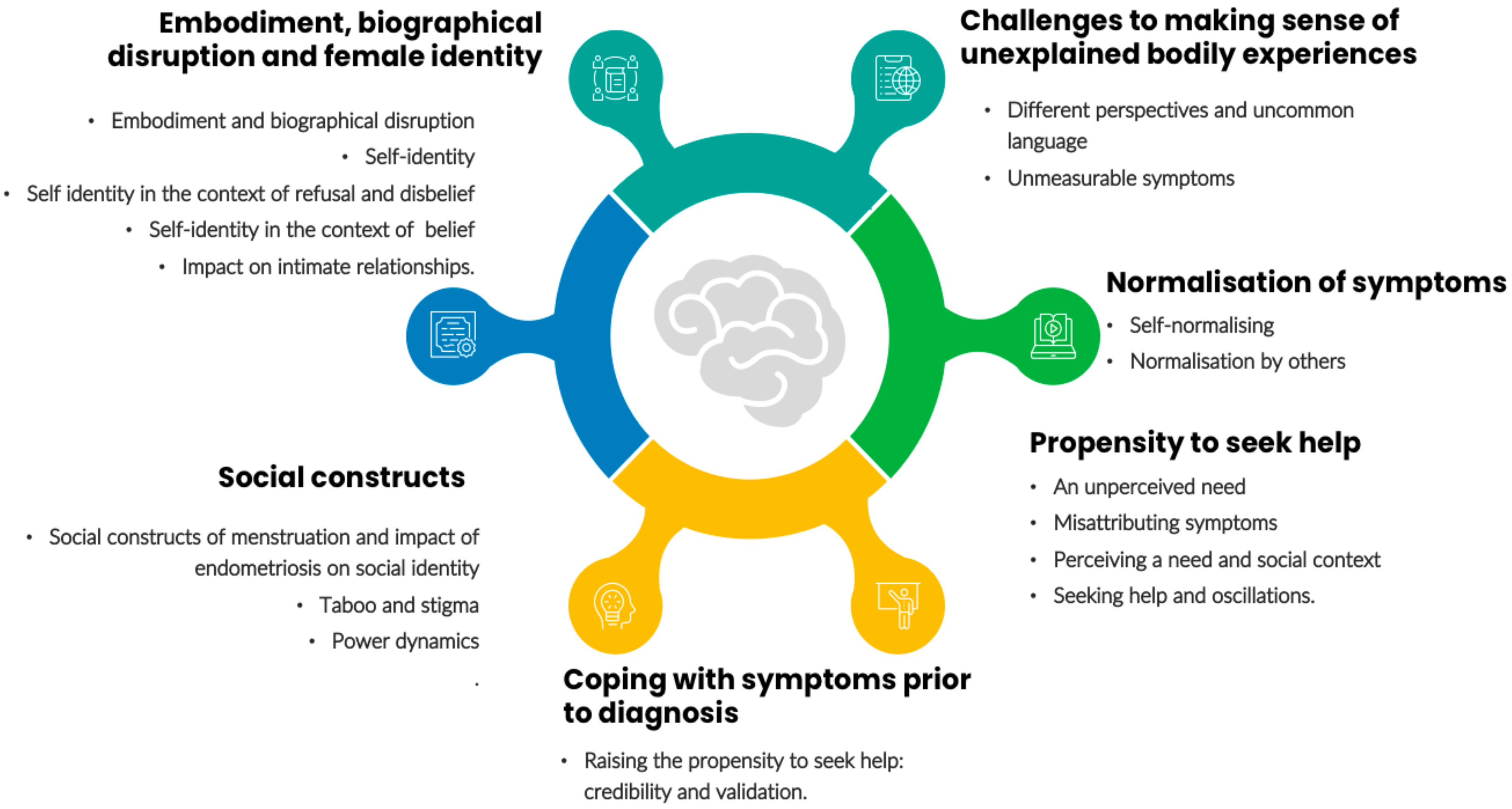
These key concepts are woven together into a dynamic theory that captures the complexity of what is happening to women with undiagnosed endometriosis as they seek to make sense of their fracturing lives. This theory organises the highly fragmented extant literature, which tends to focus on individual factors associated with delay to diagnosis in isolation. By contrast, this theory emphasises the interdependency of these factors. This dynamic understanding enables us to identify what we must change about the process of diagnosis to support female identity and reduce the delays to diagnosis in a way that the extant literature fails to do in a coherent and integrated manner. As far as I am aware, this study is the first constructivist grounded theory exploration of women's experiences of being diagnosed with endometriosis in the United Kingdom; it focuses specifically on the pre-diagnosis phase.

Concepts arising from the grounded theory are further explored in a thematic analysis of interviews with HCPs. The three themes that emerged from the thematic analysis are 'endometriosis is peppered with discrimination', 'invisibility: invisible women and the invisible line for referral' and 'visibility in a context of belief: rendering the woman visible'. The golden thread that links both phases of the study into a whole is invisibility: how women perceive and experience this and how HCPs contribute to this. Other key findings from the thematic analysis include insights into the clinical relationship between the patient and clinician, the clinician's invisible threshold for referral to secondary care, and the importance that some women place on obtaining a diagnosis of endometriosis. It is the novel two-phase research design of this PhD that creates a new understanding about the delays to diagnosis of endometriosis.

In this chapter, I will explore the key findings from both phases of the study within the context of the wider literature and in relation to the research aim: to explore and understand the experiences of women who have had a delay to diagnosis of endometriosis. This critical discussion will inform the interpretation and application of the study findings to practice, with a focus on reducing delays to diagnosis of endometriosis, which will be discussed in the implications section. The chapter begins with a discussion of the key concepts in relation to the delay to diagnosis of endometriosis, before going on to consider the impact on female identity. A diagrammatic representation of the key concepts for discussion in this chapter is shown in Figure 25.

Prior to discussing the key concepts shown in Figure 25, it is important at this stage to recognise the work of Caroline Criado Perez (2019). In her book 'Invisible women', she discusses the prejudices that women consciously and subconsciously encounter in the world. Perez (2019) discusses the gender data gap and includes eye-opening examples to illustrate her point of the inequality and bias that women experience in the world. One example includes the average size of a mobile phone and how this is more likely to be physically large for a woman’s hand, compared with how it fits in a man’s hand (Perez, 2019). Perez (2019) very clearly explains how the world is designed for men and, as such, this results in discrimination against women in society. Most importantly, Perez's (2019) book provides an opportunity for the reader to confront and openly discuss such issues of bias and discrimination against women. The grounded theory and findings from the healthcare professionals in this doctoral study resonate with the key messages in Perez's book. These will be further discussed in this chapter and considered within the scope of the wider literature.

Figure 25. The key concepts that emerged from the two phases of the study.



Embodiment, biographical disruption and female identity

- Embodiment and biographical disruption
- Self-identity
- Self identity in the context of refusal and disbelief
- Self-identity in the context of belief
- Impact on intimate relationships.

Challenges to making sense of unexplained bodily experiences

- Different perspectives and uncommon language
- Unmeasurable symptoms

Normalisation of symptoms

- Self-normalising
- Normalisation by others

Propensity to seek help

- An unperceived need
- Misattributing symptoms
- Perceiving a need and social context
- Seeking help and oscillations.

Coping with symptoms prior to diagnosis

- Raising the propensity to seek help: credibility and validation.

Social constructs

- Social constructs of menstruation and impact of endometriosis on social identity
- Taboo and stigma
- Power dynamics

10.2 Challenges to making sense of unexplained bodily experiences

This study identifies that women face significant challenges as they encounter and notice adverse bodily experiences, which are later medicalised as unexplained symptoms. Prior to seeking informal help or formal medical help, women must first recognise their symptoms as abnormal. The way in which women recognise their bodily experiences as abnormal, and the way in which others respond to these women's experiences, influence the way in which women make sense. Currently, there is no literature that explores the way in which women with unexplained symptoms suggestive of endometriosis navigate their way through to diagnosis. This PhD study adds to the existing literature by exploring how women recognise unexplained symptoms as abnormal and how they navigate through and negotiate this process within themselves and with others. An understanding of this creates new knowledge of the reasons for the delay to diagnosis. These challenges are discussed from two perspectives: the differences in symptom communication between the woman and the clinician, and the challenges of unmeasurable symptoms.

10.2.1 Different perspectives and uncommon language

This study highlights that when women first present to a GP with endometriosis-related concerns, they are unlikely to have fully made sense of their bodily experiences and therefore may find it challenging to communicate these experiences in a language that the clinician is able to understand. This study has also identified that there is often a disparity between the language women with suspected endometriosis use and the medical perspective and language a clinician uses during a consultation. Clinicians primarily focus on signs and symptoms, whereas women discuss their perceptions of their abnormal bodily experiences. For endometriosis research, this represents new knowledge; the difference in interpretation and communication between both individuals is important: if the clinician is able to understand that some women will present with what the clinician may otherwise consider to be vague descriptions of the presenting complaint, then the clinician and patient will have the opportunity to build a more effective rapport when obtaining a medical history. This finding is novel in that it demonstrates the importance of clinicians supporting women during a consultation to gather vital information that may indicate endometriosis. This is one of the ways in which the delay to diagnosis of endometriosis can be reduced.

Andersen et al (2009), in their review article, note that for a bodily sensation to be defined as a symptom, the individual (patient) will need to undergo a process of interpretation in relation to their social context. It was evident from the grounded theory in this study that this process varied for each woman and was influenced by her social circumstances. Exploring the wider literature, Bernhardson et al (2021) analysed retrospective accounts of 61 individuals with lung cancer in Denmark, Sweden and England. They found that before bodily sensations suggestive of lung cancer were interpreted as symptoms, individuals needed to legitimise these sensations. In this PhD, when some women with suspected endometriosis experienced normalisation of their bodily experiences by others, it led the women themselves to normalise their experiences, which subsequently reduced the legitimacy of these experiences.

10.2.2 Unmeasurable symptoms

From the phase one findings, women with suspected endometriosis may present with varied and unmeasurable symptoms, which are frequently mislabelled as being medically unexplained symptoms. Literature from other areas of medicine provides further insights into the way primary care physicians manage medically unexplained symptoms. A focus group study by Rasmussen and Ro (2018) involving 23 GPs showed that when clinicians approached ‘medically unexplained symptoms’ using a biopsychosocial approach, compared to a biomedical approach, more information could be obtained from a patient. In terms of suspected endometriosis, while a biomedical approach is very important, if this is combined with a biopsychosocial model it may encourage women to disclose more information and therefore lead to an earlier suspicion of endometriosis as a differential diagnosis.

The combined issues of different perspectives, the lack of a common language and unmeasurable symptoms make communication between women with undiagnosed endometriosis and HCPs problematic and creates a context of disbelief. The HCP normalises and invisibilises a woman at the cost of her female identity and halts the diagnostic process.

10.2.3 Normalisation of symptoms

Endometriosis is challenging to diagnose as there is huge variation in what might be considered normal experiences of menstruation. The grounded theory developed here explains that women's perceptions of what is considered normal menstruation varies, which leads to variation as to the meaning attributed to bodily experiences and the recognition of abnormal symptoms; subsequently, there is variation in the perceived risk of harm to quality of life and the consequent propensity to seek help. The disparity of meaning attributable to symptoms makes it difficult for a woman to make sense of her bodily experiences, rendering her vulnerable to the normalising behaviours of HCPs and significant others.

Zanden et al (2021) conducted a focus group study involving 23 women diagnosed with endometriosis and found similar findings to this PhD in terms of symptom normalisation. However, Zanden et al (2021) use the terms 'barriers' and 'facilitators' and discuss isolated incidents of normalisation rather than seeking an understanding of the dynamic connections among different factors. The grounded theory study from this PhD, however, provides a dynamic explanation of women's behaviour when making sense of their fracturing life as well as explaining what influences this behaviour in terms of structural conditions (the diagnostic process) and contexts and interactions with significant others and HCPs. It is the interconnectedness of these factors that explain the delays to diagnosis. Next, the normalisation of symptoms is discussed from the perspective of (i) self-normalisation by women with suspected endometriosis and (ii) normalisation by other people.

Self-normalising

This grounded theory explains that women with undiagnosed endometriosis will often self-normalise their symptoms as an expected part of menstruation, especially if the symptoms do not unduly impact their daily lives and their quality of life remains intact. This resonates with Alonzo's (1984) concept of 'containment', whereby if a bodily sensation can be incorporated in an individual's normal life, then it may not be considered a symptom. This grounded theory supports the extant literature and highlights the importance of adopting a sociocultural approach when undertaking a medical consultation with a patient with suspected endometriosis.

Various studies (Ballard, Lowton and Wright, 2006; Facchin et al, 2018; Grundstrom et al, 2016) discuss symptom normalisation prior to seeking medical help, but do not provide the conceptual detail to understand *how* symptom normalisation occurs. This grounded theory study explains that symptom normalisation prior to seeking medical help occurs for multiple reasons: the normalising behaviours of a significant other, women's understanding of menstruation per se and what they consider normal menstruation, and denial in relation to their symptoms.

Symptom normalisation is commonly seen prior to the diagnosis of many other medical conditions. Leventhal, Phillips and Burns (2016) discussed the common-sense model and proposed that individuals may attribute their symptoms to conditions known to them or to conditions that they feel best fit with their symptoms. Genius and Bronstein (2017) developed a theoretical model to explain that as part of the process in which individuals make sense of 'health challenges', they look for normality. The women with endometriosis who participated in phase 1 of this study also sought normality prior to their diagnosis and this may go some way to explaining why there was a delay in their presentation to a clinician.

Bury (1982), through his seminal work involving patients with rheumatoid arthritis, found that younger patients were less likely to think that their symptoms were related to rheumatoid arthritis as they thought the disease was more likely to affect 'older' individuals. These findings resonate to some extent with the endometriosis participants in this PhD: younger woman will tend to place less credibility on their symptoms and are more likely to believe that their symptoms are normal, or at least should be tolerated. Randhawa et al (2021) conducted a cross-sectional study involving 442 participants aged 15 to 19 years and found that these individuals lacked knowledge about endometriosis when compared with other illnesses such as diabetes. In addition, they provide significant insight into the knowledge gaps adolescent girls have in relation to what is considered normal menstruation (Randhawa et al, 2021). Low et al (2015) interviewed 26 women with symptoms suggestive of a gynaecological cancer, and they found that these women normalised their symptoms based on their age and sex. The findings from both Randhawa et al (2021) and Low et al (2015) support the theory from this current study whereby women self-normalise their symptoms

Gabe, Bury and Elston (2004) offer evidence to show that the way the women make sense of their bodily experiences is influenced by their social circumstances. From the current study, it was evident that the normalisation of abnormal symptoms in a context of disbelief by their mother or school nurse is more commonly experienced by younger as opposed to older women. A study by Edwards, Knoche and Kumru (2003) found that the school playground was an important area for children and offered a space for girls to discuss issues surrounding menstruation. In our study, while women did not discuss their experiences of the school playground, they did describe the way in which girls at school compared stories about menstruation and how this impacted on their perception of 'normality' and their self-normalising behaviours.

The grounded theory generated within this PhD explains how women perceive the credibility of their symptoms to be weak and therefore self-normalise their symptoms and do not initiate or suspend seeking medical help. It is not just the misinterpretation of symptoms as normal, but the woman's perception of the credibility of her symptoms that can lead to a delay in seeking medical help. This is a new insight from this PhD study. There are few studies that provide such in-depth insight into the moment a woman's perception of her symptoms changes from normal to abnormal, triggering her to seek help.

Various public health campaigns have been conducted and, reassuringly, menstrual wellbeing education has been added to the primary and secondary school curriculum in England (Endometriosis UK). This should increase awareness of 'normal menstruation' and prompt young women to seek help if they have any concerns. In the USA, the ‘Endo What’ school nurse initiative was designed to raise awareness of endometriosis; however, no studies have been conducted to evaluate its effectiveness. The present study emphasises the need for similar endometriosis awareness campaigns in the UK.

Normalisation by others

Some of the women with endometriosis who participated in phase 1 of the study discuss the influence of others in the normalisation of their symptoms (often their mother and HCPs) when attempting to access to healthcare services. These findings are consistent with the existing literature base (e.g. Ballard, Lowton and Wright, 2006; Pugsley and Ballard, 2007; Ghai et al, 2020).

Normalisation of the huge variation in bodily experiences and symptoms is discussed by both women with endometriosis and HCPs. This study explains that the normalisation of symptoms by significant others and HCPs reduces the credibility of a woman’s evidence to herself, reduces her perception of the risk of harm to her quality of life, diminishes her female identity and reduces her sense of autonomy. Normalisation of abnormal symptoms is dangerous, the *least* impact of which is delay to diagnosis of endometriosis. Fernley (2021) conducted a thematic analysis of 49 online accounts from women with endometriosis in Australia by using a Google search. Her findings showed that the normalisation of pain and symptom dismissal by clinicians contributed to the delay in diagnosis of endometriosis (Fernley, 2021). However, she did not provide any information on exactly how this process of normalisation occurs.

10.3 Propensity to seek help

Health-seeking behaviour is complex and multifaceted. The findings from this study led me to explore the literature on behaviour related to illness, first described by Mechanic and Volkart (1960), who defined illness behaviour as ‘the ways in which a given symptom may be differently perceived, evaluated and acted (or not acted) upon’. The four ways in which individuals respond to illness include how common it is, how familiar they are with it, the extent of being able to predict the end outcome for that illness and how much of a threat it poses (Mechanic and Volkart, 1960). Next, a woman's propensity to seek help for suspected endometriosis is discussed.

10.3.1 An unperceived need

The grounded theory shows that most women find it challenging to make sense of their symptoms and raise their propensity to seek help to a point where they actually do seek medical help. It is clear from previous research in other areas of medicine that simply having knowledge about abnormal symptoms is not enough to promote health-seeking behaviour (Knight et al, 2002). This grounded theory explains that, from the women's perspective, it is not so much that the women delay diagnosis because they do not seek help for acknowledged abnormal bodily experiences but rather that they do not yet perceive their bodily experiences to be abnormal and therefore do not perceive a need for a diagnosis.

10.3.2 Misattributing symptoms

This study highlights that the symptoms of endometriosis are not always 'clear cut' to women and that therefore making sense of their symptoms sufficiently to warrant seeking medical help takes time, contributing to a delay in seeking help. Published evidence suggests that when an individual experiences a symptom, over time they learn to make sense of it (Smith, 2005; de Nooijer, Lechner and de Vries, 2001) although they may not recognise the symptom(s) as a problem. A study by Koldjeski et al (2003) found that prior to seeking help, women with suspected ovarian cancer misinterpreted their symptoms thus delaying diagnosis. A recent cross-sectional survey by Rhandawa et al (2021) showed that the majority of adolescents had no knowledge of endometriosis. This important study provides insight into the fact that young women may not have the knowledge and understanding to attribute their abnormal bodily experiences to endometriosis and therefore may not seek medical help. Their findings resonate with those of this PhD study.

10.3.3 Perceiving a need and social context

In making sense of what is happening to and around them over time, women label their bodily experiences as symptoms with which they are familiar. Anthropological research has highlighted that the way in which individuals interpret ‘bodily sensations’ to be a symptom will depend on the social context in which the symptom is experienced (Pennebaker and Skelton, 1981; Hunt, Jordan and Irwin, 1989; Gannik, 1995). For instance, the theory I have developed describes how teenage women who expose their fragile understandings of their bodily experiences to their mothers allow their bodily experiences to be normalised by their mothers. Normalisation reduces a woman’s propensity to seek help; however, as a woman becomes older and struggles with being intimate in relationships, what they formerly considered to be normal changes to abnormal and their propensity to seek help increases. This study supports the idea that the social context of symptom interpretation changes women’s perceptions of what is happening to them.

This theory also explains how a woman with undiagnosed endometriosis continues to try and integrate within society to maintain her social role, despite experiencing abnormal symptoms. It is in part due to the inability to perform her social role (when her life begins to fracture) that a woman begins to recognise that there is a problem. Not all women with undiagnosed endometriosis are aware that endometriosis may be a differential diagnosis for their symptoms. However, for those who do manage to make some sense of their symptoms, this may not be sufficient to increase their propensity to seek medical help. For example, the grounded theory shows that previous experiences of consulting an HCP in a context of disbelief can result in women suspending health-seeking behaviours, sometimes for years. This study therefore supports the findings of Knight et al (2002), that having insight and knowledge about symptoms alone is not sufficient motivation to drive a woman to seek medical help.

10.3.4 Seeking help and oscillations

In a seminal text by Zola (1973), several assumptions about delayed health-seeking behaviour were challenged. These assumptions were that most people are asymptomatic, that those who seek help do so as they consider their symptoms to be serious, and that those who do not seek help are irrational. Most importantly, Zola claims that the decision to visit an HCP is based on how an individual interprets their bodily changes in relation to their own values.

The theory developed in this study explains that the decision not to visit an HCP is more a function of the refusal or disbelief context in which a woman finds herself and the consequent low degree of confidence she has in the credibility of her evidence of abnormal symptoms. Furthermore, the decision to seek medical help is solely the function of her increasing confidence in the credibility of her evidence of abnormal symptoms as she dips into contexts of belief. While ultimately it is a woman's decision, based on her own recognition of a problem, the decision to seek medical help is also heavily influenced by social interactions with others: an adverse reaction from HCPs can diminish a woman's confidence in the credibility of her evidence and cause her to cease seeking help. Thus, for example, if a clinician reassures a patient that her symptoms are of no significance or concern, then as long as the woman trusts the clinician, she is likely to feel reassured and cease any further health-seeking behaviour. Clinicians in phase 2 of this study confirmed that if a patient trusts their clinician, then the patient is more likely to believe what the clinician is advising; as a consequence of this, the normalisation of symptoms by a clinician results in the patient continuing to normalise their symptoms. A woman's worsening bodily experiences can increase a woman's propensity to seek help, while the normalising behaviour of others can decrease this propensity. In this way, women with suspected endometriosis oscillate between seeking medical help and not seeking help.

10.3.5 Coping with symptoms prior to diagnosis

Women in this study with unexplained symptoms of undiagnosed endometriosis tend to cope by perceiving their symptoms to be at ‘low risk’ of causing harm to their bodies. Their propensity to seek help is therefore low, and the women delay seeking medical help. Sowinska and Czachowski (2018) conducted semi-structured interviews with 20 patients who had medically unexplained symptoms and found that, over time, they learned to cope with their symptoms though rationalising or ignoring them. This was also seen in the current study, which demonstrates that some women realise that they are experiencing an unwanted symptom, but instead of seeking help, they watch and wait before seeking medical help. Zola’s (1973) concept of symptom temporalisation echoes the concept of watch and wait, while Bury (1982) and Dodd et al (2001) also recognise the strategy of watching and waiting.

To understand the issue of a low propensity to seek further medical help, some authors consider it helpful to understand the different phases associated with medical delay. Andersen et al (1995) outline the phases of delay in patients with cancer, which are appraisal, illness, behavioural, scheduling and treatment delay. The first three phases of delay in particular described by Andersen et al (1995) resonate with the grounded theory aspect of this PhD. Appraisal delay relates to the period during which women make sense of their bodily experiences, which can last many months. While sense-making, women will use open contexts such as online endometriosis forums to seek information and gain understanding about their symptoms. Symptom normalisation is an important factor that impacts on when women decide to and seek medical help, and therefore behavioural delay is recognised within this data. However, while the work of Anderson et al (1995) in identifying the phases of delay is interesting, the theory of making sense of a fracturing life, as proposed here, is suggested to be a more appropriate tool for HCPs to gain insights into the *causes* of delays to diagnosis for women with suspected endometriosis.

10.3.6 Increasing the propensity to seek help: credibility and validation

The grounded theory findings lead to the conclusion that the process of recognising abnormal bodily experiences and symptoms is determined by the way in which women experience and become aware of their bodily sensations. No previous studies have explored what happens at the pivotal moment when a woman with symptoms suggestive of endometriosis unequivocally recognises her bodily experiences to be abnormal and therefore a problem. While the women in this phase of the study only suspect their bodily experiences to be abnormal, they are easily persuaded from a conviction of abnormality through the normalising behaviours of others. This study has provided an explanation for the moment of full acknowledgement of the risks of harm from unexplained symptoms. One powerful example is the 'mattress moment' (discussed in chapter 6), whereby the public display of a bloodstained mattress as it was being carried to a skip led to one woman realising the magnitude of her unexplained symptoms. This was a pivotal moment of reflection for this participant and triggered her to seek help.

10.4 Models of health behaviour

There are various psychological and social models used to explain illness behaviour and the propensity to seek help. The Health Belief Model (HBM) is a framework that furthers our understanding of healthcare-related behaviours. The HBM encompasses several key beliefs that are pertinent when an individual is considering seeking medical help; these include an individual's perceived susceptibility, perceived severity, perceived barriers, and perceived benefits of a particular action (Rosenstock, 1974a). In addition, Rosenstock and colleagues (1988) later included the importance of self-efficacy in the model, when an individual wishes to display a certain behaviour or action. The HMB has been discussed in the context of many different medical conditions, including diabetes (Tan, 2004) and multiple sclerosis (Yoshitake et al., 2019).

The biopsychosocial model (BPS), developed by Engel (1977), provides insights into the complex interaction between the biological and psychosocial factors that are involved in illness. Engel (1977) argued that the existing biomedical model at the time was not sufficient to understand illness in its entirety and that further consideration was required by combining the model with psychosocial factors. Engel criticised the biomedical model in that it did not consider the social, psychological and behavioural aspects of health and illness (Wade and Halligan, 2017). The biopsychosocial model (Engel, 1977) provides clinicians with a framework in which a broader range of factors that contribute to illness can be considered.

While the HBM and BPS models are useful for appreciating the principles of health-seeking behaviour, they do not reflect how individuals arrive at a particular decision when seeking medical help. This doctoral study explains that the propensity of women with undiagnosed endometriosis to seek help is a function of how they perceive both the credibility of their evidence and the risk of harm to their quality of life. How they perceive the credibility of their evidence is heavily influenced by their interactions with others and the prevailing social context of refusal, disbelief or belief. How they perceive the risk of harm to their quality of life is influenced by a worsening of symptoms and the consequent fracturing of their lives in the physical, social and psychological dimensions. The interaction of these influences will cause women to oscillate between having a low or high propensity to seek help, until the harm being suffered is fully acknowledged and the woman has total confidence in the credibility of her evidence. At this point, her propensity to act is high, she will weaponize her identity, challenge the normalising behaviours of others, and work to change the context of disbelief to one of belief.

10.5 Social constructs

This section discusses the impact of menstruation and endometriosis on women's wider social identities, as this offers insights into both health-seeking behaviours and the subsequent delays to diagnosis. Taboo and stigma in relation to endometriosis are discussed, as well as the influence of power dynamics between a woman and her clinician during a medical consultation.

10.5.1 Social constructs of menstruation and the impact of endometriosis on social identity

Over time, much has changed with regards to the stereotypical roles that men and women play in society. For instance, the way in which individuals identify by gender has changed, with some individuals not identifying with any gender and some identifying as non-binary. In this study, women directly and indirectly provided insights into the different ways in which their identities as women influenced their interpretation of symptoms and subsequent health-seeking behaviour. All of the women had busy personal and social lives that revolved around their social identity as women, i.e. they were daughters; mothers; wives, partners or girlfriends; and employed. These social roles were central to these women's responses to their symptoms, as their symptoms impacted on their ability to perform their social roles and led to them seeking medical help. When their symptoms began to fracture these roles, they realised that 'something is not right'.

This study identifies a number of ways in which the social constructs of menstruation and the impact of endometriosis on social identity influence health-seeking behaviour. Understanding the differences between male and female health-seeking behaviours highlights important components of women's approaches that can inform the application of this grounded theory. Lee and Owens (2002) found that males perceive seeking help as being 'weak' and therefore they delay seeking help. In contrast, Facione et al (2002) found that women focussed more on the needs of other people before their own (more specifically the needs of their children and partners) and therefore delay seeking help. This finding is supported by this PhD study, with some women balancing the competing demands of a busy employment role, childcare, maintaining their personal relationships and managing a household. While women notice that they have ongoing symptoms, they continue to balance coping with these symptoms and maintaining their female roles. It is only when they are unable to continue with this balance that they realise the disruption in their quality of life and in their identity as a woman. This increases their propensity to seek medical help.

10.5.2 Taboo and stigma

The influence of stigma in relation to suspected endometriosis was discussed by the participants in phase 1 of my PhD. Sims et al (2021) conducted a review to explore the impact of stigma on the delay to diagnosis of endometriosis. As part of their wider review, they found that there is inadequate research in this area, and further research is required. The findings from both phases of this PhD provide insights into how women with suspected endometriosis feel stigmatised, with clinicians openly discussing (in phase 2) the prejudices they hold towards women with endometriosis.

HCPs in phase 2 of the study discussed how they often viewed women with endometriosis as ‘complex’ and ‘intimidating’. The focus group with nurses highlighted how they viewed endometriosis patients as demanding and requiring complex care. A focus group study involving 50 Latina women with endometriosis, recruited via convenience sampling, was conducted in Puerto Rico (Matias-Gonzalez et al, 2021). Matias-Gonzalez et al (2021) noted that participants reported how they were described as ‘changas’ (translated as ‘complainers’) by family members and healthcare professionals alike. This finding resonates with that from this PhD, in that women with endometriosis often feel stigmatised, which leads to them delaying the seeking of further medical help.

In the present study, women provided insights into how discussions about menstruation are concealed by the language used in the media by companies who provide sanitary products, as well as how such products tend to be stored ‘out of sight’ in the bathroom. Women also discussed how their ‘supposed’ roles in society as females meant they did not necessarily have time to discuss menstrual health-related issues. Chrisler (2008) discusses how some women feel that they should be ‘available’ to others (children and partners) as part of their identity as women. Another study by Chrisler (2011) found that women referred to the physiological process of menstruation in a variety of ways, including ‘time of the month’, ‘red plague’ and ‘on the rag’. Each of these euphemisms implies an element of stigmatisation when discussing menstruation. This is important as it can influence the way women behave when they are on their menstrual cycle; some for instance may avoid social activities, while others may find ways of concealing the fact, they are on their menstrual cycle by wearing certain clothing (Seear, 2009). This stigma was evident in the current study. The perceived stigma associated with discussing menstrual-related symptoms was also seen in a study by Culley et al (2013), which found that some women perceived themselves as 'weak' if they discussed their menstruation concerns with other people. Menstruation as a taboo subject is reflected in the refusal context of this grounded theory study, in which the stigma associated with experiencing and disclosing abnormal symptoms is reflected in a woman's diminished female identity.

This study shows that taboos around menstrual matters extend widely into society: some women experience approbation and stigma from other women online when discussing their symptoms, while other women experience stigmatisation from significant others and HCPs. As a result of the taboos and the stigma arising, some women in the study normalise their symptoms and reduce their propensity to seek help, delaying diagnosis. Menstrual taboos have been described by various scholars (Stubbs and Costos, 2004; Chrisler, 2013). Erchull et al (2002) conducted a qualitative study that used content analysis to examine menstrual health resources and found that there appeared to be more negative than positive messages in these resources. In addition, Polak (2006) explored online chat-room material involving women discussing their menstrual cycles. They found that an online forum offered a place for transparent discussions among women and that this generally had a positive influence on women's female identity and embodiment. The current PhD study supports Polak's (2006) findings that women with undiagnosed endometriosis are likely to use online forums to discuss abnormal bodily experiences related to their menstrual cycles.

In this PhD study, women discussed how the perception of their symptoms was influenced by other people and the media. Some women with endometriosis who participated in this study discussed how society concealed menstrual hygiene products and drew comparisons with other intimate products in society, such as toilet rolls, and how these do not tend to be concealed in the bathroom. This finding of concealment is further supported by Roberts et al (2002), who found that people were less likely to engage with a woman if she had an obviously noticeable tampon in her bag. It is important to appreciate the impact that implicit cultural rejection and refusal behaviours have on women and their identities as females. If a woman is perceived by society in this way for simply having a tampon on display in her bag, then the impact of discussing intimate details about menstruation with others is likely to be perceived as a social taboo. This provides further awareness of how a women's identity can influence her health-seeking behaviour.

The participants in phase 1 of this PhD study attempted to socially disconnect themselves from menstrual-related symptoms due to embarrassment and concealed any evidence of active menstruation by wearing specific clothing or by concealing evidence in their house. Menstruation can be objectified and medicalised by clinicians (Ehrenreich and English, 2005; Wood, Barthalow Koch and Mansfield, 2007), with less emphasis placed on the psychosocial and cultural aspects of menstruation in the clinical setting. Fredrickson and Roberts (1997) theorised that one way in which some women 'separated' themselves from the realities of menstruation is through self-objectification. Self-objectification is defined as women perceiving themselves as objects (Baldissarri et al, 2019). This finding is supported by Johnston-Robledo et al (2007), who explain that self-objectification may lead to some women feeling a sense of shame about menstruation. Andrist (2008) found that shame about menstruation may lead to women making decisions to actively inhibit the process, for instance through the use of contraception. The recognition of self-objectification behaviours, such as an expression of guilt or disgust with regards to menstruation (as seen in this PhD study) may offer another explanation for the reason of delayed presentation to a clinician.

The taboo around discussing sensitive gynaecological and psychosexual issues with a clinician is experienced by women with undiagnosed endometriosis in the refusal context of this grounded theory. This is a particular issue for teenage women. Chrisler (2011) discussed the taboo women experience in the context of menstruation. Menstruation may not be discussed by females for a variety of reasons. Cole, Grogan and Turley (2021) described the way in which women 'self-silenced' their symptoms and did not discuss their concerns in their personal relationships. While the literature discusses the impact of self-silencing on women's quality of life (Sormanti, 2010) and how women with endometriosis may not be concordant with treatment as a result (Brody et al, 2014), it is important to highlight that self-silencing may also impact on the way in which women seek medical help and how this may subsequently hinder the process of diagnosis. Jack (1991) discusses self-silencing among those with chronic illnesses in the context of their personal relationships and how this was more commonly seen in females. Individuals would engage in self-silencing to maintain their perceived identity within the role of a woman; this may be as a mother or as a female partner. Brody et al (2014) explored how in patients with HIV, self-silencing resulted in reduced adherence to medical treatment. Some participants in phase 1 of this study felt silenced by their clinicians. This was further explored with the HCPs in phase 2; it was found that women were invisibilised during a medical consultation and only visibilised by the presence of a significant other in the consultation. This is a new finding in relation to the extant literature that has explored the delay to diagnosis of endometriosis.

This grounded theory highlights the importance of demystifying endometriosis among women, society and HCPs. While significant advances have been made over the years with respect to endometriosis treatment, there remain deep-rooted taboos and stigma in relation to menstrual health. These factors are a major cause of delay to diagnosis.

10.6 Power dynamics

Many women in this study perceived a power imbalance between themselves and their GP when undergoing a medical consultation in primary care. A study by Young, Fisher and Kirkman (2019) found through interviews with 26 women with endometriosis that women were aware of the power doctors had over their wellbeing and respected their doctor's views as well as their own views about their symptoms. The grounded theory aspect of this PhD found that when women perceived a power discrepancy with their doctor, they felt undermined and thus did not always return to the same HCP for care.

The power dynamic between a patient and clinician has been recognised in many studies (Whitehead, 2007; Rees, Ajjawi and Monrouxe, 2013; Nugus et al, 2010). Power comes in many forms and is seen in many different contexts: marriage, employment, the law, between a child and parent, and in the medical context between a patient and clinician (Whitehead, 2007). Clinicians hold power through the act of diagnosing, prescribing, referring to specialties, and treating; this was discussed by HCPs in this PhD study. It was very apparent from the phase 2 findings that HCPs control access to the support women need to understand and hopefully improve their condition. In the medical context, it is important for clinicians to appreciate the *power* that they possess in their role as the gatekeepers to secondary care.

The phase 1 findings from this study show that power imbalances between the patient and clinician can be related to autonomy. This study found that many women with undiagnosed endometriosis feel powerless as a result of the very symptoms they are experiencing. When they present to their clinician, powerlessness becomes the focus of further struggles. Women try to negotiate through this power struggle, quite often without success. In response to a power imbalance, women with a stronger sense of autonomy attempt to redress this imbalance by increasing the credibility of their evidence or simply avoid the imbalance by changing their GP. Those with a weaker sense of autonomy accept the normalisation of their symptoms by GPs (or at least do not feel able to challenge it) and are likely to delay seeking further medical help for protracted periods of time as they watch and wait. This subsequently contributes to the delay in diagnosis of endometriosis.

Furthermore, the prevailing context and balance of power will influence the particular combination of bodily experiences disclosed by a woman to her HCP. Brannon and Carson (2003) discuss the notion of symptom salience, which refers to how patients choose which symptoms they think are important and worth discussing with their clinician. Symptom salience was not observed in this PhD. Rather, it is the prevailing context (of disbelief or belief) coupled with a woman's level of autonomy that heavily influences whether she will withhold or disclose information.

There has been limited research into how clinicians themselves recognise and navigate through the power dynamics during a medical consultation. Nimmon and Stenfors-Hayes (2016) explored HCPs' perceptions of power in the clinical encounter and found that clinicians do not always recognise the influence of power dynamics in these circumstances and therefore do not know how to address them. This is important, as this thesis demonstrates that when women perceive an imbalance in the power dynamics with a clinician, they avoid making the GP aware of this imbalance. It is therefore vital that clinicians reflect on their own clinical encounters, recognise any elements of power imbalance and understand how this can influence women's health-seeking behaviours.

One way in which clinicians can navigate through perceived power imbalances with a patient is by shared decision-making (Beyene et al, 2018). Shared decision-making is an approach to the medical consultation which allows the power to be distributed equally between the patient and clinician and enable the patient to make better sense of their symptoms (Beyene et al, 2018). In the case of endometriosis, through shared decision-making a clinician is able to make a better assessment of the information provided by the woman, with a view to helping her understand the various options that are available to explore her unexplained symptoms. There appear to have been no studies conducted to specifically explore how women with suspected endometriosis negotiate through the power imbalances they perceive from their healthcare interactions. This study shows that women recognise that power in the context of a medical consultation exists and that they negotiate through this, either by delaying further health-seeking behaviour, or, if they do seek such help, they come armed with knowledge about endometriosis and bring credible evidence of their symptoms, sometimes in the form of a significant other whom they recruit and bring to the consultation. The analysis of the phase two findings with HCPs suggests that when a woman brings another person to the consultation, the clinician can feel threatened and is therefore more likely to grant the request for a referral to secondary care. Both of these issues are important as they highlight how the influence of a power imbalance during a medical consultation can negatively impact health-seeking behaviour and the doctor–patient relationship, contributing to a delay in diagnosis of endometriosis.

10.7 Embodiment, biographical disruption and female identity

10.7.1 Embodiment and biographical disruption

The grounded theory in this PhD suggests that abnormal bodily experiences suggestive of endometriosis disrupt a woman's perception of her embodied self and that, sooner or later, this will result in her seeking medical help. This section will focus on female embodiment, biographical disruption and female identity.

The concept of embodiment was first coined by Merleau-Ponty (1945) and argues that the way we relate to and experience the world is through our bodies (Merleau-Ponty, 1945). Furthermore, the embodied self is considered to be a unity of body and mind, with disruption to one invariably impacting on the other (Merleau-Ponty, 1945). The related and powerful concept of 'biographical disruption' was introduced by Bury in his seminal paper (1982, p. 169) as a 'critical situation' involving: the disruption of 'taken for granted assumptions and behaviours'; the 'fundamental rethinking of a person's biography and self-concept'; and the 'mobilising of resources in facing an altered situation'. The experience of biographical disruption due to the symptoms of endometriosis and the consequent impact on women's sense of embodied self and their embodiment in the world are evident in this PhD study and are reflected in the concepts of fracturing life, making sense of that fracturing life, and investigating and coping behaviours.

The grounded theory shows that, over time, women with undiagnosed endometriosis will notice a gradual fracturing of their lives: they notice that 'something is not right'. Engman (2017) explains that for those individuals who have experienced a physical impairment since birth, then this impairment will have been embodied and embedded into their sense of self over the course of their lives. However, for those individuals where a critical situation (such as chronic pelvic pain) occurs during their teenage years or later, then their existing embodied self will be challenged, necessitating a renegotiation of self.

This theory suggests that if a woman experiences abnormal bodily experiences suggestive of endometriosis at a younger age, then the combination of the impact of the symptoms and the interactions with significant others are more likely to have a fundamental impact on her female identity. However, if these experiences are encountered later in life, then the woman will be more secure in her female identify and therefore more likely to contest the impact of these challenges on her self-identity. This is important in understanding the delays to diagnosis of endometriosis, as these perceptions of self-identity and a women's consequent resilience to the normalising behaviours of others influence how women make sense of their abnormal bodily experiences and whether they seek medical help.

Engman (2017) explored biographical disruption in solid organ transplant patients and found that the relationship between an individual's perception of embodied-self prior to the critical situation together with the impact of the illness is what determines the extent of the biographical disruption. This grounded theory provides a platform for future research to be conducted into the health-seeking behaviours of those women whose embodied self has been impacted by childhood trauma and the impact that altered self has on the health-seeking behaviours of this group of women.

Piran (2017) studied the embodied lives of adolescent girls and described the developmental theory of embodiment. Over a five-year period, Piran (2017) interviewed 27 girls aged between 9 and 14 years, focussing on their experiences of embodiment. Piran's theory suggest there are three 'domains' that influence embodiment and how adolescent girls view this, which are based on the physical, psychological and social 'domains' (Piran, 2017). Ussher (2004) performed a study involving women with severe premenstrual symptoms and found that women 'self-policed' their symptoms. Subsequently, this had an impact on the way they viewed their embodied self (Ussher, 2004, p188).

10.7.2 Self-identity

The impact of gynaecological symptoms on the quality of women's lives, as well as women's healthcare experiences of seeking help prior to diagnosis, are theorised to influence female identity. During the semi-structured interviews with endometriosis participants in phase 1, the women provided insights into the indirect impacts their unexplained symptoms had on their identity as a woman. Some explained how their symptoms impacted the way they viewed themselves as mothers, while for others, it affected their identity in personal relationships, for example where they were unable to conceive or struggled with sexual intercourse due to pain. They questioned their identity as a woman and their perceived role in society. Women with undiagnosed endometriosis also find themselves persistently undermined by the normalising behaviours of significant others and HCPs, which also diminishes their female identity. It is these social challenges to female identity, of the way in which women perceive their societal role as a woman and their self-worth as a woman in the personal context of being a mother or a partner in a romantic relationship, as well as the 'hidden pressures' they experience from other people in society within in the educational and employment context, that all impact on female identity. Together, both phases of the study demonstrated that the way in which women approach and adjust to these challenges influences their health-seeking behaviour.

10.7.3 Self-identity and the contexts of refusal and disbelief

This PhD study suggests that for women with undiagnosed endometriosis their identity as a woman is impacted as they attempt to seek help (formal or informal). Women in a refusal context experience a sense of diminished female identity. In contrast, women in a context of belief feel validated and disclose more information to a clinician. These influences provide a novel understanding of what contributes to the delays to diagnosis of endometriosis.

There are limited studies exploring how women with endometriosis negotiate their identity. The women with endometriosis who participated in phase one discussed the impact on their sense of self of not being believed by their GP. By not being believed, some women questioned whether their symptoms were 'real', and this impacted on their credibility as women. Cole, Grogan and Turley (2020) conducted an exploratory online study involving questionnaires and found women 'self-silence' their symptoms in response to other people's responses or as a way to normalise their symptoms. This finding is supported by the evidence obtained from this PhD study. However, the majority of participants in both studies identified as ‘White British’ or ‘other European’, so the findings should be considered in this context and may not be applicable to women from other ethnic groups. The grounded theory model described in this PhD not only supports this notion of self-silencing but also builds on it. It explores how a woman in a refusal context can accept the taboo, self-silences and, as result, experiences a diminishment of her self-identity. As she reaches the belief context, her identity can repair and grow as she asserts a more positive self-identity. As she gains more confidence to seek help, she will package and present her bodily experiences to the clinician in a way that is believed, achieving the much-desired referral to secondary care for further investigation.

This thesis has explored the impact of living with undiagnosed endometriosis on a woman’s female identity as she experiences different contexts and offers a new way of understanding the oscillating impacts of undiagnosed endometriosis on female identity.

10.7.4 Context of belief

Several participants with endometriosis used online forums to explore their abnormal bodily experiences or symptoms and discuss them with others. For some, using an online forum was fruitful in that it helped them to make sense of their experiences and subsequently seek medical help. Emad (2006) discusses how women with diagnosed endometriosis discussed their ‘stories’ online and how this created an ‘embodied community’ among the women that resulted in a ‘communal body’. She argues that it is this communal body that enables women to express their physical pain with each other and find a sense of meaning (Emad, 2006). The grounded theory in this PhD supports this notion, in that women with undiagnosed endometriosis fluctuate between different contexts over time, particularly the refusal and disbelief contexts, and will seek an open context of belief in the form of online forums. This study suggests that the impact on a woman who seeks support in the open context is to increase her confidence in the credibility of her evidence, influence her perception on the risk of harm from her bodily experiences and lead her to seek medical help.

10.7.5 Impact on intimate relationships

The findings from phase 1 of this study show that endometriosis can have a major impact on personal romantic relationships, whereby women may experience new difficulties during sexual intercourse, as well as changes to their sense of self, which in turn affects their bodily confidence and creates relational tensions. As a result of biographic disruption, as discussed earlier, some women question their role within a romantic relationship and reflect on their role as a woman within the context of their relationship. Hudson et al (2016) explored biographical disruption in 22 women with endometriosis and their respective partners. They found that endometriosis symptoms impacted on women's perceptions of their sexuality and femininity in heterosexual relationships and on the social lives of these individuals (Hudson et al, 2016). The present study supports Hudson et al (2016) in this regard, however, one notable difference that Hudson et al (2016) state is that some of the male partners in their study 'were more likely than women to undertake the biographical work of appraisals, that is assessing and revising the importance of sex'**.**

Both phases of this PhD study have revealed that, while the partners of the women in the study notice the disruption in intimacy within their relationship, several women brought their partner to their medical consultation to strengthen the credibility of their story. The role of the partner in this context was to convey and affirm to the GP the impact on intimacy, to ensure the woman is investigated further to seek a diagnosis. The findings from phase 2, with the HCPs, confirm the success of the women's strategy, in that GPs discussed the influence that a significant other had within a consultation and stated that they were more likely to refer a woman to a gynaecology specialist when their partner was present. This understanding has not been captured in the current evidence base and adds to what is already known about women's health-seeking behaviour. The role of HCPs in invisibilising women during a medical consultation is yet another reason for the delay to diagnosis of endometriosis.

This PhD study also provides insight into the positive influence of a partner in rendering women with suspected endometriosis visible and credible during a medical consultation. However, it also provides insights into the negative influence that a partner can have through their refusal to engage with, or their normalising behaviours towards, a woman's abnormal bodily experiences, causing her to delay seeking medical help. The impact of endometriosis on couples has recently been explored in a systematic review by Norinho, Martins and Ferreira (2020). Their findings show that endometriosis also has a significant impact on a partner's sexual function and therefore a couple-centred clinical approach should be undertaken for patients with endometriosis.

10.8 Strengths of this study and the contribution to knowledge

This section will discuss how the findings from this PhD contribute to the endometriosis knowledge base and to the wider literature.

This study is the first grounded theory study conducted in the UK to explore women's experiences of delays to diagnosis with endometriosis. It is novel in that it has explored the pre-diagnosis factors that influence the diagnosis time for endometriosis, reflecting a methodological contribution to knowledge. Only one other study has used grounded theory to explore the delay to diagnosis of endometriosis (Zanden et al, 2021). Through focus groups with GPs in the Netherlands, they explored the 'barriers and facilitators' contributing to a diagnosis of endometriosis (Zanden et al, 2021). While their study provides useful insights into some of the reasons for the delay to diagnosis, it is solely focussed on the experiences of GPs. In this PhD, the novel use of a two-phase study involving both women with endometriosis and HCPs provides a unique understanding of the delays to diagnosis of endometriosis. The grounded theory model developed in this doctoral study provides a distinctive understanding of the health-seeking behaviours of women with endometriosis. In addition, while the study by Zanden et al (2021) is extremely insightful about the way in which endometriosis impacts on women's health, the findings from this PhD offer a different perspective of women's experiences, based on the UK healthcare system.

By conducting a two-phase study exploring the perspectives of women and HCPs, this study provides a rich understanding of the reasons for the delay to diagnosis. In particular, the concept of invisibility in relation to women with suspected endometriosis and how they can be rendered visible by bringing a significant other to a consultation is a new finding Moreover, no other study has explored the delays to diagnosis of endometriosis in the UK using a study design in which the findings from the first phase influence the second phase. This is a novel and unique methodological contribution.

While there are a few quantitative, survey-based studies that have explored certain aspects of the delays to diagnosis of endometriosis, very few studies have solely explored the delay from a truly qualitative perspective. By doing so, this thesis has provided more in-depth insights into the context and meaning of women's experiences with being diagnosed with endometriosis. Most of the studies that have explored the delay to diagnosis of endometriosis have been questionnaire-based, which limits the researcher's ability to explore the meaning of women's experiences and therefore the extent of knowledge that can be gathered using this method. The use of an in-depth qualitative methodology represents a contribution to the knowledge in relation to women's experiences of diagnosis of endometriosis in the UK.

The findings from this study have provided extensive details about the health-seeking behaviours of women with suspected endometriosis. Previous studies have explored the reasons for the delays to diagnosis in isolation and often given broad and general reasons for such delays. However, this thesis, through the influence of an interpretivist stance, has integrated the various factors that result in the delay to diagnosis. In particular, these include biographical disruption and the influence of female identity on health-seeking behaviour.

This study has focussed on both participants with endometriosis and healthcare professionals. The novel use of the findings from phase one of the study to inform phase two provides a unique understanding of the delays to diagnosis of endometriosis.

10.9 Limitations of this study

As with any research study, the propositions arising from this PhD thesis should be interpreted in light of its limitations.

Participants who could not converse in English were excluded from the study. The main reason for this was that no specific funding was available for an interpreter and therefore this is acknowledged as a limitation of the study, as it might have resulted in the exclusion of perspectives different to those of English speakers.

The participants with endometriosis were only interviewed once. To capture women's experiences of delay over a period of time, it would have been useful to interview them on more than one occasion. However, practical reasons of time precluded this.

There are a number of participant-related factors in light of which the findings need to be considered. The study sample involved participants who were recruited from a tertiary referral centre in the east of England. These participants are generally considered to have advanced endometriosis, and their diagnosis journey may therefore naturally be more complex. Moreover, some participants had experienced a significant delay to diagnosis or had been diagnosed many years ago. It is important to appreciate that recall bias may have affected some of the women's accounts.

The self-selected nature of the study may itself have been a limitation. Participants self-recruited by replying to a poster advertisement in the gynaecology outpatient clinic. Therefore, the views of women whose medical care has remained within primary care may differ from those of the women who participated, and these potentially different views have not been explored. This might form an interesting follow-up study.

While there was variety in the age of participants, none of the women identified as lesbian, gay, bisexual, transgender or queer (LGBTQ). In addition, the majority of participants in phase 1 of the study identified ethnically as White British. While these are important considerations that any future studies should take into account, the findings from this PhD resonated strongly with the existing published research that involved different populations, thereby demonstrating credibility and transferability.

The GPs who participated in the focus group study all worked at a single practice in the East of England, so the views of GPs who work at other practices have not been taken into account. However, the views of other HCPs, such as nurses and gynaecologists, also contributed to the phase two study findings, meaning that the voice of these GPs was not dominant throughout the entire study.

10.10 Implications for clinical practice and suggestions for reducing the delays to diagnosis of endometriosis

In this section, I will discuss the implications emanating from the study for clinical practice, health policy and research.

Menstrual wellbeing promotion in schools has been established in England since 2020, following a public health campaign. Endometriosis awareness is also being promoted via the UK-based charity, Endometriosis UK. However, this promotion may not be available to those individuals who do not have online access, so women who lack access to the internet must be supported accordingly. Menstrual wellbeing education should also be promoted among Black and Minority Ethnic (BAME) groups and individuals who may have difficulties in accessing care, possibly because of learning difficulties, disabilities, and due to language barriers.

This PhD has identified that the awareness of endometriosis must be improved among the general public. It is therefore recommended that endometriosis should be promoted in the media by celebrities and other public figures to increase awareness.

The findings from both phases of the study highlight that there appears to be an ‘invisible line for referral’ to secondary care. Therefore, one recommendation is for clinicians to use this finding and be aware that this may exist in their own practice. The second recommendation is for the existing 2017 NICE guidance on the diagnosis and management of endometriosis to build upon the existing criteria for referral to secondary care and provide clear descriptors that clinicians can consider.

The impact of endometriosis on women in the employment context is considerable. Awareness of endometriosis and the considerable and unpredictable impact it can have on women should be increased among all UK employers. By being aware of this impact, employers will be able to support women with endometriosis at work and, in some instances, offer workplace adjustments.

It is evident that the awareness of endometriosis among clinicians remains limited. While the Royal College of General Practitioners (RCGP) has developed a Menstrual Wellbeing Toolkit to increase awareness of menstrual-related problems, further work is still required. Urgent attention from stakeholders is required to redefine and further develop the undergraduate medical school curriculum in relation to menstrual disorders, and endometriosis in particular. The postgraduate curriculum for trainee GPs must also incorporate a robust and focussed syllabus that covers endometriosis. One recommendation to ensure trainee GPs have adequate clinical exposure to patients with menstrual disorders is to incorporate a mandatory and focussed gynaecology rotation within the GP training scheme. At the moment, not all trainee GPs have exposure to an obstetrics and gynaecology rotation as part of their training.

The NICE guidance for the diagnosis of endometriosis makes some suggestions about when a woman with suspected endometriosis should be referred to secondary care. An urgent consultation is required between clinicians, relevant stakeholders, patients, and charities such as Endometriosis UK, to identify and develop a standardised referral pathway to secondary care for women in primary care with suspected endometriosis. There is wide variation in the referral pathways for such patients within the UK. As part of this referral pathway to secondary care, a standardised referral pro forma for use in primary care should be developed. This will ensure that GPs provide secondary care clinicians with consistent information about the referral and that patients have the relevant investigations, such as an ultrasound scan, prior to referral. These measures will again reduce the delay to diagnosis time.

Crucial to the process of diagnosis is the moment of vulnerability when a woman recognises something is abnormal and eventually seeks medical attention for the first time. This is a critical, influential and vulnerable point at which the clinician can have a major influence on the progression of or delay to diagnosis. It is vital, therefore, that clinicians recognise and are aware of this influential moment and the impact that they can have on a woman's propensity to seek medical help and consequently any delay to diagnosis. One recommendation is for GP surgeries to increase the consultation time, from 10 minutes to 20 minutes, for women with suspected endometriosis. This will help to ensure both that the patient has sufficient time to divulge her symptoms and that the clinician will have time to explore endometriosis as a potential differential diagnosis.

At present, the NICE guidance for diagnosing endometriosis mentions that women with suspected bowel or bladder endometriosis should be referred to a British Society of Gynaecological Endoscopy (BSGE) centre. While this guidance is a useful starting point, it does not list the BSGE centres, it does not go into details as to which signs and symptoms are suggestive of deep infiltrative disease, and it does not make clear why a referral to a BSGE centre is important for this group of patients. Another recommendation, therefore, is that the 2017 endometriosis guidelines published by NICE should be revisited with this in mind. Increasing the awareness of BSGE centres among primary care clinicians in particular must be at the forefront of the authors' minds when updating this document. In addition, primary care clinicians should work collaboratively, both with local gynaecologists and gynaecologists working at BSGE-accredited centres, to discuss cases and facilitate timely referrals to secondary care.

The findings from this PhD showed that a woman's first medical consultation can negatively influence her future health-seeking behaviour if she perceives her healthcare professional to be dismissive. It is therefore vital that primary care clinicians are aware of the importance of the 'first consultation' during which a woman may present with signs and symptoms of endometriosis.

Both phases of this PhD study showed that women can be invisibilised during medical consultations. For some women, they were visibilised through the presence and influence of a significant other during a consultation. It is important that clinicians recognise and understand such health-seeking behaviours. In cases where women with suspected endometriosis present with another person in a consultation, the clinician should be acutely aware of this and understand that women may do this in an attempt to be visibilised.

It was extremely useful to learn that some women perceive the normality of their endometriosis symptoms based on the way significant others (mother, partner, family, clinician) normalised the symptoms. It is important for clinicians in particular to have an awareness of this and use a biopsychosocial approach to medical history taking with women with suspected endometriosis.

It is clear from the scoping review in chapter 2 and the PhD study findings that younger women were more likely to experience a delay to diagnosis of endometriosis. Clinicians play a part in this delay, as well as the patient herself. Primary care clinicians may not always know where to refer younger women with suspected endometriosis for further assessment. It is therefore a recommendation that the clinical services provided by general gynaecology, paediatrics and paediatric and adolescent gynaecology (PAG) should be more joined up and focussed. Consideration should be given to ensuring that each gynaecology unit in the UK has a dedicated consultant with a special interested in PAG. Such consultants should be supported to develop their communication and clinical examination skills that are in keeping with this group of patients. Primary care clinicians should also consider endometriosis in any female of reproductive age, including the adolescent population.

The grounded theory aspect of this PhD highlighted clear evidence that women perceived power imbalances between themself and their clinician. This thesis suggests that perceived imbalances in power negatively affect a consultation and can be damaging for the patient–clinician relationship; this undermining behaviour is in part responsible for the delay to diagnosis of endometriosis. It is therefore recommended that clinicians should reflect on their own medical practice and understand that they inherently possess a degree of power by virtue of their role as a clinician, and this power must be negotiated with the patient.

Clinicians should reflect on their own verbal and non-verbal behaviour during a consultation and consider how they can actively reduce any barriers to facilitating a diagnosis of endometriosis. For instance, clinicians may wish to consider whether they normalise symptoms, and if so, why? Clinicians may also wish to ask themselves ‘how do I feel when I am about to see a patient that has been labelled as having chronic pelvic pain?’ or ‘do I have any preconceived ideas about what “the endometriosis patient” is?’

Currently, there are no validated tools in clinical practice that can be used to facilitate referral from primary care to secondary care for women with suspected endometriosis. The findings from this PhD provide insights into the sociocultural factors that influence women’s interpretation of their bodily sensations and health-seeking behaviour in women with suspected endometriosis. These insights should be used to help develop a non-invasive tool that can facilitate referral to secondary care This tool should be user-friendly, such that women who suspect they may have endometriosis can use it and take it with them to their GP. If a clinician suspects endometriosis, they should also be able to use this tool in collaboration with the patient and refer her to secondary care accordingly.

It should be recognised, based on the findings from this study and the existing wider literature, that endometriosis can impact women’s relationships. Public awareness campaigns should be designed to help individuals recognise abnormal symptoms in their female partners. In addition, if male partners were made aware of the impact endometriosis can have on a romantic relationship (for instance dyspareunia leading to withdrawal of sexual intercourse), then they may be able to encourage their female partner to seek help. An awareness of the ways in which women conceal menstruation and normalise symptoms of abnormal menstruation is important for their partner, be they male, female or non-binary, to understand who may be able to facilitate the health-seeking behaviour of their partner.

At present, there is no agreed definition for what constitutes ‘delay to diagnosis’ of endometriosis in terms of an arbitrary timeframe. Clinicians, patients and public involvement and other relevant stakeholders should consider and agree on a definition for the delay to diagnosis. This will not only help patients and clinicians to understand delay to diagnosis better but also enable research studies to adopt a clear and consistent method when exploring this area further. In addition, a standardised definition will render studies more comparable.

10.11 Future research

There are opportunities to develop both the grounded theory and the findings from the phase two study in the future. These include the following.

As mentioned in the recommendations section, no definition for what constitutes a delay to diagnosis of endometriosis exists. A Delphi study (Niederberger and Spranger, 2020) may be useful in reaching a consensus and developing this further. This would help future research studies to explore delay to diagnosis more objectively and in a standardised manner. It would also help patients and clinicians to better understand delay to diagnosis.

Self-silencing was an important area that was explored in this thesis, as well as in the wider literature. Future research should specifically explore how women with suspected endometriosis from different cultures identify with self-silencing when discussing menstrual-related concerns and how this influences their health-seeking behaviour. This may provide further information on the delay to diagnosis.

While this doctoral study has explored the experiences of individuals with a delay to diagnosis of endometriosis, it will be insightful to explore the experiences of women who have been diagnosed with endometriosis and did not experience a delay to their diagnosis and compare these two groups. This will enable important factors in relation to diagnosis in both groups to be compared.

The grounded theory developed in this PhD can be developed and tested further through theoretical sampling of specific concepts such as female identity, embodiment and biographical disruption.

10.12 Conclusion

This doctoral study illustrates that women with suspected endometriosis weigh the meaning of their symptoms and what it means for them and compare this with the impact their symptoms have on their life. For these women, it is the final fracturing of the physical, social and psychological aspects of their life that makes them realise that their symptoms are abnormal. Using grounded theory and symbolic interactionism, we are able to understand the world through the lens of these women and explore how women's perceptions of their symptoms change as their lives begin to dissolve. This is the first known grounded theory exploration of delays to diagnosis of endometriosis that offers these insights. Through the lens of healthcare professionals, we are able to understand how women with suspected endometriosis are invisibilised and eventually visibilised through the influence of a significant other.

Chapter 11 – Reflexivity

11.1 Introduction

The previous chapter discussed the findings from this PhD in relation to the wider literature. This chapter discusses the process of reflexivity, which I considered important as part of this PhD. Throughout my PhD, I have read about and engaged in the process of reflexivity. Reflexivity is described as 'the turning back of the experience of the individual upon him or herself' (Mead, 1934, p. 134) and as such, from a research perspective, it has enabled me to reflect on how I have influenced the research process and how to be aware of this. In this chapter, I will discuss my reflexive accounts which I recorded in my diary.

From the very beginning of each interview, I made field notes in a research diary. This enabled me to note down any non-verbal communication, body language and how each participant made me feel. This was useful information that may not have been apparent from the transcripts alone. This information also helped me when coding the findings. Importantly, through regular meetings with my supervisors, I was also able to promote reflexivity in my work. I would often be asked questions about the transcripts by my supervisors, which allowed me to gain more insight into the questions I was asking and the way I was asking them. The areas discussed in this section have been extracted from my reflexivity journal.

11.2 Beliefs, attitudes and assumptions

Being reflexive has been important for me on a personal level, both as a researcher and as a medical doctor. Prior to starting my PhD project, I decided to undergo a 'self-interview' with an experienced academic. This was a very powerful process, whereby I gained insights into my own preconceptions about women with endometriosis, as well as their health-seeking behaviours. During the forty-minute interview, I was asked broad questions relating to 'what is your understanding of endometriosis'?

I also thought carefully about the three definitions for ontology, epistemology and methodology. I made notes on my personal views surrounding these terms and how I saw the world. It was through this process that I realised that I wished to adopt a relativist ontology, constructivist epistemology and a grounded theory methodology.

11.3 Initial study idea and the use of qualitative methodology

Prior to commencing this project, I initially wanted to be involved in a project whereby I could create a non-invasive tool that would facilitate the diagnosis of endometriosis. However, the more I spoke to my supervisors and the more I started to engage with the literature on endometriosis, I realised the importance of qualitative work. I realised that while I wanted to create a tool, this would not have been possible without conducting 'proper' qualitative work beforehand. How could I possibly create a tool if I have not heard the voices of the very women who the condition affects? I therefore decided to focus purely on a qualitative PhD project and hopefully extend this research to the development of a tool in my post-doctoral work. My supervisors also helped me realise the importance of conducting thorough, clear and defendable qualitative research, rather than carry out a 'half-baked' project. My understanding of qualitative research has developed immensely during the conduct of this PhD.

11.4 Experience as a clinician

Prior to commencing my research, I engaged with the endometriosis team at a tertiary referral centre for one year. I sat in during the weekly endometriosis clinics to gain insights into the service and met women who had endometriosis. In my clinical practice, my experience of women with endometriosis has been with women who have been severely affected by the condition, where fertility may be an issue, who may be frustrated with the healthcare system and often women who have been bounced between specialties. It was important for me to understand how these experiences can influence the research process.

11.5 Professional role verses researcher role

An interesting paper by Richards and Emslie (2000) compared interactions between researchers and interviewees. They found that being aware of your own professional role was important. Deverell (1998, p.114) argues that 'who you are affects what you get told', and therefore gaining insights into how my professional role as a doctor can influence the research process was very important.

It is important for me to consider the influence my role as a clinician has on the research process. I introduced myself to the participants as a clinical research fellow, and all of the participants were aware that I was a doctor in obstetrics and gynaecology and employed at the research site. This meant that there was a possibility that participants may feel reluctant to discuss any potentially negative experiences relating to the research site. There was also the possibility that participants would ask me to offer clinical advice with regards to their care. One participant asked me if I was able to facilitate her appointment for a second operation. I explained that my role in this capacity was solely as a researcher and that, with her consent, I would inform her consultant gynaecologist of her concerns.

As soon as I reflected on my first semi-structured interview, I had to remind myself that I was not in a clinical consultation but in the role of researcher. This was initially challenging. As the interviews progressed, my role as a researcher became much more concrete. I no longer felt that I was solely 'a clinician'. I started to realise that my role as a clinician is there and always will be. However, it was important for me to acknowledge this and take it into account when interviewing as well as when analysing the data.

Ormston et al (2014) discuss 'empathic neutrality'; however, my objective was to be non-biased rather than 'neutral'. I was aware that I will never be able to be completely 'neutral', as I have a role as a researcher and a role as a medical professional. I was aware that my beliefs and behaviours would influence the research process. Prior to the start of each interview, I would make it clear to participants that the interview is part of a research study and not a clinical consultation. If participants had any clinical questions, then I would make a note of these at the end of the interview and direct them to the participants' clinician. The issue of power balance was also important for me to be aware of. I introduced myself as a researcher rather than a doctor. Interviews took place in the gynaecology outpatient department. I was aware that by having participants attend the hospital for the interview, there was the potential for them to 'medicalise' the interview.

When I was initially interviewing the healthcare professionals, I had the impression that they felt I was 'testing their clinical knowledge'. Therefore, I spent 15 to 20 minutes prior to the commencement of each healthcare professional interview dispelling this thought. This was something that I had not appreciated prior to commencing the interviews.

After conducting both phases of the study, I recognised the impact that my position as a clinician had on patients and how I was able to influence a consultation. The way in which I approach medical consultations, and the manner in which I interact with patients, has changed significantly since conducting this PhD project. When I am in a clinical consultation, I now listen to understand, rather than listen to respond. This was a very powerful moment for me when I initially recognised it.

11.6 Insider/outsider perspective

An individual's world view about a particular research area will be dependent on their ontological and epistemological assumptions (Gary and Holmes, 2020). Here, it is important for me to discuss the insider and outsider positions that I hold as a researcher and doctor and the tensions arising from this situation (Kirpitchenko and Voloder, 2014). Throughout the research process, I became increasingly aware of both of these positions as they were challenged, and I learned to balance them both. Kirpitchenko and Voloder (2014) discuss the importance of a researcher recognising the different positions they hold and reflecting on this to ensure they are accounted for during the research process. They also discuss the importance of being aware of *etic* and *emic* meanings during the research process and explain that a 'tone of voice can alter a meaning of a word or phrase for an insider, but a change of tone may go unnoticed by an outsider' (Kirpitchenko and Voloder, 2014, p4).

I had an insider perspective into the research area as a registrar in obstetrics and gynaecology. Through my clinical experience, I had a first-hand awareness of some of the challenges women with suspected endometriosis encountered. I was also aware of some of the challenges that clinicians faced in the gynaecology clinic with regards to the length of appointment. I was therefore aware of these influences throughout both phases of the research process. I had to ensure that I remained neutral with the participants during the interviews and focus groups, both in my tone of voice and my body language. All participants were aware of my clinical role, but it was important that I reminded them that, in terms of the PhD study, my primary role was that of a researcher. At times, this was challenging to manage, especially during the first phase of the study when some of the women asked me clinical questions in relation to their care.

As a male researcher, I had also had an outsider perspective. I was mindful of my role as a male researcher discussing female medical problems that I have no personal experience of. However, as the interviews progressed, I did not believe this to be a problem or concern in any way. In fact, it enabled me to engage with the participants much more deeply as I sought to actively clarify details during the interviews and not make assumptions about the data.

Through interviewing participants in this study, and analysing the respective findings, I have realised that as human beings, 'most people do not listen with the intent to understand; they listen with the intent to reply' (Covey S, 2004). This powerful realisation has now completely changed my clinical practice in the way I engage not only with patients, but also colleagues alike.

11.7 Researcher 'burn-out'

Conducting semi-structured interviews and transcribing them immediately afterwards was challenging. At times, following the interview, I would feel emotionally tired. While this was a reflection of my engagement as a researcher with the participants, I quickly realised that I should not do more than one interview a day. This was important as it helped me to ensure I was not emotionally ‘burned out’ and therefore allowed me to maintain focus and clarity.

11.8 Planning and designing

When I initially planned the PhD project, I had chosen to use interpretative phenomenological analysis methodology and applied for ethical approval for this. However, a few weeks after obtaining this ethical approval, I reconsidered and changed to a grounded theory approach (as described in chapter three). While I was defending my research protocol to the ethics board, I realised with hindsight that my research focus would be more appropriately answered by using grounded theory. I therefore completed the relevant amendment forms and submitted them for ethical consideration. This process made me realise that even after a research project has received ethical approval, one may consider other facets of the protocol, and therefore the research should not continue until it has been re-approved by the ethics committee. Changing my methodology also helped me appreciate that my PhD journey is part of an apprenticeship.

11.9 Attending courses

Through attending various courses on qualitative research methodology during my PhD, I was able to gain further insights into the philosophy that underpins qualitative research. Interacting with experienced qualitative researchers at these courses was a very insightful process, and it led me to appreciate the importance of reflexivity in particular.

11.10 Challenges with interviews

Although I have experience in medical consultations and communicating with patients, I do not think this prepared me for the semi-structured interviews. They were a totally different experience from what I had anticipated. I felt that my semi-structured interviews became ‘better’ as they progressed. Each interview allowed me to reflect on my approach and the way I engaged with participants. With grounded theory, as I was interviewing participants and analysing the data immediately after, I was able to be extremely reflexive. I was able to not only reflect on my approach but also on the individual interviews. This was really exciting, as I was discovering aspects about myself that I never knew existed.

I noticed that once the recording device had been turned off, participants would frequently mention other useful information. Therefore, as I progressed through my interviews, I learned the importance of telling participants that if they were happy for me to do so, then I could turn the recording device back on to capture this information.

My approach to interviewing participants with endometriosis was different to the approach I took with healthcare professionals. For instance, using known consultation strategies, such as regular summaries, appeared to be more frustrating for healthcare professionals than for the women with endometriosis. This was something I noticed as my interviews progressed. I realised that this was often due to clinical time pressures on the part of the healthcare professionals.

During phase one, one of the participants brought her mother to the semi-structured interview. While this was not a problem for me per se, it represented a procedural aspect that I had not considered in my initial research protocol. In this instance, the participant wanted her mother to be present for emotional support during the interview, but her mother was not actually involved in the study. I have been unable to find any reports in the literature with regards to the presence of others during research interviews and the impact it may have on qualitative studies.

11.11 The use of grounded theory

As part of my study, I read a lot about grounded theory and how it can be used. It was only when I applied the principles of Charmaz's GT methodology that I learned more about it. I learned that the application of her theory was not the linear process that I had initially assumed. This process led me down many methodological and analytical paths despite there being common guidance available on the constructivist GT methodology. It reminded me of performing a complex Caesarean section. Every obstetrician and gynaecologist can perform a Caesarean section; however, when encountering complexities such as heavy intraoperative bleeding, despite the protocolised measures, the 'common way' of performing a Caesarean section is no longer applicable. The surgeon must think laterally and react quickly. This felt the same when applying the constructivist GT. It was after conducting my initial interviews that I realised how I needed to change the way in which I conducted these interviews, as well as the way I analysed the data. I realised that I had to theoretically sample for participants with a perceived delay to diagnosis, and this meant I had to make an amendment to my original ethics application.

11.12 The scoping review: timing

Traditionally, grounded theorists state that a literature review should not commence prior to starting the study as it may influence the researcher. While this is important, realistically, this was not possible. The nature of a PhD project meant that I had to justify my research protocol to the university prior to acceptance, and therefore I had to conduct a scoping review. In addition, by carrying out a scoping review I could ensure that I was not replicating a similar study. The most important point to this is that I was aware of how the scoping review could influence my study and, as such, I was able to keep notes on this through my reflexive practice and acknowledge it.

11.13 Analysing data and the results chapter

Initially, I went through my preliminary findings with one of my supervisors. While she recognised my efforts and the work that I had done, she reminded me that there was still more to do. She explained that I 'should stay with the data for a bit longer' This reminded me of the importance of really thinking about my findings, and while I had tentative categories, these may not necessarily be a representation of 'the final product'. I re-read Charmaz's (2006) book and focussed on the data analysis chapter to remind myself of the principles of the constructivist grounded theory approach. I realised the importance of ensuring that my findings and approach to data analysis were very transparent.

11.14 The use of coding software versus manually coding the transcripts

During previous experience of using NVivo as part of qualitative research, I found that I struggled to manage the data. To ensure I was 'connected' with the data, especially during constant comparison that formed part of the GT phase of the study, I actively made the decision not to use NVivo in the management of my data. The use of large sheets of paper and writing down my ideas helped me greatly, as I was able to make connections within a transcript and among different transcripts much more clearly.

11.15 Change in primary supervisor

My initial primary supervisor (Dr Andrea Stockl) had to leave my supervisory team due to unforeseen circumstances. I am grateful to Dr Joanna Semlyen, who took over this supervision as my primary supervisor and guided me, along with the wider team. Dr Semlyen reviewed my thesis to date and provided me with constructive feedback on how I can improve my work.

The final chapter will provide the concluding remarks for the overall doctoral study.

Chapter 12 – Conclusion

12.1 Introduction

To recap, the aim of this study was to understand the delay to diagnosis in women who have endometriosis, while the objectives are:

1. To explore and understand the experiences of women who have been diagnosed with endometriosis (phase one).
2. To develop a theory to explain how the factors that influence delay to diagnosis in women with endometriosis can impact on the process of diagnosis (phase one).
3. To explore and understand healthcare professionals' perspectives about women's experiences of diagnosis of endometriosis, to deepen our understanding of the healthcare context and factors influencing health professionals' decision-making (phase two).

12.2 Research conceptualisation

This doctoral study was conceived as part of my role as a Clinical Research Fellow in gynaecology. My interest in this research area developed as I encountered women with endometriosis in the clinical setting and listened to them describe their protracted and troubled journeys to diagnosis. Around the time I was writing my PhD proposal, the latest NICE guidance (2017) made a clear recommendation that the delay to diagnosis of endometriosis required further exploration.

The scoping review in chapter 2 provides strong evidence that delays to diagnosis of endometriosis continue to be a problem. While the scoping review outlined broad reasons for the delay to diagnosis of endometriosis, it also provided a backdrop to understand where further research is required. The scoping review also enabled me to recognise issues and gaps in the research design of existing studies; the majority of these studies were questionnaire-based and provided superficial, fragmented and disconnected reasons for the delay to diagnosis. The scoping review highlighted the need for an in-depth, qualitative enquiry into both women's experiences of being diagnosed with endometriosis and healthcare professionals' insights into the differential diagnostic process. I decided that the aim of the research study should be to develop, in two phases, a theory to explain the delays to diagnosis of endometriosis. Phase 1 comprised a constructivist grounded theory approach, involving individual, semi-structured interviews with women who had been diagnosed with endometriosis. The key insights from phase one informed the design of phase 2, where verbatim quotes from the women interviewed in phase 1 were presented to healthcare professionals in the focus groups. The data generated were analysed using reflexive thematic analysis.

12.3 Summary of the research output from phases 1 and 2

The emergent grounded theory proposes that the main concern of women during the often protracted period prior to being diagnosed with endometriosis is making sense of a fracturing life. The way in which women engage in sense-making is heavily impacted by the prevailing context of refusal, disbelief or belief. These three contexts are created in the moment by the actions and interactions among the women and significant others, friends, strangers and/or HCPs and are shaped by the perceived power dynamics operating within each encounter. The contexts of refusal and disbelief are both heavily influenced by the social construct of menstruation and the impact of the taboos associated with this. In the face of the constraining behaviours of others, the women's experiences within and transitions between the three contexts and their journey through the process of diagnosis depend on a number of key influencing factors. These include their perception of their female identity; their investigative behaviours (especially ignoring, normalising and coping); and their perception of the risk of harm and consequent propensity to seek help (both non-medical and medical).

During consultations, healthcare professionals invisibilise women with undiagnosed endometriosis through their dismissive, discounting and normalising behaviours. The power vested in the clinicians by the women and their relative lack of autonomy allows the co-creation of contexts of refusal or disbelief. Structural discrimination in terms of HCPs' lack of training in gynaecological issues, the insufficient time available during consultations, and the invisible threshold for referral all conspire to enable the discrimination against, containment of and invisibilisation of these women. The complexity and number of endometriosis symptoms hinder HCPs in achieving a differential diagnosis. HCPs therefore appreciate the contribution of a woman's 'significant other' during a consultation, which often encourages the HCP to explore a diagnosis of endometriosis and to push the women over the invisible line of referral, weakening the context of disbelief and opening the way to a context of belief.

12.4 Conclusion

This study extends the work of Caroline Credo Perez (2019) to reveal how the structural conditions of the National Health Service and the attitudes and behaviours of some HCPs invisibilise women, leading to their endometriosis going undiagnosed.

This is the first study to explore the delays to diagnosis for women with suspected endometriosis using a coherent theoretical framework and thus provides a conceptual tool with which to organise the existing, descriptive and fragmented literature. Further it contributes a dynamic theory which can be used to predict likely future behaviours of both women with undiagnosed endometriosis and HCPs. It also identifies structural issues which need to be addressed in order to bring about positive change to the diagnostic process.

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Appendices

Appendix 1. Sample transcript of my reflexive interview with an academic

Do you think you have one perspective because of the nature of the women you see?

Yes. As our trust is a tertiary referral centre, I see women who have been affected on a severe level. I also seen women who have had a delay to diagnosis. I am aware that this is a specific population I am seeing. Endometriosis does not always have a negative impact that I see. For instance, in the community, there are many women with less severe symptoms.

What do you think of healthcare professionals?

In the community, the GP has 10 minutes. The problem is much bigger and so can be challenging to explore all the issues. If they had more time, or have a community gynaecologist to explore this further, then this may be useful. Even from medical school, when chronic pelvic effect is mentioned, it feels like 'doom and gloom' Therefore, there is a domino effect from medical school to qualified doctors.

Do you think there is a need to do something about this?

I think even before we can do something, I think it is important to listen to women. Even on forums, women mention they are not being listened to. Listening to their stories and focusing on their agenda and then marrying that up with your agenda would be useful.

What do you think your agenda is as a doctor?

I think my agenda would be to gain insight into what she thinks is wrong. Does she think endometriosis is a diagnosis? If based on my history and examination, I think endometriosis is a diagnosis, then I would want to investigate her further for this. I want her to feel empowered. By sitting in and listening to consultations, women don't necessarily know what to expect. They don't know what lies ahead. If the laparoscopy is negative, then what next? If you are fore warned, then you are forearmed.

What are the barriers to the above?

Time pressures, I think. In General Practice, if a woman has been speaking for 6 minutes, then this doesn't leave much time for further discussion. Maybe awareness of endometriosis is not that great in the community. Lack of support groups for instance may be an issue.

So, what you are saying is that more can be done to women before they arrive in your clinic?

Yes. Part of this job is by the GP and part of it can be done in the community.

Do you think GP's have the awareness?

Yes and no! At medical school, we spend 5 minutes on endometriosis! Considering that we don't know the prevalence of endometriosis, who knows how many women are in the community undiagnosed. I think taking a step back and taking this to schools can also be important. For instance, asking teenagers on what they think endometriosis is and how it can affect people.

Appendix 2. Recruitment poster

UEA University of East Anglia

Norfolk and Norwich University Hospitals NHS
NHS Foundation Trust

Suffering from endometriosis?

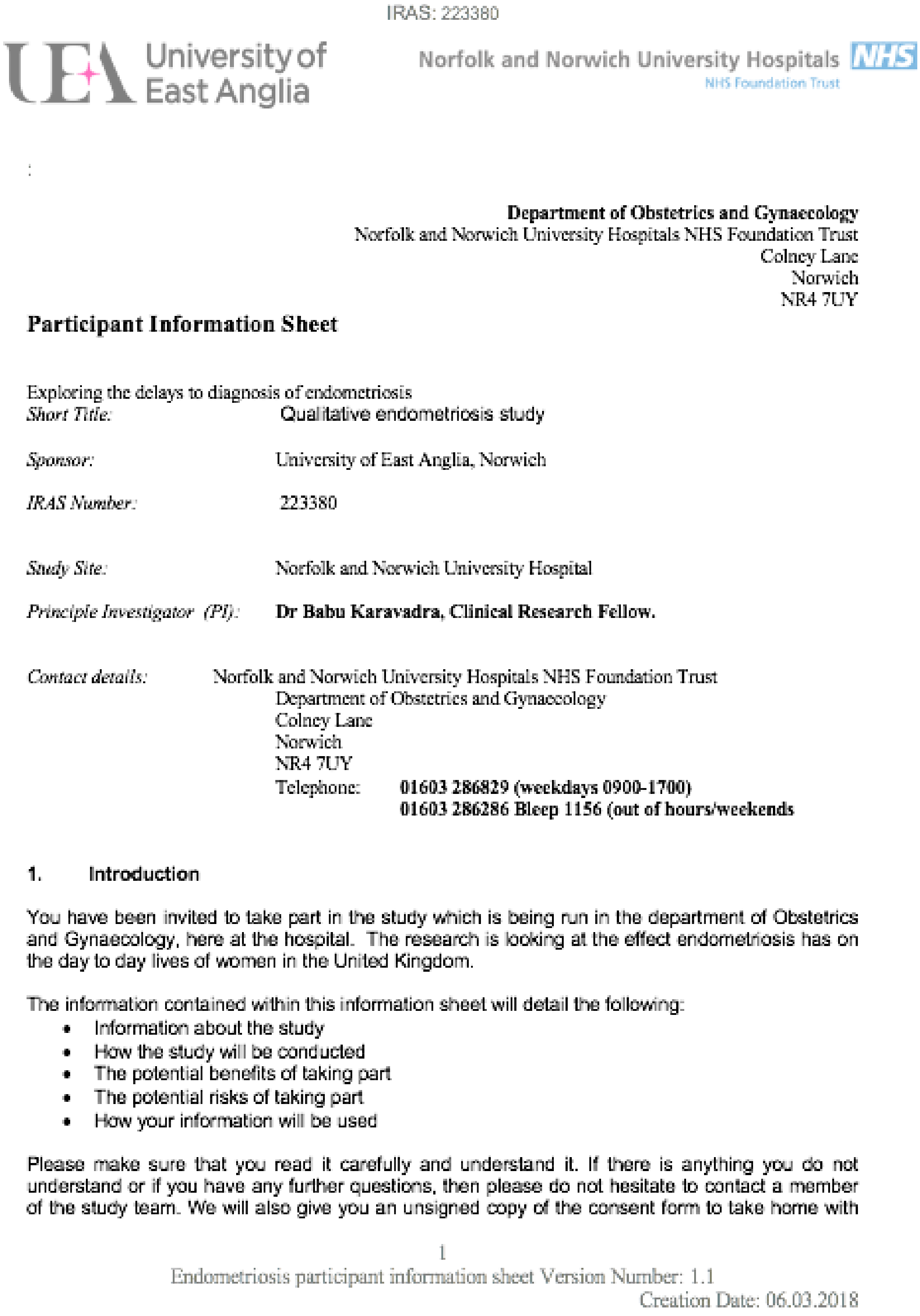
- We want to know how endometriosis affects you
- We are looking for women **aged 16 + with endometriosis** to participate in a brief interview
- We are also looking for healthcare professionals who look after women with endometriosis to take part in a brief interview

Participate in a research study

For further information, please contact
Dr Babu Karavadra (Clinical Research Fellow) on
01603 287085 or
babu.karavadra@nnuh.nhs.uk

Version 1.2 IRAS: ***223380*** *Date: 06/03/2018*

Appendix 3. Endometriosis participant information sheet



IRAS: 223380

University of East Anglia

Norfolk and Norwich University Hospitals NHS
NHS Foundation Trust

:

Department of Obstetrics and Gynaecology
Norfolk and Norwich University Hospitals NHS Foundation Trust
Colney Lane
Norwich
NR4 7UY

Participant Information Sheet

Exploring the delays to diagnosis of endometriosis

Short Title:	Qualitative endometriosis study
Sponsor:	University of East Anglia, Norwich
IRAS Number:	223380
Study Site:	Norfolk and Norwich University Hospital
Principle Investigator (PI):	**Dr Babu Karavadra, Clinical Research Fellow.**

Contact details: Norfolk and Norwich University Hospitals NHS Foundation Trust
Department of Obstetrics and Gynaecology
Colney Lane
Norwich
NR4 7UY
Telephone: **01603 286829 (weekdays 0900-1700)**
01603 286286 Bleep 1156 (out of hours/weekends

1. Introduction

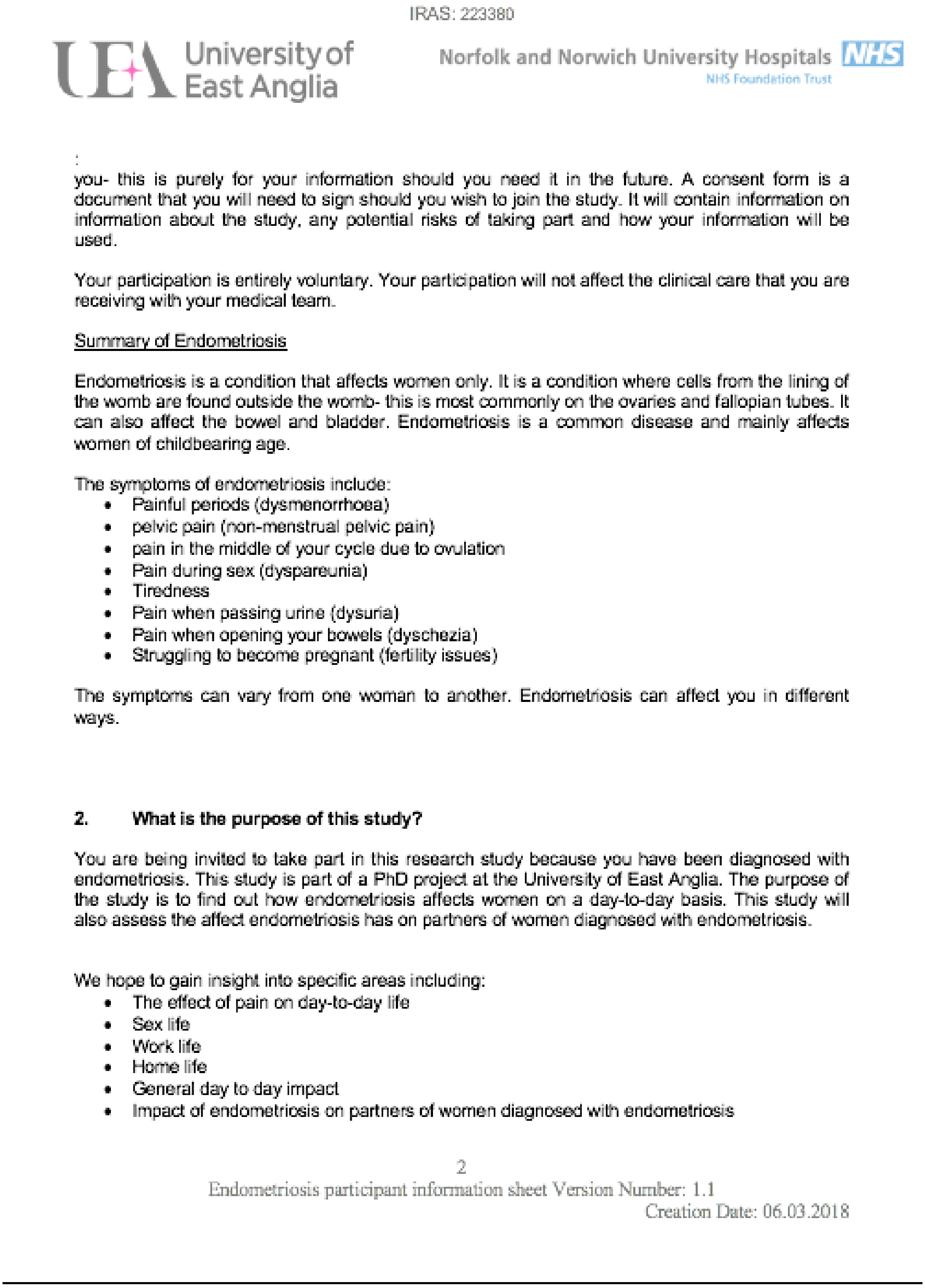
You have been invited to take part in the study which is being run in the department of Obstetrics and Gynaecology, here at the hospital. The research is looking at the effect endometriosis has on the day to day lives of women in the United Kingdom.

The information contained within this information sheet will detail the following:

- Information about the study
- How the study will be conducted
- The potential benefits of taking part
- The potential risks of taking part
- How your information will be used

Please make sure that you read it carefully and understand it. If there is anything you do not understand or if you have any further questions, then please do not hesitate to contact a member of the study team. We will also give you an unsigned copy of the consent form to take home with

1
Endometriosis participant information sheet Version Number: 1.1
Creation Date: 06.03.2018



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you- this is purely for your information should you need it in the future. A consent form is a document that you will need to sign should you wish to join the study. It will contain information on information about the study, any potential risks of taking part and how your information will be used.

Your participation is entirely voluntary. Your participation will not affect the clinical care that you are receiving with your medical team.

Summary of Endometriosis

Endometriosis is a condition that affects women only. It is a condition where cells from the lining of the womb are found outside the womb- this is most commonly on the ovaries and fallopian tubes. It can also affect the bowel and bladder. Endometriosis is a common disease and mainly affects women of childbearing age.

The symptoms of endometriosis include:

- Painful periods (dysmenorrhoea)
- pelvic pain (non-menstrual pelvic pain)
- pain in the middle of your cycle due to ovulation
- Pain during sex (dyspareunia)
- Tiredness
- Pain when passing urine (dysuria)
- Pain when opening your bowels (dyschezia)
- Struggling to become pregnant (fertility issues)

The symptoms can vary from one woman to another. Endometriosis can affect you in different ways.

2. What is the purpose of this study?

You are being invited to take part in this research study because you have been diagnosed with endometriosis. This study is part of a PhD project at the University of East Anglia. The purpose of the study is to find out how endometriosis affects women on a day-to-day basis. This study will also assess the affect endometriosis has on partners of women diagnosed with endometriosis.

We hope to gain insight into specific areas including:

- The effect of pain on day-to-day life
- Sex life
- Work life
- Home life
- General day to day impact
- Impact of endometriosis on partners of women diagnosed with endometriosis

- The reasons for the delay to diagnosis

We hope this information will provide us with detailed information on how endometriosis affects women on a day-to-day basis. Ultimately, the results will be used to help further improve services available to patients with endometriosis. The findings will also be written up as a report (PhD thesis) and be published in scientific journals.

3. What does the study involve?

The Study Protocol- what happens at the visit? (Figure 1)
Please see the next page for this information

Summary
The study will take place at the Norfolk & Norwich University Hospital in the gynaecology outpatient department. You will be asked to read through this patient information leaflet and read and sign the consent form if you are happy to take part. The consent form must be signed in person. By signing the consent form, you are confirming that you have been given all the relevant information about the study and that you are happy to take part. Once the consent form is signed; you will be invited to partake in the actual study interview. The study will remain open for a one-year period

The Study Protocol Flowchart (Figure 1)

1. **At your routine clinic visit:** We will talk to you about Endometriosis and this study

    1. This Patient Information Sheet will be given to you with a consent form to read
    2. You will receive an initial telephone call within two weeks of receiving the information sheet. This will allow us to:
        a. To make sure you understand details of the study form the participant information sheet
        b. To answer any questions, you have

↓

2. **Consent:** We will ask you to sign a consent form before we start any investigations or treatment

↓

    1. The consent form will be signed in person

3. **The interview**

↓

    1. A date and time will be arranged for you to attend the gynaecology outpatient department to carry out the interview
    2. The interview will last between 30 minutes to two hours approximately
    3. The interview will be recorded using a Dictaphone
    4. You will be able to talk freely about how endometriosis impacts you
    5. Dr Karavadra will be in the room with you.
    6. The interview will not have any other participants apart from yourself

↓

4. **After the interview**

    1. The interview recording will be transferred onto paper and stored in a safe place.
    2. No information will identify you personally
    3. The findings will be written up as a research project

5. **Completion of the study**

    1. Once all the participants have been interviewed over a one-year period, the findings will be analysed and written up as a research project.
    2. You will receive a copy of the written report should you wish

:

Pre-screening/Consent

After you have had time to consider the information in this Patient Information Sheet, we will contact you by phone to ask about whether you want to take part. If you are interested in enrolling in the study, we will arrange a Consent visit to discuss the study in detail, check your eligibility and sign the consent form.

The interview visit

This will occur at the Norfolk & Norwich University Hospital in the gynaecology outpatient's department.

The following will occur on the day of your visit:

- We will confirm your personal details.
- We will confirm that you have read the participant information leaflet and have signed and dated the consent form.
- A voice recording device will be set up in the room and the interview will be recorded from start to finish.

The following is a guide to some of the questions that will be asked:

- How are you today?
- Please can you confirm your age?
- What is your ethnicity?
- Do you have any past medical history? If so, what are these?
- Do you have any drug allergies?
- Do you smoke?
- Do you consume alcohol?
- Have you had any surgery for endometriosis? If so, what surgery was this?
- Endometriosis impacts women in many different ways. Today's focus will be on the physical pain and psychosexual aspects to endometriosis.
- Please could you begin to describe the affect pain from endometriosis has on your life?

The aim of the interview is for you to freely voice your thoughts and feelings about how endometriosis impacts you on a daily basis. We aim to ask minimal questions.

Our aim is to help you tell us what matters to you the most about endometriosis.

What do I have to do?

You can continue with your life as you would normally. There is no need to make any changes to your medical plan that has been made between you and your doctor.

Alternatives to taking part

Participation in this study is entirely voluntary. Even if you do consent to participating in this study and then later change your mind, then this will not impact your routine medical care that you

:
receive at the hospital. It is important for you to know that you are able to withdraw your consent at any time.

Once you have signed the consent form and completed the interview, all information obtained will be used in the project write up. Therefore, if at this point you decide to withdraw your consent, then the findings from the study will still be used. All findings will remain anonymous and will not contain any personal identification details such as name, address, date of birth for instance.

Benefits to taking part
The information that you provide will be used to improve the care that we provide women with endometriosis in the future. We know that endometriosis impacts women in many ways.

You may not benefit directly from taking part in this study; however, it will give you an opportunity to gain more insight into endometriosis. At the end of the interview, we will reimburse your car parking ticket and therefore you will not have to pay any parking charges. You will be provided with a signed slip and this must be taken to the information desk at the Travel Office (Level 2 of the hospital building) and they will ensure no charges are applied to your ticket.

Risks to taking part

Extra hospital visits
The study protocol requires you to attend the hospital to sign the consent form in person and attend the gynaecology outpatient department for the interview. This can all be done in one visit. This visit will be an extra visit to your routine hospital appointments.

You may feel emotions you may not have initially anticipated
The study is aimed to get information on how endometriosis impacts you on a day-to-day basis. As part of this, you may discuss very personal and sensitive issues that matter to you the most and this may potentially upset you. If this occurs, then we will ask you to contact your GP on how you can be best supported. We will also provide you with the contact details of our endometriosis Nurse Specialist, Jane Snasdell. Jane will be able to answer any general questions you have about your care. She is also able to liaise with the doctors if need be.

4. Do I have to take part?

Participation in the study is entirely voluntary. Whether you decide to participate or not, the routine clinical care you receive with your doctor will not be affected. Once you agree to be initially contacted, we will send you this leaflet and a consent form to read. You will have two weeks from receiving this information leaflet to decide if you wish to partake in the study or not. At this point, Dr Karavadra will call you and answer any specific questions or queries.

It is entirely your choice whether to take part in this study. It is once again important to mention that you can withdraw your consent at any time.

:

6. What if something goes wrong?

We do not anticipate any problems to your health by participating in this study. However, if you have any concerns about any aspect of this study, then please contact a member of the study team and they will answer any questions for you. At the end of this information sheet, contact details for all members of the study team are available.

In rare cases, if the study team feel that it is no longer in your best interest to continue on the study, you may be withdrawn. We will explain the reasons by contacting you accordingly. Your participation or withdrawal will not affect your medical care in any way.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the course of this study, then you should contact the Patient Advice and Liaison Service (PALS)) at the hospital. Further information about PALS can be obtained from the hospital.

7. Confidentiality

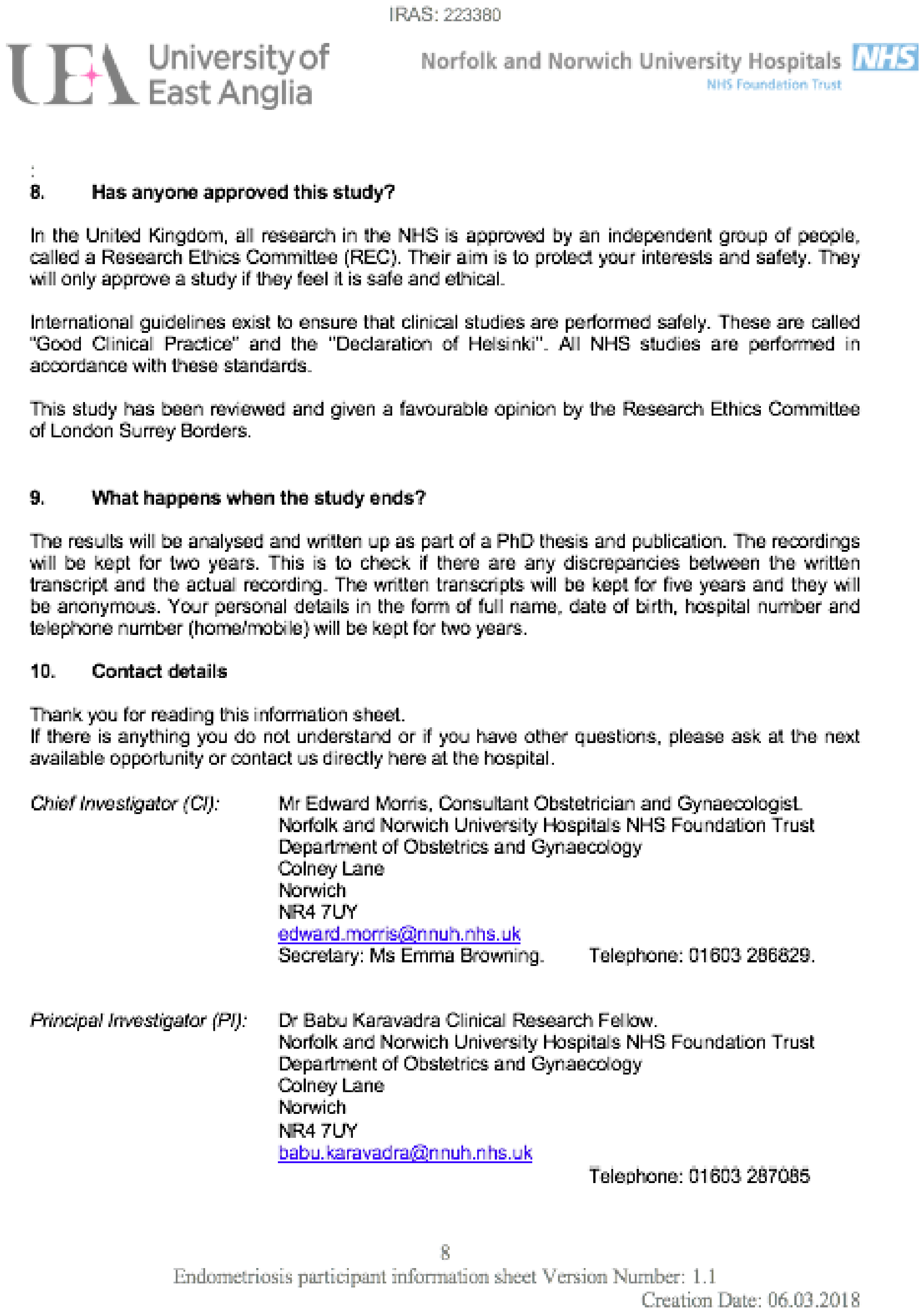
Your personal details and information from the study (medical and personal health information) are processed in accordance with UK data protection law (Data Protection Act 1998), which is designed to protect your privacy.
Your identity and other information obtained during this study will be kept confidential and you will not be identified by name or any other personal detail.

Information will be used in reports of the study or for scientific presentations and publications such as a PhD thesis. Your personal details will be made anonymous. Your personal information will be retained for 2 years, while anonymised data obtained from the interview will be retained for 5 years.

Everything you say/report is confidential unless you tell us something that indicates that you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

By signing this informed consent form, you give your permission for your information to be used and shared for the purposes of this study and at any time in the future. You have the right to withdraw your consent for this study at any time without giving a reason. This will not affect the standard of care you receive. **The information you provide during the interview is only going to be used as part of this PhD.**

If you withdraw your consent, your participation in the study will end and the study staff will stop collecting medical information from you. The information collected about you before you withdrew your permission will still be used. Information that has already been collected cannot be withdrawn.



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8. Has anyone approved this study?

In the United Kingdom, all research in the NHS is approved by an independent group of people, called a Research Ethics Committee (REC). Their aim is to protect your interests and safety. They will only approve a study if they feel it is safe and ethical.

International guidelines exist to ensure that clinical studies are performed safely. These are called "Good Clinical Practice" and the "Declaration of Helsinki". All NHS studies are performed in accordance with these standards.

This study has been reviewed and given a favourable opinion by the Research Ethics Committee of London Surrey Borders.

9. What happens when the study ends?

The results will be analysed and written up as part of a PhD thesis and publication. The recordings will be kept for two years. This is to check if there are any discrepancies between the written transcript and the actual recording. The written transcripts will be kept for five years and they will be anonymous. Your personal details in the form of full name, date of birth, hospital number and telephone number (home/mobile) will be kept for two years.

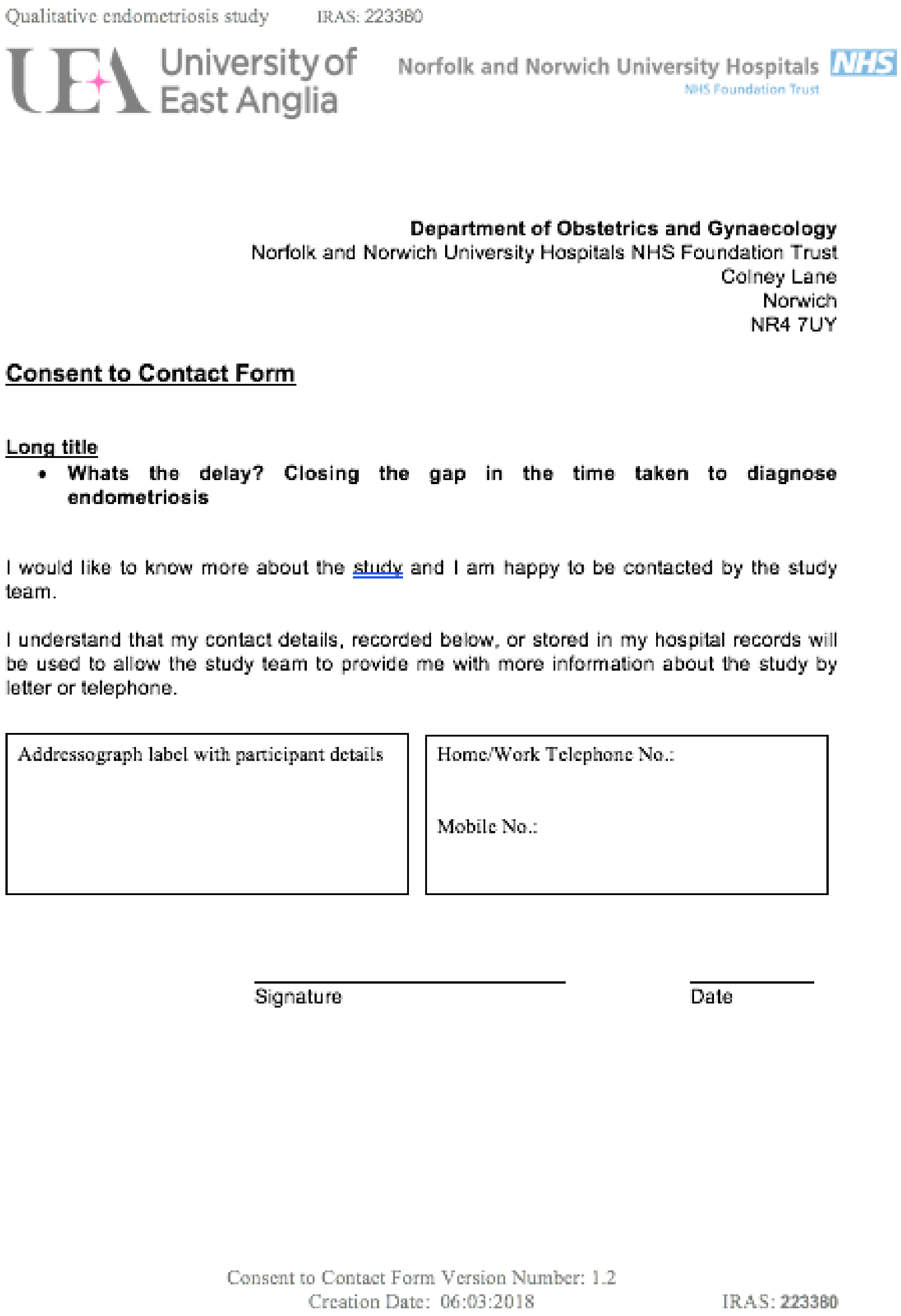
10. Contact details

Thank you for reading this information sheet.
If there is anything you do not understand or if you have other questions, please ask at the next available opportunity or contact us directly here at the hospital.

Chief Investigator (CI):
Mr Edward Morris, Consultant Obstetrician and Gynaecologist.
Norfolk and Norwich University Hospitals NHS Foundation Trust
Department of Obstetrics and Gynaecology
Colney Lane
Norwich
NR4 7UY
edward.morris@nnuh.nhs.uk
Secretary: Ms Emma Browning. Telephone: 01603 286829.

Principal Investigator (PI):
Dr Babu Karavadra Clinical Research Fellow.
Norfolk and Norwich University Hospitals NHS Foundation Trust
Department of Obstetrics and Gynaecology
Colney Lane
Norwich
NR4 7UY
babu.karavadra@nnuh.nhs.uk
Telephone: 01603 287085

Appendix 4. Consent to contact form



Qualitative endometriosis study IRAS: 223380

University of East Anglia

Norfolk and Norwich University Hospitals NHS
NHS Foundation Trust

Department of Obstetrics and Gynaecology
Norfolk and Norwich University Hospitals NHS Foundation Trust
Colney Lane
Norwich
NR4 7UY

Consent to Contact Form

Long title

- **Whats the delay? Closing the gap in the time taken to diagnose endometriosis**

I would like to know more about the study and I am happy to be contacted by the study team.

I understand that my contact details, recorded below, or stored in my hospital records will be used to allow the study team to provide me with more information about the study by letter or telephone.

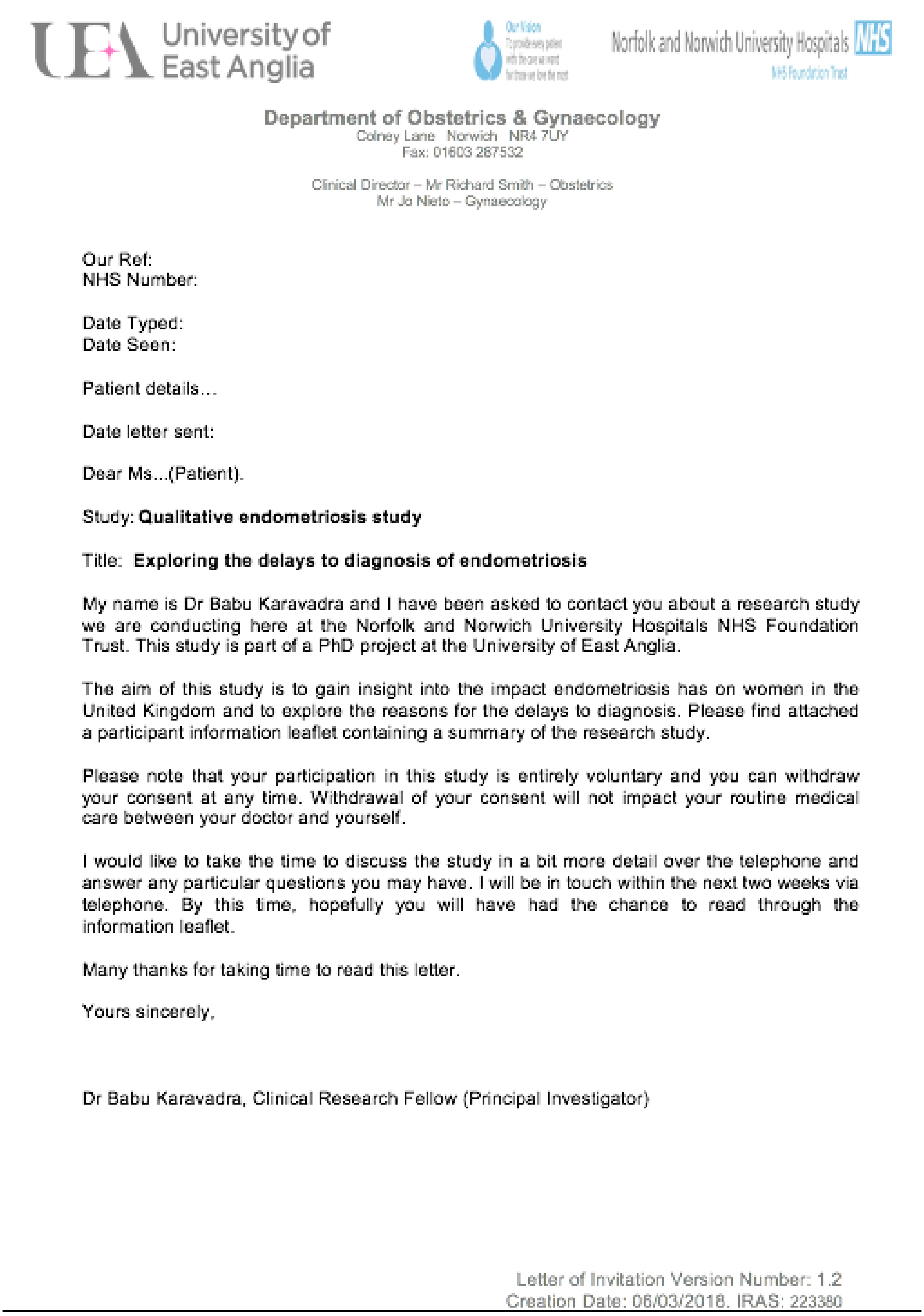
Addressograph label with participant details	Home/Work Telephone No.: Mobile No.:

Signature

Date

Consent to Contact Form Version Number: 1.2
Creation Date: 06:03:2018 IRAS: 223380

Appendix 5. Participant invitation sheet



University of East Anglia

Norfolk and Norwich University Hospitals NHS
NHS Foundation Trust

Department of Obstetrics & Gynaecology
Colney Lane Norwich NR4 7UY
Fax: 01603 267532

Clinical Director – Mr Richard Smith – Obstetrics
Mr Jo Nieto – Gynaecology

Our Ref:
NHS Number:

Date Typed:
Date Seen:

Patient details…

Date letter sent:

Dear Ms...(Patient).

Study: **Qualitative endometriosis study**

Title: **Exploring the delays to diagnosis of endometriosis**

My name is Dr Babu Karavadra and I have been asked to contact you about a research study we are conducting here at the Norfolk and Norwich University Hospitals NHS Foundation Trust. This study is part of a PhD project at the University of East Anglia.

The aim of this study is to gain insight into the impact endometriosis has on women in the United Kingdom and to explore the reasons for the delays to diagnosis. Please find attached a participant information leaflet containing a summary of the research study.

Please note that your participation in this study is entirely voluntary and you can withdraw your consent at any time. Withdrawal of your consent will not impact your routine medical care between your doctor and yourself.

I would like to take the time to discuss the study in a bit more detail over the telephone and answer any particular questions you may have. I will be in touch within the next two weeks via telephone. By this time, hopefully you will have had the chance to read through the information leaflet.

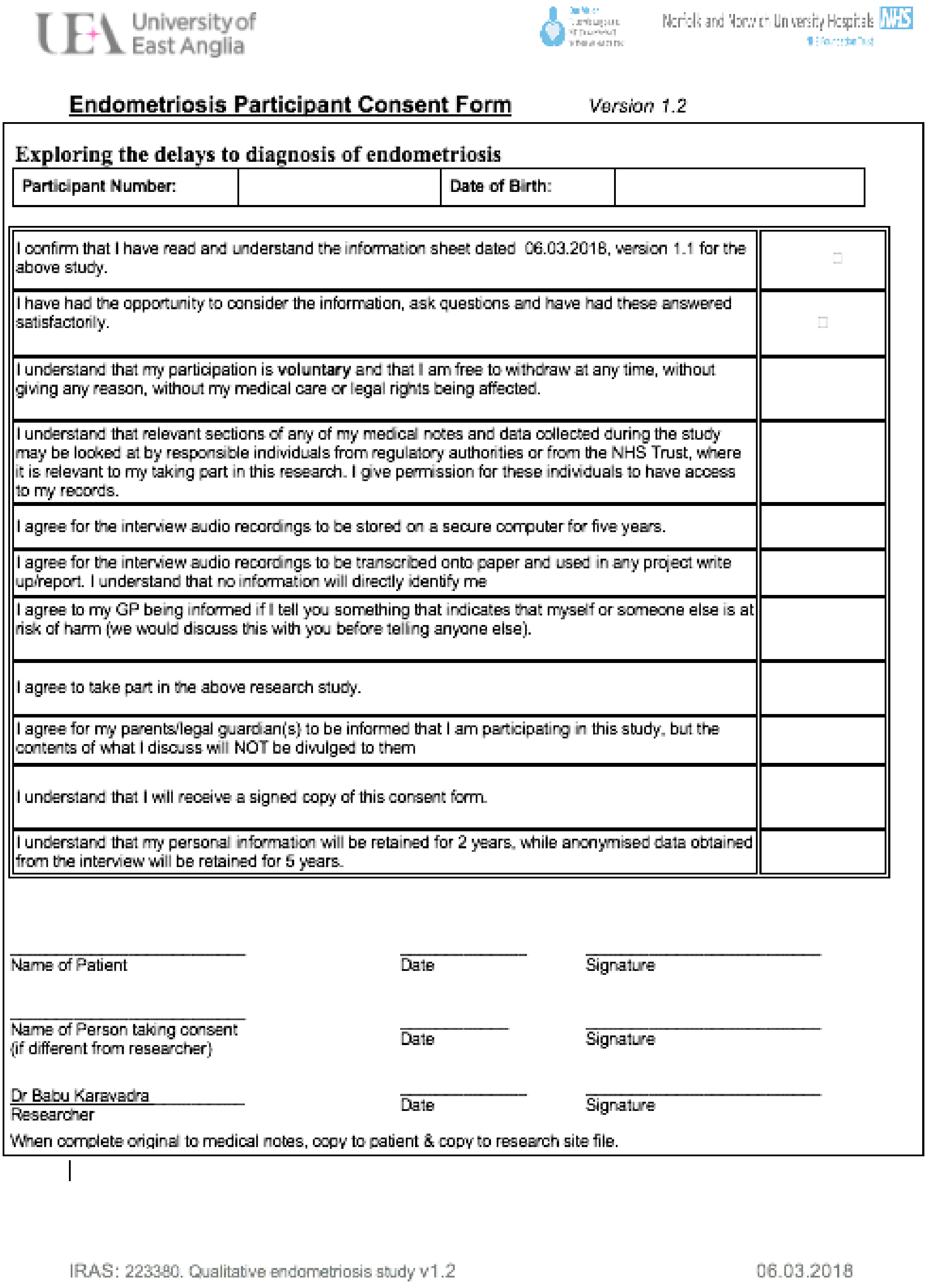
Many thanks for taking time to read this letter.

Yours sincerely,

Dr Babu Karavadra, Clinical Research Fellow (Principal Investigator)

Letter of Invitation Version Number: 1.2
Creation Date: 06/03/2018. IRAS: 223380

Appendix 6. Grounded theory phase consent form (endometriosis participants)



University of East Anglia

Norfolk and Norwich University Hospitals NHS

Endometriosis Participant Consent Form *Version 1.2*

Exploring the delays to diagnosis of endometriosis

Participant Number:		**Date of Birth:**	

I confirm that I have read and understand the information sheet dated 06.03.2018, version 1.1 for the above study.	☐
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
I understand that my participation is **voluntary** and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
I understand that relevant sections of any of my medical notes and data collected during the study may be looked at by responsible individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I agree for the interview audio recordings to be stored on a secure computer for five years.	
I agree for the interview audio recordings to be transcribed onto paper and used in any project write up/report. I understand that no information will directly identify me	
I agree to my GP being informed if I tell you something that indicates that myself or someone else is at risk of harm (we would discuss this with you before telling anyone else).	
I agree to take part in the above research study.	
I agree for my parents/legal guardian(s) to be informed that I am participating in this study, but the contents of what I discuss will NOT be divulged to them	
I understand that I will receive a signed copy of this consent form.	
I understand that my personal information will be retained for 2 years, while anonymised data obtained from the interview will be retained for 5 years.	

Name of Patient ______________ Date ______________ Signature ______________

Name of Person taking consent (if different from researcher) ______________ Date ______________ Signature ______________

Dr Babu Karavadra
Researcher ______________ Date ______________ Signature ______________

When complete original to medical notes, copy to patient & copy to research site file.

IRAS: 223380. Qualitative endometriosis study v1.2 06.03.2018

Appendix 7. Topic guide for participants with endometriosis

Introduction

- Introducing my role
- Confirming consent and signing the consent form
- Explaining that the interview is recorded via audio
- Reiterate that they can discontinue from study at any point and this will not impact their routine clinical care
- Confidentiality + clause
- Explaining the wider context of this research

Start

Experience of endometriosis and quality of life

- Ok [name of participant], please can you tell me about where your journey with endometriosis begins?

Journey to diagnosis

- Symptom recognition: What was the first thing you noticed when something was not right? What felt 'not right'?
- Recognising there is a 'problem': What was the point you felt something was not right prior to your diagnosis?

Experience with healthcare professionals

- Seeing a healthcare professional
- Experiences with healthcare professionals: When was the first time you went to see someone about your symptoms? What was it like seeing them?

Health-seeking behaviours

- What made you seek help?
- Barriers to seeking help? Was there anything that stopped you from getting help?
- Coping mechanisms used: Sometimes women who are subsequently diagnosed with endometriosis tend to have symptoms of varying severity. How did you cope with the illness?

Delay

- What does the term 'delay' to diagnosis mean for you?
- What do you think the delays to diagnosis are?
- How long was it until you were diagnosed with endometriosis?

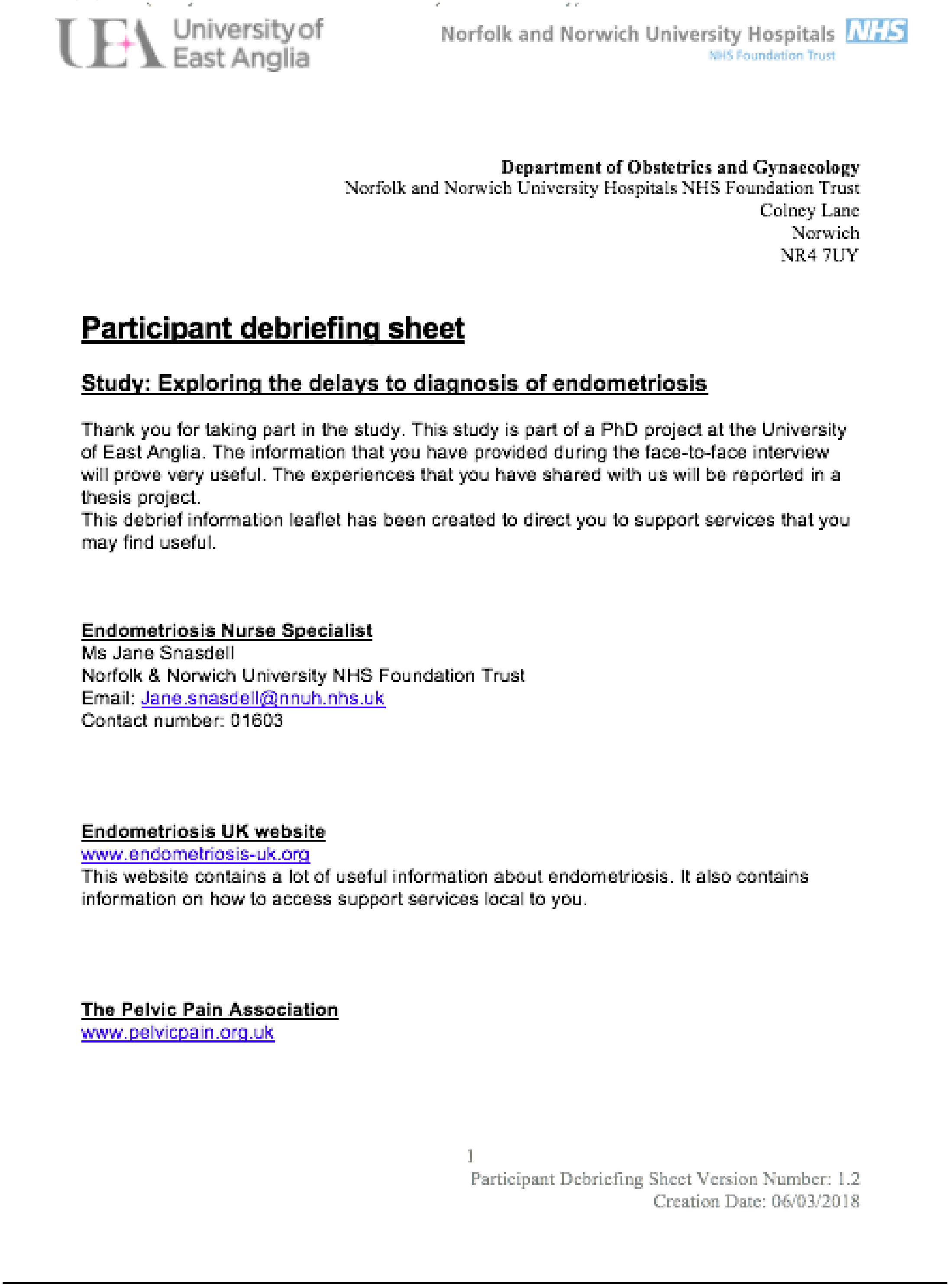
Conclusion

- Summary of discussion to clarify any points
- Opportunity for participant to ask any final questions

End

- Summarise if there is anything else the participant would like to add
- Parking reimbursement

Appendix 8. Debrief information sheet for participants in the grounded theory phase



University of East Anglia

Norfolk and Norwich University Hospitals NHS
NHS Foundation Trust

Department of Obstetrics and Gynaecology
Norfolk and Norwich University Hospitals NHS Foundation Trust
Colney Lane
Norwich
NR4 7UY

Participant debriefing sheet

Study: Exploring the delays to diagnosis of endometriosis

Thank you for taking part in the study. This study is part of a PhD project at the University of East Anglia. The information that you have provided during the face-to-face interview will prove very useful. The experiences that you have shared with us will be reported in a thesis project.
This debrief information leaflet has been created to direct you to support services that you may find useful.

Endometriosis Nurse Specialist
Ms Jane Snasdell
Norfolk & Norwich University NHS Foundation Trust
Email: Jane.snasdell@nnuh.nhs.uk
Contact number: 01603

Endometriosis UK website
www.endometriosis-uk.org
This website contains a lot of useful information about endometriosis. It also contains information on how to access support services local to you.

The Pelvic Pain Association
www.pelvicpain.org.uk

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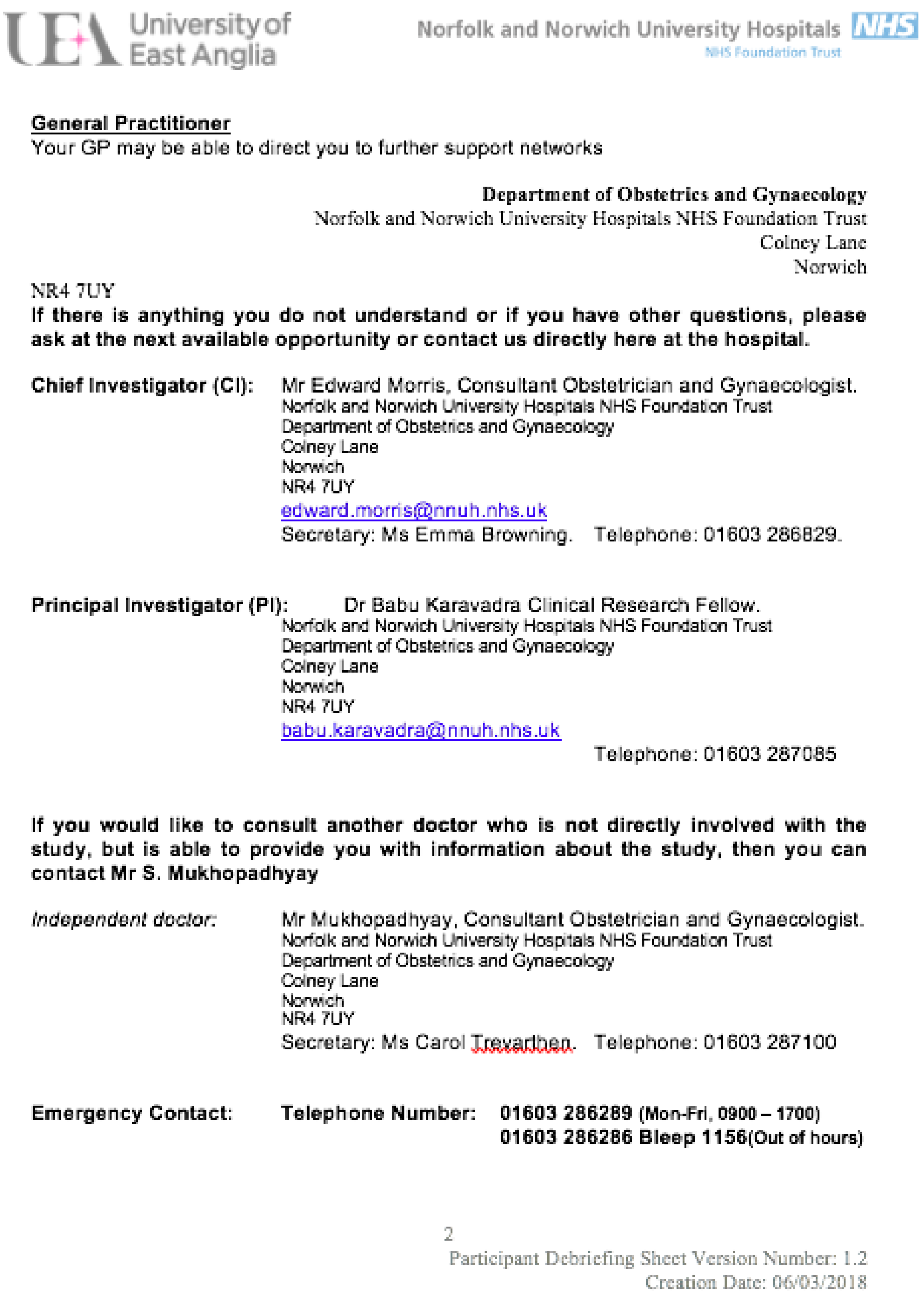
Participant Debriefing Sheet Version Number: 1.2
Creation Date: 06/03/2018



General Practitioner
Your GP may be able to direct you to further support networks

Department of Obstetrics and Gynaecology
Norfolk and Norwich University Hospitals NHS Foundation Trust
Colney Lane
Norwich
NR4 7UY

If there is anything you do not understand or if you have other questions, please ask at the next available opportunity or contact us directly here at the hospital.

Chief Investigator (CI): Mr Edward Morris, Consultant Obstetrician and Gynaecologist.
Norfolk and Norwich University Hospitals NHS Foundation Trust
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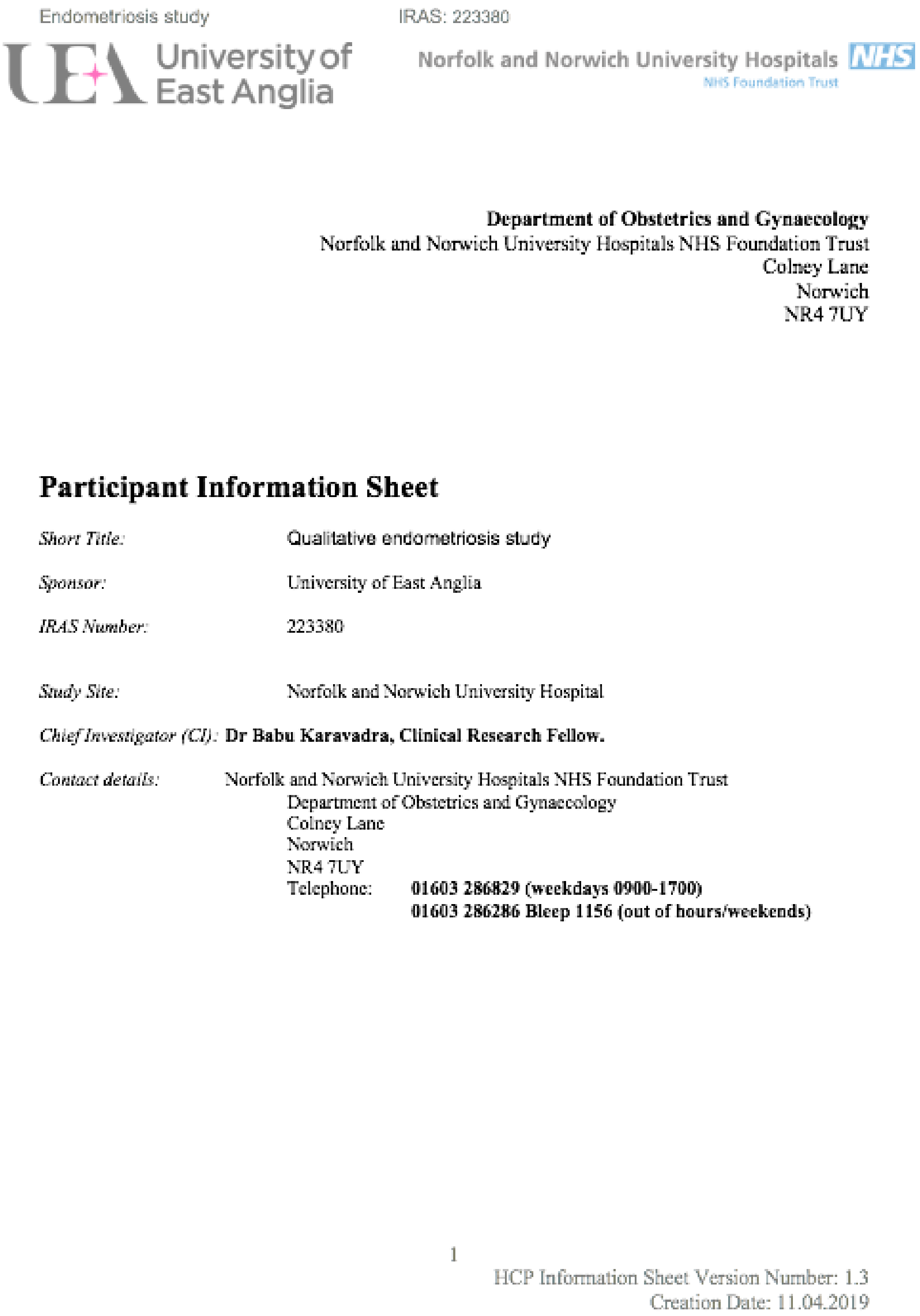
Norwich
NR4 7UY
babu.karavadra@nnuh.nhs.uk
Telephone: 01603 287085

If you would like to consult another doctor who is not directly involved with the study, but is able to provide you with information about the study, then you can contact Mr S. Mukhopadhyay

Independent doctor: Mr Mukhopadhyay, Consultant Obstetrician and Gynaecologist.
Norfolk and Norwich University Hospitals NHS Foundation Trust
Department of Obstetrics and Gynaecology
Colney Lane
Norwich
NR4 7UY
Secretary: Ms Carol Trevarthen. Telephone: 01603 287100

Emergency Contact: **Telephone Number:** **01603 286289** **(Mon-Fri, 0900 – 1700)**
01603 286286 Bleep 1156(Out of hours)

Appendix 9: Participant information leaflet for healthcare professionals (phase 2)



Endometriosis study
IRAS: 223380

University of East Anglia
Norfolk and Norwich University Hospitals NHS
NHS Foundation Trust

Department of Obstetrics and Gynaecology
Norfolk and Norwich University Hospitals NHS Foundation Trust
Colney Lane
Norwich
NR4 7UY

Participant Information Sheet

Short Title: Qualitative endometriosis study

Sponsor: University of East Anglia

IRAS Number: 223380

Study Site: Norfolk and Norwich University Hospital

Chief Investigator (CI): **Dr Babu Karavadra, Clinical Research Fellow.**

Contact details: Norfolk and Norwich University Hospitals NHS Foundation Trust
Department of Obstetrics and Gynaecology
Colney Lane
Norwich
NR4 7UY
Telephone: **01603 286829 (weekdays 0900-1700)**
01603 286286 Bleep 1156 (out of hours/weekends)

1
HCP Information Sheet Version Number: 1.3
Creation Date: 11.04.2019

1. Introduction

You have been invited to take part in the study which is being run in the department of Obstetrics and Gynaecology, here at the hospital. The research is looking at the effect endometriosis has on the day to day lives of women in the United Kingdom, but also into the reasons for the delay to diagnosis.

The information contained within this Participant Information Sheet and Informed Consent Form is very important. It tells you:

- what the study involves
- How the study will be conducted
- what the possible benefits of taking part are
- what the possible risks of taking part are
- How your information will be used

Please make sure that you read it carefully and understand it. If there is anything you do not understand or if you have any questions about the study the study team will try to answer these for you. You may take home an unsigned copy of this information sheet and consent form to read and think about or discuss with family or friends before making your decision. It is then up to you to decide whether to join the study. Your participation is entirely voluntary. If you agree to take part, you will be asked to sign a 'Consent Form'. This form says that you have been informed about the study and agree to voluntarily take part in the study.

Summary of Endometriosis

Endometriosis is a condition that affects women only. It is a condition where cells from the lining of the womb are found outside the womb- most commonly on the ovaries and fallopian tubes. Endometriosis is a common disease, affecting 5-10% of women of childbearing age. It is often diagnosed most between the ages of 30 to 45.

The symptoms of endometriosis include:

- painful periods (dysmenorrhoea)
- persistent pelvic pain (non-menstrual pelvic pain)
- pain during sex (dyspareunia)
- pain in the middle of your cycle due to ovulation
- pain when passing urine (dysuria)
- pain when opening your bowels (dyschezia)
- chronic tiredness
- difficulty getting pregnant (subfertility)

Not all patients get all of these symptoms and not all patients with these symptoms have endometriosis.

2. What is the purpose of this study?

You are being invited to take part in this research study because you are involved in the care of women with endometriosis. This study is part of a PhD project at the University of East Anglia. The purpose of the study is to find out how endometriosis affects women on a day to day basis, but also to explore the potential reasons for the delay to diagnosis. This study will also assess the affect endometriosis has on partners of women diagnosed with endometriosis.

We hope to gain insight into specific areas including:

- The impact of pain on day to day life
- Sex life
- Work life
- Home life
- General day to day impact
- Impact of endometriosis on partners of women diagnosed with endometriosis
- Impact of endometriosis on patients who are diagnosed with endometriosis between the ages of 16 to 20.
- **What support services are available**

We would specifically like to gain insight into the way you deliver care for women with endometriosis.

We hope this information will provide us with detailed information on how endometriosis affects women on a day to day basis. Ultimately, the results will be used to help further improve services available to patients with endometriosis. The findings will also be written up as a report and be published in scientific journals.

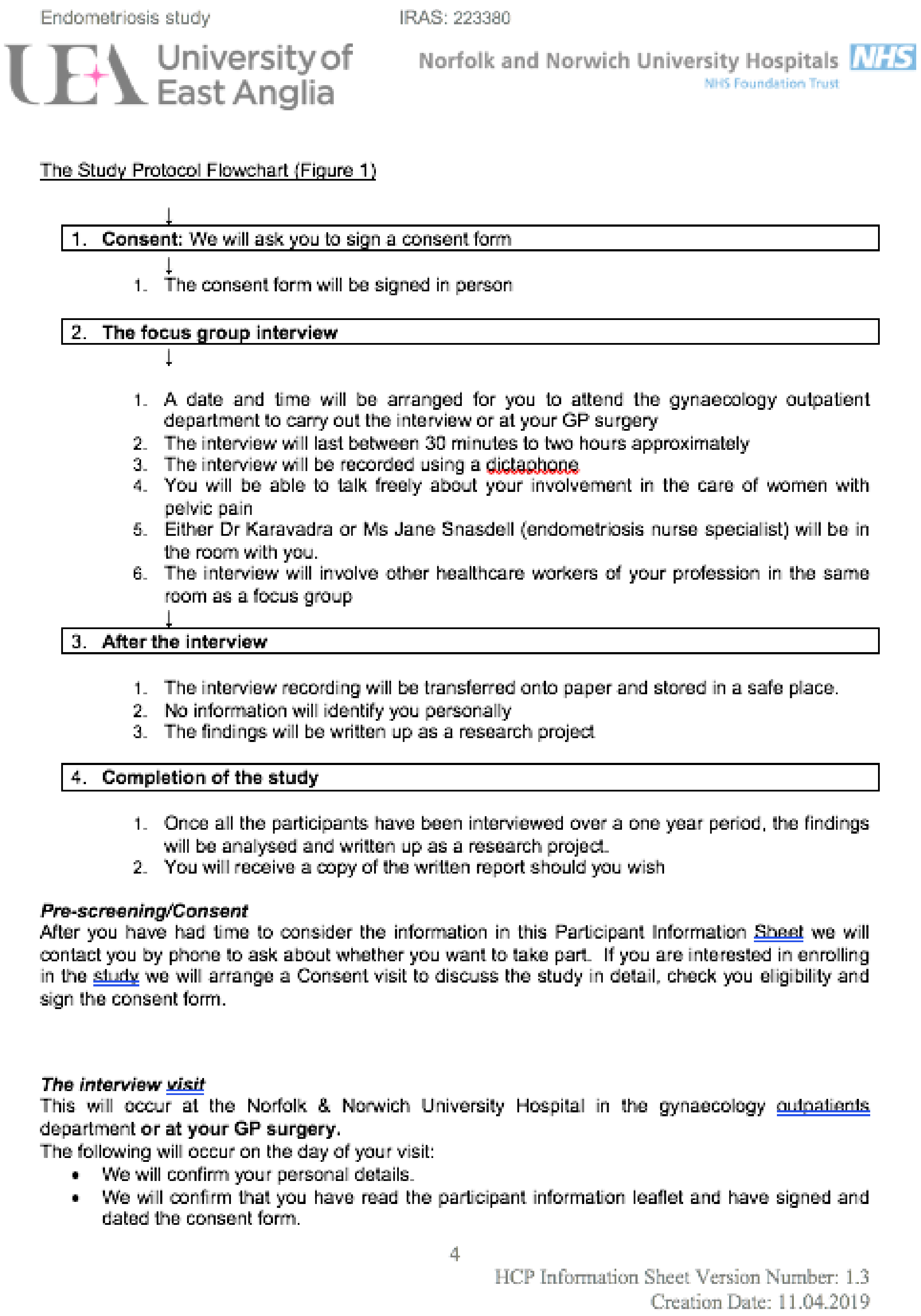
3. What does the study involve?

How many people will take part?

A total of 15 participants will be involved in this aspect of the study. The study will remain open for a one year period

The Study Protocol- what happens at the visit? (Figure 1)
Please see the next page for this information

Summary
The study will take place at the Norfolk & Norwich University Hospital in the gynaecology outpatient department or GP surgery. You will be asked to read through this information leaflet and read and sign the consent form if you are happy to take part. The consent form must be signed in person and you will be signing to confirm that you have been briefed about the study and are happy to take part. Once the consent form is signed, you will be invited to partake in the actual study interview **via a focus group.**



The Study Protocol Flowchart (Figure 1)

↓

1. **Consent:** We will ask you to sign a consent form

↓

1. The consent form will be signed in person

2. **The focus group interview**

↓

1. A date and time will be arranged for you to attend the gynaecology outpatient department to carry out the interview or at your GP surgery
2. The interview will last between 30 minutes to two hours approximately
3. The interview will be recorded using a dictaphone
4. You will be able to talk freely about your involvement in the care of women with pelvic pain
5. Either Dr Karavadra or Ms Jane Snasdell (endometriosis nurse specialist) will be in the room with you.
6. The interview will involve other healthcare workers of your profession in the same room as a focus group

↓

3. **After the interview**

1. The interview recording will be transferred onto paper and stored in a safe place.
2. No information will identify you personally
3. The findings will be written up as a research project

4. **Completion of the study**

1. Once all the participants have been interviewed over a one year period, the findings will be analysed and written up as a research project.
2. You will receive a copy of the written report should you wish

Pre-screening/Consent

After you have had time to consider the information in this Participant Information Sheet we will contact you by phone to ask about whether you want to take part. If you are interested in enrolling in the study we will arrange a Consent visit to discuss the study in detail, check you eligibility and sign the consent form.

The interview visit

This will occur at the Norfolk & Norwich University Hospital in the gynaecology outpatients department **or at your GP surgery.**

The following will occur on the day of your visit:

- We will confirm your personal details.
- We will confirm that you have read the participant information leaflet and have signed and dated the consent form.

- A voice recording device will be set up in the room and the interview will be recorded from start to finish.

The following is a guide to some of the questions that will be asked:

- How are you today?
- Please can you confirm your role?
- Please can you begin to tell us about the way care for women with endometriosis is delivered by yourself?

The aim of the interview is for you to freely voice your thoughts and feelings about how endometriosis impacts you on a daily basis. We aim to ask minimal questions.

Our aim is to help you tell us what matters to you the most about endometriosis.

What do I have to do?

Participate in a focus group. There will be three focus groups and you will participate in one which represents your job role: either a primary care nurse, a GP or gynaecologist.

Alternatives to taking part

Participation in this study is entirely voluntary. You are able to withdraw your consent at any time.

Once you have signed the consent form and completed the interview, all information obtained will be used in the project write up. Therefore, if at this point you decide to withdraw your consent, then the findings from the study will still be used. All findings will remain anonymous and will not contain any personal identification details such as name, address, date of birth for instance.

Benefits to taking part

The information that you provide will be used to improve the care that we provide women with endometriosis in the future. We know that endometriosis impacts women in many ways.

You may not benefit directly from taking part in this study; however, it will give you an opportunity to gain more insight into endometriosis. At the end of the interview, we will reimburse your car parking ticket and therefore you will not have to pay any parking charges. You will be provided with a signed slip and this must be taken to the information desk at the Travel Office (Level 2 of the hospital building) and they will ensure no charges are applied to your ticket.

Risks to taking part

Extra hospital visits

- **Not applicable**

4. Do I have to take part?

Participation in the study is entirely voluntary. Once you agree to be initially contacted, we will send you this leaflet and a consent form to read. You will have two weeks from receiving this information leaflet to decide if you wish to partake in the study or not. At this point, Dr Karavadra will call you and answer any specific questions or queries. If you wish to partake, then you will have two weeks from receiving the above information to make a decision. It is entirely your choice whether to take part in this study. It is important to mention that you can withdraw your consent at any time.

5. What if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak to the research team who will do their best to answer your questions. A contact number for the members of the research team are given at the end of this information sheet.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms are available to you (Patient Advice and Liaison Service (PALS)). Details about PALS and the complaints procedure can be obtained from the hospital.

6. Confidentiality

Your personal details and information from the study (medical and personal health information) are processed in accordance with UK data protection law (Data Protection Act 1998), which is designed to protect your privacy.
Your identity and other information obtained during this study will be kept confidential and you will not be identified by name or any other personal detail.

Information will be used in reports of the study or for scientific presentations and publications such as a PhD thesis. Your personal details will be made anonymous. Your personal information will be retained for 2 years, while anonymised data obtained from the interview will be retained for 5 years.

Everything you say/report is confidential unless you tell us something that indicates that you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

By signing this informed consent form, you give your permission for your information to be used and shared for the purposes of this study and at any time in the future. You have the right to withdraw your consent for this study at any time without giving a reason. **The information you provide during the interview is only going to be used as part of this PhD.**

If you withdraw your consent, your participation in the study will end and the study staff will stop collecting medical information from you. The information collected about you before you withdrew your permission will still be used. Information that has already been collected cannot be withdrawn.

7. Has anyone approved this study?

In the United Kingdom, all research in the NHS is approved by an independent group of people, called a Research Ethics Committee (REC). Their aim is to protect your interests and safety. They will only approve a study if they feel it is safe and ethical.

International guidelines exist to ensure that clinical studies are performed safely. These are called "Good Clinical Practice" and the "Declaration of Helsinki". All NHS studies are performed in accordance with these standards.

This study has been reviewed and given a favourable opinion by the Research Ethics Committee of London Surrey Borders.

8. What happens when the study ends?

The results will be analysed and written up as part of a PhD thesis and publication. The recordings will be kept for two years. This is to check if there are any discrepancies between the written transcript and the actual recording. The written transcripts will be kept for five years and they will be anonymous. Your personal details in the form of full name, date of birth, hospital number and telephone number (home/mobile) will be kept for two years (if applicable).

Contact details

Thank you for reading this information sheet.

If there is anything you do not understand or if you have other questions, please ask at the next available opportunity or contact us directly here at the hospital.

Chief Investigator (CI):
Mr Edward Morris, Consultant Obstetrician and Gynaecologist.
Norfolk and Norwich University Hospitals NHS Foundation Trust
Department of Obstetrics and Gynaecology
Colney Lane
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NR4 7UY
edward.morris@nnuh.nhs.uk
Secretary: Ms Emma Browning. Telephone: 01603 286829.

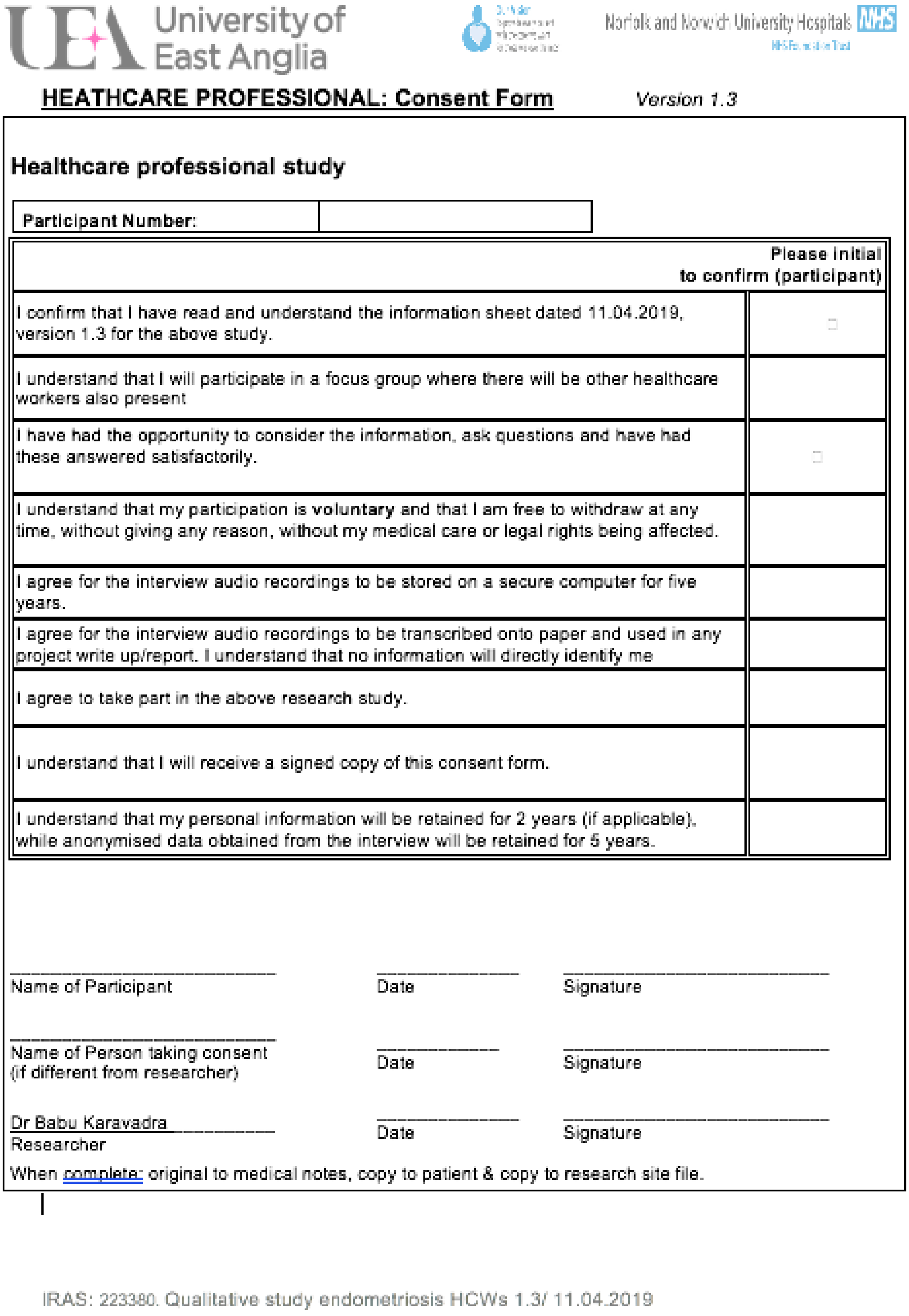
Principal Investigator (PI):
Dr Babu Karavadra Clinical Research Fellow.
Norfolk and Norwich University Hospitals NHS Foundation Trust
Department of Obstetrics and Gynaecology
Colney Lane
Norwich
NR4 7UY
babu.karavadra@nnuh.nhs.uk
Telephone: 01603 287085

If you would like to consult another doctor rather than the clinical investigation team, you may contact Mr S. Mukhopadhyay who is independent of the study but knows the details of the study.

Independent doctor: Mr Mukhopadhyay, Consultant Obstetrician and Gynaecologist.
Norfolk and Norwich University Hospitals NHS Foundation Trust
Department of Obstetrics and Gynaecology
Colney Lane
Norwich
NR4 7UY
Secretary: Ms Carol Trevarthen. Telephone: 01603 287100

Emergency Contact: **Telephone Number:** **01603 286289 (Mon-Fri, 0900 – 1700)**
01603 286286 Bleep 1156(Out of hours)

Appendix 10. Healthcare professional phase consent form



University of East Anglia

Norfolk and Norwich University Hospitals NHS
NHS Foundation Trust

HEATHCARE PROFESSIONAL: Consent Form *Version 1.3*

Healthcare professional study

Participant Number:	

	Please initial to confirm (participant)
I confirm that I have read and understand the information sheet dated 11.04.2019, version 1.3 for the above study.	☐
I understand that I will participate in a focus group where there will be other healthcare workers also present	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
I agree for the interview audio recordings to be stored on a secure computer for five years.	
I agree for the interview audio recordings to be transcribed onto paper and used in any project write up/report. I understand that no information will directly identify me	
I agree to take part in the above research study.	
I understand that I will receive a signed copy of this consent form.	
I understand that my personal information will be retained for 2 years (if applicable), while anonymised data obtained from the interview will be retained for 5 years.	

______________________________ Name of Participant	________________ Date	______________________________ Signature
______________________________ Name of Person taking consent (if different from researcher)	______________ Date	______________________________ Signature
Dr Babu Karavadra ___________ Researcher	________________ Date	______________________________ Signature

When complete: original to medical notes, copy to patient & copy to research site file.

IRAS: 223380. Qualitative study endometriosis HCWs 1.3/ 11.04.2019

Appendix 11. Topic guide for healthcare professionals (phase 2)

Introduction

- Introducing my role
- Confirming consent and signing the consent form
- Explaining that the interview is recorded via audio
- Reiterate that they can discontinue from study at any point and this will not impact their routine clinical care
- Confidentiality
- Explaining the wider context of this research

Start

Job role

- Ok [name of participant], please can you tell me briefly about your role and how this links in with caring for women with endometriosis

Participants are then provided with the following verbatim quotes separately to discuss and relate to their own medical experiences.

'It's interesting that a lot of people say that GP's are dismissive and not listening, but it's interesting how this is the other way round….I found a big difference between a general gynaecologist and someone who actually is a specialist in it. I just find the specialist gynaecologist more informative and actually did something about my endometriosis. Before, I was told by the general gynaecologist that there is nothing wrong with me!'

'Female doctors are less sympathetic. Female doctors keep saying it's period pain. But, a male doctor will listen more as he has never been through it. But, on the other hand, men want to find a solution quickly and so tell you that you have IBS. Female doctors normalise it! It's the GP's that I have had a problem with- the fight to get to the hospital. It was all about being believed. I did get lost in the system as my referral got lost by the way!'

'I did see one particular GP and she listened and how it was affecting me. She wanted to help me, and I felt listened to. With the others, I felt that they didn't listen to me and how it affected me. No one questioned why I was constantly coming in to the doctors. No one suggested other things to help me. As soon as I mentioned pain to the others, they would get me out of the door in 5 mins. But, this particular doctor, she was great. She cared. She then left!'

'I was really lucky to have my GP because she has already done a thing in gynaecology and she kind of sort of said to me that she thought it might have been endometriosis. … my GP has been nothing but brilliant throughout the whole thing and I have been under her now since, probably since …..'

‘Taking my husband in was a big step for me. Although I tell him what goes on, it’s also an opportunity for him to see I am not going mad and for the GP to see I am not going mad! I think it was when he told the GP that my quality of life and intimacy that were affected. This made the GP realise that things were not right. It was at this point that the GP thought there was a ‘problem’ I shouldn’t have to take my partner in, the doctor should have listened to me directly.’

‘I think there is this stigma attached that if you have endometriosis, you can’t cope and that you have issues’.

‘If you have a broken leg, people can see your problem and tell you to have a day off. If you have a hidden illness like endometriosis, no one understands. Therefore, social media helps have this empathy and understanding that doctors don’t give you. I mean, for GP’s its difficult. But, we are going through the same issues with my daughter- she has chronic pelvic pain and is told she has IBS. She has exactly the same problem. I am desperate to see if she has endometriosis. I understand that doctors get many women who have pelvic pain. But, there has to be a point where the doctor has to listen to you and refer you and believe you! It's frustrating as hell. No one listens!!!’

‘I am in one group with 10,000 women and the stories are so identical! The doctors seem to say the same stuff to all of us. On this group, women tell each other what to say to the doctor, how to be believed, how to dress in front of the doctor and how to be taken seriously. You want to look ill enough to be believed, but not ill enough that the doctor thinks you have got major issues and that you are obsessed with your health. In this group, women advise each other not to wear make-up or ‘look together’ and this may help being believed. There are all these tricks that women suggest being believed to manipulate the appointments to get what you want out of them’

‘You want to look unwell enough to be believed, but not look good enough that you won’t be believed and that you might be making it up. You want them to think that there is something seriously wrong with you’

‘Actually, should we start the investigations sooner? Like Urology they’ve got the one stop shop. You know the breast clinic have got the one stop shop. It’s one of them, could gynae do a one stop shop to look for polycystic ovaries, to look for fibroids, you know all of the stuff that could be causing this other than endometriosis, because obviously I understand you can’t do that. But could they look for more symptoms in a one stop shop so they could be rule out sort of thing, so then you could look at different avenues’

‘Each time I went alone to the GP, things were normalised. It was my mum who told the GP this is not normal! I would keep going to the GP and saying the same thing constantly. That’s the only way to get diagnosed. GP’s have a certain amount of time- so it might be useful to have a note book and diary to write down feelings, symptoms etc. each time you go, you can

say the symptoms are better/worse based on dates. "I told you that last time" you then have evidence- I am not here "just for period pain" it almost validates you'

'Pre-surgery, I've always been really happy with….. this is nothing against Mr X at all, he did come and speak to me after my laparoscopic, but I was so off my face on drugs, I had no idea. I had to go to my GP a few weeks later and go, can you actually explain to me what they found, just because I was so….. off my face. My husband wasn't allowed back because obviously we were in…. I would have liked to maybe been able to come back to hospital a week later and actually sit down with Mr X, or one of the team, with my husband as well, so that we could actually, when you are in a better headspace, when you are not on as many painkillers…..'

'Before being diagnosed with it, I didn't know what I was doing, but suddenly, after knowing, you readjust. Now I know why my back hurts, why I get bloating etc. These are all symptoms I can deal with'

'Yes, every time you see a different doctor, and no one really understood me. You would see a different registrar each time. 10-15 minutes for a consultation is not a long time. It almost felt like you were going to a minute taker who would go to the consultant eventually to plan anyway. It was also about finding someone who was genuinely interested in being there'

'Each time I go to A&E, they never listen. I take my discharge letters with me. You hit a brick wall. Each time they find out I am under the endo clinic at this hospital, they just say I need to talk to my own doctor. It's almost as if they give up'

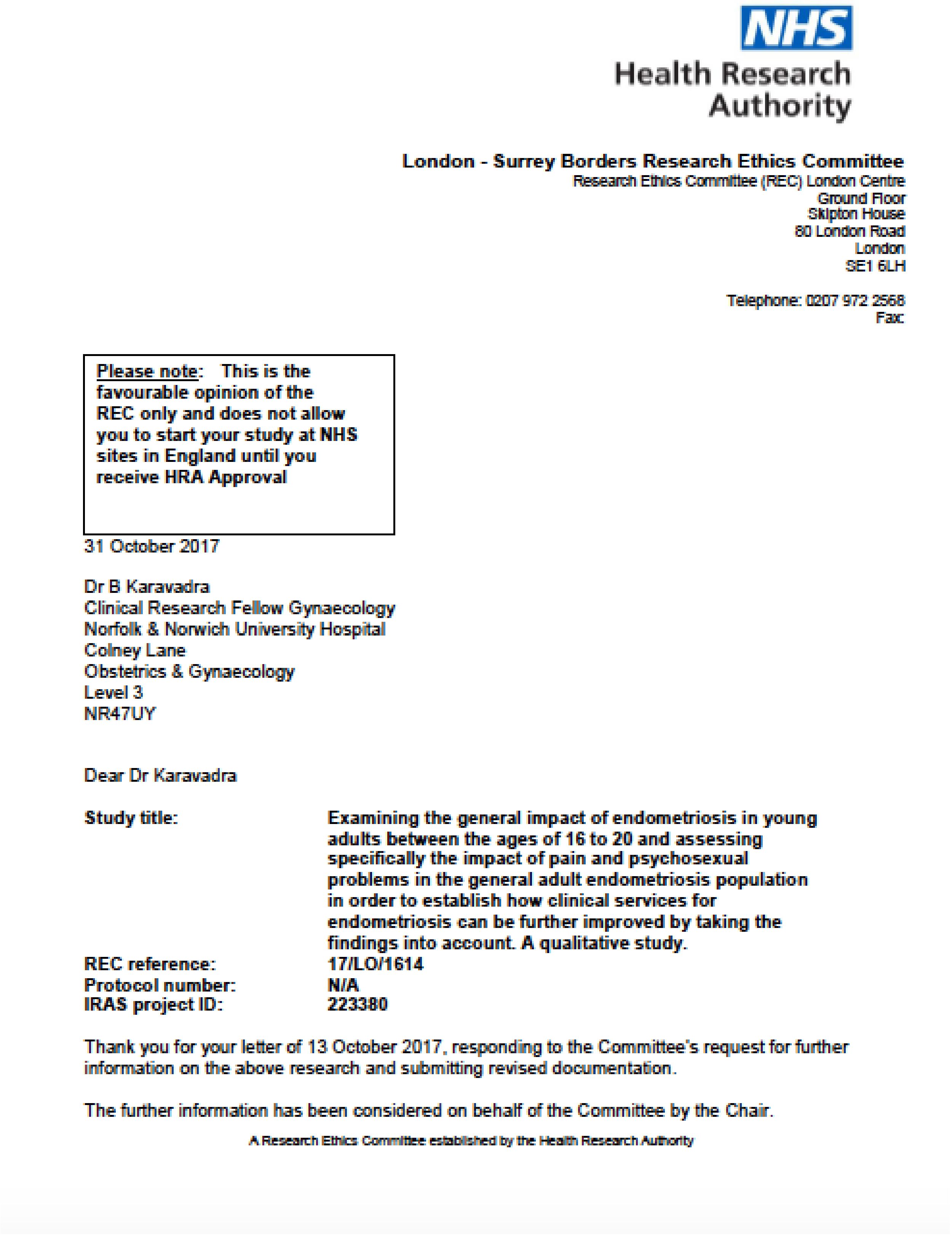
Conclusion

- Summary of discussion to clarify any points
- Opportunity for participant to ask any final questions

End

- Summarise if there is anything else the participant would like to add
- Parking reimbursement

Appendix 12. Ethics approval letter



Health Research Authority

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Research Ethics Committee (REC) London Centre
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Telephone: 0207 972 2568
Fax:

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

31 October 2017

Dr B Karavadra
Clinical Research Fellow Gynaecology
Norfolk & Norwich University Hospital
Colney Lane
Obstetrics & Gynaecology
Level 3
NR47UY

Dear Dr Karavadra

Study title:	**Examining the general impact of endometriosis in young adults between the ages of 16 to 20 and assessing specifically the impact of pain and psychosexual problems in the general adult endometriosis population in order to establish how clinical services for endometriosis can be further improved by taking the findings into account. A qualitative study.**
REC reference:	**17/LO/1614**
Protocol number:	**N/A**
IRAS project ID:	**223380**

Thank you for your letter of 13 October 2017, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

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

Confirmation of ethical opinion

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

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

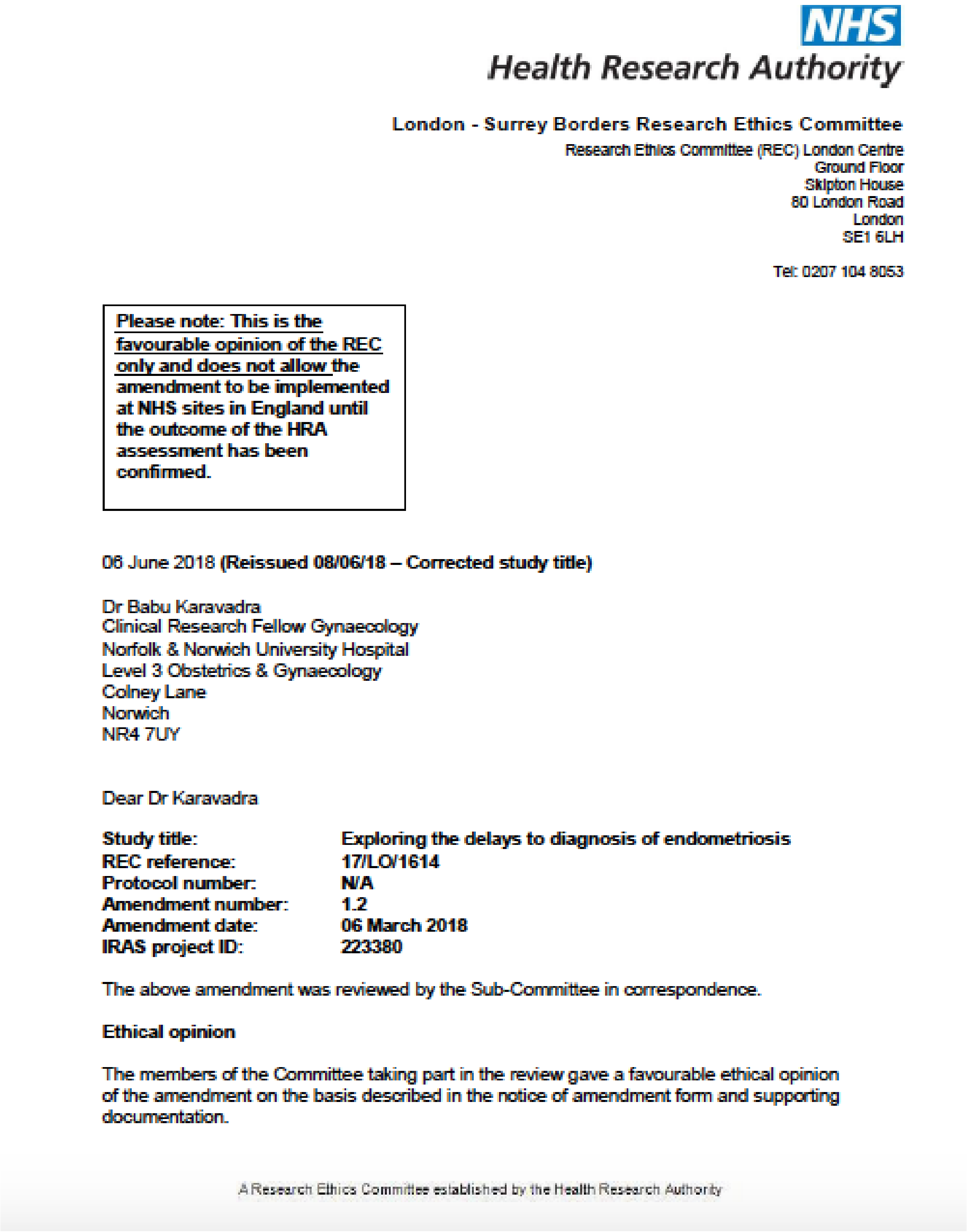
Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

Appendix 13. Ethics amendment approval letter



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Tel: 0207 104 8053

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

06 June 2018 **(Reissued 08/06/18 – Corrected study title)**

Dr Babu Karavadra
Clinical Research Fellow Gynaecology
Norfolk & Norwich University Hospital
Level 3 Obstetrics & Gynaecology
Colney Lane
Norwich
NR4 7UY

Dear Dr Karavadra

Study title:	**Exploring the delays to diagnosis of endometriosis**
REC reference:	**17/LO/1614**
Protocol number:	**N/A**
Amendment number:	**1.2**
Amendment date:	**06 March 2018**
IRAS project ID:	**223380**

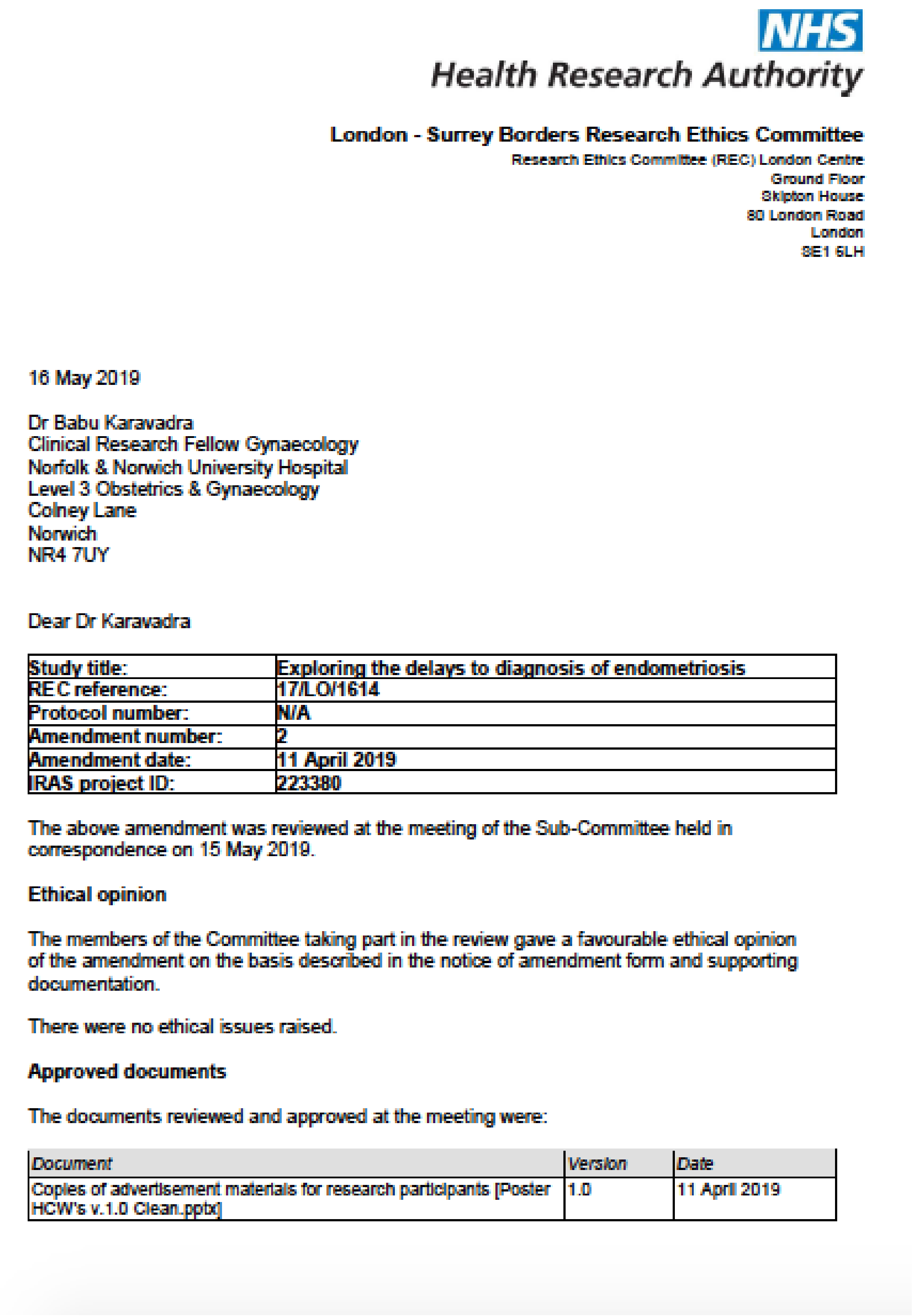
The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

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

A Research Ethics Committee established by the Health Research Authority

Appendix 14. Ethics amendment approval letter (2)



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16 May 2019

Dr Babu Karavadra
Clinical Research Fellow Gynaecology
Norfolk & Norwich University Hospital
Level 3 Obstetrics & Gynaecology
Colney Lane
Norwich
NR4 7UY

Dear Dr Karavadra

Study title:	**Exploring the delays to diagnosis of endometriosis**
REC reference:	**17/LO/1614**
Protocol number:	**N/A**
Amendment number:	**2**
Amendment date:	**11 April 2019**
IRAS project ID:	**223380**

The above amendment was reviewed at the meeting of the Sub-Committee held in correspondence on 15 May 2019.

Ethical opinion

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

There were no ethical issues raised.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Poster HCW's v.1.0 Clean.pptx]	1.0	11 April 2019

Appendix 15. Sorting verbatim quotes as part of the grounded theory process