



Endometriosis – Info for Local Reporters

Introduction

Endometriosis is a chronic, debilitating condition defined by the presence of endometrial-like tissue ('lesions'), external to the uterus - often around the reproductive organs, bowel, and bladder. It can be debilitating and can cause chronic pelvic pain, fatigue, anaemia and infertility.

There is no cure for the condition, but it can be managed with treatments that include hormone therapy and laparoscopic surgery. Since there are no accurate non-invasive biomarkers of endometriosis, the definitive diagnosis commonly requires surgical laparoscopy.

On average it takes 8 years from the onset of symptoms for patients to have a definitive diagnosis. The treatment pathway also may vary, dependent on several factors, with definitive treatment resulting in variable outcomes. Following laparoscopic surgical treatment, over time, many patients experience a flare in symptoms, so a plan for follow-up and a structured pathway for diagnosed patients are also important.

This study will review the care pathway of patients with endometriosis, looking at remediable factors in the quality of care provided.

Overall aim:

To review remediable factors in the quality of care provided to patients (aged 18 and over) with a diagnosis of endometriosis throughout their pathway of care.

Objectives

Organisational

To explore the organisational structures in place for the provision of care for patients with endometriosis, reviewing the entire pathway of care and to describe any variation that exists, with a particular focus on the following areas:

1. Triage of patients presenting with pelvic pain and suspected endometriosis
 - a. Referral process, presence of care networks, links between providers
2. Access to endometriosis specialist centres, their management structure and the quality of care provided
3. Policies/protocols/care pathways in place for treatment of endometriosis patients
 - a. Psychological assessment / support
 - b. Policies/protocols/care pathways
4. Communication

- a. Data sharing between providers
 - b. Between clinicians
5. Information/ support for patients
 - a. Mental health support
 - b. Endometriosis support groups
 - c. Treatment plan/ follow-up
 - d. Flare advice
 6. Staffing
 - a. Training provided in the recognition and care of patients with endometriosis
 - b. Access to endometriosis specialist nurses
 - c. Access to Ancillary Services
 - d. Number of (WTE) gynaecologists (with and without a special interest in endometriosis)
 7. Surgical services
 - a. The structure of the team/s providing surgical services
 - b. Record of delayed/ postponed/ cancelled procedures
 8. Imaging services
 - a. Access to types of gynaecological imaging
 - b. Referral pathway and waiting lists/ delays
 9. Follow-up on endometriosis patients' post-surgery
 - a. Follow-up of mild/moderate/severe cases
 - b. Access point for re-entry into care pathway
 10. Audit, QI, coding
 - a. Coding of endometriosis in primary and secondary care
 - b. Active local audits and quality improvement
 11. Impact of the COVID-19 pandemic on the service
 - a. Delays to surgery and/or referral
 - b. Delays for prescriptions and access to medicinal treatments

Clinical

To explore remediable factors in the process of care of patients with endometriosis throughout the pathway, with a focus on the following areas:

1. Triage of endometriosis patients/initial patient management
 - a. Use of pelvic/abdominal examinations
 - b. Use of pain management
 - c. Recognition of endometriosis and start of referral pathway
2. Information and support, access to mental health services
 - a. Understanding of diagnosing clinician
 - b. Fertility services
3. Delays in referral to a gynaecologist

4. Delay in diagnosis (primary or secondary care), treatment plans and access to an endometriosis specialist
 - a. Access to and involvement of specialist endometriosis nurses
5. Elective/emergency surgery
 - a. Type, and location of the surgery and specialties involved
 - b. Recurrence/referral for laparoscopy and specialties involved
6. Discharge and follow up: Primary and secondary care
 - a. Management plan covering:
 - i. Pain management
 - ii. Hormonal management
 - b. Re-referral pathway
 - c. Holistic care approach (addressing patients' physical, mental, social and financial needs).
 - d. Outcome measurement

Participating hospitals

Data will be collected from all hospitals in England, Wales, and Northern Ireland, that have a gynaecology department.

Method of data collection

Clinician questionnaire

Questionnaires will be uploaded to our online system, which Local Reporters can assign to the named consultant gynaecologist responsible for the patients' care when they were admitted to hospital. Instructions will be provided to pass the questionnaire on to most appropriate clinician (should it not be the named person).

Hospital organisational questionnaire

The questionnaires will collect data on the service provided to patients with endometriosis. Questionnaires will be disseminated via the online questionnaire system and Local reporters will be able to invite multiple clinicians to complete the questionnaire.

GP questionnaire

We will also be disseminating questionnaires to the GP for each patient in the case review. NB: Local Reporters will not be required to assign/ oversee the completion of these questionnaires

National data opt out: From the 1st August 2022, organisations in England need to comply with the national data opt-out. If you are returning a spreadsheet to NCEPOD after this date, prior to returning the data to us, please check the listed patient NHS numbers against the National spine and remove the details of any patients who have opted out.

PLEASE NOTE, BECAUSE OF GDPR REGULATIONS, WE ARE NO LONGER ABLE TO COLLECT CLINICIAN DETAILS WITHOUT CONSENT. WHEN ENTERING CLINICAL TEAM DETAILS PLEASE DO NOT ENTER CLINICIAN NAMES – PLEASE ONLY USE THE NAME/SPECIALTY OF THE TEAM OR A CLINICIAN CODE (THIS CAN BE A PAS CODE OR ANY OTHER THAT WOULD HELP YOU IDENTIFY THE CLINICIAN AND ALLOW US TO SELECT CASES ACROSS A RANGE OF CLINICIANS).

We would be grateful if you could return the **completed password protected patient identifier spreadsheet** to ncepod@nhs.net by **12nd December 2022**. Please then phone the office with the password to open the spreadsheet.

Further information about the study and the protocol, including frequently asked questions, can be found on our website: <https://www.ncepod.org.uk/endometriosis.html> or please contact the office on **0207 251 9060** or by email at endometriosis@ncepod.org.uk



<http://twitter.com/ncepod>

National Confidential Enquiry into Patient Outcome and Death (NCEPOD)