

# Endometriosis: A Long and Painful Road

A review of the quality of care provided to adult patients diagnosed with endometriosis

## SUMMARY



# Endometriosis: A Long and Painful Road

*A review of the quality of care provided to adult patients diagnosed with endometriosis*

A report published by the National Confidential Enquiry into Patient Outcome and Death (2024)

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The authors and trustees of NCEPOD would like to thank the NCEPOD staff for their work in collecting, importing, analysing and reviewing the data for this report: Peyman Aleboyeh, Donna Ellis, Heather Freeth, Shelly Galea, Rachael Gomez, Holly Hamilton, D'Marieanne Koomson, Nicholas Mahoney, Eva Nwosu, Karen Protopapa, Neil Smith and Anisa Warsame.

This report should be cited as: The National Confidential Enquiry into Patient Outcome and Death. 'A Long and Painful Road' 2024. London

*Cohort: 1<sup>st</sup> February 2018 - 31<sup>st</sup> July 2020*

The Medical and Surgical Clinical Outcome Review Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). HQIP is led by a consortium of the Academy of Medical Royal Colleges and the Royal College of Nursing. Its aim is to promote quality improvement in patient outcomes. The Clinical Outcome Review Programmes, which encompass confidential enquiries, are designed to help assess the quality of healthcare, and stimulate improvement in safety and effectiveness by systematically enabling clinicians, managers, and policy makers to learn from adverse events and other relevant data. HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies [www.hqip.org.uk/national-programmes](http://www.hqip.org.uk/national-programmes).

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ISBN: 978-1-917218-00-9



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# EXECUTIVE SUMMARY

Endometriosis occurs when tissue similar to the lining of the uterus is found in places outside the uterus. These deposits can bleed in response to hormones, causing pain and scarring in the pelvis. A delay in diagnosis is a significant issue as it can lead to prolonged suffering, ill health, and risks to fertility. Delays occur due to a perception that pelvic pain and heavy vaginal bleeding can be normal, and because healthcare professionals do not always consider the presenting symptoms to be endometriosis - there may be many symptoms, not just cyclical pain and heavy bleeding.

**FOR MORE INFORMATION ON ENDOMETRIOSIS VISIT: [Endometriosis UK](#)**

Endometriosis is often treated as multiple episodes of acute care, instead of on a continuum like other chronic conditions, such as diabetes or inflammatory bowel disease. This approach needs to change to enable appropriate pathways of care, holistic and medical management, discharge planning and follow-up.

## IN THIS STUDY

The pathway and quality of care provided to patients aged 18 years and over with a diagnosis of endometriosis was reviewed. The sampling period of 1<sup>st</sup> February 2018 to 31<sup>st</sup> July 2020 was used and data were included from 623 clinician questionnaires, 167 organisational questionnaires and the assessment of 309 sets of case notes. In addition, a patient survey was completed by 941 respondents and a clinician survey by 137 respondents.

### 1. Endometriosis is a chronic condition

Unlike other chronic conditions, such as diabetes, there is no pathway for endometriosis.

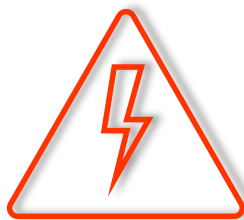


36/136 (**26.5%**) patients had a **delay in initial referral to gynaecology** and in 25/36 patients this impacted on the quality of the care they received.

124/238 (**52.1%**) patients experienced **recurrence or persistence of endometriosis symptoms** following laparoscopy. 32/124 (**25.8%**) patients had a **delay in being reseen**.

### 2. Endometriosis has symptoms and signs that need earlier recognition for appropriate timely management

Signs and symptoms of endometriosis need to be recognised and not just seen as troublesome periods.



**Presenting symptoms** were most often **painful/irregular/heavy periods** or painful intercourse in 220/234 (**94.0%**) patients. But **also bowel** in 34/234 (**14.5%**) and **urinary/bladder** symptoms in 14/234 (**6.0%**) patients, or an **inability to conceive** in 12/234 (**5.1%**).

546/941 (**58.0%**) patients surveyed **had multiple visits to the GP** before any investigations were undertaken or treatment initiated.

### 3. Endometriosis affects quality of life. All patients should be asked about the effect of disease on their life

Access to supportive services would enable patients with endometriosis to manage their condition.



**Failure to refer to supportive services** resulted in **less than best practice** for 70/309 (**22.7%**) patients.

420/941 (**44.6%**) of survey respondents stated that they were **not asked at any point about the impact of symptoms on their quality of life**.

### 4. Endometriosis requires holistic, joined-up, multidisciplinary care

Multidisciplinary care is essential to ensure patients with endometriosis have all their care needs met.



Only 73/167 (**43.7%**) of **hospitals reported MDT meetings** were held for patients with endometriosis.

Reviewers found that only 27/242 (**11.2%**) patients were **formally discussed in an MDT meeting** and 28/215 (**13.0%**) patients who were not discussed **should have been**.

## RECOMMENDATIONS [\(BACK TO CONTENTS\)](#)

These recommendations have been formed by a consensus exercise involving all those listed in the acknowledgements. The recommendations have been independently edited by medical editors experienced in developing recommendations for healthcare audiences to act on.

The recommendations highlight areas that are suitable for regular local clinical audit and quality improvement initiatives by those providing care to this group of patients. The results of such work should be presented at quality or governance meetings and action plans to improve care should be shared with executive boards. QI tools highlighted in this report will support this.

The recommendations in this report support those made previously by other organisations, and for added value should be read alongside:

- [NICE guideline NG73](#) and [NICE quality Standard QS172](#)
- [Endometriosis UK](#) and [Endometriosis Cymru](#)
- [European Society of Human Reproduction and Embryology \(ESHRE\) guideline](#)
- [British Society for Gynaecological Endoscopy \(BGSE\) accreditation](#)
- [NHSE specialist commissioning for severe endometriosis-service specification standards](#)

### OVERARCHING MESSAGE

**Endometriosis is often treated as multiple episodes of acute care, instead of on a continuum such as chronic conditions like diabetes, to enable appropriate pathways of care, holistic and medical management, discharge planning and follow-up.**

### ENDOMETRIOSIS AWARENESS

1	<b>Raise awareness about endometriosis symptoms with the public and patients, highlighting that it is a chronic condition and how they can seek help.</b>	
	<p><b>Primary audiences:</b> <i>NHS England, Welsh Government, Northern Ireland Department of Health</i></p> <p><b>Supported by:</b> <i>Royal College of Obstetricians and Gynaecologists, Royal College of General Practitioners, Royal College of Surgeons, Royal College of Emergency Medicine, Royal College of Nursing, Royal College of Paediatrics and Child Health, Department for Education, Endometriosis UK, Endometriosis Cymru</i></p>	
	<b>RATIONALE and IMPLEMENTATION SUGGESTIONS</b>	
	Improving awareness with the public may help reduce delays and improve care by earlier presentation to a GP. The following could be used: <ul style="list-style-type: none"> <li>▪ Social media campaigns on X, Facebook, TikTok, Instagram etc.</li> <li>▪ Public health awareness posters</li> <li>▪ Information on hospital intranets</li> </ul>	See also: <a href="#">Endometriosis UK: Dismissed, ignored and belittled</a> and <a href="#">NICE guideline CG138: Patient experience in adult NHS services: improving the experience of care for people using adult NHS services</a>
2	<b>Raise awareness with all healthcare professionals that endometriosis is a chronic condition and should be treated as such.</b>	
	<p><b>Primary audiences national:</b> <i>Royal College of Obstetricians and Gynaecologists, Royal College of General Practitioners, Royal College of Surgeons, Royal College of Emergency Medicine, Royal College of Nursing, Royal College of Paediatrics and Child Health, Society for Acute Medicine, British Society for Gynaecological Endoscopy</i></p> <p><b>Primary audiences local:</b> <i>Medical Directors, Clinical Directors, and Clinical Audit/Quality Improvement departments</i></p> <p><b>Supported by:</b> <i>NHS England, Welsh Government, Northern Ireland Department of Health</i></p>	

<b>RATIONALE and IMPLEMENTATION SUGGESTIONS</b>		
	<p>Endometriosis may mimic other conditions and patients may present to specialties other than gynaecology. Therefore improving awareness with all healthcare professionals, including those not directly involved in the care of patients with endometriosis, may help reduce delays and improve care by earlier:</p> <ul style="list-style-type: none"> <li>▪ Recognition of symptoms and referral – all pelvic pain, regardless of cause should be explored further</li> <li>▪ Initiation of medical management</li> <li>▪ Referral to supportive services to improve quality of life for patients and see specialists early in the condition's course.</li> <li>▪ Re-entry into the care pathway for patients with recurrent disease</li> </ul>	<p>This may be aided using:</p> <ul style="list-style-type: none"> <li>▪ Training modules</li> <li>▪ Information on hospital/GP intranets</li> </ul>
	<p><b>Improve training on the recognition of symptoms of endometriosis, such as pelvic pain and heavy menstrual bleeding.</b></p> <p><b>a. In primary care - to support healthcare professionals in the initial assessment, and any ongoing care of patients</b></p> <p><b>b. In secondary care - enhanced training on endometriosis should be made available for all healthcare professionals who might care for patients with endometriosis.</b></p> <p><i><b>Primary audiences national:</b> Royal College of Obstetricians and Gynaecologists, Royal College of General Practitioners, Royal College of Emergency Medicine, Royal College of Nursing, Royal College of Paediatrics and Child Health, British Society for Gynaecological Endoscopy</i></p> <p><i><b>Primary audiences local:</b> Medical Directors, Clinical Directors, and Clinical Audit/Quality Improvement departments</i></p> <p><i><b>Supported by:</b> NHS England, Welsh Government, Northern Ireland Department of Health</i></p>	
<b>3</b>	<b>RATIONALE and IMPLEMENTATION SUGGESTIONS</b>	
	<p>A pelvic pain lead could be responsible for upskilling staff at a regional level which would support with pathways to clarify where treatment is appropriate for primary care and what the thresholds for referral are. They could lead a team of primary and secondary care professionals with input by the MDT so that there is continuity of care but also be responsible for general awareness raising. This would enable earlier access to secondary care/specialist tertiary care/MDTs to help reduce delays.</p> <p>It would also support the creation of more women's health hubs for the non-surgical treatments of endometriosis and as a home for the MDT.</p> <p>For those working in secondary care, enhanced knowledge may lead to better treatment discussions and decision-making.</p>	<p>Those who may benefit from enhanced training would include:</p> <ul style="list-style-type: none"> <li>▪ Primary care clinicians - GPs/practice nurses/physician associates</li> <li>▪ Emergency medicine physicians</li> <li>▪ Gastrointestinal physicians and surgeons</li> <li>▪ Urologists</li> <li>▪ Pain specialists</li> <li>▪ Nurses, e.g. triage</li> <li>▪ Sonographers</li> </ul> <p>Women's health specialists would bridge the gap between the primary care and surgical care of this group of patients.</p>
<b>THE IMPACT OF ENDOMETRIOSIS ON QUALITY OF LIFE</b>		
<b>4</b>	<p><b>Ask patients with endometriosis about the effects it has over and above physical symptoms, including its impact on their daily life and refer them as needed to support services (e.g. psychology/pain services), at all stages of the pathway.</b></p> <p><i><b>Primary audiences:</b> Healthcare professionals in primary care and secondary care</i></p> <p><i><b>Supported by:</b> NHS England, Welsh Government, Northern Ireland Department of Health</i></p>	
	<b>RATIONALE and IMPLEMENTATION SUGGESTIONS</b>	
	<p>It is important to consider all comorbidities when offering timely advice for the management of endometriosis. Physical health conditions as well as mental health conditions may influence the treatment decision and care provided.</p>	<p>A quality of life assessment should start in primary care and be repeated during any admission to hospital for endometriosis. The assessment should happen again at follow-up in primary, secondary or specialist care, and during any readmission for endometriosis. Endometriosis clinical nurse specialists would be ideally placed to carry out the assessments. The assessments should be linked to patient-reported outcomes following all treatment, including surgery. Tools include:</p> <ul style="list-style-type: none"> <li>▪ <a href="#">World Health Organisation Quality of Life</a></li> <li>▪ <a href="#">Consultation/pain questionnaire</a></li> <li>▪ <a href="#">Generalised anxiety disorder assessment</a></li> <li>▪ <a href="#">Patient health questionnaire</a></li> </ul>



## ENDOMETRIOSIS MULTIDISCIPLINARY TEAMS AND CLINICAL NETWORKS

Ensure multidisciplinary teams/clinical networks are set up and utilised across all healthcare settings to help agree treatment plans and support women with confirmed endometriosis. Input from specialties should be proportionate to the patient's needs.

**Primary audiences:** Integrated care boards, Commissioners, Clinical Directors and Executive Boards

**Supported by:** Royal College of Obstetricians and Gynaecologists, Royal College of General Practitioners, Royal College of Emergency Medicine, Royal College of Nursing, Royal College of Paediatrics and Child Health, British Society for Gynaecological Endoscopy, Commissioners

### RATIONALE and IMPLEMENTATION SUGGESTIONS

5	<p>Patient access to a multidisciplinary team or, as a minimum, established pathways for referral should be accessible from both primary and secondary care, not just specialist centres.</p> <p>The use of pathways/ MDTs/clinical networks would support the patient and the clinical lead caring for the patient to ensure timely and appropriate referral back into the correct part of the pathway.</p> <p>Consideration should be given to the fact that even minimal or mild disease can still cause painful symptoms and while a full MDT meeting may not be necessary, support from a wider specialty group may be helpful.</p>	<p>The MDT/clinical networks could include:</p> <ul style="list-style-type: none"> <li>Primary care - general practitioners/practice nurses/physician associates</li> <li>Endometriosis clinical nurse specialists</li> <li>Gynaecologists</li> <li>Pain/chronic pain/pain medicine specialists</li> <li>Pharmacists</li> <li>Radiologists</li> <li>Fertility specialists</li> </ul> <ul style="list-style-type: none"> <li>Mental health/practitioner psychologists/pain psychologists</li> <li>Pelvic physiotherapists</li> <li>Specialist surgeons when needed. e.g. colorectal</li> <li>Occupational therapists</li> </ul> <p><i>This is consistent with <a href="#">NICE Guideline NG73</a> and <a href="#">British Society for Gynaecological Endoscopy (BGSE) accreditation</a></i></p>
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## MEDICAL/PAIN MANAGEMENT FOR ENDOMETRIOSIS

Manage pain effectively for patients who have endometriosis:

- Set a low threshold for the prescription of analgesia
- Set a low threshold for hormonal treatment which may improve pain as well as other symptoms – while always considering fertility intentions
- Refer to pain management services as needed
- In parallel, refer patients for non-medical pain management e.g. physiotherapy

**Primary audiences:** All healthcare professionals in primary, secondary, and specialist care who are in contact with people who have endometriosis

**Supported by:** Royal College of General Practitioners

### RATIONALE and IMPLEMENTATION SUGGESTIONS

Use of a [stepped approach to analgesia](#), including simple analgesics and/or hormone treatment could be used.

Use interactions between patients with endometriosis and prescribing healthcare professionals to undertake a medication review.

**Primary audiences:** All healthcare professionals, including pharmacists, who care for patients with endometriosis

**Supported by:** Medical Directors, Clinical Directors, and Clinical Audit/Quality Improvement departments

### RATIONALE and IMPLEMENTATION SUGGESTIONS

Any interaction with a healthcare professional, including pharmacists, is an opportunity to review medications, particularly pain medications and the long-term use of opioids, potential side effects and the efficacy of the medications.

CONSENT FOR LAPAROSCOPIES FOR ENDOMETRIOSIS		
8	<p>Provide patients with clear, written information as part of the process that allows the patient to give informed consent for the laparoscopic diagnosis/treatment of endometriosis. This should form the basis of a documented discussion with the surgeon before the day of surgery. Include:</p> <ol style="list-style-type: none"> <li>What the procedure involves</li> <li>The purpose of the procedure e.g. to diagnose, stage, treat the symptoms of endometriosis, or a combination of these</li> <li>What the patient's expectations are</li> <li>The possible effects on endometriosis symptoms</li> <li>Risks, benefits and limitations</li> <li>The need for further laparoscopic/open surgery for recurrent endometriosis or if complications arise</li> </ol> <p><i>This is consistent with <a href="#">NICE guideline NG73</a></i></p> <p><b>Primary audiences:</b> <i>Consultant surgeons, including gynecology, urology, colorectal, and general surgeons</i></p> <p><b>Supported by:</b> <i>Medical Directors, Clinical Directors, and Clinical Audit/Quality Improvement departments</i></p>	
	<p><b>RATIONALE and IMPLEMENTATION SUGGESTIONS</b></p>	
	<p>Consent is a multi-stage process (or should be) that begins with an explanation in clinic and ends with signing a form. It is not appropriate to do all of that on the day of surgery but completing consent forms on day of surgery after prior explanation maybe appropriate.</p>	<p>To understand the benefits of any future procedures the operation note should include:</p> <ul style="list-style-type: none"> <li>how many prior laparoscopies the patient has undergone for endometriosis</li> <li>a comprehensive surgical description, with photographs</li> <li>a description of why any residual endometriotic tissue was left untreated and not removed</li> <li>comments about any difficulties performing the procedure which will underpin future decisions to operate.</li> </ul>
DISCHARGE, FOLLOW-UP AND READMISSION		
9	<p>Provide patients with clear, written information at discharge following laparoscopic diagnosis/treatment of endometriosis, including who to contact and how to initiate direct access back into the endometriosis care pathway.</p> <ol style="list-style-type: none"> <li>Who to contact if they have any concerns, e.g. GP, endometriosis clinical nurse specialists, consultant</li> <li>The follow-up plan and ongoing management of the endometriosis</li> <li>The option of patient-initiated follow-up</li> <li>Types and dosages of medication they are on at discharge, including analgesia and hormone therapy</li> <li>The consideration of bone health for people with endometriosis on long-term hormonal medication, including nutrition, weight-bearing exercise and alcohol intake</li> </ol> <p><b>Primary audiences:</b> <i>All healthcare professionals who care for patients with endometriosis</i></p> <p><b>Supported by:</b> <i>Medical Directors, Clinical Directors, and Clinical Audit/Quality Improvement departments</i></p>	
	<p><b>RATIONALE and IMPLEMENTATION SUGGESTIONS</b></p>	
	<p>A clear point of access and knowing who to contact should help patients avoid delays to readmission/re-entry into the care pathway. It would also reduce unnecessary GP appointments.</p>	<p>The use of patient passports could be considered, allowing patients to hold their data.</p>
THE ENDOMETRIOSIS CARE PATHWAY		
10	<p>Formalise a care pathway for patients with or suspected to have endometriosis. This pathway should include implementation of <a href="#">NICE guideline NG73</a>, the <a href="#">European Society of Human Reproduction and Embryology (ESHRE) endometriosis guidelines</a>, as well as the recommendations from this report.</p>	
	<p><b>Primary audiences national:</b> <i>Royal College of Obstetricians and Gynaecologists, Royal College of General Practitioners, Royal College of Surgeons, Royal College of Emergency Medicine, Royal College of Nursing, Royal College of Paediatrics and Child Health, Society for Acute Medicine, British Society for Gynaecological Endoscopy, British medical ultrasound society, Pelvic Obstetric and Gynaecological Physiotherapy</i></p> <p><b>Primary audiences local:</b> <i>Medical Directors, Clinical Directors, and Clinical Audit/Quality Improvement departments</i></p> <p><b>Supported by:</b> <i>NHS England, Welsh Government, Northern Ireland Department of Health</i></p>	



RATIONALE and IMPLEMENTATION SUGGESTIONS	
	<p>A dedicated pathway should cover the care of patients presenting with possible endometriosis, to the point of discharge following surgery and include the following steps:</p> <ul style="list-style-type: none"> <li>a. Organisation of care</li> <li>b. Information and support</li> <li>c. Endometriosis symptoms and signs</li> <li>d. Pharmacological management</li> <li>e. Referral to support services to improve quality of life</li> <li>f. Consideration of fertility intentions</li> </ul>
	<ul style="list-style-type: none"> <li>g. When to refer</li> <li>h. Diagnosing endometriosis, including imaging</li> <li>i. Informed consent</li> <li>j. Surgical management</li> <li>k. Pain/chronic pain management</li> <li>l. Psychological support</li> <li>m. Follow-up care</li> <li>n. Quality of life assessments</li> </ul>
FURTHER QUALITY IMPROVEMENT OPPORTUNITIES TO IMPROVE ENDOMETRIOSIS CARE	
11	<ul style="list-style-type: none"> <li>a. Collect surgical outcome data, including patient-reported outcomes, for benchmarking.</li> <li>b. Review local practice against <a href="#">NICE guideline NG73</a>, the recommendations in this report.</li> <li>c. Undertake clinical trials to ascertain the efficacy of surgery for endometriosis-associated symptoms, especially for minimal or mild endometriosis.</li> <li>d. Assess the use of pain medication, and the medical treatment of endometriosis.</li> <li>e. Explore the use of imaging modalities in the diagnosis of endometriosis.</li> </ul> <p><b>Primary audiences:</b> Grant-making bodies such as the National Institute for Health and Care Research or Medical Research Council</p> <p><b>Supported by:</b> Relevant Royal Colleges</p>

## INTRODUCTION [\(BACK TO CONTENTS\)](#)

Endometriosis is a chronic condition in which tissue similar to the lining of the uterus grows outside the uterus. It causes an inflammatory response leading to the formation of scar tissue. The cause of endometriosis is unknown, there is no known way to prevent it and there is no guaranteed long-term cure. Endometriosis is associated with many physical and mental health symptoms, which can have an effect on quality of life, and impact fertility planning. Approximately 10% of people assigned female at birth who are of reproductive age are affected,<sup>[1]</sup> which means that there is a substantial impact on education and work with regard to days lost.<sup>[2]</sup> Despite this, there is also no defined healthcare pathway as there is for other chronic conditions such as diabetes, or inflammatory bowel disease.

Delayed diagnosis is a significant problem for women with endometriosis. More than 10,000 people took part in an inquiry by the All-Party Parliamentary Group (APPG) on endometriosis,<sup>[3]</sup> which found that 58% of people with symptoms saw their GP more than ten times before receiving a diagnosis. Often delay seeking help occurred because of a perception that pelvic pain and vaginal bleeding can be normal, and delays of many years were found to have occurred between first reporting symptoms and confirming the diagnosis. Any delay in diagnosis of this condition can lead to increased suffering, ill health, and infertility. However, healthcare professionals may not recognise the importance of symptoms or even consider endometriosis as a diagnosis.

The late Conservative MP, Sir David Amess, who chaired the APPG inquiry, said: *“It is not acceptable that endometriosis and its potentially debilitating and damaging symptoms are often ignored or not taken seriously – or downplayed as linked to the menstrual cycle and periods.”*<sup>[3]</sup>

There are several national and international guidelines written to support the care of patients with endometriosis, including NICE guideline NG73: Endometriosis; diagnosis and management,<sup>[4]</sup> and NICE quality standard 172 on endometriosis,<sup>[5]</sup> as well as the European Society of Human Reproduction and Embryology (ESHRE) endometriosis guideline of 2022.<sup>[6]</sup> These guidelines cover diagnosis, treatment of pain and infertility and recurrence. The importance of recognising signs and symptoms, employing correct diagnostic tests, the early treatment of pain with both conventional analgesic agents and hormone treatment together with more novel pharmacological approaches are highlighted throughout.

This NCEPOD study was developed with wide multidisciplinary input, reviewing the care of patients with endometriosis who underwent a surgical laparoscopy during the study period.

This study aims to identify priority areas for improvement in the treatment pathway of patients with endometriosis.

## WHAT PATIENTS SAID [\(BACK TO CONTENTS\)](#)

*"My gynaecologist was quite dismissive of some of my symptoms which I know are related to endo, though perhaps less common. She refused to give me an MRI scan and said that an excision laparoscopy was not possible"*

*"The gynaecologist I was under before told me outright it wasn't going to be endometriosis. She told me three times in one visit I should see a psychiatrist instead."*

*"I've never been referred to support services. Any referrals I have had were either at my insistence or I self-referred. I am now disabled due to the impact of my pain and symptoms."*

*"I've been waiting three years for a surgery of excision of endometriosis, and I have no life... it is affecting my career, my studies, and my personal relationships... and no one seems to care or interested in doing anything to help."*

*"As I am under three departments and two different hospitals, I often feel I am chasing information. However, my endometriosis nurse has been fantastic in facilitating multidisciplinary meetings on my behalf."*

*"The best support and advice I have received by far has been from the endometriosis nurse. They were compassionate, generous with their time, listened, and explained things clearly without making any assumptions. Care received from GPs and a gynaecologist has been very unsatisfactory."*

*"The endometriosis specialist nurse was so lovely once I got to speak to her, but getting hold of her subsequently has been challenging. I think she is likely overworked, so I do feel bad for her. Having one nurse for so many people just isn't enough."*

*"I thought that once it was removed that was it, I was never told that it could come back, and that surgery wasn't a cure."*

*"I still have endometriosis fusing my bowel and ovary. I wasn't told that the endometriosis they removed might come back."*

*"The chance of recurrence and the importance of excision were referred to, but not as thoroughly explained as I would have liked"*

*"There was no follow-up appointment. I had to go back to my GP to be referred to gynaecology AGAIN and then to see a specialist. This took years."*

*"I don't understand why you're discharged from gynaecology when you have a diagnosis of a lifelong condition that is likely to get worse. I've had to start the process again and wait 18 months for an appointment."*

*"I am under a specialist centre where I have been since January 2021. The care and understanding there are amazing. Even after treatment or surgery they don't discharge you. They keep you on their books for two years and if in that time you need to see a consultant you just phone or email the endometriosis nurse and you'll get an appointment. If after two years they haven't heard from you, they discharge you. This is a fabulous system."*

## METHOD AND DATA RETURNS [\(BACK TO CONTENTS\)](#)

### Study Advisory Group

A multidisciplinary group of clinicians was convened to define the study aim and objectives. The Study Advisory Group (SAG) comprised a patient representative along with healthcare professionals from gynaecology, surgery, endometriosis specialist nursing, radiology, pain medicine, anaesthesia, pharmacy, psychology, and physiotherapy. This group steered the study from design to completion.

### Study aim

To review remediable factors in the quality of care provided to patients aged 18 and over with a surgical diagnosis of endometriosis.

### Objectives

To explore the clinical and organisational structures in place for the provision of care for patients with endometriosis, reviewing the entire pathway of care with a focus on:

- Triage
- Endometriosis specialist centres
- Policies/protocols/care pathways in place – including delays
- Communication between providers
- Information and support for patients
- Staffing
- Surgical services
- Imaging services
- Holistic care and multidisciplinary team (MDT) provision
- Discharge and follow-up

### Study population and case ascertainment

#### Inclusion criteria

Patients aged 18 or older with a primary surgical diagnosis of endometriosis admitted to hospital during the study timeframe: 1<sup>st</sup> February 2018 to 31<sup>st</sup> July 2020.

#### Exclusion criteria

Patients who were miscoded and/or were found not to have endometriosis.

### Hospital participation

Data were included from NHS and independent hospitals in England, Wales, and Northern Ireland.

### Data collection – peer review

#### Identification of a sample population

A pre-set spreadsheet was provided to every local reporter to identify all patients meeting the study criteria during the defined time period. From this initial cohort, a maximum of eight patients were randomly selected from each hospital for inclusion in the study.

## **Questionnaires**

Three questionnaires were used to collect data for this study:

### ***Clinician questionnaire***

This questionnaire was sent electronically to the consultant gynaecologist responsible for the care of the patient at the time of their index admission to hospital for a laparoscopy for endometriosis during the study timeframe.

### ***Organisational questionnaire***

The data requested in this questionnaire included information on the services provided for patients with endometriosis.

### ***GP questionnaire***

This questionnaire was sent as a hard copy to the named GP practice for each patient in the study and collected data on interactions of the patient and their GP both pre- and post-diagnosis of endometriosis.

## **Case notes**

Copies of the case notes were requested from primary and secondary care providers for peer review. These encompassed notes from the whole timeline, including pre-diagnosis and the index admission, through to the present day.

## **Peer review of the case notes and questionnaire data**

A multidisciplinary group of case reviewers comprising consultants and trainees from obstetrics and gynaecology, radiology, endometriosis clinical nurse specialists, and general practice were recruited to peer review the case notes and associated clinician questionnaires.

All patient identifiers were removed by the non-clinical staff at NCEPOD before the case notes or questionnaires were presented to the group. Using a semi-structured electronic questionnaire, each set of case notes was reviewed by at least one reviewer within a multidisciplinary meeting. At regular intervals discussion took place, allowing each reviewer to summarise their cases and ask for opinions from other specialties or raise aspects of the case for further discussion.

## **Data collection – patient survey**

An open, anonymous online survey collected the views of patients with endometriosis, and asked questions about the quality of the care they had received. The data were not linked to the study cohort.

## **Data collection – clinician survey**

An open, anonymous online survey collected the views of clinicians treating patients with endometriosis and asked questions about their practice and training. The data were not linked to the study cohort.

## **Information governance**

All data received and handled by NCEPOD complied with all relevant national requirements, including the General Data Protection Regulation 2016 (Z5442652), Section 251 of the NHS Act 2006 (PIAG 4-08(b)/2003, App No 007), and the Code of Practice on Confidential Information. Each patient was given a unique NCEPOD number. All electronic questionnaires were submitted through a dedicated online application.

## **Data analysis**

Following cleaning of the quantitative data, descriptive data summaries were produced. Qualitative data collected from the case reviewers' opinions and free-text answers in the clinician questionnaires were coded, where applicable, according to content to allow quantitative analysis. As the methodology provides a snapshot of care over a set point in time, with data collected from several sources to build a national picture, denominators will change depending on the data source, but each source is referenced throughout the document. This deep dive uses a qualitative method of peer review, and anonymised case studies have been

used throughout this report to illustrate themes. The sampling method of this enquiry, unlike an audit, means that data cannot be displayed at a hospital/trust/health board/regional level.

### Data analysis rules

- Small numbers have been suppressed if they risk identifying an individual
- Any percentage under 1% has been presented in the report as <1%
- Percentages were not calculated if the denominator was less than 100 so as not to inflate the findings, unless to compare groups within the same analysis
- There is variation in the denominator for different data sources and for each individual question as it is based on the number of answers given.

The findings of the report were reviewed prior to publication by the SAG, case reviewers and the NCEPOD Steering Group, which included clinical co-ordinators, trustees, and lay representatives.

### Data returns

#### Clinical data

In total, 23,518 patients were identified as meeting the study inclusion criteria (Figure 1.1) for the first three months of the study data collection period. Up to six patients per hospital were selected in accordance with the sampling protocol. This resulted in 900 patients being included in the initial sample. A total of 191 patients were excluded as they did not meet the study inclusion criteria when the case notes were reviewed locally. The most common reason for exclusion was that the patient did not have endometriosis. Of the remaining sample, 623 completed clinician questionnaires were included in the analysis and 309 sets of notes were peer reviewed by the case reviewers. In addition, organisational questionnaires were received from 167 hospitals. There were 120 GP questionnaires, 941 patient surveys and 137 clinician surveys completed.

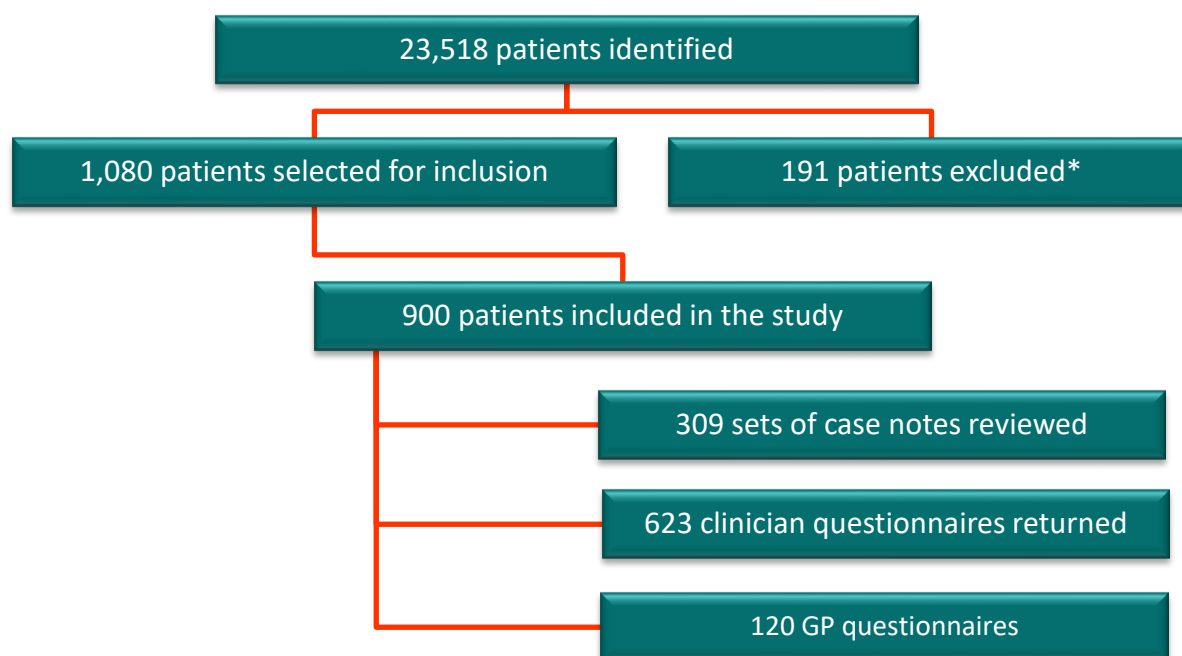


Figure 1.1 Data returned

*\*Patients who did not meet the study inclusion criteria*



## Organisational data

Organisational questionnaires were returned from 167/255 (65.5%) hospitals.

## Survey data

The patient survey was completed by 941 respondents.

The clinician survey was completed by 137 respondents (gynaecology consultants n=71, other specialty doctors n=23, primary care clinician n=6, endometriosis clinical nurse specialists n=21, allied health professionals n=11, and other n=3).

Table 1.1 summarises which data were returned for the reviewer assessment form, clinician questionnaire and GP questionnaire at different parts of the pathway. The denominator presented in the data throughout the report reflects this.

Table 1.1 Data returned

Data source	Total	Data with pre-diagnosis information	Data from diagnostic surgery	Data from index admission surgery (when not for diagnostic surgery)	Primary care information available
Clinician questionnaire	623	403	459	162	196
Reviewer assessment form	309	133	238	93	-
GP questionnaire	120	120	-	-	-

## SAMPLE POPULATION [\(BACK TO CONTENTS\)](#)

### Demographics

The study population mainly comprised women of reproductive age with a mean age of 34 years (Figure 2.1).

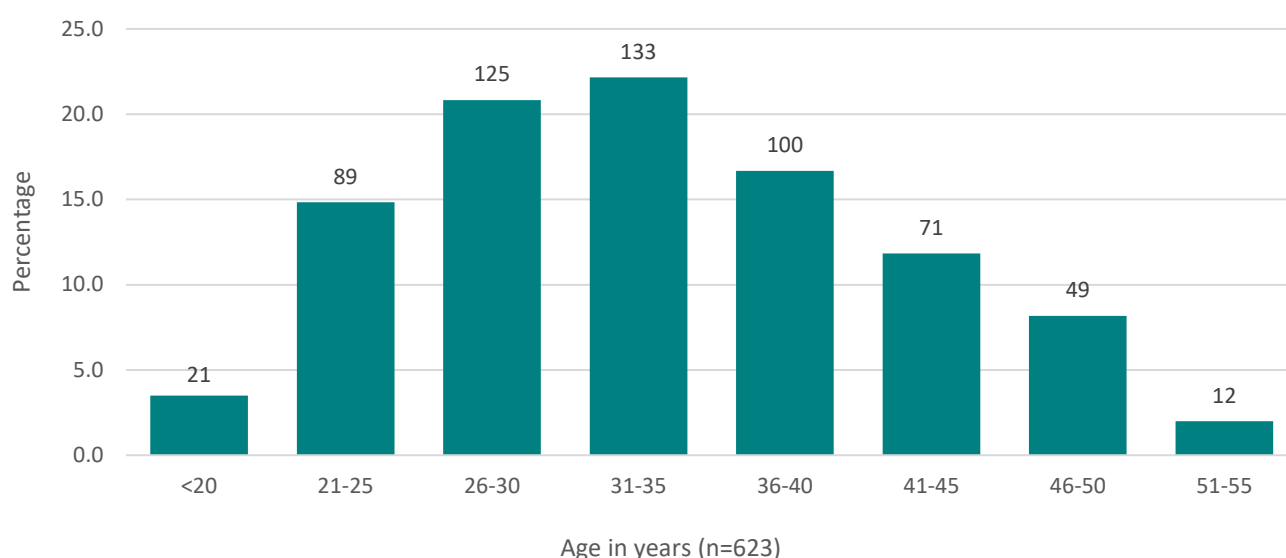


Figure 2.1 Age of the study population  
*Clinician questionnaire data*

Table 2.1 shows the ethnicity of the study population. A recent systematic review found that Asian women were more likely to be diagnosed with endometriosis, and black women less likely than white women,<sup>[7]</sup> possibly reflecting a bias in access to care. Compared with census data in England and Wales,<sup>[8]</sup> black women were under-represented, and mixed or multiple ethnic groups were over-represented in this study population. However, as the sample was randomly selected, and not based on ethnicity, it was not possible to make any specific comment about endometriosis care related to ethnicity in this study.

Table 2.1 Ethnicity of the study population

	Number of patients	%
White	477	77.4
Mixed or multiple ethnic groups	83	13.5
Asian or Asian British	45	7.3
Black, Black British, Caribbean or African	11	1.8
<b>Subtotal</b>	<b>616</b>	
Unknown	7	
<b>Total</b>	<b>623</b>	

*Clinician questionnaire data*

## Comorbidities

Data from the clinical questionnaire showed that 403/623 (64.7%) patients presented with comorbid conditions, 60/403 (14.8%) patients had comorbidities that included pain not related to endometriosis and 35/403 (8.7%) had poor mental health. This was also reflected in the patient survey, where 224/941 (23.8%) respondents reported 'back pain' and 68/941 (7.2%) said they had 'chronic widespread pain'. Survey respondents also widely reported being diagnosed with depression 415/941 (44.1%) and anxiety 464/941 (49.3%).

Endometriosis is known to be associated with other conditions such as ovarian cysts (other than endometriomas – cystic lesions that stem from endometriosis), chronic pain, subfertility, bowel conditions, autoimmune conditions and cardiac disease.<sup>[1]</sup> These conditions were reflected in the study population (Figure 2.2). Subfertility was recorded as a comorbidity in 37/403 (9.2%) patients and was also noted as a presenting symptom.

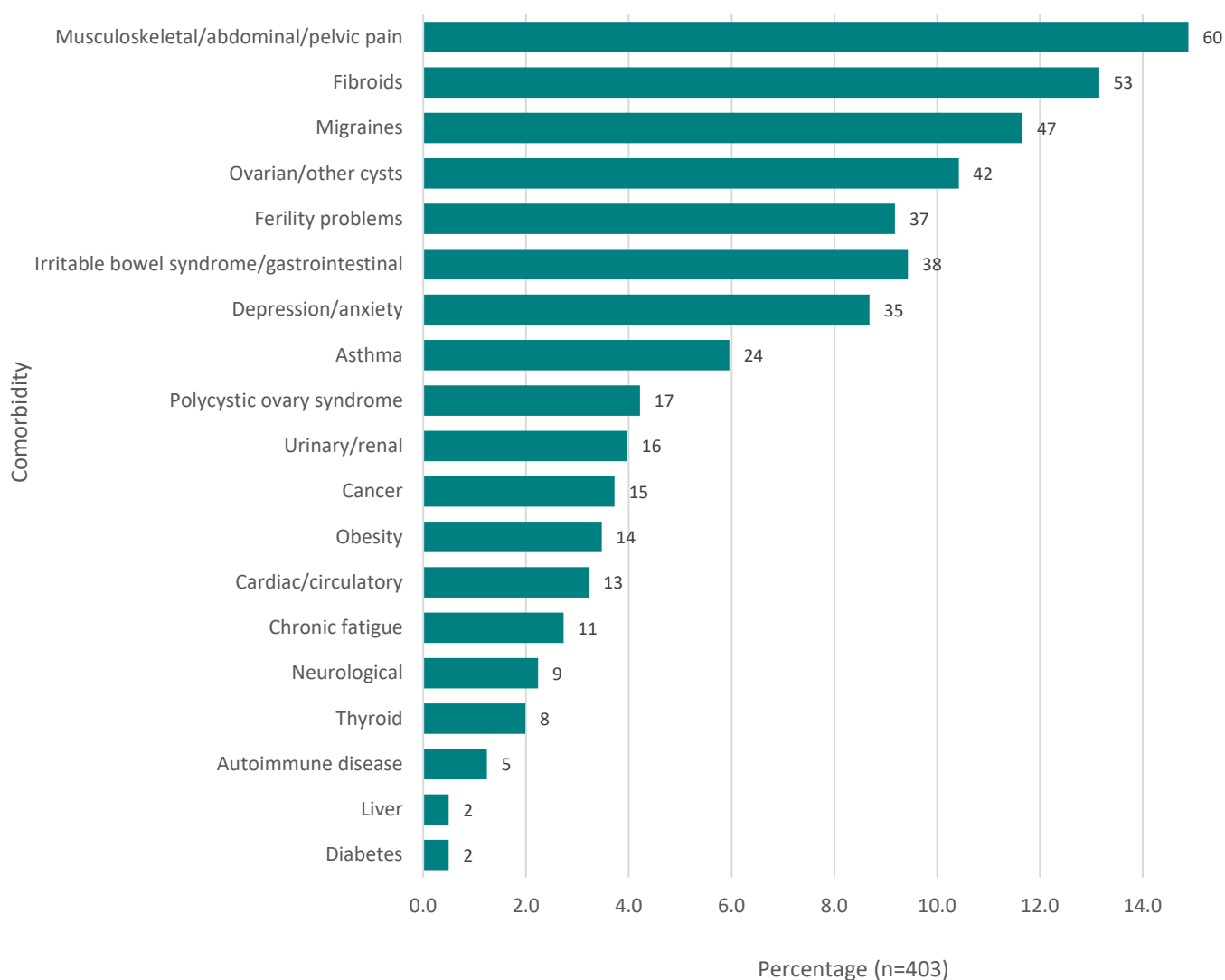


Figure 2.2 Comorbidities

Answers may be multiple; n=40, clinician questionnaire data

There is no guidance regarding formal screening for these or mental health conditions. Just 21/313 (6.7%) survey respondents (where the question was answered) and 28/623 (4.5%) patients reviewed reported they had psychological screening once they had been diagnosed with endometriosis.

## REFERENCES

1. [World Health Organisation Endometriosis Fact sheet. March 2023. Endometriosis](#)
2. [Simoens S, Dunselman G, Dirksen C, et al. The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. \*Human Reproduction\*. 2012;27\(5\);1292-9](#)
3. [Endometriosis in the UK; time for change. 2020. All Party Parliamentary Group \(APPG\) on Endometriosis Inquiry Report](#)
4. [National Institute for Health and Care Excellence. NICE guideline \[NG73\] Endometriosis: diagnosis and management. Published: 06 September 2017](#)
5. [National Institute for Health and Care Excellence. Endometriosis Quality standard \[QS172\]. Published: 06 August 2018](#)
6. [Becker CM, Bokor A, Heikinheimo O, et al. European Society of Human Reproduction and Embryology endometriosis guideline: endometriosis. ESHRE Endometriosis Guideline Group. \*Human Reproduction Open\*. 2022: Feb 26;2022Bougie O, Yap MI, Sikora L, et al. Influence of race/ethnicity on prevalence and presentation of endometriosis: a systematic review and meta-analysis. \*British Journal of Obstetrics and Gynaecology\*. 2019;126;1104-1115](#)
7. [Bougie O, Yap MI, Sikora L, et al. Influence of race/ethnicity on prevalence and presentation of endometriosis: a systematic review and meta-analysis. \*British Journal of Obstetrics and Gynaecology\*. 2019;126;1104-1115](#)
8. [UK Ethnicity facts and figures – UK population by ethnicity. Published December 2022, updated April 2023](#)

## USEFUL LINKS

	<a href="#"><u>Endometriosis UK</u></a>
 National Institute for Health and Care Excellence	<a href="#"><u>NICE Guideline NG73</u></a> <a href="#"><u>NICE Quality Standard QS172</u></a>
 BRITISH SOCIETY for GYNAECOLOGICAL ENDOSCOPY	<a href="#"><u>British Society for Gynaecological Endoscopy (BGSE) accreditation</u></a>
	<a href="#"><u>European Society of Human Reproduction and Embryology (ESHRE)</u></a>
 Royal College of Obstetricians & Gynaecologists	<a href="#"><u>RCOG</u></a>
	<a href="#"><u>Endometriosis Cymru</u></a>
 PRIMARY CARE WOMEN'S HEALTH FORUM	<a href="#"><u>Primary Care Women's Health Forum</u></a>
 World Health Organization	<a href="#"><u>Endometriosis (who.int)</u></a>
	<a href="#"><u>Endometriosis</u></a>