Commissioner's Guide to the NCEPOD Report 'Endometriosis: A Long and Painful Road'

INTRODUCTION

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.

PATIENT POPULATION

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.

KEY FINDINGS FROM THE STUDY

Delays in diagnosis/ treatment of endometriosis- Primary care

- 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.
- 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.
- 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.
- 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.
- 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).
- 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.
- 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.
- 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.
- 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.

Holistic/ multidisciplinary care/ quality of life

- 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).
- 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 psychology was available, 45/150 (30.0%) hospitals had a defined pathway to refer to psychology.
- 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.
- 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).
- 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.
- 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.
- Less than half (73/167; 43.7%) of hospitals held regular endometriosis MDT meetings.

Medical intervention

- 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.
- 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%).
- 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.
- 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.
- 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).
- 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.

Laparoscopic diagnosis/ treatment

- 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.
- 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.
- 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.

Discharge and follow-up

- 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.
- 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).

KEY FEATURES OF A SERVICE

1. Raise public awareness about endometriosis

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

2. Reduce delays in through clear, documented pathways of care

A dedicated care pathway based on the guidance provided by NICE guideline NG73, the European Society of Human Reproduction and Embryology (ESHRE) endometriosis guidelines, as well as the recommendations from this report that covers presentation to the GP, examination, imaging, referral to gynaecology, medical and surgical treatment options and the multi-disciplinary delivery of whole patient centred care would reduce delays and improve the quality of care provided. The pathway should reflect the long-term nature of the condition, with means for patients with recurrent/ persistent disease to re-enter the pathway without having to go through the referral from their GP. This could be by means of patient-initiated follow-up (PIFU) or direct access to the endometriosis nurse specialist in the endometriosis specialist centre where they were treated.

3. Training to recognise symptoms of endometriosis, that it is a chronic condition and follow a dedicated pathway of care

Training for healthcare professionals in primary and secondary care in the symptoms of endometriosis and the treatment pathway for endometriosis, incorporating the NICE guidance NG73 would improve the quality of care delivered, both in terms of delays in diagnosis and medical/ surgical treatment and in offering multidisciplinary-led care that addresses the full range of symptoms and its impact on the patient's quality of life. It should be clear that endometriosis is a long-term condition and ongoing treatment planning should reflect this.

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.

4. Multidisciplinary care

Patients with endometriosis have a wide range of symptoms and comorbidities. Patients should be questioned about the effect of the condition on their quality of life.

5. Medical management

Use of a stepped approach to analgesia, including simple analgesics and/or hormone treatment could be used. Interactions between patients with endometriosis and prescribing healthcare professionals should be used to undertake a medication review at each stage of the care pathway.

6. Laparoscopy – treatment planning, information for patients and consent

Patients should be provided 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. This should 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

Consent taking should be a multi-stage process 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.

SUPPORTING NATIONAL GUIDANCE AND REPORTS

NICE guideline NG73,

European Society of Human Reproduction and Embryology (ESHRE) endometriosis guidelines