

Endometriosis

Study Protocol – June 2022

Study Advisory Group Members

This multidisciplinary and lay group has been convened to guide the development of the study and to identify the primary aim and objectives to be met.

| | | |
|------|-------------------|--|
| Prof | Andrew Horne | University of Edinburgh |
| Mr | Andrew Kent | Royal Surrey NHS Foundation Trust |
| Dr | Anita Sharma | South Chadderton Health Centre |
| Dr | Arvind Vashisht | University College London Hospitals NHS Foundation Trust |
| Prof | Christian Becker | Oxford University Hospitals NHS Foundation Trust |
| Ms | Claudia Tye | Guy's and St Thomas' NHS Foundation Trust |
| Prof | Davor Jurkovic | University College London Hospitals NHS Foundation Trust |
| Dr | Eddie Morris | Norfolk and Norwich University Hospital NHS Trust |
| Ms | Elizabeth Bruen | Cardiff and Vale University Health Board |
| Dr | Elizabeth Ball | Barts Health NHS Trust |
| Ms | Emma Cox | Endometriosis UK |
| Dr | Ertan Saridogan | University College London Hospitals NHS Foundation Trust |
| Dr | John Hughes | South Tees Hospitals NHS Foundation Trust |
| Ms | Katie Gore | Oxford University Hospitals NHS Foundation Trust |
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| Dr | Uma Marthi | Castleton Health Centre |
| Ms | Amena Bhatti | Royal Pharmaceutical Society |

Clinical Coordinators

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|--------------|---|
| Alex Goodwin | Clinical Co-ordinator (Anaesthesia & Critical Care) |
| Katie Malbon | Clinical Co-ordinator (Paediatrics) |

Non-clinical staff

| | |
|----------------|------------------------|
| Hannah Shotton | Clinical Researcher |
| Mariusz Kosek | Researcher |
| Donna Ellis | Administrative Officer |
| Marisa Mason | Chief Executive |

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^[1]. It can be debilitating and can cause chronic pelvic pain, dyspareunia, dyschesia, and dysuria, fatigue, and infertility. The endometrial-like cells, in addition, can also implant distal to the pelvis in areas such as the lungs (thoracic endometriosis)^[4,2].

Endometriosis is the second most common gynaecological condition in the UK, affecting 1 in 10 women, and an estimated 190 million women worldwide^[3]. In total, endometriosis costs the UK economy £8.2bn a year in treatment, loss of work and healthcare costs^[4].

There is no cure for the condition, but it can be managed with treatments that include hormone therapy and 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^[3]. The treatment pathway also may vary, dependent on a number of factors, with definitive treatment resulting in variable outcomes^[5].

More than 10,000 people took part in an All-Party Political Group (APPG) inquiry, in 2020, which found that 58% of people visited their GP more than 10 times before diagnosis^[2]. The majority of these people stressed the detrimental impact the condition had on their mental health, education, and careers. The APPG further identified health inequalities for those from black, Asian and minority ethnic communities. It recommends all UK nations have compulsory menstrual wellbeing on the school curriculum and calls for training to be reviewed for GPs, nurses, and gynaecologists as well as for investment in research to find a cure^[3].

This is an under investigated, debilitating incurable condition in a discreet patient group, where the processes of care vary widely and where there is no defined and agreed care pathway. This is ideal for an NCEPOD study, and the timing of this study is also pertinent, following the APPG. A national report with recommendations on care could make a real difference to a large cohort of patients.

References

- [1] National Institute for Health and Care Excellence. (2017). *Endometriosis: diagnosis and management*. NICE Guidelines [NG73]. <https://www.nice.org.uk/guidance/NG73>
- [2] Endometriosis in the UK: time for change. (2020). *APPG on Endometriosis Inquiry Report*. <https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf>
- [3] ESHRE Endometriosis Guideline Development Group. (2022). *Endometriosis: Guideline of European Society of Human Reproduction and Embryology*. ESHRE. <http://www.eshre.eu/guidelines>

- [4] Saraswat, L., Ayansina, D., Cooper, K. G., Bhattacharya, S., Horne, A. W., & Bhattacharya, S. (2018). Impact of endometriosis on risk of further gynaecological surgery and cancer: a national cohort study. *BJOG : an international journal of obstetrics and gynaecology*, 125(1), 64–72. <https://doi.org/10.1111/1471-0528.14793>
- [5] Zondervan, K., Becker, C. and Missmer, S. (2022). Endometriosis. *New England Journal of Medicine*. https://www.nejm.org/doi/full/10.1056/NEJMra1810764?query=recirc_curatedRelated_article

Guidelines and standards

- National Institute for Health and Care Excellence. (2017). Endometriosis: diagnosis and management. NICE Guidance [NG73]. <https://www.nice.org.uk/guidance/NG73>
- National Institute for Health and Care Excellence. (2018). Endometriosis: Quality standard. NICE Guidance [QS172]. <https://www.nice.org.uk/guidance/QS172>
- British Society for Gynaecological Endoscopy. (2019). Complex Laparoscopic Surgery for Severe Endometriosis. BSGE Guidance for clinical coders. <https://bsge-online.org.uk/downloads/Complex%20Laparoscopic%20Surgery%20for%20Severe%20Endometriosis%20April%202019.pdf>
- European Society of Human Reproduction and Embryology. (2022). Management of women with endometriosis ESHRE Guidelines. <https://www.eshre.eu/Guidelines-and-Legal/Guidelines/Endometriosis-guideline>
- All Party Parliamentary Group on Endometriosis. (2020). Endometriosis in the UK: time for change. APPG on Endometriosis Inquiry Report. <https://www.endometriosis-uk.org/sites/endometriosis-uk.org/files/files/Endometriosis%20APPG%20Report%20Oct%202020.pdf>

Aims and objectives

Overall aim:

To review remediable factors in the quality of care provided to patients aged 18 and over with a diagnosis of endometriosis between the **1st February 2018 - 31st July 2020**.

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 primary care and endometriosis centres/secondary care and the presence of a specialist community service
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 patients in (and not limited to) primary care, emergency departments and gynaecology departments
 - a. Use of psychological assessment and access to specialist psychological support
 - b. Policies/protocols/care pathways covering the referral process, pain management, treatment (medication/surgery) and follow-up
4. Communication between primary, secondary, tertiary care and between different departments and specialists (data sharing, transfer of notes, correspondence etc).
 - a. Communication between clinicians, and between clinicians and the patients
5. Information provided to patients about their condition and access to support
 - a. Mental health support
 - b. Endometriosis support groups
 - c. Information about the treatment plan/plan for follow-up
 - d. Advice on what to do in event of flare up
6. Staffing
 - a. Training provided in the recognition and care of patients with endometriosis and availability for which specialties
 - b. Access to endometriosis specialist nurses: the number of WTE nurse specialists in endometriosis, their grades and the percentage of their job plans dedicated to the care of patients with endometriosis
 - c. Access to Ancillary Services with expertise in endometriosis: WTE, grades & sub-specialties of radiologists, physiotherapists, dietitians, fertility specialists, clinical psychologists, and pain specialists/pain teams and percentage of job plan dedicated to the care of patients with endometriosis

- d. Number of (WTE) gynaecologists (with and without a special interest in endometriosis) and percentage of job plan dedicated to the care of patients with endometriosis
7. Surgical services
 - a. The structure of the team/s providing surgical services
 - b. Record of delayed/ postponed/ cancelled procedures and number of patients on waiting lists
 - c. Number and type of procedures carried out:
 - i. Within each centre – BSGE centres/ non-BSGE
 - ii. By each surgeon- gynaecology/ non-gynaecology
 - iii. Evidence of follow-up/ audit of surgical outcomes
 8. Imaging services
 - a. Access to types of gynaecological imaging (ultrasound/ MRI) and imaging specialists with a special interest in endometriosis
 - b. Referral pathway and waiting lists/ delays
 - c. Repeat scanning by different providers
 9. Follow-up on endometriosis patients' post-surgery
 - a. Follow-up of mild/moderate/severe cases and variation that exists between centres
 - b. Access point for re-entry into care pathway:- severe/ mild/moderate patients
 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 (potential opiate/gabapentin use) and hormonal treatment
 - c. Recognition of endometriosis and start of referral pathway
 - d. Care of co-morbidities and prior treatments for pelvic pain?
2. Information and support, access to mental health services, offered and provided to patients suspected of endometriosis
 - a. Understanding of diagnosing clinician
 - b. Consideration for fertility preservation, infertility management and access to fertility services

3. Delays in referral to a gynaecologist
 - a. Further referral to ultrasound/MRI imaging services to make a diagnosis
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:
 - b. Pain management
 - c. Hormonal management
 - d. Re-referral pathway
 - e. Holistic care approach (addressing patients' physical, mental, social and financial needs).
 - f. Outcome measurement

Methods

1) Anonymous data collection patient survey and groups

Once the Clinician Questionnaire and Reviewer Assessment Forms have been designed, we will design a more detailed patient survey that will cover the themes noted in the objectives above (that cannot be sourced elsewhere) and also mirror the themes from the case review. We will invite a group of patients who have completed the survey to consider themes that arise in a series of discussion groups. This anonymous online survey will use the on-line questionnaire platform: QUALTRICS.

Clinical and organisation data collection

Population/inclusions

Patients aged 18 or older with a primary diagnosis of endometriosis during the study timeframe: **1st February 2018 - 31st July 2020**

Exclusions

Patients who have been miscoded and are found not to have Endometriosis

Participating providers of healthcare

All NHS and independent hospitals in England, Wales, and Northern Ireland, to which patients with endometriosis are admitted

Incidence and prevalence

Up to 1:10 women

| 2018/2019 | | Admissions | Emergency | Waiting list | Mean length of stay | Elective |
|------------------------------|------------------|------------|-----------|--------------|---------------------|----------|
| Endometriosis N80.0-N80.9 | England | 22,234 | 2,812 | 18,825 | 1.0 | 924 |
| | Wales | 938 | 113 | 793 | 1.9 | - |
| | Northern Ireland | 572 | 51 | 526 | 1.6 | 25 |
| 2019/2020 | | Admissions | Emergency | Waiting list | Mean length of stay | Elective |
| Endometriosis N80.0-N80.9 | England | 21,888 | 2,905 | 18,398 | 1.0 | 923 |
| | Wales | 897 | 73 | 801 | 1.7 | - |
| | Northern Ireland | 490 | 44 | 453 | 1.6 | 18 |
| 2020/2021 | | Admissions | Emergency | Waiting list | Mean length of stay | Elective |
| Endometriosis N80.0-N80.9 | England | 13,709 | 3,019 | 10,407 | 2.0 | 555 |
| | Wales | 872 | 71 | 753 | 1.7 | - |
| | Northern Ireland | 159 | 36 | 123 | 2.0 | 8 |

Scoping work

Four acute secondary care Trusts gave us details* of patients admitted during the period: **1st January 2021 – 31st December 2021** with a primary ICD10 code for endometriosis (N80.0-N80.9).

**without any patient identifiers*

It was noted how many of these patients had a laparoscopy (OPCS Y75, T43, Q39, Q50) and for how many it was the first record of this on the patient administration system. Whilst accepting that some patients will have been treated previously at another hospital, the aim was to enrich the identified population for those who were first diagnosed with endometriosis during the study period, so as to minimise the number of previous years of notes required to reasonably look at delays in the process of diagnosis of the condition.

Other ICD10 and OPCS codes (in addition to those specified above were requested) for that admission, in order to see the reason for admission to hospital other than for a laparoscopy. These admissions were mostly for pain management. It should be noted that these figures are from the height of the COVID-19 pandemic, and therefore the low numbers presented may reflect the delays and cancellations that occurred at this time.

The findings were as follows:

| Hospital Trust | No. of patients admitted with Endometriosis (N80.0-N80.9) | No. of patients who had a laparoscopy (OPCS Y75, T43, Q39, Q50) |
|----------------|---|---|
| 1 | 158 | 33 |
| 2 | 44 | 14 |
| 3 | 161 | 92 |
| 4 | 98 | 66 |

Methods of data collection

Identification of patient population

An Excel spreadsheet will be disseminated to local reporters at participating hospitals to populate with basic details of patients who are eligible for inclusion in the study.

We will ask local reporters to identify patients who were admitted to hospital during the study period (**1st February 2018- 31st July 2020**) with a primary diagnosis for endometriosis (ICD10 codes N80.0-N80.9*) and who had undergone a laparoscopy (OPCS codes).

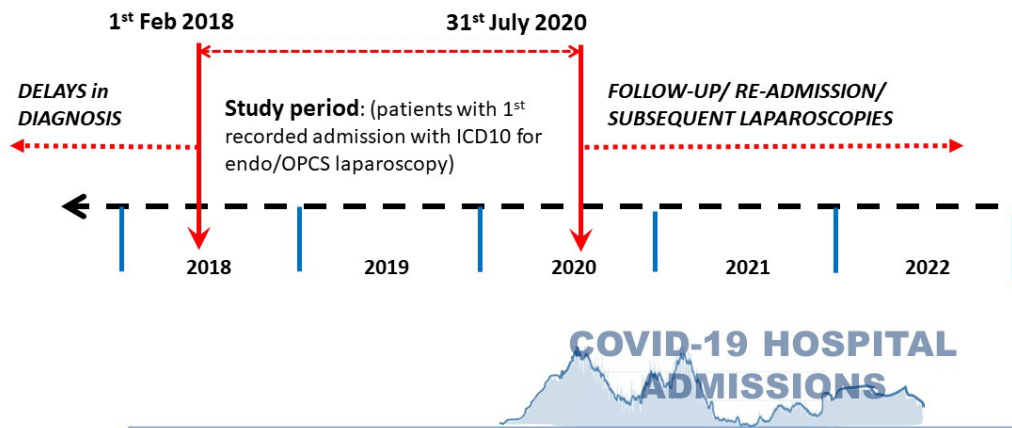
This population will include some patients for whom this was their diagnostic laparoscopy for endometriosis, and for others it will represent a subsequent laparoscopy for treatment purposes.

From the patients identified, we will include in the study sample, patients for whom the admission was when they were first diagnosed with endometriosis, using the fact that the 'index' admission represented their first recording of ICD10/ OPCS coding for endometriosis/ laparoscopy on the hospital records as a surrogate marker for the diagnostic admission.

We will limit the sample to 8 patients per hospital and a maximum of 3 questionnaires per consultant so as not to over-burden clinicians/ hospital resources.

To give us information from the whole pathway of care, we will look back at the care provided to this group of patients prior to the index admission (this could be up to 8 years prior to diagnosis), and we will also look at any outpatient follow-up appointments, attendances at the emergency department. The period following discharge is likely to include the peak of the COVID-19 pandemic and we will be cognisant of this in the design of the data collection materials.

The timeline for data collection is shown in the diagram below.



Coding

| Primary diagnosis: 4-character code and description | |
|---|---|
| N80.0 | Endometriosis of uterus |
| ‡ N80.1 | Endometriosis of ovary |
| N80.2 | Endometriosis of fallopian tube |
| N80.3 | Endometriosis of pelvic peritoneum |
| N80.4 | Endometriosis of rectovaginal septum and vagina |
| N80.5 | Endometriosis of intestine |
| N80.6 | Endometriosis in cutaneous scar |
| N80.8 | Other endometriosis |
| N80.9 | Endometriosis, unspecified |

| OPCS CODE | Description |
|-----------|---|
| Y75.2 | Laparoscopic approach to abdominal cavity NEC |
| Y75.3 | Robotic minimal access approach to abdominal cavity |
| T30.9 | Laparotomy (exploratory) |
| P29.3 | Vaginal biopsy |
| T43.9 | Diagnostic Laparoscopy |
| Q50.1 | Laparoscopic biopsy of ovary |
| T43.1 | Laparoscopic biopsy |
| Q39 | Laparoscopy fallopian tube |

| | |
|-------|--|
| Q50 | Laparoscopy Ovary |
| Q55.4 | Colposcopy |
| Q03.9 | Cervical biopsy |
| Q01.4 | LLETZ |
| Q03.3 | Cone biopsy of cervix NEC |
| Q07.4 | Total abdominal hysterectomy NEC |
| Q07.1 | Radical hysterectomy (hysterocolpectomy & excision of periuterine tissue, includes part of vagina) |
| Q08.9 | Vaginal hysterectomy |
| Q09.2 | Myomectomy (removal of uterine fibroids) |
| Q18.9 | Hysteroscopy |
| Q18.1 | Endometrial biopsy |
| Q22.1 | Bilateral salpingo-oophorectomy |
| Q23.1 | Unilateral salpingo-oophorectomy |
| Q22.3 | Bilateral oophorectomy |
| Q23.5 | Unilateral oophorectomy |
| Q43.2 | Cystectomy of ovary |
| Q23.6 | Oophorectomy of remaining ovary |
| Q47.3 | Open biopsy of ovary |
| Q22.2 | Bilateral salpingectomy |
| Q47.2 | Division of ovary adhesions-open |
| Q49.2 | Division of ovary adhesions- endoscopic |
| Q34.1 | Division of fallopian tube adhesions-open |
| Q38.1 | Division of fallopian tube adhesions-endoscopic |
| T41.3 | Division of bowel adhesions- open |
| T41.5 | Division of extensive bowel adhesions- endoscopic |
| T42.3 | Division of bowel adhesions – endoscopic |
| H12.2 | Excision of lesion of colon |
| P05.4 | Excision of vulval lesion |

NB: Plus ECDS 127161331000, SNOMED 129103003 or ICD11 GA10.Z codes for endometriosis

Questionnaires

Clinician questionnaires

1) Gynaecologist

A) History

- 1) Previous gynaecology appointments
- 2) GP referral
- 3) Imaging appointments
- 4) Events leading up to diagnosis*

B) Current 'index' admission

- 1) Laparoscopy – perioperative care
- 2) Diagnosis, information
- 3) Pain management etc.
- 4) Discharge planning/ follow up

C) Subsequent readmissions

- 1) Re-entry into pathway
- 2) GP referral
- 3) Multiple admissions

*For patients who were diagnosed prior to the index admission then we would potentially look back at their previous laparoscopies/ history but not necessarily get all the information from the period leading up to their diagnosis

2) Primary care clinician questionnaire

The general practitioner will be identified from either the hospital case notes or the central records (if recorded) via the case identification spreadsheet and they will be sent a short form to complete regarding the care provided prior to and at the time of diagnosis, and details of subsequent appointments for endometriosis.

The primary care clinician questionnaire will be sent for those patients identified as being referred for the admission by their GP (identified via the patient identification spreadsheet, the case notes or the completed clinician questionnaire). The questionnaire will be sent directly to the GP for completion either via the online questionnaire system, or as a hard copy questionnaire if the online system cannot be used.

A reminder will be sent at six weeks and ten weeks where the data is outstanding. This questionnaire will collect data regarding the care provided prior to and at the time of diagnosis, and details of subsequent appointments for endometriosis.

Organisational questionnaire

Data collected will include information about the organisation of services, care pathways (including specialist commissioned pathways), the use of guidelines and protocols, and multidisciplinary team working (as per organisational objectives).

An organisational questionnaire will be sent for completion by primary care, secondary care and specialist tertiary care providers. These questionnaires will cover the following areas for questioning:

- 1) Triage and referral process of patients
- 2) Presence of care networks
- 3) Links between GP and endometriosis centres/secondary care.
- 4) Access to endometriosis specialist centres:
 - a. their management structures
 - b. the quality of care provided
 - c. if they are meeting their requirements
- 5) Policies/protocols/care pathways in place
- 6) Psychological screening/ access to psychologist, referral, pain management, treatment and follow-up
- 7) Communication e.g. between levels of care
- 8) Pharmacy services
- 9) Information provided to patients
- 10) Access to mental health support, advice, and support groups
- 11) Staffing, specialties/ratios, awareness of the condition and the training provided to clinicians
- 12) Surgical services
- 13) Imaging services
- 14) Follow-up on endometriosis patients' post-surgery
- 15) Audit, QI, and Coding
- 16) Impact of the COVID-19 pandemic on the service

Case note review

Case note extracts will be requested for all patients included in the study sample.

Notes requested from (relating to the index admission) will include:

- Secondary / tertiary care

- 1) All historical gynaecology case notes, including (not limited to):
 - Correspondence – clinic letters, referrals etc.
 - Clinical notes, clinics attended
 - Previous operation notes
 - Imaging reports
 - Pharmacy documentation
 - Drug charts
 - Prescribed medications on admission/discharge
 - Biochemistry and histology reports
- 2) Case notes from the current 'index' admission
 - Clinical annotations

- Operation notes
 - Nursing notes
 - Imaging, histology, biochemistry reports
 - Pharmacy
- 3) Subsequent admissions for endometriosis
- Clinical notes
 - Imaging
 - Operation notes etc.

- Primary care

Primary care notes relating to relevant patient appointments in the (up to 8 year) period prior to diagnosis, including visit notes and prescriptions as well as details of communications with secondary/ tertiary care and details of any follow-up appointments or subsequent episodes of endometriosis.

Upon receipt at NCEPOD the case notes will be redacted if not already done so.

Reviewer assessment form

A multidisciplinary group of reviewers (details below) will be recruited to assess the case notes and questionnaires and give their opinions on the quality of care via the reviewer assessment form.

The Reviewer Assessment Form (RAF) will follow the pathway of care, and interrogate the quality of care provided at each stage:

- 1) Pre-diagnosis
- 2) Referral to Gynaecology
- 3) Imaging
- 4) Referral for laparoscopy
- 5) Laparoscopy treatment and diagnosis
- 6) Discharge planning
- 7) Follow up
- 8) Readmissions
- 9) Ongoing pain management
- 10) Ongoing patient support/ information
- 11) Ongoing management of medications
- 12) Effect of the COVID-19 pandemic on the service provided

Sample size

| Data source | Target number |
|------------------------------|----------------------|
| Organisational questionnaire | ~300 |
| Clinician questionnaires | ~500 |
| Case note reviews | ~400 |

Anonymous clinician survey

An anonymous on-line survey for (but not limited to): gynaecologists, emergency medicine doctors, general practitioners, nurses, physiotherapists and other healthcare professionals to complete will be created using the online questionnaire platform, QUALTRICS. The survey will look at aspects of training, the clinicians' attitude to endometriosis patients, the number of patients seen, and the time/job planning devoted to patients with endometriosis. For those clinicians who are surgeons we will, additionally to the above, look at the number of procedures performed on endometriosis patients within their hospital/endometriosis centres.

Study method test

The data collection methods and data collection tools will be tested to ensure they are robust.

Study promotion

Prior to data collection, NCEPOD will contact all local reporters and ambassadors and send a study poster to display locally to advertise the study. Social media will also be used to publicise the study.

Analysis and review of data

Reviewers

A multidisciplinary group of reviewers will be recruited to assess the case notes and questionnaires and provide their opinion on the care the patients received. The reviewer group will be comprised of (and not be limited to): gynaecologists, obstetricians, general surgeons, colorectal surgeons, pain specialists, fertility specialists, gastroenterologists, urologists, radiologists, mental health professionals, endometriosis specialist nurses, physiotherapists and general medicine practitioners.

An advertisement will be sent to local reporters to disseminate throughout the relevant departments. It will also be placed on the NCEPOD website. Successful applicants will be asked to attend a training day where they will each assess the same two sets of case notes to ensure consistent assessment. A number of meeting dates will be arranged, and each reviewer will then be asked to attend a further 6 meetings.

The meetings will either be in the NCEPOD office or carried out on-line using MS TEAMS. NCEPOD staff will ensure there is a mix of specialties represented at each meeting from across England, Wales, and Northern Ireland. Each meeting will be chaired by an NCEPOD Clinical Co-ordinator who will lead discussion around the sets of cases under review. Towards the end of the study the reviewers will be invited to attend a meeting where the data will be presented to and discussed with them. The reviewers will also be sent two copies of the draft report for their comment as this is developed.

Confidentiality and data protection

All electronic data are held in password protected files and all paper documents in locked filing cabinets. As soon as possible after receipt of data NCEPOD will encrypt electronic

identifiers and anonymise paper documents. Section 251 approval has been obtained to perform this study without the use of patient consent in England and Wales.

Dissemination

On completion of the study a report will be published and widely disseminated.

Study outputs

On completion of the study a report will be published and widely disseminated to all stakeholders to encourage local quality improvement (QI) (further details available in the communication plan). In addition to the report, supporting tools will be made available including:

- A summary report and summary sheet
- Infographics
- The recommendation checklist
- An audit tool
- A slide set
- A guide for commissioners
- Fishbone diagrams
- Useful links for patients

Examples of good practice will be shared, and additional QI tools will be developed where appropriate. Key messages from the report will be shared via social media.

Following publication, the report findings will be shared at national and local conferences, study days and other events; and papers submitted to journal for consideration for publication.

Data sharing

Post publication of the study, there is the potential to share anonymised data sets with interested parties working in the same field. This will be undertaken following a strict process and will ensure the data does not become identifiable in their nature due to small numbers.

