Black Women’s Experiences of Reaching a Diagnosis of Endometriosis

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Abstract

There is a growing body of research exploring women's experiences of endometriosis, however, no existing research has focused specifically on Black women's experiences of endometriosis and getting the diagnosis, despite recent reviews indicating that Black women may be less likely to be diagnosed (Bougie et al., 2019) and that they may be diagnosed at an older age (Li et al., 2021) than their White counterparts. This qualitative study aimed to explore Black women's experience of getting a diagnosis of endometriosis in the UK. Eight women who self-identified as Black participated in semi-structured interviews to provide insight into their experiences. Interpretative Phenomenological Analysis was used to analyse the interviews, and four main themes were developed: "The diagnosis journey was a battle", "Navigating stigma and discrimination", "The diagnosis is a double-edged sword", and "Finding ways to survive post-diagnosis". These themes reflect the challenges the participants experienced in getting the diagnosis and how these experiences were shaped by their intersecting identities of being Black and female. The findings also highlighted how many of the challenges experienced in relation to their healthcare and living with endometriosis continued post-diagnosis. The findings are discussed in relation to the limited existing research on Black women's experiences of obstetrics and gynaecological healthcare, undertaken mainly in the US, and it is considered how this current study can provide a novel insight into Black women's experiences of endometriosis within a UK setting. Clinical and policy implications and recommendations for further research are discussed.

1. Introduction

This study explored Black women's experiences of getting a diagnosis of endometriosis. To my knowledge, no research exists exploring Black women's experiences within the UK. However, research into Black women's experiences of other aspects of healthcare within the National Health Service (NHS) has suggested that Black women experience significant disparities in health outcomes, for example, within maternal healthcare and cancer (Darko et al., 2024; Moss et al., 2020; Women and Equalities Committee, 2023). Some research, although not specific to the UK, has suggested that Black women are less likely to be diagnosed with endometriosis than their White and Asian counterparts (Bougie et al., 2019).

This section will provide an overview of endometriosis, including its historical context. As there is limited research on Black women's experiences of endometriosis and broader gynaecological care within the UK, research into Black women's experiences of healthcare more broadly will be discussed. The systematic literature review will provide a more in-depth exploration of the literature on Black women's experiences of maternal healthcare in the UK.

Particular attention was paid to reflection and reflexivity to support a sensitive approach to this research, considering the power dynamics between the researcher and participants. The rationale and ways this was achieved are discussed further within the methodology section. Reflections on the researcher's position to the topic are offered, including how this relates to decision-making within the research process. Further reflections by the researcher are included in italics. Extracts from the researcher's reflective diary are also included in Appendix A.

1.1 Defining Key Terms

1.1.1 Race, *Racism*, and *Ethnicity*

In popular discourse, *race* has been used to group individuals based on physical characteristics and shared geographically based ancestry (Morning, 2007). In race-based societies, racial categories are viewed as naturally unequal and hierarchal (Smedley & Smedley, 2005). However, the lack of scientific basis for such racial categories has been demonstrated and "race" can be considered a social construct (Witzig, 1996). It is the societal beliefs about differences in physical appearance and behaviour that create the meaning of *race* (Smedley & Smedley, 2005).

This research was undertaken holding the view on race described above, whilst also considering the differences in treatment due to race as real experiences despite the lack of a scientific basis for racial categories (Strani & Szczepaniak-Kozak, 2018). Racism can be defined as a form of oppression based on societal beliefs regarding racial categories, which can be "not only interpersonal but also cultural and structural" (Speight, 2007, p. 127). Racial discrimination has been defined as a type of avoidant racism which exists in the behaviours and thoughts that maintain distance or minimise contact, either intentionally or unintentionally, between the dominant racial group and non-dominant groups (Carter, 2007). Racism involves discrimination which may be expressed overtly or subtly through individuals or institutions (Fernando, 2006).

Ethnicity is defined as groups of people who can share history, language, traditions and other aspects of culture. These groups are not fixed (Barth, 1998) and are not connected to biological variations or race (Smedley & Smedley, 2005).

1.1.2 Black

This research focuses on exploring Black women's experiences and does not specify ethnicities within this. It is acknowledged that discussing these experiences as homogenous could minimise cultural differences and diversity, and significant nuances may be missed. The term "Global Majority" is also used within this paper to recognise the importance of reframing those racialised as "ethnic minorities". Ethnic categories, as defined by the Office for National Statistics (2023), will also be used when referring to specific ethnic groups.

1.1.3 Women

It is acknowledged that not all people with a diagnosis of endometriosis will identify as a "woman". This study focuses on the experiences of people who self-identify as women, and participants were recruited in line with their self-identification. Therefore, the term "women" is used when discussing the participants in this study and in other research which has defined their participants in this way. This is not to minimise the experience of transgender men who have a diagnosis of endometriosis, who may have had unique challenges in reaching a diagnosis (Vallee et al., 2023).

1.2 Reflections on the Researcher's Position to the Topic

The researcher's context, including their beliefs, values and background, influences the research process, including the methodological and analytical decisions that are made (Manohar et al., 2017). The researcher's position is briefly outlined here, including their context and connections to the topic and consideration of their "outsider-researcher" position.

I grew up in a family where equality and fairness were important, shaping my values of equity and inclusion. I was aware that I wished to undertake research in line with these principles, so it was important to me not to perpetuate the pattern in existing research on endometriosis, where populations such as Black women have been missing from the research (Bougie et al., 2022). My intention has been to create space for these women to highlight their experiences and to challenge current healthcare systems where racism is systemic (Ramamurthy et al., 2022) and institutional (Atkin, 2018).

I have become increasingly aware of the racism I believe to exist within UK society, including within public sector systems (e.g. Finney et al., 2023; Nazroo & Becares, 2020). The significant and unequal impact of the COVID-19 pandemic on people from the Global Majority within the UK (Paton et al., 2020) and the Black Lives Matter protests following the murder of George Floyd emphasised this to me further, whilst also highlighting the privileges of being white. I have had space to further reflect on my whiteness during my doctoral training, and the difficulty of recognising how whiteness operates within my own experiences has highlighted to me the normalisation of whiteness (Durie, 2003). I acknowledge that my anti-racism journey and relationship with whiteness will be ongoing.

A researcher takes an *outsider* position where they do not share some aspects of identity with their participants (Braun and Clark, 2013). I am aware of the clear differences between my context and identity and the participants, which position me as an outsider-researcher. I identify as a white female who is not living with a chronic health condition or disability. When first drawn to this area as a potential research topic, I considered whether I was the right person to do this research. The ethics of doing research as an outsider-researcher have been discussed within the literature, and the disadvantages and advantages of this position have been reflected upon (for example, Manohar et al., 2017). Bridges (2001) summarises concerns around outsider research, including that "outsiders" cannot understand or accurately represent participants' experiences, research can be exploitive, and the experience can be disempowering when participants’ voices are represented by the researcher.

From discussions with my supervisors and peers who identify as Black women, I believed that by engaging with the research sensitively and taking steps to portray the richness and complexity of the participants’ experiences, this research could offer a valuable understanding. From the start of the project, I have considered the power difference between myself and the participants, and navigating this has shaped my decision-making within the research process.

The polarised use of outsider/insider positioning has also been critiqued, and the fluidity and complexity of these positions in real-life data collection has been recognised (Merriam et al., 2001). Whilst being aware of the differences between myself and the participants in terms of identity and experience, I was also aware of some similarities, which may mean I am partially an “insider”. Like the participants, I also identify as a woman who has experienced attending medical appointments regarding gynaecological conditions. When first drawn to this topic, I recognised that I identified with some of the experiences women describe in the existing literature around getting a diagnosis of endometriosis. I was aware that my own experiences were forming my negative views on the quality of care for women within the NHS, and these experiences were another reason for wanting to engage in this research, as I hoped to engage in research that could inform positive change.

1.3 Researcher’s Epistemological Stance

This research will be grounded within the philosophical assumptions of critical realism (Bhaskar, 1978). Critical realism takes a realist ontology that reality exists independently from human awareness and knowledge, and we can attempt to understand or access it (Albert et al., 2020; Danermark et al., 2002). Critical realism assumes that reality is stratified into three levels: the empirical, the actual, and the real. The empirical level includes the events or objects as we experience them, and therefore, events or objects can be measured empirically (Fletcher, 2017). Fletcher (2017) further describes the actual level as where events occur regardless of human experience or interpretation, and the real level where casual mechanisms, powers, or forces exist. These mechanisms can sometimes be unobservable but can produce the world of events that we experience at the empirical level (Clegg, 2016).

Critical realism assumes that all events and objects at the empirical level are viewed through the lens of human experience and interpretation. Regarding epistemology, critical realism takes a stance of epistemic relativism, in that all beliefs are socially produced, so views of the world may change and compete over space and time (Bhaskar, 1978). Our knowledge of the world is socially constructed, and therefore, changing knowledge of an unchanging object is possible (Bhaskar, 1978; Pocock, 2014). Individuals can assign different understandings to experiences due to their subjective realities (Fade, 2004). However, in contrast to social constructionism, critical realism does not consider the world to be created by our language, just described (Pilgrim, 2019).

Ussher (2010) suggests that “critical realism recognises the materiality of somatic, psychological and social experience, but conceptualises this materiality as mediated by culture, language and politics” (p. 23). Critical realism considers how context may influence women’s experiences of endometriosis at the empirical level. Social categories such as race and gender are considered social constructions, however, the categories are assumed to serve the real power relations in which causal mechanisms (such as racism and sexism) can emerge, through the social meanings that the categories convey (Martinez Dy et al., 2014). These structures are *real* in that they are not material but can have power and influence individuals (Sayer, 1992).

Critical realism was felt to be an appropriate fit for this study, as it enables the acknowledgement of the material reality of living with and being diagnosed with endometriosis as a Black woman. However, critical realism also acknowledges that accessing this reality is limited, and any understanding will reflect the participant's and the researcher's subjective interpretations shaped by their own contexts. In line with critical realism, this research takes the stance that different understandings of the participants' experiences are possible as any interpretations are subjective and shaped by the individual's context. Consequently, this research does not aim to uncover an objective reality. However, the material conditions of the social structures in which women exist and the physical realities of an endometriosis diagnosis may lead to particular ways of understanding experiences being more likely than others (Cole et al., 2021).

1.4 An Introduction to Endometriosis

Endometriosis is defined as a chronic gynaecological condition where endometrial tissue, similar to the lining of the womb, grows in other places within the body. Bleeding and inflammation are due to the endometrial tissue shedding and being unable to exit the body (Endometriosis UK, 2012). This results in physical symptoms, which can include pelvic pain, fatigue, bowel and bladder problems, heavy menstrual bleeding and pain with sexual intercourse (Lemaire, 2004). An association between endometriosis and infertility has also been established (e.g. Meuleman et al., 2009), and it is estimated that endometriosis is present in 25-40% of women with infertility (NICE, 2017).

Endometriosis has been found to impact various areas of the individual's life, including psychosocial well-being (Culley et al., 2013; Young et al., 2015). Based on a review of qualitative research, Culley et al. (2013) concluded that many women living with endometriosis worldwide experience emotional distress and that women can experience hopelessness, worthlessness, depression and feeling suicidal. Given the impact of endometriosis on areas of women's lives such as their sex life and fertility, living with endometriosis can also have an impact on women's identities as a partner, mother and a woman (Hudson et al., 2016). Currently, there is no cure for endometriosis, and treatments are offered for symptom management, including pain relief, hormone medicines and contraceptives, and surgery to remove endometriosis tissue or parts of the organs affected by endometriosis (for example, a hysterectomy) (NHS, 2024).

Endometriosis has been called an "enigma" and "mysterious" in the medical literature due to its unclear aetiology and range of clinical symptoms (Lee & Bates, 2023), where symptom severity does not necessarily correlate with the physical extent of the disease (Denny & Mann, 2007). Popular theories of aetiology were developed in the 1920s-30s within the context of social concerns around lower birth rates of upper-class women in the United States (Gordon, 2002) and subsequent interest in exploring reasons for infertility in patients with endometriosis (Bougie et al., 2022). In this context, Meigs's (1941) theory that endometriosis was associated with contraceptive use and delayed childbearing gained popularity and the view of endometriosis as being typically a white upper-class career women's disease was formed (Carpen, 2003). This theory was substantiated through methodologically flawed research until Chatman (1976) proposed that research did not suggest a difference in prevalence between Black and White women and that pelvic pain in Black women could be misdiagnosed. It is now believed that there are no racial or ethnic differences in the prevalence of endometriosis (Shaw et al., 2003).

However, this has meant that historically, it was often assumed that endometriosis was rare in Black women (Chatman, 1976). It has also been suggested that strong biases regarding the race and ethnicity of endometriosis patients have been perpetuated even in more recent medical literature, for example, a textbook published in 2013 included being White as a correct option for considering endometriosis as a possible cause of symptoms within a clinical vignette (Bougie et al., 2022).

1.5 Diagnosing Endometriosis

Endometriosis is diagnosed typically through laparoscopy (a type of keyhole surgery). However, the delay to diagnosis is well documented, and it can take an average of 8 years from the onset of symptoms to diagnosis in the UK (All-Party Parliamentary Group on Endometriosis (APPG), 2020). A study which explored patients' experiences of getting a diagnosis of endometriosis within the UK concluded that delays were experienced due to factors both at the "individual patient level" and at the "medical level" (Ballard et al., 2006).

1.5.1 Factors at the "Patient Level"

An initial delay in seeking healthcare has been identified and understood as a problem of the individual due to lack of understanding of an "abnormal" menstrual experience, lack of awareness of endometriosis, and reluctance to disclose symptoms (e.g. Ballard et al., 2006; Denny, 2009). However, beliefs and rules at a societal level have been highlighted to shape women's awareness and behaviours. Johnston-Robledo and Chrisler (2020) argue that menstruation fits with Goffman's (2009) concept of stigma as any stain or mark that sets someone apart from others and spoils their appearance or identity, as research has shown that even reminders of menstrual blood can lead to avoidance and social distancing from others, suggesting that menstruation reflects a discrediting attribute (e.g. Roberts et al., 2002). Research exploring experiences of menstruating in the UK has found women engage in efforts to conceal it due to embarrassment and fear of encountering negative attitudes (e.g. Denny et al., 2011; Tingle & Vora, 2018). Laws (1992) suggested the concept of "menstruation etiquette" to describe the societal rules regarding how women are expected to act when menstruating to avoid stigma and consequent social exclusion (Culley et al., 2013; Denny, 2004).

As heavy menstrual bleeding is a common symptom of endometriosis, the stigma surrounding menstruation may shape part of the experience of disclosing symptoms or getting medical help. Seear (2009) explored women's experiences of endometriosis and found women felt vulnerable to stigmatisation due to their symptoms. Subsequently, management strategies were employed, such as concealment and normalisation of symptoms. Other studies have also found women experiencing the normalisation of their symptoms by family members, friends or other people in their lives (Young et al., 2015). This leads to women being reluctant to disclose their symptoms as they do not want to appear unable to cope (Ballard et al., 2006).

1.5.2 Factors at the "Medical Level"

Factors relating to clinician awareness and knowledge of endometriosis have been suggested as reasons for diagnostic delays by both patients and clinicians (Wrobel et al., 2022). Clinicians' lack of knowledge could lead to difficulties in distinguishing pathological symptoms, misdiagnosis, and consequent ineffective treatment (Johnston et al., 2015). Patients have also identified the prescription of ineffective treatment and feeling ignored by clinicians as factors contributing to the delay in diagnosis (Wrobel et al., 2022).

Studies worldwide have found women report multiple appointments within primary care and experience being misdiagnosed with a psychological diagnosis (e.g. Cole et al., 2021; Young et al., 2015) and feel dismissed by medical professionals who normalise and trivialise their pain (Culley et al., 2013; Pettersson & Berterö, 2020). In the UK, research has found delays in referrals for appropriate further investigation at the primary care level (e.g. Denny & Mann, 2008).

More recently, Ghai et al. (2020) examined the diagnostic pathway in the UK following the introduction of Specialist Endometriosis Centres in 2011, which were introduced to standardise surgical treatment, reduce diagnostic delays and monitor and improve outcomes (Ghai et al., 2020). Ghai et al. (2020) found that diagnostic delays continued despite the introduction of these Specialist Centres. They reported that the normalisation of pain, the attitudes of health professionals, and the wide range of symptoms (and possible lack of clinician awareness of the wide spectrum of symptoms) contributed to diagnostic delays. Although this study only recruited from a single tertiary centre (and the demographics of the sample are omitted), it suggests that barriers to timely diagnosis may continue to exist despite introducing such specialist centres.

1.6 The Impact of the Diagnostic Process

The delay in diagnosis has implications for both women's physical and psychological well-being. NICE guidelines (2017) highlight the importance of women receiving a timely diagnosis as delay or misdiagnosis can result in a lack of access to effective treatment, prolonging suffering and affecting quality of life.

Alongside the physical consequences of delayed diagnosis, NICE guidelines (2017) acknowledge the emotional distress this process can cause. Pettersson and Berterö (2020) found women experienced a range of emotions, including feeling vulnerable, anxious, and frustrated due to their experiences of getting a diagnosis. Research has also found women report feeling anxious about their healthcare encounters and the perceived power the healthcare professional holds over their quality of life, including the ability to label them as exaggerating or mad (Young et al., 2019). Women have also reported that concerns about possible infertility result in worry, depression and feelings of inadequacy for women during the pre-diagnosis period, and in some cases, delays in being diagnosed influenced their outcomes regarding fertility (e.g. Denny & Mann, 2008; Jones et al., 2004).

Regarding receiving the diagnosis itself, women have reported experiencing mixed feelings. Studies have found that women report experiencing relief from the diagnosis, which provides validation of their symptoms and gives them a language to explain their symptoms and access support (Culley et al., 2013). Women have also reported experiencing the shock of being diagnosed with a chronic health condition (particularly if women were asymptomatic) and anger at the delay in getting the diagnosis (Culley et al., 2013; Young et al., 2015). Pettersson and Berterö (2020) found that women have reported having difficult conversations with clinicians regarding endometriosis and fertility, where this information had been delivered insensitively, leading some women to feel suicidal.

1.7 Race and Diagnosing Endometriosis

A limitation of the previous research into experiences of endometriosis and associated healthcare is that research samples lack diversity. A systematic review identified a significant focus on white women within the existing literature exploring the prevalence and clinical presentation of endometriosis, with minimal data on women from the Global Majority (Bougie et al., 2019). A similar trend appears within the qualitative research (Young et al., 2019).

Therefore, we are largely unaware of the experiences of those from backgrounds that have been underrepresented in research, including those from the Global Majority. In the UK, the APPG report (2020) has suggested that women from the Global Majority experience additional barriers in seeking support and being diagnosed with endometriosis, including misdiagnosis and difficulties accessing healthcare appointments.

A meta-analysis of 16 studies worldwide found that Black women are less likely to be diagnosed with endometriosis than their White and Asian counterparts (Bougie et al., 2019). The review does recognise the methodological flaws of the studies included, such as lack of control of confounding variables such as socioeconomic status, which may link with access to healthcare, which suggests some caution should be taken when interpreting the findings. The review considered that the differences in the likelihood of being diagnosed across racial groups may be due to variations in presenting symptoms across racial groups and an ongoing bias in diagnosis where clinicians may be less likely to consider a diagnosis of endometriosis for Black women due to the historical context of the condition. A more recent review supports these findings but only included three studies (Katon et al., 2023). Another study based in the US found that the Black women in the study were diagnosed at an older age than the white women (Li et al., 2021), which may suggest an even longer delay in diagnosis for Black women.

Pain, being a common symptom of endometriosis, is another factor suggested as having the potential to influence clinicians' consideration of a diagnosis of endometriosis in Black women (Bougie et al., 2022). Research has found that in comparison to men, women are less likely to be taken seriously and receive adequate treatment for their pain and are more likely to have their pain attributed to psychological causes by healthcare professionals (Hoffamn & Tarzian, 2001; Samulowitz et al., 2018). Zhang et al. (2021) suggest that these findings may result from biases based on gender stereotypes about pain which exist within society. Hoffman and Tarzian (2001) propose examples of such stereotypes, such as that women complain more than men, women are not accurate reporters of their pain, and women are more able to tolerate pain than men.

Disparities in pain treatment have also been found between racial groups. Research has demonstrated racial bias in the assessment and treatment of pain, for example, finding that Black patients are less likely to be given pain relief and in adequate amounts in comparison to White patients (Hoffman et al., 2016). Trawalter and Hoffman (2015) suggest that this may be due to stereotypes and beliefs which have been demonstrated empirically, for example, that Black people are "superhuman" and feel less pain than White people (e.g. Dore et al., 2014; Trawalter et al., 2012; Waytz et al., 2015). The latter belief has its roots in slavery, where it was perpetuated to justify the treatment of enslaved Black people (Trawalter and Hoffman, 2015). A US study exploring Black women's experiences of seeking medical care for sexual pain (for some in the context of endometriosis) found that many of the women experienced their pain being dismissed or not taken seriously by healthcare professionals (Thorpe et al., 2022).

As well as finding that healthcare professionals were dismissive of the participants' pain, Thorpe et al. (2022) found that the Black women in this study were dismissive of their own pain. The dismissal and normalisation of pain by Black women themselves may be explained by the *strong Black women* stereotype. The characteristics of the strong Black woman stereotype have been defined as the obligation to be strong (even when she doesn't feel like doing so) by suppressing emotions, resisting being vulnerable, being independent, being determined to succeed, and being obliged to look after others and ensure others' needs are met (Woods-Giscombé, 2010). It is suggested that the strong Black woman stereotype was initially created during slavery by Black women as a way of surviving and has been passed on intergenerationally and continues to be embraced by some Black women as a way of coping with intersectional stressors such as gendered racism and sexism (Donovan & West, 2015; Woods-Giscombé, 2010).

Research has highlighted how for some Black women, identifying with the stereotype facilitates resilience and feeling proud of themselves and their identity as a Black woman (Abrams et al., 2014). However, research has also shown Black women reject the stereotype due to their perceptions of being a strong Black woman as restrictive and placing unrealistic expectations on them (Nelson et al., 2016). There is also evidence to suggest that the awareness of this stereotype can shape Black women's relationship with seeking healthcare. For example, within perinatal mental health, identification with the stereotype has been described as a barrier to accessing support (Edge, 2008; Gardner et al., 2014; Ling et al., 2023).

Altogether, these findings suggest that dismissal by healthcare providers and/or by Black women themselves may play a role in shaping Black women's disclosure of pain to their medical providers (Thorpe et al., 2022) and, consequently, their experiences of being diagnosed with endometriosis. Denny et al. (2011) explored contextual issues surrounding endometriosis and women's awareness of the condition in focus groups of women from different ethnic backgrounds in the UK. It was found that African Caribbean women in the study felt that painful periods were personal and private and, therefore, not discussed with others, in contrast to women from other ethnic groups. This highlights how Black women may be negotiating both stigma around their female reproductive health and cultural expectations of being strong due to their Black female identities, which could shape the way they talk about pain, reproductive health and symptoms of endometriosis.

1.8 Black Women's Experiences of Gynaecological Healthcare

No research to date has explored Black women's experiences of endometriosis specifically. Most research into Black women's healthcare experiences focuses on maternal health, which is discussed further within the systematic literature review section. However, some research has been undertaken focusing on other gynaecological conditions such as polycystic ovary syndrome (PCOS), fibroids, gynaecological cancers (such as cervical, uterine, and ovarian) and Black women's experiences of infertility and hysterectomies. This research has largely been undertaken in the US, with some research in the UK focusing on maternal health and cancer.

Research has found that Black women experience difficult interactions within reproductive healthcare, such as being dismissed, invalidated and coerced when making decisions about their care (Treder et al., 2022). Dismissal and lack of information provided by healthcare professionals led to delays in care and mistrust of medical professionals for Black women seeking care for fibroids (Carey et al., 2023). A study exploring Black women's experiences of being diagnosed with PCOS found that they had to visit several doctors before getting the diagnosis and that they received little to no information when receiving the diagnosis (Vance, 2022). The participants reported feeling shocked and confused about their diagnosis and devastated about the possible implications for their fertility whilst also feeling relieved that there was a medical term for their experiences.

Experiences of racism and discrimination have been reported by Black women when accessing reproductive and gynaecological care in the US. Studies have found Black women experience healthcare professionals making assumptions based on stereotypes of Black women being promiscuous, poor or irresponsible, which impact the care they receive, as well as on whether Black women will seek further care in the future (e.g. Ceballo et al., 2015; Treder et al., 2022). Another study found that Black women alluded to vicarious experiences of racism within reproductive healthcare, such as experiences of friends, family, the wider Black female community and historical experiences of Black women (Treder et al., 2022). These experiences then shaped the participants' views and decisions around their reproductive health, for example, the likelihood of seeking healthcare. A study in the UK exploring participants' healthcare experiences with uterine cancer also found that experiences of racism, dismissal and misdiagnosis were shared within communities, discouraging others from using NHS services and creating a sense of mistrust in healthcare provision (Darko et al., 2024).

Studies have found that Black women hold an awareness of the history of gynaecology and knowledge of the ongoing inequity in reproductive and maternal care, for example, the high rates of maternal mortality for Black women (e.g. Howell, 2023; Treder et al., 2022). The development of modern gynaecology is credited to Dr James Marion Sims, who conducted experimental reproductive surgeries on enslaved Black women who were unable to give their consent (Owens, 2017). Scholars and Black women themselves have hypothesised that the awareness of this historical context may play a role in creating mistrust in medical professionals (Howell, 2023; Kota-Nyati & Hoelson, 2019; Treder et al., 2022).

In the context of these difficult medical encounters, including racism and discrimination within gynaecological healthcare, Van Noy et al. (2021) found participants questioned whether they were valued as much as White women in the clinical setting when hysterectomies were suggested as a treatment option (in some cases, first treatment option) for fibroids. Research has shown that in these contexts, Black women may use self-protective strategies such as seeking healthcare professionals of the same race, bringing an advocate to appointments, preparing for their appointments by writing an agenda or list of questions, and doing research into possible diagnoses or treatments to appear creditable (Treder et al., 2022; Sacks, 2018). Thorpe et al. (2022) note the psychological impact of these strategies on Black women, including the message that they are not worthy of care just as they are.

1.9 Summary

Altogether, the findings discussed in this section highlight that Black women may have a unique experience of endometriosis due to their intersecting identity of being Black and female. Experiences of stigma surrounding women’s reproductive health, racial and gender biases in pain assessment and treatment, and cultural beliefs and expectations, such as the strong Black woman stereotype, may all play a role in shaping Black women’s experiences of getting the diagnosis. However, as Black women are unrepresented in existing research exploring endometriosis, their experiences are largely unknown.

Some research has suggested that Black women may be less likely to receive a diagnosis (Bougie et al., 2019), or that this process may take longer than for White women (e.g. Li et al., 2021). The challenges and delays in diagnosis can have implications for both women’s physical and psychological well-being, and the need for timely diagnosis is highlighted within NICE guidelines (2017). Therefore, research is important to understand Black women’s experiences of the process to indicate how both healthcare systems and professionals can best support Black women during this time, considering both their physical and psychological well-being. This understanding may support thinking more broadly around implementing mental health and psychological support, as recommended in the APPG report, including considering the role of Clinical Psychologists and Psychological Therapists within endometriosis care. In line with the recommendations from previous research and the APPG report, this study aims to explore and provide insight into Black women’s experiences of getting a diagnosis of endometriosis in the UK.

2. Systematic Literature Review

2.1 Introduction

As previously highlighted in the introduction section, no research specifically focuses on Black women's experiences of endometriosis. Consequently, it was not possible to conduct a systematic literature review exploring the existing research, and the search was expanded to consider Black women's experiences of gynaecological healthcare more broadly. However, a decision was made not to undertake a review of Black women's gynaecological healthcare experiences due to a review of Black women's experiences of reproductive healthcare in the UK already being registered on PROSPERO.

Undertaking a review of the literature on women's experiences of endometriosis more broadly was considered. However, as discussed in the introduction, Black women's experiences of healthcare are likely to differ from White women and women of other ethnic minoritised backgrounds due to their intersecting identities of being Black and female. The difference in experience is indicated by statistics which highlight inequity in healthcare, for example, maternal mortality for Black women has been reported to be almost four times higher than for White women (MBRRACE-UK, 2023), and Black women have been found to have lower survival rates and to receive more invasive treatment following a diagnosis of cancer in the UK (Copson et al., 2014; Darko et al., 2024; Moss et al., 2020).

It was considered whether to broaden the search further and explore Black women's experiences of healthcare more generally. There are advantages to conducting broader reviews, such as being applicable to a wider range of settings or populations (Pollock & Berge, 2018). However, Pollock and Berge (2018) also suggest that a homogenous focus can offer the opportunity for a more in-depth review. A narrower focus was felt to be more useful in the context of Black women’s healthcare experiences, as there was a concern that experiences may differ significantly between different health conditions and settings, meaning it would become difficult to make meaningful comparisons due to heterogeneity within the findings.

When narrowing down the review focus again, it felt important to explore an area of healthcare within obstetrics and gynaecology, as these experiences would likely be most linked to understanding Black women’s experiences of endometriosis-related healthcare. Based on this, the search was then changed to consider Black women’s experiences of maternal healthcare in the UK. Pilot searches indicated that when looking into Black women’s experiences of healthcare related to gynaecology and obstetrics, the only area in which enough studies were found within the UK was maternal healthcare. A focus on experiences within the UK context felt necessary to continue to hold a homogenous focus, as experiences would likely significantly vary due to the different socio-political and healthcare contexts across the globe, particularly in contrast to the free-at-access NHS setting within the UK.

Previous research has reviewed the experiences of maternal healthcare in the UK for ‘BAME women’ (Khan, 2021) and the experiences of maternity services in the UK for Black, Asian and minority ethnic women (MacLellan et al., 2022). By exploring maternal healthcare experiences specifically for Black women, this review aims to expand and build on the findings from these previous reviews by having the opportunity to focus solely on Black women’s experiences. Moreover, the review by Khan (2021) only included papers published between 2013 and 2018; therefore, this review offers an updated synthesis.

As such, the review considered the following question:

What does the existing empirical literature say about how Black women experience maternal healthcare in the UK?

2.2 Search Strategy

Firstly, initial pilot searches were carried out to become more familiar with the existing research relevant to the review question. The abstracts and key terms of relevant articles were used to build the search terms. The SPIDER tool (Cooke et al., 2012) was used to support the development of the search terms (see Table 1 for search terms) due to its identified specificity when searching for qualitative research (Methley et al., 2014). Due to initial concerns about the small number of journal articles being returned through these initial searches, some broader terms were included in the search terms, such as "health care" and "ethnic minority women". This aimed to create a slightly broader search to ensure no relevant papers would be missed.

Table 1

Search Terms Developed Using SPIDER Tool

SPIDER Tool	Search Terms
S (Sample)	"black women" OR "black female" OR "black Caribbean women" OR "Black British women" OR "African Caribbean women" OR "African women" OR "Black African women" OR "black mothers" OR "ethnic minority women"
P (Phenomenon of interest)	"maternity care" OR "maternity services" OR maternity OR postnatal OR antenatal OR birthing OR perinatal OR pregnancy OR pregnant or midwife OR midwifery OR

	"maternal experience" OR "maternal health" OR "maternal care" OR "health care"
D (Design)	questionnaire OR interview* OR "case stud*" OR "focus grou*" OR observ* OR survey
E (Evaluation)	perception OR experience OR view OR perspective OR attitude
R (Research type)	qualitative OR "mixed methods"

As research into maternal healthcare experiences would likely be undertaken by researchers from various disciplines, databases were selected to reflect this. Scopus and PubMed were chosen because of their vast coverage and inclusion of peer-reviewed journals from a variety of disciplines. The CINAHL database was also searched as this covers nursing and allied health literature. The search further included Google Scholar and the reference lists of included articles to ensure a comprehensive search. Due to the large number of search results generated by Google Scholar ("about 18,500 results"), the decision was made to screen the titles of the results from pages 1-35. The decision to stop screening was made when finding no relevant results for several pages. No further studies were identified within the reference lists of included studies.

The searches were conducted in January 2024 and repeated in July 2024. Once the searches were completed, duplicates were removed, and inclusion and exclusion criteria were used to screen the results (see Table 2). Firstly, the titles and abstracts were screened according to the criteria, and then the full texts of the remaining papers were reviewed for eligibility. Figure 1 presents a PRISMA flow diagram adapted from Page et al. (2021) illustrating the screening process.

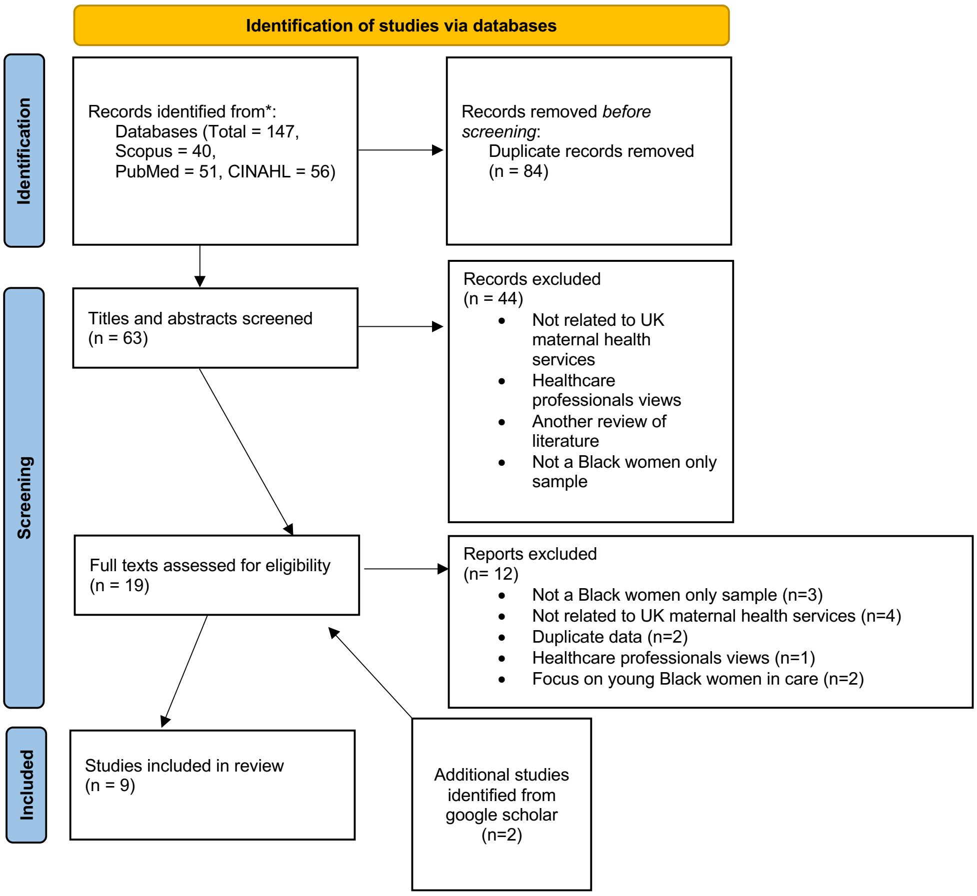
Table 2

Inclusion and Exclusion Criteria Used to Screen Studies

Inclusion Criteria	Exclusion Criteria
1. Samples who are described as/identify as Black, African, and/or Caribbean women. 2. Studies which explore experiences of accessing and using health services in the UK, directly in relation to pregnancy and/or birth, including antenatal, birthing and postnatal care/services. 3. Studies which use a qualitative methodology including mixed method studies which present qualitative findings. 4. Empirical research which is published in a peer-reviewed journal.	1. Samples that are described as 'BAME' women and do not clearly differentiate the experiences of Black, African, and/or Caribbean women throughout the findings. 2. Samples including health professionals. 3. Studies which focus on only teenage Black women under the care of the local authority. 4. Studies that do not explore experiences of accessing and using UK health services directly in relation to maternal health 5. Studies that use a quantitative methodology. 6. Grey literature or not empirical research 7. Studies which present duplicate findings, where the same findings have been presented in another included paper.

Figure 1

Screening Process Illustrated by PRISMA flow diagram adapted from Page et al. (2021)



The inclusion and exclusion criteria were developed based on the review question. ‘Maternal healthcare’ was defined based on the definition of ‘maternal health’ provided by the World Healthcare Organisation (WHO) (N.d), which suggests this “refers to health of women during pregnancy, childbirth and the postnatal period”. Therefore, studies were included if they explored Black women’s experiences of services accessed directly in relation to their pregnancy and childbirth, including in the postnatal period. The decision was made to include studies that explored experiences of both physical and mental health care in relation to maternal health. This was because, on reviewing the literature, findings suggested that women’s experiences of mental health care in their maternity journey were not discussed separately from experiences of their physical health care (e.g. Edge, 2011). Moreover, studies exploring perinatal or postnatal depression were included as findings presented experiences of healthcare and health professionals as key themes.

On reviewing the literature through the pilot searches, some studies emerged which explored 'BAME' women or ethnic minoritised women's experiences within the UK. Although some of these studies included Black women within the sample, they did not clearly distinguish Black women's experiences throughout their findings. Therefore, the decision was made to exclude these studies from this review. As this review was interested in Black women's own views on their experiences, studies including healthcare professionals' views were also excluded.

From conducting the searches, two studies were identified that focused on the experiences of teenage Black women who were looked after by the state (see Mantovania and Thomas, 2014a and Mantovania and Thomas, 2014b). On reviewing these studies, they appeared to cover a related but unique phenomenon, and a decision was made to exclude these papers (and subsequently, the exclusion criteria were amended) because their focus and sample differed from the eligible studies.

This review focuses on summarising qualitative literature, which is reflected within the eligibility criteria. This decision was made because the pilot searches did not identify any quantitative research examining only Black women's experiences of maternal healthcare in the UK. The review's focus on how Black women experience healthcare for their maternal health lends itself to being answered by qualitative research, which aims to understand peoples' experiences (Hennink et al., 2020).

2.3 Search Results

The search initially identified 147 studies and following the screening process, nine studies were found to meet the criteria and are included in this review. Table 3 provides a summary of the nine studies included in this review.

2.4 Critical Appraisal of Study Quality

An adapted version of the Critical Appraisal Skills Programme (CASP) Tool (Long et al., 2020) was used to appraise the quality of the studies included in the review. The CASP tool is an established checklist for appraising the strengths and limitations of qualitative research and was devised for use with health-related research (Long et al., 2020). Therefore, the CASP tool felt appropriate to use for this review.

The CASP tool includes ten questions with prompts. The questions ask the researcher to reflect on the appropriateness of the design and methodology, the meaningfulness of the findings, and the overall value of the study. The tool requires the researcher to give a fixed response of ‘yes’, ‘no’, or ‘can’t tell’ (where the relevant information is not reported to support decision-making) to indicate quality.

Table 3

Summary of Studies in the Systematic Literature Review

Title	Authors/Date	Aims	Methodology	Participants	Key Findings
The maternity information concerns of Somali women in the United Kingdom	Davies & Bath (2021)	To explore the maternity information concerns of Somali women in a northern English city, and to investigate the relationships of these women with maternity health professionals.	Data collection: Focus group and semi-structured interviews Data analysis: Theme Analysis	13 Somalian born women living within a northern English city, recruited through a community health worker, the project interpreter and a voluntary organisation. The majority of participants had lived in England less than 10 years.	Three themes were identified: “contact with health professionals”, “language support and information”, and “satisfaction with health professionals for Somali women”. The study found participants experienced difficulties in communication with healthcare professionals, difficulties with finding and having interpreters present in appointments, and negative attitudes and

					biases of healthcare professionals within their maternity care.
‘It’s leaflet, leaflet, leaflet then, “see you later”: black Caribbean women’s perceptions of perinatal mental health care	Edge (2011)	To examine Black Caribbean women’s perspectives on what might account for low levels of consultation for perinatal depression.	Data collection: Focus groups Data analysis: Framework analysis	42 women who self-identified as Black Caribbean. The majority of women were born in the UK. Participants were recruited through posters in community settings, use of local media, and contacts in churches and NHS organisations.	The study presents two themes: “experiences of current services and barriers to care” and “alternative models of care”. The study found that most participants described negative experiences within their maternity care, which led to a reduced likelihood of engaging with perinatal mental healthcare. It also found participants described their ideal service as one which would adopt a

					community-based, multi-agency, women-centred approach.
“We don’t see Black women here”: an exploration of the absence of Black Caribbean women from clinical and epidemiological data on perinatal depression in the UK	Edge (2008)	To explore the factors that might account for low levels of consultation for perinatal depression among Black Caribbean women and their absence from perinatal research in the UK	Reporting qualitative findings of a mixed methods study Data collection: “in depth” interviews Data analysis: Thematic analysis - Constant comparative approach (Glaser 1978)	12 women who self-identified as Black Caribbean women. The majority of women were born in the UK. Participants were recruited through a large teaching hospital and community clinics	The study presents two themes: “social and structural barriers to help-seeking” and “personal barriers to help-seeking”. The study found that the participants were unlikely to self-refer for treatment for perinatal depression due to unfamiliarity with the concept and the perceived need to minimise their distress due to fears of being seen as weak. Other barriers included health

					professionals' dismissal of their distress.
"We need to be heard. We need to be seen": A thematic analysis of black maternal experiences of birthing and postnatal care in England within the context of Covid-19	Williams, McKail, & Arshad (2023)	To explore how Black women experienced birthing and postnatal care in the COVID-19 context, including what they found helpful or unhelpful and whether Black women have any suggestions for services to improve and address inequalities.	Data collection: Semi-structured interviews Data analysis: Reflexive Thematic Analysis (RTA)	13 women who self-identified as Black (including Black mixed heritage) were recruited through support from grassroot organisations and multi-media creators, including through a podcast.	The study reported 3 main themes: "the ripples of COVID", "inequality within inequality" and "conscientious change for maternity systems". The study highlighted how COVID shaped the participants experiences of maternity care and how COVID exacerbated existing inequalities. The study identified connection and advocacy as facilitators of good care.
Daily and Cultural Issues of Postnatal	Babatunde & Moreno-	To establish cultural elements	Data collection: Focus groups	17 migrant women of African background	The study reports the following themes:

Depression in African Women Immigrants in South East London: Tips for Health Professionals	Leguizamon (2012)	related to postnatal depression through women’s narratives and to help health professionals understand and acknowledge postnatal depression signs in African women who have immigrated.	Data analysis: Thematic analysis	(mostly born in Nigeria), recruited through the support of Health Visitors, leaflets and a phone call by the researchers.	“responses to their pregnancy”, “feelings before and after giving birth”, “social support or the lack of it”, “feeling alone”, “lack of information about health services”, “poverty”, “signs of postnatal depression”, and “not coping with their situation”. The study found participants experienced healthcare professionals involved in their postnatal care to lack awareness of when they were experiencing distress or needing emotional support, and therefore

					adequate support from services was lacking. Participants also reported finding it difficult to talk to healthcare professionals about their mental health due to fear of stigma.
The experience of postnatal depression in West African mothers living in the United Kingdom: A qualitative study	Gardner, Bunton, Edge, & Wittkowski (2014)	To explore the lived experience of postnatal depression in West African mothers living in the UK	Data collection: Semi-structured interviews Data analysis: Interpretative Phenomenological Analysis (IPA)	Six mothers who considered themselves to be of Black West African origin (Nigeria = 3; Ghana = 3) were recruited through specialist NHS provision for children under five in Manchester.	The study reported 5 themes: “conceptualising postnatal depression”, “isolation”, “loss of identity”, “issues of trust” and “relationships as a protective factor”. The study found that participants did not feel they received enough support from healthcare professionals following

					birth, though comfort was gained by the immediate support which was offered. This lack of support was described as frustrating and led to feelings of distrust towards healthcare professionals. However, the study also found participants expressed wishes to talk to healthcare professionals about their mental health as they could be viewed as a confidential place to do this.
First-generation Nigerian mothers living in the UK and	Ling, Eraso & Di Mascio (2023)	To explore First-Generation Nigerian mothers'	Data collection: Semi-structured interviews	6 Nigerian-born mothers who have had children in the UK,	The analysis generated 3 main themes: "socio-cultural factors", "what

their experience of postnatal depression: an interpretative phenomenological analysis		experiences of postnatal depression and coping behaviours and treatment experiences in the UK.	Data analysis: IPA	recruited through posters displayed at parenting centres, GP surgeries, organisations and social groups across the UK.	about me? The neglected nurturer", and "loneliness and coping". The study found that inter-generational beliefs and expectations to be strong impacted on participants seeking help from professionals, whilst participants also were not asked about their emotional wellbeing by health professionals. Participants reported feeling neglected by healthcare professionals in relation to their postnatal care.
Pre- and Post-Migration Influences	Ngongalah, Rankin,	To explore African migrant women's	Data collection:	23 African migrant women (born in	The study resulted in 4 themes: "changing dietary

on Weight Management Behaviours before and during Pregnancy: Perceptions of African Migrant Women in England	Heslehurst, & Rapley (2021)	perceptions of pre- and post-migration influences on their weight-related behaviours and weight management support during pregnancy	Semi-structured interviews Data analysis: Thematic Analysis	Cameroon, Ghana, and Nigeria), recruited through community groups or organisations serving African populations in England. Participants had lived in England for 6.8 years on average (and all for longer than 6 months).	behaviours after migration", "changing physical activity behaviours after migration", "increased discourses on body weight and obesity", and "weight management advice and support received". The study found participants experienced dietary advice from midwives as inaccessible and difficult to follow, particularly where it didn't take their wider context into account. Participants reported experiencing midwives'

					advice around physical activity in pregnancy as helpful, though had some suggestions regarding how the delivery of this advice could be improved.
Late booking amongst African women in a London borough, England: implications for health promotion	Chinouya, & Madziva (2019)	To explore why Black African women in a London borough access the booking appointment (the first appointment with a midwife) after the NICE guideline of 13 weeks of pregnancy.	Data collection: Semi-structured interviews Data analysis: Framework analysis	23 women who self-identified as black African migrants born in a sub-Saharan African country, recruited through a study poster put on notice boards and distributed at a number of community-based settings.	The analysis produced 4 themes: “unresolved immigration status”, “the importance of culture”, “lack of awareness” and “cultural expressions of pregnancy”. The study found cultural, economic and political contexts within which they experienced pregnancy influenced the timing. Lack of

					information about the booking appointment, the perception that healthcare professionals would be dismissive of their cultural beliefs regarding pregnancy and having children, and unresolved immigration issues also created barriers to accessing the appointment.

For this review, an adapted version of the CASP by Long et al. (2020) was utilised (see Appendix B). This version was developed to account for the limitations of the CASP, including the lack of criterion for appraising the clarity and appropriateness of the study's qualitative paradigm. The adapted version also expands the fixed response categories to include a 'somewhat' category. The 'somewhat' category is designed to reflect where a study may have both methodological limitations and strengths to capture the complexity of quality appraisal. Table 4 provides an overview of the quality of the included studies in this review using the adapted CASP tool.

All of the studies clearly stated the research's aims and discussed its relevance and importance. As all the studies aimed to explore the participants' experiences, the qualitative methodology used was appropriate.

Most of the studies did not explicitly discuss their theoretical underpinnings or did not provide enough information to identify these. In these cases, it was not possible to determine whether the methodology remained coherent and congruent with these assumptions. The exceptions to this were Gardner et al. (2014), Ling et al. (2023) and Williams et al. (2023). A strength of the Ling et al. (2023) study is its discussion of how Interpretative Phenomenological Analysis (IPA) and its theoretical underpinnings guided the data collection and analysis, and there was evidence that the methodology and reporting of the findings remained congruent with IPA. Gardner et al. (2014) also used an IPA methodology, however, the consideration of the researcher's role in the analysis appears lacking so it was unclear whether the interpretivist assumptions of IPA were fully embedded within the research. Williams et al. (2023) discussed how a critical realist stance underpins the study, and the methods used appeared to remain congruent. Chinouya & Madziva (2019) describe using an interpretative paradigm but do not provide sufficient details of their methodology, for example, whether their data analysis framework was pre-determined or flexible, to conclude whether their methodology remains entirely congruent with this paradigm.

All studies, apart from Davies and Bath (2001), provided sufficient details on how they recruited participants. Some studies went further by considering their decision-making and discussing the rationale for their recruitment methods and sampling (Chinouya & Madziva, 2019; Edge, 2008; Ling et al., 2023; Ngongalah et al., 2021; Williams et al., 2023) and inclusion criteria (e.g. Babatunde & Moreno-Leguizamon, 2012; Edge, 2008; Edge, 2011; Gardner et al., 2014; Ling et al., 2023; Ngongalah et al., 2021; Williams et al., 2023) which were particular strengths in terms of the quality of these studies. Two studies further discussed why some participants may not have taken part or dropped out, for example, Williams et al. (2023) discussed the implications of collecting data online due to COVID-19 and Chinouya and Madziva (2019) discussed fear in relation to immigration status as a potential barrier.

In contrast, Davies and Bath (2001) provided insufficient information to evaluate the quality of their recruitment methods. Flexibility around the participant inclusion criteria is stated, for example, a participant who had not had a child was included. However, the rationale for this flexibility is not discussed so it is unclear how this supported the research aims of understanding maternity information concerns and relationships with maternity health professionals.

Table 4

Overview of Study Quality Using Adapted CASP Tool

Study	Clear statement of aims	Methodology	Research Design	Theoretical underpinnings	Recruitment strategy	Data collection	Relationship between researcher and participants	Ethical issues	Data Analysis	Clear statement of findings	Valuable
Babatunde & Moreno-Leguizamon (2012)	Yes	Yes	Yes	Can’t tell	Yes	Yes	Somewhat	Yes	Yes	Somewhat	Yes
Chinouya & Madziva (2019)	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Davies & Bath (2001)	Yes	Yes	Yes	Can’t tell	Can’t tell	Yes	Yes	Yes	Yes	Yes	Yes
Edge (2008)	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Edge (2011)	Yes	Yes	Yes	Can’t tell	Yes	Yes	Can’t tell	Can’t tell	Yes	Yes	Yes

Gardner, Bunton, Edge, & Wittkowski (2014)	Yes	Yes	Yes	Somewhat	Yes	Yes	Can’t tell	Can’t tell	Yes	Yes	Yes
Ling, Eraso & Di Mascio (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Ngongalah, Rankin, Heslehurst, & Rapley (2021)	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes

Williams, McKail, & Arshad (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

All studies described data collection methods appropriate to address the research issue. A strength of some studies (Babatunde & Moreno-Leguizamon, 2012; Chinouya & Madziva, 2019; Davies & Bath, 2001; Edge, 2011; Gardner et al., 2014; Ling et al., 2023) was the inclusion of discussion around their choice of data collection method, which was beneficial when the research aims could have been potentially met by another method.

Six of the studies detailed their considerations of the relationship between the researcher(s) and participants. This was a particular strength of the Ling et al. (2023) study, which discussed how the researcher engaged in reflexivity, peer support and supervision to increase their awareness of potential researcher biases. In the Babatunde & Moreno-Leguizamon (2012) study, this aspect appeared to have some limitations. Although there is some consideration of the relationship where the researcher's background is named as a potential limitation, further discussion on how the researchers' backgrounds may have shaped the study and how they reflected on this within the study would have been beneficial. There was no discussion of the relationship by Edge (2011) or Gardner et al. (2014). Therefore, there was insufficient information to judge whether the relationship had been adequately considered.

There was evidence that six studies also adequately considered ethical issues, including obtaining informed consent, confidentiality, minimising participant distress and providing aftercare. Three studies did not discuss any ethical issues beyond stating that they obtained informed consent. This was viewed as a reporting issue, and, therefore, not possible to judge whether ethical issues had been adequately considered in these studies, particularly as these studies did detail that ethical approval has been obtained from an ethics committee.

All studies provided sufficient detail on their data analysis method to conclude that this was sufficiently rigorous. The Ling et al. (2023) study's detailed explanation of the data analysis process was a strength. Babatunde & Moreno-Leguizamon (2012) included a table of emerging themes and the corresponding “units of meaning” and supportive quotes, which was useful in illuminating their analytic process.

Most studies present the findings clearly. A limitation of the Babatunde & Moreno-Leguizamon (2012) study was that only limited attempts had been made to establish the credibility of the findings. All studies discuss the value of the research findings, including how the research furthers understanding of Black women’s experiences based on existing literature. As highlighted by the small number of studies included within this review, Black women may be underrepresented in research understanding experience of maternal healthcare. Studies which combine the experiences of ‘BAME’ women may also lead to the loss of the complexity and nuance in experiences within and between women from the Global Majority (Parry et al., 2023). Therefore, the focus of these studies on specifically Black women appears to highlight their value, whilst all studies also offer implications for clinical practice and suggestions for further research.

Overall, the studies appeared of sufficient quality to be included within this review and some strengths of the research included have been discussed. There were no major limitations in any aspects of the design or methodology identified, although there were limitations in the reporting of some aspects for some studies. Therefore, the potential for issues with design and methodology where information was lacking cannot be completely ruled out, and this should be considered when considering the findings of this review.

2.5 Synthesis of Findings

Nine studies were included, and a thematic synthesis was conducted to synthesise the findings. Most of the studies included samples of women born in Africa. Therefore, the findings of this review largely reflect Black women's experiences who have migrated to the UK. Studies provided rationales for focusing on migrant women, such as postnatal depression being more common in such populations and research exploring their experiences being limited within the UK (e.g. Gardner et al., 2014; Ling et al., 2023) and the need to understand the uniqueness of experiencing maternal health in the context of multiple cultural frameworks for migrant populations (e.g. Chinouya & Madziva, 2019; Ngongalah et al., 2021). Altogether, the studies focused on experiences of antenatal, birthing and postnatal care. Therefore, this review's findings reflect maternal healthcare experiences across the maternity journey, including both physical and mental health care.

A thematic synthesis was carried out using the guidance by Thomas and Harden (2008). This method was chosen due to its clear steps and transparent methodology (Cochrane, n.d). A narrative synthesis approach was also considered, however as the studies included were relatively homogenous in their samples and methods, a thematic synthesis was appropriate. A narrative synthesis approach, such as Popay et al. (2006), can be advantageous when reviewing studies that are heterogeneous in their research traditions and designs (Snilstveit et al., 2012), which was not the case in this review. Due to the limited research in this area and the review's aims, a thematic synthesis also felt more appropriate than a meta-ethnography, which aims to produce new theory and conceptual models (France et al., 2019). By offering a systematic process to synthesise the findings, the clear steps provided by Thomas and Harden (2008) also felt appropriate due to the researcher having less experience synthesising qualitative research.

The findings, discussion and conclusion sections of the nine papers were extracted. Next, the three steps of thematic synthesis, as detailed by Thomas and Harden (2008), were undertaken:

1. Line-by-line coding
2. Development of descriptive themes
3. Development of analytical themes

From these steps, four main interrelating themes were developed considering the review question. The four themes are presented and discussed below. See Table 5 for a summary of the main themes and corresponding subthemes.

Table 5

Summary of Systematic Review Findings - Main Themes and Subthemes

Main Theme	Subtheme
Barriers to Accessing Maternal Healthcare	Cultural and societal beliefs shape help-seeking Healthcare perceived as unhelpful Healthcare is inaccessible
Negative Care Experiences	Lack of collaborative care Expectations of care not met Difficult relationships with healthcare professionals Racism and discrimination

Alternative Ways of Coping	
Black Women Need a Voice in Improving Services	

2.5.1 Barriers to Accessing Maternal Healthcare

All studies highlighted barriers for Black women in accessing services for their maternal healthcare. These barriers were described as personal (beliefs and experiences of the participants), factors relating to the healthcare professionals they had contact with, and structural factors relating to how services were set up and functioning.

2.5.1.1 Subtheme: Cultural and Societal Beliefs Shape Help-Seeking. Most studies highlighted cultural and societal beliefs that appeared to act as barriers to help-seeking for Black women by inhibiting them from talking about their physical and mental maternal health (Babatunde & Moreno-Leguizamon, 2012; Chinouya & Madziva, 2019; Edge, 2008; Gardner et al., 2014; Ling et al., 2023; Williams et al., 2023).

Some studies (Babatunde & Moreno-Leguizamon, 2012; Edge, 2008; Ling et al., 2023; Williams et al., 2023) found participants discussed being “strong” and how this part of their identity could prevent them from seeking support for their maternal health. Participants described not wanting to talk about difficulties with professionals, family members or friends due to fears of being perceived as weak and thus failing to meet expectations of being strong (Edge, 2008; Gardner et al., 2014; Ling et al., 2023). Significantly, needing to be strong was discussed as a barrier for seeking care in both physical and mental health settings and, therefore, may be relevant to understanding Black women’s help-seeking behaviours across maternal healthcare settings.

Being strong was described as a “cultural transmission” (Ling et al., 2023) and part of their African cultural background (Babatunde & Moreno-Leguizamon, 2012). The expectation of being strong was found to be unhelpful by impeding them from discussing difficulties (Babatunde & Moreno-Leguizamon, 2012) and receiving the support they required (Edge, 2008; Ling et al., 2023). However, Williams et al. (2023) also highlighted how being strong felt essential for survival (Williams et al., 2023) in the context of their maternity care.

An additional barrier described by Black women to seeking support for their perinatal mental health was an awareness of the stigma surrounding mental health conditions within their cultures (Babatunde & Moreno-Leguizamon, 2012; Edge, 2008; Gardner et al., 2014; Ling et al., 2023). On the other hand, Edge (2008) and Edge (2011) also found that participants expressed wanting to talk about their difficulties and a perception that getting support could be beneficial, including that this could make them “stronger” (Edge, 2008). This again reflected the belief of needing to be strong but offered a different perspective on achieving this. The wish to discuss their feelings was expressed about professional support like counselling (Edge, 2008) and peer support (Edge, 2011). Significantly, both studies included samples of Black Caribbean women mostly born in the UK, which differs from most other studies in the review which explored African migrant women’s experiences.

The studies exploring perinatal mental health also highlighted how participants’ understanding of their difficulties may shape their use of maternal healthcare. Across these studies, participants often understood their experiences in relation to their cultural context and social circumstances, frequently attributing stress in their relationships, lack of support, and feelings of isolation as causes for their difficulties (Babatunde & Moreno-Leguizamon, 2012; Edge, 2008; Gardner et al., 2014). Consequently, their experiences were not recognised as an “illness” that required treatment from healthcare professionals. This approach differs from healthcare services where such distress is conceptualised with labels such as “postnatal depression”, signifying a diagnosable condition. This mismatch in understanding was highlighted particularly within the Gardner et al. (2014) and Edge (2008) studies, where participants chose not to use the word “depression” and instead used words such as “distress” or feeling “low”. Significantly, this was found despite the researchers’ taking a medical approach to such distress and using terms such as “postnatal depression”.

2.5.1.2 Subtheme: Healthcare is Inaccessible. Studies that focused on Black women who had migrated to the UK found that unfamiliarity with the UK health service, its structure, and the roles of healthcare professionals were barriers to accessing appropriate support for maternal health (Davies & Bath, 2001; Ngongalah et al., 2021). Fears of deportation due to unresolved immigration status were also raised as a barrier to using health services when pregnant (Chinouya & Madziva, 2019).

Difficulties in communication between healthcare professionals and the participants were also identified as contributing to making healthcare inaccessible for Black migrant women. Davies and Bath (2001) found that health services did not adequately provide interpreters, which was a barrier for participants in attending and understanding important information about their care and health. This could then impact on the women accessing and getting the treatment they needed.

Other studies reported that the information about their care was provided in inaccessible formats, for example, leaflets and online services (Chinouya & Madziva, 2019), and at times not relevant considering their current lifestyle, for example, the information given about diet during pregnancy was not relevant to current dietary preferences and so did not meet their needs in the Ngongalah et al. (2021) study. Practical barriers to attending appointments were also described in studies exploring perinatal depression, such as childcare and long waiting times (Edge, 2008) and the financial resources of participants (Gardner et al., 2014).

Altogether, these findings highlight the inaccessibility of maternal healthcare across physical and mental health settings for Black women, particularly for women who had migrated to the UK. However, as most studies do not specify how long participants have lived in the UK, it is not possible to tell whether these findings are more representative of Black women who have migrated to the UK more recently. It may be possible that women will become more familiar with UK health services the longer they live in the UK, and thus, services may be experienced as more accessible.

2.5.1.3 Subtheme: Healthcare Perceived as Unhelpful. Edge (2011) found that participants attributed previous negative experiences of maternity care to being less likely to access healthcare for their postnatal physical and mental health. This study found that maternity care lacking compassion shaped perceptions on whether accessing healthcare in the postnatal period would be useful.

Edge (2008) found participants expressed apprehension around talking about their emotions with a White therapist and had doubts over being able to access culturally sensitive care and, therefore, did not perceive talking therapy for emotional and psychological difficulties to be helpful.

The issue of confidentiality of talking therapy and health services more broadly was discussed, with some expressing concerns over whether healthcare professionals could be trusted to remain confidential (Chinouya & Madziva, 2019; Edge, 2008). However, Gardner et al. (2014) found that participants expressed a preference to discuss issues with a professional as they were perceived to be more confidential than family and friends.

2.5.2 Negative Care Experiences

Most of the studies found participants described negative experiences of physical and mental healthcare in relation to their maternal health, including difficult relationships with healthcare professionals and experiences of discrimination. These difficult experiences led some women to report feeling angry (Davies & Bath, 2001), uncared for and undervalued (Edge, 2011; Ling et al., 2023; Williams et al., 2023), bad about themselves (Edge, 2011), isolated (Gardner et al., 2014), and disappointed and mistrusting of professionals (Edge, 2011; Ling et al., 2023; Williams et al., 2023).

2.5.2.1 Subtheme: Lack of Collaborative Care. Healthcare professionals were experienced as providing standardised care that was not devised collaboratively (Davies & Bath, 2001; Edge, 2011; Ling et al., 2023) and subsequently did not meet the women's needs. Some studies found that prioritising the baby's needs in postnatal care meant little time was given to the mother's needs, which could feel frustrating for mothers (Edge, 2008; Edge, 2011; Ling et al., 2023).

Some Black women reported being offered anti-depressants as the only option for treatment for postnatal depression and not being offered alternative treatment options, such as referrals for talking therapy, despite their apprehensions regarding medication (Edge, 2011; Ling et al., 2023).

2.5.2.2 Subtheme: Difficult Relationships with Healthcare Professionals. Some participants described difficult relationships with healthcare professionals within their maternity care (Davies & Bath, 2001; Edge, 2011; Gardner et al., 2014). Some studies found that when Black women did reach out for support, they experienced healthcare professionals' responses to be unsatisfactory, as professionals did not understand or explore their difficulties related to their maternal health adequately or appropriately (Babatunde & Moreno-Leguizamon, 2012; Edge, 2008; Ling et al., 2023; Williams et al., 2023).

Participants described feeling dehumanised (Edge, 2011; Williams et al., 2023) and ignored by midwives (Davies & Bath, 2001; Gardner et al., 2014; Williams et al., 2023) and that midwives lacked compassion (Davies & Bath, 2001; Edge, 2011; Williams et al., 2023). Participants described professionals' workload as a barrier to forming positive relationships (Edge, 2011).

2.5.2.3 Subtheme: Racism and Discrimination. Three studies described participants experiencing racism, which led to discrimination within their care. Williams et al. (2023) found that participants experienced racism both covertly and overtly and that healthcare professionals seemed largely unaware of their racism. Williams et al. (2023) and Davies and Bath (2001) found Black women made comparisons with the care they observed White women receive, which made explicit the impact of racism on their care. Williams et al. (2023) found that healthcare professionals held biases and assumptions about Black women, which impacted the care received. These studies also found that women’s pain and distress could be ignored or go unrecognised by healthcare professionals.

Two studies reported that participants felt discriminated against due to their culture (Chinouya & Madziva, 2019) and not speaking English, which contributed to inappropriate treatment concerning care preferences (Davies & Bath, 2001). Participants understood healthcare professionals' negative attitudes toward them as being due to professionals’ negative beliefs about women with larger families (Chinouya & Madziva, 2019 Davies & Bath, 2001). Williams et al. (2023) also highlighted how women experienced multiple layers of discrimination due to their race, gender, class, and religion.

2.5.2.4 Subtheme: Expectations of Care Not Met. Some studies found that participants made comparisons between the healthcare and social support they received in the UK with the support they would receive in their country of origin, which formed their expectations of support during pregnancy and the postnatal period (Gardner et al., 2014; Ling et al., 2023; Ngongalah et al., 2021). Studies found that the healthcare and support from professionals often did not meet expectations and left the women feeling isolated and disappointed with their care (Edge, 2011; Gardner et al., 2014; Ling et al., 2023). Due to care not meeting expectations, Ling et al. (2023) found a theme of women “pretending to be ok” in the presence of professionals such as Health Visitors.

2.5.3 Alternative Ways of Coping

In the absence of support from healthcare services, studies found Black women spoke of alternative ways of coping, which largely focused on social, relational and spiritual support.

Some studies found the value of practical and social support from family (Babatunde & Moreno-Leguizamon, 2012; Gardner et al., 2014; Ngongalah et al., 2021; Williams et al., 2023) in supporting women to cope with their difficulties postnatally. Advice from family and friends on diet during pregnancy was found to be more valued than the information midwives offered (Ngongalah et al., 2021). However, unsupportive family relationships were also discussed as sources of stress (Babatunde & Moreno-Leguizamon, 2012; Gardner et al., 2014; Ling et al., 2023). Peer support also appeared valued in some studies (Edge, 2011; Gardner et al., 2014; Williams et al., 2023).

Other strategies reported included keeping busy by leaving the house and going out to work (Gardner et al., 2014; Ling et al., 2023). A common theme across the studies exploring perinatal depression was the importance of religious and spiritual faith in coping with difficulties (Babatunde & Moreno-Leguizamon, 2012; Edge, 2008; Gardner et al., 2014).

2.5.4 Black Women Need a Voice in Improving Services

The studies highlighted several suggestions from participants on how maternal healthcare services could be improved to meet the needs of Black women. Williams et al. (2023) highlighted the importance of Black women's voices being a central and integral driver of change, alongside services taking responsibility to ensure Black women receive safe and compassionate care.

Some studies highlighted the benefits of working alongside local communities and offering community-based support (Chinouya & Madziva, 2019; Edge, 2011; Williams et al., 2023). Peer support and community groups were also expressed in some studies as a preference instead of individual support (Edge, 2011; Ngongalah et al., 2021). This preference was found for both physical and mental maternal health care, suggesting the importance of social support within the maternity journey.

Edge (2011) and Ngongalah et al. (2021) highlighted the need for women-centred care and developing support and treatment based on asking the person what they want. Notably, these suggestions are in contrast with the lack of collaborative care found to have been experienced in some of the studies. A need for health professionals to consider culture in the care they provide was also discussed as important (Babatunde & Moreno-Leguizamon, 2012; Chinouya & Madziva, 2019). A preference was expressed for Psychological Therapists of the same cultural background (Edge, 2008) to support understanding and remove barriers to accessing support. Shared identity with professionals was described as facilitating connection and good quality care in the Williams et al. (2023) study.

Edge (2011) highlighted the want for holistic services, including access to talking therapy and alternative therapies such as reflexology and therapeutic massage. This implies that a range of treatment options would be beneficial, in contrast to the treatment options offered, which focused on the biological.

2.6 Conclusion

This review explored what the existing literature says about how Black women experience healthcare for their maternal health. Common themes were identified, such as there being significant barriers for Black women to access care, and these operated across the personal, social, cultural and structural levels. When care was accessed, negative experiences were common, and these negative experiences became additional barriers by shaping Black women’s motivations to re-access healthcare in the future. Consequently, alternative ways of coping were discussed across the studies. Improvements to care were highlighted as necessary by the studies, and centred around care needing to become culturally sensitive, person-centred, and embedded within communities. Differences between the studies were found in how Black women perceived the confidentiality of professionals and services and in their wish to access support and talk about their difficulties.

A sufficient number of good-quality studies were included to answer the review question. However, when considering the findings of this review, the generalisability to current Black women's experiences should be considered with caution. As half of the studies took place before 2020, it is possible that the findings may not be entirely representative of current experiences. Moreover, most of the studies also focused on the experiences of women who had migrated to the UK, which could further limit the generalisability of the findings.

The continued lack of representation of Black women in research exploring experiences of maternal healthcare within the UK has been highlighted by this review. The fact that there were not enough studies to conduct a review exploring Black women's experiences of healthcare for endometriosis or other gynaecological conditions in the UK highlights a similar pattern within research exploring experiences of gynaecological healthcare.

This lack of representation appears to be an example of *misogynoir*, a concept defined by Bailey (2010) to describe Black women's experiences of the combined force of anti-Black racism and misogyny. Noble and Palmer (2022) discuss how misogynoir can present as the absence and erasure of Black women from popular culture within the UK, "reinforcing Eurocentric structures of power, governance, and desire" (p. 235). This could also explain

Black women's underrepresentation within gynaecological research and health research more broadly (Le et al., 2022).

2.7 Aims and Rationale for the Current Study

In line with recommendations from previous research and the APPG report, the current study aims to explore Black women's experiences of getting a diagnosis of endometriosis within the UK. To date we know little about Black women's experiences of being diagnosed with endometriosis, though research has suggested that Black women may be less likely to be diagnosed or have a longer diagnosis journey with endometriosis than their Asian and White counterparts, despite research not indicating a difference in prevalence between these groups (Bougie et al., 2019; Li, 2021).

As discussed, Black women may face multiple barriers to accessing appropriate healthcare for their symptoms of endometriosis, based on intersecting aspects of their identities. The limited existing research into Black women's experiences of obstetrics and gynaecological healthcare, as summarised within the introduction and the findings of the systematic literature review, has indicated that Black women may be receiving inadequate, and at times, harmful healthcare, which has implications for their physical and emotional wellbeing and may shape their future health-seeking behaviours.

2.7.1 Research Question

The research question for this study is:

How do Black women experience getting a diagnosis of endometriosis within the UK?

3. Methodology

3.1 Design

This study aims to explore Black women's experiences of getting a diagnosis of endometriosis and how they make sense of these experiences. Qualitative methodology was chosen as it aims to provide an understanding of peoples' experiences and the meaning they have given to them (Willig, 2019). Qualitative methodology allows for rich description whilst focusing on understanding the participant's subjective experience and, therefore, can be useful for exploratory-orientated research (Barker et al., 2015). As discussed, no previous research has explored Black women's experiences of being diagnosed with endometriosis within the UK. Therefore, qualitative methodology could allow for in-depth exploration into experiences which research has not previously explored.

3.1.1 Consideration of Methodologies

Different qualitative methodologies were considered within the initial stages of designing the study, prior to Interpretative Phenomenological Analysis (IPA) being chosen. IPA is described and the rationale for using this methodology is discussed. Table 6 provides an overview of other possible methods considered and an explanation for why they were not chosen.

3.1.1.1 Interpretative Phenomenological Analysis (IPA). IPA (Smith et al., 2022) aims to provide an in-depth exploration of how participants make sense of the world. IPA's philosophical and theoretical foundations are based on phenomenology and hermeneutics.

Phenomenology is a philosophical approach concerned with lived experience (Smith, 2011). IPA takes a phenomenological stance in that it attempts to explore, in detail, the participant's lived experiences and is concerned with the meaning the participant gives to phenomena (Smith and Osborn, 2003). IPA goes beyond descriptive phenomenology and is informed by Heidegger (1962), who stated that our experience of the world is always viewed in perspective, and experiences exist inter-subjectively in communication with others. Accordingly, IPA explores subjective lived experience by considering how a given person interprets their experiences of a given phenomenon at a given time, and how this sense-making is situated within their broader context. As this research aims to explore how Black women make sense of their experiences, IPA and its interpretative approach was felt more suitable than descriptive phenomenological approaches to move beyond just providing a description. Altogether, IPA's focus on lived experience and meaning-making was appropriate to address the research question and aims.

Although IPA aims to get as close as possible to the personal world of the participants, IPA acknowledges that access is partial and complex (Smith, 1996) and that the researcher also takes an active role in accessing and interpreting the participant's experience (Smith and Osborn, 2003). IPA involves a *double hermeneutic* where the researcher interprets the participant's interpretation of their experience (Montague et al., 2020), and the researcher's interpretation will be influenced by their own experiences. This means that instead of aiming to obtain access to a single objective reality, in line with the epistemological stance of critical realism taken in this research, IPA acknowledges that multiple interpretations of an experience are possible and will be influenced by the contexts of the participant, researcher, and, where applicable, the reader (Smith et al., 2022).

Consequently, it is important for the researcher to engage in reflexivity, considering how their biases and assumptions may play a role in their interpretation. *Bracketing* has been defined as the researcher recognising their "own perspective, pre-existing thoughts and beliefs, and developing hypotheses" and setting aside these assumptions to attend to the participant's accounts with an open mind (Starks & Brown Trinidad, 2007, p. 1375). Bracketing can, therefore, be used as a way of supporting accessing the experiences of the participant. Engaging in 'bracketing' has the potential to enrich data collection, findings and interpretation (Tufford & Newman, 2012).

IPA also takes an idiographic approach, firstly focusing on understanding the individual's unique experience, before moving on to examining commonalities between individuals. This approach allows for capturing the nuances, similarities, and differences in experience within and between individuals (Smith, 2011). It was felt that the emphasis on individual experience would be useful for this research, as it will ensure that the participants' unique contexts are not lost within the analysis, supporting a greater depth of understanding of a complex phenomenon that has not been explored directly within research before.

In addition, it has been suggested that IPA may be a useful methodology for researching individuals or groups who may be underrepresented because of its idiographic, phenomenological approach, which can privilege the voices of participants (Noon, 2018). This further supports the use of IPA in this research study, as Black women's experiences have been underrepresented in the research exploring peoples' experiences of endometriosis.

Table 6

Summary of Methodologies Considered

Other Methodology Considered	Overview and Rationale for Choosing IPA
Narrative Analysis	Narrative Analysis aims to examine the stories people tell and how they tell these

	stories to make sense of their experiences and claim identities (Riessman, 1993). Understanding how Black women make sense of their diagnosis journey through exploring how they tell their stories, and the relationship between this and identity formation, could be useful in future research. However, IPA was felt to be a more appropriate method to answer the research question of understanding how Black women experience getting the diagnosis, due to its focus specifically on describing and interpreting the lived experiences of participants.
Thematic Analysis	Thematic analysis is a method for analysing qualitative data, which aims to explore and analyse patterns within the data set, which are reported as ‘themes’ (Braun & Clarke, 2006). Unlike IPA, thematic analysis does not hold an idiographic focus and therefore only looks for themes across an entire data set. Consequently, thematic analysis can work with large, heterogeneous samples (Braun & Clark, 2021). Braun and Clark (2021) specify that thematic analysis would be better suited than IPA methodology where the research aims are not solely to explore personal experience and sense making, where samples are larger and aim to capture diversity, and where the analysis aims to capture themes across the data set,

rather than also having a focus on individual features of the cases. As the aim of this research was to focus specifically on lived experience and sense making, IPA was chosen and felt an appropriate methodology instead of Thematic Analysis.

3.1.2 Reflection

From choosing my topic, I was highly aware of my position as a white researcher and healthcare professional speaking to Black women about their experiences within the healthcare system. This awareness also came up in my thinking around choosing a methodology and factored into my decision behind why I chose IPA. I was aware my position held power and I was keen to name and pay attention to this throughout the research process. Also, being aware of my outsider position meant I was drawn to the 'double hermeneutic' underpinning IPA and the importance the methodology placed on reflexivity whilst aiming to understand the participant's experience as closely as possible. To me, this meant that I would be actively privileging the participants' voices whilst acknowledging and being aware of the difference in aspects of our identity and what my own lens (being a white female living without a chronic health condition/disability) may lead me to attend or not attend to during the interviews and analysis.

3.2 Ethics

The research project was granted initial ethical approval on 31st October 2023 (see Appendix C) by the UH Ethics Committee. An amendment was submitted regarding using additional recruitment methods (using other social media accounts and events to advertise the study), which was approved by the ethics committee on 6th December 2023 (Appendix D). A further amendment was submitted regarding using another additional method of recruitment (use of another study advert), which was approved on 29th January 2024 (Appendix E). A final amendment was submitted regarding a change to the inclusion/exclusion criteria (specifically around how the participant had obtained their diagnosis), which was approved on 8th March 2024 (Appendix F).

The British Psychological Society (BPS) Code of Human Research Ethics (2021), which provides ethical guidelines, was followed. Table 7 provides an overview of how the relevant aspects of the code for this study were considered and followed.

The BPS code states that potential risks of undertaking the study should be considered, and appropriate risk management protocols should be developed as part of the study's design (Oates et al., 2021). The appropriate University risk assessment tools were used. A risk assessment and management protocol (Appendix G) was also developed to guide the researcher if risks to participants were identified during the interviews. This included guidance on questions to ask the participant to support understanding any risk to self and identifying appropriate actions and whom these should be completed by (lead researcher or supervisor) based on the level of identified risk. The researcher drew on their therapeutic skills as a Trainee Clinical Psychologist to support their thinking about risk assessment and management. The supervisory team, which included both qualified Practitioner Psychologists, also provided support where required. Arrangements with the supervisors were made to ensure their availability during and after the interviews to support with any risk management issues.

Table 7

Ethical Considerations for the Study

Principal of Ethical Code	Study Consideration
Consent	Informed consent was gained from all participants. To support participants with giving informed consent, information sheets (Appendix H) were provided which covered information about the research, such as, the use of participant data and their right to withdraw. Participants were offered the opportunity to ask questions about taking part either by email or telephone before giving their consent. Two information sheets were provided, one before completing the initial online survey and one before the interview. This was to ensure participants were provided with the relevant information for each part of the study. The information sheet for the survey was provided as text when participants opened the survey link. The information sheet regarding the interview was emailed to the participants after they had completed the survey and expressed an interest in taking part in an interview. For the initial survey, consent was gained via a closed question as part of the survey (see Appendix I for survey questions), following the information sheet being provided. For the interviews, consent was gained by a consent form (Appendix J)

	which participants signed. A copy of this was then stored securely by the researcher and the participant retained a copy.
Right to withdraw	For the initial survey, participants were made aware in the information sheet that they would be unable to withdraw once they had submitted their answers. This was due to the data being anonymised once submitted, and therefore the researcher would be unable to remove their data. Participants were informed of their right to withdraw from the interview without providing a reason for up to two weeks following the interview. This information was provided in the information sheet, and participants were reminded again at the interview. No participants chose to withdraw.
Confidentiality	Confidentiality was maintained throughout the research process. Confidentiality and its limits was explained in the information sheets provided. All data collected from the initial survey was initially received on a password-protected survey account only accessible to the principal researcher. The data was then transferred to a password-protected file on the GDPR compliant UH One Drive (also only accessible to the principal researcher). All data collected within the interview, including the consent

	form, interview recordings and transcripts, was stored electronically on a password-protected file on the GDPR compliant UH One Drive. Interview transcripts, recordings and consent forms were kept in separate folders within the UH One Drive.
Risk of Harm	The potential for the research to cause some distress to participants due to the sensitive nature of the topic was considered, following the BPS code's (BPS, 2021) ethical principle of maximising benefit and minimising harm. Participants were broadly informed of what the initial survey and interview would cover and the potential for this to cause some distress before taking part (in the information sheets provided). This aimed to support the participants in deciding whether they wished to take part and to provide informed consent. Within the survey participants were given the option of 'prefer not to say' on the closed questions (except for questions confirming their eligibility). Participants were offered a choice of how they would like to attend the interview (either online, over the telephone, or face-to-face where we could both travel to an appropriate location). This was intended to support the participants to feel as comfortable as possible, considering their physical health as well as minimising

emotional distress. All participants chose to take part in the interview online which meant participants had the flexibility and choice of location. Participants were asked if they were in a private space and no issues were highlighted in any of the interviews regarding confidentiality.

Participants were made aware of the option to have another person present during the interview, but no participants requested this. Prior to the interview commencing, discussions took place around the possibility for the interview to cause distress and how this would be managed.

All participants reported feeling comfortable talking about their experiences with me. The researcher checked in with the participants during the interviews where appropriate, as agreed with them at the start of the interview. Three of the participants disclosed thoughts of suicide at some point during their lives during the interview. As per the risk management plan, the researcher confirmed with the participants whether they had these thoughts at present. Two participants confirmed that these thoughts were historical. One participant disclosed that they have had these thoughts more recently, however clarified that they hadn’t had any plans or intent to act on these and had established support networks and protective factors. The participant confirmed that they did not feel distressed during or after the interview and no further action was required from the researcher as per risk management protocol. Space for a debrief was provided immediately after each interview for all participants. No participants reported any psychological harm or distress during or following their participation.

All participants were provided with the contact details of the principal researcher and principal supervisor and were provided with a debrief form as part of the survey or via email following the interview (Appendix K). The debrief form included information on further support should they wish to access it.

3.3 Remuneration

Providing payment to participants in some form is commonplace within psychological research (Head, 2009). In this study, participants were given a £10 online shopping voucher as a thank-you for participating. One participant declined this offer.

The main purpose of remuneration in this case was not to provide an incentive to participate and participants were informed about remuneration after they had expressed an interest in taking part in an interview. Providing payment has been viewed as another way to attempt to minimise the imbalance of power within the researcher-participant relationship, as it can mean that the researcher isn’t the only one to benefit from the research directly (Head, 2008). This was the intention behind providing remuneration in this study.

Ethical issues have been raised around providing remuneration, for example, that it may compromise the voluntary nature of participation (Czarny et al., 2010). This study followed the BPS ethical code (2021) in that the reimbursement amount was proportionate to any burden participation may place on the individual and not so large that it would compromise an individual’s ability to freely decide whether to participate.

Another ethical issue that has been raised is the idea that payments to participants could act to marketise participants’ stories (Head, 2008). However, in the case of this research, the view was taken that the participant’s material realities, such as potentially needing to take time off work to participate, along with the wish to minimise the imbalance of power in the context of the researcher’s position, outweighed this concern.

3.3.1 Reflection

I was particularly aware of the power dynamic of me being a white healthcare professional/researcher interviewing Black women and how this may further imbalance the typical power dynamic between researcher and participants. I held this in my mind when I was thinking about potential ethical issues when developing the study, for example, when thinking about minimising harm, informed consent and remuneration. I chose to include a picture of myself in the research advert to share some aspects of my identity before the participants chose to take part. I also decided to explicitly name my position as a white healthcare professional/researcher in the initial survey when asking the women if they would like to take part in an interview and again within the information sheet provided to *participants before they gave their consent to participate in the interview. I also chose to name difficult experiences that the participants may have experienced whilst seeking a diagnosis, such as racism and discrimination, in the information sheet. Before the start of each interview, this was again acknowledged. I made participants aware that they had the choice about what they spoke about or not within the interview and that they did not need to give a reason to decline to talk about something or withdraw entirely. I hoped that these actions would help the participants give true informed consent, help to lessen the power imbalance, and acknowledge what may or may not be comfortable or possible to talk about with me.*

3.4 Member Checking Process

All participants who participated in an interview were offered the opportunity to be involved in providing feedback on the researcher's analysis to form the final findings, a process referred to as *member checking* (Goldblatt et al., 2011). Member checking has been used to establish trustworthiness (Motulusky, 2021) and to document rigour in qualitative research (Cresswell & Miller, 2000). However, the idea of member checking being used to establish trustworthiness has been critiqued, and other purposes of member checking have been described, such as enhancing reflexivity around researcher biases and supporting power sharing between researcher and participant (Thomas, 2017). Some have proposed that member checking may be used as an empowering, collaborative and voice-enhancing aspect of the research design instead of primarily a technique to establish validity (e.g. Brear, 2019; Koelsch, 2013). This view on the purpose of member checking was taken within this study, and other methods, such as peer reviewing of the analysis, were also used to support the quality of the research.

Participants were informed that participating in the member-checking process was optional. The information sheet also informed participants of the potential risk of distress from participating in member-checking. Participants consented to be contacted again on the consent form. Consent was then regained verbally at the end of the interview.

Once the initial analysis was complete, the researcher contacted participants by email between 4-7 months after the interviews were completed. At this stage, participants were again reminded that this part of the study was optional and were given the option not to take part explicitly. The researcher sent the participants a summary sheet of the analysis (an extract of the summary sheet is included in Appendix L) and asked them to provide feedback. It was discussed how to present the findings to the participants within the supervisory team to minimise the chance of any potential distress. It was decided not to share individual themes with participants. This was decided in case participants found their individual themes to be exposing and because of the limited amount of aftercare the research team could provide.

Participants were invited to give their feedback in writing via email or to discuss with the researcher if they would like to do this in another format. Two participants responded, and the implications of the response rate are discussed within the discussion section. One participant responded that they would not make any changes to the themes because they felt the themes reflected their experiences adequately. Another participant also shared that they felt the themes represented their experiences, however they also suggested some further considerations of the language used, for example, naming misogynoir within the themes to be more specific when speaking to racial and gender discrimination. The language change was considered, including thinking about how well this concept appeared to represent all the participants' experiences. This feedback was used to shape the final subtheme, "Misogynoir within healthcare", which is discussed in detail within the findings section.

During the interview, some participants organically expressed views on dissemination, and there was an opportunity to gather some of their suggestions on ways to do this, for example, suggestions of relevant organisations that would be interested in hearing about and sharing the research.

3.4.1 Reflection

Considering the power dynamic within the research, it felt important for participants to be offered the opportunity to be part of the member-checking process. One of the main purposes of member checking is to empower participants (Goldblatt et al., 2011). However, when deciding to use member checking, I was aware of the possible negative impact, for example, potential distress for participants when confronted with their narrative from the 'outside' (Hagens et al., 2009). On the other hand, I wanted participants to have the opportunity to have their voices heard throughout the research process. This was particularly important to me because research has highlighted that individuals with endometriosis can experience being dismissed, disbelieved and ignored by professionals (e.g. Cox et al., 2003). As an outsider researcher, I was also aware of the potential for member checking to reduce gaps in cultural understanding (Levitt, 2021). I felt, on balance, that it would be appropriate to discuss with participants and offer the opportunity. When I asked participants whether they would like to be involved in member-checking, they all confirmed that they would be interested in it and showed enthusiasm for this. I hoped the decision to include member-checking as part of the research would continue to minimise the power imbalance inherent in the research process, as well as develop the findings.

I noticed that some participants opened the discussion on dissemination and chose to share some ideas with me regarding this at the interview. I interpreted this as a wish to take an active role in the research and to take ownership of their experiences. I responded with gratitude and equal enthusiasm.

3.5 Expert by Experience (EbE) Consultation

It was important to involve EbEs in developing the study design, particularly due to my outsider position as a researcher and ensuring that the aims and materials were appropriate. Drawing on Arnstein's (1969) ladder of participation, the best way to describe EbE participation in this study is ‘consultation’. As part of the research process, I engaged in consultation with two charities that are involved in supporting individuals with endometriosis in the UK.

EbE views and feedback were sought on the research question and design, including all the study materials, recruitment methods, survey questions and interview schedule. This work was done through one-off meetings, telephone conversations, and emails with individuals from the two endometriosis charities. At least one of these individuals also had a diagnosis of endometriosis and identified as a woman from an ethnic minoritised background, so they were able to draw on their personal experience as well as their experience of supporting others with the condition through the charity. Their insight was valuable to developing the project, and their input will be discussed in other sections of the methodology. Reimbursement for their time and effort was discussed, and all agreed that this would be done by sharing the findings with the charities once the study is completed.

3.6 Recruitment

A purposive sampling method was chosen, using an inclusion/exclusion criterion (see Table 8) to ensure that the participants possessed the characteristics required to explore the research question. The sample was selected to be homogeneous, using the criteria below, which fits with IPA methodology (Smith et al., 2022). The aim of having a homogenous sample informed the exclusion criteria, including the exclusion of those who do not identify as female or whose gender identity does not match the biological sex they were assigned at birth. As discussed in the introduction, there is some research to suggest that transgender men may have unique challenges in reaching a diagnosis (Vallee et al., 2023) so their experiences may significantly differ.

Table 8

Participant Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
The individual identifies as both Black and female The individual's gender identity (i.e. female) matches the biological sex they were assigned at birth The individual has a confirmed diagnosis of endometriosis by surgery and received this in the UK. The individual may have received the diagnosis within the NHS or privately but will have accessed NHS services at least once (this could be an in-person/virtual/telephone appointment) regarding their endometriosis during the diagnosis process. This appointment could	Those who do not have a confirmed diagnosis of endometriosis via surgery Those who do not speak English fluently Those who did not receive their diagnosis within the UK. Those who have not had at least one appointment within the NHS in regard to their endometriosis during the diagnosis process The person does not identify as Black The person does not identify as female, and/or their gender identity does not match the biological sex they were assigned at birth Anyone under the age of 18

have been within primary care or with a specialist. The individual speaks English fluently. The individual is a current UK resident. The individual is over 18 years old	

Initially, needing the diagnosis to be confirmed by laparoscopic surgery was included as part of the criteria, which was altered to having a confirmed diagnosis by “surgery”. The initial criteria were developed based on laparoscopy being the standard method to definitively diagnose endometriosis (Endometriosis UK, 2012; Mettler et al., 2003). A decision was made to alter this criterion after a participant expressed an interest in taking part, however they had their diagnosis confirmed by open surgery. As the rationale for the criteria had been to ensure all participants had a confirmed diagnosis, the criteria were amended following receiving ethical approval.

An initial survey was developed as a way of recruiting participants to interview. Due to the lack of existing research in the area with this population, the level of interest in taking part in the research and successful ways to recruit were unknown. This was discussed within the supervisory team, and the secondary supervisor, who holds clinical and research expertise in the field of women’s health, provided guidance on this. This led to the decision to use an initial survey to support recruitment for interviews by creating a way of accessing potential participants. It allowed for assessing the level of interest in being interviewed, whilst also providing some broad descriptive data which could potentially be used within future research. Participants were informed of this potential use of the data within the information sheet. Due to the small number of responses to the survey, ultimately, this idea will not come to fruition.

The first stage of recruitment was sharing the study advertisement, which included a link to the survey. This was shared on social media by the secondary supervisor, charities, and individuals involved in women's health. Participants completed the initial survey and, as part of this, indicated whether they would like to participate in an interview. The researcher contacted participants who gave their consent to be contacted about arranging an interview. Participants were informed that depending on the level of interest, not all participants may be contacted to be interviewed. After completing the survey, all participants were given the researcher's email to contact if they wished to be informed of the study's findings.

Participants were recruited between December 2023 and March 2024. After the study advert was shared, 16 individuals completed the survey, all expressing an interest in taking part in an interview. The survey was then closed. Twelve participants were contacted in total to discuss participating in an interview. Three potential participants did not respond when contacted, and one did not ultimately wish to participate due to other time commitments. Eight participants expressed their continued interest in participating in an interview, and this was subsequently arranged.

Participants were emailed an information sheet and consent form. At this stage, participants were informed that they would also receive a gift voucher as a thank-you, and the relevant UH payment form was also sent for participants to complete. The participants were also able to ask any questions they might have. The participants signed the consent forms and returned them via email.

3.7 Participant Information

As IPA is an idiographic method, IPA studies benefit from smaller samples to facilitate a focus on the individual (Smith et al., 2022). Smith and Osborn (2003) suggest that there is no *right* sample size, and this can depend on several factors, such as the researcher's commitment to individual case analysis, the richness of individual cases, and the constraints the study is being undertaken within (Smith et al., 2022). Smith et al. (2022) have recommended for professional doctorates to consider undertaking between 6-10 interviews.

Based on these guidelines, it was aimed to recruit 6-8 participants. Considering the richness of the individual accounts, a decision was made to stop the recruitment at eight participants in total.

Participant demographic information is included in Table 9; limited identifiable information is provided to ensure anonymity.

Table 9

Participant Demographic Information

Pseudonym	Age Range	Religion	Sexual Orientation	Level of Education	Length of time between experiencing initial symptoms and receiving a diagnosis of Endometriosis	Length of time between first accessing healthcare for endometriosis related symptoms and receiving a diagnosis	Satisfaction with healthcare received in relation to getting the diagnosis of endometriosis
Farah	25-34	Muslim	Heterosexual/ Straight	Doctorate e.g. PhD	13-15 years	12 years	Very dissatisfied
Chloe	25-34	Christian	Heterosexual/ Straight	University - post graduate degree	3 years	3 years	Somewhat satisfied
Laura	25-34	No religion	Bisexual	University - undergraduate degree	10 years	10 years	Neither satisfied nor dissatisfied

Megan	35-44	Christian	Heterosexual/ Straight	University - post graduate degree	21 years	9 years	Very dissatisfied
Kayla	25-34	Christian	Heterosexual/ Straight	University - undergraduate degree	1 year	1 year	Somewhat dissatisfied
Sumaira	25-34	Muslim	-	University - undergraduate degree	11 years	8 years	Very dissatisfied
Vanessa	35-44	Mixed Faith	Bisexual	Doctorate e.g. PhD	26 years	26 years	Very dissatisfied
Alicia	25-34	Christian	Heterosexual/ Straight	University - undergraduate degree	12 years	9 years	Neither satisfied nor dissatisfied

3.8 Data Collection

3.8.1 Development of Initial Survey

In addition to assessing the level of interest and providing access to participants, an initial survey was also used so that participant demographic information was already collected before the interview. This avoided collecting this data at the beginning using closed questions, which may have potentially set the tone of the interview and led the participant to speak less freely. It also meant that eligibility was already confirmed before the interview was arranged.

A draft survey was developed and shared with the EbEs. Feedback was received and additional questions were added as part of this feedback, for example, a question was added asking whether anyone else in their family had a diagnosis (see Appendix I for final survey questions). The survey was created on Microsoft Forms.

3.8.2 Development of Interviews

Semi-structured interviews were chosen as the data collection method as this would allow for collecting rich data as IPA requires (Smith et al., 2022). Smith et al. (2022) describe *rich data* as being generated through participants being “granted the opportunity to tell their stories, to speak freely and reflectively, and to develop their ideas and express their concerns at some length” (p. 53). Semi-structured interviews also allow for flexibility and responsiveness to the participant experience, particularly concerning unexpected issues which may arise (Pietkiewicz & Smith, 2014).

The interview schedule was developed by considering appropriate guidelines and questions for research using IPA methodology (Smith et al., 2022), relevant existing research, and consulting with the supervisory team. Once an initial draft schedule was completed, it was also shared with EbEs, who did not suggest any changes. See Appendix M for the interview schedule.

The interview schedule was piloted with the first participant because of time constraints. This interview was discussed with the principal research supervisor, and it was agreed that no changes to the interview schedule were needed. As there were no changes to the interview schedule and it was felt that the participant was able to speak about their experiences in depth, the data from the first interview formed part of the final data set with the participant's consent. The interview schedule continued to be discussed as a supervisory team as the interviews progressed.

3.8.3 Reflection

As the interviews progressed, I considered how the experiences of racism/discrimination were being mentioned or talked about by participants. This was prompted by my own concerns that there may be barriers for participants and shaped by my own expectations of how much I thought these topics would be discussed. I continued to be very aware of my own visible identity, being a white healthcare professional/researcher, and how this may shape what the participants spoke about within the interviews. I discussed this within supervisory meetings and thought about whether I needed to change the interview schedule to include an explicit question asking about these experiences. This had been something I had thought about when initially developing the interview schedule, however as my research question was not interested in these experiences specifically, I decided not to include this in case it became leading for the participant. Instead, I named these experiences within the information sheet and at the beginning of the interviews. I ultimately made the decision not to change the *interview schedule as, on reflection, participants had been describing these issues but not always explicitly naming such experiences as racism or discrimination. I thought about my role as a researcher in interpreting these experiences and remaining mindful of my role in this process and the implications this would have for the findings produced.*

3.8.4 Data Collection Procedure

All participants chose to meet online, and the platform MS Teams was used. At the start of each interview, I reminded participants that they did not have to answer all the questions and could choose what to speak about during the interview. I also reminded the participants of their right to withdraw without giving a reason. The potential for some topics to cause distress and what would happen if this was the case was discussed, including how the participant may signal their distress and different options we might have if that was the case e.g. taking a break or ending the interview. No participants chose to take a break during their interview. Where required, the researcher offered check-ins and support to the participant and followed the risk management protocol. Contact with the research supervisors was regular and ongoing whilst the interviews were being undertaken to reflect on the interviews and discuss any issues.

The interviews lasted between an hour and an hour and forty-five minutes. At the end of the interview, a verbal debrief was provided, and participants were able to ask questions. Participants were then emailed a £10 gift voucher.

3.9 Data Analysis

Data was analysed following IPA methodology as guided by Smith et al. (2022). See Table 10 for the steps taken. All the analysis was completed electronically using Microsoft Word. Appendix N includes part of an analysed transcript as an example. Steps 3-5 were not always completed entirely linearly, and earlier stages in the analysis, including re-reading the transcripts, were returned to as the analysis progressed.

Table 10

Steps Undertaken for Data Analysis

Step of the Analysis	Summary of the process
Step 1 - Starting with the first case, reading and re-reading the transcript	This involved the researcher immersing themselves in the data through listening to the audio-recording and reading and re-reading the transcript. This included recording some initial observations of the transcript and a timeline of the interview (see Appendix O for an example) which were returned to in the later stages of analysis.
Step 2 – Exploratory Noting	Next comments were made in the exploratory notes column next to the transcript. This step aims to further familiarity with the transcript whilst identifying ways that the participant talks about and understands their experiences. Notes took at times a more phenomenological focus, staying closer to the explicit meaning of the participant, and at others moved to a more interpretative focus, to make sense of the patterns of

	meaning within the account. The process ultimately resulted in a combination of notes which were descriptive, linguistic, and conceptual in nature.
Step 3 – Constructing Experiential Statements	Experiential statements were developed to reflect the key features of the exploratory notes. They were developed by taking into consideration discrete chunks of the transcript. These statements related directly to the participants experience and how they made sense of this. These were noted in a further column alongside the transcript and the exploratory notes.
Step 4 – Searching for Connections Across Experiential Statements	To facilitate this step, all of the experiential statements from the transcript were added to a document in columns across the page. This made it easier to view more of the experiential statements at once and facilitated a new way of looking at the data rather than remaining in the chronology of the interview. Connections between the statements were searched for and were colour coded to reflect initial clusters of connection. This process was lengthy as statements and clusters were moved around to work towards the final personal experiential themes. At this stage some statements were discarded which were not relevant to the research question and did not connect with the clusters of statements.
Step 5 – Naming and organising the personal experiential themes (PETs)	The clusters of statements were then named to reflect their characteristics and organised

	in a table, resulting in a table of PETs (see Appendix P for example table for one participant). Subthemes were created within PETs where these best explained and organised the data in the PET.
Step 6- Repeating steps 1-5 for the remaining transcripts	The steps were repeated for each transcript, resulting in each having its own set of experiential statements and PETs. Steps 1-5 were fully completed for one transcript at a time to attempt to ensure that the idiosyncrasy of each remained the central focus of the analysis at this stage. Although as the analysis progressed the researcher will be influenced by the previous data, bracketing was utilised which was supported by the use of a reflective diary.
Step 7 – Developing Group Experiential Themes (GETs) Across Cases	Patterns of similarities and differences between the PETs were identified to develop GETs which represent the group of participants. This was done by creating a document with all the PETs and subthemes (colour coded to represent each participant) and moving these themes and subthemes around to create initial clusters which developed into the final GETs. The GETs aimed to reflect the shared and unique experiences of the participants experiences. There were some instances of a subtheme of a PET from a particular participant not fitting within a developing GET. Following the guidance by Smith et al (2022), here the subtheme was moved into another GET where there was a better fit. Subthemes

	within the GETs were developed where these best explained the data within the GET. GETs were further refined through discussion with the supervisory team (the peer validation process is discussed below) and the member-checking process. The final table of GETs is presented in Table 12 in the results section.

3.9.1 Peer Validation Process

In addition to discussions throughout the analysis with the supervisory team, the supervisory team also formally reviewed aspects of the analysis. The supervisors reviewed the GETs alongside all stages of analysis for two transcripts and the individual PETs for the remainder of the transcripts. Feedback was given on the names of the themes, for example, making the theme names more concise to ensure they clearly represented the participants’ experiences. Following this, the themes were shared with the participants as part of the member-checking process, and the final GETs were developed.

3.10 Quality Assessment of Current Study

Yardley’s (2000) criteria for evaluating the quality of qualitative research were used to assess the quality of the current study. This set of criteria was adopted due to it being recommended as a useful framework within which to evaluate and demonstrate the validity of IPA research (Hefferon & Gil-Rodriguez, 2011). Yardley (2000) proposed the following criteria to consider when assessing the quality of qualitative research: sensitivity to context, commitment and rigour, transparency and coherence, impact and importance. Table 11 provides an overview of the evaluation of the quality of the current study.

Table 11

Overview of the Evaluation of Quality of Current Study

Criteria to Assess Quality Based on Yardley (2000)	How the Current Study has Addressed Each Criterion
Sensitivity to Context	Yardley (2000) suggests that awareness of and extensive grounding in the relevant literature and existing research on the topic area, and the philosophy of the approach adopted are forms that 'sensitivity to context' can take in qualitative research. This is to support the researcher in developing a more in-depth analysis. Qualitative research can also demonstrate 'sensitivity to context' through holding an awareness of the socio-cultural setting of the study. In this study, sensitivity to context was addressed by: • As part of the development of this research, a review of the literature exploring Black women's experiences of healthcare more broadly, including undertaking a systematic literature review on their experiences of maternity care in the UK, was undertaken. The researcher also engaged with the literature around the history of gynaecology and its

	relationship with Black women and slavery. • The role of historical and socio-cultural contexts and how these contexts shape participant sense making of their experiences was considered. This was done by the researcher exploring the historical context of endometriosis and gynaecology for example. The role of such contexts in the participants' interpretation of their experiences was further considered within the analysis, for example, ultimately the subtheme "Societal and cultural beliefs about women's reproductive health" was developed.
Commitment and Rigour	According to Yardley (2000), commitment can include prolonged engagement with the topic, development of competence in the methods used and immersion in the data. Commitment was addressed in this study by: • As well as exploring the relevant empirical literature, the researcher engaged with online blogs and social media accounts where Black women have documented their experiences. • The researcher participated in teaching and peer groups to discuss the IPA methodology through the interview and analysis process.

	• As part of the analysis process the researcher immersed themselves in the data for each case and actively engaged in reflexivity. Yardley (2000) states that rigour refers to the resulting completeness of the data collection and analysis. Rigour was addressed by: • Recruitment was continued to eight participants to ensure the data collected was sufficient for a comprehensive analysis. • Using the framework for IPA by Smith et al. (2022) supported an in-depth analysis by providing clear guidance on ways to achieve this. • Peer validation of the analysis by the research supervisors was also used which is advocated by Smith (2011) as part of validity checks. • Member-checking was also used to attempt to reduce gaps in cultural understanding (Levitt, 2021) and minimise researcher bias within the analysis. Although, the impact of member-checking in this study may be ultimately limited due to minimal responses received from participants.
Transparency and coherence	Yardley (2000) suggests that coherence can describe the level of fit between the research question, the philosophical stance taken, and

the methodology used. In this study coherence was considered by:

- Thought was given to the methodology chosen and epistemological and ontological assumptions underpinning the research. Critical realism and IPA align in that they share a broadly realist ontology (Reid et al., 2005). The research question also makes such assumptions regarding ontology, assuming that there is a ‘real’ experience of Black women to explore and understand.

Regarding ‘transparency’ the research process and decision-making within this process have been detailed. The themes have been described and supported using participants’ quotes to give some insight into how these were developed from the original transcripts. Reflexivity was important to notice how the researcher’s assumptions, understandings and actions influenced the research process. Through the process, the researcher considered how their own intersecting identities have shaped their understandings and decision-making. Engaging in a reflective diary (see Appendix A for an example entry) and having reflexive conversations with the supervisory team and peers supported with ‘bracketing’ by making assumptions and understandings more conscious to the researcher.

Impact and importance	This research is exploring a novel area and aims to produce an in-depth analysis using a small sample, rather than making generalisations from a large, representative sample. It is hoped that this in-depth analysis will provide new and useful insights into a complex experience where little empirical research exists and can suggest recommendations for further research.

4. Results

4.1 Overview

This section presents the findings from the analysis of eight interviews with women who identify as Black and have experienced getting the diagnosis of endometriosis in the UK. Pseudonyms are used throughout to ensure confidentiality.

Four group experiential themes (GETs) with supporting subthemes were constructed (see Table 12 for an overview). These themes will now be described, including verbatim quotes from the interview transcripts. The findings presented here offer one interpretation of how Black women make sense of their diagnosis experience. As discussed in more detail in the methodology section, IPA involves a ‘double hermeneutic’, and therefore, these findings are an attempt by the researcher to interpret the participant’s interpretation of their experiences. The reader will also play a role in this sense-making by interpreting these findings when reading (Smith et al., 2022). Taking a critical realist position, all involved will approach this sense-making influenced by their contexts, offering different possibilities for interpretation.

IPA also takes an idiographic approach, and the findings aim to present uniqueness and nuances within individual accounts as well as the similarities and differences between participants. When developing the GETs, decisions were made about the inclusion of the final GETs by the researcher, supported by the feedback of the research supervisors and two participants through the member-checking process. Decision-making by the researcher on the inclusion of themes focused on relevance to the research question and considering the significance of the theme within the participants’ accounts. The significance of a theme was judged by how many accounts it appeared in, as well as by whether it reflected a prominent concern within a smaller subset of participants, as guided by Smith et al. (2022).

Four GETs were developed through the analysis. A full table of GETs including supporting experiential statements and verbatim quotes is included in Appendix Q. Appendix R includes a table showing how each participant is represented within the GETs and the subthemes.

4.1.1 Reflection

The analysis became the lengthiest part of the research, beyond what I expected. I recognised some of the challenges I was feeling as an outsider researcher… I felt under pressure to want to "get it right", whilst being aware of my position as an 'outsider researcher' and the limitations of my own interpretation of the participants' experiences. This created some tension for me whilst completing the analysis. I recognised the importance of reflexivity which supported me with bracketing and noticing assumptions.

An example was when I was engaging in a reflective diary entry following an interview. I was reflecting on the significance and meaning of a participant's comments on a family member's healthcare experiences, which I initially viewed as having limited relevance to the research question. However, on reflection and through conversations with the supervisory team I considered how my Western individualistic background was shaping my perspectives. I actively wanted to remain curious to the participant's account and open to noticing my assumptions throughout the analysis, although this was a time-consuming part of the research.

Table 12

Overview of GETs and Subthemes

GET	Subthemes
The Diagnosis Journey Was a Battle	Fighting for care Being dismissed and undermined by healthcare professionals Positive Experiences within healthcare are an exception not the norm Living with symptoms
Navigating Stigma and Discrimination	Misogynoir within healthcare Societal and cultural beliefs about women's reproductive health
The Diagnosis Is a Double-Edged Sword	Making meaning of the diagnosis Understanding endometriosis Hope for treatment Access to support networks
Finding Ways to Survive Post-Diagnosis	Ongoing battle with endometriosis Adjustment and acceptance Finding ways to regain control

4.2 GET 1: The Diagnosis Journey Was a Battle

This GET captures the participants' experiences of having to "battle" within the healthcare system to get the help they needed to understand their symptoms and ultimately get the diagnosis of endometriosis. Some participants also described having to "battle" with their symptoms, which had taken over their lives during this "fight" to get a diagnosis.

The four subthemes, “Fighting for care”, “Being dismissed and undermined by healthcare professionals”, “Positive Experiences within healthcare are an exception not the norm”, and “Battling to live life with endometriosis symptoms” are discussed.

4.2.1 Subtheme: Fighting for care

This subtheme describes participants’ experiences of getting the healthcare they required for their symptoms. Many participants discussed having a challenging experience getting the care they required, and some participants described this as a “battle” or a “fight”. Many participants discussed wanting to understand their symptoms and having to “fight” for further investigations was part of the “battle”:

> *“So I went to the GP and said could I have an MRI and they were like, no, you can't, erm there's nothing wrong. I said, there is something wrong, I said I've gushed through and I nearly fainted, so they reluctantly sent me for an MRI” (Megan)*

> *“I think like, the way it's built up with Endo because you know you have to fight for a diagnosis” (Sumaira)*

Most participants discussed having many appointments with a GP and in some cases, being seen in A&E and private healthcare settings before having their symptoms referred for further investigation within gynaecology or at an endometriosis specialist centre. Some participants described healthcare professionals opposing their wishes for further investigation, which delayed their diagnosis and care. This was viewed as healthcare professionals being reluctant or resistant to supporting them and something they were required to “fight” against:

> *“So it was, different because you see all these other doctors and they're trying to like push and push and push the opposite direction, like stopping you.” (Alicia)*

Many participants spoke about the labour they undertook to receive help for their symptoms. For many participants, this was described as advocating for themselves, which was required to get help within the NHS. For these participants, advocating for themselves involved preparing for their appointments in advance, including doing their research to support them within their healthcare encounters:

"I did actually some more research on endometriosis again and I I saw somewhere, something about specialist centre for endometriosis so I went to my GP and I requested to be referred to a specialist Centre for endometriosis." (Laura)

Some participants described advocating for themselves within their healthcare appointments as positive and successful. Some described feeling empowered by advocating for themselves:

"And if people try to intimidate me, it just makes me more confident because I'm like, I'm gonna push back on this. Erm you, you know, you can't make me feel small, You can't gaslight me." (Alicia)

Others described advocating for themselves as a more difficult experience where they experienced some discomfort. For Vanessa, thoughts of how she would be perceived by others had shaped this feeling of uncomfortableness and prevented her from advocating for herself in the past:

"I'm not the kind of personality that would have done that because I would have felt like I'm making a nuisance of myself and being hysterical." (Vanessa)

For some participants, advocating for themselves was not viewed as a positive, but experienced as an additional burden for them to have to navigate whilst managing their symptoms and other challenges in their lives:

"It was a lot, and then I think to also, to not have the diagnosis and then to also be constantly battling to be believed for the diagnosis. It was just, it was honestly exhausting…" (Sumaira)

A small number of participants described considering the doctor they saw for their symptoms, including accessing private healthcare. One participant discussed choosing a GP based on their specialist interest in women's reproductive health. A small number of other participants spoke about their awareness of being able to seek a second opinion. One participant spoke about seeing multiple GPs until they could find one who they felt listened to their concerns. Some participants spoke of bringing the results of investigations carried out within private healthcare to subsequent appointments within the NHS as another way to fight for their care:

"…ended up paying privately to get a whole bunch of other you know MRI diagnostics done and then taking them to my GP insisting on blood tests…' (Vanessa)

4.2.2 Subtheme: Being dismissed and undermined by healthcare professionals

All participants described difficult encounters with healthcare professionals where they felt dismissed. This dismissal occurred both within primary and secondary care settings and formed a central component of the "battle", as it prevented participants from getting the care they required. In primary care, some perceived the reluctance or resistance by healthcare professionals to facilitate further investigation for their symptoms as a dismissal:

“*Yeah, I know it was very, very frustrating because again, you feel dismissed. You're given different types of medications to try, but it's not, I didn't feel like my condition was looked into the way that it should have been looked into, erm, you know I wasn't given the right test and things like that.” (Kayla)*

Other participants described having their pain dismissed by healthcare professionals. For Farah, this was experienced in an encounter with a Gynaecologist after being referred by her GP:

“And there was this moment that you're feeling this pain, you know it is real, but actually it's somebody said to you, we looked at your inside and it's-we don't know what you're talking about.” (Farah)

For Alicia, her pain was not acknowledged by her GP when requesting to have a hysterectomy, where she experienced a hypothetical future partner’s wishes being prioritised before her own:

“I remember them saying, like, you know what if my future husband wanted kids or something like that and like so, I'm gonna have to suffer with all this pain for a a theoretical man, for whoever, like down the line.” (Alicia)

For Sumaira, dismissal came in the form of being told that her symptoms had a psychological cause when she first attended A&E for her symptoms at a young age. Sumaira understood this as being told that the severe pain she was experiencing was not real:

“So she's clearly just, like depressed or something. And the pain she's experiencing is a result of that rather than, erm, yeah, rather than, how like the actual-like nothing is wrong with her…” (Sumaira)

For Farah, these experiences of dismissal were unexpected and led her to re-evaluate her sense of self:

"It's one of these experiences where you hear people feel dismissed and complain about their experiences within the healthcare systems. And I've never had that, It-it was that disbelief that is this actually this just happened to me, I felt so-I guess there's that feeling of violated. It's like this is happening to me like this is something that happens, but it happens to other people." (Farah)

For many participants, being dismissed by healthcare professionals happened repeatedly during the diagnosis process. The experiences appeared to have an accumulative effect which impacted the participants' relationships with the NHS. The impact is described by Sumaira when she is eventually given her diagnosis but finds it difficult to believe due to feelings of mistrust:

"But I remember feeling like, I've been so gaslit by everyone I was speaking to, that even I was like, do I have endometriosis? Like is it, is this true? Like what if this is not real?" (Sumaira)

Some participants recognised a power imbalance between themselves and the healthcare professional, which contributed to their experience of being dismissed:

"From being dismissed, by healthcare professionals that have trained, you know, to know things about health, so they must be right." (Laura)

Some participants also described their experience of dismissal as being *gaslit*:

"I feel like you've been gaslit because they wanna throw these things at you rather than giving you the option of having a proper endo specialist taking like, taking your kind of like notes, your background, your history, and then communicate with you or send you for a diagnostic surgery." (Megan)

For Vanessa, experiencing being gaslit led to her own dismissal of her symptoms as a way of coping with her limited power within the healthcare system to change her experiences:

"...but you were kind of gaslit and it's just told it's normal and you minimised it." (Vanessa)

For some participants, experiences of repeated dismissal led to increased emotional distress and feeling unworthy of accessing healthcare:

"Yeah. At the time, it was just a lot of negative thoughts. Again, anxiety. I wouldn't say like suicidal thoughts, but it's just thoughts like I'm not worthy. You know, I'm not being listened to like I'm just feeling dismissed at every point." (Kayla)

These experiences of dismissal were described by some participants as having a lasting impact, and leading to them limiting their interactions with NHS healthcare post-diagnosis:

"...it made me that experience with that, said gynaecologist really made me not want to associate, not want to seek any umm, when it comes to my gynaecology health in the NHS like now thinking about doing it privately." (Farah)

"And now I think that my interactions with the healthcare system are very minimal because I just don't want to deal with that level of violence." (Sumaira)

Sumaira went on to describe her experiences of interactions with healthcare professionals as being traumatic, which presents as an ongoing fear of accessing medical care:

"Erm so yeah, overall my interactions with the healthcare system are pretty crap. I think I have a lot of like trauma around…that, like I have a lot of fear going into hospital still…" (Sumaira)

For one participant, Chloe, healthcare interactions were described as largely positive. However, even within positive encounters, interactions were nuanced and could still feel implicitly dismissive. When Chloe was given her diagnosis, she described feeling dismissed by the Gynaecologist when they did not provide any explanation or information on endometriosis, portraying endometriosis as not being worth their time:

"And to be honest, my gynaecologist wasn't great cause he just said Google it (laughs) and I was like, what is it? He said Google it, so I thought alright, OK. But he was like I can see a lot on your MRI scan you must be in horrible pain…" (Chloe)

4.2.3 Subtheme: Positive Experiences within healthcare are an exception not the norm

Most participants discussed having at least one positive experience within their healthcare encounters in relation to getting their diagnosis. For Chloe, both the GP's words and actions left her feeling cared for and valued:

"…she really, really sounded like she cared about what was going on with me, and she was just like, you need to be seen. And so, you know, she-I think she might pushed it as an emergency." (Chloe)

Positive experiences were often described as turning points or significant moments and were associated with progression towards getting the diagnosis and feelings of relief:

"and yeah, that's where things turned around for me in terms of getting to a diagnosis." (Kayla)

"Yeah it felt great because I was like, yeah, finally, like someone's hearing me someone's like on this journey with me, someone's trying to help me get things done." (Alicia)

For Laura, being referred to a Specialist Endometriosis Centre was described as life-changing, highlighting the impact of her experience of the care at the specialist centre:

"It was a really, really positive appointment, being referred to this place erm that changed my life." (Laura)

These positive experiences appeared unexpected in the context of mostly negative experiences of healthcare. Farah referred to herself as "lucky" to get the diagnosis and to have culturally sensitive healthcare from her GP:

"…I have always been lucky in healthcare because my GP is very-she's we we in London we grew up in a very culturally diverse um area so my GP was quite lovely…" (Farah)

For Vanessa, having a positive experience in hospital whilst undertaking her surgery was significant, but highlighted the lack of continuity in her care and how these positive experiences were not the norm:

"So I I don't, you know, I see it as one tiny fragmented piece of care in a much bigger picture where there's no continuity." (Vanessa)

Positive experiences with their surgical team appeared particularly important to some participants due to feelings of vulnerability experienced around having the surgery. Although not significant for all participants, some felt relieved at having healthcare professionals that represented their gender and race, as this was felt to support understanding and facilitate safety:

"So I've just had the one surgery and I was really relieved that actually the entire team were black and brown and they were all women." (Sumaira, p. 22)

4.2.4 Subtheme: Living with symptoms

Living with symptoms appeared to be another battle for participants during the diagnosis process. Participants described their struggles with living their lives as they wished, whilst their symptoms created barriers to them doing so. For many participants, there were several years between the start of their symptoms and getting the diagnosis. Some discussed times pre-diagnosis where their symptoms significantly impacted their functioning day to day:

"I would be in my bed for days with-It's not even fatigue like I would just be, you know, almost vegetative state" (Laura)

Alicia spoke of a sense of loss of control and powerlessness due to the difficulties she experienced with her periods, which caused her significant distress:

"And I would just kind of just get beside myself and get really upset about it and just be like, I don't wanna have to go through this, I don't wanna do it, I don't wanna do it. And then you going through it and it's just I can't do anything…" (Alicia)

Alicia additionally described a heightened awareness of her pain and subsequent anxiety due to worrying about how much pain she would be in:

"Because the pain was just I, my anxiety would be so bad when I knew that my period was coming because I knew the pain that I would be in." (Alicia)

Kayla also described emotional distress in the form of anxiety and panic attacks. For Kayla, worries about experiencing her symptoms around others prevented her from socialising:

> *"…I was having panic attacks at one point because I was so afraid to go into work or go into social settings with people and then, you know, have, like, an accident of like, you know, period my period starting and how heavy I would bleed or the pain…" (Kayla)*

For all participants, living with ongoing pain had been a significant part of their experience of endometriosis and, thus, part of the process of getting a diagnosis. Some participants discussed a struggle with their pain whilst trying to live their lives:

> *"So I was really pushing myself to do things like go for walks, exercise and whatnot. Erm but it was also difficult to do those things. So it was that push and pull that was constantly going on for me." (Farah)*

4.3 GET 2: Navigating Stigma and Discrimination

This GET captures the discrimination and stigma which many participants described as a difficult part of their experience of getting the diagnosis, including how these experiences influenced their access to and experience of healthcare for their symptoms. The two subthemes, "Misogynoir within healthcare" and "Societal and cultural beliefs about women's reproductive health", are discussed.

Most participants described their experiences of healthcare in relation to their identity as Black women, including their experiences of both racial and gender discrimination within their care. This appeared to reflect their experience of the combined force of anti-Black racism and misogyny, which has been defined as *misogynoir* (Bailey, 2010). Some participants also acknowledged how societal and cultural narratives around women's reproductive health shaped their experience, including how their awareness of stigma around female reproductive health made it more difficult to talk about their symptoms.

4.3.1 Subtheme: Misogynoir within healthcare

Most of the participants discussed experiencing barriers and challenges when navigating healthcare in relation to their Black female identities. Not all participants named racism or misogyny explicitly, but many made connections between their identities as Black women (as well as other aspects of their identities, such as class and sexuality) and the discrimination and negative experiences they had:

> *"And for me, having people overlook what I'm saying and undermine me, and I do think sometimes it was because of being a black woman, I do think sometimes it was because being like a working-class black woman as well…" (Megan)*

Sumaira discussed her experiences of misogynoir where she felt that healthcare professionals were unable to perceive her as someone who could be in pain and, consequently, was denied her 'fragility'. Sumaira described feeling dehumanised and being denied care as a consequence:

> *"…but I think when you actually sit there and you think about it, like being denied care, like being seen as not vulnerable when you are literally in horrific levels of pain. Umm, I think, I think it's just a really, really dehumanising experience, to be honest." (Sumaira)*

> *"Like I'm in excruciating levels of pain sometimes, and I think not being afforded that vulnerability and the vulnerability that, you know, white girls would get, I think is really hard to come to terms with because you're just like, it doesn't really matter what I do or how I*

> *present or how I talk or how little I talk. You're always going to see me as someone who is beyond experiencing pain.” (Sumaira)*

Some participants made comparisons between the care received by their White family or friends and their own, and the differences noticed highlighted how whiteness had shaped their experiences alongside racism:

> *“Erm but when my partner would speak up for me and say no, she's actually in pain, you need to do something, then something would happen, then I would be, you know, given the drip to just rehydrate me, but when it was me talking and then I was just not be, nothing would happen. Nothing more. Maybe on the fact that it's a man's, maybe on the fact that he's a white man as well…” (Laura)*

> *“And yeah, I think that that it's frustrating, like I know that my white friends are-they have also had a tough time with their diagnosis, but I know that they've never had to experience the level of kind of yeah, difficulty I guess that I have, and I think that hearing things like that, definitely made me very frustrated at the time and I was of just like ohh, OK like how come your pain is valid and but mine isn't?” (Sumaira)*

For Alicia, misogynoir meant that she would need to continue to chase up her healthcare beyond her diagnosis due to concerns that her care will not be a priority in comparison to a White person:

> *“I'm gonna be, you know, following up with the doctors about when I'm gonna get this gynaecologist appointment, Have-did you actually put it through? Like how long am I gonna have to wait because otherwise I feel like I might get left to the wayside as opposed to somebody who's not a person of colour.” (Alicia)*

Misogynoir was also described in relation to stereotypes and societal narratives of Black women which participants discussed shaping their experiences of healthcare. Farah described feeling that the stereotype of the "strong Black woman" was imposed upon her and wondered how this shaped how healthcare professionals understood her pain:

"But, I wondered how much of my identity have influenced what she said and how she engaged with me, umm and because I was in pain, I wasn't as expressive as I am today, or as I've been so I wondered if a lot of her dismissal came from maybe some perceptions or biases that she may have had about my experience." (Farah)

Sumaira also discussed how societal narratives and expectations surrounding Black women shaped her experiences of being disbelieved and expected to tolerate greater levels of pain when getting the endometriosis diagnosis:

"I think that throughout my journey with with Endo, I've had a lot of kind of racism thrown at me in the sense of or in in the form of people not believing me, people thinking that I can tolerate pain more, people not being thorough…" (Sumaira)

Megan considered whether being strong as an expectation for Black women may lead healthcare professionals not to consider the emotional and psychological impact being dismissed may have for Black women:

"But sometimes it's the psychological stuff where you know something's wrong but no one's listening, and I think GPs really don't understand how damaging that can be, and, because there's that narrative for black women being strong or being aggressive." (Megan)

Another stereotype discussed was the "angry Black women" where a small number of participants described having to navigate this stereotype by being aware of how they may be perceived by others when advocating for their care. For these participants, having to balance standing up for themselves and not being perceived as angry or aggressive increased the burden of having to self-advocate, for example, Sumaira described:

"I think that especially for black girls like advocating for yourself and, it is so difficult when you also have to juggle the fact that you could be perceived as aggressive all the time." *(Sumaira)*

For Chloe, awareness of Black women's experiences in healthcare more broadly in society also shaped how she made sense of her own experiences of healthcare, for example, knowing statistics about the negative experiences of Black women in healthcare made her positive experiences unexpected and even more significant and meaningful:

"That really meant everything to me, honestly, I'm such a person that likes to just like, do you know there's so many statistics about black women in healthcare and how badly they're treated, and I just think just that extra just that extra care really like goes along way for me." *(Chloe)*

4.3.2 Subtheme: Societal and Cultural Beliefs about Women's Reproductive Health

Most participants described some awareness of societal and cultural beliefs around women's reproductive health and how this shaped their experience of getting the diagnosis. Some participants discussed particular beliefs about women's reproductive health, such as it being "dirty" and needing to be kept private. These beliefs seemed to be shaped by stigma associated with women's reproductive health, in particular menstruation. Participants experienced feelings of shame and an associated silence within their families and communities in relation to this stigma:

> *"…it's like I'm a Muslim woman, we don't really talk about our ovaries. Like to-not to strangers, and not to family also all the time." (Farah)*

> *"I would say maybe it's kind of it's a lot in the black community anyway because even when I started to look into it and online, I don't see any like black women creating content or information or sharing information about kind of that kind of health issues." (Chloe)*

For Chloe, this silence was highlighted to her when, after receiving her diagnosis, she was shocked to find out that others in her family also had endometriosis and that this had gone unspoken:

> *"And and this is another thing I never heard of endometriosis, but after I said I had it, I then found out that people in my family have it. My aunties and everything and and it's just like, well, no one's ever said anything." (Chloe)*

For some, the stigma and associated silence experienced had implications for if and how they accessed support for their endometriosis symptoms. For Chloe, this silence meant that it was difficult to determine that her symptoms could be due to a medical condition. Chloe understood this as a reason for why she had not accessed medical help earlier in her life:

> *"But yeah, and no one else speaks about it. I think that's the-that's the thing. No one speaks about, so you don't know what's normal, what isn't normal, or when to go to the doctor or when not?" (Chloe)*

Participants felt that this stigma existed for women more broadly within society rather than just within their community or culture:

> *"And I know it's not just culturally or my community, I think just generally women there is that sort of thing of silencing, umm, our experiences when it pertains to you like women's health" (Farah)*

Megan described a journey of becoming more confident talking about menstruation from experiencing high levels of shame around her reproductive health growing up, which prevented her from talking about her symptoms. Megan described this shame as being learnt from the negative messages in society about women's reproductive health that she was exposed to:

> *"…so for me everything was framing it in a very dirty way, that it's not nice and just horrible, so I was always embarrassed about it and never really want to talk about it. Just suffered in silence." (Megan)*

When participants did talk about their symptoms, they noticed how this stigma made them feel uncomfortable or apprehensive and shaped how they were responded to by others:

> *"But I think that often other people are still really uncomfortable talking about menstruation and I think sometimes that shows up when people are like like ohh I have endometriosis and they're just like ohh no ohh like they they they feel a level of discomfort." (Sumaira)*

Participants described navigating wanting to talk about their experiences with others whilst managing feeling exposed and concerned about how they would be perceived by others:

“Even like I remember is it March the endometriosis Awareness Month? And I like to share things on my Instagram and sometimes, like, I wonder, oh goodness am I, am I saying too much?” (Farah)

4.4 GET 3: The Diagnosis is a Double-Edged Sword

This theme captures the participants’ experiences with being given the diagnosis itself and explores four subthemes: “Making meaning of the diagnosis”, “Understanding endometriosis”, “Hope for treatment” and “Access to support networks”.

Participants wondered about the diagnosis label's usefulness and had experienced both positive and negative implications. Participants described feeling hopeful that the diagnosis would enable opportunities for treatment and improve quality of life; however, some participants discussed losing this hope soon after being diagnosed.

4.4.1 Subtheme: Making meaning of the diagnosis

All participants discussed ways of making sense of the diagnosis and a range of meanings were described. For most, the diagnosis held multiple meanings, and these meanings developed and changed over time. Nearly all participants said they had been given the diagnosis too soon after their surgery, which made it difficult to understand and remember the information provided as they were still recovering from the anaesthetic. In addition, a small number of participants had not heard of endometriosis before or were not expecting the diagnosis whilst being investigated for other gynaecological conditions, so initially, they were unsure of how to make sense of the information.

Many participants described feeling a sense of relief when they were given the diagnosis. For Alicia, this sense of relief was resulting from the diagnosis providing her with a sense of connection to others, reducing the sense of difference she had felt from experiencing her symptoms:

"I think you always kind of have that sense of relief like, oh, it's not just me. I'm not alone." (Alicia)

Many participants also described feeling relief as the diagnosis validated their experiences, restoring their self-confidence, and for that reason, felt important to them:

"I think I guess it was validation that it wasn't all in my head, and, even though like I was feeling the pain every single day, there was still that part of me that was like, what if this is the bad period, what if everyone has this?" (Sumaira)

These participants experienced the validation given by getting the diagnosis as enabling their symptoms to become *real* in the context of the ongoing dismissal that all participants had experienced within their healthcare, and for some, the self-doubt and dismissal they had engaged in themselves. However, this realness was experienced in different ways for the participants. For some, the validation provided by the diagnosis changed their relationship to their symptoms, providing them with opportunities to take different approaches to looking after themselves, which was viewed positively:

"First of all it made me think right don't push yourself that much anymore, and definitely putting myself first a bit more" (Chloe)

For Laura, this process brought up feelings of anger and frustration in relation to the sense of injustice she felt due to it taking so long for her to be diagnosed:

> *“I've lost ten years of trying to sort this out and for it to just become worse and worse and worse inside just being camouflaged with the pill treatment basically. So it was really good. But yeah, I was also angry about that, for sure.” (Laura)*

Megan also described a sense of injustice and feeling angry, but for her, this was due to the perceived unfairness she felt when receiving the diagnosis confirmed she had the condition:

> *“And I was frustrated, because, I then I took even greater care, now I still take great care, but then in particular I was like, I have done nothing to contribute to this. I know that it's not my fault, but it was very angry at the fact that I had it…” (Megan)*

Others questioned what this validation meant for them practically in terms of getting further support:

> *“Now I have some sort of external validation as good as it is, it does raise a whole set of what now?” (Vanessa)*

For other participants, getting the diagnosis was significant due to what they believed or were told it would mean for their fertility, and this also shaped how they experienced getting the diagnosis:

> *“I was really scared because I thought it was something that, you know, in terms of, like consultants telling me that pregnancy and motherhood and things like that, were not on the table for me…” (Kayla)*

Implications for their fertility were described as a concern for many participants during the diagnosis process. For some, the experience of being given the diagnosis was associated with fear and uncertainty regarding their fertility outcomes and getting the diagnosis represented a loss of control over their bodies, their future motherhood, and their sense of being a woman:

> *"…and then there is that sense of, like your womanhood of like, you know, you're you're supposed to produce. We're supposed to have-This is, this is, this is the only thing that is so like that I can do and now it's being taken away from me or possibly." (Farah)*

4.4.2 Subtheme: Understanding endometriosis

Participants described one of their hopes for having the diagnostic label as providing themselves and others with an understanding of their symptoms. Most participants discussed how getting the diagnosis had helped them understand themselves and their symptoms and, therefore for this reason, was viewed beneficially:

> *"…like you can't go to a supermarket and all of the tins haven't got labels on them cause you don't know what you're getting, do you know what I mean? Like labelling serves its purpose to some degree, and I feel like with this it did…" (Megan)*

For some participants, the diagnostic label provided an understanding of what was happening in their bodies, which supported them to be more compassionate and accepting of themselves and cope with the diagnosis:

> *"…but it's allowed me to just…Be like, OK, well, this is what it is, I know what it is, I just have to just look out for anything new that I could possibly do that's gonna help with this pain…" (Alicia)*

The participants described having the diagnosis as less helpful in supporting others in their lives to understand. For Vanessa, the diagnosis label had a mixed impact on how it facilitated understanding from others. She discussed that the understanding she had gained of her symptoms had enabled her to be able to ask for help, however, others were not always able to provide support due to the uncertainty around the diagnosis:

> *"So in some ways it's allowed me to ask for and receive support or more understanding because I have this label, but on another level, you know it makes people anxious particularly the points when you don't know and it makes probably them feel helpless…" (Vanessa)*

Other participants described a lack of understanding and awareness around the diagnosis in general society, meaning that they were then tasked with having to try and support others to understand:

> *"I need needed to talk to occupational health and really explained to them like this is not period pains. This is endometriosis. It is a condition." (Laura)*

Some participants talked about difficulties with workplaces understanding endometriosis, which meant that the diagnosis felt of limited use when trying to get the support they needed:

> *"And then when it came to my disability, they just straight up discriminated against me. They refused to do occupational health, they refused to have a meeting with me about access needs. They like straight up, refuse things that are like legal requirements." (Sumaira)*

> *"Just sitting there and trying to explain to my manager about what I was going through. It was just as if, you know my symptoms were, I was over exaggerating or how can you be in so much pain?" (Kayla)*

As described by Kayla and Sumaira above, some participants described experiencing discrimination, criticism and negative reactions from managers and colleagues both pre and post diagnosis. Due to these experiences, a small number of participants described changing jobs or finding work where they could organise their time flexibly around their symptoms to help minimise the impact on their work.

For Megan, a lack of understanding and awareness of endometriosis was also experienced within her family. Her family's attempts at supporting her at times left her feeling unheard and misunderstood, which had a significant impact on her mental health:

> *"I needed more times where she didn't come in and tell me to drink aloe Vera juice cause it's gonna cure endometriosis. There are times that she really damaged my mental health to be honest" (Megan)*

For Megan, the nature of endometriosis symptoms, such as pain being a subjective and internal experience, inhibited others from understanding her experience and exacerbated her feelings or not being heard or understood:

> *"But it it, that's what bothers me that is invisible to the naked eye, that my suffering is is hidden, to be honest." (Megan)*

4.4.3 Subtheme: Hope for treatment

Nearly all participants described a hope that getting the diagnosis would be an opportunity for them to access treatment and improve their symptoms:

> *"...and the reason I'd had hope was cause I was like, well, you know, I'm being taken seriously now, there is this endo, maybe they'll tell me what kind of keyhole surgery treatment options I can have. Maybe you know now that I'm in gynae and I've been seen, and I'm on the list it'll be dealt with..." (Vanessa)*

For some participants, finding an effective treatment for their symptoms was a journey that continued post-diagnosis. Many participants discussed side effects of hormonal and contraceptive treatments, some with severe consequences for their mental health. For Chloe, finding an effective treatment for her symptoms was challenging both mentally and physically and had a significant impact:

"…and so it impacted every aspect of my life, especially being on everything that I've been on to just manage the pain and everything so, that has been kind of the worst part of it all." (Chloe, p. 25)

Some participants described how it felt when the treatment options they had been expecting following receiving the diagnosis did not materialise:

"…And I remember just that feeling of…..I guess helplessness or or or just sadness, because I'm like you gonna discharging me because this is all we all you can do like. But so what do I now do? I just have to just continue with this pain like there's nothing else…" (Alicia)

Many participants shared these feelings of helplessness, hopelessness and sadness after their expectations for treatment were not met post-diagnosis. These feelings appeared to relate to a sense of abandonment from the healthcare system, where it was a common experience for participants to have been discharged back to their GP following their diagnostic surgery and receive little follow-up care or support from the NHS subsequently:

"So you're just kind of just left feeling like, you know, it's almost like your house is burnt down and the insurance said oh we can't give you any money for it and you're sitting on top of the of the rubble, like, what? Where do we go now? What? What next? What? What do I do? Do I just stay here? Is this where I now live?" (Alicia)

"…but I think just the whole, like, OK, we've done your surgery bye, that was quite overwhelming." (Sumaira)

For some participants, trying to obtain any treatment or medical support post-diagnosis was a challenge, and they did not find that the healthcare professionals they encountered were supportive or knowledgeable about endometriosis. For a small number of participants, the severity of their symptoms post-diagnosis had led them to attend A&E, where these participants described further difficult experiences being dismissed by healthcare professionals:

"…and they said to him I could hear it unless it's an ectopic pregnancy send her away." (Megan)

4.4.4 Subtheme: Access to support networks

Most participants described how getting the diagnosis enabled them to access endometriosis-specific support networks and groups which they were unable to pre-diagnosis. Participants discussed accessing these either in person or through online spaces. A mixture of feelings about accessing these support networks were described both within participants' individual experiences and between the participants. In the absence of further advice or support from healthcare professionals post-diagnosis, Chloe discussed reading other peoples' stories online to make sense of her own experiences, which felt un-containing and increased her uncertainty around her own future:

"And I just thought everything and I started panicking and I told my husband, I don't think we're ever going to be able to have children or anything, and I duno what's gonna happen to me…" (Chloe)

Although Chloe also described finding some aspects of what she read helpful as she was able to relate to some of the experiences, she expressed a preference for having medical professionals to discuss her symptoms with to ensure information is relevant to her own situation:

"But yeah, I would have rather heard that from a medical professional telling me, you know, don't believe everything you see online and also what the symptoms could be and what they couldn't be." (Chloe)

Sumaira discussed finding some of the support groups and information difficult to access due to its exclusionary nature for people from the Global Majority, feeling that support was still reflective of the historical myths of endometriosis being a condition that only affects White women:

"No, I think it was really hard because I think the other thing is that endometriosis is still like a very white woman's disease like you, you, you, you look on places like [organisation name removed]*, and all you see-all the information reads, all the information reads as if it was written by white women for white women and you're kind of just like, OK, what about the rest of us?" (Sumaira)*

However, Sumaira also discussed being able to find support that represented people from a diverse range of backgrounds was helpful to her:

"Like I'm part of, there's like online space called [organisation name removed] and which is all like marginalised people who have endometriosis or have gynae conditions. And I think that's been a really helpful space…" (Sumaira)

Other participants also shared that accessing support groups and networks post-diagnosis was valuable to them in providing emotional and practical support:

"…and I have two support groups and those things are insane, because you can talk about, like, the worst things ever. But they get it." (Megan)

"…and the impact it had on me was a good impact because then I was able to find help in terms of starting therapy, in terms of helping with my mental health." (Kayla)

For Kayla, getting the diagnosis was significant in supporting her to access support and being able to talk about her experiences. Talking about her experiences facilitated connection and gave her a sense of empowerment, as well as being a way to regulate her emotions relating to her symptoms and diagnosis. She described talking about her experiences through support spaces as significantly improving her mood despite her symptoms not improving:

"…I feel like when you when I spoke about my experiences and my story sharing my journey, it felt a burden, was lifted off my shoulder. Like, I felt like the dark place I was in I'm not no longer there anymore, just by speaking and sharing my story." (Kayla)

"So things like that, that was the impact, it was a good positive impact that it had on me, even though I was still suffering with the symptoms, but I just felt that my stress levels were a lot lower and I know that stress is something that was exacerbating my symptoms of endometriosis." (Kayla)

For Vanessa, the support groups also facilitated a sense of connection, which was significant for her in relation to providing her with hope for the future:

"…because it was finding other black women who've been through the same shit, that made me, it gave me hope in a way, if I'm honest, that I would not otherwise have had, you know."

(Vanessa)

4.5 GET 4: Finding Ways to Survive Post-Diagnosis

All participants chose to discuss their experiences of endometriosis post-diagnosis to some degree, highlighting the chronicity of the condition and the challenges of living with endometriosis beyond getting the diagnosis. The discussion of their lives post-diagnosis appeared to reflect how pre-diagnosis experiences relating to their healthcare and managing their symptoms continued similarly post-diagnosis. Often, participants' accounts would switch between past experiences pre-diagnosis and more recent experiences post-diagnosis interchangeably as they talked about their experiences. Some participants also recognised how post-diagnosis experiences had shaped their perceptions and feelings about their diagnostic journey.

Most participants described the process of coming to terms with having a long-term health condition as part of getting the diagnosis. This theme aims to capture how the participants experienced life after the diagnosis process in relation to some of the challenges they discussed in getting diagnosed with endometriosis and how they described continuing to navigate these.

The three subthemes 'Ongoing battle with endometriosis', 'Adjustment and acceptance' and 'Finding ways to regain control' will be discussed.

4.5.1 Subtheme: Ongoing battle with endometriosis

It appeared that for some participants, the battle with endometriosis and controlling their symptoms continued despite having the diagnosis. This seemed unexpected for some participants who were hopeful for improvements in endometriosis symptoms after receiving the diagnosis. Similar to their experience pre-diagnosis, participants seemed to describe a struggle to manage their symptoms, which impacted their day-to-day lives. For some participants, pain continued to dominate their lives. Laura spoke about how the severity of her pain continued to impact on her at work:

> *"So my pain has come back and I did the 12 hour shift and I'm just, I was, I kept hiding in the toilet during that that shift because I needed to just sit on the floor." (Laura)*

Alicia described feeling frustrated at the limitations that pain was continuing to place on her day to day:

> *"But it's yeah, it's really, I guess, more just frustration out of anything just constantly being in pain all the time. Erm as of late, I don't always get the pre period pains as much, but definitely the you know the ovulation pain and the period pains and yeah, like I can't, I can't do anything its debilitating…" (Alicia)*

For some participants, the battle with endometriosis developed post-diagnosis to a fight for their fertility and to become a mother. For Kayla, the ongoing battle with endometriosis had been regarding her wish to be a mother. She described feeling that endometriosis would not allow this to happen and was shocked when she did conceive:

> *"…I was shocked when I, you know, got pregnant because I'm just thinking this endometriosis has been really taking over my life…" (Kayla)*

However, Kayla described an ongoing battle when the endometriosis symptoms returned post-pregnancy, where she felt that endometriosis was wanting revenge:

> *"…it's just that now after two years after having my child, my endometriosis symptoms are coming back again with a vengeance." (Kayla)*

The battle with endometriosis regarding fertility and motherhood was evident for other participants, where endometriosis was described as taking control of their bodies and their abilities to have children. For Megan, endometriosis was described as physically taking control of her body, which led to her having a hysterectomy:

> *"…because the endometriosis had pulled my appendix into my vagina and I could not believe-I was like I only had the surgery in Jan, and that was by by a skilled surgeon and then this happened." (Megan)*

Along with the impact on her fertility, Megan also spoke of experiencing chronic pain due to the endometriosis. Megan spoke of her resentment towards endometriosis:

> *"I haven't had a space where I haven't felt pain, so to me, endometriosis, I just call it a wicked bitch, because that's what I feel like it is…" (Megan)*

A small number of participants described trying to manage endometriosis through having multiple surgeries post-diagnosis. The recovery period following surgery was described as challenging by some participants and reflected endometriosis's power over their lives:

> *"But the pauses, it just felt like a stop on life, literally at every point that I had to go through surgery, I felt like it was like a step back, again. I was just being pushed backwards and I wasn't able to move forward with life like live a full life because of my diagnosis." (Kayla).*

4.5.2 Subtheme: Adjustment and acceptance

Nearly all the participants discussed a process of adjustment to and acceptance of their diagnosis, and for some, this was an ongoing process at the time of the interviews. The adjustment process was described differently between the participants, where the diagnosis held different meanings and had different implications. Samaira described the process as grieving for her body's past abilities:

"I think that there's been like a lot of grief and like sadness that my body isn't able to do what it could do before. And I think that I've move through that stage, I've moved through like the angry stage." (Sumaira)

Sumaira also described the diagnosis challenging aspects of her identity, such as being 'strong', and adjusting her sense of self after the diagnosis had enabled her to see and accept a 'fragile' side to herself:

"I think if anything like this diagnosis has really reminded me of my fragility…" (Sumaira)

Being given the diagnosis for Vanessa signified the reality of having a chronic health condition and subsequently needing to adapt the way she had been responding to her symptoms:

"And also, I'm realising that this is probably not gonna be something I get a solution to very quickly or at all, or I mean or can get on with, I I seem to be much better at ignoring, through ignoring it and powering through it before I had diagnosis…" (Vanessa)

Vanessa also described going through a process of adjusting her sense of self and considering how she assimilates having a chronic health condition into her identity. This process was something she described as ongoing, and which felt difficult to process at the time:

"...you know, in a year's time or two years' time, will I say I'm a black mixed-race woman from [information removed] *who loves women and also has a chronic health condition or at-I don't know. That's the thing that I feel like is bubbling under the surface, and if I'm honest, I'm resistant to. But it is the reality." (Vanessa)*

Megan also described finding the process of understanding and accepting endometriosis to be difficult, for example, she found it difficult to understand how endometriosis could have such a physical impact. This created a sense of feeling out of control of her own body. Although feeling more accepting of her situation, this feeling was making it hard for her to make "peace" with endometriosis:

"I don't feel like I've actually made peace with endometriosis. I accept my circumstances for where they are because I'm not gonna be in denial, but I haven't made peace with it because I'm just confused by the way it moves, and how it got hold of me so aggressively because I clearly had it for so long." (Megan)

Other participants felt a sense of loss of identity from being given the diagnosis. For Kayla, when given the diagnosis and told about the likely loss of her fertility, this caused significant disruption to her sense of her future self as a "mum", and thus caused confusion around who she was in the present:

"Like, I felt robbed of my dream of becoming a mum and didn't know really where to place myself." (Kayla)

Some participants also described the ongoing uncertainty surrounding endometriosis and their future living with it, which added additional challenges to adjusting and accepting the condition. Alicia considered whether there would be an "end" to endometriosis and described worries about her future and this being unknown:

> *"So even though I'm not having a period, will I still cramp or all the other effects of menopause that I don't know about yet because I have never researched into menopause, could any of those spark that and make things worse? I have no idea." (Alicia)*

4.5.3 Subtheme: Finding ways to regain control

Despite getting the diagnosis, many of the participants described continuing to feel dismissed and undermined when accessing healthcare for endometriosis. When treatment options were discussed, some participants expressed the lack of collaborative care and a lack of choice of treatment options. Many participants described feeling pressured to agree to take contraceptives as treatment, as this was often presented as their only choice:

> *"I felt extremely pressured to have the Marina coil to the point that I was being wheeled into surgery and the doctors were like, do you wanna change your mind? And I was like, no, like it it was that, I thought, I mean, that's the side point, but I felt very pressured that that was the only treatment option for me." (Sumaira)*

Some participants expressed their preference to manage endometriosis without hormonal or contraceptive treatments. For these participants, this was a way for them to take back control of their healthcare treatment and a way to reclaim power over the body too:

> *"So er yeah, but stopping the pill meant taking control back of my body, actually discovering how I feel, how it feels to be in my body without taking hormones every day." (Laura)*

Some participants discussed their experiences of choosing to decline treatment options given to them by healthcare professionals following their diagnosis. Kayla described declining treatment as a difficult but necessary decision when she did not feel she had enough information to agree to have the coil fitted. For Kayla, declining was a way of putting herself first and protecting her body from further possible harm:

"It was very hard because, you know, the the health professional is a health professional like they've, you know, they've they're giving you the best advice, the best evidence-based advice that they can give in order to help me to manage this. But then again, advocating myself was big. It was bigger than that, erm I knew what was right for my body at the time…" (Kayla)

Not all participants felt that they were able to decline treatment options. Megan spoke of the challenges of declining the treatment offered by a healthcare professional post-diagnosis and feeling that, at times, she did not have this choice. Megan made sense of this as a consequence of the power held by the healthcare professionals:

"I was like, I don't wanna do it, be on this and she said I have to do it in order for them to see that I'm accessing their care." (Megan)

For Vanessa, although she described experiencing an ongoing sense of lack of power and control within the healthcare encounter, she continued to feel motivated to make change within the healthcare system:

"I can understand that there's a gender dynamic to it, that there's a racialised dynamic to it, but…I'm less accepting and also…….More committed to addressing it, but also not that hopeful about what will change very quickly (laughs)" (Vanessa)

Some participants also described doing their own research and finding alternative options to pharmaceutical interventions by thinking holistically about treatment, such as making changes to their diets, ensuring good sleep and managing stress levels:

> *"I didn't really want to take too many contraceptives in terms of like managing my endometriosis at the time, and I just started to change my diet. I spoke to a nutritionist at the time..." (Kayla)*

These options were viewed positively and reflected another way for participants to regain control over their bodies from healthcare professionals and endometriosis itself.

5. Discussion

This study explored Black women's experiences of getting a diagnosis of endometriosis within the UK. The following GETs were developed based on the participants' experiences:

- The diagnosis journey was a battle
- Navigating stigma and discrimination
- The diagnosis is a double-edged sword
- Finding ways to survive post-diagnosis

This section will fully discuss the findings to answer the study's research question. It will also discuss the study's strengths and limitations, as well as implications and recommendations for future research.

5.1 Overview of the Findings

Overall, the findings suggest that the experience of getting a diagnosis of endometriosis was challenging for participants. Within their healthcare, participants experienced dismissal, racism and discrimination, which had an impact on the care they received. Healthcare encounters were rarely experienced as positive, but when they were, they were often viewed as a turning point where progress was made towards reaching the diagnosis.

Participants described a "fight" with the healthcare system, and at the same time, participants also had to manage their symptoms, which were described at times as debilitating. Altogether, these negative experiences led to emotional distress and had an impact on participants' mental health. The experience of receiving the diagnosis itself appeared complex, with advantages and limitations for participants.

Stigma surrounding women’s reproductive health was identified as another difficulty which participants discussed needing to negotiate. Stigma appeared to have implications for whether participants spoke about their symptoms and who to, playing a role in shaping their experiences of accessing healthcare and support whilst getting the diagnosis.

The participants all discussed their lives post-diagnosis to some degree, which appeared to symbolise that reaching a diagnosis was not seen as an ending or resolution. Therefore, the theme ‘Finding ways to survive post-diagnosis’ felt an important part of the analysis to provide a fuller understanding of the participants’ experiences of getting a diagnosis of endometriosis.

In the next section, key findings from each GET will be discussed in further depth in relation to relevant theory, research and literature. Due to the lack of existing research in exploring Black women’s experiences of endometriosis, research exploring Black women’s healthcare experiences of other gynaecological conditions in both the US and the UK will be drawn on whilst also making links where relevant with Black women’s experiences of maternal healthcare in the UK as discussed within the systematic literature review. An exploration of how the findings of this study fit with the existing research into women’s experiences of endometriosis more broadly will also be considered.

5.2 GET 1: The Diagnosis Journey Was a Battle

The study found that all participants experienced dismissal in some form within their healthcare. This experience of dismissal appears similar to African American women’s experiences of healthcare for other gynaecological conditions and sexual pain (e.g. Carey et al., 2023; Thorpe et al., 2022; Vance, 2022).

Significantly, the current study found that some participants described their experiences of dismissal as being ‘gaslit’. The phenomenon of *gaslighting* has been defined as “a person of power psychologically manipulating another into questioning their own reality” (Durbhakula & Fortin, 2023, p. 3426). Recently, the phenomenon of *medical gaslighting* has been described as occurring within healthcare (Khan & Majeed, 2024) through the denial, dismissal and downplaying of a person’s symptoms by healthcare professionals, which leads the patient to doubt their own embodied experiences (Hoberman, 2012; Sweet, 2019).

Carter (2022) has further conceptualised *anti-Black medical gaslighting,* which, fuelled by misogynoir and medical racism, involves the symptoms and embodied experiences of Black people being given less credibility and being dismissed by healthcare professionals. These phenomena appear in line with the participants’ self-described experience of being ‘gaslit’ by healthcare professionals. These experiences may also be suggestive of epistemic injustice within NHS healthcare encounters for Black women, which has been described as appearing as medical gaslighting and resulting in patients being viewed as unreliable and not having authority over their embodied experience (Boakye et al., 2024).

The findings also highlighted the acts of opposition that participants used to challenge their experiences of dismissal, for example, doing research and preparing for their medical appointments and, in some cases, accessing private healthcare and choosing or changing GP. Participants in this study commonly described these strategies as engaging in “advocacy” for themselves. Boakye et al. (2024) also found that participants described the use of self-advocacy in their Canadian study of Black women's experiences of maternity care.

Experiencing medical gaslighting has been linked to traumatic stress and being detrimental to emotional well-being (Evans et al., 2023). In relation to being dismissed, participants described experiencing negative thoughts, feeling unworthy of care, feeling anxious, and feeling fearful of using medical care, which was reflected in their actions of avoiding NHS healthcare. One participant explicitly described their experience of healthcare interactions as being "traumatic" and fearing for her life when she received inadequate medical care. This suggests the potential threat of harm that dismissal can pose for Black women.

However, the experience of dismissal within healthcare as being emotionally distressing was not universal, with one participant reporting that experiencing "gaslighting" made her more determined and confident. The Ecological Model of Medical Trauma (Hall & Hall, 2016) suggests that individual factors play a role in shaping a person's experience of the medical encounter, and consequently, if this is experienced as traumatic, which may explain the differences in experience found in the current study.

Another key finding was that for some participants, having healthcare professionals who represented their race and gender was important in facilitating the rare positive experiences they experienced. As highlighted within the systematic review, some existing research has found a preference and appreciation for shared identities with healthcare professionals (e.g. Edge, 2008; Williams et al., 2023).

However, in this study, perceived shared identity was not found to be a significant part of all positive experiences, and participants also emphasised being listened to, taken seriously, and feeling supported. Participants highlighted the significance of healthcare professionals' actions in making them feel heard and supported, such as facilitating referrals for further investigation or spending more time than expected on appointments. Together with existing research, the finding of this study begins to provide some insight into what makes a positive healthcare encounter within obstetrical and gynaecological care for Black women in the UK.

The finding that participants also appeared to be battling to manage their symptoms appears to fit with existing research, which reports the significant impact of endometriosis symptoms on all aspects of women's lives (e.g. Culley et al., 2013; Young et al., 2015). As the studies included in these reviews focus on predominately White women's experiences, the finding in the current study provides a novel insight into the experiences of living with endometriosis symptoms for Black women within the UK.

Strategies to manage their symptoms pre-diagnosis appeared to centre on masking their symptoms, such as avoiding others/withdrawing, pushing through their pain and ignoring symptoms. It is possible that these strategies could also be a consequence of the dismissal from healthcare professionals described and, therefore, a survival strategy in the face of lack of support from the health service. This idea is supported by one participant who explicitly discussed "minimising" her symptoms in response to being "gaslit". A similar finding was discussed in the systematic literature review, where Ling et al. (2023) found Nigerian mothers described "pretending to be ok" in the presence of professionals where their postnatal care did not meet their needs and expectations.

5.3 GET 2: Navigating Stigma and Discrimination

Participants described gendered and racial discrimination, which combined in the form of misogynoir within their healthcare experiences. For some, other aspects of their identities were also considered to shape their healthcare experiences, for example, their class, sexuality and ability.

Some participants understood the dismissal of their pain by healthcare professionals as also being shaped by the professional’s expectations of them to be strong. This finding suggests the possibility of healthcare professional biases in assessing and treating Black women’s pain. This is supported by existing research that suggests that Black women may not receive adequate assessment and treatment for their pain due to such healthcare professional biases (Hoffman et al., 2016; Trawalter and Hoffman, 2015). The experience of the ‘strong black woman’ schema being imposed upon Black women and shaping whether and how they can express vulnerability has also been found in a non-health context (Rabelo et al., 2021). These findings provide novel insight into how Black women experience this schema in the context of endometriosis and getting the diagnosis.

The finding that participants were aware of stigma surrounding women’s reproductive health aligns with existing research in the UK, which has found, for example, African Caribbean women to report cultural rules of silence around menstruation (Denny et al., 2011). The current study's findings appear to show Black women engaging in ‘menstrual etiquette’ (Laws, 1992) to avoid stigmatisation. Some participants described how an awareness of negative beliefs in society regarding menstruation made it more difficult to talk about menstruation and, therefore, their endometriosis symptoms. This was experienced despite some participants explicitly naming that they did not hold these beliefs themselves.

Altogether, this suggests that Black women may experience actual and/or perceived social sanctions for discussing menstruation, which may lead them to conceal, ignore or minimise endometriosis symptoms.

5.4. GET 3: The Diagnosis is a Double-Edged Sword

Participants described a complex reaction to receiving the diagnosis itself, including feelings of relief, anger and frustration at the diagnosis process, and fear and uncertainty concerning implications for fertility and changes to their bodies. This mixed reaction appears in line with research that has explored Black women's experiences of being diagnosed with other gynaecological conditions which have potential implications for fertility, for example, PCOS (Vance, 2022). It also appears in line with existing research that has explored experiences of endometriosis more broadly (e.g. Culley et al., 2013).

For many of the participants, becoming a mother was important, and this made the diagnosis difficult to receive when there were associated implications for their fertility. Ceballo et al. (2015) found that Black women can experience racialised expectations of motherhood, where motherhood was equated with being a "good" Black woman, and participants were influenced by racial stereotypes that associate Black women with being fertile. Consequently, Black women may have to navigate multiple pressures around their fertility shaped by racialised expectations of being Black and female. Infertility may, therefore, harm their sense of self, not only as women but also as Black women (Ceballo et al., 2015).

The finding that participants experienced the diagnosis as providing a greater understanding of their bodies, which for some supported their acceptance of the condition, aligns with previous research (e.g. Mills et al., 2023). However, a key finding in this study was that the diagnosis was not found to facilitate understanding from others. The finding that participants experienced discrimination, criticism and negative reactions within their workplaces due to endometriosis both pre and post-diagnosis appeared to suggest the diagnosis label had limited usefulness.

Having experienced dismissal, discrimination and stigma, it makes sense that most participants in this study described valuing the opportunity the diagnosis gave them to connect with others living with endometriosis. Participants described therapeutic effects of accessing support networks, such as emotional support and improved mood, connection, knowledge, and empowerment. The positive experience of peer support and the associated therapeutic effects found appear comparable with previous research into women's experiences with endometriosis in the UK, US, and Europe (Marki et al., 2022; Shoebotham & Coulson, 2016), and chronic illness more broadly (e.g. Van Uden-Kraan et al., 2008). Although not directly explored within this study, the findings provide some insight into Black women's experiences of support networks for endometriosis in the UK and highlight the significance of receiving the diagnosis itself in enabling access.

In the current study, some participants also highlighted when support felt unhelpful. Support was described negatively when it did not feel representative or when it reflected only the challenges and difficulties of the condition and, therefore, increased anxiety. The Social Comparison Theory proposes that people use peer support "to evaluate themselves in relation to others to validate their thoughts, emotions, and experiences, and make positive upward social comparisons to create a sense of hope in a process of recovery or self-management" (Thompson et al., 2022, p. 9). On this basis, the participants' negative experiences of support may reflect the lack of opportunity to make such positive social comparisons within the support they were accessing. Altogether, this highlights the importance of support for people living with endometriosis, being representative of the diverse range of people living with the condition and ensuring that it portrays a range of experiences that are relatable to all.

The finding that many participants hoped getting the diagnosis would enable access to effective treatment highlighted their priorities post diagnosis of improving their symptoms and quality of life. A further key finding was that many participants spoke of the difficulties in finding an effective treatment, and some experienced a lack of support from healthcare professionals in treating endometriosis. This finding echoes the APPG report (2020), which found that women reported lack of access to, and information on, effective treatments.

The diagnosis providing hope for treatment supports existing research on experiences of endometriosis more broadly (e.g. Ballard et al., 2006; Fernley, 2021). However, this study provides a novel finding that this hope soon diminished for participants after diagnosis when adequate treatment options in line with their preferences did not materialise, which left them often feeling hopeless. It is unclear from this study whether this is a unique experience for Black women within the UK, and further research exploring Black women's experience of treatment would be beneficial.

5.5. GET 4: Finding Ways to Survive Post-Diagnosis

Participants described a process of adjustment following being diagnosed with a long-term health condition. This process included navigating challenges and losses to their physical abilities, fertility, and the impact of their experiences on their sense of self and identity. One participant discussed specifically moving through stages, such as the "sadness" and "angry stage", to reach acceptance of the self-described loss of her body's physical abilities. This experience appeared to reflect the “5 Stages” model of grieving (Kübler-Ross, 1969). Stage models of grief have been critiqued for their suggestion that grief progresses through a set of emotional and cognitive stages which has been argued to oversimplify the process of grieving and assume universality, whilst ignoring the diversity and social and cultural context of this experience (Stroebe et al., 2017).

Other models have since been developed that address these limitations, such as Tonkin’s (1996) “Growing Around Grief” model. Rather than suggesting a set path that an individual needs to complete to move on from their loss, Tonkin’s model proposes that a person learns to integrate grief into their everyday lives rather than the grieving process having a definitive ending. This conceptualisation also appears relevant to the experiences of loss described by some of the participants in the current study, where the focus on and understanding of such losses developed and changed, shaped by the participants’ broader context and coinciding life events and experiences.

Experiencing grief in relation to endometriosis and its symptoms has also been found within existing research exploring experiences of endometriosis more broadly (e.g. Hållstam et al., 2018; Sayer-Jones & Sherman, 2023). Models of grief may be useful for exploring and understanding Black women’s experiences of adjusting to a diagnosis of endometriosis within future research and for any healthcare professionals supporting Black women with endometriosis.

Notably, key differences between participants who described experiencing acceptance and those who described experiencing resistance and difficulties making “peace” with endometriosis were endometriosis's impact on fertility, the reported effectiveness of treatments/reduction in symptoms, and time since diagnosis. Taylor's (1983) cognitive theory of adjustment to threatening events proposes that a search for meaning, involving understanding why an event has occurred and its impact and implications for one's life, is a key part of the adjustment process. The theory suggests that better psychological adjustment will occur where positive meaning can be derived. This may explain why some participants described having a challenging adjustment process, as these participants also described difficulties understanding and making positive meanings of the diagnosis. The finding that the process of adjustment was experienced in different ways by the participants highlights its complexity, as well as suggesting potential challenges to and facilitators for adjustment to an endometriosis diagnosis.

Some participants described how the diagnosis and related symptoms challenged their identity of being "strong". This challenge to their expectations of themselves was not viewed negatively by participants and instead was described positively as an opportunity to allow themselves to be vulnerable and move away from conforming to the strong Black woman stereotype. This finding is in line with previous research into chronic illness more broadly, which has found that positive changes in identity can occur in the context of the illness experience (Asbring, 2001).

However, the finding does contrast with research exploring the experiences of women with endometriosis within the UK by Moore et al. (2023). They found that participants described a similar shift towards feeling more vulnerable, however in contrast, this was viewed negatively, whereas women who viewed themselves as stronger due to endometriosis felt more positive about the changes in their identity. It is noted that the sample in the Moore et al. (2023) study is predominantly White women, which may explain the difference in findings. The positives seen in becoming more vulnerable found in this study may be highlighting the unique ways endometriosis may impact on identity for Black women.

The finding that some participants at times declined medical treatment offered and sought alternative ways of managing their symptoms outside of NHS healthcare is in line with existing research into women's experiences with endometriosis more broadly (e.g. Cox et al., 2003; Young et al., 2020). These actions appeared to reflect participants seeking ways to regain control in the medical encounter by advocating for themselves and making their own choices. These actions may also reflect an important part of the adjustment process. Taylor's (1983) cognitive theory of adjustment also proposes that gaining a sense of control over the condition and/or related treatment supports coping and adjustment alongside positive meaning-making.

5.6 Strengths and Limitations

5.6.1 Strengths

The study aimed to provide insight into Black women's experiences of getting a diagnosis of endometriosis. An advantage of using the IPA methodology was that it enabled the study to deeply explore and make visible the accounts of Black women. This is the first study to date to specifically focus on Black women's experiences of being diagnosed with endometriosis in the UK and, despite the small sample, these insights can, therefore, make a meaningful contribution, including making recommendations for clinical practice and informing NHS service provision, and interventions at a societal level.

Methodological rigour was established to ensure validity and reliability, for example, through peer reviewing of the analysis and researcher reflexivity. A strength of this study was the focus on reflexivity and the researcher thoroughly engaging in noticing and 'bracketing' assumptions. The data analysis process was comprehensive and followed guidelines for conducting IPA by Smith et al. (2022). This allowed for a clear data trail from the individual accounts to the final group themes presented. The flexibility offered to participants regarding how they took part in the interview, for example, either online, by phone or in person, may have helped support participation and the rich data collection within the study as participants were able to choose to participate in the way that felt most comfortable for them.

5.6.2 Limitations

The researcher's position as a White female not living with a chronic health condition will have influenced what the participants discussed and how they discussed it. The possible limitations of 'outsider research' have already been discussed. The research was undertaken sensitively, and attempts were made to minimise the concerns regarding outsider research summarised by Bridges (2001). Some examples of these attempts included member-checking, researcher reflexivity, and remuneration.

However, the impact of the researcher's position is to some extent unknown, for example, it is unclear whether this had an impact on recruitment, such as, who did and who did not participate in the study. As many of the participants spoke about developing strategies and confidence in self-advocacy in their interviews, it is possible that the participants involved in this study felt in a position to talk to a White woman holding a position of power as a researcher and others who did not feel confident to do this could have been non-explicitly excluded from participation on this basis. Furthermore, the recruitment method was also reliant on individuals having access to the internet and technology skills to access the study advert and survey which may have also impacted on who participated.

Although the aim of this IPA study was to provide in-depth insight into Black women's experiences rather than to be generalisable, the smaller sample size could be viewed as a limitation due to this restricting the generalisability of the findings. Nevertheless, the sample was in line with the recommended sample size for an IPA study and allowed for a great amount of depth and richness within the analysis.

The use of a homogenous sample is again in line with IPA; however, the level of homogeneity also has implications for the generalisability of the findings. The participants in the sample were all aged between 25 and 44 years old (with the majority aged between 25-34) and attended higher levels of education, which limits the generalisation of these findings to Black women of other ages and Black women who have not attended higher education.

Areas of heterogeneity within the sample and its implications should also be noted. Although the information was not specifically collected, many participants discussed the timeframe between getting their diagnosis and participating in the study, and this appeared to vary significantly (between a few weeks to years). As discussed, experiences post-diagnosis appeared to play a role in the participants' sense-making of the diagnosis process itself, and therefore, this variation in the length of time between diagnosis and interview may have had an impact on the findings of this study.

Variation in the sample was also noted in terms of cultural and religious backgrounds, fertility outcomes, and whether the participants had children. These experiences again appeared to play a role in the participants sense-making of their diagnostic journeys; however, this study was limited in its ability to understand these experiences in more depth due to the heterogeneity of the sample in these areas.

Member checking was utilised to further enhance reflexivity and challenge researcher biases, as well as to offer the participants an opportunity to collaborate on the findings. Despite all participants having initially expressed interest in this aspect of the study, when contacted again, the response rate to provide feedback on the findings was low. It is unclear why this low response rate occurred, however this meant that the member checking was limited in its role in enhancing reflexivity and challenging researcher bias.

A possible reason could have been the long timeframe between interviews and analysis completion for some participants (the longest being approximately seven months, the shortest being four months), or participants may have felt that the findings generally did reflect their experiences and therefore did not have anything further to add. This theory is supported by the feedback that participants who did respond gave, which suggested either no changes or minor ones. This does raise questions, however, of how able participants felt to provide feedback in such a researcher-participant dynamic as in this study and how much additional labour member-checking involves for the participant. Future research involving such a researcher-participant dynamic is recommended to consider how they may address these potential issues with member checking to ensure it fully meets its aims if utilised.

Lastly, it is important to acknowledge that the findings provide one possible interpretation of the participants' experiences, in line with IPA's use of the 'double hermeneutic'.

5.7 Implications and Recommendations

This study highlights important findings that are relevant to all health professionals working with Black women with suspected or confirmed endometriosis. As such, the clinical implications of the findings are discussed below, including potential recommendations for NHS service provision. Implications at a social and political level will also be discussed.

5.7.1 Clinical Implications

The study highlighted experiences of racism and discrimination due to the intersectional identities that Black women hold whilst experiencing a lack of control over their symptoms, bodies and healthcare. This study also found how such experiences can lead to understandable wariness of the healthcare system and, for some, actively avoiding accessing the NHS entirely. To support Black women with accessing the necessary healthcare, healthcare services/professionals should recognise the unique challenges that Black women may experience when getting a diagnosis of endometriosis and living with the condition.

Based on this study's findings, healthcare services should consider the potential for Black women with possible or confirmed endometriosis to have experienced emotional distress and medical and/or racial trauma within their healthcare. This should include a consideration of how these experiences may be impacting their sense of safety and trust in healthcare services and influencing how they access healthcare. A trauma-informed approach using the six principles of safety, trustworthiness, choice, collaboration, empowerment and cultural consideration (UK Government, 2022) may be helpful for healthcare services to consider utilising in supporting Black women living with suspected or confirmed endometriosis. Guidance on best practices for trauma-informed care in gynaecology has begun to emerge, for example, Fulton et al. (2024) focus on implementing trauma-informed care within gynaecological cancer services, including considering the needs of those from historically marginalised populations. Guidance could be further developed to consider other areas of gynaecological care, including endometriosis.

As part of a trauma-informed approach, health services/professionals could consider asking Black women (nationally and locally) what they need from healthcare services for services to feel safe and accessible and to prevent risks of re-traumatisation. Services, including charities and organisations offering support to people living with endometriosis as well as NHS services, can work with women from minoritised backgrounds to collaborate on developing culturally sensitive support, as well as acting to ensure that they are involved in any service development and research in this area. This work should actively seek to involve and reflect the views of Black women from a diverse range of backgrounds with a diverse range of experiences, as the findings of this study suggest certain factors may shape women's experiences of endometriosis care as well as their subsequent care needs.

Based on the findings, this study recommends that all health professionals within endometriosis care are supported in delivering anti-racist practice, for example, through their training and supervision. The British Medical Association (2022) has recommended that "equality, diversity and inclusion training should be mandatory in medical school curricula and should include the topic of racial bias and how it manifests in medicine" as well as discussion of health inequalities and how they can be addressed through "targeted interventions, resource allocation and at the point of individual care" (p. 18). Frameworks for teaching implicit bias recognition and management, such as by Gonzalez et al. (2021), can be utilised to support addressing biases and assumptions held by healthcare professionals in endometriosis care and should be endorsed and facilitated by leadership.

It should be acknowledged that working towards anti-racist practice and trauma-informed care will be a lengthy and ongoing process, requiring significant systemic change. Therefore, recommendations to support Black women living with endometriosis at an individual level are also recommended based on the findings of this study.

The finding that participants experienced difficulties with their emotional well-being and with psychological adjustment to getting the diagnosis supports the APPG's (2020) recommendation of mental health and psychological support being provided when needed as part of integrated care pathways within endometriosis care. At present, Psychologists do not form part of the multi-disciplinary teams within Endometriosis Specialist Centres. However, the clinical and leadership skills of Clinical Psychologists mean that they would be in a suitable position to offer a role in co-ordinating such integrated care pathways, as well as providing direct therapeutic work, and consultation, training and supervision to other healthcare staff, supporting psychological informed environments within endometriosis care. These aspects of the role of Clinical Psychologists can be provided within physical health NHS settings as stipulated by the BPS (Busuttil et al., 2024).

At present, it may be useful for healthcare professionals involved in the care of Black women with endometriosis to signpost to relevant and appropriate existing mental health services, for example, Increasing Access to Psychology Therapies Pathway for People with Long-term Physical Health Conditions (IAPT-LTC). It could also be beneficial for such services to use a trauma-informed approach when working with Black women who may have experienced racial and/or medical trauma within their endometriosis-related healthcare. There are evidence-based guidelines for offering trauma-informed assessments for psychological therapy, for example, Sweeney et al. (2021), which consider how people can experience trauma based on aspects of their identity and how further discrimination can compound the trauma experienced. These guidelines also offer suggestions on how therapists and services can work towards anti-oppressive practice within talking therapies as part of a trauma-informed approach.

5.7.2 Societal and Policy Level Implications

The findings of the current study highlight Black women’s experiences of racism and discrimination and lack of culturally appropriate care within the NHS at all stages of the diagnosis journey. This suggests the presence of systemic racism, which requires healthcare organisations and their leaders to recognise and address. The Psychologists for Social Change network has issued a response to implementing anti-racism within the NHS (Psychologists for Social Change, 2020), and commissioning boards have published their own anti-racism statements and strategies. As Clinical Psychologists are in leadership positions within the NHS, they can support systemic change. Clinical Psychologists have the knowledge of social and psychological theories and models, clinical experience working with individuals who have experienced inequalities and discrimination, and leadership skills, to support the development and implementation of such anti-racism strategies, including providing an understanding of the potential psychological impact of experiencing discrimination due to intersecting aspects of identity.

The difficulties talking about endometriosis and its symptoms found in this study suggest the need for further interventions at a societal level to reduce the stigma surrounding women's reproductive health. In line with the APPG (2020) recommendation, providing education and raising awareness around endometriosis and, more broadly, menstruation could be a useful way to challenge stigmatising societal and cultural narratives around women's reproductive health and reduce the societal silence surrounding these topics. Culturally appropriate resources on endometriosis could also be developed to be accessed online and through healthcare services.

Raising awareness of endometriosis in the UK through events such as Endometriosis Awareness Week (an international event) and campaigns organised through charities all work towards reducing the silence on endometriosis. A more comprehensive strategy for raising awareness highlighting the seriousness of the condition could be devised by a group involving people living with endometriosis alongside representatives from the government, clinicians, third-sector organisations and charities. Specifically, this research suggests the need for employers to be more aware of endometriosis and its impact on people living with the condition. Endometriosis UK has launched an ‘endometriosis employer-friendly scheme’, and the Government could have a role in encouraging employers to be part of this scheme.

Any education or intervention provided within school or community settings could be co-developed and facilitated with people living with endometriosis from Black and minoritised backgrounds to help make the intervention representative and support engagement. Any education, intervention, or policy should also consider the language used to refer to menstruation and ensure it is positive to also work towards reducing period stigma.

5.8 Future Research

Future research exploring Black women’s experiences of endometriosis and related healthcare could use a Participatory Action Research (PAR) approach, which is suitable where there is a need to address an inequitable situation and has its focus on achieving action to address this (Kidd & Kral, 2005). PAR approaches also involve collaboration with community members, who take roles as co-researchers to identify and understand the problem that needs addressing. This approach may be particularly valuable in understanding local need to support service provision and development. Using PAR could be a valuable way of understanding and improving endometriosis healthcare and quality of life for minoritised women by supporting them to draw on their own expertise, knowledge, and resources to make changes.

This study has provided an initial insight into Black women’s experiences of getting a diagnosis in the UK. Further research should build on the findings of this study, and to do this, it may be useful to use larger samples to understand whether the experiences highlighted here are common for Black women in the UK more broadly. Future research could also focus on exploring specifically the experiences of middle-aged and older Black women or adolescent Black women, as Black women of these ages were largely absent from this study.

As there is great diversity within who identifies as a Black woman, it would also be important to consider how the experiences found in this study reflect the experiences of Black women from different backgrounds, religions, and communities. Moreover, as highlighted in the limitations section, the participants in this study had all attended higher levels of education. Future research may want to consider the education attainment level within future samples, as this factor is known to correlate with other variables such as health outcomes, cognitive skills, locus of control, and economic resources (Zimmerman & Woolf, 2014). Ensuring that Black women who have not attended higher education are included in future research would be important, as these Black women were also absent from this study, meaning that their experiences remain currently unknown.

As accessing effective and supportive healthcare treatment was a significant challenge and concern to Black women in this study, it would be useful for further research to explore what constitutes and facilitates good healthcare and treatment for Black women. Research could also further explore the emotional well-being of Black women with endometriosis and whether mental health and psychological support would be useful for this population. This could inform service development and provision, such as integrated pathways for mental health and psychological support within endometriosis care.

Another valuable area for further exploration would be the experience of endometriosis and menstruation-related stigma for Black women in the UK and how this shapes their experiences of living with endometriosis and emotional well-being. This may guide future intervention at a societal and policy level for reducing stigma and promoting physical and mental well-being for Black women.

5.9 Conclusion

This study explored eight Black women's experiences of getting a diagnosis of endometriosis in the UK. The findings have highlighted the challenges Black women experience in reaching this diagnosis and how difficulties within their healthcare and with managing their symptoms can prevail post-diagnosis.

The findings suggest that Black women experience challenges unique to their intersecting identity, being both Black and female. Significantly, the study highlighted how Black women can experience combined racial and gender discrimination within their healthcare and how, altogether, these difficult experiences can lead to prolonged physical suffering as well as emotional and psychological distress. The study also found how Black women are utilising their strengths and resources to get the appropriate care they need. This included using other forms of support outside the NHS, such as peer support, which were viewed as invaluable for some.

Despite its small sample size, the findings provide a meaningful contribution by providing important and novel insights into how Black women experience getting a diagnosis of endometriosis. The findings in this study were often in line with the existing research exploring Black women's experiences of gynaecological care, despite much of the existing research taking place in the US with a different socio-political context and health system structure to the UK. As discussed, the findings in this study offered both contrasts and similarities with the broader existing research on endometriosis, which typically explores White women's experiences.

The study findings are relevant for all health professionals working with Black women living with possible or confirmed endometriosis, including psychological therapists who may be supporting such individuals with their emotional well-being and psychological adjustment to their diagnoses. The findings also have important suggestions for systemic change and societal and policy-level interventions, including considering the need for embedding anti-racist strategies within NHS healthcare and reducing stigma and discrimination towards women living with endometriosis. Such change will be a significant and ongoing task, though crucial to improve the quality of life and well-being of Black women with endometriosis.

It is hoped that this research can contribute to supporting such changes by sharing the participants' experiences and highlighting the impact of current practice that may, at times, go unseen and unspoken. Crucially, this study only provides an initial exploration, and further research should continue to build on its findings to support further understanding and future action. It is hoped that in the words of a participant, as they referred to gender and racial discrimination, as a society, we will become "less accepting and also… more committed to addressing it".

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Appendices

Appendix A
Reflective Diary Entries

Reflections on Research Design and Question Development
I met with my main supervisor today. We discussed my position as a white researcher exploring black women's experiences i.e. being in an outsider position and how I feel about this. I was really glad that she bought this up and I wish I had done from the start as I had been having thoughts about this since I refined the project. We questioned whether we should be doing the research, and if we did how could we go about it in a way that manages potential discomfort and distrust from participants and addresses power imbalance. At this time, I was weighing up not doing the research due to not wanting to risk replicating power structures in wider society in this research project, with not doing the research which means that these women's voices continue to be unheard within endo research. My feeling was that if we can continue to acknowledge my position and work to address these power dynamics then the research could be done. Although I did not feel 100% sure about this decision, though should I need to be completely comfortable with this decision? Should I not lean into this discomfort? This meeting was helpful in thinking about ways that I can negotiate these issues within the research. It also made me think that IPA is the right approach for the research, with its emphasis on bracketing, double hermeneutic and wider context.

I met with a peer who identifies as Black women to think about my research and consider some of the questions I was sitting with around whether I should be the person to do this research. I gained some valuable feedback and felt encouraged. Discussing the project with them helped me reflect on the rationale for the study and how I got to the research question. It reminded me of my values and how these had informed the development of the project around giving an opportunity for unheard voices to be heard and improving healthcare for all. I reflected on how the project could had looked different, e.g. looking at women from other ethnic backgrounds experiences, or including women from all minoritized backgrounds however this did not feel very meaningful whilst research has pointed to Black women having particularly difficult experiences in healthcare generally, and being the least likely to have a diagnosis of Endometriosis.
Following this meeting the project felt like it started to make sense to me, and I am now feeling much more positive about it.

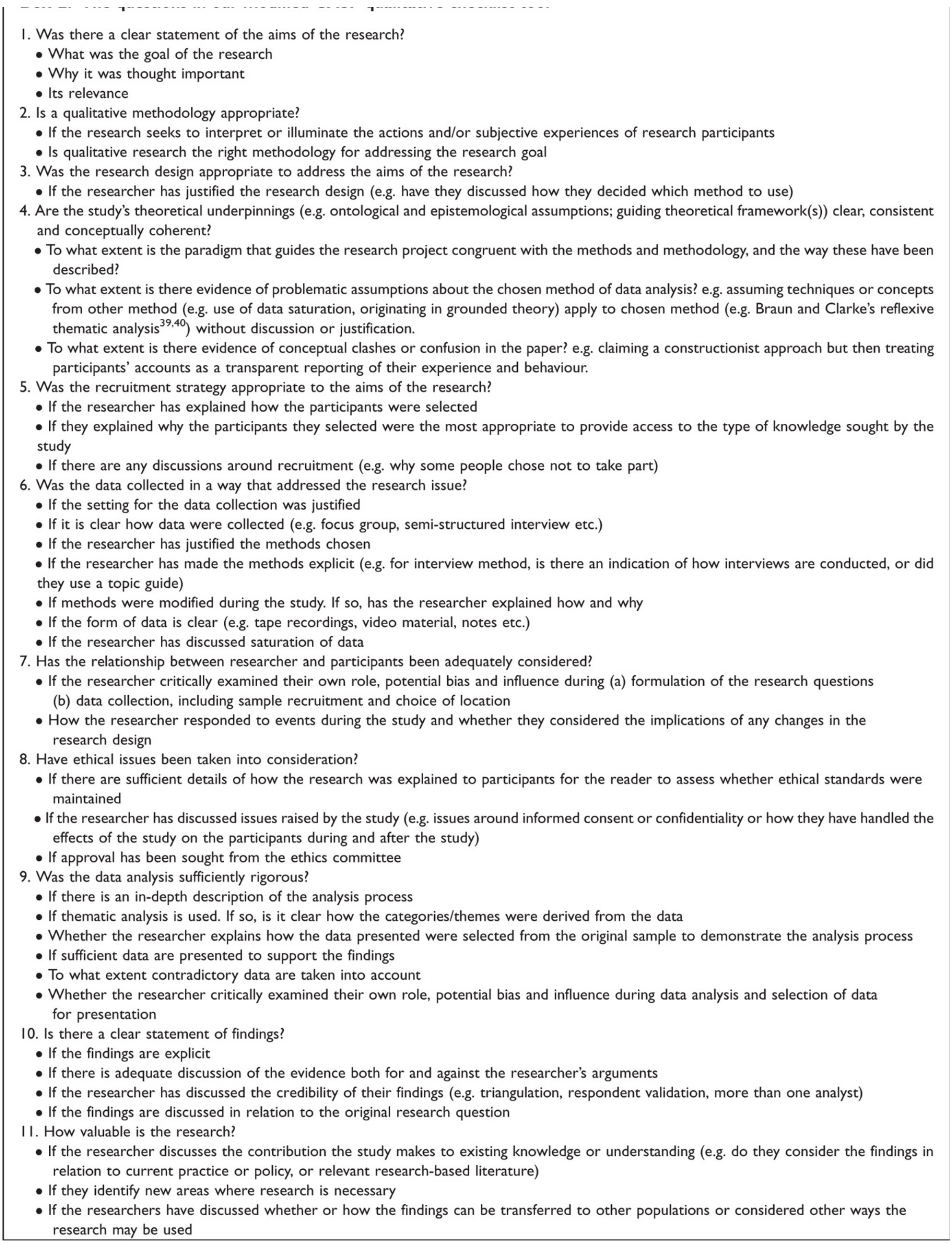
Reflections during analysis of transcript

- *Through the analysis I have noticed myself feeling anxious about 'getting it right' – I was reflecting on how this may come from me being an outsider researcher and finding it difficult to know what 'right' is i.e. what the participants interpretation really is. This reflection had prompted me to reconsider how my whiteness may be influencing the analysis and I noticed at times I was finding it difficult to explicitly name experiences racist/discriminatory. I'm aware that I am trying to remain open and curious to the participants experience and feeling as I don't always know if that is what the participant would say they are experiencing as they often have not named* *experiencing racism or discrimination explicitly either. I'm wondering if I'm finding it hard to name these experiences explicitly as racist or discriminatory as I haven't had these experiences myself as a white person. I'm also curious that a number of the participants didn't name their experiences as this. Did my identity as a white person prevent them from doing so? I also wonder if for some of the participants it is protective for themselves to not name these experiences due to what it would mean to them if they considered that they were experiencing oppression in this way.*

- *Impact of transcribing interview – very heavy, felt exhausting and confusing. Has felt difficult to interpret, the narrative has jumped around alot and I have been finding it difficult to understand the connections between different parts of their experience for the participant. What does it mean to them that they are thinking about both these different parts of their experience? Narrative jumps backwards and forwards between past (getting the diagnosis) and present – seems that experience of the diagnosis journey for the participant is very much connected to their current experience (what happened then explains what is happening to her now - blame and a sense of injustice)– still processing what happened, emotions around the diagnosis process still present, symptoms still present*

Appendix B

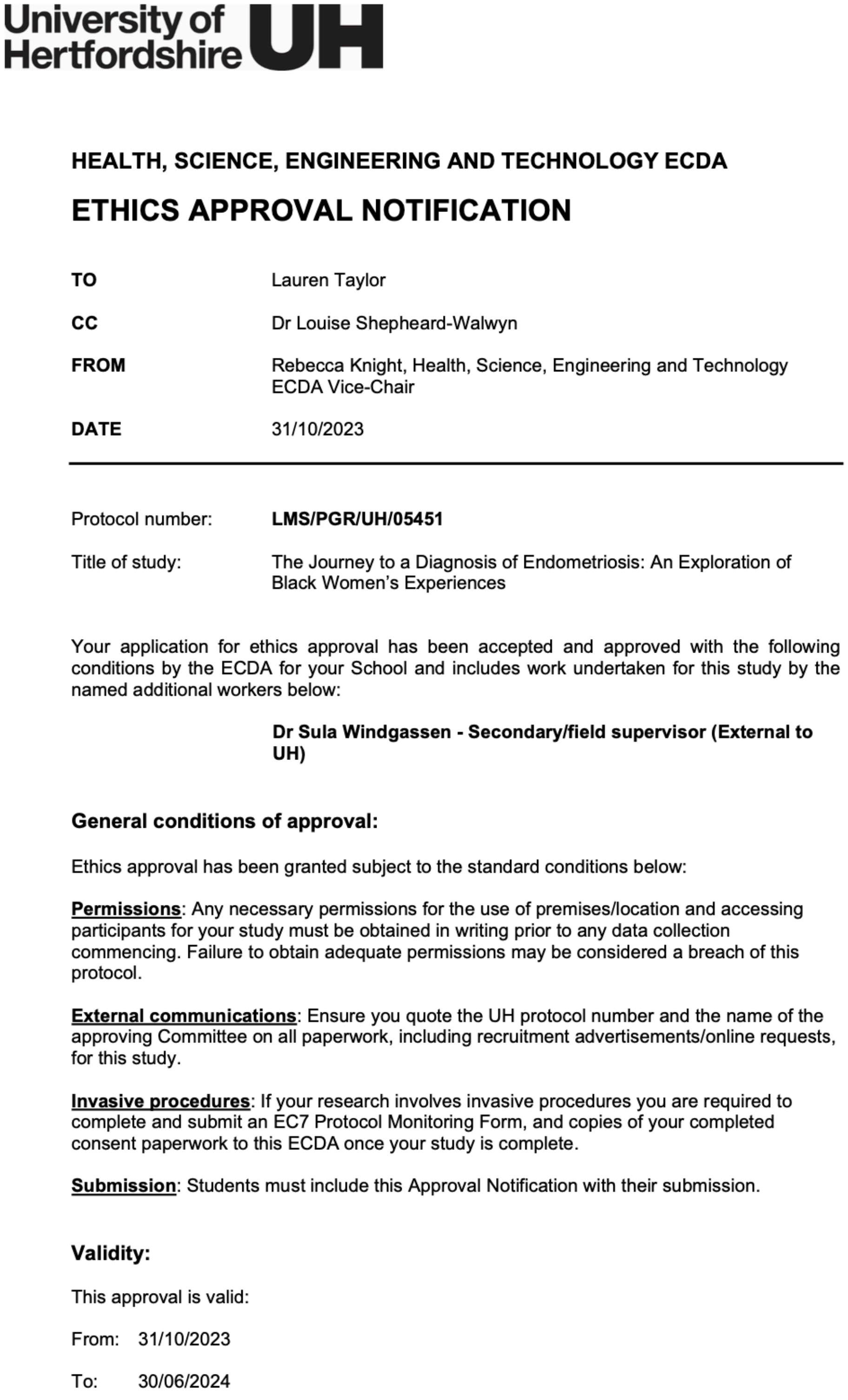
Adapted Version of the CASP tool by Long et al (2020)



1. Was there a clear statement of the aims of the research?
   - What was the goal of the research
   - Why it was thought important
   - Its relevance
2. Is a qualitative methodology appropriate?
   - If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
   - Is qualitative research the right methodology for addressing the research goal
3. Was the research design appropriate to address the aims of the research?
   - If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)
4. Are the study's theoretical underpinnings (e.g. ontological and epistemological assumptions; guiding theoretical framework(s)) clear, consistent and conceptually coherent?
   - To what extent is the paradigm that guides the research project congruent with the methods and methodology, and the way these have been described?
   - To what extent is there evidence of problematic assumptions about the chosen method of data analysis? e.g. assuming techniques or concepts from other method (e.g. use of data saturation, originating in grounded theory) apply to chosen method (e.g. Braun and Clarke's reflexive thematic analysis[39,40]) without discussion or justification.
   - To what extent is there evidence of conceptual clashes or confusion in the paper? e.g. claiming a constructionist approach but then treating participants' accounts as a transparent reporting of their experience and behaviour.
5. Was the recruitment strategy appropriate to the aims of the research?
   - If the researcher has explained how the participants were selected
   - If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
   - If there are any discussions around recruitment (e.g. why some people chose not to take part)
6. Was the data collected in a way that addressed the research issue?
   - If the setting for the data collection was justified
   - If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
   - If the researcher has justified the methods chosen
   - If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
   - If methods were modified during the study. If so, has the researcher explained how and why
   - If the form of data is clear (e.g. tape recordings, video material, notes etc.)
   - If the researcher has discussed saturation of data
7. Has the relationship between researcher and participants been adequately considered?
   - If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
   - How the researcher responded to events during the study and whether they considered the implications of any changes in the research design
8. Have ethical issues been taken into consideration?
   - If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
   - If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
   - If approval has been sought from the ethics committee
9. Was the data analysis sufficiently rigorous?
   - If there is an in-depth description of the analysis process
   - If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
   - Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
   - If sufficient data are presented to support the findings
   - To what extent contradictory data are taken into account
   - Whether the researcher critically examined their own role, potential bias and influence during data analysis and selection of data for presentation
10. Is there a clear statement of findings?
    - If the findings are explicit
    - If there is adequate discussion of the evidence both for and against the researcher's arguments
    - If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
    - If the findings are discussed in relation to the original research question
11. How valuable is the research?
    - If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature)
    - If they identify new areas where research is necessary
    - If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Appendix C

Ethical Approval – October 2023



University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO Lauren Taylor

CC Dr Louise Shepheard-Walwyn

FROM Rebecca Knight, Health, Science, Engineering and Technology ECDA Vice-Chair

DATE 31/10/2023

Protocol number: **LMS/PGR/UH/05451**

Title of study: The Journey to a Diagnosis of Endometriosis: An Exploration of Black Women's Experiences

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Dr Sula Windgassen - Secondary/field supervisor (External to UH)

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Validity:

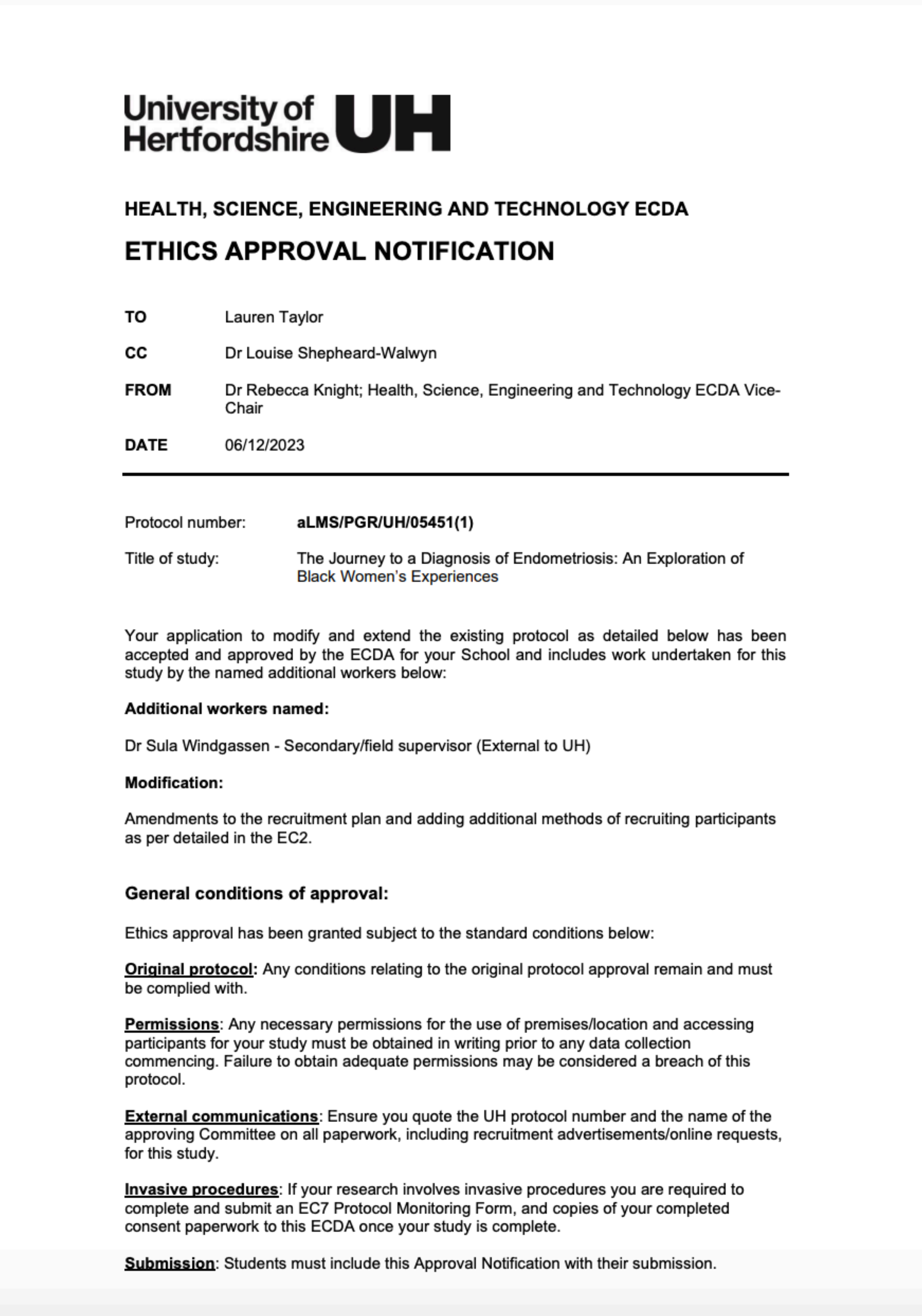
This approval is valid:

From: 31/10/2023

To: 30/06/2024

Appendix D

Ethical Approval – 1st Amendment to Study Protocol



University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO	Lauren Taylor
CC	Dr Louise Shepheard-Walwyn
FROM	Dr Rebecca Knight; Health, Science, Engineering and Technology ECDA Vice-Chair
DATE	06/12/2023

Protocol number:	**aLMS/PGR/UH/05451(1)**
Title of study:	The Journey to a Diagnosis of Endometriosis: An Exploration of Black Women's Experiences

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Additional workers named:

Dr Sula Windgassen - Secondary/field supervisor (External to UH)

Modification:

Amendments to the recruitment plan and adding additional methods of recruiting participants as per detailed in the EC2.

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Original protocol: Any conditions relating to the original protocol approval remain and must be complied with.

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

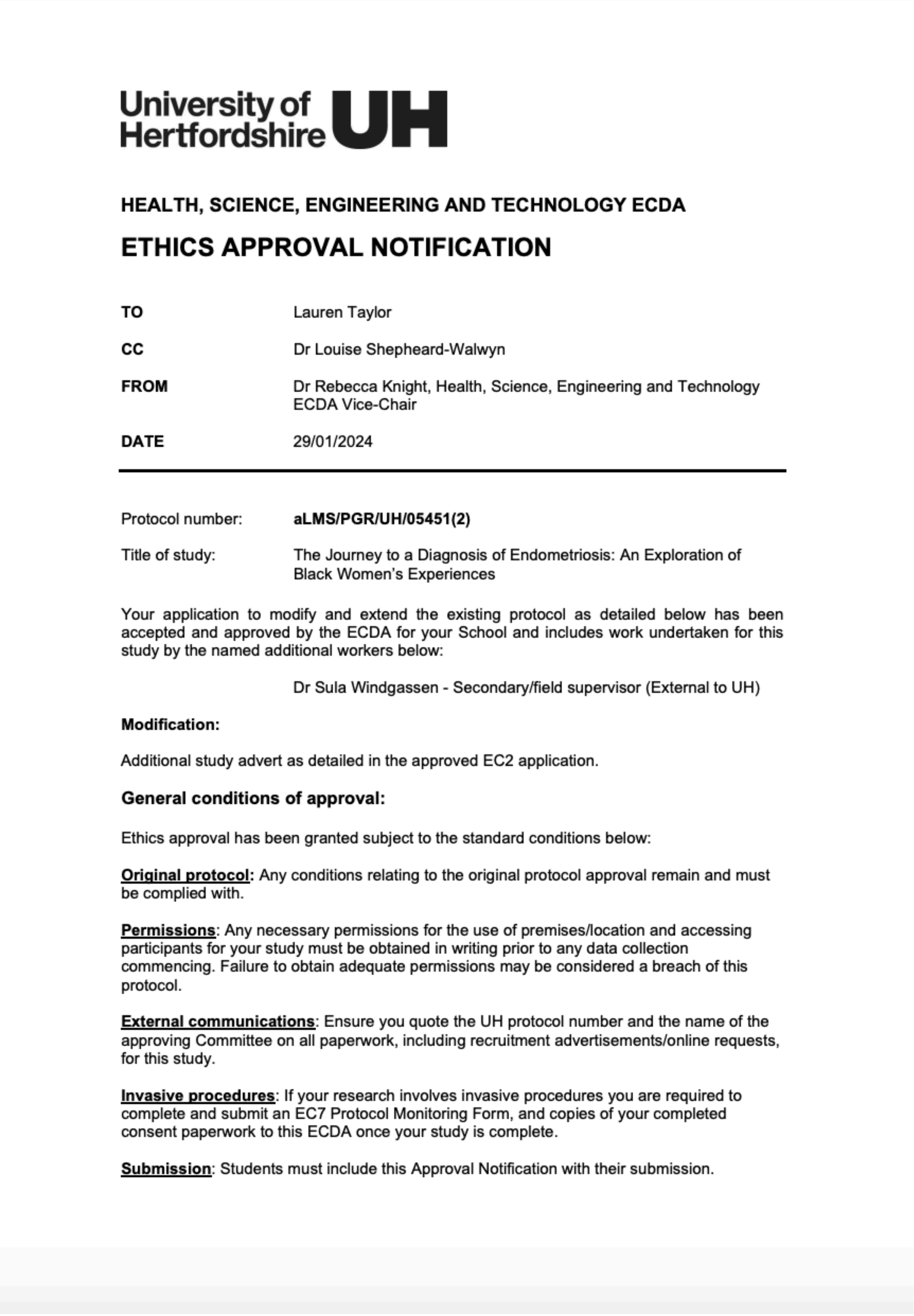
External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Appendix E

Ethical Approval – 2nd Amendment to Study Protocol



University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO	Lauren Taylor
CC	Dr Louise Shepheard-Walwyn
FROM	Dr Rebecca Knight, Health, Science, Engineering and Technology ECDA Vice-Chair
DATE	29/01/2024

Protocol number:	**aLMS/PGR/UH/05451(2)**
Title of study:	The Journey to a Diagnosis of Endometriosis: An Exploration of Black Women's Experiences

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Dr Sula Windgassen - Secondary/field supervisor (External to UH)

Modification:

Additional study advert as detailed in the approved EC2 application.

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Original protocol: Any conditions relating to the original protocol approval remain and must be complied with.

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

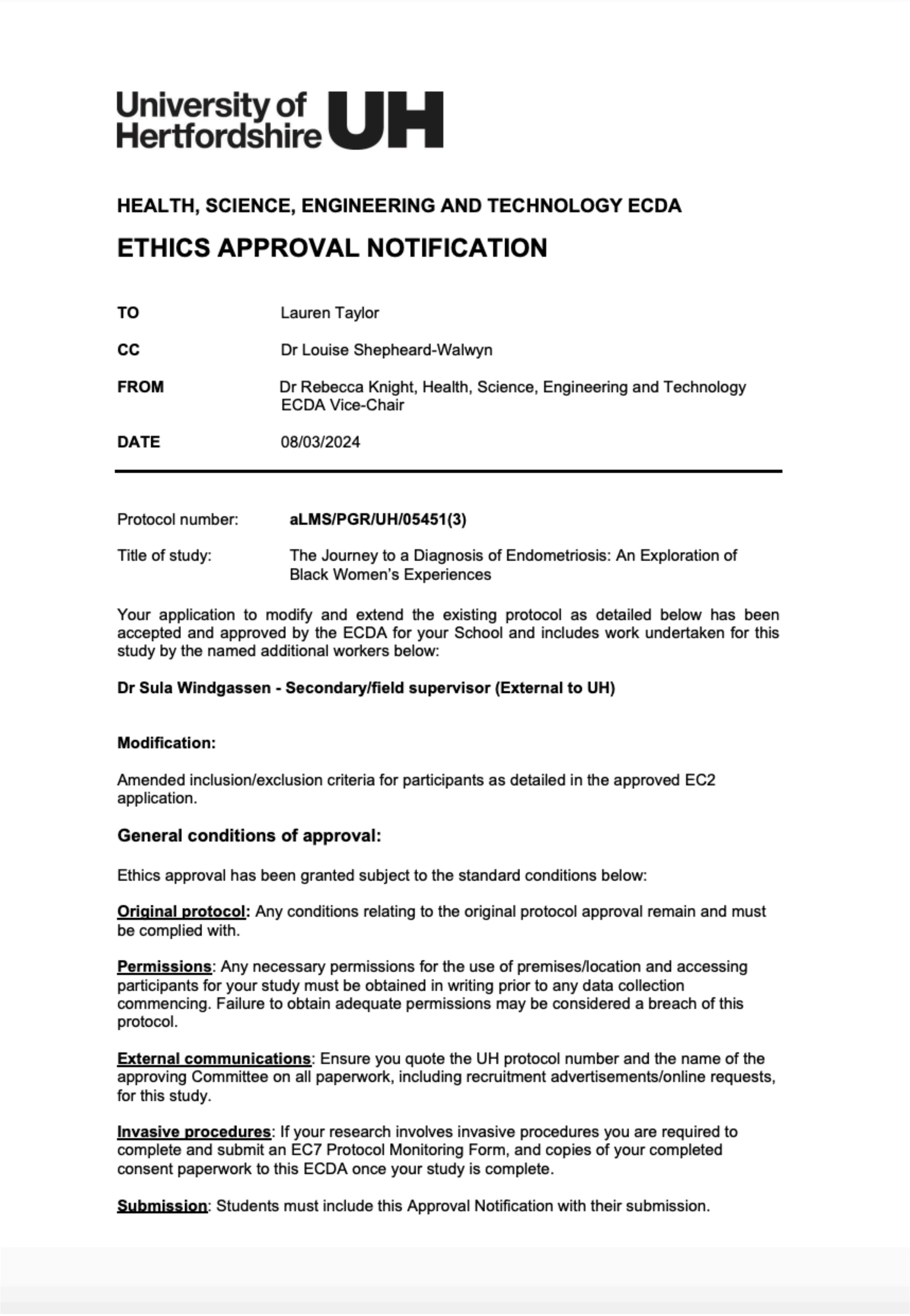
External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Appendix F

Ethical Approval – 3rd Amendment to Study Protocol



University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO	Lauren Taylor
CC	Dr Louise Shepheard-Walwyn
FROM	Dr Rebecca Knight, Health, Science, Engineering and Technology ECDA Vice-Chair
DATE	08/03/2024

Protocol number:	**aLMS/PGR/UH/05451(3)**
Title of study:	The Journey to a Diagnosis of Endometriosis: An Exploration of Black Women's Experiences

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Dr Sula Windgassen - Secondary/field supervisor (External to UH)

Modification:

Amended inclusion/exclusion criteria for participants as detailed in the approved EC2 application.

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Original protocol: Any conditions relating to the original protocol approval remain and must be complied with.

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Appendix G

Risk Assessment and Management Protocol

Study Risk Management and Assessment Plan

Confidentiality and safeguarding policy, to be explained to participants via information sheet:
Participant understands that they are participating in a study where they will share personal information about themselves. Any information shared with the researcher will be kept confidential within the researching team, unless information is disclosed that an individual is at significant risk of harm. This information will need to be shared with the project supervisor and possibly other organisations suited to assist in helping the individual stay safe. Usually this is done in agreement of the researcher and participant, but information may be shared without consent if the participant or others are at risk of significant harm. If the participant discloses that they are a victim of crime or have committed a crime then this may need to be shared with relevant authorities.

Risk assessment at interview
If a participant becomes distressed during the interview and discloses suicidal thoughts, the researcher will ask the following questions:

a. Have you attempted suicide in the past? What happened?
b. In the last two weeks have you considered ending your life?
c. Have you made any preparations towards this? (e.g. writing a will, getting affairs in order, suicide note).
d. Do you have those thoughts at the moment?
e. Do you feel able to resist these thoughts?
f. Do you intend to take your own life? How would you rate your intent on a scale of 0 to 10 (0 being no intent, 10 being high intentions)
g. What stops you from harming or killing yourself at the moment?

The subsequent processes will be determined by risk as defined in table 1. Where necessary, the researcher on the phone will conduct a crisis plan:
Crisis Plan
a. What are the circumstances likely to make things worse? NB: If very impulsive, may act without plan, consider alcohol.
b. How soon could this happen?
c. Who could you turn to for support?
d. What sort of things can do that make you feel better when you feel suicidal? (refer back to protective factors if can't provide answers)
e. What has helped in the past?
f. Who could you talk to?
g. Who could you call in an emergency?
h. Have you considered calling the Samaritans?
i. Would you consider going to your GP?
j. Would you go to A&E ?
k. How likely are you to follow this plan?
l. Are you able to reassure me that you can keep yourself safe today, this week, this month?

Participants will be provided with the following numbers:
Samaritans 116 123
NHS 111

Table 1 determines the tiers of risk and consequent action to be taken.

Table 1: Risk assessment process

Risk Level	Action	Responder
Imminent Risk: **Scenario A =** feeling hopeless about the future, current thoughts, clearly identified plan, high intent, access to means, no preventative factors (or these can easily change), past history, is not able to guarantee their safety. Immediate action is required on their behalf. **Scenario B =** feeling hopeless about the future, current thoughts, clearly identified plan (or does not wish to tell you) past history or unwilling to tell you if they are in immediate threat. They have access to the means**.**	• Elicit the individuals' precise location • Call an ambulance and police. • Notify supervisor immediately	Lead researcher
High Risk: **Scenario A =** can be the same as any of the above (hopelessness, thoughts, plans, high intent, past history, no strong protective factor or these can change) however the client **is able** to guarantee their safety for a number of days or until they can be seen by the appropriate service. **Scenario B =** feeling hopeless, current thoughts, vague plan, past history of suicide attempts and/ or self-harming but protective factors.	• Elicit the individuals' GP information and contact GP for an urgent appointment so that the GP can monitor risk • Notify supervisors immediately	Lead researcher
	• Conduct crisis plan	Supervisor
Medium Risk: Hopeless, current thoughts, vague plan **but no intent**. Can have a history of suicide attempts. Client has strong protective factors and is able to guarantee their safety.	• Elicit the individuals' GP information, phone contact to GP • Notify supervisor immediately	Lead researcher
	• Conduct crisis plan	Supervisor
Low Risk: **Scenario A =** No current or recent thoughts of risk, may have past thoughts but no history of attempt. **Scenario B =** Has thoughts that	No action required.	

life is not worth living, but no plans or intent to act on those thoughts		

Managing Risk to Self
When dealing with risk, the researcher should endeavour to follow these processes to keep individuals safe.

Imminent Risk / Crisis

- Be calm, non-judgemental and empathic; allow as much time as necessary
- Obtain details as far as possible of the suicide plan.
- Inform research supervisors that you need help whilst with participant/on the phone or video call
- Ask if anyone is with the individual. Ask the individual permission to speak to them.
- Take action to get the participant into an appropriate safe setting.
- Ask them if they are able to get to A&E department **safely**, if not, ask if someone could go with them. If no is one around, you can ask if there is anyone you could call to come and stay with them if this would help. Ask research supervisor to call them whilst you stay on the phone with the participant.
- Or offer to call the ambulance for them. Explain the ambulance can come without the flashing siren and that it can be very discreet. Ask research supervisor to call the ambulance for you whilst you are with participant/on the phone or video call to the participant.
- Discuss immediately with supervisor. If possible, remain with the participant/on hold on the phone or video call

Afterwards:

- GP should always be contacted where information is shared.

High Risk

- Obtain details as far as possible of the suicide plan.
- With the participant, agree to remove access to means or ask if anyone can do it for them
- Let research supervisors know you need help whilst with participant/on the phone or video call
- If possible, ask the participant if they can be put on hold or wait in a separate room whilst you speak to the supervisor. If not, say you will call them back.
- Discuss immediately with research supervisors.
- Explain to the individual that their safety is the most important thing to us and that we need to make sure that they get the best for of help as soon as possible.
- Explain to the individual that they need to call their GP for urgent care to ensure their safety, or that you can call their GP on their behalf.

Afterwards:

- GP should always be contacted where information is shared.

Medium Risk

- With the participant, agree to remove access to means
- Complete crisis plan (see previous page)

- Give support service information including Samaritans 24/7 helpline
- Ask participant to contact GP/inform participant you will be contacting the GP
- Inform supervisor

Afterwards:

- Phone the GP

Risk Management - Risk to the Researcher

If the lead researcher is undertaking interviews with participants in person, in environments such as the participant's home, the risk to the researcher may be unknown.

In accordance of this, the following plan is to be used in such scenario:

- Lead researcher will inform supervisory team of location/time of interview.
- Lead researcher will agree to contact supervisory team following completion of interview at an agreed time.
- If lead researcher does not contact supervisory team as agreed, supervisory team will call the appropriate service for support e.g. police.

Appendix H
Participant Information Sheets

Participant Information Sheet - Initial Survey

The Journey to a Diagnosis of Endometriosis: An Exploration of Black Women's Experiences
You are invited to take part in the research study above. This study aims to explore Black women's experiences of getting a diagnosis of endometriosis, including the psychological/emotional impact of this process, from initial symptoms to diagnosis. It is hoped that this research will help understand Black women's experiences and may make some suggestions about what support might be helpful for Black women.

What will it involve?
Taking part will involve completing a short questionnaire which will take approximately 15 minutes to complete. The questionnaire will ask about yourself, your background, and your experiences of getting your diagnosis of endometriosis. You will also be asked if you would like to talk about your experiences of getting a diagnosis of endometriosis in more detail in an interview.

All data will be anonymised when you submit your answers. **By submitting your answers you are providing your consent to take part.**

Do I have to take part?
It is completely up to you whether you decide to take part in this study. If you start to complete the questionnaire and change your mind, you can withdraw by closing your browser and exiting the questionnaire. Once you have submitted your answers you will be unable to withdraw from the study as your data will be anonymised at this stage.

Who can take part?
To take part you will need to meet the following criteria:

- You are over the age of 18
- You identify as Black, female, and you were assigned the gender female at birth
- You have a diagnosis of endometriosis, diagnosed via laparoscopy, and you received this diagnosis in the UK
- You are currently a UK resident
- You speak English fluently
- You accessed NHS services at least once in relation to your endometriosis symptoms before being diagnosed

What are the possible disadvantages, risks or side effects of taking part?
You will be asked about your personal experiences related to your experiences of endometriosis and getting a diagnosis, and thinking about these experiences could potentially cause you some distress. No further follow-up care will be provided by the research team and by consenting to participate you are agreeing to manage any distress you may experience independently. **If you wish to talk to someone about your experiences following completing the questionnaire, please see below the contact details for organisations you could contact:**

Endometriosis UK Volunteer led Support Line: 0808 808 2227
Samaritans 24/7 Free Helpline: 116 123
The Endometriosis Foundation: www.theendometriosisfoundation.org/join-our-community

What will happen to the data collected in this study?
All data collected (including any contact details) will be stored electronically on a password-protected file on the GDPR compliant University of Hertfordshire One Drive which will only be accessible to the research team. Any data collected from the questionnaire may be used in future research/publications beyond this study and will be kept securely for up to 5 years. After this, all data will be destroyed securely.

If you have any further questions about the research or taking part, please contact the lead researcher Lauren Taylor via email address: l.l.taylor2@herts.ac.uk

Thank you for considering taking part!

Participant Information Sheet – Interviews

PARTICIPANT INFORMATION SHEET

Title of study

The Journey to a Diagnosis of Endometriosis: An Exploration of Black Women's Experiences

Introduction

You are being invited to take part in the second part of this study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask any questions or for further information to help you make your decision. Please do take your time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of this study?

This study aims to explore Black women's experiences of getting a diagnosis of endometriosis, including the psychological/emotional impact of this process, from initial symptoms to diagnosis.

It is hoped that this research will help understand Black women's experiences and may make some suggestions about what support might be helpful for Black women. The research may also indicate areas where future research may be beneficial to further understand women's experiences of endometriosis and the process of getting a diagnosis.
In the event of any significant change to the aim(s) or design of this part of the study, you will be informed and asked to renew your consent to participate.

Who can take part?

To take part you will need to meet the following criteria:
- You are over the age of 18
- You identify as Black, female and you were assigned the gender female at birth

- You have a diagnosis of endometriosis, diagnosed via laparoscopy, and you received this diagnosis in the UK
- You are currently a UK resident
- You speak English fluently
- You accessed NHS services at least once in relation to your endometriosis symptoms prior to being diagnosed.

What will taking part involve?
Taking part in this next part of the study will involve talking about your experiences of being diagnosed with endometriosis in detail, in an interview with the lead researcher. For the duration of the interview, you will need to be in a private and comfortable space. If this is not the case at any time in the interview, the researcher will pause the interview and offer you anopportunity to move to another location or a time to reschedule. You may wish to have a family member or friend present for support during the interview (although they cannot contribute to the interview itself).

The interview will take approximately 1 hour. The interview could take place online using a video call platform, over the telephone, or face-to-face depending on your preference. The interviews will be recorded. If taking place online, a video recording will be taken. If your interview takes place in person or over the phone, the interview will be audio recorded.

Participants are also invited to review the findings of the study before they are finalized and discuss how the final findings could be shared. Following the completion of all the interviews, participants will be asked to provide some feedback on whether the initial themes developed by the researcher reflect their experiences. Your feedback will then be used to refine and further develop the themes, resulting in the final findings. This part of the study is optional and you will be asked if you wish to take part in this process. You can change your mind about taking part without providing a reason.

Do I have to take part?
It is completely up to you whether you decide to take part in this part of the study. If you do decide to take part you will have a copy of this information sheet to keep and be asked to sign a consent form. Agreeing to participate in this next part of the study does not mean that you must complete it. You are free to withdraw without giving a reason at any time during the interview and up to two weeks following your interview.

What will happen if I don't want to carry on with the study?
If you change your mind about taking part in the interview you can withdraw without providing a reason in the following ways:

- If you no longer want to participate during the interview you can let the researcher know that you no longer wish to continue with the interview. The interview recording and any data already collected will be destroyed and will not be included in the findings of the study.
- If you change your mind and wish to withdraw your interview from the study after this has taken place, you can contact the researcher using the contact details provided and request this. You do not need to give a reason. You can request for your interview to be withdrawn up to two weeks following the interview. After two weeks you will be unable to withdraw your interview.

What are the possible disadvantages, risks or side effects of taking part?
During the interview, you will be asked to talk about personal experiences related to your experiences of endometriosis and getting a diagnosis in detail. You may have experienced some difficult experiences such as racism and discrimination when accessing healthcare, and it may understandably feel difficult to talk about some of these experiences. Your

experience of being interviewed may also be impacted by the researcher's identity (a white researcher/healthcare professional).

At the start of the interview, you will be asked if there is anything which the researcher can put in place to support you to feel as comfortable as possible during the interview. If you want to participate in an interview this may be something you wish to think about in advance of your interview, however, this is optional if you wish to and not an expectation. The researcher will hold the responsibility for creating a supportive and containing space during the interview.

There is a possibility that talking about your experiences may cause you distress and you may want to consider how able you feel to talk about your experiences of endometriosis and getting a diagnosis at this time before agreeing to take part.

If you choose to take part, you can choose not to talk about a particular experience or answer any of the questions during the interview without giving a reason. If you were to experience distress during the interview, you would be able to pause or end the interview and either reschedule or withdraw from the study without providing a reason. It will be discussed at the start of the interview how you may signal to the researcher that you are feeling distressed. You will also be provided with the contact details of support services upon completion of the interview.

There is also the possibility that agreeing to review and provide feedback on the research findings could cause distress. This part of the study is optional, and you can change your mind following the interview without providing a reason.

No further follow-up care will be provided by the research team and by consenting to participate you are agreeing to manage any distress you may experience independently.

If you did require urgent support due to experiencing high levels of distress and/or expressing a risk of harm to yourself or others during the interview the researcher/research team would support you to complete a support plan and if required, the researcher/research team would contact the appropriate service to support you to keep safe, for example, 999 or request details of your GP.

What are the possible benefits of taking part?
You may find it helpful to talk about some of your experiences and it is hoped that taking part will be a positive experience. By taking part you will be contributing to providing insight and understanding into Black women's experiences, which could help the research to make some suggestions about how Black women may be best supported during the diagnosis process and beyond.

How will my taking part in this study be kept confidential?
Any information shared with the lead researcher will be kept confidential within the research team. If information is disclosed that an individual is at significant risk of harm, this information will need to be shared with the research supervisors and possibly other organisations suited to assist in helping the individual stay safe. Usually, this is done in agreement with the participant, but information may be shared without consent if you or others are at risk of significant harm.

Please note that if, during the interview, information is shared about any individual who has either committed a crime or is a victim of crime then this may need to be shared with the appropriate authorities and, under such circumstances, you will be withdrawn from the interview.

In any publication of the study and its findings, all data (including any personal information such as demographic information and quotes from the interviews) will be anonymised using the pseudonyms given to participants and any identifiable information will be omitted to ensure confidentiality.

Audio-visual material
For interviews which take place in person or over the phone, your interview will be recorded using a password-protected digital recorder device. The digital recorder device will be kept securely. Your interview recording will then be transferred and stored securely on a password-protected file on the GDPR compliant UH One Drive which will be accessed by the research team only. For interviews taking place online, the video recording of your interview will be immediately saved to a password-protected file on the GDPR compliant UH One Drive which will be accessed by the research team only. Your interview recording will be stored securely on a password-protected file on the GDPR compliant UH One Drive which will be accessed by the research team only. Your recording will not be displayed or transmitted. Your interview will be transcribed by the researcher and the transcript will also be stored on a password-protected file on the GDPR compliant UH One Drive which will be accessed by the research team only.

What will happen to the data collected within this study?
All data collected within the interview, including the relevant consent form, interview recordings and transcripts, will be stored electronically on a password-protected file on the GDPR compliant UH One Drive until the completion of the study (approximately September 2024). After which it will be destroyed under secure conditions by the lead researcher. The data from your interview will not be used in any further studies.

The data collected from the questionnaire you completed in the first part of this study may be used in further studies/publications and this will be stored securely for up to 5 years following collection. After which it will be destroyed under secure conditions by the research team.

What will happen to the results of this study?
It is planned for the findings of the study to be published in an academic journal, shared at relevant research conferences, and shared with organisations and health professionals who work with and support women with endometriosis.

This research is also being undertaken as a thesis for the lead researcher's Doctorate in Clinical Psychology at the University of Hertfordshire and will contribute to the fulfilment of this. On completion, the thesis will also be accessible in the University of Hertfordshire online research archive.

Who has reviewed this study?
This study has been reviewed by:
The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority
The UH protocol number is LMS/PGR/UH/05451
The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:
https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs
(after accessing this website, scroll down to Letter S where you will find the regulation)

Who can I contact if I have any questions?
If you would like any further information or have any questions about this research please contact Lauren Taylor (lead researcher) via email l.l.taylor2@herts.ac.uk

Although we hope it is not the case, if you have any complaints or concerns about

any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:
Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

Thank you very much for reading this information and giving consideration to taking part.

Appendix I

Initial Survey Questions

1. I have read the information provided above and agree to take part in this study. By submitting my answers I am providing my consent to participate. Required to answer. Single choice.

I agree

2. Can you confirm that you have a diagnosis of endometriosis, diagnosed via laparoscopy? Required to answer. Single choice.
Yes
No

3. Can you confirm that you identify as Black? Required to answer. Single choice.
Yes
No

4. Can you confirm that you identify as female and your gender identity is the same as the sex you were assigned at birth? Required to answer. Single choice.
Yes
No

5. What is your age group? Required to answer. Single choice.
18-24
25-34
35-44
45-54
55-64
64 and above
Prefer not to say

6. What is your sexual orientation? Required to answer. Single choice.
Heterosexual/Straight
Gay women/Lesbian
Bisexual
Prefer not to say

7. What is the highest level of education you have completed? Required to answer. Single choice.
Primary school
Secondary school
College/Apprenticeship
University - undergraduate degree
University - post graduate degree
Doctorate e.g. PhD
Prefer not to say

8. What is your current employment status? Required to answer. Single choice.
Employed - Full time
Employed - Part time
Self employed
Unemployed/seeking employment
Student

Retired
Prefer not to say

9. What is your religion? Required to answer. Single choice.
Christian
Buddhist
Hindu
Jewish
Muslim
Sikh
Atheist
No religion
Prefer not to say

10. How old were you when you first experienced your symptom(s) of endometriosis? Required to answer. Single line text.

Enter your answer

11. How old were you when you first sought healthcare (either within the NHS or privately) for your symptom(s) of endometriosis? Required to answer. Single line text.

Enter your answer

12. How old were you when you received your diagnosis of endometriosis? Required to answer. Single line text.

Enter your answer

13. What healthcare services did you access regarding your symptom(s) in the process of getting a diagnosis of endometriosis? Please select all that apply. Required to answer. Multiple choice.
GP surgery
Endometriosis Specialist Centre
Gynaecology Service
Accident and Emergency Services/Urgent Care
Not sure
Prefer not to say

14. What health professionals did you see in relation to your symptom(s) of endometriosis in the process of getting diagnosed? Please select all that apply. Required to answer. Multiple choice.
GP
General Practice Nurse
Gynaecologist
Endometriosis Specialist Nurse/Clinical Nurse Specialist
Surgeon
Not sure
Prefer not to say

15. How satisfied were you with the healthcare you received in relation to getting your diagnosis of endometriosis? Required to answer. Single choice.
Very satisfied
Somewhat satisfied
Neither satisfied nor dissatisfied
Somewhat dissatisfied
Very dissatisfied

16. Did you access private healthcare during the process of getting your diagnosis of endometriosis? Required to answer. Single choice.
Yes
No
Not sure
Prefer not to say

17. Were you diagnosed with any other gynaecological health conditions before getting a diagnosis of endometriosis? Required to answer. Single choice.
Yes
No
Not sure
Prefer not to say

18 . If you answered yes to the above question, please state which other gynaecological health conditions you were diagnosed with prior to endometriosis. Multi Line Text.
Enter your answer

19. Did anyone in your family have a diagnosis of endometriosis prior to you getting a diagnosis? Required to answer. Single choice.
Yes
No
Not sure
Prefer not to say

20. Would you be interested in taking part in an interview to talk about your experiences in more detail? The interview would take place either in person, online or over the phone, depending on your preference. The interview would last approximately 1 hour. The interview would take place with the lead researcher, who identifies as a white female. Required to answer. Single choice.
Yes
No

21. Would you be interested in reviewing and providing feedback on the initial findings of the study and/or making suggestions on how the findings could be shared once the study is completed? Required to answer. Single choice.
Yes
No

22.If you have answered yes to either questions 20 or 21, please could you provide the best way of contacting you (e.g. a phone number or email address) below, so the researcher can get in touch with you to discuss this further. You can choose to opt out of these parts of the study if you no longer wish to participate. Multi Line Text.
Enter your answer

Appendix J

Participant Consent Form – Interviews

CONSENT FORM

I, the undersigned *[please give your name here, in BLOCK CAPITALS]*

…..………

hereby freely agree to take part in the study entitled

The Journey to a Diagnosis of Endometriosis: An Exploration of Black Women's Experiences

(UH Protocol number LMS/PGR/UH/05451)

If you agree, please initial box

1. I confirm that I have been given a Participant Information Sheet giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, and how the information collected will be stored and for how long. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of this part of the study I will be informed, and asked to renew my consent to participate in it.	
2. I have been assured that I may withdraw my interview from the study up to two weeks following participating in this without having to give a reason. I understand that following this two week period I will be unable to withdraw my data.	
3. In giving my consent to participate, I understand that voice or video recording of the interview will take place and I have been informed that this recording will not be transmitted/displayed.	
4. I have been given information about the risks of taking part in an interview. I have been told about the aftercare and support that will be offered to me in the event of this happening.	
5. I have been told how information relating to me will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.	
6. I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities.	
7. I agree for the lead researcher to contact me again following my interview to invite me to provide feedback on the study's initial findings and/or discuss how the study's findings could be shared **(optional)**	

Signature of participant…………………………………..…Date………………………..

Signature of (principal) investigator Date

Name of principal investigator *[in BLOCK CAPITALS please]*

Appendix K

Debrief Forms

Debrief Information – Initial Survey

Thank you for taking part in this study.

It is hoped you have had a positive experience completing this questionnaire. If you wish to talk to someone about your experiences of endometriosis following completing the questionnaire, please see below the contact details for organisations you could contact:

Endometriosis UK Volunteer led Support Line: 0808 808 2227
The Endometriosis Foundation: www.theendometriosisfoundation.org/join-our-community
Your GP/Or call NHS 111

Samaritans 24/7 Free Helpline: 116 123

NHS talking therapy service: https://www.nhs.uk/service-search/mental-health/find-an-NHS-talking-therapies-service

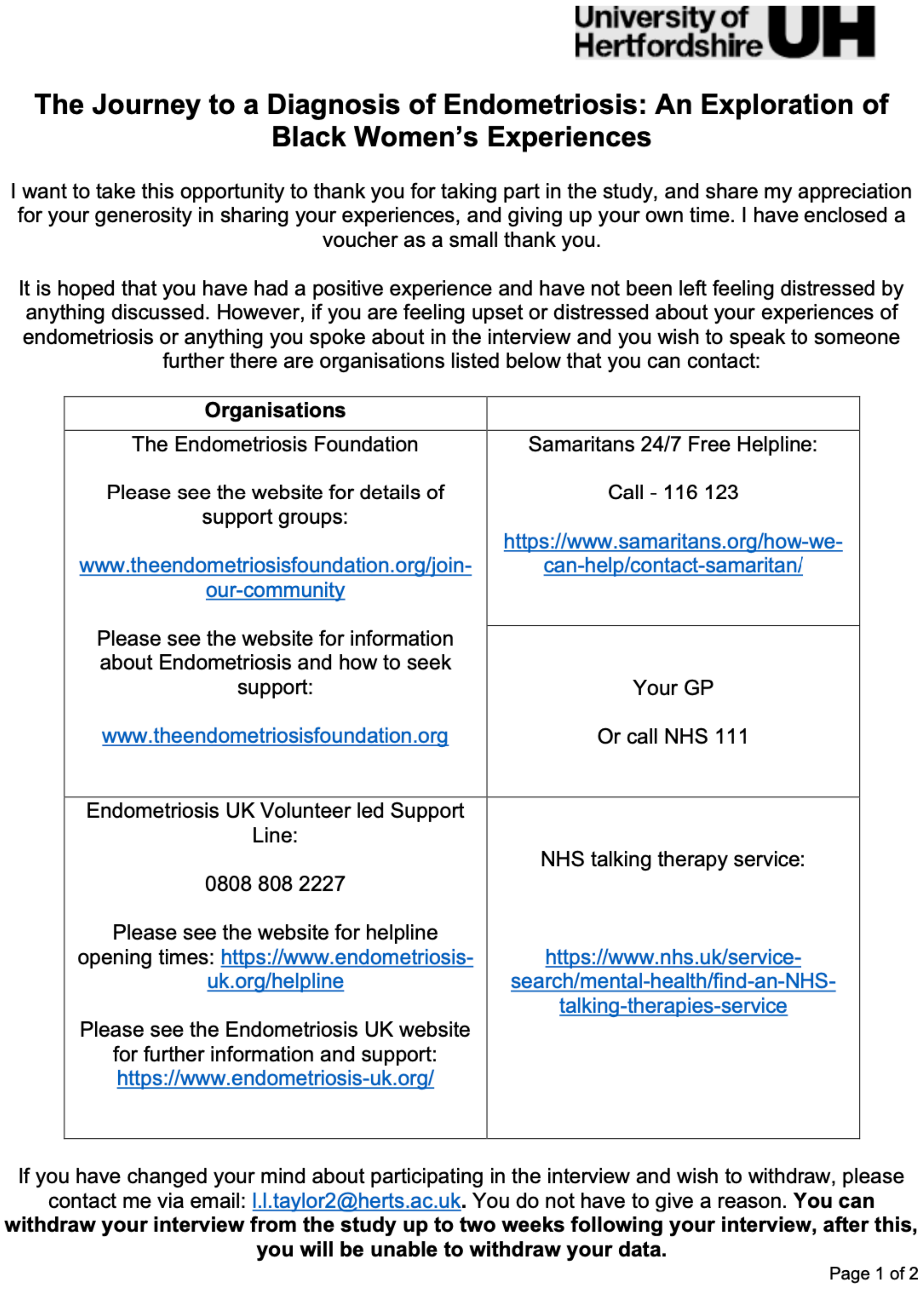
If you have agreed to be contacted again to talk about your experiences in more detail in an interview, and/or to review the initial findings or to discuss sharing the study's findings once completed, the researcher will be in touch. Please be aware that unfortunately, it may not be possible to contact every individual if there is significant interest in these aspects of the study and your interest is greatly appreciated.

If you would just like to hear about the findings of the study once completed, please feel free to contact the researcher on: **l.l.taylor2@herts.ac.uk** and you will be updated once the study is complete.

If you have any further questions, please do not hesitate to contact the lead researcher at l.l.taylor2@herts.ac.uk or the research supervisor, Dr Louise Shepheard-Walwyn at l.shepheard-walwyn@herts.ac.uk

Thanks again for taking part!

Debrief Form – Interviews



University of Hertfordshire UH

The Journey to a Diagnosis of Endometriosis: An Exploration of Black Women's Experiences

I want to take this opportunity to thank you for taking part in the study, and share my appreciation for your generosity in sharing your experiences, and giving up your own time. I have enclosed a voucher as a small thank you.

It is hoped that you have had a positive experience and have not been left feeling distressed by anything discussed. However, if you are feeling upset or distressed about your experiences of endometriosis or anything you spoke about in the interview and you wish to speak to someone further there are organisations listed below that you can contact:

Organisations	
The Endometriosis Foundation Please see the website for details of support groups: www.theendometriosisfoundation.org/join-our-community Please see the website for information about Endometriosis and how to seek support: www.theendometriosisfoundation.org	Samaritans 24/7 Free Helpline: Call - 116 123 https://www.samaritans.org/how-we-can-help/contact-samaritan/
	Your GP Or call NHS 111
Endometriosis UK Volunteer led Support Line: 0808 808 2227 Please see the website for helpline opening times: https://www.endometriosis-uk.org/helpline Please see the Endometriosis UK website for further information and support: https://www.endometriosis-uk.org/	NHS talking therapy service: https://www.nhs.uk/service-search/mental-health/find-an-NHS-talking-therapies-service

If you have changed your mind about participating in the interview and wish to withdraw, please contact me via email: l.l.taylor2@herts.ac.uk**.** You do not have to give a reason. **You can withdraw your interview from the study up to two weeks following your interview, after this, you will be unable to withdraw your data.**

If you have agreed to be contacted again to review the initial findings, or to discuss ideas about sharing the study's findings once completed, I will be in touch as discussed.

If you would just like to hear about the findings of the study once completed, please feel free to contact me via email: l.l.taylor2@herts.ac.uk and I can update you once the study is complete.

Thank you once more for participating!

If you have any further questions about the study or wish to discuss your participation further, please see the lead researcher and the research supervisor's contact details below:

Lauren Taylor – Lead Researcher:

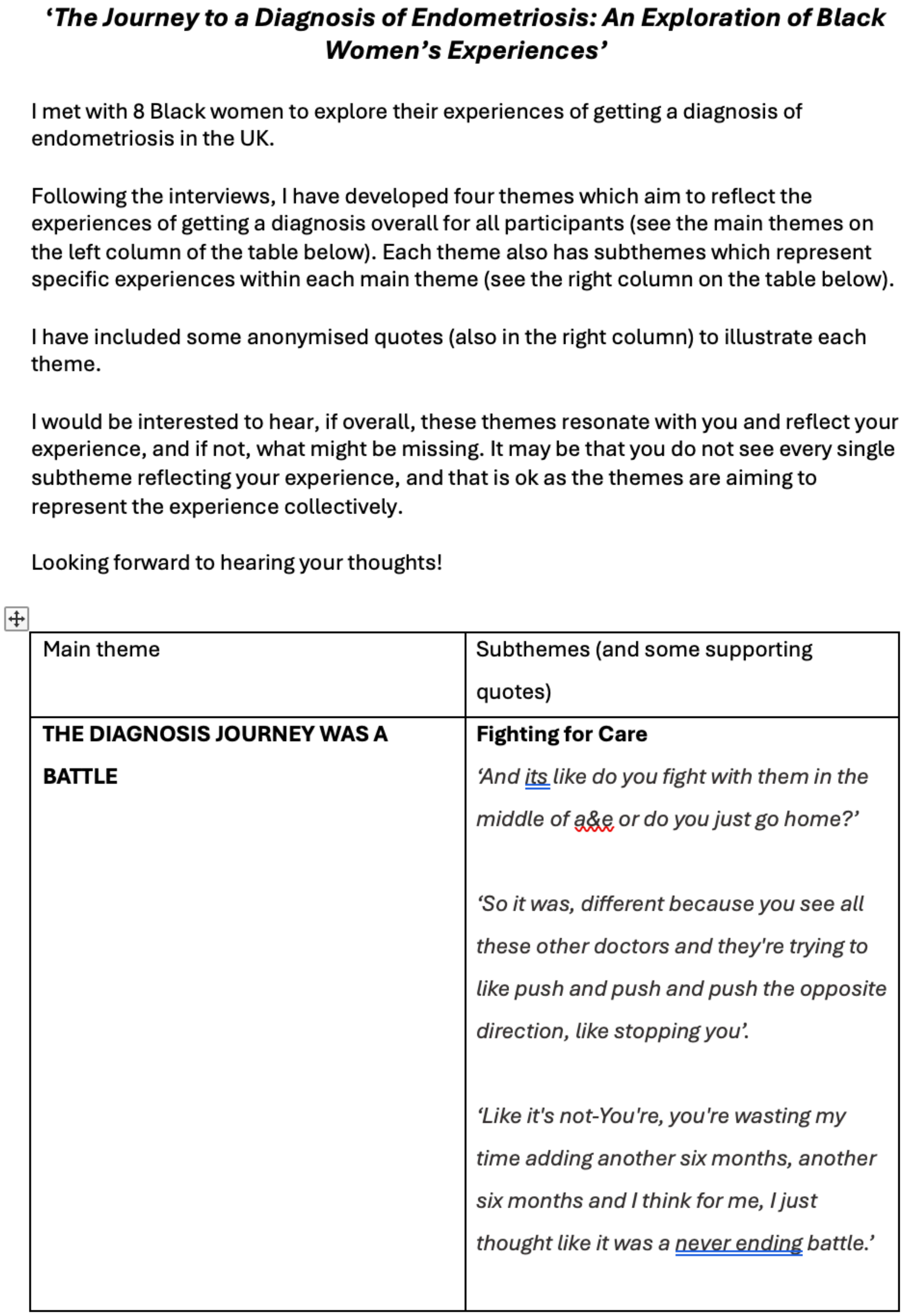
l.l.taylor2@herts.ac.uk

Dr Louise Shepheard-Walwyn – Principal Research Supervisor:

l.shepheard-walwyn@herts.ac.uk

Appendix L

Extract of Summary Sheet of Themes Sent to Participants



'The Journey to a Diagnosis of Endometriosis: An Exploration of Black Women's Experiences'

I met with 8 Black women to explore their experiences of getting a diagnosis of endometriosis in the UK.

Following the interviews, I have developed four themes which aim to reflect the experiences of getting a diagnosis overall for all participants (see the main themes on the left column of the table below). Each theme also has subthemes which represent specific experiences within each main theme (see the right column on the table below).

I have included some anonymised quotes (also in the right column) to illustrate each theme.

I would be interested to hear, if overall, these themes resonate with you and reflect your experience, and if not, what might be missing. It may be that you do not see every single subtheme reflecting your experience, and that is ok as the themes are aiming to represent the experience collectively.

Looking forward to hearing your thoughts!

Main theme	Subthemes (and some supporting quotes)
THE DIAGNOSIS JOURNEY WAS A BATTLE	**Fighting for Care** *'And its like do you fight with them in the middle of a&e or do you just go home?'* *'So it was, different because you see all these other doctors and they're trying to like push and push and push the opposite direction, like stopping you'.* *'Like it's not-You're, you're wasting my time adding another six months, another six months and I think for me, I just thought like it was a never ending battle.'*

	Being Dismissed and Undermined by Healthcare Professionals *‘so I started battling with the GP and saying I need to be referred to a gynaecologist and they said no, they want to try and put me on the coil again.’* *‘And to be honest, my gynaecologist wasn't great cause he just said Google it (laughs) and I was like, what is it? He said Google it, so I thought alright, OK. But he was like I can see a lot on your MRI scan you must be in horrible pain…’* *‘And there was this moment that you're feeling this pain, you know it is real, but actually it's somebody said to you, we looked at your inside and it's we don't know what you're talking about.’* *‘When I asked him about the pain, he was like, yeah, there's nothing wrong (laughs) So what do you do right? Like you just- It's not that they're not nice people, but they don't take your pain seriously.’* **Positive Experiences Within Healthcare are an Exception not the Norm** *‘…she really, really sounded like she cared about what was going on with me, and she was just like, you need to be*

Appendix M

Semi-Structured Interview Schedule

Introduce interview – Researcher to remind participant that they can choose what they talk about in the interview, including acknowledging that the participant may have had difficult experiences within healthcare (Racism, discrimination). Researcher to remind participant that they can choose to withdraw from the study at any time without giving a reason. Researcher to ask participant if there is anything they can do to support the participant to feel as comfortable as possible during the interview. Researcher to confirm with participant that they are in a private and comfortable space.

Interview Schedule:

1. Tell me how you came to have a diagnosis of endometriosis?

Prompts
Can you tell me when you first noticed symptoms?
What happened before/after that?
How did that feel?
Did you notice having any thoughts about that?

2. How did you experience the healthcare you received during this time?

Prompts
How did you experience interactions with/treatment by healthcare professionals?
How did you feel about this?
Did you notice having any thoughts about that?

3. Did the process of getting a diagnosis affect your everyday life?

Prompts
Work/school, relationships, well-being, hobbies and interests
How did this feel?
Did you notice having any thoughts about that?
What did this mean to you?

4. How would you describe yourself?

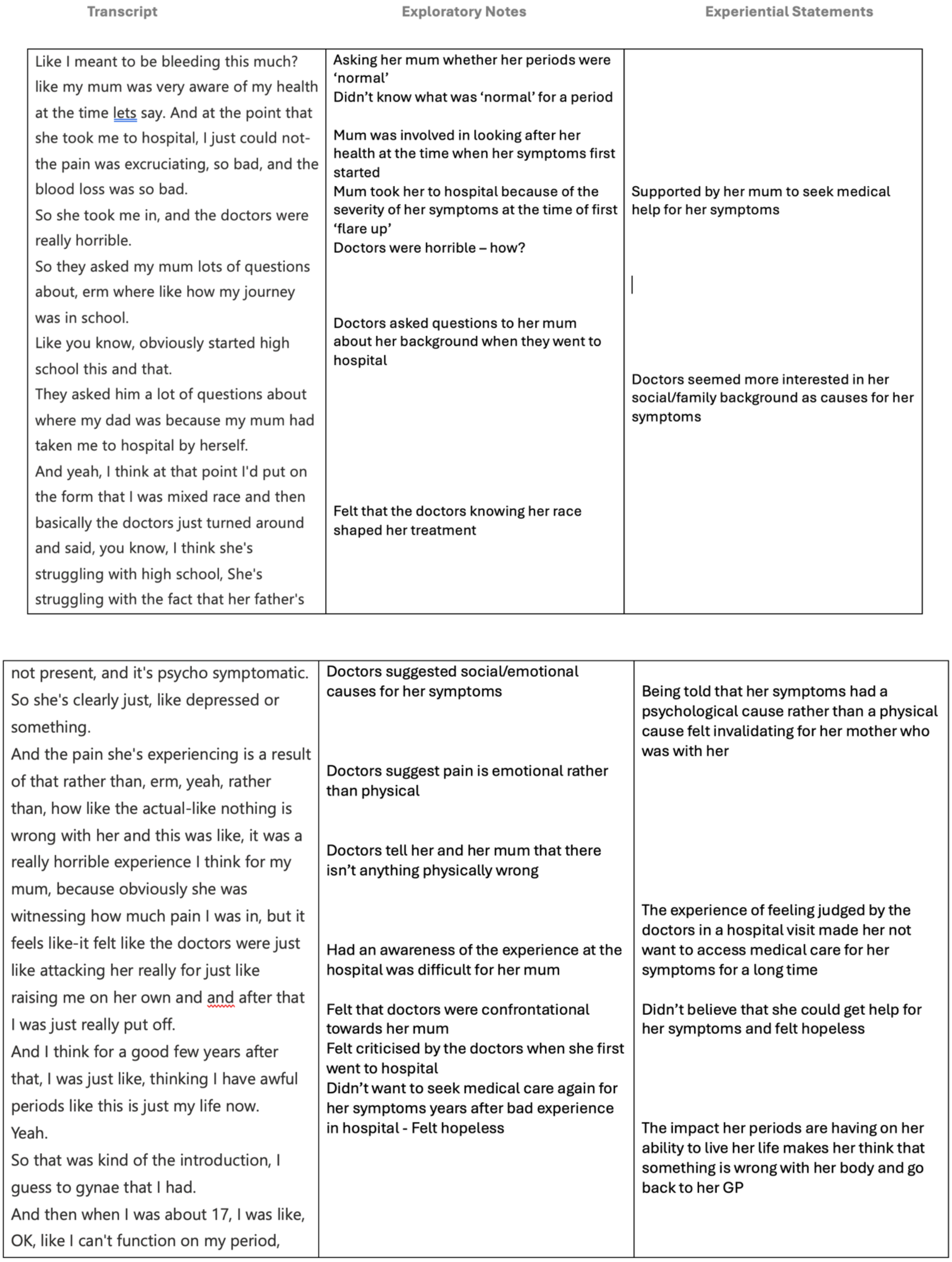
5. Has getting a diagnosis of endometriosis changed how you see yourself?

Prompt
If so, how?

6. What does being diagnosed mean to you?

Prompts
How did it feel to be diagnosed?
What did it mean for your health and symptom management? Overall wellbeing?

Appendix N
An Extract from an Analysed Transcript Including Exploratory Notes and Experiential Statements



Transcript	Exploratory Notes	Experiential Statements
Like I meant to be bleeding this much?	Asking her mum whether her periods were 'normal' Didn't know what was 'normal' for a period	
like my mum was very aware of my health at the time lets say. And at the point that she took me to hospital, I just could not- the pain was excruciating, so bad, and the blood loss was so bad.	Mum was involved in looking after her health at the time when her symptoms first started Mum took her to hospital because of the severity of her symptoms at the time of first 'flare up'	Supported by her mum to seek medical help for her symptoms
So she took me in, and the doctors were really horrible.	Doctors were horrible – how?	
So they asked my mum lots of questions about, erm where like how my journey was in school. Like you know, obviously started high school this and that.	Doctors asked questions to her mum about her background when they went to hospital	
They asked him a lot of questions about where my dad was because my mum had taken me to hospital by herself.		Doctors seemed more interested in her social/family background as causes for her symptoms
And yeah, I think at that point I'd put on the form that I was mixed race and then basically the doctors just turned around and said, you know, I think she's struggling with high school, She's struggling with the fact that her father's not present, and it's psycho symptomatic. So she's clearly just, like depressed or something.	Felt that the doctors knowing her race shaped her treatment Doctors suggested social/emotional causes for her symptoms	Being told that her symptoms had a psychological cause rather than a physical cause felt invalidating for her mother who was with her
And the pain she's experiencing is a result of that rather than, erm, yeah, rather than, how like the actual-like nothing is wrong with her	Doctors suggest pain is emotional rather than physical Doctors tell her and her mum that there isn't anything physically wrong	
and this was like, it was a really horrible experience I think for my mum, because obviously she was witnessing how much pain I was in, but it feels like-it felt like the doctors were just like attacking her really for just like raising me on her own and and after that I was just really put off.	Had an awareness of the experience at the hospital was difficult for her mum Felt that doctors were confrontational towards her mum Felt criticised by the doctors when she first went to hospital	The experience of feeling judged by the doctors in a hospital visit made her not want to access medical care for her symptoms for a long time
And I think for a good few years after that, I was just like, thinking I have awful periods like this is just my life now. Yeah. So that was kind of the introduction, I guess to gynae that I had.	Didn't want to seek medical care again for her symptoms years after bad experience in hospital - Felt hopeless	Didn't believe that she could get help for her symptoms and felt hopeless
And then when I was about 17, I was like, OK, like I can't function on my period,		The impact her periods are having on her ability to live her life makes her think that something is wrong with her body and go back to her GP

something is wrong and when I went to the doctor and all they wanted to do was put me on birth control and I was just like, no, I'm not feeling this. So again, I didn't really do anything because I was just like, well, they don't take me seriously, all they tried to do is offering hormones and no one-like I hadn't even heard the word endometriosis. Yeah. **Interviewer** 6:07 What was it like for you when- Yeah, at that, when you went to the hospital with your mom and they spoke to you about kind of, they were asking those questions about Dad. What was that like for you? Do you remember? **Participant** 6:18	Age 17 - symptoms stopping her from functioning She knew something wasn't right with her periods Went back to the GP and was offered contraception as a treatment option Did not want to take contraception as a treatment Didn't feel like she could get the help she needed as wasn't taken seriously by HCP Being offered contraception made her feel dismissed Endometriosis had not been mentioned at this stage	GP had their own agenda in her appointment – GP was only interested in prescribing her contraception Feels dismissed by GPs approach to the appointment

I think it was, it was really dehumanizing. I think I, you know, I looked after my grandma as a child, like I was a young carer, so I was really used to seeing how how, like the medical health system treats people in general, particularly people from from black and brown backgrounds. So I guess I had observed that, I'd observed my family members being treated quite unfairly, but I guess because at that point my experiences with racism, let's say, hadn't been so obviously structural, like I didn't have that in my vocabulary. But when I went to doctors and the doctor didn't believe me, I guess I just didn't know, I didn't think that that was something that was gonna happen. And and I remember feeling like really ,embarrassed and scared, like I thought they were telling me that I was crazy.	Treatment in first hospital visit was dehumanizing Experiences caring for her grandma shapes her knowledge of the medical health system Feels a difference between how the medical system treats people from Black and Brown backgrounds in comparison to people from White backgrounds Felt that previous racism observed within the medical system had been specific interpersonal incidents Hadn't experienced structural racism before having her own experiences of seeking healthcare Wasn't expecting to not be believed about her symptoms by HCPs – wasn't expecting healthcare system to be racist	Perceives treatment by HCPs as being due to her identity as a Black women and that this felt unfair Understands her experiences of racism within her diagnosis journey to exist within the structures of healthcare and present at the interpersonal level Thought that the doctors thought that she was making her symptoms up which felt humiliating and scary Invalidation by doctors was unexpected at this time as held the belief that healthcare professionals were there to help

And I was just like, I felt a lot of shame around that. At the same time as being like, but I'm in really bad pain, can't you tell? And and yeah, it was it was really, really difficult to to vocalize how that made me feel like at such a young age still having that mentality that like ohh you'll go to the doctors and they'll believe you, to being in an environment where I felt like nobody believed me at all was um yeah, really challenging. **Interviewer** 7:25 Umm yeah, I'm wondering if that experience of structural racism has come up anywhere else for you within your journey that you've described today? **Participant** 7:33 Yeah. I mean, I honestly continuously like I think	Not being believed by HCPs implied that she was 'crazy' – felt that doctors thought that she was imagining or making up her symptoms Felt ashamed by Doctors responses of dismissal Disbelief that doctors do not recognise her pain Hard to articulate how being dismissed by doctors made her feel at the time Young age shapes how she understood the experience of being dismissed by Doctors Being dismissed by Doctors was unexpected and altered her expectations of the medical encounter	Was difficult to understand when her healthcare experiences did not meet her expectations as this was a surprise Having less experience with the medical system at a younger age played a role in how she understood the initial experiences of healthcare on her journey experiences of racism played a significant role in her experience of the diagnosis process Had been struggling with her symptoms and didn't feel that she could continue living this way Saw getting the diagnosis as a way to help things get better
erm, continuously, when when my endo, when it finally got to a point where I need the diagnosis, I went to the doctors, and so I went to the hospital, I went to A&E with my best friend, and my best friend's also a mixed race Black girl, and um it was in the middle of the pandemic and she took me to the hospital because I just could not stop bleeding. And I remember being told by a doctor like Ohh women of your ethnicity just have really bad periods. And I was kind of like you don't even know what my ethnicity is, this is ridiculous, but I was also really shocked by that. And then they offered me paracetamol, and then I found out later that they didn't, even though a gynaecologist had sent me in and said I think shes having ectopic, even though there was just pain on one side, they didn't even check if I	racism has been a constant in shaping her experiences in her diagnosis journey with endo Point of 'need' of diagnosis – no longer can continue with symptoms impacting her as they were Needed diagnosis - accessed medical care to get diagnosis Awareness of how her own and her friends identities as mixed race Black girls shaped their treatment in A&E Friend accompanied her to A&E due to excessive bleeding Doctor made assumptions about her ethnicity in the care received in A&E Doctor not interested in finding cause for her heavy bleeding Doctors understanding of her symptoms didn't make sense to her as these were based on assumptions the Doctor was making about her ethnicity Shocked by racial biases in her treatment by Doctor in A&E – what shocked her? Didn't feel that her symptoms were investigated appropriately when she went to the hospital Didn't feel that doctors believed her about how severe her pain was	Did not feel that the Doctor's understanding about her symptoms being related to her ethinicty was credible. Felt shocked by overt racism- that a doctor would make an assumption about her ethnicity and use this to dismiss her symptoms Felt invalidated through the actions of the doctors and how she was treated Felt very concerned about her physical wellbeing following her visit to A&E as did not feel she received appropriate care

was pregnant and I was just like, this is horrendous right. Like you don't believe that I'm in pain, you think I'm exaggerating, you think that I can just take a paracetamol and I'll be fine, and you'll actually missing something that could be, really like could kill me. And in the time between being discharged from A and E and then going to have to pay for my own scan, I was actually just sat there every day Like what if I die? It was, It was terrifying and I think that throughout my journey with with Endo, I've had a lot of kind of racism thrown at me in the sense of or in in the form of people not believing me, people thinking that I can tolerate pain more, people not being thorough like I think it's especially because because I am of mixed heritage, people often don't ask the right questions like they don't ask about my	Being told to take paracetamol for her pain felt dismissive – Doctors did not believe how severe her pain was Felt concerned about her symptoms being undiagnosed and the impact this could have on her Following dismissal of her symptoms in A&E she felt scared she might die from her symptoms Experiences within her diagnostic journey shaped by racism Her interpersonal interactions in medical encounters were underpinned by racism Discriminated against within the medical encounter due to her race	Racism has shaped her interactions with healthcare professionals in the form of racist assumptions made about her experience of pain as a Black women
family history or they assume that if I explain one type of my ethnicity to them that they've got the full picture, whereas it actually is really important to know that I'm like East African as well as South Asian because, you know, there are some kind of, I guess like health problems more associated with the black community that they weren't even checking for erm and yeah, I think I think as well like the actual time its taken, So it took basically 13 years for a diagnosis, and I know that for white women it's around seven years. But the fact that it took even that like basically double that for me, definitely, I think it's is because of racism, because my pain wasn't seen as kind of, as important or worth learning about or worth asking about as well. And I also just think that one thing, one like really strange moment for me was meeting other people who have	HCPs had made incorrect assumptions about her race which influence what diagnoses are considered and checked for Feels that the diagnosis process would have been different if she was a white women Felt her pain wasn't perceived as being worthy of care by HCPs Felt that being a Black women shaped how HCPs perceived and responded to her pain Strange moment – 'unexpected'?	Assumptions made by HCPs about her race have shaped her healthcare and treatment Being positioned as being less worthy in society as a Black women shaped her treatment by healthcare professionals and delayed her getting a diagnosis When meeting other white women with endometriosis she realised the difference in her treatment – wasn't offered the same pain management

endometriosis, and in particular meeting white women with endometriosis. And hearing about all of the treatment offers that they got and realising I just didn't have any of that. Like I didn't, there were no, like one of my friends with endo she was referred for like pain physio, another person was referred to holistic services and these are all either in the borough that I live in or like neighbouring boroughs. So I know that they have the exact same services available, but yeah, definitely hearing that the solution for me was you can tolerate it and if you can't, we'll just pump you with drugs and we won't investigate. I think definitely was was because of this idea that either I was making it up or that I was more able to tolerate pain. **Interviewer** 10:43	Meeting White women with endometriosis post diagnosis highlighted differences in what treatment had been offered to her Did not receive treatment options for her pain post diagnosis Felt she was expected to tolerate her pain Didn't feel that HCPs were interested in finding a cause to her pain Felt that as a Black women she was perceived to be lying about her pain or more able to tolerate it	Felt that she was perceived as less trustworthy or more able to tolerate her pain as a Black women which shaped her healthcare treatment

Yeah. How did it feel when? Yeah. You kind of spoke to others who also have endometriosis, and you found that out. How did-Yeah, What was that experience like? **Participant** 10:52 I felt really failed, and I think that that comes like, that was a really dark moment for me when I realized that I could literally have been dying and people didn't see my life as well, like saving or valuing. And that's for me, was really, really hard. And erm, yeah, like I think that I think for me like going around the world as a, as a mixed woman, I'm always aware that there's racism around me, but for some reason the racism I've experienced in the	'dark moment' – felt failed by healthcare professionals Didn't feel that HCPs valued her life being a Black women Awareness of racism existing in the world in which she is having her experiences in but not always aware of the direct impact it may be having on her	Her healthcare experiences were a realisation for her of how Black women are positioned as less worthy in society Racism experienced within healthcare in the diagnosis process felt more overt and visible than racism she has observed before

healthcare system has felt so much more like personal and pointed because it's been so like it's it's been right in my face. Like, I'm literally crying asking for help and and people don't take me seriously and. And yeah, I think that that it's frustrating, like I know that my white friends are-they have also had a tough time with their diagnosis, but I know that they've never had to experience the level of kind of yeah, difficulty I guess that I have, and I think that hearing things like that, definitely made me very frustrated at the time and I was of just like ohh, OK like how come your pain is valid and but mine isn't?	Racism felt direct and personal in her healthcare experiences during the diagnosis process– different to her experiences of racism before Her overt displays of distress (crying) were not taken seriously by healthcare professionals Racial discrimination in her healthcare felt frustrating Hearing about others experiences made racial discrimination apparent to her Hearing about others experiences made her question why her pain is not seen as valid by healthcare professionals	Was frustrated by knowledge of how her white friends have benefited from white privilege in their diagnosis journeys Observing whiteness in the diagnosis journey makes her feel invalid

Appendix O

Example of Recording Initial Observations of Transcript as Part of Step One of Analysis

Why minimising the time of diagnosis journey?
Being taken seriously – reciprocal (participant and professionals and between participant and mother).
Worry/anxiety – unknown? Picking up on others anxiety? – waiting raised anxiety due to uncertainty
Google it – why was this suggested? Why did participant laugh? Uncomfortableness? Later talks about the difficulties of this experience – increased anxiety
Surprise diagnosis -endo unknown– symptoms unspoken – But then what's normal? – when symptoms were spoken and normalness was questioned, then participant chooses to act and seek help, though materially symptoms haven't changed, validation gives permission? Normalness defined through dialogue – speaking with family
Fertility is spoken about – why? Importance of fertility apparent to participant through her account e.g. expressed by being a prominent feature in her worries and in her thinking about treatment decisions
No one speaks about it – leads participant to reflect from family to more broadly within Black community, but also how Black women are represented within Endo content/information
Tensions between sharing and choosing not to share – participant reflects on experiences of sharing/ positives and difficulties around sharing in her family, and draws on broader cultural rules and beliefs

But positive experiences speaking with GP about symptoms – felt cared for, despite worry about the unknown/seriousness of the problem.

Experiences with health professionals good and bad stayed with the participant
Bad experiences put in the context of societal dismissal/lack of empathy for women's health problems

Interactions with professionals, scans and waiting increased anxiety – but professionals also validated participants experiences by naming (legitimising?) pain
Waiting for diagnosis – participant tried to seek information available e.g. online and through family health experiences to make sense of own experiences
Pushing through, pushing pain away – doubting own experiences – waiting and finding out information online without professional support and the uncertainty this caused also led to doubting own experiences
Belief that pain is normal has allowed participant to dismiss own experiences, push away pain and then doubt own experiences
Pushing through is part of who the participant is
Participant puts healthcare experiences in the context of being a black women and their experiences of healthcare more broadly to understand own experiences
Needing validation from professionals (others) to legitimise pain
Using family experiences to make sense of own experiences

Appendix P

PETs Table for Participant Four

Personal Experiential Themes and Subthemes

A. THE HARM CAUSED BY THE DIAGNOSIS PROCESS

Lack of care by HCPs has a psychological impact – assumption of Black women being strong prevent this from being considered (p.10)
"but sometimes it's the psychological stuff where you know something's wrong but no ones listening, and I think GP's really don't understand how damaging that can be, and, because there's that narrative for black women being strong or being aggressive."

The length of time it took to get the diagnosis meant that getting the diagnosis couldn't prevent her suffering (p.54)
"The diagnosis helped me get a better understanding of what was happening, but it came too late."

Got the diagnosis too late to prevent long term consequences for her health and fertility (p.38)
"…I have to fight to get seen and I did and it worked, but it was too late. By the time everything came around."

Being offered hormonal treatments prevented further investigation and treatment whilst exacerbating her suffering (p. 39)
"I wish that they wouldn't think straight away to just use these treatments because it's very damaging and it prolongs suffering as well."

The process to getting the diagnosis had lasting physical and psychological damage to her (p. 55)
"Either way I'm glad that I got it, but that surgery, what the initial gynecologist did set me up in a bad way for adhensions, and pain and trauma and... I don't know I've forgiven her for it to be honest, I don't know if I ever have."

B. LEARNING TO SELF-ADVOCATE

Self-Advocacy was a necessary burden
Successfully advocates for further investigation against resistance of the GP (p.2)
"So I went to the GP and said could I have an MRI and they were like, no, you can't, erm There's nothing wrong. I said, there is something wrong, I said I've gushed through and I nearly fainted, so they reluctantly sent me for an MRI…"

Forced to take on an active role and persist to get further treatment post diagnosis (p. 3)
"I went back to [information removed] and said that I need some help Like I went into A&E and I was like someone from A&E needs to take me to Tuke Ward and tell them to see me. So they saw me and they sent me for an MRI…"

Doing the work to get others to listen to her has been exhausting (p. 6)
"…it's been rough trying to get people to listen and pay attention…"

Had to make professionals take her seriously to get access to healthcare she needed (p. 7)
"And it's like, I don't really like living a life where you aim to prove people wrong, But when it comes to your health and you know something's wrong, you have to prove the professionals wrong just for you to get the help that you need…"

A dilemma of being the ‘perfect patient’ – balancing needing to avoid healthcare being withdrawn with self-advocating to get her needs met (p. 10)
“…or they don't want to listen to what you have to say and if you're being quiet forthcoming with your views, they wanna say…”

Different strategies used to self-advocate
Having to pick when to fight her battles with healthcare professionals (p.49)
“And its like do you fight with them in the middle of a&e or do you just go home?”

Her distress was a way to communicate with her GP (p. 2)
“…basically so they agree to refer me after crying…”

Bargaining with GP to get needs met (p. 2)
“…and I was like, I'm not leaving until I get referred to gyanecologist, I've done what they said, I tried the coil…”

Prepares in advance of her appointment to support her experiential knowledge about her body with research evidence (p. 2)
“And I was like, I know, I have endometriosis and she was like why? I said because everything's changing like, my boobs just started to expand, I had a friend who had endometriosis and I just did my research. So, she agreed to book me in for surgery…”

Attending A&E helped her evidence her pain- Could use A&E attendance as evidence for her pain when she see’s a specialist (p. 49)
“But for me, I learned that if you keep going back as well and it registers on the system that you've been in a&e, when you do finally get to see a specialist, you can bring that up and like use it to your advantage.”

Learning to self-advocate
Didn’t have the understanding of her body or what she needed before the diagnosis – more difficult to advocate for herself (p. 7)
“…between lets say 2018 to 2020 I was not able to advocate for myself cause I didn't know I was advocating for, I didn't know what was going up against, I just knew that something was wrong…”

Getting the diagnosis has given her an awareness of what she needs (p. 8)
“…whereas now I come armed with like my notes like and I I tell them how to speak to me…”

It was a process for her of having to learn how to self-advocate through her own experiences (p. 18)
“So that's why I would say arm yourself with your notes and I had to learn that, I didn’t really have anyone guiding me at the time and I think that was my biggest issue…”

Developed a way of talking about endometriosis to get her needs met post diagnosis – no longer her role to manage other’s discomfort (p. 19)
“It just became so natural to me, Because I stopped caring what they thought, because I knew that for me to survive and me to excel and get my promotions, I need to just be as open and honest. And if they're uncomfortable with it, that's their discomfort, it can't be mine.”

Has developed a confidence that now enables her to find advocating for herself easier in medical appointments (p. 21)
"So now I don't get nervous when I go to medical appointments. I'm just like they better listen to me because they're gonna come off worse than I am."

It was a realisation that she could advocate for herself (p. 22)
"…but for me, it's about just realizing that I actually have a voice."

C. **HAVING LIMITED POWER IN THE HEALTHCARE ENCOUNTER**

Lack of choice over her care
"Her wish for further investigation of her symptoms is denied by GP– the start of the battle (p.2)
So I started battling with the GP and saying I need to be referred to a gynaecologist and they said no, they want to try and put me on the coil again."

HCPs decide whether she gets care (p. 14)
"…you have to get referred to the specialist if they're willing to refer you, you then wait X amount of months for your appointment with specialist, then you see them and they decide if you're gonna go for a scan."

Her needs not recognised in the decision making of HCPs (p. 14)
"…its just decision making that don't really kind of like revolve around your needs.
It's just like whether in their head they agree with what you're saying or they think it needs further investigation."

Did not have a choice but to accept the treatment option offered (p. 5)
"I was like, I don't wanna do it, be on this and she said I have to do it in order for them to see that I'm accessing their care."

Healthcare was not collaborative – making choices or preferences about her care would be perceived negatively (p. 9)
"…if decline it for whatever reason they then say that you're not like making use or accessing the help available, but that's not help, that's like a death sentence in my opinion, Do you know what I mean?"

Felt pressured into agreeing with HCPs decisions during her diagnostic journey (p. 17)
"But if I was in my early 20s, I would have been railroaded at every stage because, I didn't know how to to advocate for myself."

GPs has power to offer treatment at primary care level and gatekeep investigation by a specialist
"And I and that's what I mean when I say, I feel like you've been gaslit because they wanna throw these things at you rather than giving you the option of having a proper endo specialist taking like, taking your kind of like notes, your background, your history, and then communicate with you or send you for a diagnostic surgery. (p. 10)"

Lack of power in healthcare post-diagnosis
assumptions made by others based on her identity as a Black working class women that she cannot understand her own body (p.7)

“And for me, having people overlook what I'm saying and undermine me, And I do think sometimes it was because of being a black woman, I do think sometimes it was because being like a working class black woman as well..”

Medical knowledge was privileged when thinking about her treatment rather than her experiential knowledge (p.39)
“Do you really think it's wise Giving me another dose? but I took it because they know better, right?”

HCPs held control over when she could be seen about her treatment (p.39)
“…as soon as you accept the coil, they're gonna banish you for that six to nine months because they're gonna say wait for the coil to take effect…”

Had to prove herself and be the ideal patient to access treatment (p. 40)
“And it was against my better judgment, but, I had to trust them because I needed to prove to them I'm willing to listen to them, but I need additional help…”

Her pain is viewed as not worthy enough for treatment by medical professionals – continues to struggle to get treatment post-diagnosis (p. 5)
“…and they said to him I could hear it unless it's an ectopic pregnancy send her away.”

D. THE JOURNEY DOESN’T END AT GETTING A DIAGNOSIS

Diagnosis highlighted lack of control over body
Getting the diagnosis made Endometriosis and the damage it had done become real (p.44)
“And because it was stage four and in the note she was like ohh, it's completely obliterated your pouch of Douglas, I didn't know what a pouch of Douglas was, but I zoned in on the word. Obliterated.”

Getting the diagnosis/having first surgery signified loss of control over her body (p. 45)
“Where it is what it is, there's nothing more that I can do, do you know what I mean and feeling that when I first had that first surgery, I was just like I knew it. I just knew.”

Getting her diagnosis helped her make sense of her symptoms to some degree – helped understand why she was having her symptoms but how this could happen in her body remained difficult to understand (p. 44)
“I felt like validated and what I was experiencing going through. But I was just like how does the body even do this? So I was a bit confused as well.”

Finds out by having the surgery that her body was not as it should be (p. 3)
“…my uterus's was messed up, everything was messed up.”

Endometriosis continues to dominate her life
multiple surgeries to control endometriosis had an impact on her body (p. 5)
“…now you've had that final, that third operation she knew for a fact that it was gonna cause more trauma to my body, which it did.”

Pain continues to have an impact on her mood (p. 46)
*“…Like we got in the car, I drove to the show, I didn't have anything pleasant to say because I was in **pain**.”*

Endometriosis continues to take over her body (p. 4)
"…because the endometriosis had pulled my appendix into my vagina and I could not believe-I was like I only had the surgery in Jan, and that was by by a skilled surgeon and then this happened."

Felt powerless over her body - Her body had betrayed her (p. 50)
"…I was so angry because I was like, how dare my body do this?"

Hysterectomy represented the damage done to her by endometriosis (p. 53)
"The damage was done, and that hysterectomy for me it was a realization that I'm a thirty-three year old having a hysterectomy."

Feelings of anger at endometriosis for not giving up with tormenting her (p. 52)
"I haven't had a space where I haven't felt pain, so to me, endometriosis, I just call it a wicked bitch, because that's what I feel like it is…"

An ongoing journey in accepting endometriosis
Difficult to process and understand what endometriosis had done to her body (p.52)
"when they're like, the appendix is in your vagina, I was like, how the hell does that even happen?"

Accepting endometriosis is a challenge and continues to resent the control it has over her body (p. 45)
"So it's just a living, and existing with it that I have to make peace with. And there are days I'm just fine, I'm just like it is what it is, I'm in pain, but it's life and there are other days where I'm just so angry…"

Challenges with understanding endometriosis continue to make her feel out of control which she finds difficult to accept *(p. 53)*
"I don't feel like I've actually made peace with endometriosis. I accept my circumstances for where they are because I'm not gonna be in denial, but I haven't made peace with it because I'm just confused by the way it moves, and how it got hold of me so aggressively because I clearly had it for so long."

Getting the diagnosis gave her a sense of injustice (p.44)
"And I was frustrated, because, I then I took even greater care, Now I still take great care, but then in particular I was like, I have done nothing to contribute to this. I know that it's not my fault, but it was very angry at the fact that I had it…"

Her journey was not as she expected it to be post diagnosis – was a loss of her expected future (p. 53)
"This is it, I thought I thought I'd still keep my both my ovaries and I'll be fine, I won't have to go into surgical menopause and then eight months later I'm in surgical menopause. And that that's another fight on his own."

Still difficult for others to understand
Culture shapes how her family understand and respond to her endometriosis (p. 30)
"So family not as great as the friends have been, very Caribbean, very as I said pray it away."

Others still do not take her symptoms seriously (p.16)
"Having people around you say oh take this supplement, do this, do that, are you sure it's not this, I'm like, I'm sure because its endometriosis and fibromyalgia, do you know, I mean…"

Family’s attempts at supporting her reflect difference in understanding of endometriosis and felt frustrating to not be understood (p.32)
“I needed more times where she didn't come in and tell me to drink aloe Vera juice cause it's gonna cure endometriosis. There are times that she really damaged my mental health to be honest…”

There is a lack of awareness of endometriosis and felt frustrating to not be understood (p. 16)
“Well oh you shouldn't be in meetings, so I shouldn’t work because I'm chronically ill, which means I always have some type of like, health issue or symptom impacting in my life.”

The lack of visibility of her endometriosis is a barrier to others understanding her experience (p. 56)
“But it it, that's what bothers me that is invisible to the naked eye, that my suffering is is hidden, to be honest.”

Having the diagnosis meant there was no longer conflict with others over what was wrong (p. 47)
“…it meant that I couldn't be challenged on whether or whether not I had it after that moment and…”

It has been difficult for others (with or without endometriosis) to understand her symptoms or the impact they have on her (p.15)
“Getting people to understand that you're not making it up, that when you cancel for something, it's because you're an agony. Just because they haven't experienced it doesn't-It doesn't impact your life, but also for those other friends who have endometriosis, but they have stage two very minimal symptoms. They're like well my endo’s not like that. Well, that's that's your body.”

E. RELATIONSHIP TO HELP-SEEKING TRANSFORMED THROUGH DIAGNOSTIC JOURNEY

Asking for help now feels possible
Came to realise the importance of having emotional support in her personal relationships whilst going through the diagnosis process (p. 19)
“It was very difficult to kind of like allow someone to come in and be a partner, but it was at the right time and I trust that no matter what, because, having emotional support meant that even times when I was vulnerable I could lean on him and recharge and then be able to go and fight my own independent battle within work, do you know what I mean?”

Began to trust her friends and feel safe to get emotional support (p. 25)
“And then when I realized that they actually want to help me and they should help me because that's how friendships work, I started asking people for emotional support, and it kind of just went from there.”

Her relationship has changed with help seeking –she is now someone who can ask for help (p. 26)
“So, when it comes to asking for help now, I always do…”

Change in her relationship to help seeking gives her contradicting feelings – She still has negative beliefs about asking for help (p. 27)
“I overthink like oh I've asked for help do these people think I'm a weakling, do they think that like I'm a burden. So I still struggle with it, but I've accepted it and made peace with it and I will ask for help and struggle with the fact that I’ve asked for help but I will still ask for help…”

In a process of negotiating asking for help and what it means about herself to do this (p. 27)
"So now I at least I do ask for help, but I beat myself up about it, and I'd like to conquer that bit at some point because it's not healthy and I feel like it would just make me more unwell to be honest."

Turning points in her relationship with help seeking
Symptoms prevent her from doing her job - Had to get support at work (p. 24)
"so, I needed to be able to work from home, otherwise I knew I wasn't gonna survive.
Which meant I had to speak to my line manager about it, which meant I then had to go through HR, do you know what I mean?"

Support from the endometriosis community has been unconditional and valuable (p.25)
"…and I have two support groups and those things are insane, because you can talk about, like, the worst things ever. But they get it."

Realisation that other's responses to her expressing her needs did not reflect her self – this changed her relationship with asking for help from medical professionals (p. 29)
"If I'm not fine, I'm gonna say I'm not fine, because… When I realized that if you told people the truth, they have the decision to either help you or not help you, that's on them."

Being introduced to the endometriosis community changed her relationship to asking for help (p. 25)
"And then when I was like introduced to the support chats for endometriosis and stuff, ***those changed everything****."*

Suffering in Silence – past difficulties asking for help
Seeking support from friends didn't align with how she saw her role as someone who looked after others (p. 25)
"and it's things like with my friends, I wouldn't go to them for, like, mental health support ever because I was always the person that's the one that they they come to for support themselves."

Seeking help puts her in a vulnerable position (p. 25)
"I need some support, and I hated asking for that. I hated it. Like I don't want no one to like, I don't like being bothered for one, but I don't want anyone…Being in my life that deep, if that makes sense…"

Asking for help signifies that she has failed in her role as a carer for others (p. 24)
…when I started become unwell I then had to ask him to do things like the school run and take [name removed] to like the childminder for me, and I hated it because I was like I'm failing that's my duty, that's my role and he was like, no, that's ***our*** *role.*

Beliefs about herself not being important have shaped her relationship with asking for help (p. 27)
"I think it's because I didn't ask for help so long, especially in the abusive relationships, that I've got into a vicious cycle of putting myself down. Not not viewing myself as important as those around me."

Negative beliefs about asking for help have prevented her from asking for help in the past (p. 27)
"…and I'd like to kind of like someday conquer that overthinking bit and that worry bit and that feeling like a burden, because before it would stop me from asking for help."

did not feel she should access healthcare for her period pain – period pain was normalised (p. 33)
“…but when it comes to GP's and stuff, you're only taught to go if, like, you're really poorly and, a period your told is normal so how are you gonna know that it means that you’re also poorly?”

Periods felt shameful due to stigma surrounding women’s reproductive health (p. 35)
“And I was ashamed of my kind of like female health.”

Feelings of shame around her menstruation restricted her from talking about her symptoms (p. 35)
“…so for me everything was framing it in a very dirty way, that its not nice and just horrible, so I was always embarrassed about it and never really want to talk about it. Just suffered in silence.”

Appendix Q
Final GETs Table

Experiential Group Themes with Supporting Experiential Statements and Quotes

A. THE DIAGNOSIS JOURNEY WAS A BATTLE

Fighting for care

Successfully advocates for further investigation against resistance of the GP

So I went to the GP and said could I have an MRI and they were like, no, you can't, erm There's nothing wrong. I said, there is something wrong, I said I've gushed through and I nearly fainted, so they reluctantly sent me for an MRI (Megan, p.2)

Having to pick when to fight her battles with healthcare professionals

And its like do you fight with them in the middle of a&e or do you just go home? (Megan, p.49)

Not being listened to was becoming threatening to her– instincts took over

I think I went on autopilot, and it was that fight or flight and I was just like I have to fight to get seen and I did and it worked (Megan, p.38)

Advocating for herself enables her feel in control and empowered

And if people try to intimidate me, it just makes me more confident because I'm like, I'm gonna push back on this. Erm you, you know, you can't make me feel small, You can't gaslight me.I will, I like, I know myself, I know my truth (Alicia, p. 30)

Found some GPs would oppose her preferences for her care

So it was, different because you see all these other doctors and they're trying to like push and push and push the opposite direction, like stopping you. (Alicia, p. 20)

Needed to advocate for herself with HCPs to change her situation

But yeah, it was about advocating for myself. I needed to build back up that confidence in order to advocate for myself, to get to where I am today, yeah. (Kayla, p. 27)

Advocating for herself in her GP appointment helped her be able to have a different experience in her appointment

Like you know, I'm actually advocating for myself now, and yeah, I think I'm going off topic, But yeah, I think that that's how I felt. I felt rushed in the beginning, but once I prepared myself going into consultation, then it it did help the process a bit more. (Kayla, p. 20)

Preparing for her next GP appointment gave her confidence in herself and her own knowledge of her body and confidence to have a more positive experience with the GP

It felt liberating in terms of being able to go in feeling prepared to talk to a GP, knowing that I had a negative like had previous negative experiences before. But I just went in open minded, optimistic and just advocating for myself because I know my body best. (Kayla, p. 21)

Felt as if there were a number of barriers to getting the diagnosis which she had to struggle to overcome

Like it's not-You're, You're wasting my time adding another six months, another six months and I think for me, I just thought like it was a never ending battle. (Sumaira, p. 7)

GP appointment felt more like a burden for her than supportive – felt like she had to prove herself and work to persuade the GP

Like having to prove something to you like you're the doctor you went to school for this? So why am I having to to tell you to how to do your job? (Sumaira, p. 30)

Having to fight to be taken seriously to get the diagnosis was another burden on top of living with severe symptoms

It was it was a lot, and then I think to also, to not have the diagnosis and then to also be constantly battling to be believed for the diagnosis. It was just, it was honestly exhausting… (Sumaira, p. 7)

Had to overcome significant challenges to get the diagnosis

I think like, the way it's built up with Endo because you know you have to fight for a diagnosis (Sumaira, p. 24)

Felt very concerned about her physical wellbeing following her visit to A&E as did not feel she received appropriate care

Like you don't believe that I'm in pain, you think I'm exaggerating, you think that I can just take a paracetamol and I'll be fine, and you'll actually missing something that could be, really like could kill me. And in the time between being discharged from A and E and then going to have to pay for my own scan, I was actually just sat there every day Like what if I die? (Sumaira, p. 4)

Thought that she was an inconvenience when advocating for herself at the GP

I'm not the kind of personality that would have done that because I would have felt like I'm making a nuisance of myself and being hysterical. (Vanessa, p. 26)

Used private healthcare as evidence to support her in her NHS care

…ended up paying privately to get a whole bunch of other you know MRI diagnostics done and then taking them to my GP insisting on blood tests… (Vanessa, p. 3)

Prepared for her appointment to be able to advocate for herself

I did actually some more research on endometriosis again and I I saw somewhere, something about specialist centre for endometriosis so I went to my GP and I requested to be referred to a specialist centre for endometriosis. (Laura, p. 2)

Discomfort with acting in a way that is incongruent with how she sees herself

I was like, yeah, I'm requesting this and this is happening and yeah, and inside, I'm like, oh, my God what are you saying you can't talk like that. Yeah, it was very much a Fake it to make it situation (laughs). (Laura, p. 18)

Doing her own research as an attempt to legitimise her own knowledge in the healthcare encounter

I was like no it's not I've done, I've looked into papers and I think is related to my stress and so no, no, no, no it's not.. like what? (Farah, p.10)

Being dismissed and undermined by healthcare professionals

HCPs focus on symptom management rather than finding a cause for her symptoms felt dismissive and unhelpful

Yeah, I know it was very, very frustrating because again, you feel dismissed. You're given different types of medications to try, but it's not, I didn't feel like my condition was looked into the way that it should have been looked into, erm, you know I wasn't given the right test and things like that. (Kayla, p. 26)

Experiences of being dismissed by HCP accumulated during the process of getting diagnosed and shaped beliefs about herself being unworthy of care

"Yeah. At the time, it was just a lot of negative thoughts. Again, anxiety. I wouldn't say like suicidal thoughts, but it's just thoughts like I'm not worthy. You know, I'm not being listened to like I'm just feeling dismissed at every point." (Kayla, p. 25)

Interactions within the healthcare system have been distressing and now feels fearful of going into hospital

"Erm so yeah, overall my interactions with the healthcare system are pretty crap.
I think I have a lot of like trauma around…that, like I have a lot of fear going into hospital still…" (Sumaira, p. 22)

Being told that her symptoms had a psychological cause rather than a physical cause felt invalidating for her mother who was with her

So she's clearly just, like depressed or something. And the pain she's experiencing is a result of that rather than, erm, yeah, rather than, how like the actual-like nothing is wrong with her… (Sumaira, p. 3)

Was difficult to believe the diagnosis – there was a sense of mistrust and needing to be cautious about information from health professionals

But I remember feeling like, I've been so gaslit by everyone I was speaking to, that even I was like, do I have endometriosis? like is it, is this true? Like what if this is not real? (Sumaira, p. 11)

Pain and its impact goes unacknowledged when the doctor advised against having a hysterectomy in case a future male partner may want to have children

I remember them saying, like, you know what if my future husband wanted kids or something like that and like so, I'm gonna have to suffer with all this pain for a a theoretical man, for whoever, like down the line. (Alicia, p. 3)

Dismissal by healthcare professionals makes her feel unworthy of care

It's like, why did you call Kind of. You know, you don't, you're not bleeding-I'm not bleeding to death. And they're they're here now. And I felt so bad. (Laura, p. 8)

Healthcare professional's expertise have power over deciding cause and treatment of symptoms

Erm you just need to take the pill and she prescribed me the pill-the combined pill and that helped with my symptoms and I forgot about endometriosis cause she said, you know, she was a doctor and she said that's not what I have. (Laura, p. 1)

Greater value placed on medical knowledge vs experiential knowledge – she placed the expertise with the medical professional

From being dismissed, by healthcare professionals that have trained, you know, to know things about health, so they must be right. (Laura, p. 31)

Her wish for further investigation of her symptoms is denied by GP– the start of the battle

so I started battling with the GP and saying I need to be referred to a gynaecologist and they said no, they want to try and put me on the coil again. (Megan, p.2)

GPs has power to offer treatment at primary care level and gatekeep investigation by a specialist

'And I-and that's what I mean when I say, I feel like you've been gaslit because they wanna throw these things at you rather than giving you the option of having a proper endo specialist taking like,

taking your kind of like notes, your background, your history, and then communicate with you or send you for a diagnostic surgery. (Megan, p. 10)

Her pain was dismissed by HCP when she raised this

When I asked him about the pain, he was like, yeah, there's nothing wrong (laughs)
So what do you do right? Like you just- It's not that they're not nice people, but they don't take your pain seriously. (Vanessa, p. 10)

She minimised her symptoms in response to being told they were normal by healthcare professionals

…but you were kind of gaslit and it's just told it's normal and you minimized it. (Vanessa, p. 7)

Didn't seek medical help for her symptoms after stopping the contraceptive pill as didn't believe that she would be helped

So I came off them, but by that point I think I'd concluded that there's really very little point in consulting medical professionals, because I kind of knew the drill at this point. (Vanessa, p. 10)

Medical professionals have determined the legitimacy of her pain

And there was this moment that you're feeling this pain, you know it is real, but actually it's somebody said to you, we looked at your inside and it's we don't know what you're talking about. (Farah, p.6)

Not putting herself through accessing NHS care for gynaecological health again

…it made me that experience with that, said gynecologist really made me not want to associate, not want to seek any umm, when it comes to my gynecology health in the NHS like now thinking about doing it privately. (Farah, p. 16)

Feeling dismissed and validated in same healthcare encounter

And to be honest, my gynaecologist wasn't great cause he just said Google it (laughs) and I was like, what is it? He said Google it, so I thought alright, OK.
But he was like I can see a lot on your MRI scan you must be in horrible pain… (Chloe, p. 2)

Positive Experiences within healthcare are an exception not the norm

Being taken seriously by the GP as reflected by her actions made her feel cared for

…she really, really sounded like she cared about what was going on with me, and she was just like, you need to be seen. And so, you know, she-I think she might pushed it as an emergency. (Chloe, p. 9)

The healthcare professional prioritising her care meant a lot

I really appreciate that because I knew he was going in-He was literally dressed to go in the theatre and and he came and just took a few minutes to come and tell me in person... (Chloe, p.19)

Felt lucky to get a diagnosis of endometriosis

…and I was lucky enough to move through the system… (Farah, p.5)

It isn't her expectation to receive culturally sensitive healthcare

…I have always been lucky in healthcare because my GP is very-she's we we in London we grew up in a very culturally diverse um area so my GP was quite lovely… (Farah, p.10)

Expected to find the medical encounter difficult *well, this is-the thing is like you go in and you're riddled with anxiety. (Megan, p.13)*

Being listened to and respected by GP hadn't been the norm in her healthcare interactions
OK, well, I wanna have the surgery to see if it's somewhere else and there was no pushback from her. She's like, OK, let's get that booked in for you then. So it was, different… (Alicia, p. 20)

Felt relieved to be listened to by a healthcare professional about her symptoms – felt optimistic that progress towards understanding and treating her symptoms could now be made
Yeah it felt great because I was like, yeah, finally, Like someone's hearing me someone's like on this journey with me, someone's trying to help me get things done. (Alicia, p. 21)

The way she was treated at the endo specialist centre changed her life
It was a really, really positive appointment, being referred to this place erm that changed my life. (Laura, p. 19)

Turning point in her journey in relation to moving towards a diagnosis was when the GP listened to her
and yeah, that's where things turned around for me in terms of getting to a diagnosis. (Kayla, p. 26)

The appointment with this GP was thorough and was not what she was expecting based on her previous experiences with HCPs
…I was just feeling like, oh, this is gonna be another one of, you know, the experiences that I've had before. But it was so much different, like it was a relief erm, being able to just have that time to talk to the GP about, you know, I had to start from the beginning… (Kayla, p. 27)

Felt safe and supported to have a surgical team that represented her own race and gender
So I've just had the one surgery and I was really relieved that actually the entire team were black and brown and they were all women. (Sumaira, p. 22)

Feels that the positive experiences she has had in healthcare only form one small part of the process and highlight the lack of continuity of her care
So I I don't, you know, I see it as one tiny fragmented piece of care in a much bigger picture where there's no continuity. (Vanessa, p. 21)

Living with symptoms
Battling with pain
*So I was really pushing myself to do things like go for walks, exercise and whatnot.
Erm but it was also difficult to do those things. So it was that push and pull that was constantly going on for me. (Farah, p.6)*

Pain took control and dominated her life
I would be in my bed for days with-It's not even fatigue like I would just be, you know, almost vegetative state (Laura, p. 2)

Symptoms impact all aspects of her life
at some point you're gonna have a point where you can't really socialize, you can't work, you can't do anything. (Laura, p. 3)

Pain became so severe that it was affecting her ability to work

And then probably the only time that changed was when I started getting very severe pains again, when I was about 28 at the time I worked for a company that had private healthcare, a-er my manager suggested because I was missing time off work that I went and saw her gynae. (Vanessa, p.10)

Feeling powerless to her periods caused her distress
And I would just kind of just get beside myself and get really upset about it and just be like, I don't wanna have to go through this, I don't wanna do it, I don't wanna do it. And then you going through it and it's just I can't do anything… (Alicia, p. 11)

Battling with enduring pain to prevent her from having to take more pain relief
And so I kind of like battle with do I do that so I'm not taking paracetamol and ibuprofen three weeks out of the month or do I try and nip it in the bud and start taking it when I feel a twinge so that I don't have the pain. (Alicia, p. 8)

Was fearful of being negatively judged by others due to her symptoms
…I was having panic attacks at one point because I was so afraid to go into work or go into social settings with people and then, you know, have, like, an accident of like, you know, period my period starting and how heavy I would bleed or the pain.. (Kayla, p. 7)

Uncertainty of the cause of her symptoms feeling scared and worried
You feel scared and worried, and just a mix of emotions because you don't know what's going on, erm and after that I just got thinking about well I just wanna be seen by a gyaencologist as soon as possible to find out what this is. (Chloe, p. 9)

B. NAVIGATING STIGMA AND DISCRIMINATION

Misogynoir within healthcare

Was frustrated by knowledge of how her white friends have benefited from white privilege in their diagnosis journeys
And yeah, I think that that it's frustrating, like I know that my white friends are-they have also had a tough time with their diagnosis, but I know that they've never had to experience the level of kind of yeah, difficulty I guess that I have, and I think that hearing things like that, definitely made me very frustrated at the time and I was of just like ohh, OK like how come your pain is valid and but mine isn't? (Sumaira, p. 6)

Has found it difficult to advocate for herself without being perceived as the 'angry black women'
I think that especially for black girls like advocating for yourself and, it is so difficult when you also have to juggle the fact that you could be perceived as aggressive all the time. (Sumaira, p. 15)

Racism has shaped her interactions with healthcare professionals in the form of racist assumptions made about her experience of pain as a Black women
I think that throughout my journey with with Endo, I've had a lot of kind of racism thrown at me in the sense of or in in the form of people not believing me, people thinking that I can tolerate pain more, people not being thorough… (Sumaira, p. 5)

Has learnt through her journey that whiteness restricts her from having the opportunity to express her pain and for this to be recognised by others
Like I'm in excruciating levels of pain sometimes, and I think not being afforded that vulnerability and the vulnerability that, you know, white girls would get, I think is really hard to come to terms

with because you're just like, it doesn't really matter what I do or how I present or how I talk or how little I talk. You're always going to see me as someone who is beyond experiencing pain. (Sumaira, p. 19)

Healthcare professionals have upheld whiteness in their attitudes towards her care – felt that she was not seen as human

…but I think when you actually sit there and you think about it, like being denied care, like being seen as not vulnerable when you are literally in horrific levels of pain. Umm, I think, I think it's just a really, really dehumanizing experience, to be honest. (Sumaira, p. 19)

Her healthcare experiences were a realisation for her of how Black women are positioned as less worthy in society

I felt really failed, and I think that that comes like, that was a really dark moment for me when I realized that I could literally have been dying and people didn't see my life as well, like saving or valuing. (Sumaira, p. 6)

The 'strong black women' schema shapes how she should experience and respond to her pain

…this idea of, you know, you're strong black woman like and and and it's such a-I hate it-I don't-I did not want to use that term, but there is this and and then it becomes… a social script that you have umm, that you shouldn't feel pain or you-I mean when you do feel pain its quite sensitive like you, you're showing a sensitive side of yourself. (Farah, p.9)

wondered about how perceptions and biases around how Black women experience pain may have been shaping her treatment

erm but obviously she can see from my systems and like the remainder of my facial features that I am a black woman. But, I wondered how much of my identity have influenced what she said and how she engaged with me, umm and because I was in pain, I wasn't as expressive as I am today, or as I've been so I wondered if a lot of her dismissal came from maybe some perceptions or biases that she may have had about my experience. (Farah, p. 9)

Feeling 'lesser' due to her earlier life experiences of whiteness shapes her expectations of treatment in healthcare

Yeah, you know, feeling lesser than, you know, I grew up in [information removed], which is a predominantly white country, being always the only brown child. (Laura, p. 17)

Discrimination within healthcare prevents pain being recognised

Erm but when my partner would speak up for me and say no, she's actually in pain, you need to do something, then something would happen, then I would be, you know, given the drip to just rehydrate me, but when it was me talking and then I was just not be, nothing would happen. Nothing more. Maybe on the fact that it's a man's, maybe on the fact that he's a white man as well… (Laura, p. 8)

Assumptions made by others based on her identity as a Black working class women that she cannot understand her own body

And for me, having people overlook what I'm saying and undermine me, And I do think sometimes it was because of being a black woman, I do think sometimes it was because being like a working class black woman as well.. (Megan, p.7)

Lack of care by HCPs has a psychological impact – assumption of Black women being strong prevent this from being considered *but sometimes it's the psychological stuff where you know something's wrong but no ones listening, and I think GP's really don't understand how damaging that can be, and, because there's that narrative for black women being strong or being aggressive. (Megan, p.10)*

Feels frustrated as thinks about the gender and race inequalities limiting endometriosis treatment options

Erm but underneath that, if I allow myself to feel it, I know there's just this feeling of, like, just hopelessness and frustration, because I really think that if men went through this, we'd have a solution. That's the honest opinion. That's the honest thing, and I think probably if it wasn't disproportionately black women that went through it, we'd have a solution to this thing. (Vanessa, p. 5)

The healthcare system has additional barriers for women for colour to have to navigate

they're more likely to fob you off because you are a person of colour, so you have to keep pushing and fighting. And I think that's what makes having to navigate the healthcare system that little bit much harder as well because of things like that. (Alicia, p. 30)

She is required to follow up on her care as a women of colour to prevent white people's care from being prioritised above her own

I'm gonna be, you know, following up with the doctors about when I'm gonna get this gynaecologist appointment, Have-did you actually put it through? Like how long am I gonna have to wait because otherwise I feel like I might get left to the wayside as opposed to somebody who's not a person of colour. (Alicia, p. 30)

Having a positive experience in the healthcare system was very significant to her in the context of her knowledge of Black women's healthcare experiences

That really meant everything to me, honestly, I'm such a person that likes to just like, do you know there's so many statistics about black women in healthcare and how badly they're treated, and I just think just that extra just that extra care really like goes along way for me. (Chloe, p. 19)

Societal and cultural beliefs about women's reproductive health

Islamic cultural norms shape how reproductive health is spoken about

…it's like I'm a Muslim woman, we don't really talk about our ovaries. Like to not to strangers, and not to family also all the time. (Farah, p.19)

Worries about breaching cultural norms and rules around talking about reproductive health

even like I remember is it March the endometriosis Awareness Month? And I like to share things on my Instagram and sometimes, like, I wonder, oh goodness am I, am I saying too much? (Farah, p. 20)

Stigma exists within society more broadly and not specific to a particular culture or community

And I know it's not just culturally or my community, I think just generally women there is that sort of thing of silencing, umm, our experiences when it pertains to you like Women's Health *(Farah, p. 20)*

Awareness of the silence on women's health issues within the Black community

I would say maybe it's kind of it's a lot in the black community anyway because even when I started to look into it and online, I don't see any like black women creating content or information or sharing information about kind of that kind of health issues. (Chloe, p 4.)

Culture shapes how her family understand and respond to her endometriosis
So family not as great as the friends have been, very Caribbean, very as I said pray it away. (Megan, p. 30)

Periods felt shameful due to stigma surrounding women's reproductive health
And I was ashamed of my kind of like female health. So I was ashamed, I was embarrassed (Megan, p. 35)

Periods felt shameful due to societal narratives surrounding menstruation which were shared within the family
I remember my mom told me when I was younger that dustbin men didn't like taking women's sanitary towels in the bin because it was disgusting, so I always had that type of thing in my head too and I was just like people really think it's disgusting, don't they? (Megan, p. 35)

Feelings of shame around her menstruation restricted her from talking about her symptoms
…so for me everything was framing it in a very dirty way, that its not nice and just horrible, so I was always embarrassed about it and never really want to talk about it. Just suffered in silence. *(Megan, p. 35)*

Awareness of the beliefs in her culture around western medicine not being beneficial
…but culturally it was a sense where because you're taught that you know, medication, some of the times they're not really good for you and you know it's best for you to try, like, different herbs or different teas and things like that instead of going through, like the pharmacy route. (Kayla, p. 35)

Mensuration is a taboo in Caribbean culture
It's very hush hush, I would say. When it comes to anything sort of like talking about menstruation or reproductive health conditions, people don't really talk about it. (Kayla, p. 34)

Taking a step away from her cultural beliefs to manage her symptoms
…and I think he said it was a cultural thing as well, which I've unlearned a lot in terms of, like coming from a Caribbean background erm, you try and use like more complementary therapy, things like herbs and things like that to try and heal your body. So it's not all about medications and pharmacy things and stuff like that, but I've unlearned a lot of things erm which has helped me along the way to manage my symptoms as well. (Kayla, p. 34)

Aware that period stigma in wider society can shape how others respond to her diagnosis
I never had that whole like ohh periods are weird, periods of dirty. But I think that often other people are still really uncomfortable talking about menstruation and I think sometimes that shows up when people are like like ohh I have endometriosis and they're just like ohh no ohh like they they they feel a level of discomfort (Sumaira, p. 16)

Period stigma shapes how she feels talking about endometriosis - Talking about endometriosis can cause her to feel worried about exposing too much of herself
But yeah, I've definitely felt like, I've definitely felt like it, erm, It can't be quite difficult to talk about gynae related stuff without feeling that whole like am I sharing too much? Is this too intimate? Is this too much detail? (Sumaira, p. 16)

Periods aren't spoken about - Not having the opportunities to learn what is and isn't normal mensuration which creates a barrier for her to access medical care

But yeah, and no one else speaks about it. I think that's the-That's the thing. No one speaks about, so you don't know what's normal, what isn't normal, or when to go to the doctor or when not? (Chloe, p. 4)

The lack of treatment options for endometriosis makes her feel that it isn't a condition that is taken seriously
It isn't taken seriously and you know your solutions are pump yourself with hormones or suffering in silence again, you know. (Vanessa, p.4)

C. THE DIAGNOSIS IS A DOUBLE-EDGED SWORD

Making meaning of the diagnosis
The endometriosis diagnosis was accompanied by a threat to her future motherhood
I was really scared because I thought it was something that, you know, in terms of, like consultants telling me that pregnancy and motherhood and things like that, were not on the table for me… (Kayla, p. 2)

Having Endometriosis is a threat to your womanhood
…and then there is that sense of, like your womanhood of like, you know, you're you're supposed to produce. We're supposed to have-This is this is this is the only thing that is so like that I can do and now it's being taken away from me or possibly (Farah, p. 22)

Getting the diagnosis gave her a sense of injustice
And I was frustrated, because, I then I took even greater care, Now I still take great care, but then in particular I was like, I have done nothing to contribute to this.
I know that it's not my fault, but it was very angry at the fact that I had it… (Megan, p.44)

She now has permission to be 'unwell' – changes to how she approaches being unwell through the diagnostic process
But just having this time erm really made me also just think about, you know, it's OK to like call in sick if you don't feel great, like it's OK to just take that time for you when you need it. (Chloe p. 23)

The diagnosis itself doesn't change the pain she is experiencing
now I remember the really, really low days even after having the diagnosis when it was really, really bad. Like when the pain was really bad. (Laura, p.4)

A delay in diagnosis meant a worsening prognosis
I've lost ten years of trying to sort this out and for it to just become worse and worse and worse inside just being camouflaged with the pill treatment basically. So it was really good. But yeah, I was also angry about that, for sure. (Laura, p. 19)

Diagnosis validated her when she had started to doubt her own experiences
I think I guess it was validation that it wasn't all in my head, and, even though like I was feeling the pain every single day, there was still that part of me that was like, what if this is the bad period, what if everyone has this? (Sumaira, p. 11)

Having a diagnosis makes endometriosis real and has conflicting feelings about this
now I have some sort of external validation as good as it is, it does raise a whole set of what now? (Vanessa, p. 7)

Knowing about the diagnosis reduces her feelings of isolation and difference
I think you always kind of have that sense of relief like, oh, it's not just me.
I'm not alone. (Alicia, p. 16)

Getting the diagnosis made Endometriosis and the damage it had done become real
And because it was stage four and in the note she was like ohh, it's completely obliterated your pouch of Douglas, I didn't know what a pouch of Douglas was, but I zoned in on the word. Obliterated. (Megan, p. 44)

Having a diagnosis of endometriosis means a loss of control over your body
…everything else I was like yeah, you can manage, You can get it sorted and this thing that you can't control, right? You can't control. (Farah, p. 22)

Getting the validation from the diagnosis has changed her relationship with being strong
It was nice to to to have that language and to be able to-also to have something for myself to be like yeah, you're in pain, like, just take a chill pill and it's OK almost. (Farah, p.15)

Getting the diagnosis has enabled her to rethink how she looks after herself
first of all it made me think right don't push yourself that much anymore, and definitely putting myself first a bit more (Chloe, p. 23)

Understanding endometriosis
Finding out that she has endometriosis has given her understanding that facilitated her acceptance of herself as a human being with strengths and limitations
And so yeah, like I think that that's what I mean about like coming to peace with my diagnosis I'm no longer like frustrated at my body for not working, it just is what it is. (Sumaira, p. 31)

Getting the diagnosis has given her understanding of her symptoms which has helped with the process of acceptance
…but it's allowed me to just…Be like, OK, well, this is what it is, I know what it is, I just have to just look out for anything new that I could possibly do that's gonna help with this pain… (Alicia, p. 31)

Having the diagnosis has given her a language to articulate and communicate her symptoms however this is not always understood by others
I need needed to talk to occupational health and really explained to them like this is not period pains. This is endometriosis. It is a condition. (Laura, p. 6)

Getting the diagnosis was helpful to make sense of what was wrong
…like you can't go to a supermarket and all of the tins haven't got labels on them cause you don't know what you're getting, do you know what I mean? Like labelling serves its purpose to some degree, and I feel like with this it did… (Megan, p.47)

Others still do not take her symptoms seriously
Having people around you say oh take this supplement, do this, do that, are you sure it's not this, I'm like, I'm sure because its endometriosis and fibromyalgia, do you know, I mean… (Megan, p.16)

Family's attempts at supporting her reflect difference in understanding of endometriosis and felt frustrating to not be understood

I needed more times where she didn't come in and tell me to drink aloe Vera juice cause it's gonna cure endometriosis. There are times that she really damaged my mental health to be honest (Megan, p.32)

There is a lack of awareness of endometriosis and felt frustrating to not be understood
Well oh you shouldn't be in meetings, so I shouldn't work because I'm chronically ill, which means I always have some type of like, health issue or symptom impacting in my life. (Megan, p. 16)

The lack of visibility of her endometriosis is a barrier to others understanding her experience
But it it, that's what bothers me that is invisible to the naked eye, that my suffering is is hidden, to be honest. (Megan, p. 56)

It has been difficult for others (with or without endometriosis) to understand her symptoms or the impact they have on her
Getting people to understand that you're not making it up, that when you cancel for something, it's because you're an agony. Just because they haven't experienced it doesn't-It doesn't impact your life, but also for those other friends who have endometriosis, but they have stage two very minimal symptoms. They're like well my endo's not like that. Well, that's that's your body. (Megan, p.15)

Feels that the diagnosis has had different responses from others – some understand better and some feel more anxious as they cannot help her
So in some ways it's allowed me to ask for and receive support or more understanding because I have this label, but on another level, you know it makes people anxious particularly the points when you don't know and it makes probably them feel helpless… (Vanessa, p. 32)

Didn't get the support in the workplace she needed post diagnosis
And then when it came to my disability, they just straight up discriminated against me. They refused to do occupational health, They refused to have a meeting with me about access needs. They like straight up, refuse things that are like legal requirements. (Sumaira, p. 18)

Symptoms were invalidated at work by managers when she would try and explain
just sitting there and trying to explain to my manager about what I was going through. It was just as if, you know my symptoms were, I was over exaggerating or how can you be in so much pain? (Kayla, p. 6)

Felt under pressure to not take time off work so she isn't judged by others
…but I've come into work because I don't want to be that burden or be that colleague that, Oh my gosh, she's always off sick. And you know, because there was always little discussions about that at work… (Kayla, p. 6)

Left job roles post diagnosis because of how her symptoms have affected her at work and hasn't felt supported
…I've actually left three NHS jobs within the, within six years of me being a nurse because of how much endometriosis has affected me at work and not really erm managers and like you know, people-your colleagues not really understanding your diagnosis. (Kayla, p. 5)

Hope for treatment
Getting the diagnosis started the next journey of finding treatment
Yeah, means that you, you know, you know what to research to get better. (Laura, p. 26)

Feelings of hopelessness return when feeling unable to get help
I started crying because I was like if my consultant's, now doesn't believe me either, then that's it I'm not gonna get any help. (Laura, p. 9)

Process of searching for an effective treatment has a significant impact on her
…and so it impacted every aspect of my life, especially being on everything that I've been on to just manage the pain and everything so, that has been kind of the worst part of it all. (Chloe, p. 25)

Her pain is viewed as not worthy enough for treatment by medical professionals – continues to struggle to get treatment post-diagnosis
…and they said to him I could hear it unless it's an ectopic pregnancy send her away. (Megan, p. 5)

Was left to cope with diagnosis and implications for her fertility without much support
And erm there wasn't really much support at the time. I didn't really receive a lot of information from the surgeon or the GP in regards to endometriosis, having this diagnosis. It's just that I was given, you know, leaflets, told to check on the NHS website and things like that… (Kayla, p. 2)

Not having enough support post diagnosis from healthcare professionals perpetuated mental health difficulties brought on by the diagnosis
…but there wasn't, enough support for me, so I was very much in a dark place for quite some time with that diagnosis. (Kayla, p. 2)

Research into treatments that had been done was not representative of Black women which made it less meaningful to her in terms of helping her find effective treatment
You knew what the diagnosis meant and you knew that there wasn't a cure, but there wasn't really a lot of research done, especially around like, my diverse background as well. So I didn't know what type of support was available to me… (Kayla, p. 10)

Had felt hopeful that getting the diagnosis would help her get better
… as people are like when you get the diagnosis, there is this idea that everything will get better… (Sumaira, p. 24)

Discharge from gynaecology was abrupt and felt overwhelming to not have any further support
…but I think just the whole, like, OK, we've done your surgery bye, that was quite overwhelming. (Sumaira, p. 24)

Felt hopeful after getting the diagnosis -had an expectation that there would be treatment options
…and the reason I'd had hope was cause I was like, well, you know, I'm being taken seriously now, there is this endo, maybe they'll tell me what kind of keyhole surgery treatment options I can have. Maybe you know now that I'm in gynae and I've been seen, and I'm on the list it'll be dealt with…(Vanessa, p. 4)

No one has responsibility to provide oversight to her care prevents her from progressing with any treatment
…like I can be discharged, not fully healed from a surgery, never seen again in person, have these interactions with people on the ward. And that's where the problem starts and now I'm back at square one with an endo diagnosis and pain. And it's OK you can carry on and try and get pregnant now if you want, but I'll I won't be seeing you again. That's it. (Vanessa, p. 20)

Getting the diagnosis is an anti-climax -the hope she had of having a pain free life is lost after not getting the treatment she expected and being discharged from hospital

…And I'm like, yes, OK Finally, great, like, I feel ecstatic, I feel excited, Like finally, I'm gonna figure out what I can do with this pain to then now being told, OK, we've done everything that we can do now we're gonna discharge you and then just going like super low. (Alicia, p. 21)

Feeling helpless post diagnosis – nothing she can do to stop her pain

…And I remember just that feeling of…..I guess helplessness or or or just sadness, because I'm like you gonna discharging me because this is all we all you can do like..But So what do I now do? I just have to just continue with this pain like there's nothing else… (Alicia, p. 21)

Felt lost post diagnosis – abandoned by medical healthcare and didn't know what to do to help herself

So you're just kind of just left feeling like, you know, it's almost like your house is burnt down and the insurance said oh We can't give you any money for it and you're sitting on top of the of the rubble, Like, what? Where do we go now? What? What next? What? What do I do? Do I just stay here? Is this where I now live? (Alicia, p. 22)

Access to support networks

Hearing other women's experiences has advantages and disadvantages

But yeah, I would have rather heard that from a medical professional telling me, you know, don't believe everything you see online and also what the symptoms could be and what they couldn't be. And yeah, I would rather have a conversation, but Googling it was a scary experience, to be honest. (Chloe, p. 18)

Reading about others experiences of endometriosis without support from medical professionals increased the uncertainty

And I just thought everything and I started panicking and I told my husband, I don't think we're ever going to be able to have children or anything, and I duno what's gonna happen to me… (Chloe, p. 18)

Support from the endometriosis community has been unconditional and valuable

…and I have two support groups and those things are insane, because you can talk about, like, the worst things ever. But they get it. (Megan, p. 25)

Talking about her experience post diagnosis was a release of her emotions – changed the way she was feeling

…I feel like when you when I spoke about my experiences and my story sharing my journey, it felt a burden, was lifted off my shoulder. Like, I felt like the dark place I was in I'm not no longer there anymore, just by speaking and sharing my story. (Kayla, p. 36)

Support group was able to have a positive impact despite her symptoms not changing – improving her mental wellbeing

So things like that, that was the impact, it was a good positive impact that it had on me, even though I was still suffering with the symptoms, but I just felt that my stress levels were a lot lower and I know that stress is something that was exacerbating my symptoms of endometriosis. (Kayla, p. 12)

Being part of the group enabled her to get practical advice on how to support her mental health

…and the impact it had on me was a good impact because then I was able to find help in terms of starting therapy, in terms of helping with my mental health. (Kayla, p. 12)

Being part of the support group and sharing her experiences was empowering

It was powerful. I would say that was the word. It was powerful in terms of listening and being able to share our stories because it felt like I had a voice now like I was being heard by somebody who has been in my shoes, and I've also been in their shoes. (p. 11)

Feels like historical context of endometriosis being a white woman's disease prevails in the support that is out there

No, I think it was really hard because I think the other thing is that endometriosis is still like a very white woman's disease like you, you, you, you look on places like [organisation name removed] and all you see-all the information reads, all the information reads as if it was written by white women for white women and you're kind of just like, OK, what about the rest of us? (Sumaira, p. 25)

Finding a safe space where she feels represented has been helpful to get advice and information that is relevant for her

And I think I've been really lucky that I've had quite a lot of online spaces to talk to people as well. Like I'm part of, there's like online space called [organisation name removed] and which is all like marginalized people who have endometriosis or have gynae conditions. And I think that's been a really helpful space to just be like ohh hey like, has anyone had this side effect or has anyone tried this? (Sumaira, p. 26)

Making connections with other Black women with similar experiences gave her hope that there was help and support out there

…because it was finding other black women who've been through the same shit, that made me, it gave me hope in a way, if I'm honest, that I would not otherwise have had, you know. (Vanessa, p. 24)

D. FINDING WAYS TO SURVIVE POST-DIAGNOSIS

Ongoing battle with endometriosis

The length of time it took to get the diagnosis meant that getting the diagnosis wasn't able to prevent her suffering

The diagnosis helped me get a better understanding of what was happening, but it came too late. (Megan, p. 54)

Got the diagnosis too late to prevent long term consequences for her health and fertility

…I have to fight to get seen and I did and it worked, but it was too late. By the time everything came around. (Megan, p. 38)

Multiple surgeries to control endometriosis had an impact on her body

…now you've had that final, that third operation she knew for a fact that it was gonna cause more trauma to my body, which it did. (Megan, p.5)

Endometriosis continues to take over her body

…because the endometriosis had pulled my appendix into my vagina and I could not believe-I was like I only had the surgery in Jan, and that was by by a skilled surgeon and then this happened. (Megan, p. 4)

Felt powerless over her body - her body had betrayed her
…I was so angry because I was like, how dare my body do this? (Megan, p. 50)

Hysterectomy represented the damage done to her by endometriosis
The damage was done, and that hysterectomy for me it was a realization that I'm a thirty-three year old having a hysterectomy. (Megan, p. 53)

Feelings of anger at endometriosis for not giving up with tormenting her
I haven't had a space where I haven't felt pain, so to me, endometriosis, I just call it a wicked bitch, because that's what I feel like it is… (Megan, p. 52)

Endometriosis had been taking over her life physically and emotionally post diagnosis
…I was shocked when I, you know, got pregnant because I'm just thinking this endometriosis has been really taking over my life… (Kayla, p. 5)

Endometriosis has returned post pregnancy and this feels like a punishment
…it's just that now after two years after having my child, my endometriosis symptoms are coming back again with a vengeance. (Kayla, p. 3)

Pain continues to be severe post diagnosis
So my pain has come back and I did the 12 hour shift and I'm just, I was, I kept hiding in the toilet during that that shift because I needed to just sit on the floor. (Laura, p. 7)

Frustrated and anxious that she is in pain and cannot escape
…erm, so yeah, just, that's how I'm feeling, just the anxiety, the frustration and just not really knowing what else I can do. (Alicia, p. 7)

Pain dominates her life- is very aware of her pain day to day
But it's yeah, it's really, I guess, more just frustration out of anything just constantly being in pain all the time. Erm as of late, I don't always get the pre period pains as much, but definitely the you know the ovulation pain and the period pains and yeah, like I can't, I can't do anything its debilitating… (Alicia, p. 7)

Adjustment and acceptance
Considerations of how she talks about endometriosis and protects herself is ongoing
I'm just like wondering because I'm constantly trying to step away from one space to another. So oneself that is like no, it shouldn't be shameful as I'm talking to you, it's like I should be doing more. And then there is that thing of it's quite sensitive and it's quite delicate and you're exposing yourself as almost isn't it? (Farah, p. 21)

Has been through a process of adjusting her identity accompanied by grieving for the body she has lost
I think that there's been like a lot of grief and like sadness that my body isn't able to do what it could do before. And I think that I've move through that stage, I've moved through like the angry stage. (Sumaira, p. 13)

Her mentality of being strong has been challenged by her diagnosis of endometriosis
I think if anything like this diagnosis has really reminded me of my fragility… (Sumaira, p. 31)

Conversations about loss of fertility spark confusion around her identity – having to re-make sense of who she is in the present because of this disruption to her future self

Like, I felt robbed of my dream of becoming a mum and didn't know really where to place myself. (Kayla, p. 4)

Difficult to process and understand what endometriosis had done to her body
when they're like, the appendix is in your vagina, I was like, how the hell does that even happen? (Megan, p. 52)

Accepting endometriosis is a challenge and continues to resent the control it has over her body
So it's just a living, and existing with it that I have to make peace with. And there are days I'm just fine, I'm just like it is what it is, I'm in pain, but it's life and there are other days where I'm just so angry… (Megan, p. 45)

Challenges with understanding endometriosis continue to make her feel out of control which she finds difficult to accept
I don't feel like I've actually made peace with endometriosis. I accept my circumstances for where they are because I'm not gonna be in denial, but I haven't made peace with it because I'm just confused by the way it moves, and how it got hold of me so aggressively because I clearly had it for so long. (Megan, p. 53)

The reality of being diagnosed with a chronic health condition means she cannot continue to ignore her symptoms and needs to adjust
And also, I'm realizing that this is probably not gonna be something I get a solution to very quickly or at all, or I mean or can get on with, I I seem to be much better at ignoring, through ignoring it and powering through it before I had diagnosis… (Vanessa, p. 7)

Currently still in the process of understanding and adapting to the diagnosis
…you know, in a year's time or two years time, will I say I'm a black mixed race woman from [information removed] who loves women and also has a chronic health condition or at-I don't know. That's the thing that I feel like is bubbling under the surface, and if I'm honest, I'm resistant to. But it is the reality. (Vanessa, p. 29)

Feels uncertain about how endometriosis may affect her in the future
So even though I'm not having a period, will I still cramp or all the other effects of menopause that I don't know about yet because I have never researched into menopause, could any of those spark that and make things worse? I have no idea. (Alicia, p. 28)

The uncertainty of the condition lives on post diagnosis
…endometriosis you can't plan when you're gonna be in pain… (Laura, p. 29)

Finding ways to regain control
Medical knowledge was privileged when thinking about her treatment rather than her experiential knowledge
Do you really think it's wise Giving me another dose? but I took it because they know better, right? (Megan, p.39)

HCPs held control over when she could be seen about her treatment
…as soon as you accept the coil, they're gonna banish you for that six to nine months because they're gonna say wait for the coil to take effect… (Megan, p. 39)

Did not have a choice but to accept the treatment option offered

I was like, I don't wanna do it, be on this and she said I have to do it in order for them to see that I'm accessing their care. (Megan, p. 5)

Healthcare was not collaborative – making choices or preferences about her care would be perceived negatively

…if decline it for whatever reason they then say that you're not like making use or accessing the help available, but that's not help, that's like a death sentence in my opinion, do you know what I mean? (Megan, p. 9)

Found that her healthcare post diagnosis wasn't collaborative or supportive around thinking about her treatment

And I didn't want the coil and I felt so extremely pressured to make like these huge decisions about my reproductive health. (Sumaira, p. 25)

Felt that she was not given choices over her treatment options

I felt extremely pressured to have the Marina coil to the point that I was being wheeled into surgery and the doctors were like, do you wanna change your mind? And I was like, no, like it it was that, I thought, I mean, that's the side point, but I felt very pressured that that was the only treatment option for me. (Sumaira, p. 12)

Using her own knowledge of her body to support her with declining coil as an option for treatment

And because I've always had bad responses to hormones, I was like, look, I'm staying on my pill, I'm not having the coil. No, thank you. (Sumaira, p. 12)

Taking control of future treatment plans post diagnosis

…the main thing is I'm trying to not be on anything. That's really what I-where I want to be. (Chloe, p. 25)

Made a choice to decline contraceptive treatment following her surgery to protect her body from further harm

I declined after the surgery because I didn't have enough information about the coil and erm I just didn't wanna throw myself into something again. (Kayla, p. 3)

Doing her own research on her treatment was more important to her at this stage than taking surgeon's advice

But I wanted to do my own research and just be more in tune with my body before putting myself in those type of positions. (Kayla, p. 30)

Felt pressured to accept contraceptive treatment to manage the endometriosis

…after surgery I just felt that contraceptives were being drilled into me to say that, you know, this is the only way that you're gonna be able to manage this diagnosis from now on… (Kayla, p. 14)

Treatment offered doesn't meet her needs and putting herself first by declining is most important at this stage

It was very hard because, you know, the the health professional is a health professional like they've, you know, they've they're giving you the best advice, the best evidence based advice that they can give in order to help me to manage this. But then again, advocating myself was big. It was bigger than that, erm I knew what was right for my body at the time… (Kayla, p. 30)

Empowering to now be able to make her own treatment choices

So er yeah, but stopping the pill meant taking control back of my body, actually discovering how I feel, how it feels to be in my body without taking hormones every day. (Laura, p. 13)

Doesn't feel that powerlessness stops her from feeling motivated to try to influence change in healthcare

I can understand that there's a gender dynamic to it, that there's a racialised dynamic to it, but…I'm less accepting and also…….More committed to addressing it, but also not that hopeful about what will change very quickly (laughs) (Vanessa, p.11)

Appendix R

Individual Participant Representation in GETs and Subthemes

Themes	Subthemes	Farah	Chloe	Laura	Megan	Kayla	Sumaira	Vanessa	Alicia
THE DIAGNOSIS JOURNEY WAS A BATTLE	Fighting for care	✓		✓	✓	✓	✓	✓	✓
	Being dismissed and undermined by healthcare professionals	✓	✓	✓	✓	✓	✓	✓	✓
	Positive experiences within healthcare are an exception not the norm	✓	✓	✓	✓	✓	✓	✓	✓
	Living with symptoms	✓	✓	✓		✓		✓	✓

NAVIGATING STIGMA AND DISCRIMINATION	Misogynoir within healthcare	✓	✓	✓	✓		✓	✓	✓
	Societal and cultural beliefs about women's reproductive health	✓	✓		✓	✓	✓	✓	
THE DIAGNOSIS IS A DOUBLE-EDGED SWORD	Making meaning of the diagnosis	✓	✓	✓	✓	✓	✓	✓	✓
	Understanding endometriosis			✓	✓	✓	✓	✓	✓
	Hope for treatment		✓	✓	✓	✓	✓	✓	✓
	Access to support networks		✓		✓	✓	✓	✓	

FINDING WAYS TO SURVIVE POST-DIAGNOSIS	Ongoing battle with endometriosis			✓	✓	✓			✓
	Adjustment and acceptance	✓		✓	✓	✓	✓	✓	✓
	Finding ways to regain control		✓	✓	✓	✓	✓	✓	