



## A Long and Painful Road

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

**STAKEHOLDER MEETING**  
APRIL 27<sup>th</sup> 2026

This stakeholder meeting, convened by NCEPOD, reviewed the impact of the endometriosis report *A Long and Painful Road* and considered progress against its recommendations. The discussion brought together representatives from Endometriosis UK, commissioning bodies, NHS trusts, the British Society for Gynaecological Endoscopy (BSGE), the Royal College of Obstetrics and Gynaecology (RCOG), primary care, nursing and academic leadership. Across the meeting, speakers consistently emphasised that endometriosis is still too often managed as a series of acute episodes rather than as a chronic condition, contributing to delayed diagnosis, fragmented follow-up, inconsistent access to multidisciplinary support and poor continuity of care.

## Impact of the report

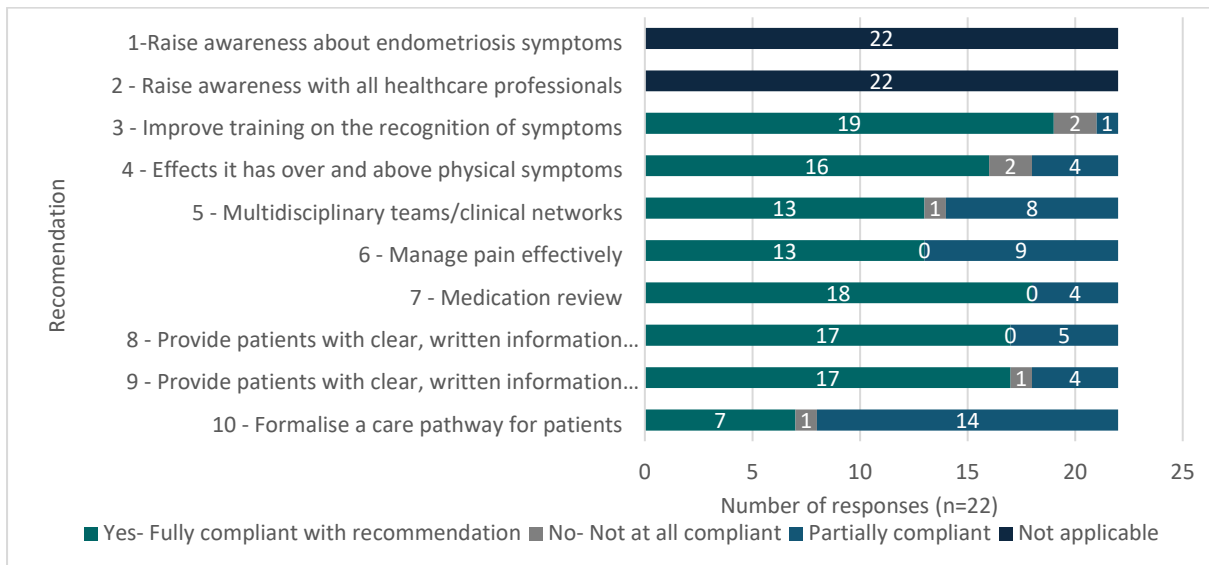
### Impact

**ARTICLES, GUIDELINES & REPORTS**

- Incorporated into and aligned with update of **NICE NG73 (2024)**
- **The BMJ**: Elisabeth Mahase, "Endometriosis: Lack of care pathway and poor symptom recognition are hindering care, report warns" (July 2024).
- **Royal College of Obstetricians and Gynaecologists (RCOG)**: Response to a review of quality of care provided to adult patients with endometriosis (July 2024).
- **Endometriosis UK**: New research highlights changes urgently needed in endometriosis care (July 2024).
- **The BMJ** Restructuring endometriosis care (2024) — De Silva, Sharon Dixon
- **BJGP Life (2024)**: Endometriosis – findings from the National Confidential Enquiry into Patient Outcome and Death
- **Healthwatch Camden**: Living With Endometriosis In Camden (2024)
- Referenced in: **Endometriosis UK**: The State of Endometriosis Care in the UK: A Roadmap For Driving Down Diagnosis Times And Improving Access To Care (2026)

**PARLIAMENTARY DEBATES / PUBLICATIONS**

- June 2025: Referenced in Oral Answers to Questions on Endometriosis regarding the **implementation of the Women's Health Strategy and NICE guidelines**.
- March 2026: Mentioned in the **Endometriosis: Workplace Rights debate** regarding the Employment Rights Act 2025.
- March 2026: Used as evidence in the **Women's Health Strategy: Endometriosis and Fibroids** debate to address the average diagnosis time of nearly 9 years.
- April 2026 Referenced in **The Renewed Women's Health Strategy for England** – Department of Health & Social Care.



While most trusts reported improvements in staff training on symptom recognition (19/22), medication reviews (18/22), and written information on consent and discharge (17/22 each), progress was less consistent in other areas. Sixteen trusts said they were better recording the impact of endometriosis on daily life, and 13 reported having multidisciplinary teams and effective pain management in place. However, only 7 trusts had formally implemented a care pathway, highlighting that although some recommendations are being taken forward, delivery remains uneven and more structured, evidence-based implementation is still needed.

*"Direct assessment/entry back into endometriosis pathway is not established, as there is not a dedicated Specialist team for endometriosis... Regarding the initial point of contact, nurse specialists would help with this aspect of care, again similar to the role of cancer specialist nurse."*

*"It has just been discussed in one of the audit meetings; there is a plan with recommendations and timeframes to implement in 2026.."*

*"The Endometriosis report has been shared at the Gynaecology Clinical Audit meeting this month. This led to a discussion about the importance of appropriate counselling to the patients re: their treatment and managing the condition which isn't curative.."*

*"Information available from Endometriosis UK and this is used in clinics as a point of reference for patient information – unable to clarify how widely used this is. Would be a good quality improvement project post epic to utilise this functionality and improve patient involvement in decision/consent process  
Could be audited to assess current practice. What is described is optimal and epic does allow sharing of information using the 'MyCare app' easily.."*

*"Although compliant with NG73 there is currently no audit evidence collected. We are considering undertaking an independent audit in 2026 "*

*"To fully comply with the recommendations requires a regional appointment of a pelvic pain lead. This would be a potentially helpful role as could co-ordinate a regional level service working with colleagues in other trusts for MDT/education/training purposes.."*

## Key Messages and Recommendations

### OVERARCHING MESSAGE OF THE REPORT

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.

# 1

### KEY MESSAGE 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**.

**Recommendation 1: Raise awareness among the public and patients that endometriosis is a chronic condition.**

- Stakeholders noted that while local initiatives are encouraging, national progress remains slow, and diagnosis times are actually increasing.
- Successful local models include community outreach and "coffee mornings" designed to break the silence and stigma surrounding the condition in specific communities.

- Public education events involving both patients and their personal support networks have proven effective in improving understanding of the condition as a lifelong journey.

**Recommendation 2: Raise awareness among healthcare professionals that endometriosis is a chronic condition.**

- The condition is now more firmly established in GP education, training, and examination content, leading to higher suspicion of the condition in primary care.
- Awareness has improved among emergency clinicians, who are increasingly considering endometriosis as a potential diagnosis for acute presentations.
- A significant remaining barrier is that hospital management teams often view the condition through an "acute" lens, prioritising surgical throughput over the continuity of care required for chronic patients.

**Recommendation 10: Formalise a care pathway for patients with confirmed or suspected endometriosis.**

- This was a primary point of discussion, with experts calling for a mandatory pathway to prevent patients from "falling through the cracks" between different parts of the NHS.
- Improved access to specialist ultrasound was highlighted as a way to direct patients to the right pathway sooner—identifying who needs complex surgery versus holistic care.
- Stakeholders argued that the current hospital funding models (new-to-follow-up ratios) actively work against the long-term, consistent follow-up that these patients require.

**Recommendation 8: Provide clear written information to support informed consent before surgery.**

- While most hospitals report that they now provide written information before surgery, there is a concern that this may be a "tick-box" exercise that doesn't reflect the actual patient experience.
- Many patients still undergo surgery with unrealistic expectations, not fully grasping the high risks of symptom recurrence or persistent post-operative pain.
- True informed consent requires a deeper understanding of the limitations of surgery, rather than just receiving a leaflet.

**Recommendation 9: Provide clear written discharge information and follow-up arrangements after surgery.**

- Widespread concern remains that patients leave the hospital without clear instructions on recovery, who to contact in an emergency, or how to access long-term help.

- GPs often lack the detailed treatment plans and follow-up information needed to support the patient once they return to primary care.
- It was stated that GPs need clearer follow-up information, including treatment plans, because many patients return to primary care without adequate guidance.
- It was suggested that it should be mandatory for patients to have a contact point and a defined pathway after surgery, especially given the risk of ongoing symptoms and recurrence.

**2**

**KEY MESSAGE 2: ENDOMETRIOSIS HAS SYMPTOMS AND SIGNS THAT NEED EARLIER RECOGNITION & APPROPRIATE TIMELY MANAGEMENT**

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

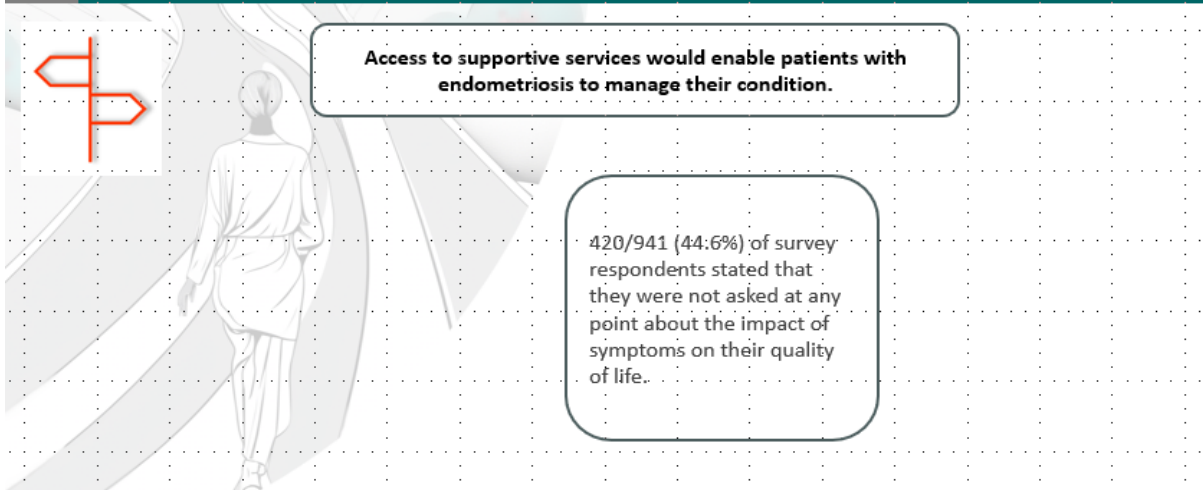
546/941 (58.0%) patients surveyed had multiple visits to the GP before any investigations were undertaken or treatment initiated.

**Recommendation 3: Improve training on recognition of symptoms.**

- Practical tools, such as the “6P” poster, have been distributed to pharmacists and dentists to catch potential symptoms outside of a traditional GP setting
- School-based initiatives are being used to educate young people about gynaecological health at an earlier stage, helping them identify abnormal symptoms sooner.
- While these local educational programmes are effective, there is a consensus that they require a more consistent, nationwide rollout to be truly impactful.

# 3

## KEY MESSAGE 3: ENDOMETRIOSIS AFFECTS QUALITY OF LIFE. ALL PATIENTS SHOULD BE ASKED ABOUT ITS EFFECT ON THEIR LIFE



### Recommendation 4: Ask patients about the impact on quality of life.

- There was strong support for this recommendation.
- There is support for using standardised questionnaires from the very first primary care appointment to document the social, psychological, and financial toll of the disease.
- The meeting highlighted the severe consequences of the condition, including its links to self-harm, emotional distress, and the inability to maintain employment.
- Pilot work is underway to ensure this quality-of-life data follows the patient into secondary care, ensuring their holistic needs are not lost in clinical settings.

### Recommendation 6: Manage pain effectively.

- This area received the most critical feedback, with many stating that effective pain support is still largely inaccessible to the majority of patients.
- A "catch-22" exists where patients are often excluded from specialist pain services until they have a formal diagnosis, leaving them without support during the years they are waiting for surgery.
- The current system often fails to provide the integrated, multidisciplinary pain management that is essential for chronic symptom control.

## 4

## KEY MESSAGE 4: ENDOMETRIOSIS REQUIRES HOLISTIC, JOINED-UP, MULTIDISCIPLINARY CARE



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

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

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.

### Recommendation 5: Ensure multidisciplinary team input and networks.

- Speakers described some positive examples of multidisciplinary working but noted that access remains uneven.
- Inconsistency in Access: While speakers shared positive examples of integrated care, they emphasized that access to multidisciplinary support remains highly uneven across different regions and hospital types.
- The District General Hospital (DGH) Model: A successful model was highlighted involving a specialist clinic within a DGH that maintains strong links to tertiary (specialist) care. This setup allows for multidisciplinary discussions involving pain services and other medical specialties tailored to the specific needs of the patient.
- Inclusion of Holistic Services: There is a growing recognition that an MDT should extend beyond surgeons and nurses to include dietetics and social prescribing, supporting a more holistic approach to managing the chronic nature of the condition.
- Specialised Nutritional Support: A pilot project at a major London trust demonstrated the value of a named women's health gastro-dietitian. This role has significantly improved the quality of support for patients, particularly those dealing with the gastrointestinal symptoms often associated with endometriosis.
- Resource and Waiting Time Barriers: Despite the clear benefits of these integrated teams, "supportive therapies" (such as nutrition or pain management) continue to face long waiting times, which remains a primary challenge to successful implementation.
- Would you like me to summarise the key themes from all these recommendations into a single overview for a presentation or report?

The meeting concluded that the NCEPOD report has had a clear influence in raising awareness and informing policy discussion, but implementation of its recommendations remains variable and incomplete. The strongest recurring messages from speakers were the need to recognise endometriosis as a chronic condition, establish formal care pathways, improve follow-up after surgery, expand specialist nursing and multidisciplinary support, and strengthen education across primary care, emergency care and other relevant specialties. Participants also emphasised the need for better measurement of progress over time so that references to the report can be matched by demonstrable service improvement.