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# All-Party Parliamentary Group on Black Health

## **Breaking the Silence:** Fibroids, Black Women, Time for Change



Secretariat - **CAHN**  
Caribbean & African Health Network

funded by



2025





## About This Report

This report has been written by The Caribbean & African Health Network (CAHN) as the Secretariat to the All-Party Parliamentary Group (APPG) on Black Health and finalised in consultation with the APPG officers.

The Health Foundation and Theramex have both provided a grant to support this work. It has not influenced the development or content of the report. Editorial control rests solely with the officers of the APPG.

Further details about the APPG on Black Health are available via the official APPG register and website.

This is not an official publication of the House of Commons or the House of Lords. It has not been approved by either House or its committees. All-Party Parliamentary Groups are informal groups of Members of both Houses with a common interest in particular issues. The views expressed in this report are those of the group.



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## APPG Report

### All-Party Parliamentary Group

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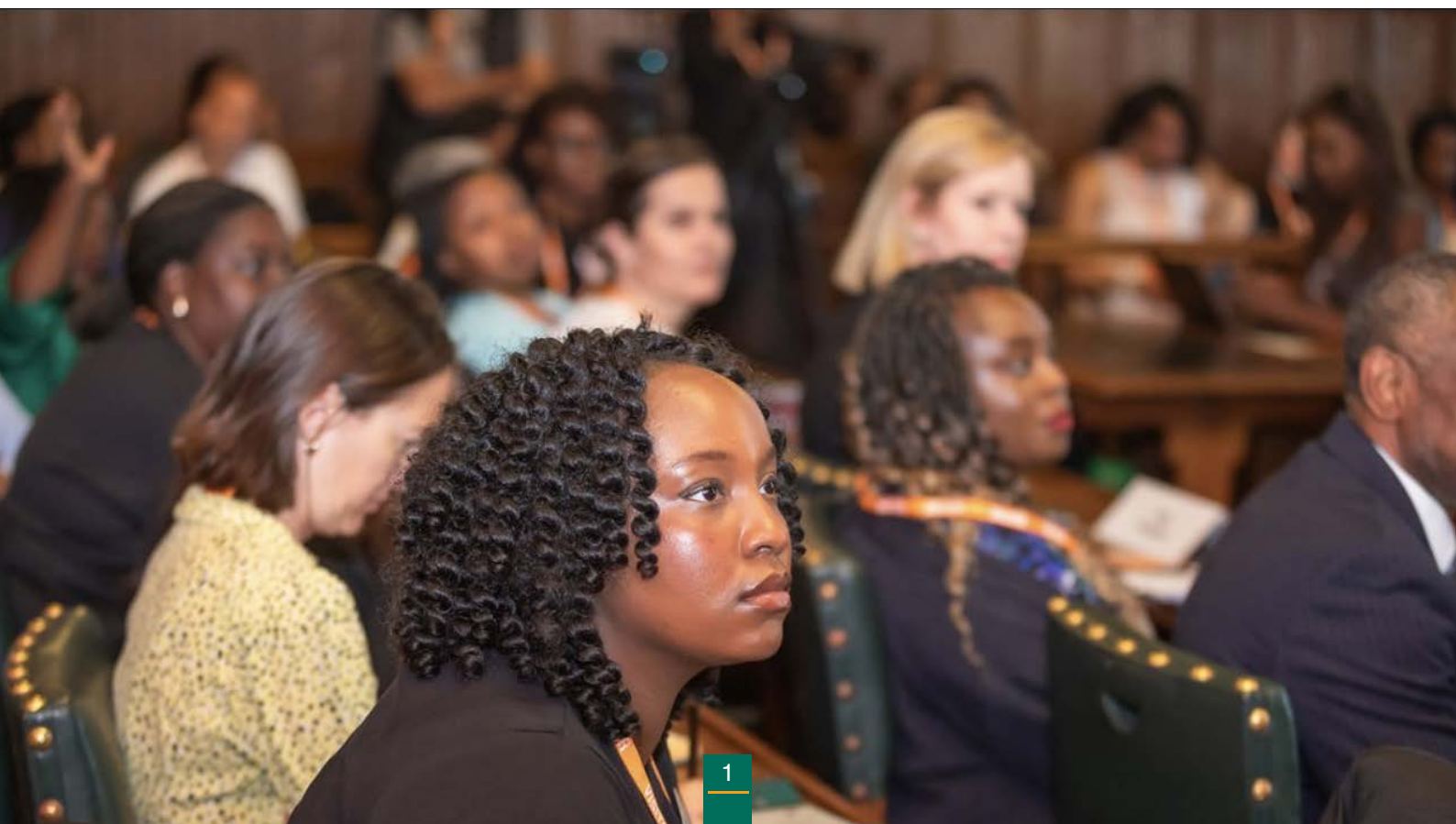
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## Acknowledgements

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Black  
Health

## 1 Foreword by Dr Paulette Hamilton MP

As Chair of the All-Party Parliamentary Group (APPG) on Black Health, I am proud to introduce this report, developed as part of our ongoing work to improve health outcomes for Black communities across the UK. With the support of the Health Foundation and the Caribbean & African Health Network (CAHN) as our secretariat, we are beginning to confront long-standing disparities in care. Our first parliamentary meeting on uterine fibroids marked a pivotal moment in that journey. It was a powerful and overdue conversation about a condition that has long been neglected in public health discourse, despite its profound impact on women's lives.

The meeting brought together clinicians, researchers, campaigners, and women with lived experience. It was a deeply moving discussion, where women shared stories of pain, frustration and, often describing years of being dismissed, misdiagnosed or simply not heard. Their voices were clear and urgent: the current approach to fibroids is failing too many, particularly Black women who are disproportionately affected and often face barriers to timely, compassionate care.

This report captures the key themes that emerged from that meeting, as well as the journey that led us there. It also reflects the momentum that followed including the launch of a national fibroids survey, which has already reached nearly 500 respondents and produced an interim analysis. This growing body of evidence is helping us build a clearer picture of the scale, impact, and inequalities surrounding fibroids in the UK.

The challenges before us are significant but this report begins to address these issues by laying the groundwork for continued action, policy development and further research. It sets the stage for the work ahead.

I am committed to working with CAHN and our partners to take the next steps. Together, we will continue to raise awareness, push for better services, and ensure that Black women's health is no longer sidelined. This is about equity, dignity, and justice and we are ready to move forward.

**Paulette Hamilton MP,**  
Chair of All-Party Parliamentary Group on Black Health

## 2 Executive Summary and Recommendations

This report captures the launch of the All-Party Parliamentary Group (APPG) on Black Health and its first thematic priority: Reproductive Equity & the Fibroids Crisis.

The inaugural parliamentary session, chaired by Dr Paulette Hamilton MP on 14 May 2025, brought together over 90 stakeholders including parliamentarians, clinicians, researchers, and women with lived experience for a powerful discussion on uterine fibroids.

The decision to focus on fibroids was shaped by two years of community-led advocacy, including International Women’s Day events that highlighted the scale of the crisis and the urgent need for action. These efforts, led by CAHN and other Black-led organisations laid the groundwork for fibroids to become the APPG’s first priority.

### Key milestones this quarter included:

- Completion of a national Call for Evidence to capture diverse experiences.
- Launch of a fibroids survey, which received nearly 500 responses; interim analysis is presented in this report
- Media engagement campaign on fibroids awareness supported by Theramex amplifying lived experiences of those affected.
- An Initial ministerial engagement request with DHSC and Women’s Health Strategy leads

The parliamentary session marked a pivotal step in addressing fibroids, covering stories of delayed diagnoses, inadequate care, and systemic neglect particularly among Black women.

### The interim findings of the national fibroids survey reinforce these concerns:

- Over half of respondents experienced diagnostic delays exceeding two years
- Many reported limited awareness of fibroids prior to diagnosis, often reaching crisis point before seeking help
- A significant proportion felt their pain and symptoms were dismissed or minimised by healthcare professionals
- Respondents described the emotional toll of living with fibroids, including anxiety and isolation
- Fertility journeys were frequently disrupted, with reported impacts on pregnancy outcomes
- There was strong demand for specialist care, better information, and culturally competent support

These findings, alongside clinical and academic contributions, shaped the following recommendations:

	Theme	Recommendations
A	Awareness, Education & Empowerment	<ol style="list-style-type: none"> <li>1. Launch culturally tailored campaigns via trusted community networks.</li> <li>2. Fund and scale culturally grounded and community led initiatives for education and peer support.</li> </ol>
B	Clinical & System Capability	<ol style="list-style-type: none"> <li>3. Integrate fibroid-specific modules into curricula, with a focus on racial disparities.</li> <li>4. Establish dedicated fibroid centres with surgical, fertility, and mental health expertise.</li> <li>5. Embed anti-racism and cultural humility in clinical training to support informed consent.</li> </ol>
C	Research & Innovation	<ol style="list-style-type: none"> <li>6. Fund studies on genetics, environment, and lived experience especially among Black women.</li> <li>7. Invest in innovation for less invasive treatments, early diagnostic tools, and improved fertility care.</li> <li>8. Ensure sustained funding for fibroid research and treatment to close the gap with other women’s health priorities</li> </ol>
D	Accountability & Collaboration	<ol style="list-style-type: none"> <li>9. Set measurable targets to reduce delays and improve access to equitable care.</li> <li>10. Build partnerships across NHS, community organisations, academia, and policy.</li> <li>11. Commit to ensuring that fibroid care is treated as a clear priority, with measurable targets, within DHSC and NHS England’s delivery of the Women’s Health Strategy.</li> </ol>

*These recommendations will guide the APPG’s next phase of work, as it continues to advocate for systemic change in Black women’s health.*

## 3 Background & Introduction

### What are Uterine Fibroids?

Uterine fibroids are non-cancerous growths that affect around two in three women in the UK at some point in their lives. Despite this prevalence, they remain poorly understood, under-researched, and under-prioritised within women's health policy.

For many, fibroids cause no symptoms, but for others they result in heavy bleeding, pain, fertility challenges, and significant impacts on quality of life. These burdens fall disproportionately on Black women, with up to 80% experiencing fibroids by the age of 50.

Black women also tend to experience earlier onset, more severe symptoms, and worse outcomes, yet there is little disaggregated data or culturally specific research to explain or address these disparities.

### Why focus on Fibroids?

Fibroids have historically received limited attention within health policy and research, despite their significant impact on women's lives. This gap has contributed to inconsistent clinical guidance, fragmented care pathways, and a lack of systematic support, which in turn perpetuates disparities in diagnosis, treatment, and care.

Earlier research, alongside two years of community-led advocacy including International Women's Day events, highlighted these gaps and the urgent need for action, prompting the APPG to focus on fibroids as a parliamentary priority.

Addressing fibroids now presents an opportunity to advance reproductive justice, improve health equity, and ensure that women's health priorities are adequately reflected in national policy.

In response, the inaugural parliamentary session of the All-Party Parliamentary Group (APPG) on Black Health marked the first formal parliamentary engagement on fibroids as a reproductive justice issue. Organised by the Caribbean & African Health Network (CAHN), the event brought together MPs, clinicians, researchers, and community advocates to spotlight systemic neglect, share lived experiences and call for urgent policy reform.

### Aims of the Session

The meeting aimed to:

- Raise political awareness of fibroid-related health inequalities and the urgent need for action
- Promote culturally competent care, early intervention and improved clinical pathways
- Advocate for dedicated research, sustained funding clinical training, specialist services and measurable accountability

Together, these aims signal a pivotal step toward addressing long-standing reproductive health disparities and driving systemic change. The chapters that follow provide deeper insight into the evidence, engagement, and analysis that underpin this call to action.



# 4 Evidence & Engagement

## Chapter 1 – Community and Stakeholder Engagement

The prioritisation of uterine fibroids as the first thematic focus of the APPG on Black Health was the direct result of a community-driven approach to research, consultation, and mobilisation. From the outset, CAHN adopted a model of engagement that placed Caribbean and African women at the centre of the conversation, recognising that meaningful change in health equity must be rooted in lived experience and collective action.

### 1.1 Building Momentum: International Women’s Day 2024

In 2024, CAHN convened a landmark International Women’s Day event focused on womb health. This initiative was co-designed and executed in partnership with a coalition of Black-led, women-focused organisations including Women Worth, MGTY, Cancer Care Diaspora, Afrocats, Nigerian Women Group, and Ministry of Angels. Weekly planning meetings from January to March ensured that the event was both representative and impactful.

The event drew over 500 attendees, creating a vibrant and inclusive space for dialogue, education, and advocacy. Through workshops, panel discussions, and breakout sessions, participants explored a wide spectrum of womb health issues from infertility and endometriosis to menopause and fibroids. These women’s personal testimonies of pain, neglect, and resilience challenged prevailing assumptions and gave urgency to the discussions. The scale of engagement reflected a deep commitment to collective learning, empowerment, and systemic change.

This momentum directly inspired the creation of CAHN’s Womb Health Survey (2024). Grounded in the lived experiences, concerns, and themes raised at the event, the survey was designed to capture both quantitative and qualitative insights from Caribbean and African women across the UK. It explored sociodemographic influences on diagnosis, barriers to timely treatment, health-seeking behaviours, and community-driven recommendations for improving care.



### 1.2 Findings from Womb Health Survey (2024)

The survey findings were striking. By age 50, up to 70 percent of White women and 80 percent of Black women are diagnosed with fibroids, with women aged 35 to 64 facing the highest risk. Black Caribbean women were nearly twice as likely to receive a fibroid diagnosis compared to Black African women, with estimated prevalence rates of 60 to 80 percent versus 30 to 40 percent. These insights confirmed what community members had long been expressing: fibroids are not only prevalent but emblematic of broader disparities in reproductive healthcare.

The survey also highlighted systemic challenges including medical neglect, unconscious bias, cultural stigma, and delays in care. Despite these barriers, most women did not seek second opinions, though those who did reported improved outcomes when treated by culturally competent professionals. The recommendations that emerged, from enhanced screening and support networks to cultural sensitivity training, were firmly rooted in the voices of those most affected.

Stakeholder engagement extended beyond community organisations. Healthcare professionals, equality leads, local authority executives, and civic representatives participated in the events and consultations, lending institutional weight to grassroots advocacy. Their involvement helped bridge the gap between lived experience and policy influence, reinforcing the need for more inclusive and responsive healthcare systems.

CAHN’s approach demonstrates the transformative potential of community-led engagement. By centring Caribbean and African women, building coalitions with trusted organisations, and translating dialogue into data, CAHN created a powerful model for change. The decision to prioritise fibroids within the APPG was not made in isolation; it emerged from a process that honoured community voices, fostered collaboration, and demanded accountability. This process offers a valuable lesson: community-led initiatives and coproduction generate solutions that genuinely reflect the needs and realities of those they serve.

### 1.3 Further Findings from Community-Focused Interactions<sup>1</sup>

On 7 March 2025, the Caribbean & African Health Network (CAHN) hosted its annual International Women’s Day event once more, this time themed “Womb Health in the Digital Era.” The event welcomed over 300 attendees from diverse backgrounds, continuing the tradition of creating space to celebrate and explore critical issues in women’s health.

A central feature was a focused workshop on uterine fibroids, directly shaped by the findings of the CAHN Women’s Womb Health Survey (2024). In this session, 31 Caribbean and African women shared their personal experiences in a breakout discussion facilitated by Tina Backhouse of Theramex, a committed advocate for tackling uterine fibroids and wider gynaecological disparities in Black women. The harrowing stories shared, and one to one conversation not only echoed the survey findings but also reaffirmed them, demonstrating the consistency of women’s experiences across different forums. This continuity of evidence strengthened CAHN’s resolve to prioritise fibroids in 2025.

The session also demonstrated the potential of innovation. Participants highlighted how AI-powered diagnostics, telehealth services, and mobile health applications tailored to menstrual and fibroid tracking could improve early detection and access to care. Centring fibroids within these conversations is not only a matter of technological advancement but also a call for reproductive justice.

### 1.4 Expanding Reach: Digital Engagement

Beyond in-person events, CAHN broadened its outreach during Fibroids Awareness Week and Month through a series of online Health Hour webinars on zoom and other social media platforms. Across three sessions, more than 1,200 participants engaged with lived experience stories, expert insights, and culturally grounded advice about fibroids. The events sparked increased helpline enquiries and second-opinion referrals to specialist Black clinicians.

One participant reflected on the impact of a session:

**“I finally felt seen and heard. For the first time, I understood my symptoms weren’t just mine, they were part of a wider issue affecting so many of us.”**

This wave in engagement demonstrated the impact of accessible, culturally competent outreach in addressing reproductive health disparities and highlighted other issues of concern.

By amplifying the voices and experiences of Black women, we take vital steps toward building a more inclusive and equitable healthcare system that truly serves all communities. Yet these conversations also revealed just how many gaps remain in our collective understanding of fibroids. To address this, CAHN prioritised commissioning a scoping review to examine what is and crucially, what is not known about fibroids in the UK. This review, alongside our community engagements, provided the evidence base that shaped discussions at the APPG on Black Health, ensuring that the lived realities of Caribbean and African women were brought directly to policymakers.

The next chapter explores the general findings of the scoping review.



<sup>1</sup> Accessible here - <https://www.cahn.org.uk/wp-content/uploads/2025/03/IWD-Event-and-Womb-Health-Report.pdf>

In early 2025, CAHN commissioned a rapid scoping review (Ruddock et al 2025) to examine the current state of knowledge about uterine fibroids among Black Caribbean and African women in the UK. The purpose was to identify what is known, what remains uncertain, and where further research is urgently needed.

## 2.1 Methods

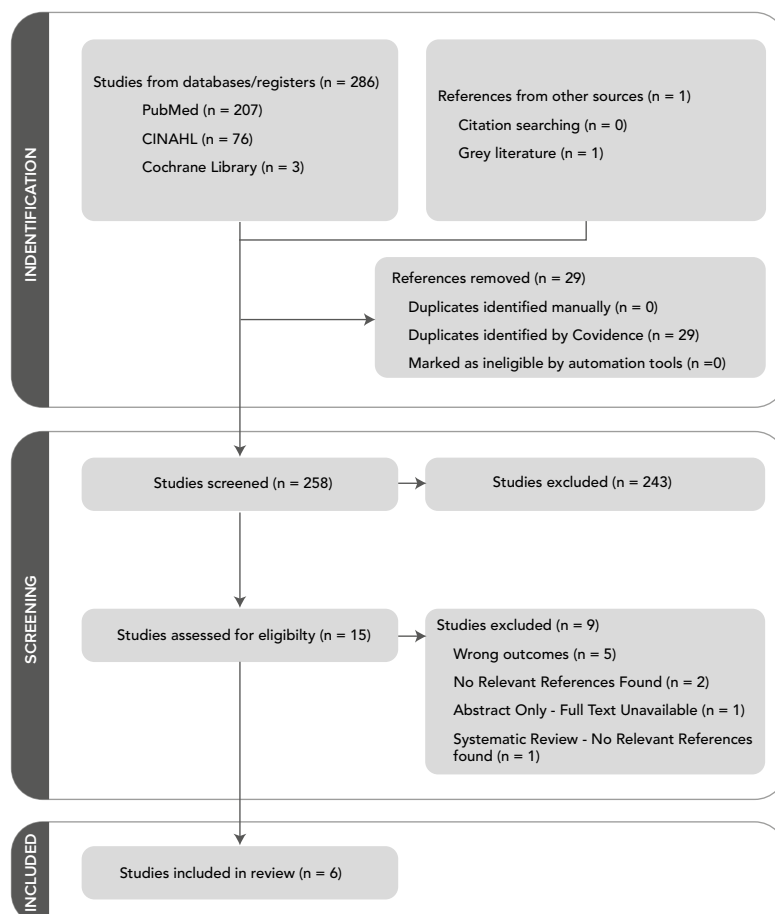
The review searched academic databases (MEDLINE, CINAHL, Cochrane Library) and grey literature (evidence not formally published in journals, such as government reports or community research) to capture studies conducted in the UK that reported on fibroids in African and/or Caribbean women. Research covering genetics, risk factors, clinical presentation, treatment outcomes, quality of life, complications, healthcare access, and patient experiences was included.

## 2.2 Results

The search revealed a significant gap in UK-based research on fibroids. Between 2014 and 2021, only six relevant studies were identified: one genetic study (a genome-wide association study or GWAS), one clinical trial, two observational studies, and two case reports.

**Despite the limited evidence base, several important findings emerged, particularly concerning Black women in the UK:**

- Genetic predispositions: Research indicated that fibroids in women of African descent may be influenced by both shared and ancestry-specific genetic factors, underscoring the need for more inclusive genetic studies
- Potential risk factors: Vitamin D deficiency was identified as a possible contributor to fibroid development among Black women, pointing to broader issues of nutritional inequality and access to preventive care
- Treatment outcomes: Myomectomy, the surgical removal of fibroids while preserving the uterus, was associated with better quality-of-life outcomes than Uterine Artery Embolisation (UAE), a non-surgical procedure that shrinks fibroids by blocking their blood supply. This finding is especially relevant for women seeking to maintain uterine integrity and highlights the importance of ensuring equitable access to surgical options
- Recovery disparities: Black women were reported to experience longer recovery periods following myomectomy compared to other groups. This raises concerns about post-operative support, pain management, and systemic differences in recovery care
- Complications: Although rare, severe complications related to fibroids were documented, reinforcing the need for early diagnosis and culturally responsive care pathways



## 2.3 Conclusion

The scoping review confirmed the significant burden of uterine fibroids among Caribbean and African women in the UK but also revealed a critical lack of dedicated research. With only a handful of studies available and even fewer disaggregating data by ethnicity the evidence base remains too thin to guide effective policy or clinical practice.

The findings further reflected the need for:

- Large-scale epidemiological studies that examine prevalence, risk, and protective factors
- Comparative effectiveness trials to determine the most suitable treatment options
- Deeper exploration of patient experiences to inform culturally competent care
- Policy interventions that ensure equitable access to treatment and awareness-raising for Black women

This review served as a foundation for discussions at the APPG on Black Health, where the scarcity of evidence was acknowledged as a systemic issue requiring urgent attention. It also laid the groundwork for the subsequent call for evidence through a newly created and fibroid specific national PROMs (Patient-Reported Outcome Measures) survey, to capture women lived experiences on a much larger scale.

In this way, lived experience, emerging evidence, and strategic advocacy came together to shape the national conversation on fibroids, bringing grassroots mobilisation directly into the policy arena and allowing policymakers to hear first-hand the urgency of addressing fibroid inequalities at the APPG meeting.



### Reproductive Equity and the Fibroids Crisis

Date: 14 May 2025 | Location: Committee Room 12, House of Commons

Secretariat: Caribbean & African Health Network (CAHN)

Attendance: Over 90 stakeholders, including MPs, clinicians, researchers, advocates, and media representatives

#### 3.1 Overview of the Session

Building on CAHN's community-led survey and rapid scoping review, this inaugural meeting of the APPG on Black Health addressed the urgent and under-recognised issue of uterine fibroids, which disproportionately affect Black Caribbean and African women in the UK.

The session aimed to:

- Raise awareness among policymakers
- Present evidence-based findings
- Advocate for culturally competent care and systemic reforms

**90**  
People attended

The focus on fibroids highlighted the broader reproductive health inequalities facing Black women and highlighted the need for improved research, clinical training, specialist centres, and public awareness campaigns.

#### 3.1 Strategic Context

The meeting aligned with the APPG's mission to raise political awareness of stark health inequalities disproportionately impacting Black communities in the UK. It also supported CAHN's Public Affairs and Policy Unit ongoing effort to engage in facilitating ongoing parliamentary engagement, including roundtables, inquiries, and field visits. The session also reflected the Health Foundation's commitment to equity, evidence-based policy, and the integration of lived experience into system reform.

#### 3.3 Meeting Agenda

1. Welcome and Introductions – Paulette Hamilton MP
2. Parliamentarian Contributions – Marsha De Cordova MP, Ben Coleman MP
3. Rapid Scoping Review Presentation – Professor Faye Ruddock DL
4. Panel Presentations – Clinicians, researchers, and advocates
5. Open Q&A – Contributions from community members and professionals
6. Summary of Recommendations
7. Next Steps and Closing Remarks – Paulette Hamilton MP



### 3.4 Summary of Key Insights from the Session

This table (figure 1) summarises key insights from stakeholder discussions and literature review, highlighting the multifaceted challenges Black women face in relation to fibroid diagnosis, treatment, and care. The entries reflect not only clinical disparities but also broader systemic and structural barriers that contribute to unequal outcomes. From disproportionate prevalence and under-researched experiences to economic costs and institutional neglect, the table illustrates how fibroids are emblematic of deeper reproductive health inequities.

<b>Disproportionate Impact:</b>	Black women are approximately 80% more likely to develop fibroids, often younger and with more severe symptoms.
<b>Systemic Neglect</b>	Pain is frequently dismissed or minimised leading to delayed diagnosis and inadequate treatment. i.e. hysterectomy is overused; and there is no national strategy.
<b>Research Gaps</b>	Only six UK-based peer-reviewed studies include Black women’s fibroid experiences, revealing a critical lack of data on genetics, lived experience, treatment outcomes, and preventative factors such as vitamin D deficiency.
<b>Lack of Awareness</b>	No push to increase awareness in communities affected.
<b>Economic Burden</b>	Fibroids contribute to an estimated £11 billion in lost productivity annually.
<b>Structural Racism</b>	Structural racism contributes to mistrust, delayed diagnosis, insufficient clinician training, and inadequate patient education.
<b>Surgical Complexity</b>	Lack of trained specialists and absence of dedicated fibroid centres exacerbate disparities.
<b>Lack of National Strategy</b>	There is currently no coordinated national response or specialist infrastructure for fibroid care.

Figure 1: Summary of Key Insights from Parliamentary Discussion

### 3.5 Speakers and Contributors

- Professor Faye Ruddock – Professor of Health Equity and Chair of CAHN
- Dr Loretta Ogboro-Okor – Consultant Obstetrician and Gynaecologist; Director General, Edo State Diaspora Agency
- Candice Bryan – Founder of Noire Wellness; Lived Experience Presenter
- Dr Priscilla Day-Walsh – Next Generation Fellow at the Centre for Trophoblast Research, Homerton College, Cambridge
- Dr Edmond Edi-Osagie – Consultant Gynaecologist and Fibroid Specialist
- Tina Backhouse – Pharmaceutical Executive and Women’s Health Advocate

#### 3.5.1 Professor Faye Ruddock: Rapid Scoping Review

Professor Ruddock presented CAHN’s 2025 Rapid Scoping Review (Ruddock et al), which identified significant gaps in fibroid care and research affecting Black women in the UK:

- Limited UK-based research on Black women’s experiences with fibroids
- Disproportionate use of hysterectomy as a treatment option and longer post-operative recovery periods for Black women
- Potential links between vitamin D deficiency and fibroid prevalence
- Black women experience 50% higher stillbirth rates and 22% higher rates of premature birth compared to white women
- Black women are often offered hysterectomies as a first-line treatment after delayed diagnosis
- Non-surgical options like myomectomy or medical therapies remain underutilised

Her presentation highlighted the lack of depth in critical areas such as genetics, lived experience, treatment outcomes, and preventative factors. Notably, no UK study has yet established the actual prevalence of fibroids in Black women.

## Professor Ruddock emphasised the urgent need for:

- Large-scale epidemiological studies to examine prevalence, risk, and protective factors, addressing the very limited UK evidence.
- Comparative trials to identify effective treatments.
- Deeper exploration of patient experiences to guide culturally competent care and address the disproportionate burden of fibroids on Black women.

### Personal Illustrative Case Study: Diagnostic Bias

Professor Ruddock shared a personal account involving a GP practice in Greater Manchester. When she requested a vitamin D test while experiencing fibroid-related symptoms, she was told:

“We don’t routinely test for vitamin D deficiency because it’s assumed that most people in the UK are deficient, especially during the winter months. As a result, we recommend supplementation rather than testing, regardless of ethnicity.”

#### GP Practice, Greater Manchester

##### In response, Professor Ruddock stated:

“The consensus can’t be that we are all vitamin D deficient, so nobody needs to be checked especially when Black communities are at significantly higher risk of severe deficiency and related complications. A blanket approach risks masking health inequities rather than addressing them.”



### 3.5.2 Dr Loretta Ogboro-Okor on Lived Experience, Clinical Practice & The Intersections of Both

Delivered a dual perspective as both a clinician and a patient. Drawing from her own story, Dr Loretta described the devastating consequences of fibroids which can range from being entirely asymptomatic to causing severe health complications. In her case, initially small fibroids grew to the size of a 30-week pregnancy, obstructing pelvic blood vessels and leading to blood clots that were misdiagnosed as asthma. The delayed diagnosis ultimately culminated in a cerebrospinal fluid leak and emergency brain surgery.

Dr Loretta explained that her symptoms were initially dismissed by her GP as a reaction to pollen. As a Black woman and NHS gynaecologist, she had expected a high standard of care but instead encountered systemic failure. She emphasised that because fibroids do not always cause pain they are so often dismissed or underestimated unless their placement within the womb creates complications.

Her story illustrated the dangers of delayed diagnosis and systemic dismissal often faced by Black women:

**“We must recognise that Afro-Caribbean women often present late not due to negligence, but due to cultural norms of ‘soldiering through.’”**

**“Unquestionably, this was the result of missed diagnosis and delayed care within the system one I worked in and that was meant to protect me.”**

To achieve equity in reproductive healthcare, Dr Loretta stressed the importance of confronting subconscious bias and recognising intersectionality, as these factors directly affect diagnosis, treatment, and care pathways. Her key recommendations included:

- Strengthening medical training and curricula to integrate lived experiences and racial disparities.
- Increasing investment in fibroid-specific research to close knowledge and outcome gaps.
- Implementing a two-way approach to progress: action at individual, community, institutional, and governmental levels.
- Enhancing collaboration between key stakeholders such as the GMC, RCOG, NICE, government agencies, and community groups.
- Leveraging existing community structures and strengthening diaspora-community links.

### 3.5.3 Candice Bryan Founder of Noire Wellness; Lived Experience Presenter

Candice shared her 25-year journey with fibroids, beginning in adolescence with debilitating period pain. She spoke candidly about the emotional and spiritual toll of managing heavy bleeding at work and the constant anxiety of public embarrassment. At one point, she recalled that her anaemia was so severe that she was offered a blood transfusion, a suggestion she declined due to deep-seated distrust in the healthcare system.

Instead, her care team provided an iron transfusion – a powerful example of culturally competent care that respected her concerns and ultimately safeguarded her health.

Candice’s lived experience led her to establish a culturally grounded health and wellbeing company ‘Noire Wellness’, turning personal pain into purpose. Her story highlights the urgent need for empathetic, informed, and culturally responsive care for Black women navigating the fibroids crisis

**“No more burying our stories. No more suffering in silence. Our systems must stop pathologising the very traditions that have kept us alive.”**

**“Listening to people’s concerns, preferences, and providing options is key”**

### 3.5.4 Dr Priscilla Day-Walsh on The Overarching Consequences of Fibroids

Dr Day-Walsh provided a historical and political overview of health inequalities, drawing parallels between the neglect of sickle cell disorder and uterine fibroids. She called for public health campaigns, early detection, and holistic care models.

**“Fibroids are a major driver of reproductive health inequalities. Failure to act now would constitute systemic neglect.”**

Dr Day-Walsh also highlighted that Black women are more likely to suffer severe symptoms, including heavy bleeding, pregnancy complications, fertility challenges, and complex caesareans. Yet fibroids are often diagnosed late, with treatment options like hysterectomy and hormone therapy prioritised, many of which do not preserve fertility.

**She warned that:**

**“less invasive treatments disappear as fibroids grow,” and criticised the lack of transparency around treatment decisions.**

Dr Day-Walsh underlined the wider toll of fibroids: lost workdays, social isolation, deteriorating mental health, and reduced quality of life. She noted that while fibroids cost the UK an estimated £11 billion annually, they remain marginal in both clinical education and research funding. Many lecturers and students, she said, “know very little about fibroids,” which perpetuates poor treatment and harmful advice.

Drawing on her and her team's work co-organising the Breaking the Silence Around Uterine Fibroids conference at Homerton College, she called for urgent action. Her recommendations included:

- Public health campaigns on fibroids, comparable to those for breast or prostate cancer
- Early detection and timely diagnosis
- Wider access to less invasive treatments tailored to individual needs
- Support for holistic approaches, including mental health and lifestyle interventions
- Increased UK research and funding (currently just six peer-reviewed studies exist)
- Improved awareness and training for healthcare professionals
- Stronger patient advocacy and support

*The Impact of fibroids on Fertility is a real concern impacting many Black women and their pregnancies.*

### 3.5.5 Dr Edmond Edi-Osagie on Fibroids Specialism

Dr Edi-Osagie spoke to the clinical complexity of fibroids and the lack of trained specialists.

**“There’s a significant number of women, disproportionately Black women, who would benefit from high-quality surgical care but are steered away from it. That’s a failure of training, of access, and of the system.”**

He advocated for the establishment of dedicated fibroid centres, similar to the UK's Endometriosis Centres, and highlighted the need for surgical excellence and patient-centred care.

He described the tragic consequences of delayed access to care:

**“One of the most heartbreaking things I see is women who come to me after 15 years of pain... and by then their ovarian reserve is gone.”**

### 3.5.6 Tina Backhouse

Offering both a personal and industry perspective, Tina highlighted the stark contrast in media coverage between endometriosis and fibroids. Despite fibroids being more common, they receive far less attention and investment. She also spoke candidly about how ethnicity may shape treatment pathways:

**“As a woman with fibroids, I’ve never been offered a hysterectomy. There could be many reasons but one of them should not be my ethnicity.”**

Tina went on to reflect on the pharmaceutical industry's historic neglect of women's health, particularly Black women. She called for inclusive innovation, equitable access to treatments, and culturally competent information.

**“Every woman deserves options whether it’s surgery or medicine. But it must be her informed choice.”**

## 3.6 Q&A Highlights and Community Voices

The Q&A session raised critical questions and reflections on pelvic organ prolapse, diaspora comparisons, informed consent, endocrine disruptors, GP training, and systemic barriers. Responses emphasised the need for early education, culturally aware networks, and structural reform.

The open floor discussion raised critical questions and reflections from attendees:

- An anonymous female attendee raised a question about what the causes of fibroids were, especially in Black women. Professor Faye Ruddock explained that while the exact cause remains unclear due to limited UK-based research, contributing factors include genetics, elevated oestrogen, environmental chemicals, and chronic stress particularly affecting Black women. Dr Loretta Ogboro-Okor added that fibroids are hormonally sensitive, with oestrogen and stress playing key roles in their growth and progression.
- Anonymous male research professor proposed the idea of studies comparing diaspora and Nigerian populations to explore environmental vs. genetic factors.
- Anonymous female community member raised concerns about the lack of Informed Consent. Dr Loretta advocated for culturally aware networks to improve patient understanding.
- Anonymous female community member asked about unrelated complications i.e. whether fibroids cause other health issues. Dr Loretta stressed the need for early education and nuanced care.
- Anonymous female community member asked what is being done to provide Support for Black Women by the institutions that regulate women's health. Kate Lancaster (Royal College of Obstetricians and Gynaecology) responded with statistics on funding gaps and waiting lists.
- Anonymous female asked what government needs to act. Dr Paulette Hamilton MP committed to ministerial engagement and evidence presentation.
- Anonymous female clinician flagged Endocrine Disruptors as a research priority

- Two anonymous female clinicians called for curriculum reform and better training for GPs, especially with reference to women's health.
- One anonymous female shared her decision to refuse a myomectomy on the day of surgery because the surgeon could not guarantee she would wake up with her womb intact. Her story reflects the trauma of limited choices and fear of irreversible outcomes.

**“Some surgeons are too hasty to remove the womb. Yes, hysterectomy may rarely be necessary but many Black women present later, when options are limited.”**

### 3.7 What Needs to Happen

The APPG session highlighted that meaningful change requires both system reform and parliamentary action.

#### 3.7.1 Policy and System Reform

- Identify responsible ministers and establish measurable national targets to reduce reproductive health inequalities.
- Develop specialist fibroid centres and strengthen surgical training to ensure equitable access to high-quality care.
- Increase NHS provision of minimally invasive treatment options.
- Fund research into lived experience, vitamin D deficiency, and treatment outcomes.
- Reform GP and medical school curricula to improve awareness and competence among healthcare providers.
- Support culturally grounded models of care that respect patient concerns and traditions.
- Mandate workplace protections for those experiencing fibroid-related absenteeism.
- Challenge the media to give fibroids the same urgency and visibility as other gynaecological conditions.

## END OF MEETING SUMMARY

The APPG meeting generated new insights while reinforcing longstanding concerns, with significant potential to inform national policy and clinical practice. Discussions underscored key issues, including vitamin D deficiency as a modifiable risk factor, the lack of specialist surgical training and fibroid centres, insufficient training across healthcare providers, systemic bias in treatment pathways, and the exclusion of lived experience in research. The session also illuminated the multifaceted burden of untreated fibroids, economic, psychological, physical, and social, further strengthening the APPG's mission to advance awareness, evidence-based policy, and equitable healthcare.

This gathering marked a pivotal moment in the APPG's work, translating years of grassroots engagement into tangible parliamentary action. With more than 90 attendees and many more expressing interest in attending, the event demonstrated both the urgency of the issue and its widespread national relevance. Nearly half of participants travelled from outside London, including some from Scotland, underlining the clear need for a UK-wide approach to womb health equity.

The meeting not only laid the foundation for future advocacy but also reignited national conversations on gynaecological health. It generated fresh momentum for CAHN's work, drawing in individuals and organisations eager to collaborate, raise awareness, and tackle conditions such as endometriosis, which until recently was wrongly perceived as affecting only white women. By centring lived experience and integrating clinical and academic evidence, the recommendations from this session now shape the APPG's strategic direction and policy priorities, marking a new chapter in inclusive, community-informed health reform.

The scale of interest and urgency made it clear that immediate next steps were required. This is why, following the session, the APPG launched a call for evidence to capture the experiences, insights, and priorities of those most affected. This process ensured the momentum of the meeting translated directly into shaping the next phase of our work.

### Executive Summary

Uterine fibroids are non-cancerous growths of the uterus. Fibroids disproportionately affect Black women, who experience earlier onset, more severe symptoms, and higher incidence compared to other racial groups. These disparities are compounded by systemic inequities in healthcare, including delayed diagnoses, limited access to less-invasive treatments, and a lack of culturally competent care. Black women frequently report feeling dismissed by healthcare professionals and often rely on informal networks for information. The APPG on Black Health, in partnership with the CAHN, launched a formal Call for Evidence to address this reproductive health inequity. A rapid scoping review revealed a severe lack of UK-specific research, prompting a nationwide survey to gather lived experiences. Preliminary findings and analysis confirm widespread challenges and highlight the urgent need for policy reform, targeted funding, and improved healthcare practices.

### Methods

Following the APPG meeting, a nationwide survey was launched to collect lived experiences. The survey remained open until the end of July 2025.

At the time of writing, nearly 500 responses had been received, with 350 analysed for this interim report.

### Interim Survey Findings

#### Demographics

- Majority of respondents were aged 40+ (73%), with many postmenopausal.
- 70% identified as Black British; 46% of Caribbean descent.
- Majority of urban representation, especially London, with national reach across the UK.
- 69% were UK-born or long-term residents, reflecting healthcare experiences shaped within the UK system.

#### Diagnosis & Awareness

- 79% had been screened, but diagnosis was typically reactive triggered by symptoms or incidental findings.
- 26% had lived with fibroids for over 10 years; 10% for more than 20 years.
- 58% were unaware of fibroids prior to diagnosis, indicating poor public health education and barriers to early detection.

#### Treatment & Healthcare Experience

- 27% were not offered any treatment; many faced delays or dismissal.
- Myomectomy (27%) was more common than hysterectomy (15%), but access to less-invasive options like UAE (7%) and FUS (6%) was rare.
- NHS second opinion pathways were underutilized due to systemic barriers and lack of confidence.
- Many women sought alternative or complementary treatments, driven by dissatisfaction and desire for holistic, culturally relevant care.

#### Fertility & Information Seeking

- 24% had difficulty conceiving; 10% experienced miscarriages; 16% delayed conception due to symptoms.
- Informal networks were primary sources of information: friends/family (38%), forums (36%), social media (33%).
- GPs were cited by only 20%, significantly below specialists (39%), revealing a gap in primary care trust and expertise.

#### Symptom Severity & Quality of Life

- High symptom severity was consistently reported.
- Quality of life scores were low, with a clear inverse relationship between symptom severity and health-related quality of life (based on UFS-QOL data).

#### Implications for Policy, Practice, and Research

##### Policy

- Designate fibroids as a public health priority, with dedicated funding for research and care.
- Ensure equitable access to timely diagnosis and the full spectrum of treatment options, including fertility-preserving procedures.
- Develop national guidelines for proactive screening.
- Mandate culturally competent care training for healthcare professionals.

## Practice

- Improve primary care training and diagnostic pathways.
- Ensure comprehensive discussions of treatment options and remove barriers to second opinions.
- Launch culturally relevant public health campaigns to raise awareness and promote early detection.
- Integrate holistic care approaches that address psychosocial and fertility impacts.

## Research

- Address gaps in epidemiology, fertility outcomes, mental health, healthcare access, and economic impact.
- Disaggregate data by specific ethnicities for targeted interventions.
- Investigate the effectiveness and integration of complementary and alternative treatments.

## Next Steps

Building on the interim findings, the APPG on Black Health and CAHN will take the following actions to advance the agenda for equity in fibroid care:

- Complete Full Analysis of Survey Data** Continue analysing the remaining survey responses to ensure a comprehensive understanding of the lived experiences of Black women across the UK.
- Publish Full Report** Develop and disseminate a full report that integrates all findings, including qualitative submissions and stakeholder insights, to inform national policy and practice.
- Parliamentary Engagement** Present findings to policymakers and parliamentarians to advocate for the designation of fibroids as a public health priority and secure dedicated funding.
- Stakeholder Roundtables** Host follow-up roundtables with healthcare professionals, researchers, and community leaders to co-design solutions and implementation strategies.
- Public Awareness Campaigns** Launch culturally tailored campaigns to raise awareness about fibroids, promote early detection, and empower Black women to seek timely care.
- Research Mobilisation** Encourage academic institutions and funding bodies to prioritise research on fibroids in Black women, with emphasis on disaggregated data and holistic care models.
- Monitoring and Accountability** Establish mechanisms to track progress on policy commitments, healthcare improvements, and research outputs, ensuring transparency and sustained impact.

### Demographic and Awareness Profile of Respondents with a Fibroid Diagnosis

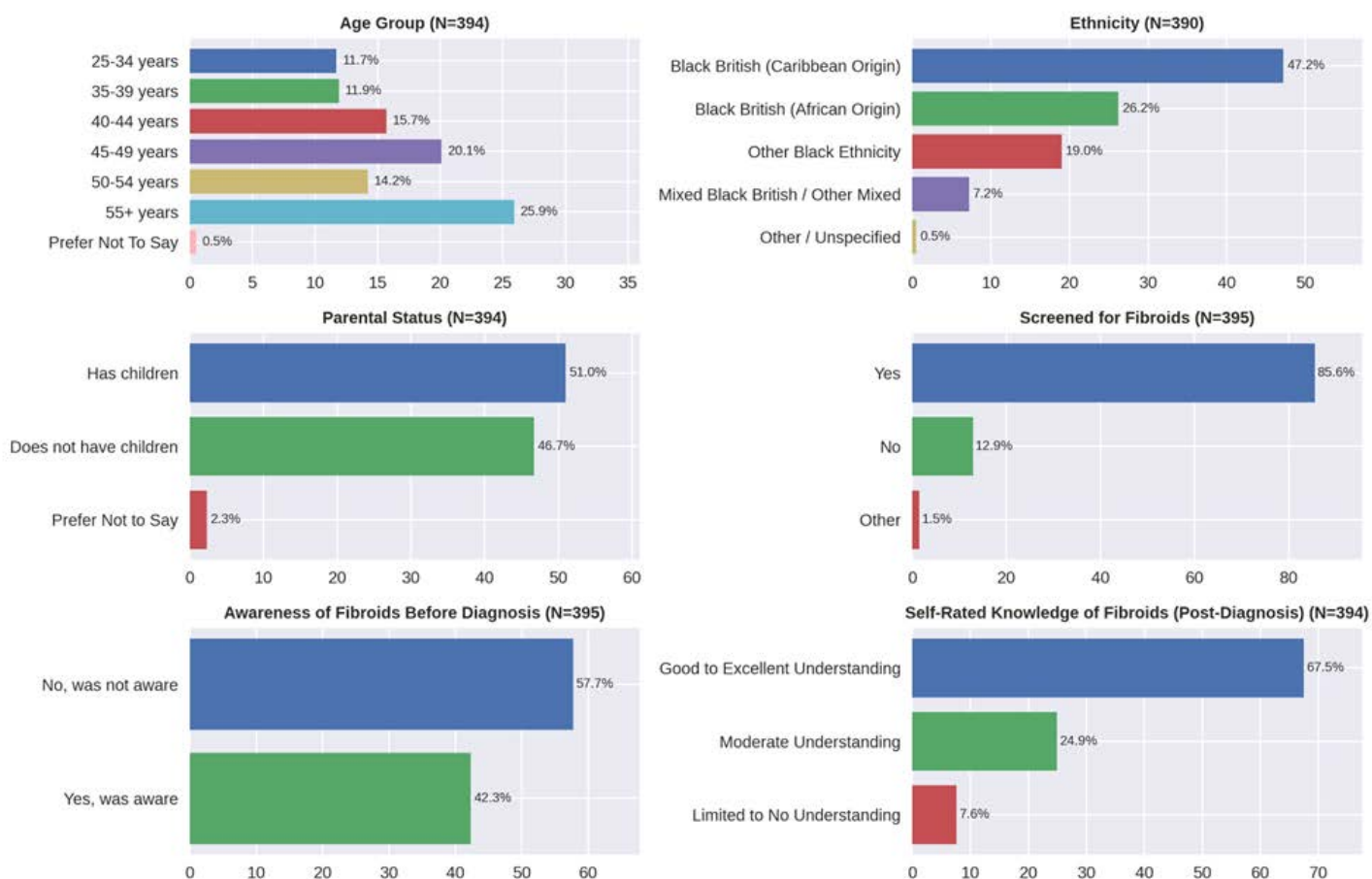


Figure - full analysis of demographic and awareness profile

The evidence gathered across community engagement sessions, parliamentary discussions, and formal submissions reveals a deeply entrenched crisis in fibroid care, shaped by clinical neglect, cultural invisibility, and systemic inequities. This chapter presents the dominant themes that emerged throughout the inquiry, offering a lens through which to understand the lived realities of Black British women and the structural conditions that contribute to poor outcomes.

**Invisibility in Health Discourse** - Although fibroids are among the most common gynaecological conditions, they remain largely absent from mainstream health narratives. This invisibility is especially pronounced in relation to Black women, whose experiences are frequently excluded from public health campaigns, policy discussions, and media coverage. The result is a widespread lack of awareness among both the general public and healthcare professionals, leading to delayed diagnoses, limited treatment options, and a persistent underestimation of the condition's impact. Contributors repeatedly emphasised that fibroids are not rare, but they are rarely prioritised. This neglect reinforces a cycle of silence and stigma, leaving many women to manage their symptoms without adequate support or recognition.

**Structural Racism and Clinical Dismissal** - A recurring and deeply troubling theme was the influence of structural racism on clinical experiences. Black women described being routinely dismissed, disbelieved, or pressured into invasive procedures such as hysterectomy, often without full information or consideration of alternatives. These accounts reflect a broader pattern of racial bias within the healthcare system that erodes trust and compromises care. Clinicians and advocates called for urgent reforms, including mandatory anti-racism training, culturally responsive care frameworks, and accountability mechanisms to ensure respectful, informed, and equitable treatment. Rebuilding trust between Black communities and healthcare providers was described as both essential and immediate.

**Research Gaps and Data Deficits** - The lack of UK-specific research on fibroids in Black women was identified as a major obstacle to progress. Without robust data, it is difficult to design effective interventions, secure targeted funding, or hold institutions accountable for disparities in care. Contributors highlighted the need for longitudinal studies, community-based research, and methodologies that prioritise lived experience alongside clinical metrics. This absence of evidence also affects policy development, leaving decision-makers without the necessary tools to respond effectively. The call for investment in academic research was framed not only as a matter of knowledge but also as a matter of justice, visibility, and structural change.

**Emotional and Psychological Toll** In addition to physical symptoms, fibroids place a significant emotional and psychological burden on those affected. Women spoke of enduring pain, isolation, and fear while navigating a healthcare system that failed to listen or respond. The mental health impact was intensified by the lack of peer support, culturally relevant services, and holistic care pathways. The inquiry revealed a clear demand for community-led models of care that integrate emotional wellbeing, reproductive health, and cultural understanding. Peer support networks, counselling services, and integrative therapies were all identified as essential components of a more compassionate and responsive system.

**Conclusion: A Lens for Action** These themes do not exist independently; they intersect and reinforce one another, creating conditions in which Black women experience disproportionate harm. Addressing the crisis in fibroid care requires more than clinical reform. It calls for a reimagining of how care is delivered, how research is conducted, and how communities are involved. The insights in this chapter provide the foundation for the challenges, solutions, and strategic actions explored in the following sections. They are not simply reflections; they are a guide for change.

## Why so many Black women may be at risk of uterine Fibroids



### OESTROGEN

Promotes the growth of smooth muscle and fibrous tissue



### GENETICS

Genetics change in cells can trigger tumour formation



### STRESS

May disrupt hormonal levels, accelerating tumour growth



### ENVIRONMENTAL CHEMICALS

May mimic oestrogen, contributing to tumour formation



Building on the themes presented earlier, this chapter identifies the key challenges that hinder progress in fibroid care and explores potential solutions proposed by contributors throughout the inquiry. These challenges are interconnected and deeply embedded in institutional structures. CAHN operates as a strategic disruptor leveraging lived experience, expert collaboration, and grassroots leadership to exert pressure on systems, influence decision-making, and redefine the pathways to equity and justice.

### Systemic Barriers to Equitable Care

One of the most persistent challenges is the lack of trust between Black communities and healthcare providers. This distrust stems from repeated experiences of dismissal, coercion, and neglect. Many women reported feeling unheard or invalidated during clinical consultations, particularly when seeking non-invasive treatment options. The absence of national guidelines on fibroid care further complicates this issue, leaving clinicians without a consistent framework and patients without reliable support.

Additionally, the fragmentation of care where gynaecological, mental health, and community services operate separately creates a disjointed experience that fails to meet the full needs of patients. This siloed approach limits continuity, reduces access to holistic support, and places the burden of coordination on individuals already navigating complex health challenges.

Systemic bias and mistrust also pose significant barriers. Black women often feel unheard or disrespected in clinical settings, which discourages engagement and follow-up care. Embedding cultural humility and anti-racism in clinical practice, alongside community-based education, can help rebuild trust and improve patient experience.

### Challenges in Primary Care and Treatment Access

Primary care plays a critical role in early identification and referral, yet many GPs lack adequate training on fibroids. Contributors highlighted that symptoms are often misinterpreted or dismissed, leading to delayed diagnoses and limited treatment options. Addressing this requires curriculum reform, continuing professional development, and the integration of fibroid-specific modules into medical education.

Another challenge is the limited availability of non-invasive treatment options within the NHS. Many women are offered hysterectomy as a first-line solution, despite its long-term implications. Expanding access to alternatives such as uterine artery embolisation, myomectomy, and pharmaceutical treatments is essential to ensure informed choice and patient-centred care.

### Underinvestment and Policy Gaps

Despite the high prevalence of fibroids, the condition remains low on the policy agenda. Contributors pointed to chronic underinvestment in both research and service provision, particularly studies that centre Black women's experiences. This reflects broader patterns of racial and gender bias in medical research and policy development. Without dedicated resources, innovation is limited and disparities persist.

The absence of national guidelines on fibroid care further compounds these issues. Clinicians lack a consistent framework, and patients face uncertainty and inconsistency in their care journeys. Establishing clear standards and pathways would support more equitable and effective service delivery.

### Mitigation Strategies and Promising Models

Throughout the inquiry, contributors proposed a range of strategies to address these challenges. These included:

- Community-led health initiatives that centre lived experience and build trust.
- Culturally responsive training for clinicians, with a focus on anti-racism and communication.
- Integrated care models that combine physical, emotional, and social support.

Local programmes such as fibroid support groups and culturally tailored reproductive health clinics, which were cited as promising examples.

However, these initiatives often operate without sustainable funding or institutional support, which limits their reach and effectiveness. Contributors stressed the need for national coordination and long-term investment to expand successful models and embed equity into routine care.

### Conclusion: From Barriers to Solutions

The challenges outlined in this chapter are complex and deeply rooted but they are not insurmountable. Progress depends on listening to lived experience, investing in community expertise, and embedding equity into every aspect of care. For VCSE organisations like CAHN, the path forward lies in partnership, advocacy, and sustained support to help shape more inclusive and responsive systems.

## 8 Chapter 7 – Learning and Adaptation

This chapter reflects on the lessons learned throughout the inquiry and offers strategies for adapting fibroid care in the UK. It draws on the experiences of patients, clinicians, researchers, and advocates to identify what must change and how systems can evolve.

**Lessons from the Inquiry Process** The inquiry demonstrated that meaningful change begins with meaningful engagement. Black women’s testimonies were not just contributions to the evidence base they were catalysts for reflection and action. The process highlighted the importance of creating safe spaces for dialogue, validating lived experience, and challenging institutional resistance. It also revealed the limitations of conventional policy-making approaches that often exclude marginalised voices.

**Adaptive Models of Care** Contributors advocated for models of care that respond to the complex realities of fibroid treatment. These include holistic health frameworks that integrate reproductive, mental, and cultural wellbeing; peer-led support networks that foster community resilience; and flexible service designs that accommodate diverse needs. Adaptation also involves re-thinking how care is delivered, moving away from rigid clinical hierarchies toward collaborative, person-centred approaches.

**Embedding Equity and Sustainability** Adaptation is not only about innovation it is about embedding equity into the core of healthcare systems. This requires sustained investment, inclusive research practices, and accountability mechanisms to ensure that progress is measurable and lasting. Contributors called for partnerships between NHS bodies, academic institutions, and community organisations to co-create solutions that are both effective and enduring.

**Conclusion: Preparing for Implementation** The insights in this chapter prepare the ground for the final section of the report, which focuses on action and implementation. Learning and adaptation are not endpoints; they are ongoing processes that must inform every step toward achieving equity in fibroid care.

## 9 Chapter 8 – Investment in UK Academic Research

### Bridging the Research Gap for Black Women with Fibroids

Despite the high prevalence and severe impact of uterine fibroids among Black women in the UK, academic research on this issue remains alarmingly sparse. The rapid scoping review conducted by CAHN identified only six peer-reviewed UK studies focused on fibroids in women of Caribbean and African descent. This lack of empirical evidence has profound implications not only for clinical care and public health policy, but also for the visibility and prioritisation of Black women’s health within the academic landscape.

#### 1. The Case for Targeted Research Investment

Fibroids are not a niche concern they are a widespread reproductive health issue with disproportionate effects on Black women. Yet, the absence of robust UK-based data means that clinical guidelines, treatment pathways, and public health interventions are often shaped by international evidence that may not reflect the lived realities of Black British women. Academic institutions must recognise this gap as a matter of health equity and invest in research that is:

- **Ethnically Disaggregated:** Studies must distinguish between different Black ethnic groups (e.g., Caribbean, African, Black British) to uncover nuanced patterns in prevalence, symptom severity, and treatment outcomes.
- **Community-Informed:** Research should be co-designed with affected communities to ensure relevance, cultural sensitivity, and trust.
- **Multidisciplinary:** Fibroids intersect with reproductive health, mental health, social determinants, and healthcare access requiring collaboration across medical, social science, and public health disciplines.



## 2. Priority Research Areas

To build a meaningful evidence base, academic investment should focus on the following domains:

Research Domain	Key Questions
Epidemiology	What is the true prevalence of fibroids among Black women in the UK?
Reproductive Outcomes	How do fibroids affect fertility, conception, and pregnancy outcomes?
Psychosocial Impact	What are the mental health and quality-of-life consequences of living with fibroids?
Healthcare Access	What barriers do Black women face in accessing timely, appropriate care?
Economic Burden	What are the direct and indirect costs of fibroids for individuals and the NHS?
Cultural Competency	How can training and service design improve clinical interactions and trust?
Alternative Therapies	What is the role and efficacy of complementary treatments used by Black women?

These priority research domains also align with national health system goals. For example, epidemiology and healthcare access support the NHS 10-Year Health Plan's shift from treatment to prevention. Cultural competency and psychosocial impact contribute to Core20PLUS5 by addressing care inequalities in underserved populations. Research into alternative therapies and economic burden can inform community-based models and digital innovation, supporting the shift from hospital to community and from analogue to digital.

## 3. Institutional Responsibility and Funding

Universities, research councils, and funding bodies including the NIHR, UKRI, and Wellcome Trust must take proactive steps to address this research gap. This includes:

- Creating dedicated funding streams for Black women's health research
- Embedding equity criteria in grant evaluations
- Supporting early-career researchers from underrepresented backgrounds
- Partnering with community organisations to ensure inclusive research design and dissemination

## 11 Chapter 9 – Call to Action: Achieving Equity in Fibroid Care

This final chapter consolidates the findings and insights presented throughout the report and outlines the strategic actions required to address disparities in fibroid care affecting Black women in the UK. It serves as a roadmap for implementation, policy reform, and sustained impact. Drawing on evidence from the Rapid Scoping Review, Womb Health Survey, and lived testimonies, this chapter translates research into practical steps for change.

### Summary of Report Findings

- Black women face disproportionate burdens in fibroid diagnosis, treatment, and outcomes.
- Clinical bias and lack of culturally competent care contribute to delayed interventions.
- Research on fibroids rarely includes Black women's experiences or biological factors.
- Community organisations play a critical role in education, support, and advocacy.
- There is an urgent need for coordinated policy, funding, and service reform.

### Urgency of Action

This final chapter consolidates the findings and insights presented throughout the report and outlines the strategic actions required to address disparities in fibroid care affecting Black women in the UK. It serves as a roadmap for implementation, policy reform, and sustained impact. Drawing on evidence from the Rapid Scoping Review, Womb Health Survey, and lived testimonies, this chapter translates research into practical steps for change.

## Strategic Recommendations

Eleven recommendations were developed through the APPG meeting and supporting evidence. Each includes rationale, implementation steps, and designated leadership

Recommendation	Why It Matters	What to Do	Who Should Lead
<b>A - Awareness, Education &amp; Empowerment</b>			
1). Raise Awareness & Health Literacy	Many Black women are unaware of fibroid symptoms until crisis point.	Launch culturally tailored campaigns via trusted community channels (churches, salons, diaspora networks).	DHSC, NHS England, Public Health England, CAHN, local authorities
2) Support Community-Led Care Models	Community organisations are trusted and culturally aligned.	Fund and scale initiatives like Noire Wellness and diaspora medical networks.	ICBs, VCSE funders, local authorities
<b>B - Clinical &amp; System Capability</b>			
3) Integrate Fibroid Content into Medical Training	GPs and students lack confidence in diagnosis and care.	Include fibroid-specific modules in curricula with focus on racial disparities and patient-centred care.	RCGP, GMC, medical schools, Health Education England
4) Establish Dedicated Fibroid Centres	No specialist centres exist despite surgical complexity and high prevalence.	Create multidisciplinary hubs with surgical, fertility, and mental health expertise.	NHS England, ICBs, RCOG, DHSC
5) Deliver Culturally Competent Care	Black women's pain is often minimised and preferences ignored.	Embed cultural humility and anti-racism in clinical training; support informed consent with community advocates.	NHS Trusts, Royal Colleges, Health Education England, GMC
<b>C - Research &amp; Innovation</b>			
6). Invest in Targeted Research	Only six UK studies include Black women's fibroid experiences.	Fund research into genetic, environmental, and lived experience factors (e.g. vitamin D, endocrine disruptors).	NIHR, UKRI, academic institutions, DHSC
7) Investment in innovation and technological improvements	Treatments are invasive and outdated; innovation can improve outcomes and reduce disparities.	Invest in innovation for less invasive treatments, early diagnostic tools, and improved fertility care.	NIHR, UKRI, academic institutions, DHSC
8) Long term funding of research and treatment	Fibroid care is chronically underfunded despite its high prevalence and impact.	Ensure sustained funding for fibroid research and treatment to close the gap with other women's health priorities.	NIHR, UKRI, academic institutions, DHSC
<b>D - Accountability &amp; Collaboration</b>			
9) Set Clear Government Targets	Previous maternal health recommendations were rejected for being "too rigid."	Establish measurable goals to reduce delays, improve access, and increase funding.	DHSC, Parliamentarians, Treasury
10) Foster Cross-Sector Collaboration	No single sector can address the complexity of fibroid care.	Build partnerships across NHS, community organisations, academia, and policy.	CAHN, NHS Trusts, academic institutions, local authorities
11) Prioritising Fibroid care in Women's Health	Fibroids remain marginalised in national strategy despite widespread impact.	I Commit to ensuring that fibroid care is treated as a clear priority, with measurable targets, within DHSC and NHS England's delivery of the Women's.	DHSC, Parliamentarians, NHS England

## APPG Commitments & Strategic Next Steps

The APPG on Black Health and CAHN will pursue the following actions to advance equity in fibroid care. Several organisations and stakeholders have already expressed interest in supporting and implementing key recommendations from this report. Notably, an element of the recommendations have already received commitment to be funded by Theramex and will be piloted across three areas of the UK. These early commitments signal readiness for change and provide a strong foundation for collaborative action.

In addition, the APPG and CAHN will work closely with primary care networks to improve early detection, referral pathways, and culturally competent support for Black women. This includes engaging GPs, practice nurses, and integrated care teams to embed fibroid awareness and care into routine services.

All implementation efforts will be aligned with the “Three Shifts” outlined in the NHS 10-Year Health Plan: (1) shifting care from hospital to community, (2) transitioning from analogue to digital systems, and (3) moving from treatment to prevention. Fibroid care reform supports these shifts through community-led models, digital awareness tools, and early intervention strategies.

This work also complements other strategic policy levers, including the Core20PLUS5 framework, the Women’s Health Strategy, and the NHS Long Term Workforce Plan. These connections will be leveraged to embed fibroid care within broader health equity and system transformation agendas.

**1. Complete Full Analysis of Survey Data -** Continue analysing responses to ensure a comprehensive understanding of Black women’s lived experiences across the UK. Insights will inform service design, training content, and community engagement strategies.

**2. Publish Full Report (Autumn 2025) -** Finalise and disseminate a comprehensive report integrating all findings, including qualitative submissions and stakeholder insights. Share with Parliamentarians, DHSC, NHS England, Royal Colleges, and community stakeholders. Disseminate a tailored version to APPG members, partner organisations, and advocacy networks to support implementation and engagement. Publish a public-facing summary to support advocacy and awareness. Ensure alignment with NHS strategic priorities, including the Women’s Health Strategy and Core20PLUS5.

**3. Parliamentary Engagement (Autumn 2025–Winter 2026) -** Present findings to policymakers and advocate for fibroids to be designated a public health priority. Secure dedicated funding and policy commitments. Publish an impact report by February 2027 to mark the end of the award period. Highlight how fibroid care reform supports the Three Shifts of the NHS 10-Year Health Plan.

**4. Stakeholder Roundtables -** Host follow-up roundtables with healthcare professionals, researchers, and community leaders. Co-design solutions and implementation strategies for fibroid care reform. Include primary care representatives to strengthen early intervention and referral pathways.

**5. Public Awareness Campaigns -** Launch culturally tailored campaigns to raise awareness, promote early detection, and empower Black women to seek timely care. Explore digital platforms and community health networks to support outreach and education.

**6. Research Mobilisation -** Encourage academic institutions and funders to prioritise fibroid research focused on Black women. Emphasise disaggregated data, holistic care models, and lived experience. Support pilot studies and evaluations aligned with prevention and personalised care.

**7. Monitoring & Accountability -** Establish mechanisms to track progress on policy commitments, healthcare improvements, and research outputs. Ensure transparency, community oversight, and sustained impact. Report outcomes against NHS equity metrics and local health improvement plans.

**8. Call for Partnerships and Collaboration -** Invite NHS bodies, academic institutions, VCSE organisations, and funders to collaborate on implementing the recommendations. Facilitate joint initiatives, pilot programmes, and co-designed solutions that reflect community needs and clinical priorities. Establish a formal mechanism for partnership engagement and knowledge exchange. Three pilot sites have already committed to implementing elements of the recommendations with secured funding. These will serve as testbeds for scalable models of care.



## 12 Chapter 10 – Funding Priorities

Achieving equity in fibroid care requires more than policy ambition it calls for sustained and strategic investment across research, infrastructure, service development, and community engagement. For organisations like CAHN, meaningful impact depends on funding models that recognise the value of grassroots expertise and long-term partnership.

This section outlines a funding framework to support the priority areas identified throughout the report, particularly those shaped by thematic analysis and proposed mitigation strategies. While CAHN cannot drive systemic change alone, targeted investment enables us to play a vital role in bridging gaps, amplifying lived experience, and supporting more inclusive approaches to care.

### 1. Investment Domains

Funding should be directed toward four interconnected pillars:

• **Research Grants - Support studies focused on:**

- o Black women's lived experiences with fibroids
- o The role of vitamin D deficiency and endocrine disruptors
- o Barriers to diagnosis and treatment within marginalised communities

• **Service Development - Invest in:**

- o Establishing fibroid centres of excellence across the UK
- o Clinical training programmes for GPs and frontline staff
- o Integrated care pathways that include mental health and reproductive support

• **Community Initiatives - Fund culturally aligned programmes that deliver:**

- o Education and awareness in underserved communities
- o Peer support networks and patient navigation services
- o Community-led data collection and engagement

• **Advocacy & Awareness - Resource public-facing campaigns to:**

- o Raise awareness of fibroids and their impact
- o Challenge stigma and misinformation
- o Engage media and influencers to amplify lived experience

### 2. Potential Funders & Partners

Strategic investment should be mobilised from a diverse range of funders, including:

- National Institute for Health and Care Research (NIHR)
- UK Research and Innovation (UKRI)
- Department of Health and Social Care (DHSC)
- Integrated Care Boards (ICBs)
- Voluntary, Community and Social Enterprise (VCSE) sector partners

### 1. Strategic Investment Areas

To build a responsive and inclusive research ecosystem, funding should be directed toward:

- **Community-Based Research Hubs** Establish regional centres in underserved areas to facilitate localised data collection, community engagement, and culturally competent research.
- **Digital Infrastructure Invest** in platforms that enable real-time data sharing, remote participation, and scalable research models supporting the NHS's shift to digital-first care.
- **Equity-Focused Capacity Building** Fund training, mentorship, and career development for researchers from underrepresented backgrounds, ensuring diverse leadership in fibroid research.
- **Priority Research Domains** Support studies that address psychosocial impact, cultural competency, economic burden, and healthcare access aligned with Core20PLUS5 and NHS prevention goals.

## 2. Strategic Alignment with National Health Priorities

While CAHN alone cannot shift national systems, strategic funding enables VCFSE organisations like ours to contribute meaningfully to long-term change. By supporting community-led research and digital platforms, funders help strengthen the NHS's move toward more community-based models of care. Equity-focused investment complements national priorities such as Core20PLUS5 by improving access to research and addressing disparities in outcomes. Continued support for inclusive, interdisciplinary research ensures that innovation is shaped by the lived experiences of those most affected by fibroids bringing valuable insight to national efforts and helping bridge gaps between policy and practice.

## 3. Implementation & Accountability

To ensure impact and transparency:

- **Governance:** Establish a national advisory board to oversee funding allocation and monitor progress.
- **Partnerships:** Encourage co-investment from government, academia, industry, and community organisations.
- **Evaluation:** Track outcomes through annual reviews, community feedback, and equity metrics

	Milestone	Date
	APPG Meeting on Fibroids	May 2025
	Call for Evidence Launched	June–August 2025
	Summary Report Finalised	October 2025
	Ministerial Engagement Begins	November 2025
	Policy Recommendations Submitted	December 2025
	Final Report Published	February 2027

## 13

### Closing Statement

The recommendations, commitments, and funding priorities outlined in this report are designed to drive systemic change anchored in equity, accountability, and lived experience. Progress will depend on coordinated leadership, transparent monitoring, and sustained engagement with affected communities.

With funding secured for pilot programmes in Manchester, Birmingham, and London, implementation is already underway. These pilots will test scalable models for community-based, culturally competent fibroid care. Meaningful progress will require thoughtful policy change integrating these recommendations into national health strategies, commissioning frameworks, and clinical guidance.

Equally vital is sustained investment and proper resourcing to ensure that action is not one-off, but continuous. Funding must be delivered in substantial, upfront allocations not piecemeal or fragmented so that organisations can recruit staff, build infrastructure, and deliver services without delay or uncertainty.

This is particularly significant for Black-led organisations, which have consistently driven progress in health equity and community engagement, yet continue to face systemic funding disparities. The lack of core funding combined with fragmented, delayed payments places undue strain on already limited resources. This not only disrupts service delivery but also affects staff retention and the ability to offer stable, high-quality support to those most in need. Over time, such funding practices risk perpetuating the very inequities these organisations are working to dismantle.

This funding model is not only inefficient it reinforces structural discrimination and undermines the very organisations best positioned to lead meaningful change.

CAHN and its partners are looking forward to advancing fibroid care that is equitable, effective, structurally embedded, sustainably funded, and shaped by the voices of those most impacted.

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