Disbelieved, Dismissed, Delayed

Endometriosis Diagnosis Inequalities in Ethnically Diverse Communities

Cysters

ENDOMETRIOSIS UK

Foreword

Neelam Heera Shergill

CEO, Cysters

There is a particular kind of exhaustion that comes from living in pain and not being believed. I personally have experienced both.

For over a decade, Cysters has walked alongside people navigating reproductive and menstrual health conditions that are too often minimised, misunderstood, or misdiagnosed. We were founded because of those gaps. Because of the silence. Because of the stigma. Because of the gaslighting. And because too many of us were told our pain was normal when it was anything but.

This report does something that has been urgently needed for years. It names what so many from the global majority have known instinctively but struggled to prove: inequality in endometriosis diagnosis is not accidental. It is patterned. It is structural. And it is racialised.

The findings are plain to see. An average diagnosis time of 11 years for people from ethnically diverse communities. A critical delay of more than four years between seeing a gynaecologist and finally receiving answers. Nearly 7 in 10 respondents believed their ethnicity played a role in their journey. Just 11% feel healthcare providers are culturally sensitive.

These are not marginal differences. These are systemic failings.

At Cysters, we work at the intersection of race, gender, reproductive justice and health inequality. We know that when healthcare professionals assume Black women have a higher pain threshold, when South Asian women are reduced to stereotypes like “Mrs Begum syndrome”, when East Asian patients are infantilised, when trans, queer and non-binary patients feel unsafe to discuss their identities or identities assumed, diagnosis is not just delayed. It is obstructed.

The myth that people from ethnically diverse communities are “hard to reach” is dismantled clearly in this research. Respondents sought help earlier than the UK-wide average. They returned to their GPs repeatedly. They advocated for themselves. They were persistent. The problem is not a lack of help seeking. The problem is a lack of listening, referring, believing.

It is also important to say this: This report was unfunded. It was carried out through the labour, time, and emotional energy of minoritised individuals who are already living with the impact of inequality. Once again, it has been those most affected who have had to gather the evidence, tell their stories, and push the data forward simply to be heard.

If we are serious about changing the discourse around endometriosis care and racial health disparities, then we must fund the people and organisations embedded in these communities. We must resource research, outreach, peer support and advocacy work that is already happening on the ground. We cannot continue to rely on unpaid labour and goodwill to expose structural injustice. Putting money where our mouths are is not optional. It is essential.

These are not marginal differences. These are systemic failings.

As the CEO of a grassroots charity, rooted in community, I am clear that change cannot come from policy statements alone. It requires investment in culturally competent care. It requires mandatory and meaningful anti-racism training across the NHS workforce. It requires better ethnicity data. It requires research funding that reflects the diversity of those affected. It requires partnership with community organisations who already hold trust within marginalised groups.

Endometriosis does not discriminate biologically. But our healthcare system does. Addressing diagnosis times without addressing racial bias will only entrench inequality further.

This report is not the end of the conversation. It is the start. We stand ready to continue this work. Not simply to shorten diagnosis times, but to transform the care itself.

Because pain should never have to prove itself.

Neelam Heera Shergill,
CEO, Cysters

Emma Cox

CEO, Endometriosis UK

At Endometriosis UK, we are determined that everyone affected by endometriosis should get prompt diagnosis and the best treatment and support. It is shocking that it currently takes 9 years and 4 months on average to get a diagnosis in the UK, and indefensible that it takes 11 years on average for those from ethnically diverse communities.

Throughout this report, racial bias has been highlighted as a key concern. More than two thirds (68%) of respondents believed their ethnicity played a role in their diagnosis, proved a barrier to diagnosis, or was the subject of assumptions made by healthcare practitioners. Governments must tackle racial bias as a priority and ensure mandatory training is delivered across the NHS workforce.

As we continue our campaign for governments across the UK to commit to a target of reducing diagnosis times to an average of a year or by 2030, this target must be for everyone with endometriosis. Nobody should have to fight for the care that they need. Yet we know that those with endometriosis have to, and this report highlights that for those from ethnically diverse communities, the fight is harder.

We are proud to be collaborating with Cysters, a charity that do incredible work to raise awareness and drive change for marginalised communities. We want to ensure nobody faces discrimination or additional challenges in accessing a diagnosis and care they need. We urge everyone reading this report to join us in campaigning for change.

Nobody should have to fight for the care that they need.

Collectively we must now work to tackle the inequalities faced and ensure this becomes a Government priority. Through this report, we provide ways in which Governments can and must do better. This must be the start of the conversation, not the end, and we look forward to working with Governments and NHS's in each nation to ensure that these recommendations become a reality.

Emma Cox,
CEO, Endometriosis UK

Sarah Harris

Trustee, Cysters, and Lead Researcher

As an endometriosis researcher, I have spent numerous hours over the last few years exploring barriers to endometriosis diagnosis. Across my work I've come across dozens of factors that play a role in why it takes individuals so long to get a definitive diagnosis; sexism, stigma, and social class, just to name a few. But there is one factor that was rarely mentioned, despite the field of endometriosis research growing at a rapid rate over the years – ethnicity.

There is no question that those from ethnically diverse communities are subject to health inequities, so it was astounding to me that this hadn't been explored in the context of endometriosis. Therefore, when Cysters & Endometriosis UK approached me about leading this research project, my answer was obvious.

As a Pakistani woman with lived experience of medical racism, reading responses to the survey, and interviewing those with endometriosis across a diverse range of ethnicities felt both empowering, as well as deeply infuriating. It is evident that now more than ever, our communities are working tirelessly to fight for equality, but it shouldn't be this hard. Despite the non-discriminatory principals that should be instilled across healthcare practice, it is evident through our findings that this is not the case. This report is a reminder that there is still much more than needs to be done.

This is just the beginning.

It is evident that now more than ever, our communities are working tirelessly to fight for equality, but it shouldn't be this hard.

This project has been a labour of love and resistance over the last 2 years. I have worked on it alongside a full-time PhD, as well as my own battle with this horrible disease. But I knew that this work was vital. I am so incredibly grateful to both Cysters & Endometriosis UK for giving me this opportunity, and to all those who took the time to share their testimonials – this report is for you.

Sarah Harris,
Trustee, Cysters, and
Lead Researcher

Key Findings

Our survey shows that people from ethnically diverse communities across the UK wait 1 year and 8 months longer to get an endometriosis diagnosis than their white counterparts. This is despite waiting less time before deciding to see a GP about their symptoms, and waiting less time to be referred to a gynaecologist.

On average, the ethnically diverse patients we surveyed waited 11 years to get a diagnosis of endometriosis. This was 1 year and 8 months longer than the average diagnosis time (9 years and 4 months) reported in Endometriosis UK's diagnosis report: The state of endometriosis care across all 4 nations (2026), of which 93% of respondents were from white ethnic backgrounds.

The most significant delay occurred between first seeing a gynaecologist and being diagnosed with endometriosis. People from ethnically diverse communities waited more than twice as long (4 years) at this stage as the UK-wide average (1 year and 10 months).

Racial bias was highlighted as a key concern in both the survey data and interview responses, particularly for Black respondents. More than two thirds (68%) of respondents believed their ethnicity either played a role in their diagnosis, proved a barrier to diagnosis, or was the subject of assumptions made by healthcare practitioners.

Similarly, just 11% of respondents believed healthcare providers are culturally sensitive and responsive to the needs of endometriosis patients from ethnically diverse communities.

In interviews with endometriosis patients from ethnically diverse communities, as well as in the write-in sections of the survey, key issues raised included: racist myths and assumptions, particularly about Black patients having a higher pain threshold; gaslighting, dismissal and disbelief from healthcare professionals; normalisation of pain; and feeling that they were treated differently from white patients.

2026 UK-wide Report	Disbelieved, Dismissed, Delayed
Average diagnosis time	
9 years & 4 months	11 years
Average time before seeing a GP	
3 years & 6 months	1 year & 11 months
Average time from GP to Gynae	
7 years & 7 months	7 years
Average time from Gynae to diagnosis	
1 year & 10 months	4 years

Background

We have seen a significant rise in awareness of endometriosis in the last few years. However, it has been documented in literature that the condition is still at times considered a “middle-class, white women’s disease.” Both Endometriosis UK and Cysters know that, whilst endometriosis affects people from all backgrounds, many of those people do not feel represented by mainstream representation of endometriosis patients.

In 2023, Endometriosis UK undertook an online survey to determine the average length of time to secure a diagnosis of endometriosis, and to better understand the experiences of people seeking a diagnosis in the UK. There were 4371 responses to the question ‘Which of these best describes your ethnic group?’:

- White - 79% (3454 responses)
- Mixed race - 1% (44 responses)
- Asian or Asian British - 3% (125 responses)
- Black or Black British - 2% (90 responses)
- Arab - 0% (6 responses)
- Other - 0% (17 responses)
- Prefer not to say - 15% (635 responses)

Whilst Endometriosis UK knew that findings from their 2023 report would play an important role in raising awareness of delayed diagnosis, the responses to this question highlighted a clear gap in demographics. Cysters and Endometriosis UK believe it is crucial to work in partnership to ensure all voices are heard in discussions about healthcare policy and initiatives surrounding endometriosis. And so this joint project was conceived.

This report aimed to gather insights into the diagnosis experiences of endometriosis patients from ethnically diverse communities. Participants were encouraged to share their experiences openly and honestly, knowing their responses would contribute to shaping more inclusive healthcare policies. Findings from this report will be gathered and shared with decision makers in Parliament and the NHS to inform policy and resource allocation.

Findings from desktop review

Prior to the writing of this report, an informal desktop review was conducted to identify the existing material on this topic. This desktop review synthesised available UK-based peer reviewed research, population data, policy documents, parliamentary evidence, charity reports, community-led work, and reputable media coverage in relation to the delayed diagnosis of endometriosis amongst those from ethnically diverse communities in the UK. Where UK-specific evidence is limited, this is explicitly noted.

Diagnostic delay in the UK: established context

Existing large-scale UK survey evidence demonstrates that delayed diagnosis is a systemic feature of endometriosis care. Endometriosis UK's national diagnosis surveys show that most respondents experienced multiple GP consultations before referral, with many reporting dismissal, normalisation of pain, or misattribution of symptoms to stress or menstruation (Endometriosis UK, 2023). Media coverage and parliamentary debate have reinforced the characterisation of endometriosis as a condition frequently overlooked or deprioritised within the NHS (The Guardian, 2023a: APPG on Endometriosis, 2020).

The 2024 National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report described endometriosis care as fragmented, reactive, and insufficiently embedded within chronic disease management pathways, contributing to prolonged diagnostic journeys (NCEPOD, 2024).

Ethnicity, diagnosis patterns and inequality in the UK

Population-level data

The most robust UK quantitative evidence on ethnicity and endometriosis diagnosis comes from Office for National Statistics (ONS) linked administrative data. Analysis of hospital and primary care records between 2011 and 2021 shows significant variation in recorded endometriosis diagnoses by ethnic group, with several minoritised ethnic groups less likely to have a recorded diagnosis compared with White British Women (ONS, 2023a; ONS, 2023b).

ONS cautions that these findings should not be interpreted as reflecting true prevalence differences. Instead, they may indicate under-diagnosis, delayed diagnosis, differential access to specialist services, or differences in help-seeking and recording practices. This distinction is critical for policy interpretation.

Qualitative and community-based UK research

The ENDOCUL (Endometriosis and Cultural Diversity) Project represents the most substantial UK research programme explicitly addressing ethnicity and endometriosis. Through focus groups with women from African Caribbean, South Asian, Chinese, Greek and Greek Cypriot communities, the project identified culturally mediated barriers to awareness, help-seeking, and engagement with healthcare services (Denny et al., 2019).

Key findings included:

- Limited awareness of endometriosis within some communities
- Cultural taboos around menstruation and pelvic pain
- Language barriers and lack of culturally appropriate information
- Perceived dismissal or misunderstanding by healthcare professionals

The project also highlighted the absence of tailored NHS resources and the need for culturally competent communication and interpretation support (Culley et al., 2017).

Emerging UK evidence centering ethnically diverse communities' diagnostic experiences

Direct UK evidence on diagnostic delay among Black women remains sparse. However, a recent UK doctoral thesis provides important qualitative insight. Taylor (2025) explored Black women's experiences of reaching an endometriosis diagnosis in the UK, identifying themes of prolonged dismissal, repeated self-advocacy, racialised stereotypes relating to pain tolerance, and mistrust in healthcare encounters. While based on a small sample, this work is one of the first UK studies to explicitly centre Black women's diagnostic journeys.

Parliamentary, policy and health system evidence

Concerns about inequitable diagnosis are reflected in UK policy and parliamentary sources, even where formal data remains limited. The All-Party Parliamentary Group (APPG) on Endometriosis, explicitly acknowledged that patients from ethnically diverse communities may face additional barriers to diagnosis and care, calling for improved data collection and targeted research (APPG on Endometriosis, 2020).

Written evidence submitted to parliamentary inquiries, including submissions from clinicians, researchers, and advocacy organisations, has repeatedly highlighted longer diagnostic pathways for patients from ethnically diverse communities, citing compounded effects of gender bias, racial bias, and socioeconomic inequality (House of Commons, 2024; NHS Race and Health Observatory, 2023). The NICE Endometriosis Guideline (NG73) and associated equality impact materials acknowledge that evidence is insufficient to fully assess diagnostic differences by ethnicity, underscoring a structural gap in the research base that informs national clinical guidance (NICE, 2017; NICE, 2024).

The Women's Health Strategy for England recognises endometriosis as a priority condition but does not include ethnicity-specific diagnostic targets, reflecting the current limitations of available evidence (DHSC, 2022).

Media and public discourse

Reputable UK media outlets, particularly The Guardian, have played a significant role in amplifying patient experiences of diagnostic delay and institutional neglect. Coverage of Endometriosis UK survey findings and the NCEPOD report has helped situate endometriosis within broader debates on women's pain, credibility, and health inequality, although it is noted that patients from ethnically diverse communities are often under-represented in these mainstream narratives (The Guardian, 2023a; The Guardian, 2024).

Evidence gaps and implications

This desktop review identifies several critical gaps in the UK evidence base:

- Limited UK-specific quantification of diagnostic delay by ethnicity, beyond diagnostic prevalence patterns
- Scarcity of large-scale qualitative studies explicitly focused on people from ethnically diverse communities
- Inadequate routine data on ethnicity across diagnostic pathways, including primary care and pre-diagnosis stages
- Minimal evaluation of interventions designed to reduce diagnostic delay in ethnically diverse communities

Notably, NICE and parliamentary sources explicitly acknowledge these gaps, reinforcing the need for targeted, equity-focused research.

Summary of desktop review

In summary, while delayed diagnosis of endometriosis is well documented in the UK, robust, ethnicity-specific data remains limited. Available population data, qualitative research, community-led work, and parliamentary evidence collectively suggest that people from ethnically diverse communities face additional barriers and potentially longer diagnostic delays, but the scale and mechanisms of these disparities are not yet fully quantified.

This evidence gap itself constitutes a key finding and provides a strong rationale for dedicated research, improved data collection, and policy action – particularly in the context of the UK's commitments to health equity and the Women's Health Strategy.

Methodology

Our research consisted of a mixed-methods approach – combining a desk review, survey responses, and ten one-to-one interviews. This multifaceted approach allowed us to meaningfully document the lived experiences of those from ethnically diverse communities who had undertaken a journey to seek out a diagnosis of endometriosis in the UK. This methodology was considered to be the most appropriate and beneficial way to build a robust and nuanced understanding of this experience. As lead researcher, Sarah Harris undertook the desk review and interviews.

Survey

Based on questions that had been asked in Endometriosis UK's 2023 Diagnosis Survey, the research team was able to build upon these to tailor our survey questions towards the experiences of diagnosis for those from ethnically diverse communities.

The survey was launched online in April 2024 and closed in August 2025. Responses to the survey took longer than expected to gather.

> **“As a young black girl I feel like I was sexualised early and [they] never believed that I had not participated in sexual acts. As a schoolgirl with zero sexual activity, I was made to attend sexual health and family planning clinics before receiving any gynaecology care or appointments.”**

Demographics

578 people from ethnically diverse communities responded to our survey. For this analysis we have included 351 respondents living in the UK, and diagnosed in the UK between 2015 and 2025, to ensure the data is directly comparable with our Endometriosis UK's most recent diagnosis report, The state of endometriosis care across all 4 nations: A roadmap for driving down diagnosis times and improving access to care (March 2026). We refer to data from this report as the UK-wide average.

Respondents came from a range of ethnic backgrounds, of which 42% were South Asian, 30% Black, and 23% from mixed ethnic backgrounds. The remaining respondents' ethnic backgrounds were 'Arab', 'Chinese', 'Other Asian background' or 'Other ethnic group'.

Most (81%) were born in the UK, and all lived in the UK Almost all (97%) the respondents lived in England, with 38% from London and 11% elsewhere in the south east. Of the remaining respondents, 15% lived in the West Midlands, 9% in the North West, 7% in the East Midlands, 6% in the East of England, 6% in Yorkshire and Humberside, and smaller numbers elsewhere in the UK.

Just 3% lived in Scotland, the country with the longest average diagnosis time in our UK-wide report (2026). A further 1% lived in Wales and less than 1% (one respondent) in Northern Ireland.

Nearly all (97%) identified as female. A further 2% identified as non-binary, one respondent identified as male, and one selected 'prefer not to say'.

The majority of respondents (48%) were born during the 1990s, with 37% born in the 1980s, 8% in the 2000s, 7% in the 1970s, and just one respondent born in the 1960s. The average respondent was 35.

We also carried out in-depth interviews with ten endometriosis patients from ethnically diverse communities. Two identified as non-binary and the rest as female, and they ranged in age from 20 to 47. Three came from Black African or Caribbean backgrounds, three from mixed ethnic backgrounds (white and South Asian, white and Chinese, Arabic and North African), and the remaining four from Afghan, Pakistani, Indian and Chinese backgrounds.

The journey to diagnosis

There is a common assumption among UK healthcare providers that those from ethnically diverse communities are "hard to reach", and slower to seek medical care, because of cultural stigmas surrounding menstrual health. However, for the respondents in our survey, this was not the case.

Respondents to our survey took on average less than two years (1 year and 11 months) after first noticing their symptoms to see their GP. This means they sought help more than 18 months earlier than the UK-wide average of 3 years and 6 months.

They also waited less time to see a gynaecologist, with an average wait of 7 years from seeing their GP to seeing a gynaecologist. This is seven months less than the UK-wide average of 7 years and 7 months.

Despite this, most respondents (80%) had visited a GP five or more times – and 54% had at least ten appointments – before endometriosis was even mentioned. In our UK-wide report, these figures fell to 66% and 39%, suggesting patients from ethnically diverse communities had to be even more determined than their white counterparts when seeking answers for their symptoms.

As one survey respondent told us: "It took a decade of heavy bleeding and pain for a GP to ask me, 'Has anyone ever found out why you bleed so much?'"

Several of the women we interviewed also felt they'd had to fight harder for their diagnosis than white women they knew. Mehar told us: "Sometimes it feels like it's been more of a fight for me."

"I'd say they are more reluctant to believe us. I did have a few racist incidents with one GP," said Prajakta, 20, who comes from an Indian background. "We know other people who went to the same doctor and said they were really good. But when it came to us, it was very different - their attitude and dismissal was very strong. We were treated like we were very stupid and didn't know what we were talking about."

Of the 97% of respondents who had seen a GP before being diagnosed, nearly half (47%) the those from ethnically diverse communities we surveyed had seen five or more different GPs - slightly less than the 53% who gave the same response in our UK-wide survey.

Far from being "hard to reach", these

	2026 UK-wide Report	Disbelieved, Dismissed, Delayed
Symptoms to GP	3 years & 6 months	1 year & 10 months
GP to gynaecologist	7 years & 7 months	7 years
GP to diagnosis	9 years & 4 months	11 years

findings paint a picture of patients who were both proactive and persistent about seeking answers and referrals from their GP - even when that meant consulting with multiple GPs, or with the same GP on multiple occasions.

Yet our findings also show that, once they had been referred, people from ethnically diverse communities waited more than twice as long on average between seeing a gynaecologist and being diagnosed with endometriosis.

The average gap between those from ethnically diverse communities first seeing a gynaecologist and finally receiving their diagnosis was slightly more than 4 years. In our 2026 UK-wide survey, this gap was less than 2 years (1 year and 10 months).
This delay is particularly significant given the majority of respondents were diagnosed by a gynaecologist. Interviewee Zaynah told us: “In [one] year I saw six different gynaecologists because they just did not want to listen. A lot of them said I was just really young and this would pass.”

In terms of diagnostic pathways for those from ethnically diverse communities, 52% of respondents with a diagnosis were diagnosed through surgery and 42% by scan, with the remainder diagnosed by symptoms or another pathway. In our UK-wide report, we saw averages of 64% diagnosed by surgery and 27% by scan, suggesting those from ethnically diverse communities were less likely to be diagnosed by surgery and more likely to be diagnosed via imaging.

Whilst historically diagnostic surgery combined with a biopsy was considered the only definitive way of diagnosing endometriosis, there have been developments in recent years in imaging (ultrasound, MRI). Those trained and experienced in gynaecological imaging may identify deep endometriosis. However, a ‘normal’ scan does not rule out endometriosis.

Cultural stigmas did come up in the interviews we conducted. 20-year-old Zaynah, whose ethnic background is Pakistani, was supported by her mother in appointments throughout her teens, but told us: “I don’t really speak about [my endometriosis] that much with my wider family. In Pakistani culture generally, if someone has an illness, it isn’t spoken about.”

Similarly, in 27-year-old Mehar’s Afghani community, “nobody really spoke about periods, it was just whispered about. When it came to the pill [as a treatment option], there was stigma around the fact it's known as the birth control pill, and what if you can't have kids in the future."

Another interviewee, a 37-year-old Black African woman who shares her experiences as Aseda, said: "I think there's an element where it's treated as part of being a woman; periods come with pain. My mum did come to appreciate that it was a big thing, and became my biggest cheerleader, but there were times when I really did think 'Am I just lazy? Am I just not strong enough to bear the pain?' The talk was always, 'People suffer this, it's not an illness - get up and do what you have to do'."

Despite these challenges, the majority of respondents to our survey (94%) had been able to speak to someone about their symptoms before first going to a

Diagnosis experiences

Being disbelieved or accused of 'making a fuss about nothing' is an alarmingly common experience for many patients with endometriosis, whatever their ethnic background. 74% of people from ethnically diverse communities said they had encountered this kind of comment - less than the 82% of respondents in the UK-wide survey - although this rose to 86% for respondents from mixed ethnic backgrounds.

"I just kept going back to the GP, saying, 'I'm in pain, this is not okay.' And I was dismissed a lot, like I was a small child who doesn't know themselves. It was very frustrating - I would leave there in tears most of the time. After a while, I didn't know what else to say or how to keep going back," said interviewee Gar Mei, 39, who is non-binary and from a mixed White British and Chinese background.

Similarly, one respondent to our survey wrote: "It feels like I have been gaslit by GPs and they have never taken my symptoms seriously."

While the overall picture is negative, it's worth noting that there were people from ethnically diverse communities who told us about experiencing positive care and understanding health professionals, and being seen and diagnosed quickly. One told us: "As a woman of colour I was treated fairly and quickly."

6% reported being diagnosed within two years of seeing their GP for the first time. One in four were able to see a gynaecologist either the same year (13%) or the year after (12%) first seeing their GP. This demonstrates not only that good practice is possible, but that some patients do have a more positive diagnosis journey.

However, these experiences were sadly far outnumbered by the negatives. Free text responses to the survey referred to gaslighting, normalisation of pain, racist medical assumptions that Black women have a higher pain tolerance, and other traumatic experiences.

Racial bias and cultural sensitivity

Racial bias emerges as a key theme in the diagnosis experiences of endometriosis patients from ethnically diverse communities.

Respondents were asked the following three questions:

- Do you think your ethnicity played a role in your endometriosis diagnosis journey?
- Do you think your ethnicity was a barrier to you receiving an endometriosis diagnosis?
- Do you think healthcare professionals made assumptions about your symptoms and treatment plan due to your ethnicity?

68% of respondents replied ‘yes’ to one or more of these questions, while just 7% answered ‘no’ to all three.

This was reflected in both the write-in responses to our survey and the more in-depth interviews we carried out. One respondent wrote: “Race has played a huge part in how poorly I’ve been treated.” Another told us: “My pain has been completely dismissed and ignored whilst white people in A&E in front of me were treated genuinely.”

We also asked: ‘Do you believe healthcare providers are culturally sensitive and responsive to the needs of women from ethnic minority backgrounds with endometriosis?’ Just 11% answered ‘yes’, with 68% saying ‘no’, and the remainder saying ‘unsure’. There was a clear feeling that cultural sensitivity is lacking, even among respondents who didn’t believe their ethnicity impacted their own treatment.

Racist assumptions were a recurring theme. “[They] assumed I did not speak English because I was dressed traditionally. [They assumed] I am not educated or astute. Rude nurses and doctors spoke about me in front of me,” one respondent wrote.

Do you believe healthcare providers are culturally sensitive and responsive to the needs of women from ethnic minority backgrounds with endometriosis?

11%
said Yes

68%
said No

21%
were Unsure

> **“My pain and fatigue was not believed and I was always asked whether I had issues at home, rather than being believed about my symptoms.”**

This was particularly true for Black respondents. “I believe my pain and symptoms were dismissed due to medical racism and stereotypes about Black women having a higher pain threshold,” one respondent wrote.

“As a young black girl I feel like I was sexualised early and [they] never believed that I had not participated in sexual acts. As a schoolgirl with zero sexual activity, I was made to attend sexual health and family planning clinics before receiving any gynaecology care or appointments,” another respondent wrote.

The same respondent continued: “My pain and fatigue was not believed and I was always asked whether I had issues at home, rather than being believed about my symptoms. There was surprise that I had a two-parent household, and usually an assumption that my Dad was my husband or partner, even as a teenage girl. [I was even told] maybe it was the food from my country, and following a UK diet could be more beneficial, without [them] asking or going through what my diet was.”

28-year-old interviewee Amaara, who is non-binary and Afro-Caribbean, also described feeling that their pain was taken less seriously as a Black person, and that assumptions were made about their lifestyle.

“Because I’m Afro-Caribbean, they assumed I might have a different diet that’s high in sugar, and I felt like they didn’t believe me when I said I don’t drink,” they told us.

In their interview, Gar Mei described feeling infantalised as an East Asian patient. “I believe I’m treated a lot younger than I am. I’m nearly 40, I have a teenage daughter and a lot more life experience than some of these doctors - it’s so frustrating. I get that I look younger than a lot of people my age, but that doesn’t mean I am younger or more naive,” they said.

“I do think, as a female-presenting Chinese person, you’re belittled a little bit more. It doesn’t help having a vagina and a uterus, but then as soon as you walk through the door and you look ten years younger than you’re supposed to be, you’re treated even younger than that.”

Several South Asian survey respondents referred to ‘Mrs Begum (or Mrs Bibi) syndrome’, a racist and sexist stereotype used to imply South Asian women’s pain and symptoms are exaggerated. One wrote: “[My] GP, gynae and work colleagues blamed it on mental health and attention seeking; at times I felt I experienced Mrs Begum syndrome.”

Another told us: “At age 12, when my mother took me to hospital, I heard the (white) HCP and hospital staff say

Mrs Begum. I corrected them that our surname was Kaur, thinking they had confused me, and they laughed. Years later I understood what was actually meant by that comment."

Several respondents had made complaints, but felt these were ignored or dismissed. One wrote: "I have been labelled as 'angry' when I wrote a very professional complaint email about my experience". Another told us they had been unable to make a complaint, saying: "NHS complaints systems are rubbish."

An intersectional issue

Our findings also highlight that endometriosis patients may be affected by multiple, intersecting forms of bias, as well as their ethnicity. One non-binary respondent told us: "I do not disclose my gender identity to my doctors in case their bias also affects, or prevents, the minimal care I receive."

For Amaara too, assumptions about their lifestyle as an Afro-Caribbean person intersect with biases based on their religion, gender and sexuality. "If I go to an appointment in a headscarf, or presenting more Muslim, I feel like there's more emphasis on me getting married and having a child - like they're more comfortable pushing certain religious ideas. I've noticed there's also a discomfort around the fact I'm queer," they said.

Impact of delays

Both the interviews we conducted and the free text responses to our survey illustrate some of the longer term impacts of delayed diagnosis.

Unsurprisingly, both the delays and the experiences of bias had a clear impact on patients' mental health. "It takes a lot of support. My mental health before I got diagnosed was so horrible because of the constant dismissal," said Prajakta.

"We get told a lot that we're victims when we complain about racism - but if you can't acknowledge that you're being invalidated whilst you're being invalidated, you will go crazy," Amaara said. "It's not about being framed as a victim and wanting pity from people, it's about getting the support you need. I know if I'd got the support I needed earlier, I probably wouldn't have fibromyalgia [as well] now."

Several respondents referred to lasting trauma and a loss of faith in the healthcare system as a result of their experiences. One wrote: "It has given me a huge distrust in doctors and medical professionals because I was ignored and gaslit by them for years." Another told us: "These [HCPs] are people I put my whole trust in and [who] have scarred me for life." Others described feelings of loss and uncertainty about their futures. "I still feel I don't really know what's in my future," one wrote. In particular, several expressed sadness and anxiety about the impact on their fertility: "I feel like the delayed diagnosis has meant that my fertility and ability to have children has been taken from me."

One survey respondent's comments also remind us that diagnosis is not the end of the delays: "Took years to diagnose and now the long wait to be seen by pain management and endo specialists."

Findings by ethnicity

Of all the those from ethnically diverse communities we surveyed, those from mixed ethnic backgrounds fared worst, waiting 12 years and 3 months on average for their endometriosis diagnosis, almost 3 years longer than the UK-wide diagnosis time of 9 years and 4 months.

They were among the quickest to see their GP after noticing symptoms - waiting 1 year and 9 months on average. However, they then faced long delays from GP to gynaecologist (7 years and 9 months) and delays of almost 5 years (4 years and 11 months) from gynaecologist to diagnosis.

Black patients had the quickest diagnosis time, 10 years and 2 months, although this was still 10 months longer

	Mixed Ethnic background	Black background	South Asian background
Length of time to diagnosis	12 years & 3 months	10 years & 2 months	11 years & 8 months
Average time before seeing a GP	1 years & 9 months	2 years & 1 month	1 year & 8 months
Length of time from GP to Gynae	7 years & 9 months	6 years & 3 months	7 years & 9 months
Gynae to diagnosis	4 years & 11 months	4 years	3 years 11 months

than the UK-wide average. They also got to see a gynaecologist quickest, waiting 6 years and 3 months on average. This was despite waiting longer (2 years and 1 month) before having an initial conversation with their GP.

However, it's worth noting that Black respondents still waited twice as long (4 years) as the UK-wide average between seeing a gynaecologist and getting a diagnosis.

They were also the most likely to report that bias had an impact on their diagnosis. 72% of Black respondents felt that healthcare professionals had made assumptions about their symptoms and treatment plan based on their ethnicity, and 67% believed their ethnicity was a barrier to diagnosis.

This indicates that, even if Black patients have a shorter overall diagnosis journey than other those from ethnically diverse communities, they feel particularly poorly treated along the way - as the quotes on the previous pages demonstrate.

Those from a South Asian background were the quickest to initially seek help from their GP, but had among the longest wait (7 years and 9 months) from first seeing their GP to being seen by a gynaecologist. Their overall diagnosis time was 11 years and 8 months - more than two years longer than the UK-wide average.

South Asian respondents were less likely to report experiencing racial bias, with around half answering "yes" to our questions on racial bias. However, two thirds (66%) of South Asian respondents did not believe healthcare providers are culturally sensitive and responsive to the needs of endometriosis patients from ethnic minority backgrounds.

Conclusions & recommendations

We know that endometriosis does not discriminate. It affects one in ten women and those assigned female at birth, regardless of their ethnic backgrounds. Yet our findings show that there is discrimination and inequality in endometriosis diagnosis and accessing care. Patients from ethnically diverse communities wait longer to be diagnosed with endometriosis than the UK average, and many face racism, bias and insensitive treatment during their diagnosis journey.

Addressing these inequalities must be at the forefront as we continue working to drive down endometriosis diagnosis times across the UK. This report is just the start of the conversation about racial bias in endometriosis care; we urgently need funding and resources to continue this work and address the limitations of our existing research. With this in mind, we recommend the following actions:

1. **All UK Governments to commit to a target of an average of year or less for endometriosis diagnosis by 2030, including targets to end inequalities in outcomes.**

   Any policy work to reduce endometriosis diagnosis times must include clear targets to address the unequal waiting times faced by patients from ethnically diverse communities. This should include improving data collection, so that data on diagnosis times and outcomes is disaggregated by ethnicity. Co-production is essential to ensure ethnically diverse voices are heard, listened to, and inform decision making at Government and local NHS level.

2. **Increased investment and funding for research to ensure those from ethnically diverse communities are represented.**

   This must include adequate funding for outreach work, to build trust, awareness and engagement with underrepresented communities. Grassroots community campaigns should include culturally sensitive, multilingual information and resources, as well as peer support groups run by and for people from ethnically diverse backgrounds.

3. **Improved and appropriate messaging and communications on hormonal management options.**

   Prescribing hormones is a common way to try and manage endometriosis symptoms, to reduce pain and prevent its growth. Healthcare practitioners must be aware of the potential cultural stigma and taboo that may be associated contraception in some communities, and ensure patients, their caregivers and anyone involved in their care, are given the correct information about the different options available and why they are being offered. Developing hormonal treatments that are not primary purpose licensed as contraceptives, rather are designed and licensed specifically for endometriosis management, would be a way to support understanding and usage.

4. **Ensuring equitable access to services.**

   This should include equitable access to specialist endometriosis centres and improved specialist capacity. For patients referred into general gynaecology services, it should include equitable access to the most effective diagnostic pathways. Many respondents also highlighted the importance of signposting patients to relevant support services, and recognising the emotional toll of living with endometriosis.

5. **Ensuring the NHS workforce is equipped to understand and respect the needs of those from ethnic diverse communities and that services are set up to reflect these needs.**

   Cultural competency training should be mandatory, interactive and ongoing for all HCPs at all stages in their careers. Patients from ethnically diverse communities should feel fully supported to make complaints, and confident that this won’t negatively impact their future care. There should be clear pathways and accountability for HCPs when complaints are made against them.

A note on language

Language evolves, and so does the way we describe identity, power and community. Throughout this report the term ethnically diverse is used, as it was the most widely recognised term at the time the research design and survey questions were developed. As the report progressed, and as wider conversations around equity and representation have continued to develop, other terms such as those from ethnically diverse communities, marginalised communities, and ethnic minorities groups have also been used in discussion and analysis.

Increasingly, many organisations and advocates are moving towards the term Global Majority. This language reflects the reality that people who have historically been labelled as “minorities” in the UK and other Western contexts are, in fact, the majority of the world’s population. It is part of an effort to challenge deficit based framing and to recognise the richness, leadership and knowledge held within these communities.

While the term Global Majority better reflects the language many of us now use, it is not consistently reflected throughout the body of this report due to the timing of the research and the need to maintain consistency with survey wording and existing datasets. Going forward, we are committed to continuing to evolve our language in ways that centre dignity, challenge structural power imbalances, and position our communities with the respect and recognition they deserve.

We also recognise that language around gender continues to evolve in reproductive health conversations. Endometriosis primarily affects women and those assigned female at birth, but it also affects trans men and non binary people. Throughout this report we have tried, where possible, to use the term people to reflect this reality. Cysters and Endometriosis UK work with everyone affected by menstrual and reproductive health conditions, and our intention is never to erase or dismiss anyone’s existence. Instead, we aim to use language that recognises the diversity of those living with these conditions while remaining clear about the gendered inequalities that shape diagnosis and care.

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This report would not have been possible without the strength, honesty and generosity of the endometriosis community.

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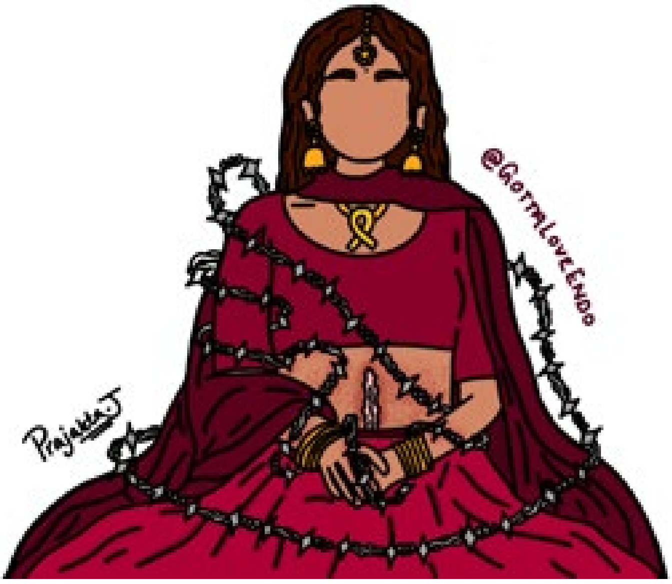
A special thank you to Prajakta Parimi, who volunteered her time and talent to create the artwork for this report. Her work powerfully captures the reality of living with endometriosis and the weight of the experiences shared throughout this research.



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