Endometriosis: A Long and Painful Road

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

NCEPOD

Improving the quality of healthcare

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: 1st February 2018 - 31st 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.

ISBN: 978-1-917218-00-9

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This report is dedicated to Mr Ian Martin, who sadly died shortly before its publication. Ian worked with NCEPOD for over 25 years, serving as a case reviewer, clinical co-ordinator, trustee, and our Chair.
He was one of NCEPOD's most dedicated supporters, a respected colleague, and a dear friend who will be deeply missed.
His contributions to NCEPOD will be remembered as his enduring legacy.

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 1st February 2018 to 31st 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

Raise awareness about endometriosis symptoms with the public and patients, highlighting that it is a chronic condition and how they can seek help.

Primary audiences:* *NHS England, Welsh Government, Northern Ireland Department of Health
Supported by: *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*

RATIONALE and IMPLEMENTATION SUGGESTIONS

Improving awareness with the public may help reduce delays and improve care by earlier presentation to a GP. The following could be used:

- Social media campaigns on X, Facebook, TikTok, Instagram etc.
- Public health awareness posters
- Information on hospital intranets

See also: Endometriosis UK: Dismissed, ignored and belittled and NICE guideline CG138: Patient experience in adult NHS services: improving the experience of care for people using adult NHS services

2

Raise awareness with all healthcare professionals that endometriosis is a chronic condition and should be treated as such.

Primary audiences national:* *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
Primary audiences local:* *Medical Directors, Clinical Directors, and Clinical Audit/Quality Improvement departments
Supported by: NHS England, Welsh Government, Northern Ireland Department of Health

RATIONALE and IMPLEMENTATION SUGGESTIONS

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:

- Recognition of symptoms and referral – all pelvic pain, regardless of cause should be explored further
- Initiation of medical management
- Referral to supportive services to improve quality of life for patients and see specialists early in the condition's course.
- Re-entry into the care pathway for patients with recurrent disease

This may be aided using:

- Training modules
- Information on hospital/GP intranets

3

Improve training on the recognition of symptoms of endometriosis, such as pelvic pain and heavy menstrual bleeding.

a. **In primary care - to support healthcare professionals in the initial assessment, and any ongoing care of patients**
b. **In secondary care - enhanced training on endometriosis should be made available for all healthcare professionals who might care for patients with endometriosis.**

Primary audiences national: ***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***
Primary audiences local: ***Medical Directors, Clinical Directors, and Clinical Audit/Quality Improvement departments***
Supported by: *NHS England, Welsh Government, Northern Ireland Department of Health*

RATIONALE and IMPLEMENTATION SUGGESTIONS

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.
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.
For those working in secondary care, enhanced knowledge may lead to better treatment discussions and decision-making.

Those who may benefit from enhanced training would include:

- Primary care clinicians - GPs/practice nurses/physician associates
- Emergency medicine physicians
- Gastrointestinal physicians and surgeons
- Urologists
- Pain specialists
- Nurses, e.g. triage
- Sonographers

Women's health specialists would bridge the gap between the primary care and surgical care of this group of patients.

THE IMPACT OF ENDOMETRIOSIS ON QUALITY OF LIFE

4

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.

Primary audiences: ***Healthcare professionals in primary care and secondary care***
Supported by: *NHS England, Welsh Government, Northern Ireland Department of Health*

RATIONALE and IMPLEMENTATION SUGGESTIONS

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.

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:

- World Health Organisation Quality of Life
- Consultation/pain questionnaire
- Generalised anxiety disorder assessment
- Patient health questionnaire

ENDOMETRIOSIS MULTIDISCIPLINARY TEAMS AND CLINICAL NETWORKS

5

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

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.
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.
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.

The MDT/clinical networks could include:

- Primary care - general practitioners/practice nurses/physician associates
- Endometriosis clinical nurse specialists
- Gynaecologists
- Pain/chronic pain/pain medicine specialists
- Pharmacists
- Radiologists
- Fertility specialists
- Mental health/practitioner psychologists/pain psychologists
- Pelvic physiotherapists
- Specialist surgeons when needed. e.g. colorectal
- Occupational therapists

This is consistent with NICE Guideline NG73 and British Society for Gynaecological Endoscopy (BGSE) accreditation

MEDICAL/PAIN MANAGEMENT FOR ENDOMETRIOSIS

6

Manage pain effectively for patients who have endometriosis:

a. Set a low threshold for the prescription of analgesia
b. Set a low threshold for hormonal treatment which may improve pain as well as other symptoms – while always considering fertility intentions
c. Refer to pain management services as needed
d. 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.

7

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

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:

a. What the procedure involves
b. The purpose of the procedure e.g. to diagnose, stage, treat the symptoms of endometriosis, or a combination of these
c. What the patient's expectations are
d. The possible effects on endometriosis symptoms
e. Risks, benefits and limitations
f. The need for further laparoscopic/open surgery for recurrent endometriosis or if complications arise

This is consistent with NICE guideline NG73

Primary audiences:* *Consultant surgeons, including gynecology, urology, colorectal, and general surgeons
Supported by: *Medical Directors, Clinical Directors, and Clinical Audit/Quality Improvement departments*

RATIONALE and IMPLEMENTATION SUGGESTIONS

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.

To understand the benefits of any future procedures the operation note should include:

- how many prior laparoscopies the patient has undergone for endometriosis
- a comprehensive surgical description, with photographs
- a description of why any residual endometriotic tissue was left untreated and not removed
- comments about any difficulties performing the procedure which will underpin future decisions to operate.

DISCHARGE, FOLLOW-UP AND READMISSION

9

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.

a. Who to contact if they have any concerns, e.g. GP, endometriosis clinical nurse specialists, consultant
b. The follow-up plan and ongoing management of the endometriosis
c. The option of patient-initiated follow-up
d. Types and dosages of medication they are on at discharge, including analgesia and hormone therapy
e. The consideration of bone health for people with endometriosis on long-term hormonal medication, including nutrition, weight-bearing exercise and alcohol intake

Primary audiences:* *All healthcare professionals who care for patients with endometriosis
Supported by: *Medical Directors, Clinical Directors, and Clinical Audit/Quality Improvement departments*

RATIONALE and IMPLEMENTATION SUGGESTIONS

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.

The use of patient passports could be considered, allowing patients to hold their data.

THE ENDOMETRIOSIS CARE PATHWAY

10

Formalise a care pathway for patients with or suspected to have endometriosis. This pathway should include implementation of NICE guideline NG73, the European Society of Human Reproduction and Embryology (ESHRE) endometriosis guidelines, as well as the recommendations from this report.

Primary audiences national:* *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
Primary audiences local:* *Medical Directors, Clinical Directors, and Clinical Audit/Quality Improvement departments
Supported by: *NHS England, Welsh Government, Northern Ireland Department of Health*

RATIONALE and IMPLEMENTATION SUGGESTIONS

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:

a. Organisation of care
b. Information and support
c. Endometriosis symptoms and signs
d. Pharmacological management
e. Referral to support services to improve quality of life
f. Consideration of fertility intentions
g. When to refer
h. Diagnosing endometriosis, including imaging
i. Informed consent
j. Surgical management
k. Pain/chronic pain management
l. Psychological support
m. Follow-up care
n. Quality of life assessments

FURTHER QUALITY IMPROVEMENT OPPORTUNITIES TO IMPROVE ENDOMETRIOSIS CARE

11

a. Collect surgical outcome data, including patient-reported outcomes, for benchmarking.
b. Review local practice against NICE guideline NG73, the recommendations in this report.
c. Undertake clinical trials to ascertain the efficacy of surgery for endometriosis-associated symptoms, especially for minimal or mild endometriosis.
d. Assess the use of pain medication, and the medical treatment of endometriosis.
e. Explore the use of imaging modalities in the diagnosis of endometriosis.

Primary audiences:* *Grant-making bodies such as the National Institute for Health and Care Research or Medical Research Council

***Supported by:** Relevant Royal Colleges*

FOREWORD (BACK TO CONTENTS)

Endometriosis has a dramatic detrimental effect on the quality of life of many women. It currently takes an average of eight years for patients in the UK presenting with symptoms to receive a diagnosis, yet it is clear from this study that many patients present with pelvic pain and symptoms which ought to immediately suggest endometriosis as a differential diagnosis. The absence of a joined-up, dedicated pathway means that patients are moved back and forth between services, delaying the time to diagnosis and treatment.

Comorbidities in this group of patients are common and their healthcare needs to involve a multidisciplinary specialist team (MDT), who can tailor individualised care packages for this difficult-to-manage condition wherever the patient is seen – whether in primary care, a district general hospital or a specialist centre. However, in this study barely one in ten patients were discussed at such an MDT.

While the least delay in the overall pathway occurred between GP to gynaecology referral, a substantial number of survey respondents sought a private referral. Although this reduced their waiting time to see a gynaecologist and achieve a definitive diagnosis, many independent sector providers were then unable to offer the ongoing holistic care pathway needed.

To date, there are no non-invasive tests able to confirm a definitive diagnosis of endometriosis. Laparoscopic biopsy, with its attendant risks, remains the gold standard. Furthermore, there is limited evidence to show that surgical intervention to excise or ablate lesions is effective in relieving symptoms. Medical management involving painkillers and hormonal treatment is the mainstay for this chronic, often incurable, condition, but these frequently come at the expense of unwanted side effects. Furthermore, hormonal treatments are not always an option for women who are trying to conceive. However, there may be hope on the horizon. Recent genetic studies have identified different sub-types of lesions, and a salivary diagnostic test is under evaluation.[1] Research is also exploring the possibility that there may be a link between endometriosis and chronic infection,[2] opening a potential avenue of antibiotic treatment to control symptoms, and a recent clinical trial has been initiated to explore a new non-hormonal antibody treatment.[3]

In 2018, Australia launched a National Action Plan on Endometriosis to make a "*tangible improvement*" to people's quality of life, with research funding, education campaigns, a national clinical trials registry and specialist clinics. Other countries have since followed their lead. Perhaps this could also be considered in the UK.

As ever I am hugely grateful to all those enthusiasts who have given so freely of their time, both on the study advisory group and by reviewing the data; supported by our clinical co-ordinators and dedicated in-house staff. Without their efforts this important study would not have been possible.

I C Martin, NCEPOD Chair

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,[4] which means that there is a substantial impact on education and work with regard to days lost.[5] 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,[6] 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.*"[6]

There are several national and international guidelines written to support the care of patients with endometriosis, including NICE guideline NG73: Endometriosis; diagnosis and management,[7] and NICE quality standard 172 on endometriosis,[8] as well as the European Society of Human Reproduction and Embryology (ESHRE) endometriosis guideline of 2022.[9] 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.”

CHAPTER 1: METHOD AND DATA RETURNS

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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: 1st February 2018 to 31st 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.

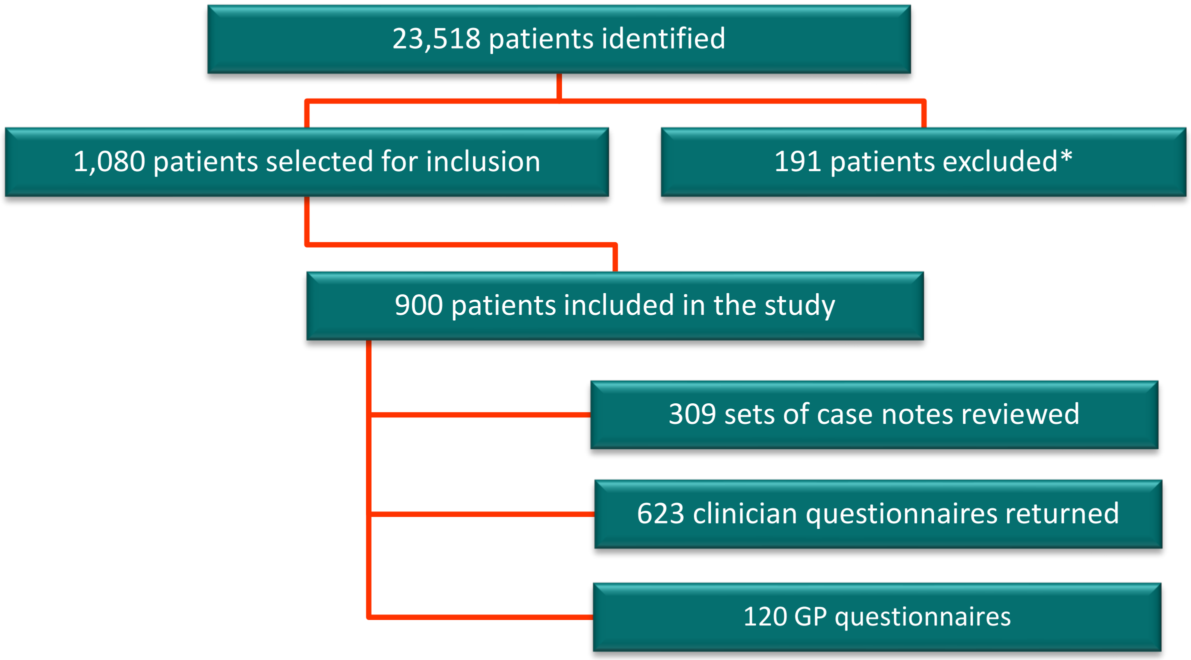

Figure 1.1 Data returned

**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.

Table1.1 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	-	-	-

CHAPTER 2: 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).

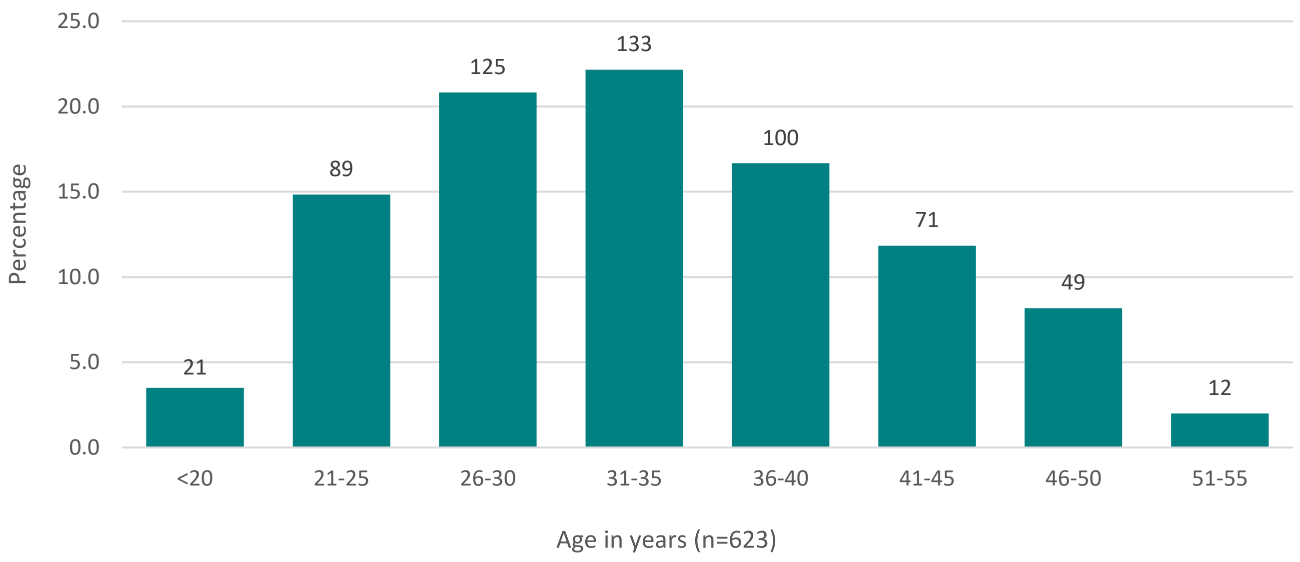

Figure 2.1 Age of the study population

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,[10] possibly reflecting a bias in access to care. Compared with census data in England and Wales,[11] 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
Subtotal	**616**	
Unknown	7	
Total	**623**	

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.[4] 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.

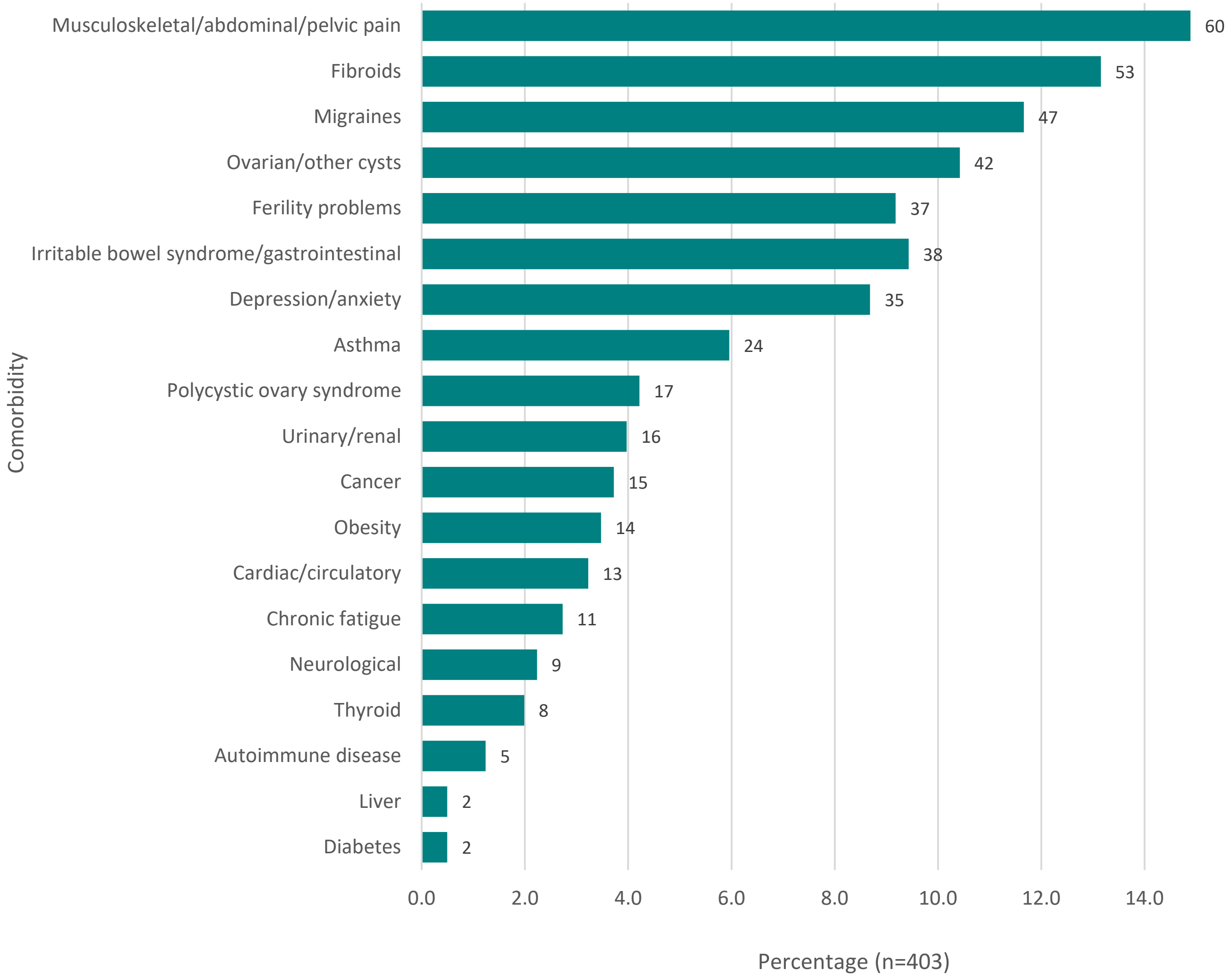

Figure 2.2 Comorbidities

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.

CHAPTER 3: PRESENTATION TO DIAGNOSIS

(BACK TO CONTENTS)

Primary care

Presenting symptoms

The diagnosis of endometriosis should begin with thorough history-taking, a discussion of fertility intentions, and physical examination. The history may often overlap with other diagnoses, or because endometriosis may be affecting a system other than the reproductive system, investigations and referral to services, other than gynaecology, may be needed. There are no features from the history that can absolutely confirm or rule out a diagnosis of endometriosis; it can only be confirmed on imaging, laparoscopic visualisation or biopsy. However, there are symptoms and signs which would suggest endometriosis and they should be recognised.[4]

Data from the clinician questionnaire showed that 496/623 (79.6%) patients presented to their GP with symptoms of endometriosis prior to diagnosis and 80/623 (12.8%) patients were initially referred to specialties other than gynaecology.

Presenting symptoms were variable in the patients in this study, but the majority presented with painful periods and/or heavy menstrual bleeding, irregular bleeding and/or painful intercourse (220/234; 94.0%) (unknown in 169). The location and type of pain (cyclical vs non-cyclical) were mixed. Some patients presented with bowel symptoms (18/234; 7.7%) and urinary/bladder symptoms (14/234; 6.0%). Inability to conceive (subfertility) was a presentation in 12/234 (5.1%) patients and was recorded as a comorbidity in a further 32 patients (Figure 3.1).

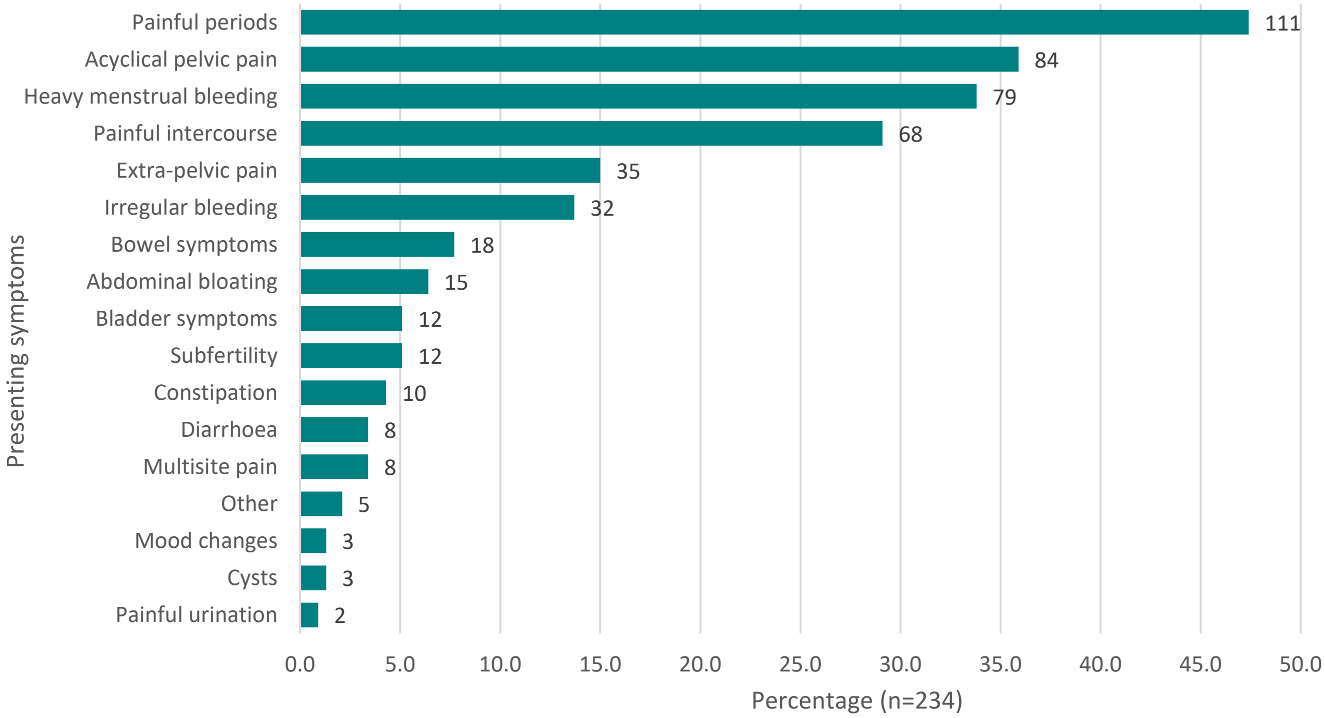

Figure 3.1 Symptoms with which the patients presented to their GP

Answers may be multiple; n=234, clinician questionnaire data

Patient views on their endometriosis care

The patient survey revealed a stark perception of how patients with endometriosis felt treated by their GP, although it is important to note that the respondents were self-selecting and not a representative sample, putting themselves forward because of suboptimal care. However, the findings were consistent with previous work gathering patient views.[5]

More than half (490/941; 52.1%) of the survey respondents felt 'not at all', or 'not very' listened to by their GP. A similar number (452/941; 48.0%) felt that their GP had 'not been at all', or 'not very' compassionate about their symptoms of endometriosis. This was reflected in the fact that 546/941 (58.0%) respondents had multiple visits to the GP before any investigations were undertaken or treatment initiated. A total of 703/941 (74.7%) respondents felt that there was room for improvement in the care that they received from their GP.

Additionally, despite the existence of a national endometriosis charity, Endometriosis UK, and a wealth of patient information leaflets, data from the clinician questionnaire reported only 30/152 (19.7%) (unknown in 44) patients were provided with information from the GP.

Examination in primary care

NICE guidance on endometriosis recommends that the GP carries out a pelvic (internal) and abdominal examination on women presenting with symptoms suggestive of endometriosis as palpation of pelvic structures can aid in diagnosis.[7]

According to the reviewers there was evidence in the case notes that 52/88 (59.1%) patients were examined by the GP (unknown in 45). Of the 36 patients who were not examined, the reviewers stated 19 should have been. Reasons for not examining the patients included patient factors (did not want an examination) or organisational factors (the consultation was via video/telephone, or a chaperone was not available).

When GPs were asked about performing an internal pelvic examination, 48/87 said that they did undertake one and that the findings altered the management for 8/48 patients (unknown in 33). It was of note that in 21/48 patients examined, GPs stated that they did not feel confident in performing a pelvic examination, despite the examination going ahead.

From the patient survey, 393/941 (41.8%) respondents said that they had a pelvic examination during a consultation with a GP and 566/941 (60.1%) said that they had an abdominal examination. The choice of examination may be a medical decision, but the low number of pelvic examinations carried out does demonstrate poor adherence to NICE guidance and could potentially lead to a less focused referral process.

Referral to gynaecology

Reviewers stated that for 31/118 (26.3%) patients there was room for improvement in the referral letter to gynaecology services (unknown in 120) (Table 3.1). Commonly missing from the letter were details from the patient's history, findings from examination, whether hormonal medications had been used and the patient's fertility status. These are all details which are helpful to triage patients to appropriate services and reduce the delay in time to diagnosis and appropriate care.

Table 3.1 Referral to gynaecology

	Yes	%	No	%	Subtotal	Insufficient data	Total
Room for improvement in the referral letter to gynaecology	**31**	26.3	**87**	73.7	**118**	120	**238**
Referral to gynaecology included a working diagnosis that mentioned endometriosis	**74**	47.4	**82**	52.6	**156**	82	**238**
There was a delay in the initial referral to gynaecology	**36**	26.5	**100**	73.5	**136**	102	**238**

Case reviewer data

Reviewers believed that for 36/136 (26.5%) patients there was a delay in initial referral to gynaecology (unknown in 102) and in 25/36 the quality of the care they received was impacted by this (Table 3.1).

The reviewers found that 40/238 (16.8%) patients were initially referred to non-gynaecological services including general surgery, gastroenterology/colorectal surgery, fertility services and urology. Twenty of the patients referred to other services (20/40) went on to have further investigations, and for ten of those patients, reviewers thought that these investigations contributed to the delay in diagnosis. It was unclear as to whether the investigations were necessary.

Secondary care

The pathway and provision of specialist care for endometriosis are divided, depending on the patient's severity of the endometriosis. Severity of the endometriosis relates to the extent of the endometriosis and not to degree of symptoms, yet it is often used as the reason for referral to a British Society of Gynaecological Endoscopy (BSGE) specialist centre. However, patients can have debilitating symptoms with less severe endometriosis. This division of pathways can lead to variation in time to appropriate management of severe endometriosis as well as assessment of quality of life, multidisciplinary team (MDT) working, referral to support services and access to care.

Time to gynaecology review

The overall timeframe from a patient presenting with symptoms until diagnosis is known to be long[6] (see Figure 3.5 later in the chapter). Data in this study showed that the shortest part of the pathway appeared to be from the point of the GP referring the patient to gynaecological services, to the patient being seen by the gynaecology team, which occurred within nine months of referral for 162/230 (70.4%) patients.

There were 204/724 (28.2%) survey respondents who chose to be seen by a private gynaecologist due to delays in this part of the pathway (referral from GP to an NHS gynaecology service) (unknown in 217). The reviewers stated that although private care may offer a timelier first gynaecology appointment, ongoing continuity of care with a holistic approach may not be done well. The average wait time for a gynaecology consultation was more than six weeks for 66/67 NHS hospitals but less than six weeks for 16/28 independent hospitals surveyed. However, only 4/28 of the independent hospitals reported that they provided full holistic care for endometriosis patients.

British Society of Gynaecological Endoscopy centres

The BSGE has developed national criteria to specify standards of service and workload required for patients considered to have severe endometriosis.

There are 63 UK specialist endometriosis centres (BSGE). The case review showed that there were 58/309 (18.8%) patients seen within BSGE centres, with 23 patients being directly referred by the GP, which would have reduced a delay in diagnosis. Ten patients required referral by secondary care gynaecology to the specialist centre, and 11 via the emergency department. Organisational questionnaires were received from 55 BSGE centres. The vast majority (53/55) accepted direct referrals from primary care.

Reviewers were of the opinion that 28/251 (11.2%) patients who were not referred to a BSGE centre should have been (unknown in 58). The reasons given were mainly the severity/complexity of the endometriosis and the requirement for holistic care.

Examination in secondary care

NICE guidance recommends that all patients are examined within secondary care gynaecological services.[7] In 442/623 (70.9%) patients, the clinicians had information about the first referral. From these data it could be seen that 250/442 (56.6%) patients had an abdominal examination and 268/442 (60.6%) had a pelvic examination (Table 3.2).

Table 3.2 Examinations undertaken by the gynaecologist for the symptoms of endometriosis

	Number of patients	%
Abdominal examination	250	56.6
Pelvic examination	268	60.6
Unknown	86	19.5

Answers may be multiple; n=442, clinician questionnaire data

In 86/442 (19.5%) patients it was unknown whether an examination took place at all. This was of note given that in 203/289 (70.2%) of the 442 patients who were examined resulted in positive findings (Figure 3.2). However, it should be acknowledged that there may be reasons why a patient might decline a pelvic examination and so it may be more appropriate to request an ultrasound scan (USS) or magnetic resonance imaging (MRI) at this point; despite these imaging modalities not being recommended as the first line of investigation.

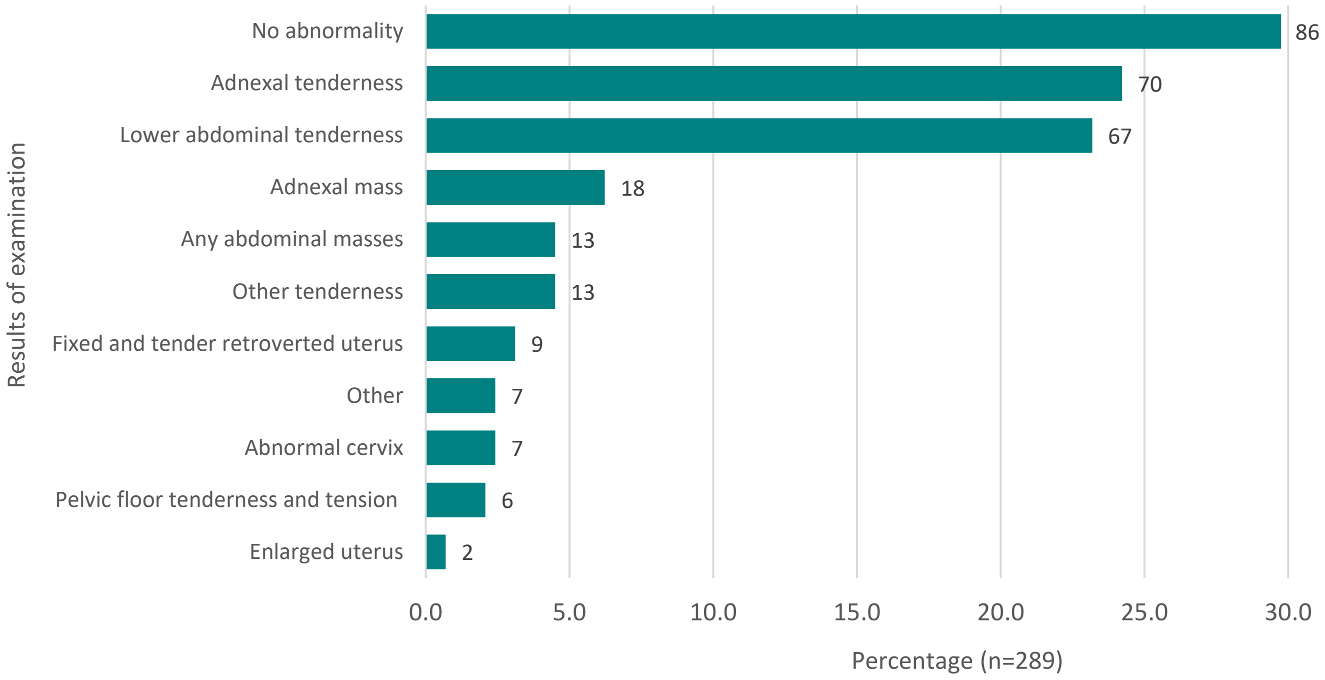

Figure 3.2 Findings of examination
Clinician questionnaire data

Imaging

The clinician questionnaire demonstrated that prior to a diagnosis of endometriosis 424/549 (77.2%) patients were referred for an ultrasound scan (unknown in 74). Ultrasound imaging had been requested by the GP prior to the individual being seen by the gynaecology team in 232/393 (59.0%) patients (unknown in 31). Ultrasound had also been requested by other services including acute physicians (11/393; 2.8%) and other specialty doctors (18/393; 4.5%). Gynaecologists first requested imaging in 132/393 (33.6%) patients (Figure 3.3).

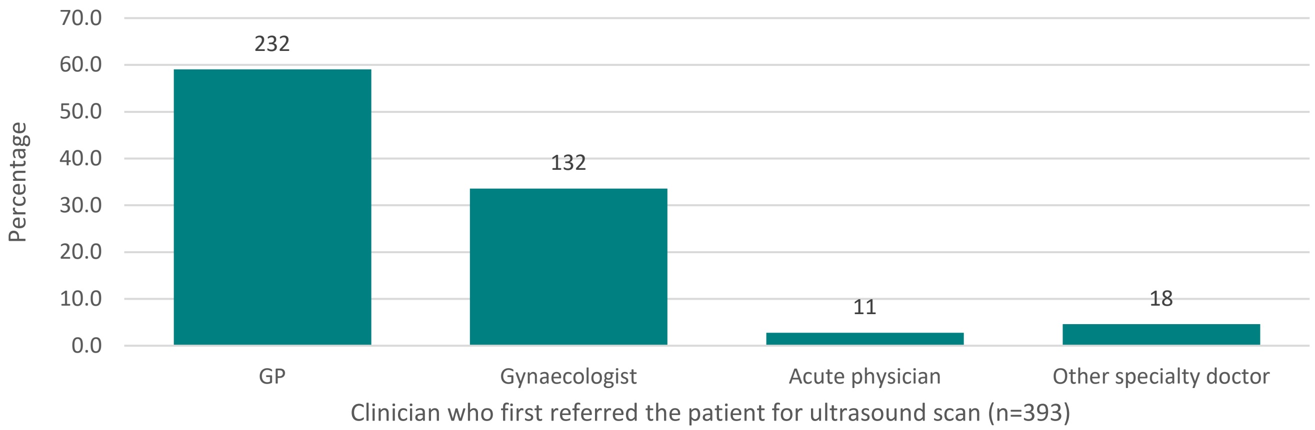

Figure 3.3 Specialty of the clinician who first referred the patient for an ultrasound scan
Answers may be multiple; n=393, clinician questionnaire data

A transvaginal ultrasound scan, as recommended by NICE,[7] was undertaken in 332/424 (78.3%) patients. However, only 32/332 (9.6%) of the ultrasound scans were performed by someone with specialist training in ultrasound use for diagnosing endometriosis. This potential lack of specialist training may contribute to the delay in endometriosis being recognised and a missed opportunity for referral for laparoscopy, and appropriate treatment.

There were 78/623 (12.5%) patients who had an MRI scan prior to diagnosis. MRI is not recommended as a first line investigation and so reasons for having an MRI may have been due to the patient declining ultrasound, examination and/or ultrasound not being feasible, or potentially a differential diagnosis requiring another imaging modality. Of the patients who had an MRI scan, only 28/78 were reported by an endometriosis specialist. Although this represents a higher proportion than the reporting for ultrasound scans, the lack of specialist training is again potentially contributing to delays in reaching a diagnosis of endometriosis.

Data were available in the case notes regarding imaging before diagnosis on 166/238 (69.7%) patients. From these data, endometriosis was seen on imaging in 62/166 (37.3%) patients. Reviewers thought that there was room for improvement in imaging in 32/166 (19.2%) patients. Five of these patients should have had an ultrasound requested by the GP prior to referral. Six patients had a significant delay in imaging, causing a delay in attaining the final diagnosis. Reviewers stated that six patients should have had an MRI scan given how they presented and/or the inability to examine them. Reporting was poor in six of the patients, and 13 patients had no imaging reported at all.

Imaging reports were communicated back to the GP for 348/363 (95.8%) patients (unknown in 61).

Policies and procedures outlining expectations for endometriosis care

The organisational questionnaire collected data on overarching policies within individual hospitals and expectations of the clinic visit. There were 161/167 (96.4%) hospitals in which a review of endometriosis symptoms was stipulated, and 158/167 (94.6%) recommended a review of previous imaging. An outline of possible treatment options was suggested in 145/167 (86.8%) hospitals (Figure 3.4). Other stipulations included referral for ultrasound if not already undertaken, referral for MRI if warranted and assessment of fertility needs as well as referral to fertility services.

Only 110/167 (65.9%) hospitals from which an organisational questionnaire was returned reported that patients were routinely provided with all information about their condition. This was mostly in the form of a printed leaflet or verbally at the clinic appointment. Only 40/167 (24.0%) hospitals reported routinely directing patients to endometriosis patient support groups and other holistic services such as pain clinic, fertility services, or mental health assessment and support (Figure 3.4).

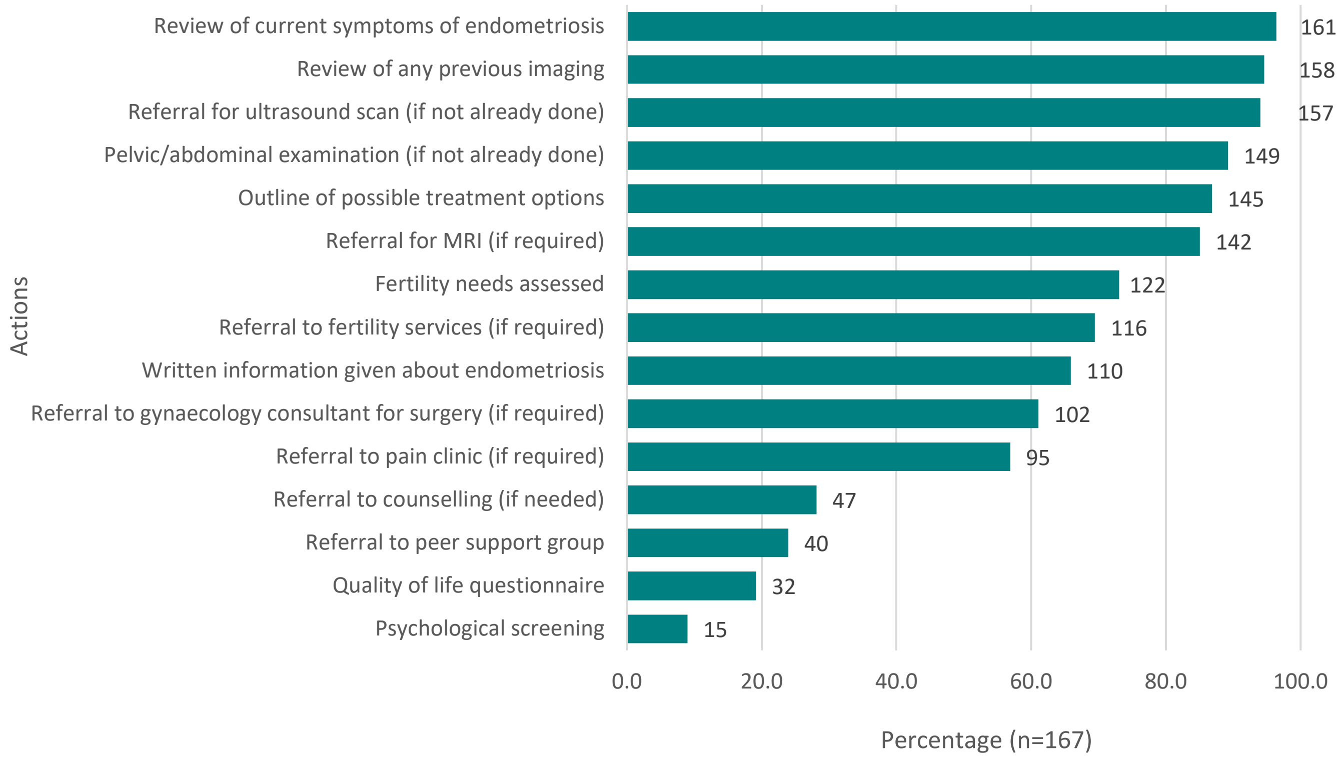

Figure 3.4 Policy of actions to be carried out at initial gynaecology clinic appointment
Answers may be multiple; n=167, organisational data

Patient views on their endometriosis care

When asked if patients felt listened to by the gynaecologists in relation to their symptoms, 227/725 (31.3%) responded 'not at all' or 'not very much', 199/725 (27.4%) 'somewhat', and 299/725(41.2%) responded 'yes' or yes to a great extent' (unknown in 216). These responses were more positive than those relating to the same question about GPs. However, given this is their area of expertise, it would be expected that the specialist would be more engaged.

Endometriosis clinical nurse specialists

Most specialist BSGE centres returning organisational data (52/55) reported that there were one or more whole time equivalent endometriosis clinical nurse specialists dedicated to the service (2/100 non-BSGE centres). However, only 11 of the 58 patients treated in a BSGE centre, whose care was assessed as part of the case review, were seen by an endometriosis clinical nurse specialist at any point in the pathway (and none of those treated in non-BSGE centres).

There were 200/941 (21.3%) survey respondents who had been seen by an endometriosis clinical nurse specialist, and they were positive about the care they received. Of these, 144/200 (72.0%) felt 'listened to' by the endometriosis clinical nurse specialist and 148/200 (74.0%) found them to be compassionate.

Delay in initiation of appropriate care

It has been previously reported that diagnosis is frequently delayed, taking on average eight years.[12] Figure 3.5 shows that in this study, the mean time from first appearance of symptoms to presentation to the GP was 4.1 years (range 0 to 40 years), with 588/840 (70%) survey respondents reporting it took them two years to present to the GP with symptoms. The mean time from presentation at the GP to diagnosis of endometriosis was 4.7 years (range 0.1-19 years). This delay in diagnosis is not only costly in terms of loss of education and work productivity for the patient but can also impact on fertility and lead to chronic pain; all of which results in a significantly higher use of healthcare.[13]

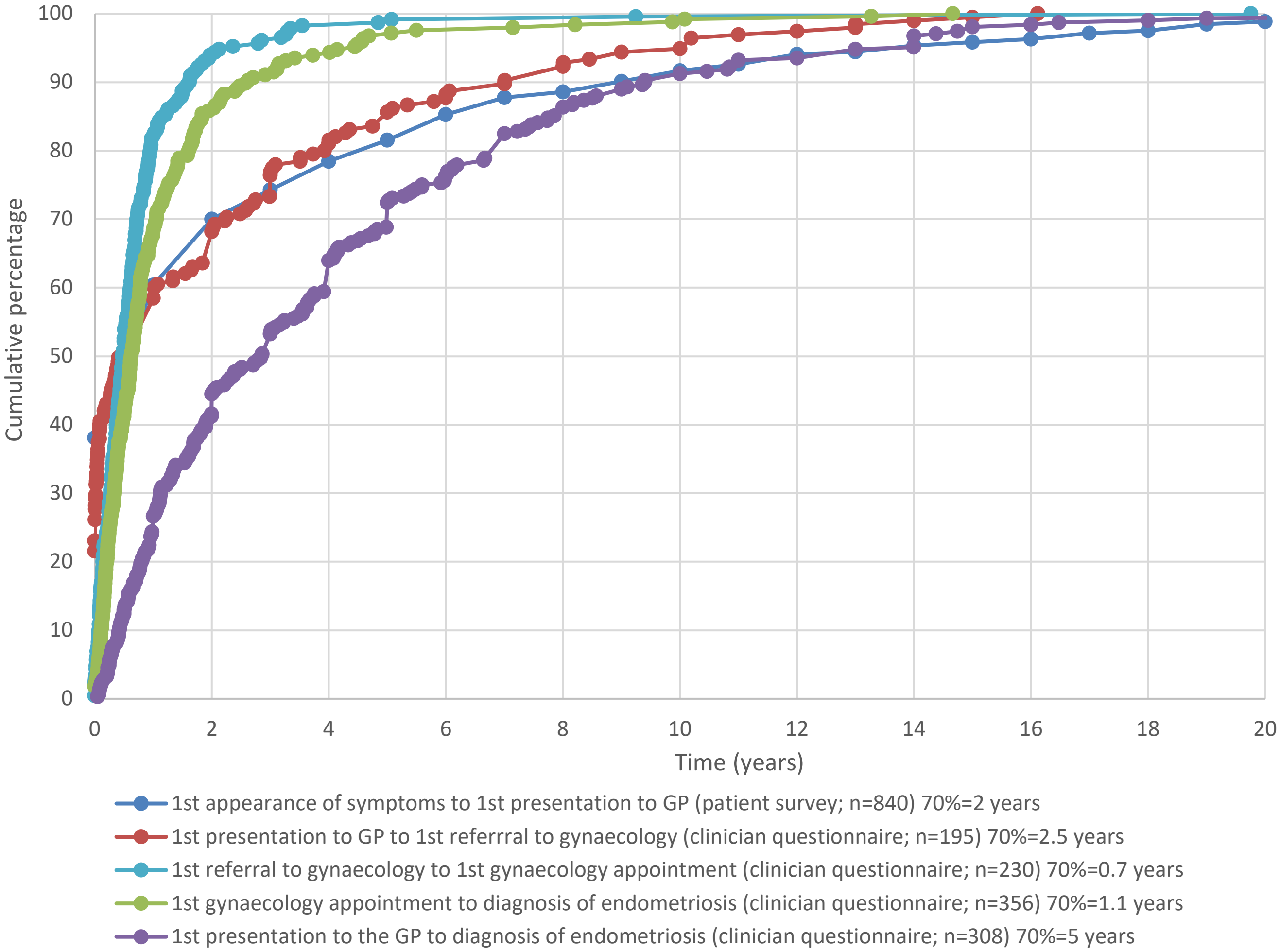

Figure 3.5 timeline of events in the treatment pathway for endometriosis

Figure 3.5 demonstrates the timeline of events in the treatment pathway for endometriosis for the patients in this study. It illustrates that once symptoms are recognised and reported, referral to appropriate services takes place and the time delay reduces. This suggests that education of both patients and GPs is essential in helping people to recognise symptoms of endometriosis to reduce the delay in initiating appropriate management.

Case study 1 illustrates how the delays in the pathway can occur.

CASE STUDY 1

A 24-year-old woman presented to her GP with heavy menstrual bleeding and pain. The GP treated her with the combined oral contraceptive pill. She had multiple visits to the GP over three years, with continuing pain for which the GP prescribed analgesia which included codeine. No further investigations were undertaken during this time. After three years, she stopped taking the combined pill as she wanted to get pregnant. However, 18 months after that she was referred to fertility services by the GP as she was not pregnant and was experiencing worsening pelvic pain. The fertility services requested a pelvic ultrasound which showed an endometrioma. They then referred her to local gynaecology services where she was seen three months later. She was listed for a laparoscopy and cystectomy, which happened six weeks later, and endometriosis was diagnosed.

It took around five years for this patient to be given a diagnosis of endometriosis and for appropriate treatment to be initiated. If the GP had suspected endometriosis at an earlier stage, then a pelvic examination and an ultrasound scan may have been performed sooner, leading the patient along the correct pathway for an earlier diagnosis of endometriosis and appropriate management. The delay in diagnosis also delayed appropriate fertility management.

Delay in initiation of appropriate management and treatment was seen in 48/240 (20.0%) (unknown in 69) patients reviewed and was not solely due to lack of education as can be seen in Table 3.3. In. However, lack of education still underpinned much of the delay in the view of the reviewers, as this led to delay in the gynaecology team referring for surgery (12/48) and ineffective prior laparoscopy (4/48).

Table 3.3 Reasons for delay

Reason for delay	Number of patients
COVID-19 pandemic	15
Delay in recognition/ referral from primary care	14
Patient factors	13
Delay in gynaecologist referral for surgery	12
Endometriosis/ clinical factors	10
Organisational factors	6
Ineffective prior laparoscopy	4

Answers may be multiple; n=48, case reviewer data

In the clinician survey reasons given for delay in initiation of appropriate management and diagnosis were multiple. In addition to education, lack of administrative support, poor MDT provision *'just corridor conversations, no formal MDT',* lack of theatre capacity and patients being passed from one service to another with a lack of joined-up care, were all reasons cited for a delay. Reviewers were of the opinion that the delay in diagnosis caused a worsening of symptoms in 22/48 patients, and that this affected the outcome in 7/22 patients.

Training

There were 62/137 (45.3%) clinicians who completed the survey who said that they had attended additional training in the care of patients with endometriosis during the previous five years. This was provided by the workplace for only 11/62 clinicians. There were 50/137 (36.5%) clinicians who worked in a BSGE centre.

"Many doctors, including gynaecologists, still believe that a painful period is normal, painful intercourse needs a psychosexual counsellor and painful defecation means irritable bowel syndrome." (Quote from the clinician's survey in response to reasons for a delay in diagnosis)

The organisational questionnaire showed the availability of training in the care of patients with endometriosis in (76/167; 45.5%) hospitals, with 70/76 hospitals offering it to gynaecologists and 34/76 to endometriosis clinical nurse specialists (Table 3.4). Other specialists within a hospital would not be expected to undergo endometriosis training, but hospitals and professional bodies should raise awareness of endometriosis and how it might present within other specialties.

Table 3.4 Healthcare professionals who receive training in the care of patients with endometriosis

	Number of hospitals
Gynaecologists	70
Other nursing staff	38
Other medical staff	36
Endometriosis clinical nurse specialists	34
Other surgical staff	32
Ancillary healthcare professionals	20
Other	5

Answers may be multiple; n=76, organisational questionnaire data

CHAPTER 4: HOLISTIC CARE

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Holistic care

Screening for comorbidities and quality of life, holistic care as well as patient-reported outcome measures (PROMs) and patient support is important to ensure a good balance between treatment and the impact of endometriosis on everyday life, especially for those patients trying to conceive. Holistic care not only integrates fertility wishes into the patient's care, but also enables signposting to other services such as dietary interventions, exercise, sleep hygiene and stress management.

Holistic care needs are variable depending on the extent of the endometriosis. Patients with severe endometriosis who are referred to a British Society for Gynaecological Endoscopy (BGSE) centre may have quite different experiences of holistic care to those being treated in secondary care. Our data showed that not all patients with severe endometriosis involving the bowel and bladder are necessarily referred to BSGE centres – only 22/46 of those identified in the study as meeting those criteria were referred to a specialist centre. Additionally, given that superficial endometriosis can also present with significant symptoms and comorbidities, those patients not referred to BSGE centres may additionally benefit from the more holistic and multidisciplinary team (MDT) approach that the BSGE centres should be providing.

Data from the clinical questionnaire showed that onward referrals to mental health services (9/573; 1.6%) and pain clinics (46/573; 8.0%) were low. The most common referrals were to fertility services (80/573; 14.0%) and surgical specialties (65/573; 11.3%), while 319/573 (55.7%) patients had no onward referrals documented (unknown in 50) (Figure 4.1).

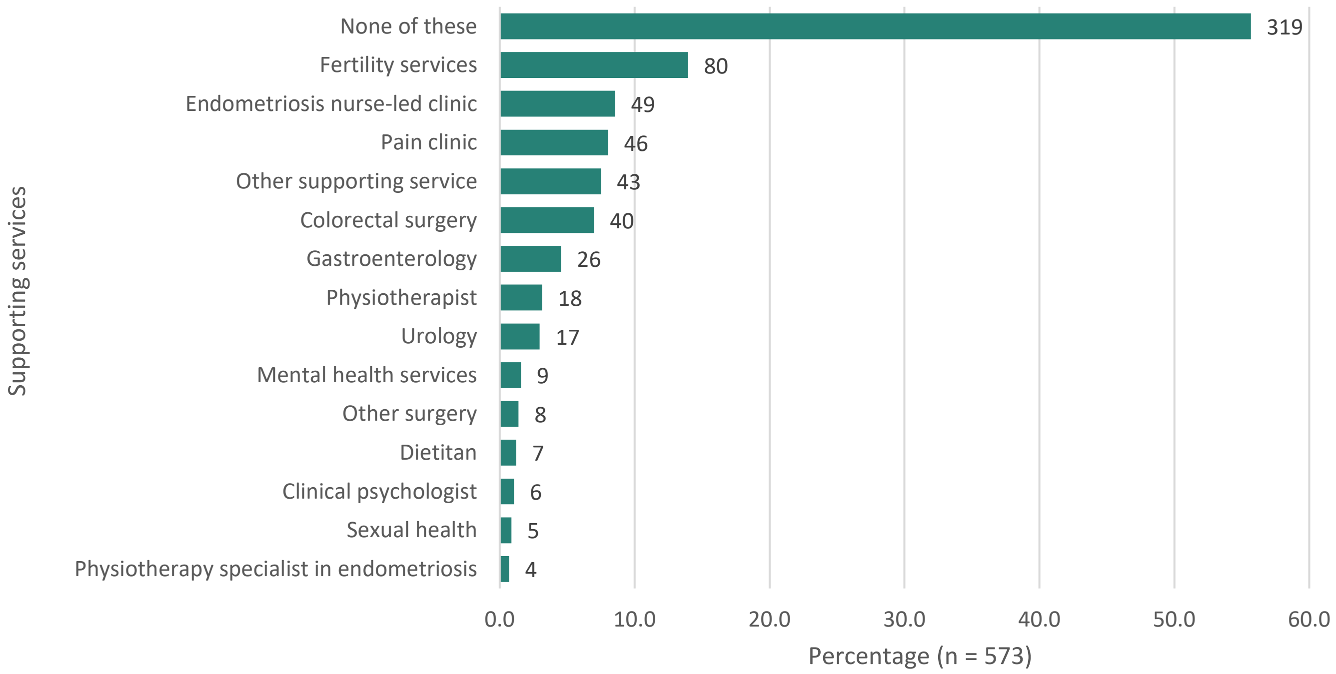

Figure 4.1 Support services offered
Answers may be multiple; n=573 (unknown in 50), clinician questionnaire data

Pain and poor mental health are among the two most prevalent presenting comorbidities or symptoms. At an organisational level, only 15/167 (8.9%) hospitals reported routine psychology screening within the clinic appointment. Just 17/167 (10.2%) hospitals had a full-time psychologist within the service. If no psychologist was available, 45/150 (30.0%) hospitals had a defined pathway to refer to psychology.

Screening for poor mental health was either not done routinely, or poorly documented with reviewers noting that 251/261 (96.1%) patients had no documentation of mental health screening within the patient notes (unknown in 48).

Reviewers identified 22 patients who had co-existing poor mental health recorded. Of these, only three were referred to mental health services. Reviewers believed that a further 16 of the 22 patients should have been referred.

The reviewers identified that failure to refer to supportive services resulted in less than best practice in 70/309 (22.7%) patients. They believed that 24/70 patients should have had their care within a specialist endometriosis centre to benefit from the MDT working. Furthermore, 13/70 patients should have been referred to mental health services, 16/70 to a pain clinic, 7/70 to nutritional support and cardiovascular health, 19/70 to fertility services and 6/70 to peer support groups. These figures reflect a lack of joined-up thought and care for these patients whose quality of life would benefit from an MDT and holistic approach.

Quality of life assessments and patient-reported outcome measures (PROMs)

The service requirement for BSGE centres stipulates that patient-reported outcome measures (PROMs) are used to assess the individual symptoms and the global quality of life score is measured at a single point in time to be used to audit outcome.[14] Comparing the pre-operation scores with those from two years post operation would be expected to show improvement.

Only 18/623 (2.9%) patients in the study were referred to physiotherapy despite the high numbers reporting pain, much of which was musculoskeletal or pelvic pain and would benefit from physiotherapy.

Almost half (420/941; 44.6%) of survey respondents stated that they were not asked at any point of the pathway about the impact of symptoms on their quality of life. Where it was answered, a small number (22/667; 3.3%) said that they were referred to supportive psychology services, while 118/732 (16.1%) were referred to a pain clinic and 108/732 (14.8%) to fertility services. These are low numbers of referrals given the prevalence of these comorbidities among patients diagnosed with endometriosis.

Asking all patients to complete a quality of life questionnaire during a gynaecology consultation is not always realistic, but all history taking should include some element of psychosocial history and the impact of symptoms on daily living. Appropriate third sector organisations and allied health professionals may provide significant benefit to many of these patients (**USEFUL LINKS**).

Quality of life assessments, such as patient-reported outcome measures (PROMs) can also be an important part of the follow-up appointment to assess the effectiveness of treatment and to review the ongoing management plan. Clinicians completing questionnaires reported that 202/623 (32.4%) patients did not have any form of quality of life assessment carried out as part of their care. For those who did, most commonly it was an assessment of pain 271/532 (50.9%) (unknown in 91) (Figure 4.2).

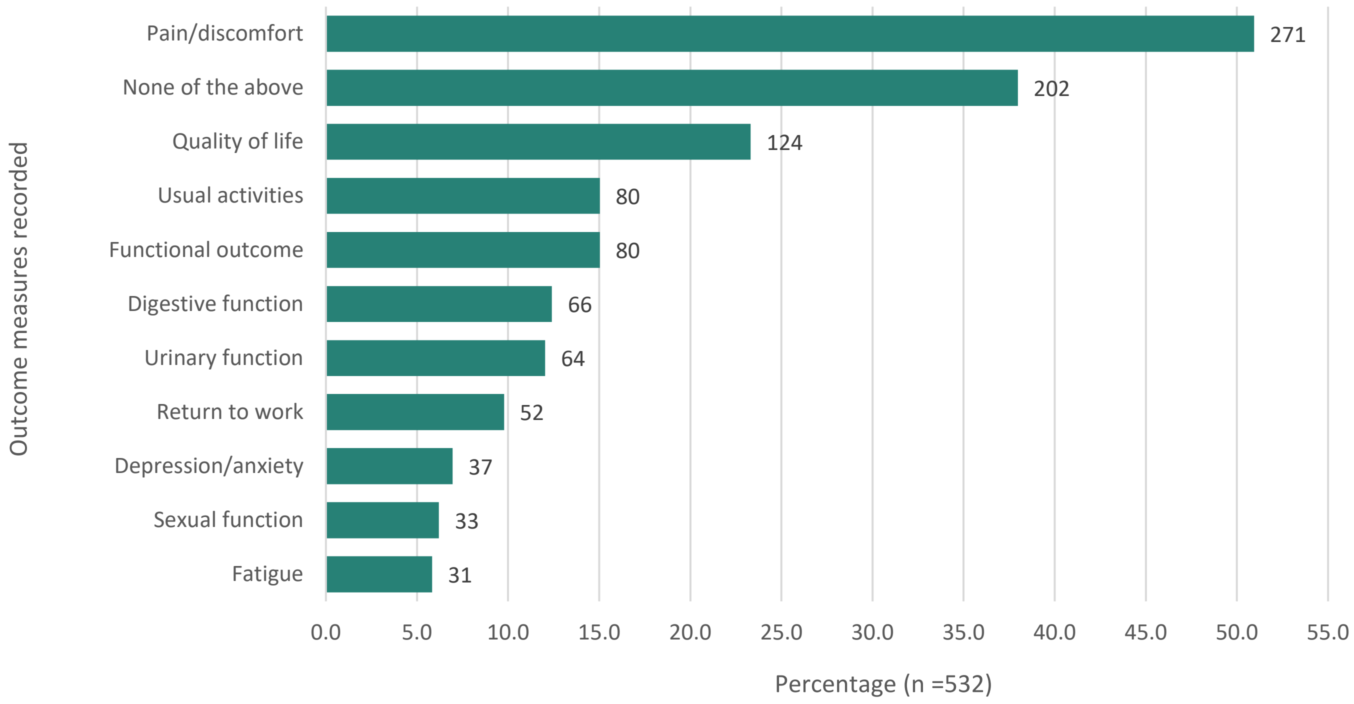

Figure 4.2 Patient-reported outcome measures
Answers may be multiple; n=532 (unknown in 91), clinician questionnaire data

The organisational questionnaire data showed that patients were routinely asked to complete quality of life questionnaires at their initial appointment and in 42/167 (25.1%) hospitals PROMs were carried out at a follow-up appointment. In only 3/167 (1.8%) hospitals was psychological screening routinely performed. The fertility status of patients was assessed in 40/167 (24.0%) hospitals and there were 149/167 (89.2%) hospitals that outlined possible treatment options as well as the risks and benefits of the treatment. However, overall, the routine holistic assessment of patients by taking a psychosocial history at the initial outpatient clinic appointment could be improved.

Fertility

Endometriosis does not necessarily cause infertility but there is an association with fertility problems, although the cause is not fully established. Even with severe endometriosis, natural conception is still possible. It is estimated that 60-70% of women with endometriosis can get pregnant spontaneously.[15] However, infertile women are six to eight times more likely to have endometriosis than fertile women,[16] hence close liaison with fertility specialists is important when treating patients with endometriosis.

It was evident from the case reviews that fertility services often work separately from endometriosis services; referring in and out, without joined-up care. Almost a third of patients were identified with fertility concerns (94/309; 30.4%), with 65/94 being referred to fertility services. Reviewers identified that 22 patients had room for improvement regarding fertility services.

There were 732/941 (77.8%) survey respondents who had surgery, of which 199/542 (36.7%) stated that they had a conversation regarding prioritising fertility before surgery for endometriosis (unknown in 190). However, examples of good practice were found in the case notes as demonstrated in case study 2.

CASE STUDY 2

A 27-year-old woman presented to her GP with pelvic pain and heavy menstrual bleeding which she said was affecting her quality of life. She was finding it difficult to continue working as a schoolteacher. The GP performed a pelvic examination which was normal. He requested a pelvic ultrasound scan and referred her to gynaecology services in secondary care. He also prescribed mefenamic acid and tranexamic acid as she declined hormonal treatment due to concerns about its effect on her mood. The GP enquired about her mental health as her records showed that she had previously attended an emergency department due mental ill health. The patient admitted that her mood was low, and the GP referred her to mental health services. The GP provided the patient with information about Endometriosis UK as they thought that this might be the diagnosis.

This case study illustrates good holistic care. The GP recognised that the patient may have endometriosis. As well as providing information about the condition, they discussed the impact of the condition on the patient's quality of life. The GP recognised the need for mental health support and made a referral. The GP also addressed the patient's symptoms by providing treatment while she awaited specialist review.

Multidisciplinary teams

Like other chronic conditions managing endometriosis effectively requires a robust multidisciplinary working. The bringing together of individuals for MDT meetings may take many different forms. BSGE centres are expected to conduct 'formal' MDT meetings for patients with severe endometriosis.[14] Given the chronicity of endometriosis, it seems important that all patients should be discussed by a wider professional team. It was found that less than half (73/167; 43.7%) of hospitals held regular endometriosis MDT meetings.

All of the BSGE centres (55/55) reported holding endometriosis MDT meetings, compared with 18/112 (16.1%) hospitals that were not BSGE centres. Reviewers found that only 27/242 (11.2%) (unknown in 67) patients were formally discussed in an MDT meeting and 28/215 (13.0%) patients who were not discussed should have been.

It appeared that not all patients with endometriosis were discussed within the MDT. The organisational data demonstrated that it was largely the patients with deep, severe, recto-vaginal, complex, and extra-pelvic endometriosis who were discussed (those seen in BSGE centres) and yet we know that superficial endometriosis can cause significant symptoms and so have an equally adverse effect on the patient's life. These patients would also benefit from the support of a more robust MDT approach (Figure 4.3).

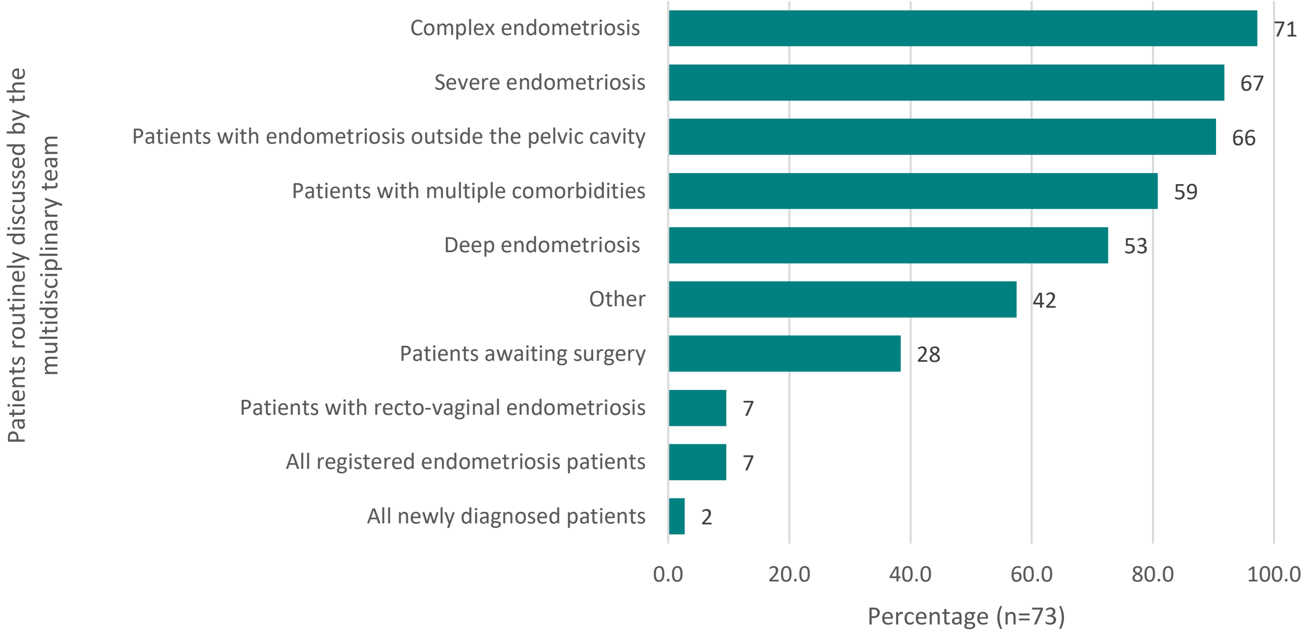

Figure 4.3 Patients who were discussed at MDT meetings
Answers may be multiple; n=73, organisational data

The clinician survey data highlighted areas of good practice being around the provision of holistic care with several clinicians citing examples. However, this approach should be ‘core business’, not the exception.

Table 4.1 shows which specialties were involved in the MDTs. However, these were not always whole-time equivalent roles. Within the MDTs, 111/167 (66.4%) hospitals had one whole-time gynaecologist, 34/167 (20.3%) had two, and 36/167 (21.5%) had three or more. Only 8/167 (4.8%) hospitals had more than one whole-time endometriosis clinical nurse specialist. In terms of pain specialists, 25/167 (14.9%) hospitals had one whole-time pain specialist within the endometriosis team, while 6/167 (3.5%) did not have any pain specialist available.

Thirty-one hospitals had one or more dedicated colorectal surgeons as part of the service, 26/167 (15.5%) hospitals had one or more whole-time fertility specialist employed in the team and three hospitals had a dedicated physiotherapist. Forty-seven hospitals had at least one or more radiologist specialising in endometriosis.

Table 4.1 All the healthcare professionals who comprised the multidisciplinary team

	Number of hospitals	%
Gynaecologist	160	95.8
Radiologist	96	57.5
Colorectal surgeon	93	55.7
Urologist	85	50.9
Pain specialist	73	43.7
Endometriosis clinical nurse specialist	64	38.3
Reproductive medicine specialist	58	34.7
Physiotherapist	40	24.0
Histopathologist	35	21.0
General surgeon	35	21.0
Pharmacist	33	19.8
General nurse	29	17.4
Gynaecology specialist nurse	19	11.4
Psychologist	17	10.2
Dietitian	10	6.0
Occupational therapist	4	2.4
Other	10	6.0

Answers may be multiple; n=167, organisational data

CHAPTER 5: MEDICAL CARE (BACK TO CONTENTS)

The most common presenting symptom of endometriosis is pelvic pain. If a GP suspects that a patient may have endometriosis, they should consider a patient's circumstances, symptoms and priorities, particularly with regard to planning a pregnancy and aspects of daily living, before prescribing medication. NICE recommends that patients should be offered initial management of pain, which is often the main symptom, with paracetamol or a non-steroidal anti-inflammatory drug (NSAID) either alone or in combination with hormonal treatment before considering referral to a gynaecology specialist.[7]

Medical treatment may be started prior to laparoscopic confirmation. Hormone treatments include progestogens, combined oral contraceptives, gonadotrophin-releasing hormone (GnRH) agonists and antagonists and the aromatase inhibitors as examples. These drugs have all been shown to reduce pain in patients with endometriosis.[7] Neuromodulators (e.g. anti-depressants, selective serotonin reuptake inhibitors (SSRIs) or anticonvulsants), used mainly by pain medicine specialists, may also be used in primary care. However, they have not been shown to be superior and are associated with dose-limiting side effects.[17]

In this study, 47/90 patients referred to a gynaecology specialist had medications prescribed by their GP before attending the gynaecology department (unknown in 43). The most common therapy prescribed by GPs was hormonal treatment 36/47 (Table 5.1). Ten patients were prescribed tranexamic acid to reduce heavy menstrual blood loss, although its efficacy to improve the pain associated with endometriosis has been questioned.[18]

Table 5.1 Medications prescribed by GP

	Number of patients
Hormonal treatment	36
Pain medication	21
Tranexamic acid	10

Answers may be multiple; n=47, case reviewer data

Of the 733/941 (77.9%) survey respondents prescribed hormonal treatments, only 363/687 (52.8%) had any improvement in symptoms when first prescribed medications by their GP (Table 5.2), and only 209/733 (28.5%) had a follow-up appointment.

Table 5.2 Hormonal treatment was successful in easing endometriosis symptom-related pain

	Number of patients	%
Yes	49	7.1
No	294	42.8
Somewhat	314	45.7
Declined treatments	30	4.4
Subtotal	**687**	
Unknown	46	
Total	**733**	

Patient survey data

A total of 294/687 (42.8%) respondents to the patient survey said they experienced no improvement with medication. Despite this, 200/244 (82.0%) had no further investigation by their GP (Table 5.3).

Table 5.3 GP continued to further investigate the cause if symptoms

	Number of patients	%
Yes	26	10.7
No	200	82.0
Somewhat	18	7.3
Subtotal	**244**	
Unsure	50	
Total	**294**	

Patient survey data

The efficacy of hormonal treatment was also recognised by the clinicians in secondary care, where 377/623 (60.5%) patients received this therapy, most commonly levonorgestrel releasing intrauterine systems (153/377; 40.6%), combined hormonal contraception (120/377; 31.8%), gonadotrophin-releasing hormone (GnRH) agonists (116/377; 30.8%) and oral progestogen (115/377; 30.5%) (Figure 5.1).

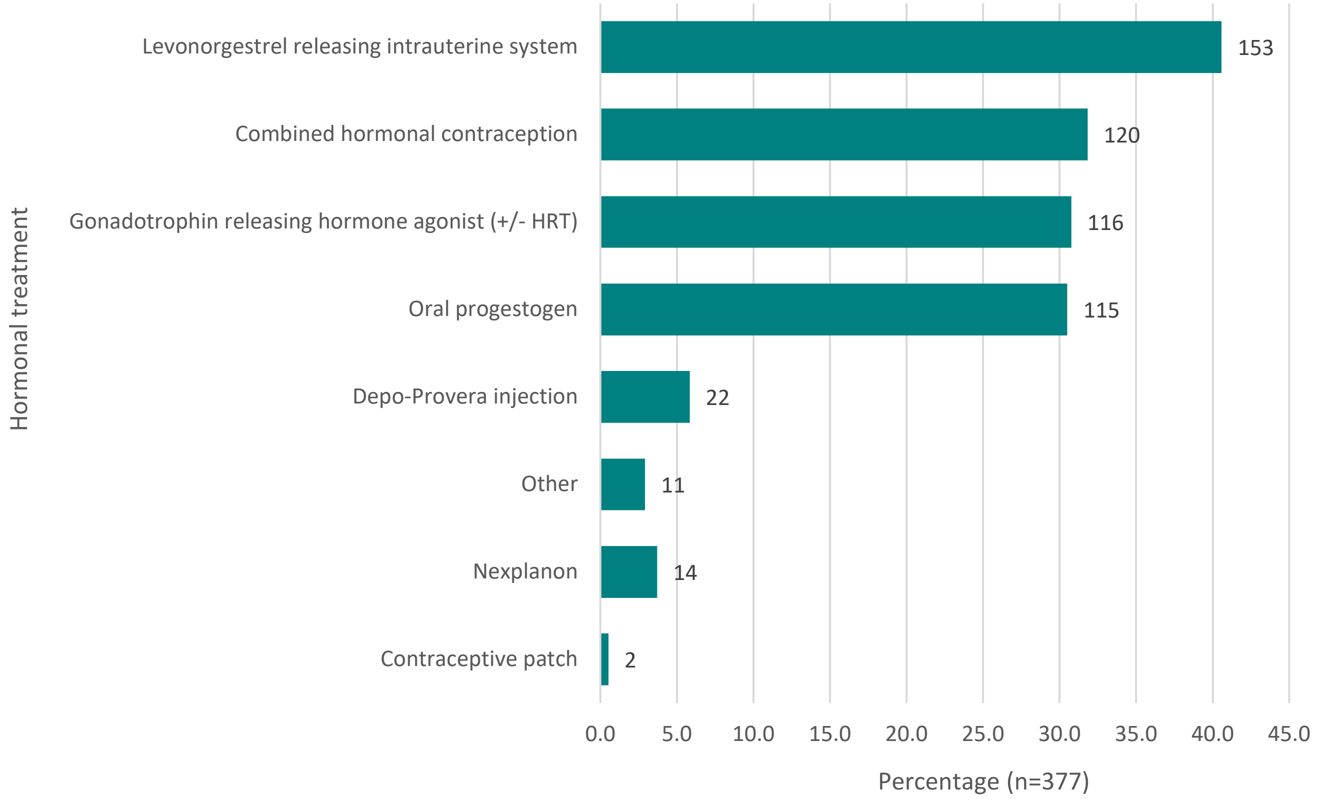

Figure 5.1 Hormone treatments given

Answers may be multiple; n=377, clinician questionnaire data

A total of 217/623 (34.8%) patients received no hormonal treatments; the most common recorded reason was that they were trying to conceive (88/217; 40.6%) or patient choice for reasons other than fertility (39/217; 18.0%) (unknown in 29) (Table 5.4).

Table 5.4 Reasons no medication was prescribed

	Number of patients	%
Fertility reasons	88	40.6
Unknown	81	37.3
Patient choice (other than fertility reasons)	39	18.0
Symptoms resolved without treatment	18	8.3
Patient had already been prescribed hormonal treatment	16	7.4
Treatment was not previously effective	16	7.4
Endometriosis discovered at surgery	15	6.9
Patient was already on an alternative successful treatment	6	2.8

Answers may be multiple; n=217, clinician questionnaire data

Pain medication and management

Endometriosis associated pain includes non-menstrual pelvic pain as well as painful intercourse, and pain when urinating or defaecating. Pain is the most common symptom experienced and pain medication is therefore an important part of a management plan.

In this study, pain medication was only prescribed to 231/425 (54.4%) patients (unknown in 198), most commonly by the GP (152/231; 65.8%) or gynaecologist (109/231; 47.2%) with NSAIDs being the most common class of drug prescribed (15/231; 79.9%) (Tables 5.5 and 5.6), although these may be underrepresented as they are cheaper to buy over the counter than to have prescribed. Only 46/623 (7.4%) patients saw a pain medicine specialist, despite 185/238 (77.7%) presenting with pain and 60/403 (14.8%) having pain-related comorbidities.

Table 5.5 Who prescribed pain medication

	Number of patients	%
General practitioner	152	65.8
Gynaecologist	109	47.2
Other clinician (emergency medicine, surgery)	23	10.0

Answers may be multiple; n=231, clinician questionnaire data

Table 5.6 Pain medication prescribed

	Number of patients	%
NSAIDs	155	67.1
Opioids	73	31.6
Unknown	35	15.1
Amitriptyline*	24	10.4
Paracetamol	18	7.8
Gabapentin	12	5.2
Other	10	4.3
Pregabalin	8	3.5
Duloxetine*	5	2.2

*Answers may be multiple; n=231 *Antidepressant drugs, clinician questionnaire data*

There were 52/231 (22.5%) patients who were prescribed antidepressant drugs. The evidence for antidepressants is weak and side effect data are lacking, as are long-term efficacy and safety profiling.[19]

Hormonal treatments have been shown to reduce pain symptoms. GnRH agonists have been found to be effective in reducing endometriosis-associated pain. There is a concern over the side effect profile of these agents which may be mitigated with the concurrent use of hormone replacement therapy.[20] Of the 170/623 (27.3%) patients on GnRH agonists, 25/170 (14.7%) experienced side effects, which include menopausal symptoms, hot flushes, mood swings, irritation, and sleep disturbance.

Other medication was prescribed in 36/623 (5.8%) patients. This was most commonly tranexamic acid (17 patients), then medication to increase or decrease bowel activity in 12 patients. Overall, 69/456 (15.1%) (unknown in 167) patients experienced side effects of the medication they were prescribed. The clinicians treating the patient recorded that hormonal treatment was stopped in 136/377 (36.1%) patients, in 42/136 (30.9%) patients this was due to side effects.

Medication reviews

The General Medical Council (GMC) requires doctors to ensure that there are suitable arrangements in place for the monitoring, follow-up, and review of medications.[21] Medication reviews allow shared decision-making, personalising each treatment plan while considering the safety and effectiveness of prescribed drugs.

All medications have side effects, and it is important that they are reviewed regularly, particularly hormone treatments in this group of patients. However, only 20/47 patients who had medicines prescribed by their GP had an adequate medication review in the reviewers' opinion.

There were 103/448 (23.0%) patients who did not have their medication reviewed by the treating gynaecologist (unknown in 175). The reviewers considered that 73/218 (33.5%) patients had inadequate medication reviews (unknown in 91), and of that group 32/73 had no review of medication plan documented at all.

"I have had horrible side effects – intermittent bleeding, extreme hormonal reactions, migraines weight gain, low mood. There was no review of my medication. I struggled to get an appointment with the GP so just stopped taking them". A patient

CHAPTER 6: SURGICAL CARE (BACK TO CONTENTS)

Laparoscopy is a type of keyhole surgery performed under general anaesthesia used to diagnose and treat conditions within the abdomen.[22] At the time of this study it was described as the gold standard for the diagnosis of endometriosis.[23,24] However, subsequent advances in the quality and availability of imaging modalities for some forms of endometriosis have led clinicians to question this.[9] Some types of endometriosis, such as ovarian endometrioma and deep endometriosis may be reliably diagnosed by ultrasound or magnetic resonance imaging (MRI). However, for superficial endometriosis laparoscopic identification with histological confirmation remains essential as current imaging techniques lack reliability in identifying or ruling out small lesions.

Surgical diagnosis

In this study the majority (428/459; 93.2%) of patients had their diagnosis made by surgical diagnostic laparoscopy and the inclusion criteria determined that all patients would have undergone laparoscopy during the index admission. The site of endometriosis recorded at laparoscopy in this cohort of patients is shown in Figure 6.1. These data confirm that superficial endometriosis is most identified at surgical laparoscopy.

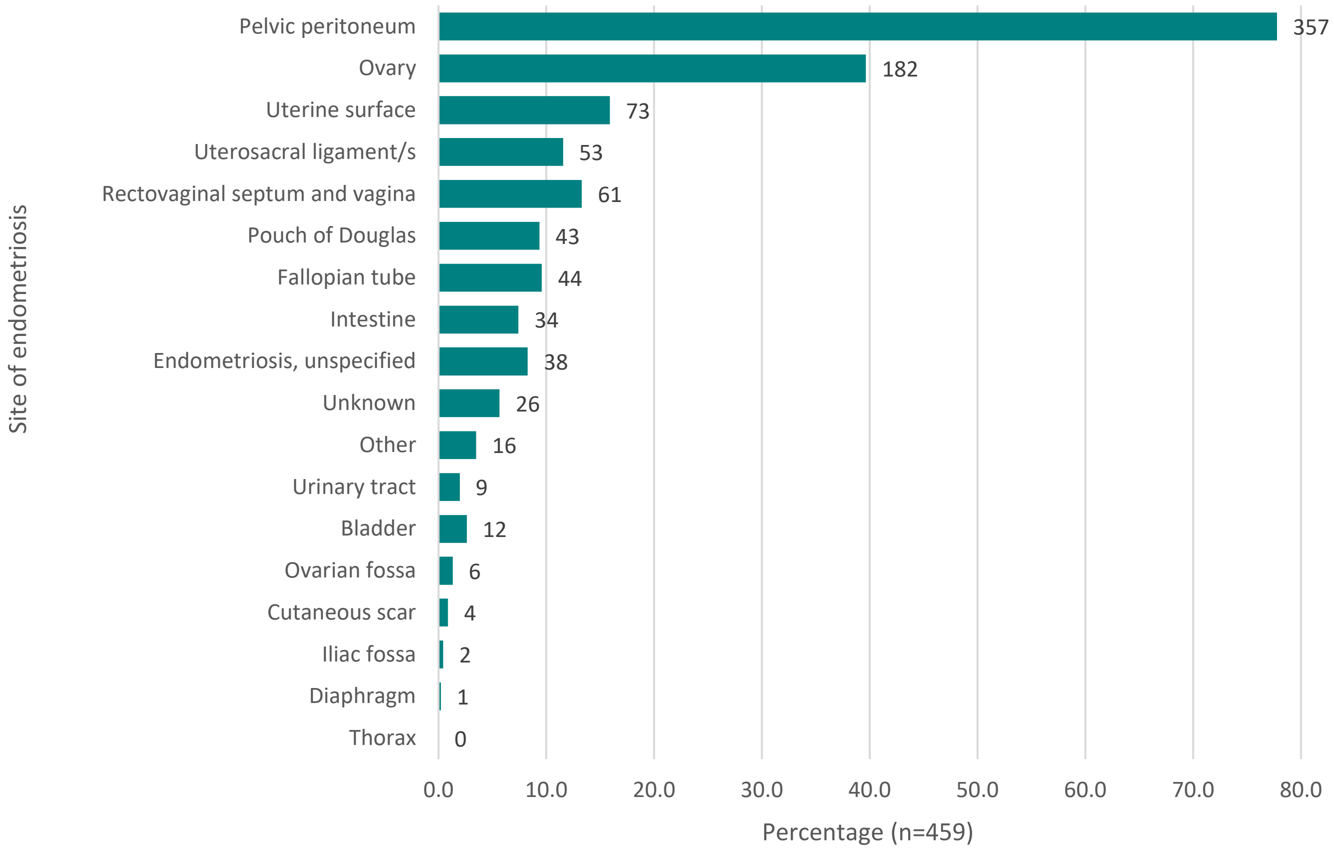

Figure 6.1 Site of endometriosis

Answers may be multiple; n=459, clinician questionnaire data

The American Society for Reproductive Medicine (ASRM) classification system was used to define severity (Table 6.1).[25] More recently, the American Association of Gynaecologic Laparoscopist's (AAGL) 2021 endometriosis classification has been introduced.[26] It allows surgeons to identify objectively intraoperative findings that reliably discriminate surgical complexity levels better than the ASRM staging system. The AAGL severity stage correlates comparably with pain and infertility symptoms with the ASRM classification stage.

Minimal and mild endometriosis was identified in 282/459 (61.4%) patients and moderate or severe endometriosis was identified in 107/459 (23.3%)patients (Table 6.1). From the clinician questionnaire it could be seen that 117/623 (18.7%) patients were diagnosed with deep endometriosis and 26/623 (4.2%) with endometriosis outside the pelvic cavity.

Table 6.1 Stage of endometriosis at diagnosis

Stage	Classification	Description*	Number of patients	%
I	Minimal	A small number of superficial implants and mild adhesions	182	39.7
II	Mild	More, slightly deeper implants	100	21.8
III	Moderate	Small chocolate cysts on one or both ovaries, with many deep implants and more severe adhesions	47	10.2
IV	Severe	Large chocolate cysts on one or both ovaries, with many deep implants and more severe adhesions; rectum may adhere to posterior of uterus	60	13.1
	Not recorded		63	13.7
	Total		**459**	

Clinician questionnaire data

** American Society for Reproductive Medicine*

During laparoscopy, it is recommended that a biopsy of lesions is taken to either confirm the diagnosis of endometriosis or to exclude malignancy.[7,9] Only 51/459 (11.1%) patients who had a laparoscopy, or another surgical procedure had a biopsy taken.

Surgical procedures performed

Laparoscopy is associated with less pain, shorter length of stay, faster recovery and a better cosmetic result compared with open surgery. European Society of Human Reproduction and Embryology (ESHRE) endometriosis guidelines suggest that there might be reductions in painful periods and painful urination in patients in whom lesions were excised as opposed to ablated. However, a recent systematic review concluded that in minimal and mild endometriosis there was no significant difference in outcomes between excision and ablation.[27] A recent Cochrane review considered that it was uncertain whether laparoscopic surgery reduced overall pain associated with minimal to severe endometriosis. There is moderate evidence that laparoscopic surgery increased viable intrauterine pregnancy rates.[28] Further guidance may become available with the outcome of the ESPriT2 trial, a National Institute for Health and Care Research-funded trial looking at the effectiveness of laparoscopic removal of isolated superficial peritoneal endometriosis for the management of chronic pelvic pain.[29]

In this study, laparoscopic ablation was the most common procedure performed (250/459; 54.5%) (Figure 6.2). Other surgical procedures were in line with the severity of the condition.

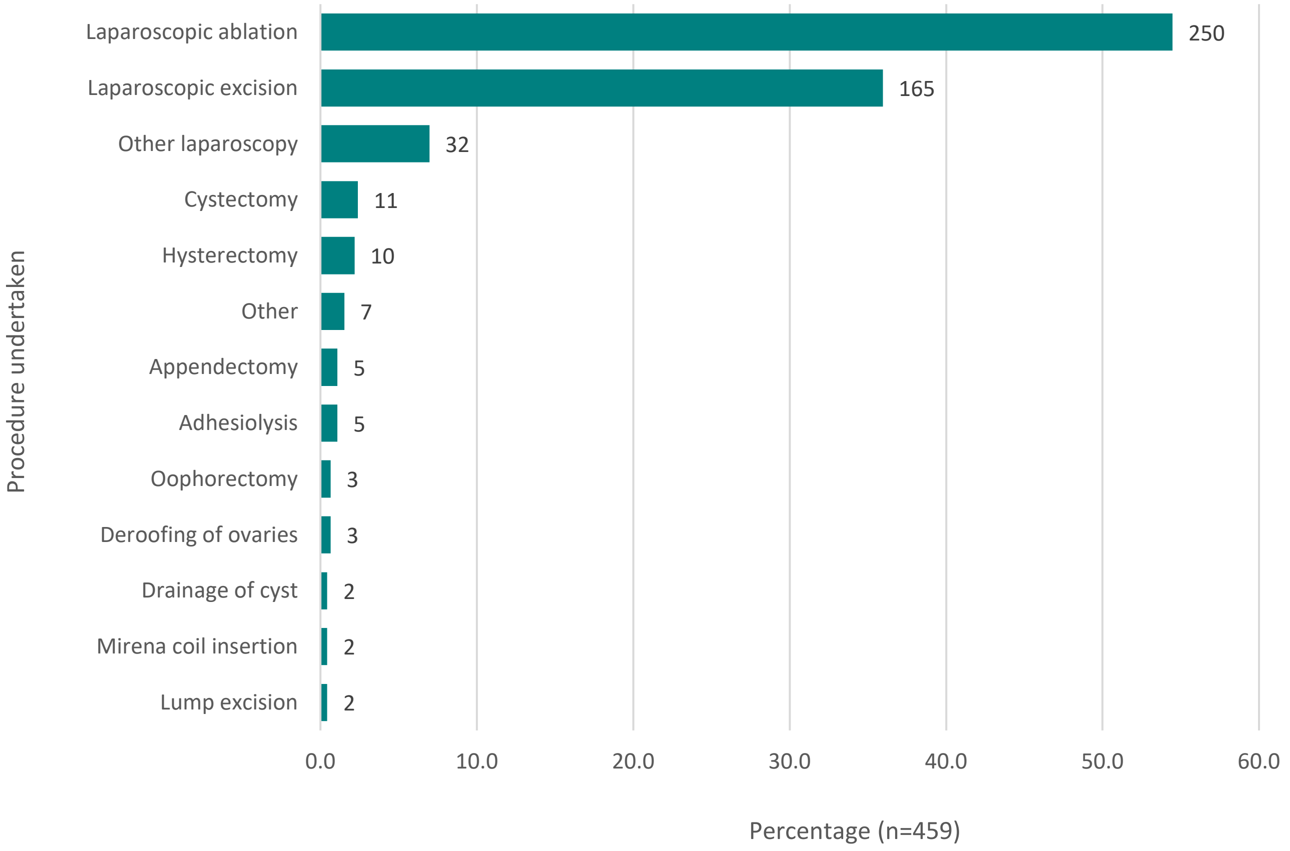

Figure 6.2 Procedure undertaken
Answers may be multiple; n=459, clinician questionnaire data

Consent
The General Medical Council (GMC), Royal College of Obstetricians and Gynaecologists (RCOG) and the Royal College of Surgeons (RCS) have published guidelines to aid doctors in gaining adequate consent from fully informed patients.[30-32] The key principles are to inform and then discuss with the patient all treatment options together with their implications and material risks. Consent should be written and recorded together with a record of any discussions. The standard of consent is not a new concern raised in NCEPOD reports.[33]

In this study, the reviewers considered that 35/219 (16.0%) patients (unknown in 90) had not had the risks and benefits of the procedure adequately explained and that in 56/212 (26.4%) (unknown in 93) there was room for improvement in the consent process. This was confirmed in the patient survey which showed that 91/542 (16.8%) patients had no discussion with clinicians about the risks and benefits of surgery.

The reviewers gave more detail on where improvements could be made for the 56 patients who fell into this category:

- 22/56 patients had potential risks missing from the consent form
- 10/56 patients consented on the day of the procedure
- 18/56 patients had insufficient discussion
- 3/56 patients had no risk quantification on the consent form
- 18/56 patients did not have the benefits of procedure discussed with them

Consent guidelines state that patients should be given enough time to make an informed decision which may require discussion over more than one appointment. This process should be well in advance of the treatment. Data from the clinician questionnaire showed that 161/459 (35.1%) patients had their consent taken on the day of the procedure, which is not in line with national guidance. The patient survey also confirmed a deficit in discussion prior to surgery, with 204/542 (37.6%) respondents stating that the limitations of the procedure were not discussed.

CASE STUDY 3

A 42-year-old woman presented with pain when urinating and pelvic pain. Radiological examination was inconclusive and laparoscopic examination and treatment were offered. A record of all discussions with the patient were documented, which included both surgical and medical options together with their risks and benefits. The patient opted for surgical diagnosis and treatment.

The reviewers considered the documented explanation of all options to be good practice and it ensured that the patient gave informed consent.

Operation during the index admission

The reviewers considered that 78/248 (31.5%) operation records were incomplete for the operation during the index admission (unknown in 61); 35/78 records had no details of the procedure performed (Table 6.2). The GMC requires all doctors to record their work clearly accurately and legibly[32] and the RCS has issued guidelines on what should be included in an operating note.[33] In view of the chronicity of endometriosis an accurate record of any operation is essential.

Table 6.2 Items missing from the operation note

	Number of patients
Details lacking about procedure performed*	35
No grade of surgeon	20
No detail about the reason for the procedure	21
No detail about the catheterisation/ pressures	3
No date of operation*	6
No detail about the extent of endometriosis/size of endometrioma*	9
No detail about the grade/severity of the endometriosis*	6
Details lacking about the incision location*	8
Lacking complete assessment of right side*	1

Answers may be multiple; n=78, clinician questionnaire data

Those marked by an asterisk in the table below are included in the RCS guidelines.

CASE STUDY 4

A 27-year-old woman referred to gynaecology with a presumed diagnosis of endometriosis by her GP underwent a laparoscopy performed by a trainee without obvious supervision. Extensive peritoneal endometriosis was identified, and lesions treated with diathermy. The consent form made no mention of diathermy or excision. No sample was taken for histological diagnosis. No precise record, photographic evidence or staging of the condition were recorded in the notes. The follow-up plan on the surgical note did not match the advice in the discharge letter.

The reviewers considered this case highlighted several issues. The need for informed consent, the need to record operative findings in a standard manner, the need for histological diagnosis and the importance of ensuring robust postoperative instructions and follow-up. Together with the benefit and need to ensure senior experienced input is always available.

Complications of surgery

Laparoscopic surgery is expensive, invasive, and associated with morbidity and mortality. However, direct photographic and histological confirmation of endometriosis lesions can be an important positive psychological factor for women who have been experiencing the often- debilitating symptoms of an otherwise invisible condition. The benefits of laparoscopic surgery need to be weighed against the risks. In this study 17/459 (3.7%) patients had a complication, most commonly wound/deep pelvic infection. This is in line with published rates.[34]

Delays to surgery – index admission

Clinicians completing questionnaires considered that the laparoscopy was delayed in 32/162 (19.8%) patients. The principal reasons for delay to surgery were organisational (16/32), GP referral to gynaecology (8/32) and clinical reasons (6/32).

Discharge summary

Clinicians completing questionnaires found that 134/162 (82.7%) patients had a discharge summary available (Figure 6.3).

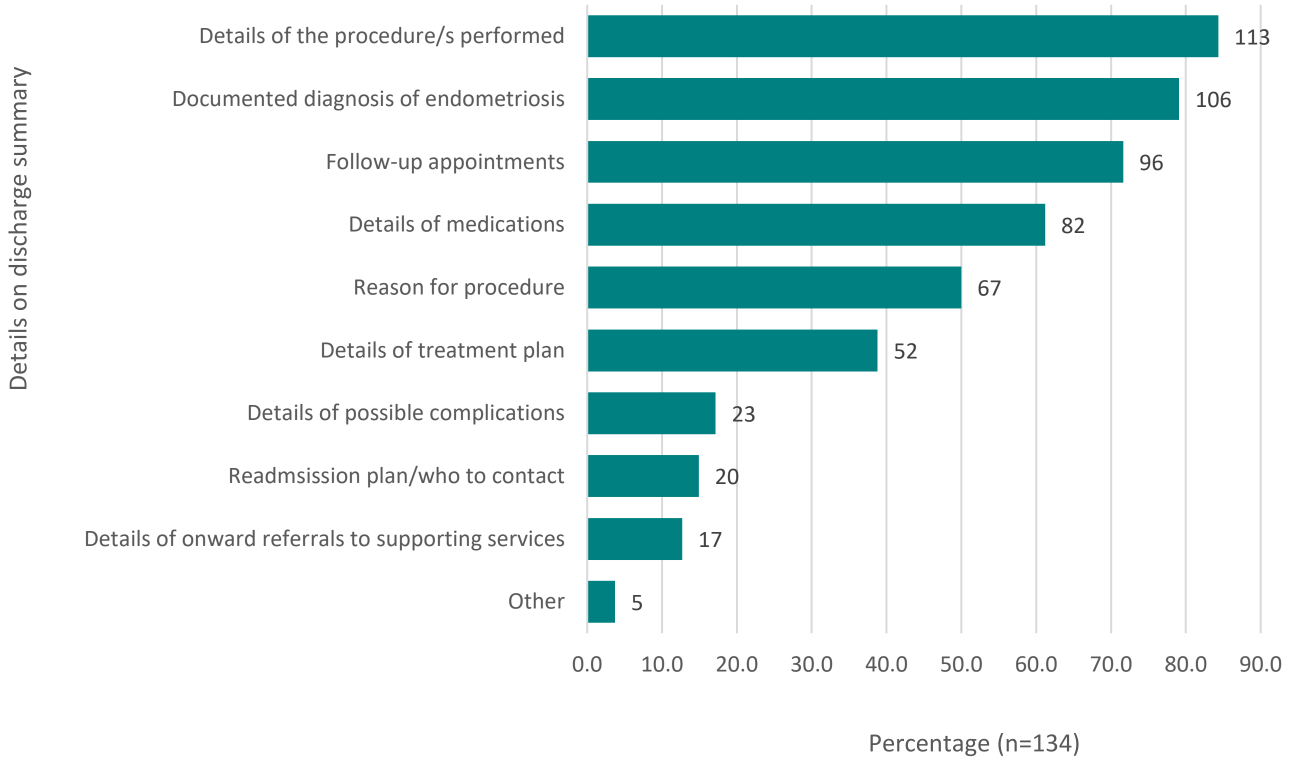

Figure 6.3 Contents of the discharge summary
Answers may be multiple; n=134, clinician questionnaire data

Details of readmission plans, who to contact if symptoms return and onward referrals to supporting services were often omitted from the discharge summary (20/134; 14.9%). This was of particular note as 33/162 (20.4%) patients had residual endometriosis recorded at the end of the index operation.

Most GPs (109/120; 90.8%) reported that they were sent a copy of the discharge summary. However, poor communication from the hospital to the GP was a theme arising from the patient survey.

"After my procedure my GP surgery was sent my notes. They consisted of two words: 'Had operation'. I had an 18-day stay in hospital due to complications. Communication from the hospital to my GP has been disgracefully awful". A patient

From the patient's perspective, only 127/732 (17.3%) of those who completed the patient survey were satisfied with the results of surgery and 215/542 (39.7%) were referred for repeat laparoscopies or other surgery relating to their endometriosis.

Governance

It is important that data are collected to inform the healthcare organisation and patients of outcomes. It was reported from 145/167 (86.8%) hospitals that data on acute surgical complications were recorded, meaning that

22/167 (13.2%) did not. Furthermore 53/167 (31.7%) reported that data were not collected on how many of each procedure were performed by individual surgeons (Table 6.3).

Table 6.3 Records kept on surgery for endometriosis

	Number of hospitals	%
Details of surgical procedures carried out	150	89.8
Acute surgical complications	145	86.8
Cancelled/delayed/postponed procedures	129	77.2
Late surgical complications	116	69.5
The number of procedures performed by each surgeon	114	68.3
Patient recorded outcome measures (PROMs)	8	4.8
None of the above	6	3.6
Unknown	4	2.4
Other	150	89.8

Answers may be multiple; n=167, organisational questionnaire data

CHAPTER 7: FOLLOW-UP AND READMISSION (BACK TO CONTENTS)

The healthcare system needs to support patients with endometriosis. It is a chronic condition requiring long-term treatment with medication and surgery. Patients need easy access to care and appropriate follow-up, and resources to support self-care.

Following admission for a laparoscopy, data from the clinician questionnaire showed that 67/492 (13.6%) patients did not have a management plan regarding their symptoms (Table 7.1).

Table 7.1 A management plan was put in place

	Number of patients	%
Yes	425	86.4
No	67	13.6
Subtotal	**492**	
Unknown	131	
Total	**623**	

Clinician questionnaire data

There were 143/308 (46.4%) patients with a management plan in place for the continued medical management of their condition with hormonal treatment. For 78/308 (25.3%) patients it included referrals to other specialties and for 23 patients the management plan was simply for the patient to contact their GP if they experienced recurrence of symptoms (unknown in 117).

Not all patients were followed-up after having their laparoscopy (132/516; 25.6%) (unknown in 107). Of those who were followed-up, where data were available, 222/347 (64.0%) were with the operating surgeon, but the majority were with the gynaecologist (326/347; 94.0%). For 190/347 (54.8%) patients the follow-up appointment was with both. A total of 18 patients were followed-up by the GP only (Figure 7.1).

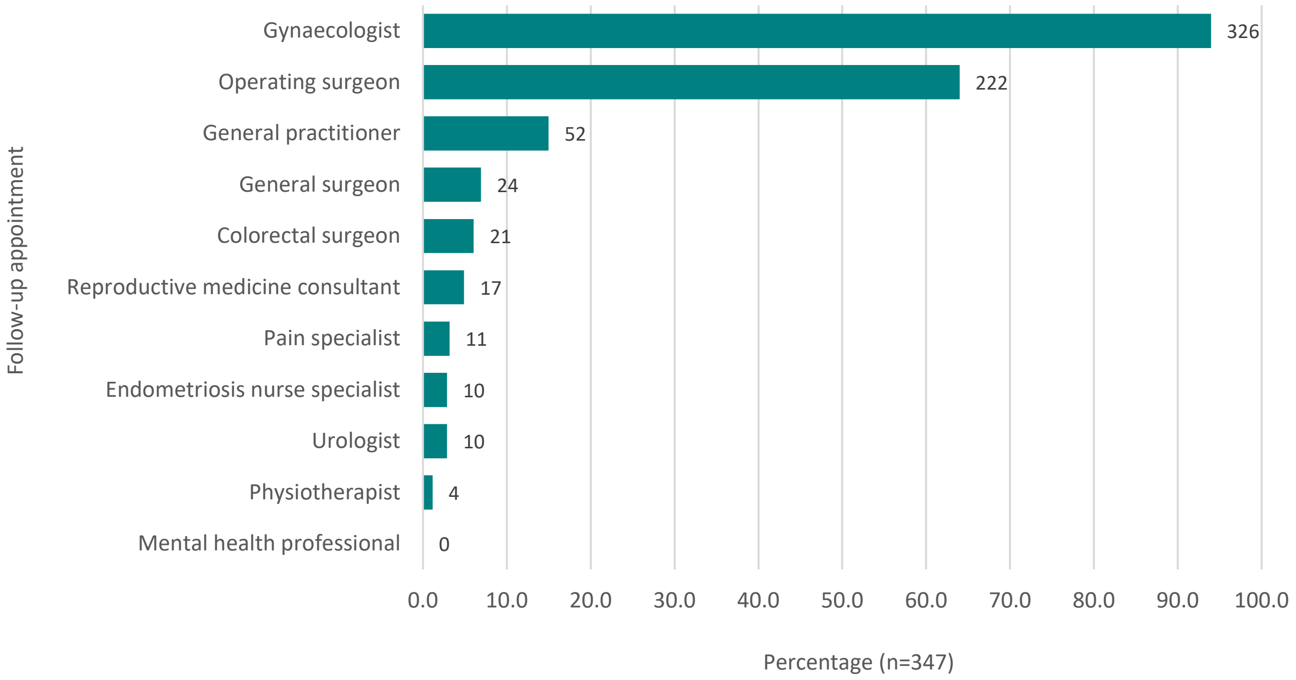

Figure 7.1 Healthcare professionals who held the follow-up appointment
Answers may be multiple, n=347; clinician questionnaire data

Initial follow-up (following the index admission) was reasonably timely, with the majority of patients being seen between two and six months after their procedure (54/81; 66.6%) (unknown in 12). The organisational questionnaire showed that in most hospitals (117/167; 70.1%) there was a routine follow-up appointment following the initial appointment after the laparoscopy, with most appointments occurring within six months (Figure 7.2).

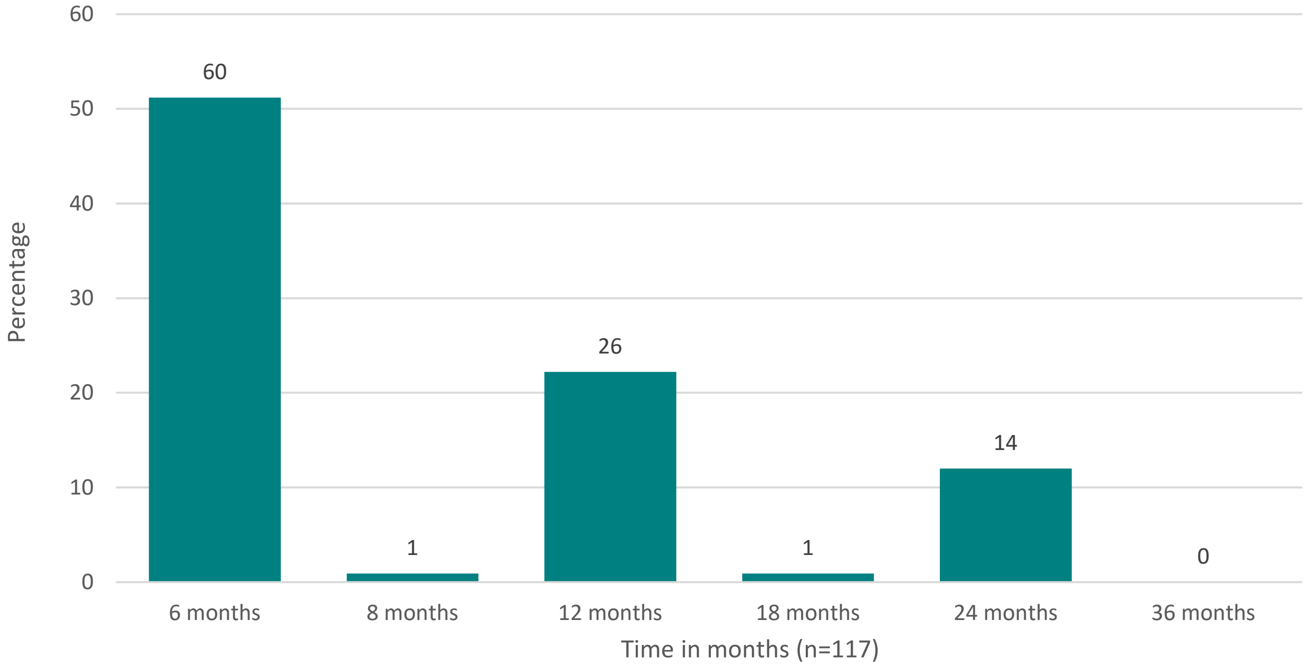

Figure 7.2 Timeframe of subsequent follow-up appointments (time post-discharge from hospital following diagnostic laparoscopy)
Answers may be multiple, n=117, organisational data

The NHS commissioning service contract (England only) for severe endometriosis states that elective outpatient follow-up should occur at three months by a consultant and at six months by a nurse, with patient-reported outcome measures, including quality of life assessments at six, 12 and 24 months post-surgery.[35] It should be noted that patients with severe endometriosis being treated in British Society of Gynaecological Endoscopy (BSGE) centres are more likely to have planned timely follow-up as stipulated in the specialist service requirement. It is the patients who have superficial endometriosis but are symptomatic who may benefit from routine early follow-up.

There were 132/167 (79.0%) hospitals that offered patient-initiated follow-up. As this is a relatively new concept, it will hopefully lead to improved access to care for those patients who were previously discharged and needed to return to the GP for another referral back into the system.

The case reviewers found that 124/238 (52.1%) patients experienced recurrence or persistence of endometriosis symptoms following admission for laparoscopy. Reviewers thought that 32/124 (25.8%) patients experienced a delay in being investigated and/or treated for the recurrence of symptoms. Many (48/124; 38.7%) had to start the process over again and go back to the GP for referral back to the gynaecologist, endometriosis gynaecologist or another specialty. Only 12/124 (9.7%) were able to contact the gynaecology team or endometriosis clinical nurse specialist directly. And only 6/124 (4.8%) patients needed to attend emergency or ambulatory services acutely.

The organisational questionnaire showed that most patients were advised to see their GP if they experienced a recurrence of symptoms (125/167; 74.9%). Only 16/167 (9.6%) hospitals had a dedicated helpline for endometriosis patients.

It was reported from 48/167 (28.7%) hospitals that contacting the endometriosis clinical nurse specialist or the named gynaecological consultant directly (68/167; 40.7%) (Table 7.2) was supported. In 73/167 (43.7%) hospitals it was possible to give patients contact details of a keyworker who they could access following discharge from hospital.

Table 7.2 What patients were advised to if they had symptoms after discharge

	Number of hospitals	%
Visit their GP for re-referral	125	74.9
Contact their named endometriosis clinical nurse specialist directly	48	28.7
Contact their named consultant gynaecologist consultant directly	68	40.7
Contact the dedicated endometriosis helpline	16	9.6
Unknown	5	3.0
Visit the emergency department	2	1.2
Other	2	1.2

Answers may be multiple n=167, organisational data

According to the reviewers, 54/124 (43.5%) patients required readmission for a further laparoscopy (unknown in 114). Nine out of 54 patients required multiple laparoscopies, and 215/542 (39.7%) of the patients surveyed also had had subsequent laparoscopies or surgery relating to endometriosis.

Lack of direct access was also highlighted as a concern in the patient survey, with only 73/542 (13.5%) patients having direct access to see a healthcare professional if experiencing recurrent symptoms, the remainder having to go back to the GP for referral back into the system.

“After my diagnostic laparoscopy the gynaecologist discharged me and I have now been waiting almost a year since my GP re-referred me back to the gynaecologist, for an appointment again. I feel that endometriosis sufferers should be seen far sooner and not have to wait so long for referrals once they have their diagnosis.” A patient.

CHAPTER 8: OVERALL QUALITY OF CARE (BACK TO CONTENTS)

Case reviewers were asked to grade the overall care an individual patient received (Figure 8.1).

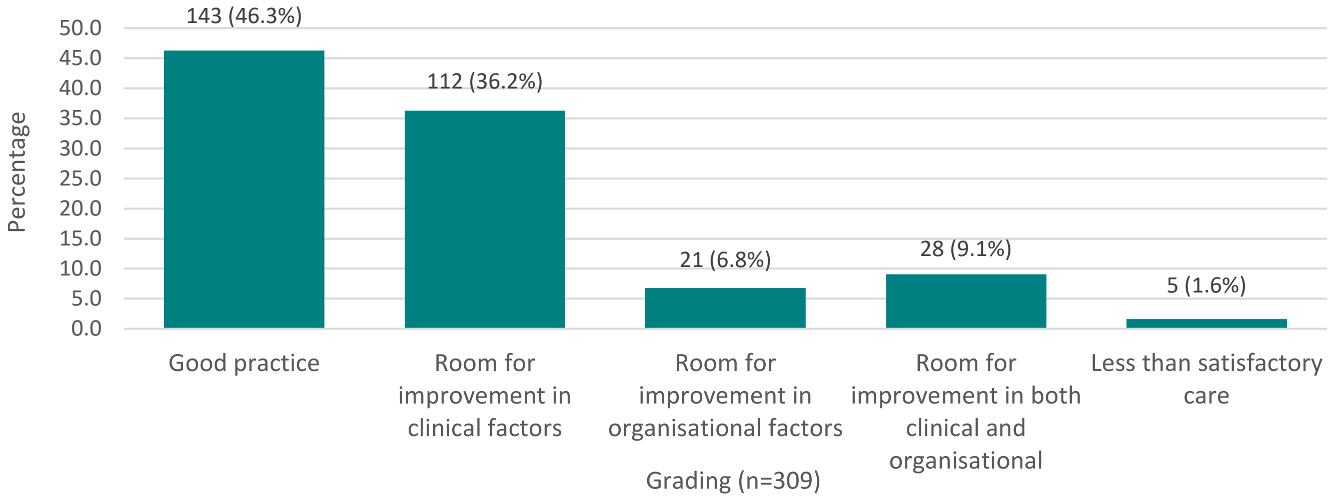

Figure 8.1 Overall quality of care
Case reviewer data, n=309

The reasons given by reviewers for grading cases as 'room for improvement in clinical aspects of care' fell into the common themes shown in Table 8.1, which reflect the data presented throughout this report. Some have an organisational component, despite being rated as clinical aspects of care.

Table 8.1 Themes/reasons for room for improvement in clinical aspects of care

	Number of patients	%
Lacking holistic care referrals, including fertility	36	21.7
Lack of follow-up appointment/continuity of care	29	17.5
Treatment decision	28	16.9
Delay/lack of imaging	17	10.2
Delayed referral from GP	17	10.2
Patient should have been treated in a specialist centre	14	8.4
Multidisciplinary team discussions	13	7.8
Medication review	11	6.6
Issues with consent process	11	6.6
Lack of patient information, support, discussions	8	4.8
Delayed decision for laparoscopy	8	4.8

Answers may be multiple; n=166, case reviewer data

The reasons given for grading organisational aspects of care as 'room for improvement' were around delays to surgery (particularly during the COVID-19 pandemic), the lack of a care pathway (and delays caused by this) and disjointed care delivered with a lack of continuity across providers.

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GLOSSARY

Amitriptyline	An antidepressant medication that helps relieve pain
Aromatase inhibitors	A medication that lowers oestrogen levels
Autoimmune conditions	These occur when the immune system is overactive, causing it to attack and damage the body's own tissues
Deep endometriosis	The spread of endometriosis into neighbouring organs to a depth of at least 5mm beneath a peritoneal covering
Peritoneal covering	The lining of the abdominal cavity
Duloxetine	An antidepressant medication that helps relieve pain
Endometriomas	Cystic lesions that stem from endometriosis
Endometriosis	A condition in which tissue similar to the lining of the uterus grows outside the uterus
Endometriosis staging	The stage classification as minimal, mild, moderate, and severe, and each score was reclassified as 1 to 5, 6 to 15, 16 to 40, and more than 40. Tubal endometriosis was omitted from the revised classification, and the lesions of endometriosis were classified as superficial and deep lesions. The size of deep ovarian endometriosis >3 cm scored 20 points, and dense ovarian adhesion and dense tubal blockage were adjusted upward to 16 points. In addition, a single finding of complete cul-de-sac obliteration scored 40 points and was classified as severe disease. In 1996, this scoring system was renamed as the revised American Society for Reproductive Medicine (rASRM) classification
Gabapentin	A medication that helps relieve nerve pain
Gonadotrophin releasing hormone (GnRH)	A medication that stops oestrogen being produced
Laparoscopy	A surgical procedure used to examine the organs in the belly (abdomen)
Magnetic resonance imaging (MRI)	An imaging method used to look inside the body
Non-steroidal anti-inflammatory medication (NSAID)	Stops the body from producing certain chemicals that cause inflammation
Opioids	A group of pain-relieving medicines
Ovarian cysts	A fluid-filled sac that develops on an ovary
Patient reported outcome measures (PROMs)	Questionnaires that collect health outcomes directly from the people who experience them
Pregabalin	A medication that helps with pain and anxiety
Progestogens	One of three types of sex hormones
Subfertility	Any form of reduced fertility with prolonged time non-conception
Superficial endometriosis	The most common form of endometriosis, that forms as a shallow lesion along the membrane lining the abdominal cavity
Tranexamic acid	A medication used to treat or prevent excessive blood loss
Ultrasound scan (USS)	An imaging method used to look inside the body

USEFUL LINKS

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

ACKNOWLEDGEMENTS

This report could not have been achieved without the involvement of a wide range of individuals who have contributed to this study and without whom this report would not have been possible.

Our particular thanks go to:

The Study Advisory Group (SAG) who advised NCEPOD on the design of the study

Elizabeth Ball	Consultant in Obstetrics and Gynaecology
Moji Balogun	Consultant in Radiology (Gynaecological imaging specialist)
Christian Becker	Consultant in Obstetrics and Gynaecology
Amena Bhatti	Consultant Pharmacist (Royal Pharmaceutical Society)
Elizabeth Bruen	Specialist Nurse Practitioner (British Society of Gynaecological Endoscopy)
Emma Cox	Chief Executive, Endometriosis UK
Katie Gore	Physiotherapist (Pelvic Health Specialist)
Margreet Hendriks	Highly Specialist Psychologist (Maternity and Gynaecology)
Tim Hillard	Consultant in Obstetrics and Gynaecology (Royal College of Obstetricians and Gynaecologists)
Tom Holland	Consultant in Obstetrics and Gynaecology
Debra Holloway	Specialist Nurse Practitioner (Royal College of Nursing)
Andrew Horne	Consultant in Obstetrics and Gynaecology (Royal College of Obstetricians and Gynaecologists)
John Hughes	Consultant in Pain Medicine (Faculty of Pain Medicine)
Davor Jurkovic	Consultant in Obstetrics and Gynaecology (Gynaecological Ultrasound)
Andrew Kent	Consultant in Gynaecological Surgery (British Society of Gynaecological Endoscopy)
Uma Marthi	General Practice (Endometriosis UK)
Edward Morris	Consultant in Obstetrics and Gynaecology (Past president Royal College Obstetricians and Gynaecology)
Ertan Saridogan	Consultant in Reproductive Medicine
Anita Sharma	General Practice
Claudia Tye	Advanced Nurse Practitioner in Gynaecology and Endometriosis (British Society of Gynaecological Endoscopy)
Arvind Vashisht	Consultant in Obstetrics and Gynaecology (British Society of Gynaecological Endoscopy)
Katy Vincent	Consultant in Obstetrics and Gynaecology

The case reviewers who undertook the peer review

Shine Akhtar	Clinical Nurse Specialist in Gynaecology
Jane Allen	Consultant in Obstetrics and Gynaecology
Saikat Banerjee	Consultant in Reproductive Medicine and Surgery

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Junaid Rafi	Post CESR SAS doctor (Obstetrics and Gynaecology)
Jyoti Sharma	ST7 Obstetrics and Gynaecology
Paul Simpson	Consultant in Obstetrics and Gynaecology
Ben Snowden	ST6 Obstetrics and Gynaecology
Anna Stephenson	Advanced Clinical Nurse Practitioner
Luveon Tang	Specialist trainee in Obstetrics and Gynaecology
Kinza Younas	Consultant in Obstetrics and Gynaecology with special interest in fertility and minimal access surgery and recurrent miscarriage

Thanks also go to

The NCEPOD local reporters who facilitated data collection and return at their hospital(s).
The NCEPOD ambassadors – senior clinicians who championed the study locally.
The clinicians who completed questionnaires.
The clinicians who completed the survey.
The patients who completed the survey and took part in the focus groups.
Karen Porter for her editorial expertise.