healthwatch Lambeth

I'm Equal. I Matter. I'm Here.

Black women's experiences of fibroids and endometriosis care in Lambeth

The Brave Project – *Black Reproductive Health: Advancing Voices and Experiences*

Contents

About Healthwatch Lambeth

Healthwatch Lambeth is the independent champion for people who use health and social care services in Lambeth. We work to ensure that local people's voices are heard and that their experiences influence how services are designed, delivered, and improved.

As a charity with statutory functions, we have a duty to:

- Provide information about local health and social care services
- Help people find and access the support they need
- Involve communities in how services are commissioned and delivered
- Represent the views and experiences of local people to decision-makers
- Make recommendations to improve services
- Share insight with Healthwatch England and, where appropriate, the Care Quality Commission.

We are also members of the Lambeth Health and Wellbeing Board and the Lambeth Together Care Partnership Board.

More information about us can be found on the Healthwatch Lambeth website.

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We would also like to thank our Project Advisory Group for their advice on the project design and analysis and for providing feedback on this report. Thank you to our amazing volunteers Roisin Alamo-Doyle and Mia Wyles for their invaluable support with the literature reviewing and analysis for this project.

Executive Summary

Healthwatch Lambeth carried out this project to better understand Black women's experiences of fibroids and endometriosis care in Lambeth. Their stories show the significant impact that these conditions have on women's health, wellbeing, and quality of life and highlight practical steps local services can take to improve experiences of care for Black women.

Key findings

Symptoms were normalised. Many women grew up believing heavy bleeding and pain were a normal part of being a woman. Family and community expectations to be strong and self-manage contributed to normalisation and delays in seeking help and diagnosis.

Symptoms were serious, disruptive, and life-altering. Severe pain, heavy bleeding, fatigue, and fertility concerns affected women's sleep, work, travel, social life, family life, confidence, and future plans. Many described organising their lives around symptoms.

Professional responses shaped experiences of care. While some women encountered compassionate, proactive professionals who listened, believed them, and investigated their symptoms, others described a more difficult journey. They experienced repeated minimising, downplaying, or dismissal of symptoms as "just hormones" or attributed to menopause. Others were given medication to manage symptoms without further investigation. Women described having to attend multiple appointments, push for referrals, and provide evidence of their symptoms to be taken seriously. While some felt female professionals were more understanding, most did not care about professionals' gender as long as they were listened to and taken seriously.

Race and gender influenced care. Some women felt that the prevalence of fibroids among Black women was used to normalise symptoms instead of creating urgency for action. Assumptions about Black women's pain tolerance, attitudes, and behaviour also affected their care, with some feeling pressure to manage their communication with professionals to avoid negative stereotyping and being labelled as "aggressive". There were concerns about a lack of knowledge about Black women's bodies and better representation among staff.

Diagnosis and treatment were often delayed. Women had to attend multiple appointments before being referred for scans or specialist care. Delays were also caused by long waiting times and poor follow-up between services.

Treatment discussions were not consistently person-centred. While some women felt involved in decisions, most felt treatment discussions were too clinical, rushed, or limited to one option. Women wanted clear explanations

of the risks, benefits, and alternatives, and consideration of their preferences, fertility plans, and fears.

Aftercare was often insufficient. Women described being discharged after surgical procedures without adequate information, pain management support, or follow up, leaving them feeling unprepared and unsupported during recovery.

Women often had to manage alone. When services did not meet their needs, women relied on personal coping strategies to manage symptoms and online research and peer support groups to fill information gaps. Self-advocacy was seen as necessary to access care.

Women were clear about what needs to change. Their experiences highlight the need for earlier intervention, better communication, more personalised care, and action to address inequalities. These findings directly inform the recommendations in this report and align with the *Renewed Women's Health Strategy for England* (2026) and wider NHS priorities to reduce inequalities (3, 33-34).

Recommendations

Healthwatch Lambeth is calling on local services to take the following actions to improve care for Black women experiencing fibroids and endometriosis:

1. **Improve early recognition, investigation, and referral in primary care** so repeated reports of severe symptoms and disruption to daily life trigger reassessment and timely investigation or referral, instead of leaving women to manage alone.
2. **Improve menstrual health education and early access to specialist support** so young women understand what is normal, when to seek help, and can access specialist care for symptoms such as heavy bleeding, severe pain, and fatigue.
3. **Strengthen listening and validation in GP care** so women feel believed and taken seriously without being rushed and having to evidence the impact of their symptoms.
4. **Improve communication and continuity** so women do not have to repeat their story at every appointment, with clearer record keeping, follow-up on actions, and continuity of care.
5. **Reduce delays to diagnosis and specialist care** by reviewing local pathways, improving access to scans and specialist appointments, and ensuring women receive updates whilst waiting.
6. **Address racial bias and improve equitable access** through training and reflective practice, helping professionals recognise assumptions about Black women's pain and behaviour and provide more culturally responsive care. Data should be used to identify inequalities in referral, wating times, and outcomes.

7. **Improve patient involvement in specialist consultations** so that treatment discussions are personalised and collaborative, with clear explanations of all available treatment options, including risks, benefits, and alternatives, and sufficient time for women to consider choices aligned with their preferences, fears, and reproductive plans.
8. **Strengthen clinical and emotional follow-up and aftercare by** ensuring women receive practical recovery guidance, pain management support, and routine follow-up after procedures so they do not feel abandoned after treatment.
9. **Provide clear and practical information throughout care** so women better understand their symptoms, what is normal, when to seek help, diagnoses, treatment pathways, and support options.
10. **Involve Black women with lived experience in service design and improvement** to ensure future improvements reflect Black women's experiences and address inequalities.

Further details on how these recommendations can be implemented are provided in the full recommendations at the end of this report.

Introduction

Healthwatch Lambeth carried out a project to better understand Black women's experiences of fibroids and endometriosis care in Lambeth. This work was informed by early feedback from local women about the challenges in accessing care and by national evidence of inequalities in care. Black women in Lambeth with experience of living with these conditions shared their stories through interviews. This report presents their experiences of care and highlights the impact these conditions have on their health and wellbeing.

Background

Uterine fibroids and endometriosis are common gynaecological conditions that can cause significant pain, heavy bleeding, fatigue and fertility-related concerns, with wide-ranging impacts on physical health, emotional wellbeing, work and relationships (1–6, 18-23).

Prevalence and treatment

Fibroids are non-cancerous tumours of the uterus and represent one of the most common gynaecological conditions globally (1-2). Existing literature shows that Black women experience a higher prevalence of fibroids than White women (1,2,4-9,32). Black women are also more likely to develop larger fibroids and present with more severe symptoms, affecting their quality of life and reproductive health (2,4-10).

Data from the US shows Black women are more likely to undergo surgical treatment for fibroids than other ethnic groups (1,7,8). This echoes data on uterine cancer care in the UK, where Black women are presented with hysterectomy as the only option with limited discussions of fertility-preserving alternatives (8,12).

Endometriosis is a chronic condition in which tissue similar to the uterine lining grows outside the uterus causing inflammation, severe knife-like pelvic pain, scar tissue formation and potential infertility (18,19). There is currently no cure for endometriosis and treatment focuses on pain relief, hormone-based therapies or surgical options (23).

Although UK-specific prevalence data of endometriosis in Black women is unavailable, international research suggests that Black women may be less likely to be diagnosed with endometriosis (19,21,24). US data suggests that despite little difference in prevalence between ethnic groups, Black women experience worse clinical and surgical outcomes than their White counterparts (32).

Experiences of care

Across both conditions, the literature points to shared, systemic issues shaping Black women's experiences throughout the care pathway. These include the normalisation of severe menstrual and pelvic symptoms through the "strong Black woman" trope, delays in diagnosis, unconscious bias and structural racism within healthcare settings, limited access to culturally relevant information, and reliance on persistent self-advocacy to access specialist care (8,19,22).

Enquiries by the All-Party Parliamentary Group (APPG) and the Caribbean & African Health Network (CAHN) into Endometriosis (2020) and Black Health and Fibroids (2025) found that many women face delays in diagnosis, poor communication and minimisation of symptoms (20,33).

These issues are highly relevant in the context of the Renewed Women's Health Strategy for England (2026) which highlights the need to improve women's experiences of care, reduce delays in diagnosis, and tackle inequalities (3).

Impact on quality of life

Delays in diagnosis and treatment often compromise women's quality of life. The severity of fibroids and endometriosis symptoms can impact women's physical health, mental wellbeing and ability to work and socialise (8, 16,17,1-22). Fibroids can also affect women's ability to have children, causing distress and strained relationships (8). For some women with endometriosis, getting a diagnosis can bring validation and hope, but this is short-lived if it does not lead to treatment or symptom relief (19).

Gaps in evidence

While much of the existing evidence draws on national and international data, there is limited UK and local insight on Black women's experiences to inform service improvement within specific communities (2,8,9,12,18–24).

Local context: Lambeth

At present, there is limited data capturing Black women's experiences of care for fibroids and endometriosis in Lambeth, an area with significant sexual and reproductive health inequalities that disproportionately affect Black and other minority ethnic communities (22, 29-31).

In line with Healthwatch Lambeth's role in amplifying the voices of local people, this project sought to understand how nationally documented issues are experienced locally and what Black women in Lambeth say would make care more accessible, responsive, and equitable (24, 31).

The findings in this report are particularly timely given that local systems are required to respond to national women's health priorities whilst addressing persistent racial inequalities in access to health care and outcomes.

Project Aims and Rationale

In 2024/25, Black women shared concerning feedback about their experiences of fibroids and endometriosis care through our feedback service. Issues raised included referral delays, cancelled procedures, poor coordination between primary and secondary care, difficulties accessing prescribed treatment, communication breakdowns, concerns about informed consent, and the emotional distress associated with navigating services. The cases highlighted potential gaps in local gynaecology pathways and concerns about equitable access to care.

In response, this project aimed to conduct an in-depth qualitative enquiry to understand the experiences of Black women in Lambeth living with fibroids and/or endometriosis, including their care pathways and the impact on their physical, emotional, and reproductive health.

This qualitative enquiry sought to:

- Generate insight into Black women's knowledge and lived experiences of fibroids and/or endometriosis, including routes to diagnosis, treatment and access to support.
- Understand the full impact of these conditions on physical health, emotional wellbeing and day-to-day lives, including implications for reproductive health.
- Identify what good care looks like from Black women's perspectives, including improvements needed to information, support and care pathways.
- Inform co-produced service improvement by defining clear priorities for change based on Black women's lived experiences, ensuring recommendations are grounded in what matters most to those affected.

The project builds on limited existing evidence by focusing on the lived experiences of Black women in Lambeth. It provides local insight to inform learning, drive service improvement and support more person-centred and responsive approaches to gynaecological care.

Methodology

Research Design

The project adopted an exploratory qualitative design, using focus groups and individual semi-structured interviews to hear the stories of Black women in Lambeth living with fibroids and/or endometriosis. Women were also invited to share their experiences via email, offering an alternative and convenient way to contribute.

Co-production of interview topics

At the start of the project, we held an online meeting with a group of Black women affected by fibroids and/or endometriosis to introduce the project and co-produce the themes for the interview guide, ensuring questions were relevant, accessible, and sensitive. Topics included:

- Experiences of living with fibroids and/or endometriosis and impact on women's lives.
- Experiences of seeking help and receiving a diagnosis.
- Experiences of accessing care, treatment, and ongoing support across the care pathway.
- What worked well and how the care pathway should be improved to better meet women's needs.

Project Advisory Group

We set up an Advisory Group made up of healthcare professionals and Black women with experience of fibroids and endometriosis to guide delivery, support dissemination, and advocate for improvements in care (see Appendix B).

Recruiting participants

We produced and promoted the project through a flyer which we circulated online and at in-person community events, through the local authority, NHS trusts, voluntary-sector organisations, and community networks.

These included:

- Ascension Trust, an inter-denominational organisation supporting the health and wellbeing of Black communities nationally and in Lambeth.
- Baytree Centre, a social inclusion and educational charity for women and girls.
- Black Thrive, a facilitation team striving for meaningful change and progress for Black Lambeth residents.
- British Caribbean Doctors & Dentists Association
- CAHN – Caribbean & African Health Network
- HBD (Hills, Brook and Dales) Women's Network
- Lambeth Community Connectors
- Lambeth Together meetings and forums
- Lambeth Together Wellbeing Bus
- Sankofa Sisters Wellness Collective
- St Mark's Church, Kennington
- Guy's & St Thomas' Hospital NHS Foundation Trust
- King's College Hospital NHS Foundation Trust

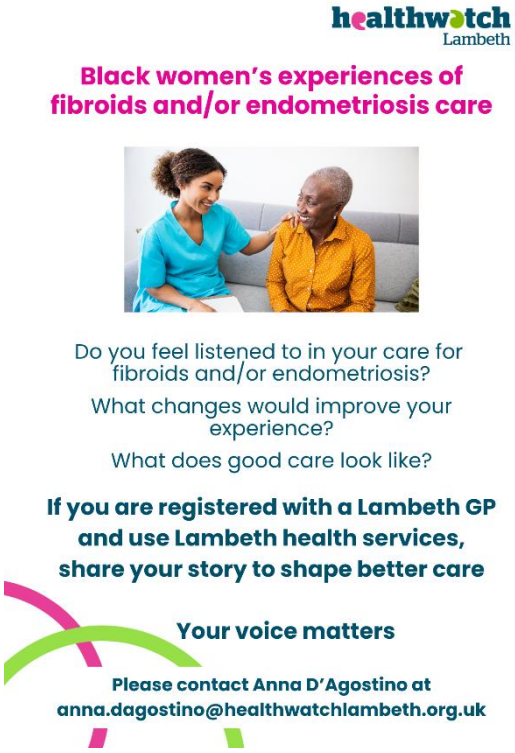

Figure 1 – Survey Promotional Poster

These organisations supported promotion of the project and helped encourage Black women to take part.

Interviews and consent

In total, 20 Black women affected by fibroids and/or endometriosis consented to share their experiences. Women were offered a choice of in person or online via Teams or Zoom meetings to share their stories. This resulted in:

- One online focus group with five women from a Black women's wellbeing group.
- Thirteen individual interviews; twelve online and one in person.
- Two women shared their stories via email.

This engagement generated sufficient qualitative insight to identify and explore the key challenges participants experienced.

Given the sensitivity of the topics, we used a trauma-informed approach, explaining the process and reassuring all participants about their anonymity and the possibility of withdrawing at any time. We used non-judgmental open-ended questions and encouraged women to only share what feedback they felt comfortable with.

All participants provided verbal and written consent in advance and reconfirmed their consent at the start of any recorded interview.

Data analysis

All interviews and focus groups were transcribed and checked for accuracy.

We then conducted a thematic analysis to identify recurring patterns, shared experiences, and differences across participants, including variations by age, ethnic background, and condition.

Of the twenty women that took part, sixteen reported experiencing fibroids, and four reported experiencing both fibroids and endometriosis. Because symptoms can overlap, it was not always possible to determine which condition women were referring to when describing their experiences.

Where women had only one condition, or clearly named the condition they were discussing, their quotes were categorised accordingly. In other cases, we considered the symptoms described. Where women referred to heavy bleeding, prolonged periods, blood clots, and anaemia, their accounts were interpreted as mainly relating to fibroids. Descriptions centred on severe pelvic pain or painful menstruation were considered more indicative of endometriosis.

Where experiences could not be confidently linked to either condition, extracts were labelled as 'unclear' (see Table 1).

Preliminary findings were presented to the Project Advisory Group to ensure analysis was consistent and accurately reflected participants voices and experiences.

Strength and Limitations

Strengths

- Interview themes were developed in collaboration with Black women affected by fibroids and/or endometriosis and drew on initial feedback provided by Black women to inform interview topics.
- Promotion the project through NHS trusts and community organisations including Black-led networks helped make the project

more accessible to women who may not usually participate in research.

- A flexible approach to data collection, including online and in-person conversations, supported women's participation.
- A sensitive, trauma-informed, non-judgemental interview approach helped participants feel safe and supported to share honest responses.
- Involvement of healthcare professionals and women with lived experience in the advisory group enhanced the quality and relevance of the project.

Limitations

- Detailed demographic information was not available for focus group participants and those who submitted written accounts. This limited our ability to make detailed comparisons based on age and ethnic group.

Participant Profile

In total, twenty Black women participated in the project. Of these:

- Sixteen women had fibroids only.
- Four women had both fibroids and endometriosis.

Approximately 70% were aged between 25-49 with the rest aged between 50 -64 years.

Ethnicity data was provided by 13 participants, of whom 70% identified as Black British Caribbean. Others identified as Black British African, Black South American, or Black Asian.

Detailed demographic information was not collected for the focus group participants, although the group they belonged to was specifically for Black Caribbean and Black African women. In addition, two women responded by email.

Table 1 – Profile of women and conditions referenced in interview narratives

Name	Age	Ethnicity	Condition	Symptoms referenced in narrative
Fola	25-49	Black British African	Fibroids	Heavy bleeding, anaemia and fibroids diagnosis clearly stated
Naomi	50-64	Black British Caribbean	Fibroids	Heavy bleeding, anaemia and fibroid surgery discussion
Danielle	25-49	Black British Caribbean	Fibroids and endometriosis	Focus on pain (unclear)
Aisha	25-49	Black British Caribbean	Fibroids and endometriosis	Severe bleed and pain from adolescence
Rochelle	50-64	Black British Caribbean	Fibroids	Symptoms linked to fibroids
Janelle	25-49	Black British Caribbean	Fibroids	Heavy bleeding and fibroid diagnosis
Zara	25-49	Black British African	Fibroids	Focus on fibroid treatment pathway
Vanessa	25-49	Black British Caribbean	Fibroids	Fibroids discussed explicitly in relation to GP interactions
Yvonne	50-64	Black British Caribbean	Fibroids	Fibroids discussed explicitly throughout interview
Sandra	50-64	Black British Caribbean	Fibroids	Heavy bleeding and fibroids management
Maria	25-49	Black South American	Fibroids and endometriosis	Participant reports both conditions- symptoms overlap

Nadia	25-49	Black British Asian	Fibroids	Fibroids discussed in context of GP context
Olivia	25-49	Black British Caribbean	Fibroids	Heavy bleeding and fibroid treatment journey; mentions possibly having Adenomyosis or Endometriosis but not diagnosed
Keisha	-	-	Fibroids	Referred to fibroids in discussions about care pathway
Hannah	-	-	Fibroids	Referred to symptoms and treatment for fibroids
Focus group participants	-	Mixed group of black women, some of whom were Black African	Four women with fibroids One with both fibroids and endometriosis	Four women make specific reference to fibroids in relation to diagnosis and impact on daily life. One references both conditions when discussing diagnosis.

NB – *To help bring women's experiences to life while protecting confidentiality participants have been given pseudonyms throughout the report with their condition included for context.*

Findings

This section presents the themes that emerged from focus groups, interviews, and written feedback. It highlights how symptoms were understood and managed, interactions with health professionals, experiences of diagnosis, treatment, and aftercare, and what women said are priorities for improvement.

Normalisation of symptoms

Most women lived with symptoms for many years before realising they were connected to fibroids and/or endometriosis. For some, symptoms began in adolescence or early adulthood, while others described severe pain and heavy bleeding from when they first began menstruating.

Limited information and discussions around menstrual health often shaped how women understood their symptoms. Heavy bleeding, flooding, and other menstrual changes were understood as a normal part of being a woman, rather than something that might need medical attention. This meant that opportunities for earlier diagnosis and support were often missed.

Rochelle lived with heavy periods for decades but only considered that she may have fibroids when the bleeding became significantly worse and began to affect her health, an experience shared by many women we interviewed.

> "I didn't put the symptoms of fibroids together until recently. I've had heavy periods for years, decades. In the last five years, they got significantly worse, to the point they made me anaemic and went from being heavy periods to being flooding. I didn't know that was a symptom of fibroids." – **Rochelle (fibroids)**

Olivia described how her symptoms gradually worsened over the years, especially after giving birth. She compared her pain to childbirth to illustrate how severe her symptoms had become.

> "It constantly feels like my womb is being ripped out. That's the best way to describe it." – **Olivia (fibroids and potentially endometriosis)**

Cultural expectations

For some women, the normalisation of symptoms was reinforced by family and community experiences such as when heavy periods were common among female relatives.

However, shared experiences could also prompt women to seek care. For instance, Janelle described how she began questioning her symptoms when her sister went through her own gynaecological investigations:

"Upon reflection, I've had symptoms for many years but didn't know. I just thought it was normal to have heavy periods and flooding, because nobody told me any different. It's a bit strange, because my mum and several of my sisters have all had fibroids. The only reason [I was diagnosed] is because my sister was tested for gynae issues." – **Janelle (fibroids)**

Women also spoke about how cultural expectations to be strong and self-manage affected their willingness to seek help. Fola illustrates:

"[In our community], fibroids are something you just sort out yourself… A lot of women have it, so it's seen as normal and not taken seriously." – **Fola (fibroids)**

Similarly, Rochelle spoke about the familial pressures and cultural expectations of being a strong matriarch while experiencing pain and poor mental health.

"Being vulnerable, having depression, anxiety… that's not permitted… as a woman in the Black community, that's an unspoken rule. Matriarchs are the backbone of the community… of the family. You're the strongest link, so if you crack, everyone else's foundation shakes. It's a lot of responsibility to bear." – **Rochelle (fibroids)**

Life altering impact of symptoms

Across all interviews, women did not describe fibroids and endometriosis symptoms as minor or routine. Instead, they described them as serious, disruptive, and often all-consuming conditions that affected every aspect of daily life.

Symptoms were sometimes seen as unmanageable and could cause a complete functional shutdown. Severe bleeding and pain shaped women's ability to work, travel, sleep, socialise, care for children, maintain relationships, feel confident, go out in public, and plan their future.

Functional shutdown

For some women, pain was described as extreme, exhausting, and at times incapacitating, affecting walking, sleeping, eating, concentrating, and remaining upright. Danielle's account is particularly vivid:

"I was saying that I'm in pain and no one was really hearing. [Doctors would say] "Oh, it's normal", but it's not normal. It's not normal for me to be crying. It's not normal for me to be… rocking backwards and forwards, fainting, vomiting, just trying to do everything I can to stop the pain. There was a time my legs just wouldn't move, and I had to be carried to the toilet." – **Danielle (fibroids and endometriosis)**

Fatigue and anaemia compounded this burden further, as repeated blood loss could undermine women's ability to think clearly, sustain energy, and even do their jobs safely or effectively. For Zara, fibroids represented a professional and emotional strain at work:

"I'm struggling at work… and I'm worried about patient safety because I'm a nurse… I go to work, I get muddled, I get tired." – **Zara (fibroids)**

Similarly, heavy bleeding restricted movement, disrupted work, and led to shame, social withdrawal, and isolation. Naomi described bleeding as halting her normal functioning:

"I was changing [sanitary towels] like every 30 minutes… I just couldn't do much… It stopped my entire life. It was almost like something just dripping, the tap running." – **Naomi (fibroids)**

Embarrassment, loss of confidence and body image

Heavy bleeding and the risk of leaking and staining clothes made women feel constantly vigilant, self-conscious, and with reduced confidence. This fear affected what they wore, where they went, and how comfortable they felt in public. Nadia's account conveys what she did to avoid feeling humiliated:

"I was very self-conscious because of the heavy bleeding… I wouldn't wear any light colours and would have spare underwear in my bag, just in case. I was constantly going to the toilet to check." – **Nadia (fibroids)**

For some, managing severe symptoms meant dealing with embarrassment and loss of dignity. Sandra's account illustrates:

"I was bleeding really heavily to the point where I was leaking. I ended up having to literally buy adult nappies and put the pads inside of them because of how

much blood there was. I couldn't go to work because of the leaking and how embarrassing it was." – **Sandra (fibroids)**

Body image was also affected. Fola described how visible bloating and abdominal swelling affected her self-confidence and identity.

"I can't put on a tight clothing because I have this bulge… my tummy is like someone… five months pregnant." – **Fola (fibroids)**

Self-consciousness and loss of confidence affected women's desire to socialise and be out in public.

"I personally suffered with fibroids and endometriosis, and I think the main mental effect is really the low confidence…the fear of being in public." – **Focus group participant**

Life organised around symptoms

The impact of these conditions extended to women's participation in everyday life. Women described feeling a loss of control, as their lives had to be organised around the menstrual cycle and anticipated pain, bleeding, and exhaustion. Danielle's account describes the impact of this:

"I check my work calendar, my personal calendar, my period calendar…I no longer plan things the week of my period, so I don't work out, I don't do anything. I just accept that this is what it is." – **Danielle (fibroids and endometriosis)**

Family life under strain

Home and family life were also deeply affected, with women struggling to parent, participate in family life, and remain emotionally available to those around them while coping with symptoms, as shown in Maria and Zara's accounts.

"My kids were complaining, oh, you're always sleeping, you're always saying your stomach's hurting… but I was genuinely in pain." – **Maria (fibroids and endometriosis)**

"I'm a solo parent… my son… is on the spectrum and I'm trying to juggle looking after him, working, and then dealing with my own health condition." – **Zara (fibroids)**

Fertility and future planning

For some, the impact also extended to fertility and future hopes of parenthood, as the link of fibroids to potentially reduced fertility created additional anxiety and stress. For Yvonne, this affected both her present wellbeing and her sense of time and future possibilities.

"I was trying to become pregnant… it affected my mood; it affected my being. Time was getting on and my childbearing years are ticking away." – **Yvonne (fibroids)**

Hannah shared how a miscarriage led to her fibroids being identified. This left her with the emotional aftermath of a miscarriage and uncertainty about her future fertility, made worse by a lack of follow up care.

"My miscarriage a profound loss, came with an added burden: a diagnosis that has still not been explored further. I have had no follow-up, no plan, no clarity about the fibroids or their impact on my future fertility. Now at 39…I hold onto the vision of motherhood. But behind that hope sits a quiet fear: what will these fibroids mean for me?" – **Hannah (fibroids)**

Overall, the evidence suggests that fibroids and endometriosis were experienced as profoundly disruptive, life-altering conditions with far-reaching consequences reducing quality of life and forcing women to adapt every part of their life around their symptoms.

Interactions with health professionals

Women's experiences of professional care varied considerably. Some described compassionate and proactive professionals who listened, believed them, and investigated their symptoms. Many others spoke of a more difficult journey characterised by dismissal, mistrust, inconsistent responses, a focus on symptom management without investigation, and the need to push repeatedly for appropriate support.

When women felt heard and supported

A small number of women described highly supportive, responsive, and person-centred interactions, characterised by health professionals who listened attentively, validated concerns, and acted where needed. Rochelle describes waiting to speak to a GP who she knew would listen to her.

"I know that I had one of the best doctors in my GP practice. He has a waiting list as long as two arms and two legs. And I don't mind waiting because I want to see

my doctor, because I can freely speak and say, this is what's happening." – **Rochelle (fibroids)**

When women felt able to speak openly and be taken seriously, this often led to appropriate follow-up, including referrals for further investigation. Fola and a focus group participant describe professionals taking action:

"My GP was concerned because I was quite anaemic, so said he would refer me so I could discuss with a specialist." – **Fola (fibroids)**

"I went to my GP, a female GP, amazing, and she referred me to Guy's and St Thomas's hospital for an ultrasound scan." – **Focus group participant**

Nadia described a positive experience of care when discussing her scan results with a consultant. She valued the time the consultant took to explain her condition in detail, using scans and diagrams to help her clearly understand the location and impact of her fibroids. This approach helped Nadia feel listened to, reassured, and better informed about her symptoms.

"The consultant sat there, put the time in, got the MRI up and told me to take a video [of him explaining] 'it's this fibroid here and that's affecting your back here.' He was the first one to actually tell me about my fibroids. It didn't feel like I was going mad. I got a lot more information, a lot more time and care." – **Nadia (fibroids)**

When women felt dismissed and not taken seriously

Conversely, many women said they did not feel listened to or taken seriously by GPs and other health professionals. Despite the impact of symptoms on their lives and wellbeing, many women left appointments feeling unheard and dismissed without explanations or further investigation.

For most, this was not just one difficult appointment, but something that happened repeatedly over time. Yvonne described years of raising concerns without feeling that the seriousness of her symptoms was recognised:

"I had always suffered from heavy periods, from being a young girl… Twenty years on, I'm still complaining about heavy periods, and [health professionals] are telling me, 'It's alright, you're fine, don't worry about it.'" – **Yvonne (fibroids)**

Many women felt their symptoms were normalised and downplayed by health professionals, as "just heavy periods", "hormones", or something to be managed through routine treatment, rather than signs of a condition requiring further investigation. For some women like Vanessa, the normalisation of symptoms continued even after diagnosis:

"They just said, 'Oh, it's just fibroids, it's normal'. And so, I didn't think anything of it." – **Vanessa (fibroids)**

In some cases, women were treated for the effects of their symptoms, through treatments like iron tablets or contraception, but not for the underlying causes. In this context, treatment itself could become a dismissal, as it managed the effects without answering: what is causing this?

Aisha's experience illustrates:

"They only prescribed some iron for me to take because I was losing a lot of blood, becoming anaemic... but [they] didn't look into why I was bleeding that heavily. All those signs were ignored." – **Aisha (fibroids and endometriosis)**

Dismissal from health professionals meant the burden of getting action often fell on the women themselves. For instance, Rochelle and Olivia shared that describing pain was not enough; they had to provide evidence to be believed.

"It was only until I showed a physical picture [that I felt listened to.] I'm used to having to take pictures, evidence... I can't just go to the doctors and cry, Oh God, I'm not feeling good... You're not going to be listened to. You have to go above and beyond – make notes, report record, and give evidence of what's going on with you." – **Rochelle (fibroids)**

"I don't feel like they [GPs] take it seriously. I actually fished out a clot from the toilet and put it in my hand and took a picture, just so I had some visual evidence to show the doctor." – **Olivia (Fibroids)**

Interpretation of symptoms through age and life stage

Women's symptoms were also interpreted through the lens of age and reproductive life stage. For younger women, symptoms were often treated as ordinary periods or linked to hormones. Contraception was presented as the solution without conducting further investigation. For Maria, her pain was explained away as a result of hormones and childbirth:

"I remembered the midwife saying, 'Oh, it's probably because you've had so many babies… You've got too many hormones in your body', but I was experiencing pain." – **Maria (fibroids and endometriosis)**

For older women, symptoms were sometimes understood in relation to perimenopause or menopause. Bleeding was frequently linked to hormonal changes, HRT, and changing menstrual patterns. Other symptoms of fibroids like hot flushes and disrupted sleep were treated alongside menopause-related changes, without clear separation between the two. This led to uncertainty about treatment options and whether symptoms would resolve naturally. Yvonne illustrates the worry and frustration around this:

"The GP said 'you're going through perimenopause… normally those [fibroids] would shrink naturally, so there isn't anything more that we can do for you.' But the perimenopause can go on for 10 or 15 years, so I'm expected to live with these symptoms for further time! I was dismissed all that time ago before I had a child, and now 16 years later, I'm being dismissed because I'm going through perimenopause." – **Yvonne (fibroids)**

Differences between health professionals

Care often depended on which health professional a woman happened to see. Some women had to have several appointments, repeat their story, or change GPs until they were seen by someone that took them seriously, as described by Naomi:

"I changed GP, because the very first one didn't even refer me to a hospital. They just gave me iron." – **Naomi (Fibroids)**

Aisha shared a similar account about specialist care where she described very different experiences at two hospitals. The first hospital she went to did not conduct further investigation or offer her treatment options. In the second, a doctor took her seriously and finally referred her to a specialist.

"At [Hospital one] I knew I had large fibroids, but they refused to operate because I was too young, so they weren't helping me at all. When I went to [Hospital two], they listened to me and I felt heard. One doctor looked at what was happening and said she needed to do keyhole surgery to see what was going on. She told me, 'I'm going to help you.' I felt so relieved. That was the best time of my life, the happiest time ever. I finally felt that I'd been heard." – **Aisha (fibroids and endometriosis)**

Women also described experiencing conflicting clinical opinions, results, and treatment suggestions. A focus group participant described being sent to multiple gynaecologists who provided contradictory explanations, leaving her with no clear clinical path forward.

"I still don't have any solution to anything, because gynaecologists disagree on what could be causing so much pain." – **Focus group participant**

Another focus group participant experienced inconsistent ultrasound results, which she attributed in part to healthcare professionals' lack of familiarity with scanning Black women's bodies:

"I've had several ultrasound scans, and they all show different number of fibroids and cysts and even show things in the wrong location, because the radiographers are not experienced with how to put the camera in the right place for a Black woman's body." – **Focus group participant**

Health professionals' gender and race

Some women felt the gender of the health professional affected their experience of care, but this was not a defining factor. What mattered most to women was whether they felt listened to, believed, and supported.

Nadia described a turning point when she saw a female GP after multiple consultations where her symptoms had been dismissed.

"It would have been about at least four visits [to GPS] and they were mostly male. [They would say] 'it's just heavy periods, take over-the-counter medication.' It was only when a new female GP referred me that I felt I was being heard...it felt like hallelujah, someone's taking my concerns seriously enough to talk to me about it. It's about listening and empathising. That's the biggest difference: somebody listening." – **Nadia (fibroids)**

Female doctors were sometimes associated with greater empathy and a willingness to act. They were also perceived by some as having greater understanding of women's bodies and experiences. Sandra described encounters where she felt male doctors seemed uncomfortable discussing menstrual health, shaping the quality of her interactions.

"I think men are squeamish anyway... as a woman, you see blood all the time... I just feel they are very uncomfortable in addressing [menstrual issues]." – **Sandra (fibroids)**

Some women also described positive experiences of being seen by Black health professionals. These are explored in the next section.

Race and gender

In women's accounts, care was often influenced by race, gender, and cultural background. Some spoke about racism, assumptions, and unequal treatment in healthcare. Others felt their experiences reflected a wider pattern of women's health being minimised and dismissed, with some pointing to other factors like class, education, and disability. Overall, many felt that identity affected whether their symptoms were believed and acted on.

Normalisation of Black women's suffering

Some women felt their symptoms were repeatedly dismissed and normalised by health professionals because of their identities as Black women. Fibroids were seen as a condition that particularly affected Black women, but this did not lead to better support or earlier intervention. Instead, it reduced the urgency of further investigation and treatment.

Danielle recalled an early consultation where a doctor used her identity as a Black woman to explain her symptoms in a way she felt dismissed and minimised her pain.

> "I spoke to a male doctor, and his response was, 'You're a black woman, that's common in Black women.' It infuriated me because it felt just insensitive, with no care. Because we are known to have these issues, that doesn't mean that it's okay." – **Danielle (fibroids and endometriosis)**

Yvonne described a similar experience, where she was repeatedly told that fibroids affected "women like yourself", without being offered much support.

> "All of the GPs and professionals that I saw during that time were White. It was very much delivered to me that fibroids are something that affects women that are Black or of Caribbean descent. That was my perception… that it's something that Black women just get… That was said to me on more than one occasion but [health professionals] did not offer any support in changing it." – **Yvonne (fibroids)**

Assumptions about Black women's tolerance for pain also negatively affected experiences of care. Janelle described the emotional strain of advocating for herself and challenging assumptions within a system where health professionals are unaware of the impact of these attitudes.

"I should be treated like a human being. I should be treated like white women get treated…I'm not strong. I cannot bear pain. I can't tolerate certain things…It's so tiring being a black woman… because you have to advocate for yourself on a whole different level. I feel like GPs and doctors don't even realise they're doing it. It's very institutionalised in a sense. It's normal to assume that black women can do this, or they can do that, or their bodies react differently… And I think, no, we're all human, and I should be treated just like that lady over there." – **Janelle (fibroids)**

Stereotypes in care

Women also described how stereotypes affected how professionals responded to them. In some cases, women felt they had to manage how they spoke and behaved in healthcare interactions to avoid being judged negatively or unfairly.

"There is this stigma with Black women, that we're aggressive… You're trying to get your point across… but you're also conscious that you can't behave in a certain way because they'll label you." – **Sandra (fibroids)**

Knowledge and representation in healthcare professionals

Women also challenged whether healthcare professionals had enough knowledge of Black women's bodies to respond to their needs, diagnose, and care for them appropriately. One focus group participant highlighted:

"Our doctors are not even equipped to deal with Black women that have fibroids…Why don't we have doctors that can understand our anatomy within the NHS?" – **Focus group participant**

Another participant emphasised the need for greater representation among healthcare professionals, as she felt that this would improve diagnosis, challenge assumptions and build trust.

"Changing the mentality and getting more Black, African and Caribbean professionals that know about the anatomy of Black women and improve diagnosis." – **Focus group participant**

Some women highlighted the importance of having Black healthcare professionals they could connect to. Janelle spoke about feeling understood by a Black nurse:

"[The nurse that spoke to her before her surgery] was a Black lady and I ended up speaking to her for about an hour and a half. She just got it. She just understood… There was a connection of understanding, of I know what you're going through. It was what I've needed. Empathy is necessary, but it's hard to get empathy when you don't connect with a person." – **Janelle (fibroids)**

Unequal treatment of women's health

Some women questioned whether their concerns were dismissed because of how Black women's health, and women's health in general, are treated in Western medicine. Both Yvonne and Vanessa point out the significance of this:

"If more women that were not Black were affected by it, then maybe [fibroids care] would have a higher priority, because I feel that the priority for fibroids is low. The priority for women's health is low." – **Yvonne (fibroids)**

"I don't know if it's necessarily because we're black women, or if it's just because we're women… I don't think that the Western medicine world values women in general." – **Vanessa (fibroids)**

Maria also reflected on how race should also be understood alongside other factors, including communication style, education, and social background:

"You could run the risk of people homing in on experiences that they've faced that aren't linked to them being Black… they may be linked to being female, disability, or social background… you might not be respected because of the way that you speak." – **Maria (fibroids and endometriosis)**

Hannah's written feedback further illustrates how women's pain is ignored and erased.

"Women's pain is too often dismissed, minimised, or normalised until it becomes invisible. What we need moving forward is simple: to be believed. To be taken seriously. To receive investigations not as a last resort, but as a genuine attempt to understand and relieve our suffering." – **Hannah (fibroids)**

Timely support and avoidable delays

Women felt positively when system responses felt timely or aligned with their perception of the urgency and severity of their symptoms. For instance, Maria reflected on how quickly she was referred to a hospital appointment when she suspected she had fibroids:

"I was happy with the speed at which the doctor called me back. It made me feel like he took me seriously…the time it took [to get a hospital appointment] was literally under 7 days… I appreciated that." – **Maria (fibroids and endometriosis)**

However, delays were common throughout the care pathway for most women. Symptoms were often overlooked for a long time or only taken seriously after they worsened, and referrals to further investigation could take months. The issue was not only late diagnosis, but missed opportunities to intervene earlier, before options for treatment became limited.

Missed opportunities for earlier diagnosis and treatment

As outlined above, many women needed to raise their concerns multiple times before they were taken seriously. Often, diagnosis only came after symptoms worsened or another event led to further investigation. By then, their fibroids were already advanced.

Maria lived with symptoms from her early twenties but only discovered she had fibroids when she was scanned for a possible miscarriage. She expressed disappointment at not being diagnosed sooner, particularly given the known prevalence of fibroids among Black women:

"Since I was about 23, I'd been complaining, but no one had managed to diagnose it [fibroids]. The only reason I had a scan was because I thought I was miscarrying. I was a bit disappointed, because Black women are known for getting fibroids anyway." – **Maria (fibroids and endometriosis)**

Several women looked back on points in their care where they felt that timely advice, clearer explanations or earlier treatment could have changed what happened later. Zara described learning about her fibroid when it was still small, and feeling that intervention at that stage might have reduced the likelihood of surgery:

"The first time I had a scan, it was about two centimetres… I was hoping that someone would have convinced me of the benefit of being on a coil or any hormone suppressant to reduce the growth of the fibroid. If they had helped me, I

wouldn't get to a point where surgery is my only option. I wouldn't be thinking of surgery now." – **Zara (fibroids)**

Long waits for referrals and specialist care

Once they had finally been listened to, women often faced long waits for referrals and specialist care. Fola described the wait for specialist care as excessive:

"Timing. One year was too much… I had waited for like, eight months for this appointment… one year was just too much." – **Fola (fibroids)**

Women had to endure long waits while coping with heavy bleeding, pain, fatigue and anaemia and with the emotional toll of trying access care while feeling unheard and unsupported. Nadia describes the physical toll and frustration of waiting and repeatedly trying to get help:

"Making these GP appointments, going back over and over again, repeating myself. It felt like it was falling on deaf ears. It felt [the GP] was reluctant to do any referral whatsoever… [The referral] took eight months. I was tired because I was losing that much blood and was anaemic, and my periods were going on longer and longer." – **Nadia (fibroids)**

Inconsistent care

For some women, delays were made worse by inconsistent investigation, poor follow-up, and changes to appointments. This created more uncertainty and made it harder to move towards a clear treatment plan. Danielle illustrates:

"My experience with them [NHS] has just been quite slow…with my appointments this year, it's literally been moved three times, and every time it's like months later. And I understand that they've got their reasons, but it also feels like you don't care much about what I'm dealing with." – **Danielle (fibroids and endometriosis)**

Poor continuity also added to the feeling that their concerns were not being followed up properly. Zara described this clearly:

"There's no continuity. Doctors are not talking to each other and not following up on my previous appointment. It's a communication gap." – **Zara (fibroids)**

Treatment discussions and choice

Women received a range of treatments, from hormonal treatments to more invasive options, including surgical removal of fibroids via fibroid embolization, hysteroscopy, or myomectomy and hysterectomy.

Experiences of treatment discussions were mixed. Some women felt listened to, respected, and involved, while others described conversations that felt brief, negative, or clinician led. Across these accounts, women wanted clear information, balanced discussions, and a stronger sense that decisions were being made with them, not for them.

Positive experiences of treatment explanation

Some women described positive conversations where they were listened to and given clear options to choose from according to their needs and fears. What stood out most was not the treatment itself, but the way the conversation happened.

Fola described feeling heard when a specialist took her fear of surgery seriously. Rather than being pushed towards one option, she was talked through different treatments and allowed to choose what she felt most comfortable with. Even though the treatment later proved too limited, she recalled the discussion positively as her views were considered.

> "When I got there, I spoke to the specialist, and they gave me options, different options, non-invasive, because I said I wasn't going to have any surgery...I explained my fears so they gave me all the treatments I could take... and the good thing is, they told me to choose which one I wanted and I chose a non-invasive one... I was listened to because I chose the treatment." – **Fola (fibroids)**

For Naomi, hysterectomy brought immense relief following a long and difficult treatment journey. She went through many failed attempts to manage symptoms through medication, a coil that made her bleed heavily, and an injection that made things worse. By the time surgery was offered, she was exhausted and wanted an end to the heavy bleeding that had taken over her life.

> "I don't know if there were any alternatives to hysterectomy... by that time, I got tired of trying different things. I was relieved, because I just thought, I don't want to bleed anymore. I had enough... After I had the hysterectomy, nothing, that was it." – **Naomi (fibroids)**

Limited information, uncertainty, and fear

Many women did not feel fully informed or involved in treatment discussions. Maria and Olivia describe how options were not properly

explained, or that discussions were too brief for them to understand what options really meant in terms of risks, side effects, and aftercare.

"[The clinician] told me what my options were, that it was either medicine or minor surgery… But he never offered to give me tablets… I don't feel like we had an in-depth conversation." – **Maria (fibroids and endometriosis)**

"[Clinicians should] explain the results clearly, what all the options are, and what the aftercare would be." – **Olivia (fibroids)**

Rather than providing a balanced explanation, some women felt that risks were emphasised more than benefits. Vanessa described feeling that treatment discussions focused exclusively on disadvantages.

"I don't feel like advantages were explained… it was all just negative, negative, negative." – **Vanessa (fibroids)**

Women's treatment decisions were also shaped by anxiety, uncertainty, and previous experiences, such as fear of surgery, worry about side effects, or doubt that treatment would work. Women felt they needed more support to navigate these feelings and make a decision. Danielle described her fear of both surgery and the potential recurrence of symptoms:

"The surgery makes me a bit nervous…because I look at a lot of my friends who have had surgeries to remove their fibroids, but their fibroids have now started to grow back. I'm reluctant to do the surgery if it's going to come back." – **Danielle (fibroids and endometriosis)**

Personal circumstances and preferences

Several women felt that treatment decisions were too clinician-led, with not enough opportunity for their concerns, preferences, or life circumstances to shape the conversation.

For some, hysterectomies were presented as the only solution, without considering the impact on their lives. Rochelle described feeling like her clinician only focused on 'solving' her condition without considering her personal circumstances.

"He said we could just do a full hysterectomy. He didn't ask me how I felt about whether I wanted to have a family or have any more children. He just went

straight into, 'This is the issue. This is the solution.' In a way, I didn't feel involved in the decision-making." – **Rochelle (fibroids)**

Conversely, Sandra wanted a hysterectomy, as it would grant her peace of mind after repeated hysteroscopies and ongoing cancer scares. However, she strongly felt that her reasoning had not been given enough weight alongside clinical opinions.

"I think it should be my decision… You can tell me the risks. You can tell me why you don't think I need a hysterectomy, but I think the reasons I want it should be weighed up… I don't think it should be a standard pathway… if I want to explore the option of a hysterectomy, I think I should be given that opportunity." – **Sandra (fibroids)**

Keisha's written feedback reflects on the feeling that women were not treated like active decision-makers in their own care:

"I don't feel that this way of dealing with fibroids is patient centred… it's like professionals aren't treating you like a person who can make informed decisions about yourself and your body." – **Keisha (fibroids)**

Aftercare and feeling abandoned

Women consistently reported poor aftercare following procedures. From immediately post-operation to discharge and recovery, women felt unsupported, unheard, and concerned about how to manage with limited information.

Naomi described being in severe pain after her hysterectomy without timely pain relief, despite repeatedly asking for help. She was then discharged before she felt ready, with little discussion about why she was going home or what support she would need.

"I sat in this ward from morning till night… groaning with pain… and then that one thing they could have given me… they never gave it to me…They asked if I wanted to go, and I said, No, I didn't feel ready… then someone came up with the tablets… that's when I knew I was going home." – **Naomi (fibroids)**

Once home, Naomi struggled with pain, constipation, bathing, mobility, and knowing what level of activity was safe. Much of this had to be worked out through repeated GP contact or by trial and error.

"After the operation, there was no aftercare. No one offered me nothing; I had to figure it out for myself. There's certain things I just didn't know. I remember I got out of the car, took 10 steps and was like, oh my god, I can't walk. I had to be put in a wheelchair, because my legs wouldn't allow me to do it." – **Naomi (fibroids)**

Aisha shared how she felt unprepared to deal with the aftercare needed once discharged from hospital. She also felt she was not given sufficient time or support before going back to work.

"After the operation, I went home, not educated on aftercare. How should I look after myself? I had to stay home three months after the operation, because it was taking long to heal. Every few weeks, I had to go to my GP to get a sick note to send to my work which was a lot of stress as well. I should have had a bit more time to heal and go back to work. I didn't get that support." – **Aisha (fibroids and endometriosis)**

The lack of emotional support following surgery was also emphasised. Nadia's care focused on the physical aspects of the procedure, neglecting the 'emotional journey' she was experiencing. A follow-up appointment to discuss her post-operation concerns was not offered. In her words, the 'human side' was lost.

"The surgery was fine, that was explained but [no] aftercare or follow-up, to talk about the experience, how you feel now the operation is done, the emotional side – because it's an emotional journey. I think the NHS and public health have missed the human side of it now. It should be automatic to book in an appointment two weeks after the procedure, even by telephone. When it's not done, it feels like being abandoned." – **Nadia (fibroids)**

Managing alone

Repeated negative experiences led many participants to express mistrust and disappointment towards healthcare providers and the NHS more broadly. A focus group participant illustrates:

"I don't have a lot of hope within any NHS system, no matter what it is, because there's a lot of walls and a lot of barriers within our own society. Never mind going to see the doctor." – **Focus group participant**

In the absence of effective medical support, women demonstrated resilience through extensive coping strategies moving from self-

management, information seeking, self-advocacy, and peer support to manage their conditions and find alternative sources of care.

Self-management strategies

Many women described turning towards self-management out of necessity. This included changing routines, planning around their cycle, making lifestyle adjustments, and drawing on whatever strategies helped them get through the day. Women learned what combinations of medication, heat, rest, or movement gave some relief, even where these measures were difficult, limiting, or far from ideal. Danielle describes the range of strategies used to manager her painful symptoms.

"I got to a stage where my period was just so bad...So what I'll do is wake up in the morning, I'll take paracetamol and ibuprofen and then get in the shower and have the hot water just constantly running so that it stays warm. And then by the time I get out, the paracetamol and Ibuprofen have kicked in. Then I have a little bit of rest, [I've learned] different methods to work with [my conditions]." – **Danielle (fibroids and endometriosis)**

Other accounts show how women tried to hold on to activities that helped them cope. Zara explains how movement, in particular swimming, was especially important.

"I would say the best thing that helps me cope is exercise... Swimming...I think it's probably the exercise that keeps me going..." – **Zara (fibroids)**

Information seeking

Women spoke about a gap between the information they needed and what they received. This was not just about getting more information, but about getting information that was clear, practical, and allowed them to understand when something was not normal.

Vanessa explained this clearly:

"Do we actually understand... what a fibroid is? We get thrown around words, but it doesn't necessarily mean anything to us. Maybe explaining the symptoms better, not just saying heavy bleeding [but] explaining that if you're changing your pad every hour, then that's a big cause for concern." – **Vanessa (fibroids)**

Because of the lack of clear information, many women said they had to look things up themselves to understand their conditions, as illustrated by Danielle:

"I have done a lot of the work to find out for myself about the things that I know. It didn't come from my GP or other a professional." – **Danielle (fibroids and endometriosis)**

Fola described how earlier access to clear guidance could have changed the course of her care. For her and many women, better care should have follow up information, practical guidance, and routes to wider support.

"One thing I regret now is the fact that I didn't research from the beginning into what I should do, what I shouldn't have done...I think women that go to their GP should also be referred to a group of dietitians, or another group at the hospital that would give them more information on how they should manage it... I didn't have it." – **Fola (fibroids)**

Self-advocacy as a necessity

Across women's accounts, self-advocacy emerged as something they had to develop after softer attempts to seek help had not been enough. Many women, like Yvonne and Danielle, described feeling the need to be forceful and persistent, as getting help often depended on how strongly they were able to push.

"I'm not going to give up on [getting help], because I know that sometimes, the harder you shout... you have to keep making noise for them to not just forget you." – **Yvonne (fibroids)**

"In my interactions with the GP, if you don't advocate for yourself, you will not get it. And I had to realise that. I had to be quite forceful, and I had to be like, well, I'm not leaving without it for me to even get the referral..."
– **Danielle (fibroids and endometriosis)**

Olivia highlighted the importance of challenging expectations that make Black women suffer in silence.

"Speak up. The strong black women, rhetoric is sometimes killing us because we're suffering in silence." – **Olivia (fibroids)**

Zara emphasised the importance of taking an active role in managing your own health, being persistent, and speaking up. She also described using her own experience to support other women:

"You should be in charge of your health and be very persuasive. Now, I feel more empowered to challenge these health professionals and say, do you know what? That's not good enough. I'm not going to wait. I want something else done… and that is me growing in confidence as a woman, as an adult… Now I have this voice. Be informed, because your sister next door might have fibroids and because you're informed, you can do that journey with her." – **Zara (fibroids)**

In all these accounts there is an explicit message to other women shaped by experiences of an unresponsive system.

Peer support and shared experiences

Peer and community support also emerged as an important source of reassurance, understanding, and practical help. Some women looked beyond formal healthcare for spaces where they could speak openly, exchange knowledge, and feel less isolated.

Yvonne highlights this in her story about the value of online forums.

"I have joined online forums… The experiences that people talk about, regardless of whether they're in the UK or not, seems to be the same… we're all experiencing the same dismissiveness around fibroids or endometriosis." – **Yvonne (fibroids)**

Vanessa questioned the expectation that support should come only through doctors. Instead, she actively built a supportive environment for herself when formal services felt too limited.

"Why are we solely reliant on the doctor? Why don't we understand enough about… what potential things might be causing us to feel this way?… I created my own space with my women's circle… it's like a support group… where you can discuss whatever." – **Vanessa (fibroids)**

Sandra takes this further by calling for community-based places where women could go to talk, access information, and understand options.

"There should be centres where women can go to be able to talk to people… somewhere that's got all the information that can tell you what your options are." – **Sandra (fibroids)**

What needs to change

Women identified clear priorities for improving care, including earlier investigation, clearer explanations and information, quicker access to

specialist support, more personalised assessments, better follow-up, and simpler routes into services. Together their accounts show that better care is not only clinical, but is about being listened to, believed, and supported throughout their care journey.

A more thorough approach from the start

Women emphasised the need for a more thorough, in-depth approach from the start of care. They wanted professionals to look at the wider picture instead of focusing on one symptom per appointment. This included asking about lifestyle, diet, and patterns of pain over time, as Nadia explains:

"There should be a questionnaire... lifestyle and diet are a big one, as well as... pain monitoring or like a diary for month or something like that." – **Nadia (fibroids)**

Quicker access to specialist support

Women felt that GPs did not always have the specialist knowledge needed for complex conditions such as fibroids and endometriosis. Despite symptoms being noted, many left consultations without clear answers, guidance, or next steps.

Maria illustrated the importance of referrals well. She wished for easier access to someone that understood her condition, instead of having to return to the GP without progress.

"I feel like that's what's let me down... GPs can only ask me my symptom, but they can't tell me what the issue is... the next step would have been to refer me to a gynaecologist to have that conversation. I think you need to have a specialist... somewhere that you can go directly, as opposed to going to your GP. I haven't really seen a medical practitioner who gave me the confidence that they know how to treat me, because they know what this is all about." – **Maria (fibroids and endometriosis)**

Better follow-up and aftercare

Women also highlighted the importance of follow-up and aftercare, especially after treatment or surgery. For them, care did not end when a procedure was finished. Recovery brought new questions, symptoms, and worries, and women wanted support to help them manage this stage properly.

Personalised care

Women were also clear that care should not be the same for everyone. Better support meant moving away from a one-size-fits-all response and paying attention to each woman's history, symptoms, needs, and circumstances. This matters because women's experiences often built up over time, and care needed to reflect that complexity. Sandra describes the importance of this.

"Things shouldn't be standard. It shouldn't be one size fits all… Look at the individual circumstances… make it a bit more personal." – **Sandra (fibroids)**

Listening to women and trusting their accounts

Personalised care was closely tied to the need to be listened to, believed, and not dismissed. Women wanted professionals to treat their experiences as important clinical information and to recognise that patients know when something has changed in their own bodies.

"What I just want to say is for healthcare professionals to be able to know that a patient knows their body better." – **Focus group participant**

Fair, respectful and culturally safe care

Women also spoke about the need for fair, respectful, and unbiased treatment, especially for Black women. Yvonne highlighted the need for training in cultural bias to address this:

"I think that further training is needed around the cultural bias that is inflicted against Black women by professionals. When health issues affect people that are not White, I feel they are favoured more. How they deliver information, how they speak to women… every case should be treated individually, and not just typecast into, oh, because you are Black and you are female, and you fit these criteria." – **Yvonne (fibroids)**

Janelle also emphasised the need for professionals to listen without prejudice, speak respectfully, and avoid making assumptions based on race or background.

"We are not listened to. There's a stereotype of us. Most of the people who are looking after me are Caucasian. I choose not to judge you on your colour… So, don't make that judgement about me. See me as a human being, heartbeat, two eyes, and nose… see me as an individual, not as a person that you've seen on social media, or you've heard about, or you had a past bad experience with. Treat me as an individual here today. It matters. I matter." – **Janelle (fibroids)**

Conclusion

Healthwatch Lambeth carried out this project to understand Black women's experiences of fibroids and endometriosis care in Lambeth. The project provides important local evidence into the impact of these conditions on women's health, wellbeing, and quality of life and identifies how experiences of care can improve.

Existing research shows that Black women are more likely to experience fibroids, develop severe symptoms, and face poorer outcomes for fibroids and endometriosis (2,7-8). Women in this project shared very similar accounts of severe pain, heavy bleeding, anaemia, and disruption to every aspect of their lives.

Although women described a difficult journey to care, good care was linked to feeling listened to, taken seriously, and having their concerns acted on quickly. Women also valued health professionals who took time to explain test results and treatment options clearly and treated them as individuals.

However, positive experiences were often the exception. Women's stories reflect wider evidence of delays in diagnosis and treatment, poor communication, and minimisation of symptoms, as found in the APPG and CAHN enquiries into Endometriosis and Fibroids (20,33). Women told us their symptoms were often normalised by healthcare professionals without further investigation. Many spoke about having to prove their symptoms or 'push' for care. Once they were seen, many felt they were given limited treatment options and described feeling abandoned in aftercare. Faced with long waits for referrals, treatment, and support, women were left to manage alone.

A crucial finding was the role of race and cultural assumptions in shaping women's experiences of care. While health professionals often acknowledged fibroids as common among Black women, this did not lead to better care. Instead, some women felt that their symptoms were taken less seriously because they were Black or that assumptions were made about their pain tolerance and attitudes. Some described pressure to manage how they communicated to avoid being labelled as "aggressive". These experiences reflect wider evidence on racial bias and structural inequalities in healthcare (1,26-27,33).

Our findings are highly relevant to the 2026 Renewed Women's Health Strategy for England (3) which highlights the need to improve women's experiences of care, reduce delays in diagnosis, and tackle inequalities in access and outcomes. They also align with wider NHS priorities to reduce health inequalities through Core20PLUS5 (34).

The experiences shared by Black women in this project show why these priorities matter and why local action is needed. The recommendations that follow set out practical steps that services in Lambeth can take to improve care them.

Recommendations

These recommendations are drawn from Black women's experiences of fibroids and endometriosis care in Lambeth. They are intended to improve local pathways, patient experience, and equity of access.

Delivering these recommendations require coordinated action across primary care, specialist services, commissioners, and system partners in line with the priorities set out in the Renewed Women's Health Strategy for England 2026, particularly around improving women's experiences of care, reducing diagnostic delays, and improving information and choice (3). The recommendations align with other NHS England initiatives to reduce health inequalities, like the Core20PLUS5 (34).

Early Recognition and Timely Access to Care

1. Improve early recognition, investigation, and referral in primary care

Women described repeated presentations of heavy bleeding, severe pain, flooding, and anaemia without escalation. Access to investigations and referrals should not depend on how persistent or confident women are in advocating for themselves.

- Symptoms that persist across multiple consultations should prompt reassessment of care. This reflects the patient safety initiative Jess's Rule, which emphasises that repeated concerns should trigger further review rather than dismissal.
- Ensure that symptoms which are described as disruptive and life altering also trigger further assessment.
- Where treatments such as hormonal contraception or iron supplementation are not effective, women should be reviewed with clear next steps agreed, such as further investigation or referral.
- Introduce and document clear review points to prevent repeated presentation of symptoms without escalation.
- Avoid requiring women to repeatedly evidence symptoms before action is taken.

2. Improve menstrual health education and access to early specialist support

Women described living with heavy bleeding, flooding, severe pain, and fatigue for many years before realising these symptoms could be linked to fibroids, endometriosis, or other gynaecological conditions. For some,

symptoms began in adolescence but were normalised as "just periods", meaning opportunities for earlier advice and support were missed.

Commissioners and providers could improve early access to support by:

- Providing clear, age-appropriate, and culturally relevant menstrual health information for young women and girls.
    - This could include what is normal, what is not, and when to seek help.
    - This should be available through schools, community settings, GP practices, and online.
- Reviewing access to specialist gynaecology support for young women, including whether the current capacity of the paediatric gynaecology clinic is sufficient to meet demand.

Quality of Care, Communication, and Continuity

3. Strengthen listening and validation in GP care

Many women did not feel listened to, believed or taken seriously by their doctors. They left appointments feeling dismissed, especially when the impact of their symptoms on their daily lives was not acknowledged.

GPs should prioritise listening and acknowledge the impact of symptoms by:

- Giving women time to explain their symptoms.
- Explicitly exploring how symptoms affect daily life, work, caring responsibilities, and wellbeing.
- Validating pain, distress, and life disruption to improve experience and trust.

4. Improve communication and continuity

Women felt they had to repeat their story over and over again because professionals were not communicating with each other, causing delays and frustration.

Continuity could be improved by:

- Recording clear notes and agreed actions to avoid patients having to re-explain their history.
- Ensuring that GPs review notes before appointments.
- Offering more continuity where possible so women see the same GP for ongoing gynaecological issues.

5. Reduce delays to diagnosis and specialist care

Women described long waits for scans, referrals, and specialist appointments, with little communication or support. Several felt their symptoms worsened during this time, at times limiting their treatment options.

Commissioners and providers should review referral pathways for fibroids and endometriosis to reduce unnecessary delay. This could include:

- Clear referral criteria for fibroids and endometriosis from primary care gynaecology services, to support more consistent decision-making.
- Quicker access to diagnostic scans where symptoms are severe, aligning with the national Women's Health Strategy to reduce delays for common women's health conditions.
- Information for women about expected waiting times and what to do if symptoms worsen.

Equity, Anti-Racism, and Culturally Competent Care

6. Address racial bias and improve equitable access

This was one of the strongest findings from the engagement. Some women felt their pain was dismissed because they were Black women, while others described experiencing stereotypes about pain tolerance and behaviour.

NHS service providers should strengthen anti-racism and culturally competent practice by:

- Providing mandatory training and reflective learning on cultural competence, bias, and inequalities in women's health.
- Ensuring professionals:
    - Do not normalise fibroids or symptoms based on ethnicity.
    - Avoid assumptions about pain tolerance or behaviour.
    - Deliver respectful, person-centred care.
- Reviewing referral patterns, waiting times, and outcomes to identify and address inequalities.

Person- Centred Treatment and Decision-Making

7. Improve patient involvement in specialist consultations

Some women felt that treatment decisions were rushed, overly clinical, or focused on one solution such as hysterectomy. Women wanted their fertility

plans, fear, and preferences to be considered. Positive experiences were linked to clear explanations and time to discuss options.

Gynaecology services should strengthen shared decision-making by:

- Ensuring that decisions are made collaboratively, reflecting the woman's priorities.
- Clearly explaining scan results, treatment options, risks, and benefits in plain language to support decision-making.
- Ensuring reproductive choices are discussed and avoid making assumptions based on age.
- Giving women time to consider their options for major decisions.

Follow-up and Recovery

8. Strengthen clinical and emotional follow-up and aftercare

Poor aftercare was a main concern for women. Many described being discharged after surgical procedures without enough pain management, advice on recovery, or follow-up support.

Hospitals should provide clear aftercare advice/support and routine follow-up after surgical procedures. This should include:

- Written recovery guidance.
- Information on pain management, recovery expectations, and clear contact points if complications arise.
- Telephone or digital follow-up as a low-cost option to provide reassurance and identify ongoing needs, particularly when treatment has not fully resolved symptoms.

Information and Empowerment

9. Provide clear and practical information throughout care

Women wanted more information that was clear, practical, and allowed them to understand when something was not normal. Women said that terms like 'fibroids' and heavy bleeding were used without practical explanation. Many had to search online or rely on peers to understand their symptoms and diagnosis.

Primary care and gynaecology services should ensure women receive clear, practical, and accessible information, which could include:

- Explanations of fibroids and endometriosis in simple language that will help women understand what symptoms are normal and when to seek help.

- Information about the care pathway, treatment options, self-management, and what to expect over time.
- Signposting to trusted local or national organisations and community and voluntary partners providing culturally relevant information and peer support.

Co-Production and System Improvement

10. Involve women with lived experience in service design and improvement

Women highlighted the importance of involving Black women with lived experience in service improvement and design to help create more equitable, responsive, and person-centred care.

Services should actively involve Black women with lived experience in shaping services by:

- Using co-design approaches such as advisory groups, workshops, and feedback sessions.
- Ensuring improvements reflect real experiences and address identified inequalities

Taken together, these actions will reduce delays, improve experiences of care, and ensure Black women are listened to, supported, and treated equitably throughout their care journey.

Appendix A – Detailed review and references

Uterine fibroids and endometriosis are common gynaecological conditions that can cause significant pain, heavy bleeding, fatigue and fertility-related concerns, with wide-ranging impacts on physical health, emotional wellbeing, work and relationships (1–6, 18-23).

Fibroids

Fibroids are non-cancerous tumours of the uterus and represent one of the most common gynaecological conditions globally (1-3). Existing literature shows that Black women experience a higher prevalence of fibroids than White women (1,2,4-9,32).

Studies consistently show that Black women are more likely to develop larger fibroids and present with more severe symptoms, contributing to greater impact on physical and emotional wellbeing including reduced quality of life and increased risk of reproductive complications compared to non-Black women (2,4,8,10).

In the United States, Black women are significantly more likely to undergo surgical treatment for fibroids than White women and other racial groups (1,7,8). Although UK-based comparative data by ethnicity remain limited (11), similar ethnic disparities are observed in uterine cancer care (12). In both contexts Black women felt hysterectomy was presented as the only option with limited discussion of newer or fertility-preserving options (8).

Despite extensive evidence of the disproportional burden of fibroids among Black women, research on fibroid management lacks ethnic diversity limiting applicability to Black populations (14,15). Findings from the Caribbean and African Health Network (CAHN) indicate that many Black women experience persistent barriers throughout the care pathway, such as delayed diagnosis, symptoms being dismissed, a reliance on persistent self-advocacy, and unequal access to appropriate treatment options (8).

Delays in diagnosis and treatment often compromised women's ability to have children, causing emotional distress and strained relationships, with some abandoning plans to start a family. Ongoing fibroid symptoms also had a significant impact on mental wellbeing, including exhaustion, anxiety, isolation and depression, alongside financial strain caused by time off work due to symptom severity (8,16,17).

Endometriosis

Endometriosis is a chronic condition in which tissue similar to the uterine lining grows outside the uterus causing inflammation, pain, scar tissue

formation and potential infertility (18,19). Women with endometriosis often describe severe knife-like pelvic pain that can be debilitating and affect many areas of life including work, socialising, and maintaining relationships (22). These symptoms are frequently normalised by both women and healthcare professionals, often dismissed as a normal part of menstruation or simply considered a case of being 'unlucky' (20,22). There is currently no cure for endometriosis and treatment focuses on pain relief, hormone-based therapies or surgical options (23).

Endometriosis affects around 10% of women of reproductive age with more than 1.5 million women in the UK alone. Evidence also highlights long diagnostic delays across the population, with women in the UK waiting an average of seven to ten years for a diagnosis (20,21).

Although UK-specific prevalence data for Black women is unavailable, international research suggests that Black women may be less likely to be diagnosed with endometriosis than other ethnic groups (19,21). Historically endometriosis has been characterised as affecting White women who delay childbearing, alongside a belief that it is less common among Black women and those from lower socioeconomic backgrounds (21,24).

Combined with the underrepresentation of Black women in research, these assumptions have contributed to significant gaps in knowledge and responsiveness within services (24). Furthermore, US data suggests that despite little difference in the prevalence of endometriosis between ethnic groups, Black women experience worse clinical and surgical outcomes than their White counterparts (32).

Black women have experienced difficult interactions within reproductive healthcare including feeling dismissed, repeated invalidation and dismissal of symptoms, and coercion when making decisions about their care (19). Women noted the need for assertive self-advocacy to access specialist care in order to be taken seriously (22).

There is limited research on Black women's experiences of endometriosis in the UK (19). However, a non–peer-reviewed doctoral thesis, *Black Women's Experiences of Reaching a Diagnosis of Endometriosis in the UK*, highlights significant barriers to care (19). Participants described a "battle" to have their pain recognised, with symptoms often dismissed or attributed to psychological causes. Many felt that intersecting factors such as race, class, and sexuality, alongside stereotypes like the "strong Black woman" trope, contributed to their pain being minimised, and culturally sensitive care was rare and often considered a matter of 'luck' (19).

Endometriosis had a profound impact on quality of life, contributing to anxiety, loss of control, and fear of pain. Cultural stigma around reproductive health within some communities also delayed help-seeking. While diagnosis provided validation and hope, for some this was short-lived when it did not lead to effective treatment or symptom relief (19).

Gaps in evidence

Across both conditions, the literature points to shared, systemic issues shaping Black women's experiences of care. These include the normalisation of severe menstrual and pelvic symptoms, delays in diagnosis, unconscious bias and structural racism within healthcare settings, limited access to culturally relevant information, and reliance on persistent self-advocacy to access specialist care.

Enquiries by the All-Party Parliamentary Group (APPG) and the Caribbean & African Health Network (CAHN) into Endometriosis (2020) and Black Health and Fibroids (2025) found that many women face delays in diagnosis, poor communication and minimisation of symptoms (20,33).

There is also limited research that reflects Black women's lived experiences in the UK (2,8,9,12,18–20, 21-24). While much of the existing evidence draws on national or international data, there is limited local place-based insight to inform service improvement within specific communities (2,8).

Local context: Lambeth

This evidence gap is particularly relevant in Lambeth, an area with significant sexual and reproductive health inequalities that disproportionately affect Black and other minority ethnic communities (22, 29-31). At present, there is limited Lambeth-specific data capturing Black women's experiences of care for fibroids and endometriosis.

In line with Healthwatch Lambeth's role in amplifying the voices of local people, this project sought to understand how these nationally documented issues are experienced locally and what Black women in Lambeth say would make care more accessible, responsive and equitable (24, 31).

The findings presented in this report build on existing evidence while grounding it in the lived experiences of Black women in Lambeth, providing insight to support learning, service improvement and more person-centred approaches to gynaecological care.

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Appendix B – Project Advisory Group

Project Advisory Group Members

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