



THE STATE OF ENDOMETRIOSIS CARE IN THE UK:

**A ROADMAP FOR DRIVING
DOWN DIAGNOSIS TIMES AND
IMPROVING ACCESS TO CARE**

FOREWORD

FROM EMMA COX, CEO, ENDOMETRIOSIS UK:



Diagnosis times for endometriosis are getting worse. The average time it takes to get a diagnosis of endometriosis in the UK is now a truly unacceptable 9 years and 4 months on average, up from 8 years in 2020. For ethnically diverse communities diagnosis takes even longer, 11 years on average. These inequalities must not be ignored.

The report highlights that those with diagnosed endometriosis all too often have their symptoms and experiences ignored and dismissed. We would like to emphasise the additional barriers faced by ethnically diverse communities in accessing a diagnosis and care; without a commitment to tackling inequalities in care, the suffering of those from marginalised communities will remain overlooked. A special thank you to the team at Cysters, led by Neelam Heera-Shergill, who we are partnered with to highlight the experiences of ethnically diverse communities.

Without a diagnosis, treatment cannot be accessed, and the disease may progress. Endometriosis may have a significant, sometimes devastating impact on all aspects of life: education, career, relationships, sexual relationships, fertility and overall quality of life. This report explores the human cost of failing to invest in endometriosis care, as well as presenting a clear and robust economic case for investment, that put simply, Governments across the UK cannot afford to ignore.

We highlight a clear roadmap for how Governments can improve endometriosis care and reduce diagnosis times, reducing patient suffering and saving NHS resources. With a whopping £11bn a year being the estimated economic cost in the UK just for absenteeism due to severe period pain and heavy periods, alongside endometriosis, fibroids, and ovarian cysts, the economic argument is clear, and changes must not be put off any longer.

But there is hope. This report is being published at a time when there is significant opportunity for change, with Governments across the UK finally starting to shift priorities. The 10 Year Health Plan in England, the introduction and promise of Women's Health Plans in all 4 nations, and commitments to improve NHS workforce capacity and morale, are all positive steps in the right direction. But all these plans must now be matched with commitments, action, and change to improve endometriosis diagnosis and care for all.

For decades, we've heard the same, all too familiar stories of those with endometriosis or symptoms continuing to feel overlooked by healthcare systems that are failing to meet the demand of patients with menstrual health conditions. 2026 needs to be the year of change - change that ensures the next generation of those with endometriosis are not let down.

We urge anyone reading this report to do so with a view of wanting to see change. We hope you'll join Endometriosis UK in ensuring change happens.

Thank you to everyone who has completed our surveys and provided their personal stories. It's only through your generosity in sharing your experiences that we have been able to put together this report. We couldn't do it without you; thank you.

BACKGROUND TO THE SURVEY

This report is based on an online survey undertaken by Endometriosis UK in September – October 2025. We used the data from 3,075 respondents who had received a diagnosis of endometriosis from a healthcare practitioner in the UK since 2015; over 50% had received a diagnosis since 2023. Comparison data is from surveys undertaken in 2023, between March and August (Endometriosis UK, 2024) and January – February 2020 (APPG, 2020).

We partnered with the charity Cysters to identify the experiences of ethnically diverse communities. An online survey ran over summer 2025, and for this report 351 responses were used, of respondents had who had received a diagnosis of endometriosis from a healthcare practitioner in the UK since 2015.

Cysters and Endometriosis UK will be publishing a stand-alone report *Hidden in Pain: Endometriosis Diagnosis Inequalities in Ethnically Diverse Communities* in late March 2026, to shine a spotlight on the unacceptable inequalities in endometriosis diagnosis faced in the UK.

KEY FINDINGS

Diagnosis times for endometriosis in the UK are getting worse. Despite increased awareness and policy commitments, the UK average time to diagnosis has now risen to 9 years and 4 months, up from 8 years and 10 months in 2023, and 8 years in 2020. Further research in partnership with Cysters highlights that the average time to diagnosis rises to 11 years for ethnically diverse communities. This represents a sustained failure of the healthcare system to recognise and respond effectively to one of the most common chronic conditions affecting women and those assigned female at birth.

Endometriosis diagnosis times in the UK: Average time from first visit to GP with symptoms to diagnosis

	2025	2023	2020
UK (total)	9 years 4 months	8 years 10 months	8 years
England	9 years 4 months	8 years 10 months	8 years
Wales	9 years 11 months	9 years 11 months	9 years
Northern Ireland	9 Years 10 months	9 years 5 months	8 years 6 months
Scotland	10 years 2 months	8 years 10 months	8 years 6 months

Ethnically diverse communities, UK	11 years
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In addition to the average time whilst seeking help, respondents took on average 3.5 years from first noticing symptoms to seeking help from a healthcare practitioner. There has been no significant change in this length of time since 2020.

Whilst seeking medical help with symptoms, prior to diagnosis, 83% of respondents reported being told by a healthcare practitioner that they were “making a fuss about nothing”, that their symptoms were normal, or experiencing similar dismissal. This is an increase compared with previous surveys.

	2025	2023	2020
Told by a healthcare practitioner they are 'making a fuss about nothing' or receive similar comments, or the severity of their symptoms is not believed	82%	69%	75%

“ GP told me pain was normal for women. I was told it was all in my head. I was told I was too young to have health problems. I was told it was psychosomatic and there was nothing there. ”

(Diagnosed 2025)

“ I have had so many examples of this. From a young age I was told it was normal and I was overreacting. But the one that stands out the most was my first gynaecologist who didn't ask about the pain I experienced, and simply said to me “I assume you're here because you think you have endometriosis, whilst people are talking about it more which is great it's still a really rare disease. If you said your period cramps are bad I suspect this is just because you have bad periods, but because your periods are regular you can't have endometriosis. ”

(Diagnosed 2025)

“ I was repeatedly made to feel like I was making my symptoms up. I was made to feel like I was crazy. I still feel like no one believes or trusts me when I share my opinions in my personal relationships. Endo affected my relationship with my partner as we couldn't have sex at certain times of the month due to me being in pain, and I found that doctors only really took my pain seriously when I mentioned it having an impact on my male partner's life too. In fact they only really listened to me when I started bringing him along with me to appointments. ”

(Diagnosed 2025)

“ It has been awful. I have been made to feel crazy by so many doctors. I have felt alone and been left with no help. There isn't enough research into the condition and it needs to be taken seriously. ”

(Diagnosed 2025)

Over half (55%) of respondents had attended A&E due to their symptoms; 29% went three or more times. Yet when asked what happened when you went to A&E, with symptoms prior to diagnosis, 46% responded 'Nothing; I was told to go home'.

	2025	2023	2020
Visited A&E due to symptoms because of symptoms prior to diagnosis	55%	52%	50%
When asked what happened the first time you went to A&E, chose 'Nothing; I was told to go home'	50%	19%	No data
Attended A&E 3 or more times because of symptoms	29%	26%	

80% were prescribed hormonal contraception prior to any investigations; of those, 55% these received no discussion about possible causes for symptoms. This results in normalisation of symptoms, and no information – and in many cases no awareness at all – that their symptoms may be due to an underlying disease. Without this information, there can be no informed choice about care, management, and treatment.

	2025	2023	2020
Prescribed hormonal contraception for symptoms prior to any investigations	80%	78%	76%
Of which, received no discussion about possible causes for symptoms	55%	44%	40%

Asked to consider with hindsight - now they know the symptoms of endometriosis - when they first had symptoms, 65% felt their symptoms started when they were 17 or under, however only 35% sought medical help for them at the time. Endometriosis UK's previous research has demonstrated that the younger an individual seeks help for their symptoms, the more likely they are to have their symptoms dismissed, and it takes longer to get a diagnosis. We believe a key reason is the normalisation of severe period pain, the level of which is often not believed, combined with lack of knowledge in healthcare practitioners that endometriosis can occur from puberty.

“ As soon as my periods started, I was getting agonising pain. I'd skip school, burn my skin with hot water bottles and take pain killers far more frequently than I should have. At the age of 14 I was put on a pill to reduce the pain. Eventually this stopped working. I kept going back to doctors, hoping they'd take me seriously. It took me eventually moving to a new town, where I got a better GP who really listened to my concerns. ”

(Diagnosed 2025)

Endometriosis also impacts on mental health, the toll of having many years of having symptoms normalised, the severity not believed, and diagnosis delays, coming to terms with living with a chronic condition. 98% of respondents reporting endometriosis having an impact on their mental health; 63% said this was a significant impact.

“ The long diagnosis time made it really difficult to speak about my condition at work and to explain my chronic pain to friends/family/potential partner I felt really alone, the toll on my mental health was massive. ”

(Diagnosed 2025)

“ I am 21 years old and this year my mental health was genuinely so bad, the only way out I thought was suicide. I strongly believe something needs to be done! I do not want another young girl feeling this way. It is horrible! I can't put into words how sad this year has been for me, I've been made to feel like I was a liar. It's sad to say but if my mum hadn't have paid privately, I don't know if I'd have been able to live like this anymore. ”

(Diagnosed 2025)

Due to the long times to get a diagnosis, and for many having their pain and symptoms questioned along the way, on diagnosis the initial reaction is often one of relief.

“ Validated. There was something wrong with me all along but no one listened. Upset about poor 14 year old me struggling unnecessarily and no one listening to her. ”
(Diagnosed 2025)

“ I felt over the moon that I finally had a diagnosis so that teachers, other family members and just anyone would actually take me seriously now and know I’m not faking the pain, however also a bit defeated as there is no cure. ”
(Diagnosed 2025)

“ I feel a sense of relief, like it wasn’t all in my head. Frustrated I had to suffer for so many years. ”
(Diagnosed 2025)

“ Mixed emotions. Relieved to know I’m not mad but worried for the future because there’s a section they can’t remove. ”
(Diagnosed 2025)

These findings point to a system that continues to normalise endometriosis and symptoms, fails to provide timely investigation or support, and delays referrals to secondary and specialist care.

WHERE THE SYSTEM IS FAILING

The NICE Guideline on *Endometriosis: diagnosis and management* was first published in 2017, and the section on diagnosis updated in 2024. This sets a baseline for endometriosis care. The accompanying NICE Quality Standard on Endometriosis was published in 2018, and includes that all healthcare practitioners should be aware of endometriosis symptoms and suspect endometriosis if they are presented. But neither the Guideline nor Quality Standard have been implemented in any nation in the UK.

Implementing the NICE Guideline and Quality Standard would provide a baseline for care across the UK, and reduce the postcode lottery of access to high quality care there is at present. Updating the Guideline to take into account endometriosis outside the pelvis, pain management other than drugs, and recent developments in imaging is needed to raise standards across the board. It is vital that audit is put in place to ensure implementation takes place and progress can be monitored.

A significant driver of worsening diagnosis times seems to relate to delays in accessing secondary or tertiary care:

- Waiting times for gynaecology remain high, with one third (32%) of respondents waiting over a year after referral, and 9% waiting over 2 years.
- At the start of 2026, almost three-quarters of a million women are waiting for gynaecology care, with the Royal College of Obstetricians and Gynaecologists (RCOG) warning of widening inequalities (RCOG, 2026). Gynaecology is the largest speciality for those on waiting lists aged 18-64. (NHS England, 2025)
- Repeat appointments, repeat A&E attendances, and fragmented pathways are placing unnecessary burden on the NHS while prolonging patient suffering.

Although increased use of imaging has shortened diagnosis times once patients reach specialist care, access to that care remains the critical bottleneck, and accessing someone trained in gynaecological imaging is very much a postcode lottery.

It is disappointing to see the significant increase in the average diagnosis time in Scotland, at 10 years 2 months taking almost a year longer than in England (9 years 4 months). Significant and long waiting lists to access gynaecology and specialist endometriosis centres seem to be a major contributing factor.

We acknowledge the positive work that the Scottish Government have been doing over the last 3 years, including developing education and training resources for healthcare practitioners, publishing an Endometriosis Care Pathway for NHS Scotland, and improving endometriosis information on the NHS Inform Women's Health Platform. Crucially, the recent announcement of funding to tackle backlogs in gynaecology waiting times along with the published aim of reducing diagnosis times for endometriosis and menstrual health conditions, demonstrate commitment from the Scottish Government.

We now need to see this commitment turn into action. There must be a step change in access to care for those in Scotland with suspected or confirmed endometriosis in 2026, and evidence that diagnosis times are starting to fall.

“ I was lucky because my GP listened to me when I initially said I was having health issues but it still took about 8 months from my initial appointment with them for them to refer me to gynaecology. I was referred to NHS (Scotland) gynaecology in April 2024 at which point the average waiting time was around 67 weeks. It is now almost November 2025 and I am still waiting for an initial consultation with an NHS specialist and the average waiting time for NHS (Scotland) has increased to 114 weeks! ”

(Diagnosed 2024)

REASONS FOR HOPE

There are indications of improvements in primary care. Whilst it takes on average 10 appointments with symptoms before a GP mentions endometriosis, GPs mentioned they suspected endometriosis in their first two appointments for 14% of respondents, up from 10% in both 2023 and 2020. This small gain needs to be nurtured, not overwhelmed by systemic pressures elsewhere.

“ My new doctor was fantastic, she requested advice and guidance from gynae to support me in the meantime, she took me seriously, encouraged me to visit as regularly as needed, and expedited the referral due to psychological distress. ”

(Diagnosed 2025)

The recently announced NHS Online, a virtual hospital in England due to launch 2027, could be a step forward in prompt access to specialist support and triage to prompt local initial investigations. Menstrual health conditions, including endometriosis, will be one of the priority areas. NHS Online hospital will offer a virtual care option, using the NHS App to triage patients and provide fast access to specialist clinicians online. Where needed, specialists will be able to arrange any tests required locally.

Patients will continue to have the choice of face-to-face appointments, and anyone who needs physical examinations, investigations or procedures will still receive them in hospital or at local community hubs. However, adding a national online service could enable those with endometriosis and other menstrual health conditions to access specialist expertise much more quickly. This has the potential to support earlier diagnosis, speed up access to ongoing treatment and effective management, reduce unnecessary delays, and improve access to surgery where required – saving NHS resources whilst reducing patient suffering and potential disease progression currently experienced with long diagnosis and waiting times.

For NHS Online to succeed, it will need to be properly resourced and designed to deliver safe, effective care. This includes timely access to sufficient numbers of appropriately trained clinicians across the country, as well as access to high quality tests, such as having gynaecology-trained ultrasound sonographers in local Community Diagnostic Centres. Only with these foundations in place can the programme deliver on its ambition to reduce diagnosis times and improve the quality of care.

Endometriosis UK looks forward to working with NHS England as this service develops, to ensure NHS Online delivers meaningful and lasting improvements for everyone affected by menstrual health conditions, including endometriosis.

There are interesting developments in imaging, especially ultrasound, that if rolled out offers great potential for diagnosing especially deep endometriosis – although noting a ‘normal’ scan does not rule out endometriosis. This would also enable better diagnosis of adenomyosis, which may have similar symptoms. It is thought 30-40% of those with endometriosis also have adenomyosis, and both must be considered together to ensure the best management and treatment.

Dr Paula Cowan, Medical Director for Primary Care NHS England North West Region, describes developing a new care pathway for Endometriosis for their region, launched January 2026.

What initially started as a piece of work to address long surgical waiting times in secondary care for patients with severe Endometriosis, has developed and expanded to include primary care and Public Health.

In September 2023, we convened colleagues, both managerial and clinical from secondary care, to assess the long waiting times. This focused initially on surgical waits and the need for gynae and colorectal input and how this could be addressed.

Out of 2 Teams workshops came 3 workstreams: Clinical, Data and Workforce. The work of these groups led to discussion around referral pathways and soon expanded to include primary care with a real focus on patient pathways and the need for these to be streamlined.

Throughout all of our work we engaged with Endometriosis UK and have had patient representation, telling their stories and using their case studies to help focus us on the need for a much more joined up approach. The need to truly listen to

patients, understand their real issues and improve the pathway and time to referral and diagnosis. We have also used data and developed digital tools.

In March of 2024, we held a face to face workshop and since then have developed clinician and patient pathways, education support tools and delivered webinars on workforce and how this can play a key role in improving surgical wait times.

Our data has also helped us to recognise inequalities and focus on how we can ensure all our patients are receiving timely care and referral. We have worked with public health on ensuring that clinicians are aware of the links between Endometriosis and conditions such as CVD and Cancer and how active health promotion is weaved into our work.

We recognise the role of Women's hubs and community delivery of women's health in supporting these pathways and how we can continue to support patients with Endometriosis post secondary care discharge.

In summary, the work undertaken and what I am eager to continue is ensuring more support and focus on the following:

- 1.** Improve early consideration of and awareness of the diagnosis of Endometriosis in primary care
- 2.** Improve referral pathways, including use of diagnostics
- 3.** Listen to and recognise symptoms in patients, acknowledging the impact on physical, mental health, social settings, work and home life and also highlighting the need to address the health inequalities in this area.
- 4.** Understand the impact of Endometriosis and link to other conditions, highlighting awareness of link to CVD and Ovarian Cancer, and ensuring screening and prevention are highlighted.

THE COST OF INACTION

Delayed diagnosis may result in disease progression and harm to patients and places a significant burden on the wider economy and health system. Repeated GP appointments, avoidable A&E attendances, delayed treatment, and worsening health outcomes represent poor use of NHS resources.

More widely, menstrual health conditions, including endometriosis, result in an estimated £11 billion a year cost to the UK economy due to absenteeism (NHS Confederation, 2024). Failure to address diagnosis delays risks increasing economic inactivity, workplace disadvantage, and demand for welfare support.

Conversely, diagnosis makes a tangible difference: 79% of respondents reported an improvement in the quality of their care after receiving a diagnosis. For many, diagnosis also provides psychological validation after years of dismissal.

WHAT NEEDS TO CHANGE

Governments across the UK must treat endometriosis as a common, chronic condition that requires systematic action, not isolated initiatives (NCEPOD, 2024). This report sets out a clear and achievable ambition: to reduce average diagnosis time to one year or less by 2030.

To achieve this, Governments should focus on three strategic priorities:

1. Fix capacity and access

- a. Reduce gynaecology waiting times through targeted investment and workforce planning.
- b. Ensure endometriosis is prioritised in financial allocation and service planning.
- c. Improve data collection to match capacity to demand.

2. Move diagnosis closer to the community

- a. Expand access to investigation through Community Diagnostic Centres, Women's Health Hubs and other local models, with ultrasound by those trained and experienced in gynaecological ultrasound available to all.
- b. Ensure services are properly resourced, staffed, and integrated with specialist pathways.
- c. Reduce inequalities in diagnosis times and access to care, for example for ethnically diverse communities.

3. End dismissal and delay

- a. Mandate effective training in menstrual health, including endometriosis and adenomyosis, across medical and healthcare education and professional development.
- b. Fully implement and strengthen NICE guidance, including clearer referral pathways.
- c. Improve menstrual health education in schools and protections in the workplace.

CONCLUSION

The evidence is clear: diagnosis delays are not improving, and in many cases are getting worse. Without decisive action, patients will continue to experience avoidable harm, and the NHS and economy will continue to bear unnecessary costs.

The opportunity for change exists. What is now required is leadership, accountability, and delivery.

ENDOMETRIOSIS, AND ADENOMYOSIS

Endometriosis is a disease that affects 1 in 10 women and those assigned female at birth from puberty to menopause – although the impact may be felt for life. It is a chronic, long-term condition that can cause painful periods that interfere with everyday life, chronic pelvic pain, heavy menstrual bleeding, bowel and bladder problems, difficulty getting pregnant, and fatigue.

Symptoms vary person to person, from mild and manageable, to severe and debilitating

with permanent damage to organs. Without timely diagnosis, the disease may progress, leading to poorer health outcomes.

Despite its prevalence, there has been a historic lack of priority given to endometriosis diagnosis and care. The fact gynaecology waiting times went up by the highest percentage of any medical speciality over the pandemic and have remained high is a clear demonstration of the lack of priority given to endometriosis and menstrual health.

Many with endometriosis also have adenomyosis, which can have some similar symptoms. Due to a lack of research, it's not known how exactly how many have both diseases, however current estimates are up to 40% of those with endometriosis also have adenomyosis. 32% of respondents to our survey had been diagnosed with adenomyosis as well as endometriosis.

Adenomyosis must be considered along with endometriosis, to ensure the best management and treatment. If an individual has both diseases and only one is managed and treated, then symptoms may persist

REFERENCES

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APPG (2020) - [Endometriosis in the UK: time for change. APPG on endometriosis Inquiry Report 2020](#)

Endometriosis UK (2023) - [“Dismissed, ignored and belittled” The long road to endometriosis diagnosis in the UK March 2024](#)

NHS Confederations (2024) - [Women’s health economics: investing in the 51 per cent | NHS Confederation](#)

NCEPOD (2024) - [Endometriosis: A Long and Painful Road](#)

NICE (Published 2017, updated 2024) - NICE Guideline [Endometriosis: diagnosis and management](#)

NICE (Published 2018) - NICE Quality Standard [QS172](#)

RCOG (2026) - [New Year: still waiting for a way forward](#)

Cysters & Endometriosis UK report *Hidden in Pain: Endometriosis Diagnosis Inequalities in Ethnically Diverse Communities* will be published in March 2026.

Cysters is a grassroots charity committed to breaking down the systemic barriers that create menstrual, mental, maternal, and menopausal health inequalities.

ABOUT ENDOMETRIOSIS UK

Endometriosis UK are the UK’s leading charity for all those affected by endometriosis, determined to ensure that everyone gets prompt diagnosis and the best treatment and support. We fight to make change happen for everyone with endometriosis, to end chronic menstrual related pain being brushed off as normal and raise awareness of endometriosis with the wider public. We’re here to provide vital support services, reliable information and a community for those affected by endometriosis. For further information, visit: www.endometriosis-uk.org

 endometriosis-uk.org

 [endometriosis.uk](https://www.instagram.com/endometriosis.uk)

 [endometriosis.uk.org](https://www.facebook.com/endometriosis.uk.org)

 [endometriosis.uk](https://www.tiktok.com/@endometriosis.uk)

 [Endometriosis UK](https://www.linkedin.com/company/endometriosis-uk)



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