# “Dismissed, ignored and belittled”

## The long road to endometriosis diagnosis in the UK

March 2024

ENDOMETRIOSIS UK

# EXECUTIVE SUMMARY

Endometriosis is a disease that affects the physical and mental health of 10 % of women and those assigned female at birth from puberty to menopause – although the impact may be felt for life. That's over 1.5 million people in the UK, and nearly 200 million globally. It costs the UK economy around £8.2 billion every year in healthcare costs, loss of work and treatments[1].

Endometriosis may have a significant, sometimes devastating impact on all aspects of life: education, career, relationships, sexual relationships, fertility and quality of life. Despite this, it is a disease that the majority of people have never heard of. Without awareness, pain and symptoms can be dismissed, and brushed aside as 'normal' when they are anything but. Without a diagnosis, treatment can't be accessed, and the disease may progress.

# BACKGROUND TO THE SURVEY

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. We used data from 4,371 participants who had previously received a diagnosis from a healthcare practitioner in the UK. Comparator data comes from a similar survey undertaken in 2020 just before the Covid pandemic, and the All Party Parliamentary Group (APPG) on Endometriosis report with data from April 2020 and published in October 2020.[2]

***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.***

## KEY FINDINGS

Our survey shows that diagnosis times in the United Kingdom (UK) have got worse over the last 3 years, increasing to an average of 8 years and 10 months, up from 8 years in 2020.[3]
Diagnosis times have increased across all four nations of the UK.

**Average length of time to diagnosis across the UK**

| | 2023 | 2020 |
|---|---|---|
| UK | 8 years 10 months | 8 years |
| England | 8 years 10 months | 8 years |
| Scotland | 8 years 10 months | 8 years 6 months |
| Northern Ireland | 9 years 5 months | 8 years 6 months |
| Wales | 9 years 11 months | 9 years |

Between March and August 2023, we gathered data from 5,500 people. For this report, we selected those who stated they were diagnosed by a medical practitioner in the UK, a total of 4,371. Of these, 72% were diagnosed surgically by laparoscopy (keyhole surgery), and 18% by scan such as an MRI or ultrasound. Of those not diagnosed by surgery, 61% had since had a laparoscopy to treat endometriosis. The survey asked respondents details of their diagnosis journey, including the number of times they had contact with the health system and their experiences of interacting with healthcare practitioners prior to receiving a diagnosis.

## THE DIAGNOSIS EXPERIENCE

Responses to the survey showed that the route to a diagnosis is often circuitous, tortuous and lengthy, with the majority repeatedly seeking help from various parts of the health system over many years:

- 74 % had attended 5 or more GP appointments with symptoms prior to diagnosis.
- Almost half of all respondents - 47% - had visited their GP 10 or more times with symptoms prior to diagnosis.
- With symptoms and before a diagnosis, 52% had visited A&E at least once, with 26% visiting A&E 3 or more times with symptoms.
- 20% reported seeing a gynaecologist 10 or more times before being diagnosed.

Worryingly, 78% of our respondents who later went on to receive a diagnosis of endometriosis had experienced one or more doctor telling them they were making a ‘fuss about nothing’ or similar comments and many had the severity of their symptoms questioned by healthcare practitioners. The number of people reporting this experience has increased from 69% in our 2020 survey.

The survey showed that prompt diagnosis does and can happen in some cases. Where symptoms were recognised and considered in a timely way, we heard of cases where a diagnosis was secured in under a year. 10% of respondents reported that GPs mentioned they suspected endometriosis at either their first or second appointment where symptoms were discussed. Prompt recognition of symptoms and support to get a diagnosis should be the norm, not the exception.

## WHY DO WE NEED TO REDUCE DIAGNOSIS TIMES?

With a diagnosis, informed choices can be made about treatment and management. Getting access to the right treatments and support at the right time, from skilled and experienced healthcare practitioners, gives the best chance for endometriosis to be managed effectively. But access to treatment and support cannot be secured without first gaining a diagnosis. No diagnosis means no access to treatment or management of the condition, meaning that the disease may progress, risking permanent damage to internal organs and worsening physical symptoms and mental health impacts.

More timely diagnosis also has the potential to bring significant benefits to the wider health system. Streamlining the diagnosis process would reduce wasted appointments with GPs, in hospitals and in Accident and Emergency departments - resources that could be more usefully deployed elsewhere, such as in reducing waiting times for gynaecology services and providing treatment.

## WHY ARE DIAGNOSIS TIMES LONG, AND INCREASING?

The rise in diagnosis times can be attributed to several causes:

The Covid pandemic had a significant impact and effect on the NHS, and this could partly explain the increase in diagnosis times. However, it is important to recognise that gynaecology waiting times increased by the highest percentage of any speciality during the pandemic.[4] This points to the fact that menstrual and gynaecological health is not being viewed as a priority by decision makers, who subsequently fail to devote the level of resource needed.

The survey results show a demonstrable lack of awareness of endometriosis and its symptoms by healthcare practitioners, along with a lack of understanding – or sometimes belief – in its impact. This means that those seeking help for their endometriosis symptoms can have their concerns dismissed or diminished, making timely diagnosis far less likely.

The survey showed that respondents waited an average time of 3 years and 9 months before first seeking help from a GP for their endometriosis symptoms. There are low levels of awareness about endometriosis and the main symptoms, meaning people are unlikely to suspect that they have the condition or to push healthcare practitioners for a timely diagnosis.

To add to this, societal and cultural dismissal of period pain as ‘normal’ or not serious can result in those with symptoms not seeking medical help, especially when they know the NHS is under pressure.

# CONCLUSION AND RECOMMENDATIONS

Now is the time to reverse the trend and take real steps forward in driving down diagnosis times for endometriosis. To shorten the diagnosis time and improve the general experience of being investigated and diagnosed with endometriosis, we are calling for action in the following areas:

The time it takes to secure a diagnosis of endometriosis in the UK is too long and is getting worse. The impact on people living with the symptoms of endometriosis is profound:

- The four Governments of the UK should commit to a target of an average diagnosis time for endometriosis of 1 year or less by 2030.

We recognise that Governments across the UK are working to improve women’s health, including endometriosis, through the publication of specific strategies:

- We call on the Governments of the UK to allocate sufficient and ring-fenced funding to ensure they can fulfil the ambitions contained within their plans.

The current waiting times to access gynaecology services are driving up diagnosis times:

- NHS commissioners and providers across the UK must recognise the impact endometriosis can have and plan capacity to provide the care needed to diagnose and treat the disease; give due priority to endometriosis as they do with other conditions with similar impacts; and drive down gynaecology waiting times.

Securing a diagnosis is an important step. However, once diagnosed, people with endometriosis need better access to quality care and management:

- All UK Governments and NHS commissioners and providers should recognise the scale of endometriosis as a common and chronic disease and provide sufficient resources to manage the disease accordingly, including over the long-term.
- The NHS in each nation should develop a centralised pathway of care for thoracic endometriosis. NICE should include endometriosis outside the pelvis in its guideline on endometriosis.
- The NHS in all four nations should recognise the needs of adolescents and teenagers, and start providing paediatric gynaecology services to ensure they can access appropriate support, diagnosis and treatment.

Low levels of public awareness of endometriosis as well as societal and cultural dismissal of menstrual pain means people often experience symptoms for years without seeking a diagnosis from healthcare practitioners:

- Governments across the UK should invest in public health education campaigns focused upon recognising common endometriosis symptoms, to empower those experiencing symptoms to go to their GP and ask, ‘could this be endometriosis?’

The survey highlights the need for effective and age-appropriate menstrual health education in schools to promote better awareness and timely diagnosis of endometriosis and other menstrual health conditions for young people. In England, menstrual wellbeing has been included in the school curriculum, however this is yet to be fully implemented. The Scottish Government has committed to providing education in schools and learning about menstrual well-being and conditions which can affect the reproductive system is mandatory within the curriculum for Wales framework. No commitment currently exists in Northern Ireland:

- Governments across the UK should fully implement commitments on compulsory menstrual wellbeing education in all schools for all pupils.

The survey makes clear the need for healthcare practitioners to understand and consider the signs of endometriosis; and to not dismiss pelvic and period pain that interferes with everyday life as 'normal':

- Menstrual health and endometriosis education should be included in all curriculums for healthcare practitioners, so they receive this training as students.
- Royal Colleges and relevant professional bodies should improve the provision of education on endometriosis and menstrual health as part of specialist and ongoing training, with a particular focus on GPs, Gynaecologists, nurses, A&E practitioners and community pharmacists.

The NICE Guideline on Endometriosis was issued in 2017 and has been adopted in all four nations of the UK. The Quality Standard[5] accompanying the guideline, published in 2018, states that healthcare practitioners should know and consider the symptoms of endometriosis and follow the diagnostic pathway set out. A partial review of the NICE Guideline is being undertaken in 2024, including a new section on diagnosis:

- NHS commissioners and providers must fully implement the NICE Guideline on Endometriosis: diagnosis and management.
- Governments and health leaders across the UK must take steps to ensure a full and thorough implementation of the NICE guideline, including an assessment of key barriers to implementation. We recognise the Scottish Government has already commissioned Endometriosis UK to undertake research to understand the provision of, and barriers to, care for endometriosis.[7]
- We urge NICE to undertake a full review of the Guideline on Endometriosis, including identifying and rectifying omissions such as non-pharmacological pain management, mental health, and endometriosis outside the pelvis. The partial review of the guideline currently being undertaken should take into account best practice and new developments around imaging, including ultrasound and MRI for diagnosis.

Developments in scanning and imaging technology, as well as the development of non-invasive tests, have the potential to make a difference to diagnosing endometriosis and a range of other menstrual health and gynaecological conditions:

- We call on the Government in England to plan, fund and implement more widespread access to gynaecological imaging including within the proposed new Women's Health Hubs and Rapid Diagnostic Centres. We call on Governments in Scotland, Wales and Northern Ireland to identify and deliver an accessible and effective gynaecological imaging service.
- Professional bodies should improve and implement training in gynaecological imaging for sonographers, radiologists, radiographers and other relevant medical practitioners.

Research into endometriosis is vital to advancing our understanding of the disease, including its causes, potential treatments and for developing less invasive diagnostic methods. But very little research exists:

- Governments in the UK should commit to funding research into new treatments and effective management of endometriosis as part of their investment into women's health.

## WHAT IS ENDOMETRIOSIS?

Endometriosis is a disease where cells similar to those in the lining of the womb grow elsewhere in the body. Each month these cells react to the monthly menstrual cycle in the same way as those in the womb lining, building up and then breaking down and bleeding. Unlike the cells in the womb that leave the body as a period, this blood has no way to escape. This can cause inflammation, pain and the formation of scar tissue.

Endometriosis affects 1 in 10 women and those assigned female at birth regardless of ethnicity, from puberty to menopause - although the impact may be felt for life. That’s over 1.5 million in the UK, and almost 200 million globally. It costs the UK economy £8.2 billion every year in healthcare costs, loss of work and treatments[8].

Some with endometriosis may have no or mild symptoms, whilst at the other end of the spectrum, symptoms can be severe and debilitating. Symptoms vary for each individual depending on where their endometriosis is, with severe, chronic pelvic pain being the most common symptom. Symptoms include:

- chronic pelvic pain
- painful periods
- painful bowel movements
- pain when urinating
- painful sex
- difficulty getting pregnant
- fatigue

Many with endometriosis also experience heavy menstrual bleeding.

Living with endometriosis can have a significant impact on mental as well as physical health. 95% of those living with endometriosis report that the condition has a negative impact on their wellbeing.[9] Severe and sometimes debilitating pain, not being able to undertake day-to-day activities including attending work or education, whilst being told that it’s ‘normal’ or ‘you’ve a low pain threshold’ or even not being believed can have a serious detrimental impact on self-esteem and mental health.

There are several different classifications of endometriosis used over the years and across the globe. Currently, organisations in the UK such as the British Society for Gynaecological Endoscopy (BSGE), the Royal College of Obstetricians and Gynaecologists (RCOG), the National Institute for Health and Care Excellence (NICE), and academic researchers commonly refer to the following categories of endometriosis:

- Deep endometriosis - where endometriosis is found 5mm or more below the tissue surface, for example affecting the bowel or bladder. The term ‘recto-vaginal endometriosis’ may be used to describe deep endometriosis which involves the rectum and vaginal area (recto-vaginal septum, vagina, utero-sacral ligaments, rectum).

- Peritoneal endometriosis - where endometriosis develops on the surface of the lining of the abdominal cavity, which is called the peritoneum. Sometimes referred to as ‘superficial endometriosis’ with superficial meaning ‘on the surface’.
- Endometriomas – where cysts form on the ovaries due to endometriosis.

Whilst historically called ‘a gynaecological disease’, endometriosis is sometimes found outside of the pelvic cavity. The most common sites for endometriosis outside the pelvic cavity are on the diaphragm and in the chest (thoracic cavity), referred to as thoracic endometriosis. Limited research means little is known about the frequency of thoracic endometriosis, however it could impact on up to 12% of those with pelvic disease[10]. The condition rarely occurs without pelvic disease.

The severity of symptoms does not relate to the type or amount of endometriosis. The location, and whether endometriosis is impacting on organs and nerves determines the type of symptoms experienced.

## WHAT IS ADENOMYOSIS?

Adenomyosis is a condition where the lining of the womb (uterus) starts growing into the muscle in the wall of the womb. This tissue responds to the hormonal changes in the menstrual cycle and thickens, breaks down and bleeds. Adenomyosis affects approximately 1 in 10 women and those assigned female at birth. Symptoms can include:

- painful periods
- heavy bleeding during your period
- pelvic pain (pain in the lower part of your tummy)
- bloating, heaviness or fullness in your tummy (abdomen)
- pain during sex

Some people with adenomyosis have no symptoms.

There are similarities between the definition and symptoms of endometriosis and adenomyosis. In fact, the International Classification of Diseases produced by the World Health Organisation includes the index terms ‘endometriosis interna’ and ‘endometriosis of uterus’[11].

Management options for adenomyosis symptoms include hormones and non-steroidal anti-inflammatory drugs (NSAIDs), which may also be used for endometriosis. Whilst it is considered common for individuals to have both endometriosis and adenomyosis, unfortunately due to a lack of research we do not know the percentage that have both endometriosis and adenomyosis.

## THE VALUE OF DIAGNOSIS

For people living with endometriosis, securing a diagnosis of their condition is vitally important. With a diagnosis, informed choices can be made about treatment and management and in many cases, symptoms can be relieved. Getting access to the right treatments and support, at the right time and in the right place with access to skilled and experienced healthcare practitioners, gives the best chance for endometriosis to be managed effectively. Reducing diagnosis times would bring enormous benefits to those living with endometriosis, saving many years of suffering and distress whilst undiagnosed. Without a diagnosis, the disease may progress, risking permanent damage to internal organs and worsening physical symptoms and mental health impacts.

More timely diagnosis also has the potential to bring significant benefits to the wider health system. Streamlining the diagnosis process would reduce wasted appointments with GPs, in hospitals and in Accident and Emergency departments - resources that could be more usefully deployed elsewhere, such as in reducing waiting times for gynaecology services and providing treatment.

Despite this, for many people, the journey towards a diagnosis of endometriosis is far too long.

## WHAT SHOULD THE DIAGNOSIS PATHWAY LOOK LIKE?

According to the NICE guideline, when women first present to a healthcare practitioner with 1 or more of:

- chronic pelvic pain
- period-related pain (dysmenorrhoea) affecting daily activities and quality of life
- deep pain during or after sexual intercourse
- period-related or cyclical gastrointestinal symptoms, in particular, painful bowel movements
- period-related or cyclical urinary symptoms, in particular, blood in the urine or pain passing urine
- infertility in association with 1 or more of the above,

then some initial symptoms management should be offered. Options include:

- a short trial (for example, 3 months) of paracetamol or a non-steroidal anti-inflammatory drug (NSAID) alone or in combination
- hormonal treatment (combined contraceptive pill or a progestogen)

If the trial of paracetamol or NSAID does not provide adequate pain relief, and/or the initial hormonal treatment for endometriosis is not effective, health practitioners should then consider referral to gynaecology, paediatric & adolescent gynaecology, or a specialist endometriosis service for further investigations.

If fertility is a priority for the individual, then the management of endometriosis should have multidisciplinary team involvement with input from a fertility specialist.

# BACKGROUND TO THE SURVEY

Back in Spring 2020,[13] Endometriosis UK conducted research to establish how long it takes to secure a diagnosis of endometriosis and found an average time of eight years. To gain a more up-to-date understanding of diagnosis times, and to better understand the experiences of people seeking a diagnosis in the UK.

Between March and August 2023, we gathered data from 5,500 people. For this report, we selected those who stated they were diagnosed by a medical practitioner in the UK, a total of 4,371. Of these, 72% were diagnosed surgically by laparoscopy (keyhole surgery), and 18% by scan such as an MRI or ultrasound. Of those not diagnosed by surgery, 61% had since had a laparoscopy to treat endometriosis. The survey asked respondents details of their diagnosis journey, including the number of times they had contact with the health system and their experiences of interacting with healthcare practitioners prior to receiving a diagnosis.

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# LIMITATIONS IN THE DATA

Our 2023 survey responses were proportionate to the population in each nation, but it should be noted that the number of responses for Northern Ireland and Wales were not statistically significant, see the methodology section for more information.

Whilst the ethnicity of respondents who identified as ‘white’ was proportionate to the ethnicity data collected in the Census 2021, the remaining data was not illustrative of the ethnic diversity of the UK, with 11% of respondents choosing to not respond to the ethnicity question. We acknowledge that regretfully this means this data does not represent experiences of diagnosis of those from marginalised ethnic groups.[14]

# THE DIAGNOSIS JOURNEY THROUGH THE HEALTH SYSTEM

## EXPERIENCES OF PRIMARY CARE

For most people who are experiencing the symptoms of endometriosis, including 97% of respondents to our survey, their first point of call is their General Practitioner (GP). The survey showed that when looking back at their diagnosis journey and considering when they first had what they now know were symptoms of endometriosis, respondents waited an average of 3 years and 9 months before first seeking help from a GP.

From first going to a GP with symptoms, to receiving a diagnosis of endometriosis, the average time in the UK was 8 years and 10 months. Prior to receiving a diagnosis, people living with symptoms commonly reported multiple visits to see their GPs. The top 3 symptoms for the first visit to a GP were:

- Period-related pain affecting daily activities and quality of life.
- Pelvic pain.
- Heavy menstrual bleeding.

The first two of these are recognised as the most common symptoms of endometriosis, with heavy menstrual bleeding known to be experienced by many with endometriosis. Despite presenting with common symptoms, GPs mentioned they suspected endometriosis in only 10% of first or second appointments.

Worryingly, 74% of respondents shared that they had attended 5 or more GP appointments before endometriosis was even suspected. 47% of respondents had attended 10 GP appointments before endometriosis was identified as a potential cause of their symptoms.

One respondent told us:

> *“The whole process was horrendous. I suffered 18 years’ worth of GP appointments telling me to keep period logs. I begged for further investigations and was ignored until my first female GP who then referred me to a gynaecologist at a hospital” (diagnosed in 2022).*

Before any investigations for endometriosis took place, 84% of survey respondents were prescribed hormonal medications such as the contraceptive pill, coil or contraceptive implants, to manage their period pain or period problems. In 51% of these cases hormonal medication was prescribed without any discussion into the possible causes of pain or period problems. In 29% of these cases there was some discussion about the possible causes of pelvic pain, although endometriosis was not mentioned. Endometriosis as a possible cause of people’s symptoms was only discussed in 11% of cases where hormonal medication had been prescribed.

## DISMISSED AND NOT BELIEVED

Whilst seeking help with symptoms, 78% of respondents stated that they had been told by a doctor they were ‘making a fuss about nothing’ or similar comments, or that the severity of their symptoms was not believed. This has increased from 69% since the survey was last carried out in 2020.

Feedback on their experiences indicates a lack of knowledge or understanding of endometriosis and its symptoms by healthcare practitioners. Our assumption from the data is that 51% of those with symptoms who were later diagnosed as having endometriosis, had their symptoms normalised by their GP. As part of this, 63% of those surveyed were sent away and recommended over-the-counter painkillers when they discussed their symptoms. People told us:

> *“I was constantly dismissed, ignored and belittled by medical professionals telling me that my symptoms were simply due to stress and tiredness. I persevered for over 10 years desperate for help” (diagnosed in 2023).*

> *“I am a transgender man. A male GP told me that the stress I experienced from having periods (due to my gender dysphoria) was exacerbating what would otherwise be normal period pains” (diagnosed in 2019).*

## EXPERIENCES OF SECONDARY CARE

Where people are suspected as having endometriosis, GPs should consider whether a referral to a gynaecologist is needed for further investigations. The survey showed that where a successful referral to a gynaecologist is secured, this does not always lead to a diagnosis of endometriosis. 20% of those surveyed reported seeing a gynaecologist 10 or more times before being diagnosed. One respondent told us;

> *“The first gynaecologist I was referred to was exceptionally dismissive - he denied my experience and told me I was ‘probably not in that much pain’ and ‘just having normal periods” (diagnosed in 2022).*

Prior to receiving a diagnosis, just over half of survey respondents (52%) had presented at an Accident and Emergency (A&E) department after experiencing severe symptoms. Shockingly, 26% of survey respondents had visited A&E 3 or more times.

We asked people who had attended A&E to describe what happened to them on their first visit (multiple options could be selected):
- 25% were prescribed painkillers
- 19% were told to go home
- 19% were told to buy over-the-counter pain killers
- 18% were investigated for things other than endometriosis
- 17% were seen by a gynaecologist or referred to one
- 12% were admitted to hospital
- 4% had emergency surgery

Only 2% of those presenting at A&E with symptoms were investigated for endometriosis.

We heard:

> *“An A&E Doctor told me I was anxious and when I suggested endometriosis as a cause for my severe pain and bowel issues, he told me ‘endometriosis only affects the reproductive organs” (diagnosed in 2021).*

> *“A&E nurses told me that everyone has period pain so take paracetamol and go home” (diagnosed in 2023).*

## NEW RESEARCH FOR 2024

**NCEPOD study**

Endometriosis is currently the subject of an in-depth review by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD), an organisation whose work programmes aim to support healthcare professionals to improve the quality of care provided to future patients.

The NCEPOD study will include a multidisciplinary review of endometriosis care from initial presentation in primary care through referral to gynaecology, laparoscopic diagnosis, follow-up appointments and re-admissions following initial surgery. Online, anonymous surveys will be used to collect the views of patients with endometriosis and clinicians who treat them. In addition, an organisational questionnaire will examine the structure of the service.

This comprehensive national review will provide an in-depth picture of the care provided to patients with endometriosis when it is published in July 2024. It is likely to echo the themes highlighted in this report, as well as highlighting the clinical and organisational improvements that are needed in the service.

**NHS Confederation**

The NHS Confederation is currently undertaking a women's health economics analysis, with a preliminary focus on obstetrics and gynaecology services. The purpose of the work is to show the economic benefits of investing in women's health.

The analysis will be comprised of three key components: 1) a state of play for women's health inequalities throughout the country; 2) a return on investment (ROI) model for additional public investment in obstetrics and gynaecology services; and 3) an analysis of select areas such as primary and secondary dysmenorrhea, the menopause, infertility, and pregnancy loss on the wider economy.

This report intends to quantify the intrinsic links between investment in women's health and wider economic growth to make the case to government that women's health, the NHS, and the wider economy cannot continue to be viewed as separate concerns.

**Office for National Statistics (ONS)**

The ONS is undertaking an evaluation to investigate the impact of endometriosis on women's participation in the workforce. Working in partnership with Leicester University, Exeter University and the Department for Health and Social Care, the ONS will use datasets which cover the majority of the working-age population of England to determine:

- Does diagnosis and treatment of endometriosis impact labour market outcomes, including being in employment and net pay?
- How long are women waiting from first presentation in primary care to receiving an endometriosis diagnosis in hospital?
- Which groups of women are most likely to be disproportionally affected by endometriosis?

The work will be delivered throughout 2024 and will result in a series of ONS publications, academic articles and policy briefings.

# ENDOMETRIOSIS AND FERTILITY

Whilst many with endometriosis will be able to get pregnant naturally, endometriosis is one of the leading causes of infertility in women and those assigned female at birth in the UK. For many with a diagnosis of endometriosis, fertility and fertility preservation is a significant concern. For some, a diagnosis of endometriosis comes as a result of investigations following fertility issues. For others, the lack of a timely diagnosis of endometriosis means they can lose the opportunity to consider the potential impact on fertility and to take steps towards fertility preservation.

People told us:

> *“I visited the GP multiple times as a teenager with debilitating period pain and was put on a number of different painkiller medications, followed by the pill. I only got referred to a gynaecologist in my 30s after struggling to conceive, which was when endometriosis was first mentioned and I had a subsequent diagnosis” (diagnosed in 2022).*
>
> *“Before being diagnosed I went through multiple rounds of IVF which was never going to work. I was told due to high levels of CA125 I probably had cancer. The whole experience has been years of ongoing mental and physical damage that could of been avoided” (diagnosed 2022).*

In some cases, endometriosis can result in painful sex. Through the survey we heard that painful sex is a symptom of endometriosis that is often minimised by healthcare practitioners, despite its potential impact on relationships and, should someone want to conceive, pregnancy outcomes.

We heard:

> *“When discussing that the severity of pain during intercourse has meant that my partner and I have been unable to have sex, which has caused serious ramifications on our relationship, I was told that if it is such a problem I should just tolerate it and have sex.” (diagnosed in 2020).*
>
> *“A GP told me, ‘If you want children you’re going to have to deal with what’s normal for a woman, it seems you’re overreacting.’” (diagnosed in 2020).*

# EXPERIENCES OF ADOLESCENTS AND TEENAGERS

For some, endometriosis symptoms can start from puberty, yet we heard of many cases where adolescents and teenagers had their pain and symptoms normalised and dismissed. Of our survey respondents, 31% were 16 or under when they first considered whether symptoms they were experiencing could be due to a medical condition rather than just being ‘normal’. When asked to look back with the understanding of endometriosis they have now, this figure increased to 56%. People told us:

> *“When I first went to the GP as a teenager, I was told I was being dramatic and would get used to the period pain I was having” (diagnosed in 2023).*
>
> *“I was told all pain was in my head, I was too young to know what I was talking about, pain is normal despite it making me faint and nauseous and miss school” (diagnosed in 2022).*
>
> *“I was told when in my teens and early 20s that period pain was normal. I tried explaining that this amount of pain was more than what is considered normal but it didn’t really get anywhere” (diagnosed in 2022).*

Being 'too young' to have endometriosis is a myth that must be overcome. The impact of lost education and academic attainment can have a lifelong impact on career and prospects. The psychological effect of being told your pain is not real, or not believed, can be significant:

> *"My earliest memory of this is when I went to the GP with my mum at 12 years old due to the horrible pain. He told us that the only treatment was birth control, but I was too young and that it was known to have negative effects, including on fertility. The issue was, that he offered no other solutions, did no tests, did no referrals. And the way he said this information scared the living daylights out of my mother and I remember leaving feeling like I wasn't understood, because I had no answers; but I didn't know how to put it in words yet. The next time I was able to go to the GP about this, on my own, was when I was 16. I was diagnosed in 2021 (age 19) when I had the fortune to go the private route" (diagnosed in 2021).*

## POSITIVE EXPERIENCES

Our survey showed that prompt diagnosis does and can happen in some cases. Where symptoms were recognised and considered in a timely way, we heard of cases where diagnosis was secured in under a year. 10% of respondents reported that GPs mentioned they suspected endometriosis at either their first or second appointment where symptoms were discussed. Prompt diagnosis such as this should be the norm, not the exception.

We heard examples of good practice and the positive steps being taken by some medical practitioners to provide high quality support, as well as to signpost individuals towards the information they need:

> *"My GP was very good and explained [endometriosis] and pointed me towards further info." (diagnosed in 2019).*
>
> *"…On my 1st visit to the gynaecologist he said he believed I had deep infiltrating endometriosis and told me to look at "Endometriosis UK" and see if I could relate to it… He wrote it down for me…" (diagnosed in 2022).*
>
> *"I have a specialist team now who sent me to the Endometriosis UK website. Gave me lots of helpful leaflets and one of the nurses also suffers so she pointed me towards a local online support group" (diagnosed in 2021).*

## ENDOMETRIOSIS OUTSIDE THE PELVIS

Endometriosis is most commonly found in the pelvic cavity and has generally been classified medically as a gynaecological condition. But it is important to acknowledge that endometriosis can also be found elsewhere in the body. Limited information is known due to lack of awareness, recognition and research, however it's thought up to 12% of those with pelvic disease could also have endometriosis outside the pelvis – which would be around 180,000. The most common type of extra-pelvic endometriosis is thoracic endometriosis, where endometriosis is on the diaphragm, or in the chest or lungs.

At the request of Endometriosis UK and patients, the BSGE and RCOG undertook research to identify the condition and made a series of recommendations for decision makers. It found that there is a lack of standardised treatments, geographical inequity in accessing care, and a lack of coordinated care nationally.

# DISCUSSION: WHAT ARE THE BARRIERS TO TIMELY DIAGNOSIS?

## THE CHALLENGE OF DIAGNOSIS

It's often said by healthcare practitioners that endometriosis is complex to diagnose. There is currently no blood or urine test, and it does not always show up on scans. Symptoms overlap with other conditions, such as Pelvic Inflammatory Disease, fibroids, Irritable Bowel Syndrome and interstitial cystitis and a diagnosis of endometriosis can require ruling these out, whilst determining if any conditions are concurrent.

A reliable biomarker test, such as a blood or urine test, to diagnose endometriosis is much needed and would make a significant difference. However, we refute the premise that endometriosis is always complex to diagnose, for many of those with endometriosis present with classic symptoms. If the symptoms were known and recognised, and those presenting believed, endometriosis should be considered at an early stage. Our research clearly demonstrates that symptoms are often just not recognised by healthcare practitioners, their severity and impact may not be believed, and may be normalised.

The National Institute for Health and Care Excellence (NICE) published the guideline *Endometriosis; diagnosis and management in 2017*.[16] This states that healthcare practitioners should, "suspect endometriosis when people are presenting with one or more of the following symptoms or signs:

- Chronic pelvic pain.
- Period related pain.
- Deep pain during or after sexual intercourse.
- Period-related or cyclical gastrointestinal symptoms, in particular, painful bowel movements.
- Period-related or cyclical urinary symptoms, in particular, blood in the urine or pain passing urine.
- Infertility in association with 1 or more of the above."

The guideline is clear that all healthcare practitioners should know and consider the symptoms of endometriosis. Implementing this basic guidance, issued over 6 years ago, would have made a significant difference in driving down diagnosis times.

## AN OPPORTUNITY FOR IMPROVED DIAGNOSIS: IMAGING

Gynaecological imaging techniques have developed in recent years, especially around ultrasound. Endometriomas – cysts on the ovary caused by endometriosis – should be able to be seen by ultrasound. However, with recent developments in imaging, healthcare practitioners with the right training, skills, experience and equipment, are able to identify some types of endometrioses, along with some presentations of adenomyosis, through an ultrasound or sometimes MRI. At present, the right equipment and the medical professionals with the right skills and experience, are only available at a limited number of specialist endometriosis centres. This means there is often a postcode lottery of diagnosis. As well as providing an earlier presumptive diagnosis of endometriosis, a great benefit of improved imaging, would be to enable surgeons to plan operations more effectively.

## COVID AND WAITING LISTS

Due to current waiting times within the NHS, many patients are having to wait for an extended period of time for gynaecology services, including diagnosis surgery. In parts of the UK this is 2+ years. This can further delay access to potential treatment and symptom management. The RCOG's 2021 report 'Left too Long'[17] considered the scale and impact of gynaecological waiting times and reported that gynaecology waiting lists across the UK had reached a combined figure of over 570,000 – just over a 60% increase on pre-pandemic levels. It also noted gynaecology waiting lists in England grew the most in percentage terms of all elective specialities. At the time of this report's publication, gynaecology waiting lists in England alone stood at over 600,000.

Once a diagnosis is received, many expect that their long wait to put a name to their symptoms will unlock treatments and give them access to high quality care. Disappointingly, even with a diagnosis, it is important to acknowledge that the pathway to accessing treatment and management can also present many challenges, due to the delays and shortages experienced within the health system.

## THE POLICY LANDSCAPE IN 2024

Governments across the UK have outlined their priorities for diagnosis of endometriosis.

Scotland launched its Women's Health Plan in 2021. Its aim is to reduce health inequalities and it identifies six priority areas including menstrual health, menopause and Endometriosis. The plan includes a commitment to reducing endometriosis diagnosis times, improving care pathways, and implementing menstrual health education in schools. It also contains a focus on improving awareness of endometriosis among healthcare practitioners such as GPs, hospital consultants and A&E doctors.

England's Women's Health Strategy was published in Summer 2022. It is a 10-year strategy which sets out the government's plans for improving women and girls' health outcomes and how the system listens to women. The strategy sets out the ambitions for everyone to be educated on menstrual and gynaecological health from a young age, and to tackle societal and workplace taboos. It also sets out ambitions for women and girls to be able to access high-quality, personalised care in a timely manner, including access to specialist care for conditions such as endometriosis, and for healthcare professionals to be well-informed about women's health.

Menstrual health and gynaecological conditions are one of the government's 2024 priorities for implementation of the strategy. The focus of this work is raising awareness of menstrual problems and endometriosis and encouraging women and girls to seek help, improving access to services including through investing in women's health hubs, and improving advice and guidance for healthcare professionals through an updated NICE guideline. We welcome the 10-year ambition in the Women's Health Strategy for England that healthcare practitioners will be well-informed about the importance of women's health, and that better education and ongoing training will be provided during medical training and throughout a medical career.

We also welcome the Welsh Government's Quality Statement on Women's Health[19], specifically listing endometriosis as one of the conditions for which gender inequality and a need for gender competent services arises. We look forward to the women and girl's health 10-year plan, which is yet to be implemented. In December 2022, the NHS Wales Collaborative published 'A Discovery Report: Foundations for a Women's Health Plan.' Reporting the perspectives of women and girls from across Wales, this document highlighted perceived gaps in current service provision and identified opportunities for improvements in women's health, inclusive of access to support and treatment for endometriosis. NHS Wales 10-Year Plan will act as the vehicle for taking forward these improvements. The Welsh Government has funded specialist Endometriosis Nurses within each health board across NHS Wales since 2021.

The Department of Health in Northern Ireland announced plans for a Women's Health Action Plan which will focus on areas which cover the whole life course, including fertility and pregnancy, post-natal healthcare, baby loss, menopause, and gynaecological services. In December 2023, the Department of Health in Northern Ireland established a Women's Health Policy Network, which will include taking forward the recommendations listed within the recently issued Gynaecology 'Getting it Right First Time (GIRFT) report for Northern Ireland,[20] which includes a focus on endometriosis care.

## CONCLUSION AND RECOMMENDATIONS

Now is the time to reverse the trend and take real steps forward in driving down diagnosis times for endometriosis. To shorten the diagnosis time and improve the general experience of being investigated and diagnosed with endometriosis, we are calling for action in the following areas:

The time it takes to secure a diagnosis of endometriosis in the UK is too long and is getting worse. The impact on people living with the symptoms of endometriosis is profound:

- The four Governments of the UK should commit to a target of an average diagnosis time for endometriosis of 1 year or less by 2030.

We recognise that Governments across the UK are working to improve women's health, including endometriosis, through the publication of specific strategies:

- We call on the Governments of the UK to allocate sufficient and ring-fenced funding to ensure they can fulfil the ambitions contained within their plans.

The current waiting times to access gynaecology services are driving up diagnosis times:

- NHS commissioners and providers across the UK must recognise the impact endometriosis can have and plan capacity to provide the care needed to diagnose and treat the disease; give due priority to endometriosis as they do with other conditions with similar impacts; and drive down gynaecology waiting times.

Securing a diagnosis is an important step. However, once diagnosed, people with endometriosis need better access to quality care and management:

- All UK Governments and NHS commissioners and providers should recognise the scale of endometriosis as a common and chronic disease and provide sufficient resources to manage the disease accordingly, including over the long-term.
- The NHS in each nation should develop a centralised pathway of care for thoracic endometriosis.

NICE should include endometriosis outside the pelvis in its guideline on endometriosis.

- The NHS in all four nations should recognise the needs of adolescents and teenagers, and start providing paediatric gynaecology services to ensure they can access appropriate support, diagnosis and treatment.

Low levels of public awareness of endometriosis as well as societal and cultural dismissal of menstrual pain means people often experience symptoms for years without seeking a diagnosis from healthcare practitioners:

- Governments across the UK should invest in public health education campaigns focused upon recognising common endometriosis symptoms, to empower those experiencing symptoms to go to their GP and ask, ‘could this be endometriosis?’

The survey highlights the need for effective and age-appropriate menstrual health education in schools to promote better awareness and timely diagnosis of endometriosis and other menstrual health conditions for young people. In England, menstrual wellbeing has been included in the school curriculum, however this is yet to be fully implemented. The Scottish Government has committed to providing education in schools and learning about menstrual well-being and conditions which can affect the reproductive system is mandatory within the curriculum for Wales framework. No commitment currently exists in Northern Ireland:

- Governments across the UK should fully implement commitments on compulsory menstrual wellbeing education in all schools for all pupils.

The survey makes clear the need for healthcare practitioners to understand and consider the signs of endometriosis; and to not dismiss pelvic and period pain that interferes with everyday life as ‘normal’:

- Menstrual health and endometriosis education should be included in all curriculums for healthcare practitioners, so they receive this training as students.
- Royal Colleges and relevant professional bodies should improve the provision of education on endometriosis and menstrual health as part of specialist and ongoing training, with a particular focus on GPs, Gynaecologists, nurses, A&E practitioners and community pharmacists.

The NICE Guideline on Endometriosis was issued in 2017 and has been adopted in all four nations of the UK. The Quality Standard[21] accompanying the guideline, published in 2018, states that healthcare practitioners should know and consider the symptoms of endometriosis and follow the diagnostic pathway set out. A partial review of the NICE Guideline is being undertaken in 2024, including a new section on diagnosis:

- NHS commissioners and providers must fully implement the NICE Guideline on Endometriosis: diagnosis and management.[22]
- Governments and health leaders across the UK must take steps to ensure a full and thorough implementation of the NICE guideline, including an assessment of key barriers to implementation. We recognise the Scottish Government has already commissioned Endometriosis UK to undertake research to understand the provision of, and barriers to, care for endometriosis.[23]

- We urge NICE to undertake a full review of the Guideline on Endometriosis, including identifying and rectifying omissions such as non-pharmacological pain management, mental health, and endometriosis outside the pelvis. The partial review of the guideline currently being undertaken should take into account best practice and new developments around imaging, including ultrasound and MRI for diagnosis.

Developments in scanning and imaging technology, as well as the development of non-invasive tests, have the potential to make a difference to diagnosing endometriosis and a range of other menstrual health and gynaecological conditions:

- We call on the Government in England to plan, fund and implement more widespread access to gynaecological imaging including within the proposed new Women's Health Hubs and Rapid Diagnostic Centres. We call on Governments in Scotland, Wales and Northern Ireland to identify and deliver an accessible and effective gynaecological imaging service.
- Professional bodies should improve and implement training in gynaecological imaging for sonographers, radiologists, radiographers and other relevant medical practitioners.

Research into endometriosis is vital to advancing our understanding of the disease, including its causes, potential treatments and for developing less invasive diagnostic methods. But very little research exists:

- Governments in the UK should commit to funding research into new treatments and effective management of endometriosis as part of their investment into women's health.

## APPENDIX: METHODOLOGY AND DEMOGRAPHICS OF RESPONDENTS

Endometriosis UK's diagnosis survey 2023 was undertaken using an online survey which was widely promoted online during March to August 2023.

5,500 responses were received. For this report, we selected those who stated they were diagnosed by a medical practitioner in the UK, a total of 4,371. Of these, 72% were diagnosed surgically eg laparoscopy (keyhole surgery), and 18% by scan eg MRI, ultrasound. Of those not diagnosed by surgery eg laparoscopy, 61% had since had a laparoscopy to treat endometriosis.

73% of respondents were diagnosed in the last 6 years. Broken down, 52% were diagnosed during the period 2020 – 2023, and 21% from 2016 – 2019.

Compulsory questions enabled us to identify average diagnosis times and the method of diagnosis. Due to the nature of diagnosis and the different pathways followed, other questions were optional as they were not applicable to all. Results and percentages given are based on the number of respondents per question.

For prior year comparators, we used two sources of data from surveys we have previously undertaken:

1. Endometriosis in the UK: time for change, 2020 – undertaken by Endometriosis UK for the APPG on Endometriosis, with over 10,000 responses received.
2. Endometriosis UK's diagnosis survey 2020 – undertaken in Dec 2019 – Jan 2020, with over 5,000

responses received.

Respondents were self-selecting, electing to complete an online survey which had been seen on social media, via an Endometriosis UK mailing or on the Endometriosis UK website. The survey results are not a representative sample.

| 2023 | | |
|---|---|---|
| | **Count** | **Percent** |
| England | 3715 | 85.0% |
| Northern Ireland | 91 | 2.1% |
| Scotland | 358 | 8.2% |
| Wales | 207 | 4.7% |
| Total | 4371 | 100.0% |

In terms of age, 90% of respondents were aged 18-44 years old.

Of those responding, 53% had a degree or equivalent, higher degree or post graduate qualification, with a further 9% having other higher education below degree level, taking this to 62%. From the Office of National Statistics Census 2021 data, across England and Wales, 34% had qualifications at level 4 or above. Higher levels of education are associated with a range of health benefits.[24]
We highlight this because if those with higher education attainment are having such problems getting a diagnosis as demonstrated by our survey results, we assume that those with lower education attainment are likely to have even more problems and barriers to getting a diagnosis and accessing care.

Whilst the ethnicity of respondents who identified as ‘white’ was proportionate to the ethnicity data collected in Census 2021, the other ethnicity data was not illustrative of the ethnic diversity of the UK, with 11% of respondents choosing to not respond to the ethnicity question. We acknowledge that this means this data does not fully represent experiences of diagnosis of those from marginalised ethnic groups, and we are looking at ways to work with partners to identify the experiences of diagnosis across different ethnic groups.

99.5% of respondents described their gender as female, with 0.2% describing themselves as male and 0.3 % preferring not to say. Census 2021 reported for the England and Wales population that 0.1% identifying as a trans man, 0.06% as non-binary and 0.24% stating that their gender identity was different from the sex registered at birth but giving no details.

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11 *https://www.who.int/standards/classifications/classification-of-diseases*

12 *NICE Guideline on Endometriosis: diagnosis and management - algorithm for diagnosing and managing endometriosis NICE: 2017*

13 *All-Party Parliamentary Group (APPG) on Endometriosis (2020) Time for Change*

14 *Endometriosis UK are currently looking at ways to work with partners to better understand the specific experiences of diagnosis across different ethnic groups.*

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16 *Recommendations | Endometriosis: diagnosis and management | Guidance | NICE*

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# ABOUT ENDOMETRIOSIS UK

Endometriosis UK is the leading UK charity championing the rights and needs of those with endometriosis.

We are determined to ensure that everyone gets prompt diagnosis and the best treatment and support. The endometriosis community is at the heart of all we do, and we strive to support and represent all experiences. We're here to provide vital support services, reliable information and a community for those affected by endometriosis.

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