

ENDOMETRIOSIS: Clinical Questionnaire

A. Introduction

What is this study about:

This study will look at the care provided to patients aged 18 and over, with a diagnosis of endometriosis. It will look at the whole pathway of care from the events leading to the initial diagnosis and treatment, to discharge, follow-up and subsequent attendances and admissions for the investigation and treatment of endometriosis, reviewing any remediable factors in the quality of care provided.

Inclusions:

Patients, aged 18 and older, who were admitted to hospital with a diagnosis of endometriosis during the study period: 1st February 2018 - 31st July 2020 (this is the "index admission") and have undergone a laparoscopic (or other surgical) procedure to treat their symptoms.

Exclusions:

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

Who should complete the questionnaire?

The questionnaire should be completed by the gynaecologist responsible for the patient at the time of the index admission (or by another consultant gynaecologist nominated by the Local Reporter).

Please do not include any patient identifiers in the free text boxes.

Questions or help:

Further information regarding this study can be found here: <https://www.ncepod.org.uk/endometriosis.html>
If you have any queries about this study or this questionnaire, please contact:
endometriosis@ncepod.org.uk or telephone 020 7251 9060.

Definitions

A list of definitions can be found at

<https://www.ncepod.org.uk/pdf/current/Endometriosis/Endo%20CQ%20definitions.pdf>

CPD accreditation

Consultants who complete NCEPOD questionnaires make a valuable contribution to the investigation of patient care. Completion of questionnaires also provides an opportunity for consultants to review their clinical management and undertake a period of personal reflection. These activities have a continuing medical and professional development value for individual consultants. Consequently, NCEPOD recommends that consultants who complete NCEPOD questionnaires keep a record of this activity which can be included as evidence of internal/self directed Continuous Professional Development in their appraisal portfolio.

About NCEPOD

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) reviews healthcare practice by undertaking confidential studies, and makes recommendations to improve the quality of the delivery of care, for healthcare professionals and policymakers to implement. Data to inform the studies are collected from NHS hospitals and Independent sector hospitals across England, Wales, Northern Ireland and the Offshore Islands. NCEPOD are supported by a wide range of bodies and the Steering Group consists of members from the Medical Royal Colleges and Specialist Associations, as well as observers from The Coroners Society of England and Wales, and the Healthcare Quality Improvement Partnership (HQIP).

Impact of NCEPOD

Recommendations from NCEPOD reports have had an impact on many areas of healthcare including: Development of the NICE 'Acutely ill patients in hospital guideline' (CG50) - following publication of the 2005 'An Acute Problem' report. Appointment of a National Clinical Director for Trauma Care - following publication of 'Trauma: Who Cares?' 2007. Development of NICE Clinical Guidelines for Acute Kidney Injury, published in 2013 - 'Adding Insult to Injury' 2009. Development of ICS Standards for the care of adult patients with a temporary Tracheostomy, published 2014 - 'On the right trach?' 2014. Development of guidelines from the British Society of Gastroenterology: acute lower gastrointestinal bleeding, published 2019 - 'Time to Get Control' 2015. Development of the British Thoracic Society's Quality Standards for NIV, published 2018 - 'Inspiring Change' 2017.

This study was commissioned by The Healthcare Quality Improvement Partnership (HQIP) as

part of the Clinical Outcome Review Programme into Medical & Surgical care.

B. Patient details

The index admission for this study refers to the first recorded admission to hospital for a laparoscopy* during the study period (01/02/2018- 31/07/2020) for endometriosis (dates of admission / discharge for the index admission are indicated on the previous "assignments" screen of the questionnaire portal

1. What was the age of the patient at the time of the index admission*?

**The index admission refers to the episode of care which identified the patient for the study (01/02/2018 - 31/07/2020, displayed as part of the patient details on the previous "assignments" screen)*

 years

Value should be no more than 120

Unknown

2. Ethnicity:

- White British/White other
- Black/African/Caribbean/Black British
- Asian/Asian British (Indian, Pakistani, Bangladeshi, Chinese, other Asian)
- Mixed/Multiple ethnic groups
- Unknown

If not listed above, please specify here...

3a. Was there a documented learning disability?

- Yes No Unknown

3b. If answered "Yes" to [3a] then:

What was the documented learning disability?

4a. Did the patient have any co-morbidities related to endometriosis?

- Yes No Unknown

4b. If answered "Yes" to [4a] then:

Please list any co-morbidities related to endometriosis:

Answers may be multiple, please select all that apply

- Uterine fibroids
- Migraines
- Irritable bowel syndrome
- Interstitial cystitis
- Rheumatoid arthritis
- Psoriatic arthritis
- Osteoarthritis
- Dyschezia (painful bowel movement)
- Painful bladder syndrome
- Adenomyosis
- Back pain
- Chronic widespread pain
- Autoimmune disease
- Fibromyalgia
- Chronic fatigue syndrome / myalgic encephalomyelitis
- Ovarian cancer
- Cancer of the reproductive organs
- Early natural menopause
- Ovarian cysts

Please specify any additional options here...

5a. Did the patient have any co-morbidities that were not related to endometriosis?

- Yes No Unknown

5b. If answered "Yes" to [5a] then:

Please list any comorbidities not related to endometriosis:

1a. Please select all those who saw the patient in relation to their symptoms prior to diagnosis of endometriosis:

**please see definitions*

- General practitioner
- Emergency department
- NHS Gynaecology department (non-specialist BSGE centre*)
- NHS Gynaecology department (BSGE centre*)
- Independent hospital gynaecology department
- Other specialty department
- Unknown

Please specify any additional options here...

Presentation to the GP

1b. If answered "General practitioner", "Emergency department", "NHS Gynaecology department (non-specialist BSGE centre*)", "NHS Gynaecology department (BSGE centre*)", "Independent hospital gynaecology department" or "Other specialty department" to [1a] then:

In the case note record, do you have access to any information regarding the patient's visit/s to the GP prior to diagnosis?

- Yes
 No
 Unknown

2. If answered "General practitioner" to [1a] and "Yes" to [1b] then:

When did the patient first present to their GP practice with symptoms relating to endometriosis?

Please include dates in DD/MM/YYYY format. If exact date is unknown, if possible, please just include month and year

3. If answered "General practitioner" to [1a] then:

Please indicate the symptoms that the patient first presented with to the GP, prior to their first referral to gynaecology:

Answers may be multiple, please select all that apply

- | | |
|---|---|
| <input type="checkbox"/> Acyclical pelvic pain | <input type="checkbox"/> Constipation |
| <input type="checkbox"/> Extra-pelvic pain | <input type="checkbox"/> Painful periods (dysmenorrhea) |
| <input type="checkbox"/> Heavy menstrual bleeding (menorrhagia) | <input type="checkbox"/> Irregular bleeding |
| <input type="checkbox"/> Multi-site pain | <input type="checkbox"/> Dyschezia |
| <input type="checkbox"/> Diarrhoea | <input type="checkbox"/> Abdominal bloating |
| <input type="checkbox"/> Bladder symptoms | <input type="checkbox"/> Painful urination (dysuria) |
| <input type="checkbox"/> Painful intercourse (dyspareunia) | <input type="checkbox"/> None of these |
| <input type="checkbox"/> Unknown | |

Please specify any additional options here...

4a. If answered "General practitioner" to [1a] and "Yes" to [1b] then:

Is there any evidence that the GP carried out any examinations/investigations relating to endometriosis, prior to the diagnosis?

- Yes
 No
 Unknown

**4b. If answered "Yes" to [4a] then:
Please provide the details and dates of the examinations**

Please include dates in DD/MM/YYYY format

**5a. If answered "General practitioner" to [1a] and "Yes" to [1b] then:
Was there any evidence in the notes that the GP provided the patient with information and support regarding their suspected endometriosis?**

Yes No Unknown

**5b. If answered "Yes" to [5a] then:
Please provide further details:**

Referral to gynaecology and attendance at gynaecology clinic

6. In the case note record, is there any information regarding the first referral to gynaecology and/ or attendances at the gynaecology clinic, prior to diagnosis of endometriosis?

Yes No Unknown

**7a. If answered "Yes" to [6] then:
Date of first referral to gynaecology**

Unknown

**7b. If answered "Yes" to [6] then:
If exact date unknown, could you estimate the month and year of the first referral to gynaecology?**

**8a. If answered "Yes" to [6] then:
In your opinion, could the patient have been referred to gynaecology sooner?**

Yes No Unknown

**8b. If answered "Yes" to [8a] then:
Please provide details**

9a. If answered "Yes" to [6] then:

Did the referral to gynaecology include a working diagnosis that mentioned endometriosis?

- Yes No Unknown

9b. If answered "Yes" to [6] and "Yes" to [9a] then:

What term was used to describe the working diagnosis of endometriosis in the referral to gynaecology?

- Suspected endometriosis Probable endometriosis Query endometriosis

Please specify any additional options here...

10a. If answered "Yes" to [6] then:

Please give the date that the patient was first seen in the gynaecology clinic regarding their symptoms of endometriosis:

- Unknown

10b. If answered "Yes" to [6] then:

If date unknown, please could you estimate the month and year the patient was first seen in the gynaecology clinic regarding their symptoms of endometriosis:

11a. If answered "Yes" to [6] then:

Please indicate the examinations undertaken by the gynaecologist, for the symptoms of endometriosis:

- Abdominal examination Pelvic examination Unknown

Please specify any additional options here...

11b. If answered "Abdominal examination" or "Pelvic examination" to [11a] and "Yes" to [6] then:

Did the examination/s identify:

Answers may be multiple, please select all that apply

- Any abdominal masses
 Adnexal mass
 Lower abdominal tenderness
 Fixed and tender retroverted uterus
 Adnexal tenderness
 Pelvic floor tenderness and tension (If pelvic floor assessed)
 Unable to answer

Please specify any additional options here...

12. If answered "Yes" to [6] then:

Did the patient have contact with a endometriosis nurse specialist, prior to diagnosis?

- Yes No Unknown

Non-gynaecological pathway

13a. At any time prior to diagnosis of endometriosis, was this patient referred to a non-gynaecological specialty pathway for management of endometriosis symptoms?

- Yes No Unknown

**13b.If answered "Yes" to [13a] then:
Please give details**

**14a.If answered "Yes" to [13a] then:
Did the patient subsequently undergo any non-gynaecological, endometriosis related,
treatment/investigations?**

Yes No Unknown

**14b.If answered "Yes" to [14a] then:
Please give details and relevant date/s**
Please include dates in DD/MM/YYYY format

Imaging

16. Prior to diagnosis of endometriosis, was the patient referred for an ultrasound scan (USS) relating to the symptoms of endometriosis?

Yes No Unknown

**17. If answered "Yes" to [16] then:
Who first referred the patient for an USS, prior to diagnosis of endometriosis?**

The patient's general practitioner The patient's gynaecologist
 Acute physician Other specialty doctor
 Unknown

If not listed above, please specify here...

**18a.If answered "Yes" to [16] then:
What date was the patient first referred for an USS?**

Unknown

18b. If answered "Yes" to [16] then:

If the exact date of the USS is not known, if possible please estimate the month and year:

19. If answered "Yes" to [16] then:

What type of USS did the patient have?

Answers may be multiple, please select all that apply

- Trans-abdominal Trans-vaginal Trans-rectal No ultrasound scan
 Unknown

Please specify any additional options here...

20. If answered "Yes" to [16] then:

Was the patient scanned by someone specially trained in endometriosis scanning?

- Yes No Unknown

21. If answered "Yes" to [16] then:

Were the results of the USS shared with the patient's GP?

- Yes No Unknown

22. Prior to diagnosis, was the patient referred for any Magnetic Resonance Imaging (MRI) scans?

- Yes No Unknown

23a. If answered "Yes" to [22] then:

What was the date of the MRI scan?

23b. If answered "Yes" to [22] then:

If the exact date of the MRI is not known, if possible please estimate the month and year:

24. If answered "Yes" to [22] then:

Was the patient scanned by someone specially trained in endometriosis scanning?

- Yes No Unknown

If not listed above, please specify here...

25. If answered "Yes" to [22] then:

Were the results of the MRI shared with the patient's GP?

- Yes No Unknown

D. First diagnosis of endometriosis

1a. Date of diagnosis

Please include dates in DD/MM/YYYY format

Unknown

1b. If the exact date is not known, please estimate the month and year.

2. What was the diagnosis?

Answers may be multiple, please select all that apply

- | | |
|--|---|
| <input type="checkbox"/> Endometriosis on the uterine surface | <input type="checkbox"/> Endometriosis of ovary |
| <input type="checkbox"/> Endometriosis of fallopian tube | <input type="checkbox"/> Endometriosis of pelvic peritoneum |
| <input type="checkbox"/> Endometriosis of rectovaginal septum and vagina | |
| <input type="checkbox"/> Endometriosis of intestine | <input type="checkbox"/> Endometriosis in cutaneous scar |
| <input type="checkbox"/> Endometriosis of thorax | <input type="checkbox"/> Endometriosis in the bladder |
| <input type="checkbox"/> Endometriosis of the urinary tract | <input type="checkbox"/> Endometriosis, unspecified |
| <input type="checkbox"/> Unknown | |

Please specify any additional options here...

3. Has the patient been diagnosed with deep endometriosis?

involving the bowel, bladder or ureter

- Yes No Unknown

4. Has the patient been diagnosed with endometriosis outside of the pelvic cavity?

- Yes No Unknown

5. In the case note record, is there any information from the hospital admission when endometriosis was first diagnosed?

The diagnosis may have been during the index admission* or may have happened prior to this (*see definitions).

- Yes No Unknown

6a. If answered "Yes" to [5] then:

How was the diagnosis of endometriosis confirmed?

Answers may be multiple, please select all that apply

- | | | |
|--------------------------------------|----------------------------------|---|
| <input type="checkbox"/> Laparoscopy | <input type="checkbox"/> Biopsy | <input type="checkbox"/> Other surgical procedure |
| <input type="checkbox"/> Imaging | <input type="checkbox"/> Unknown | |

Please specify any additional options here...

**6b. If answered "Imaging" to [6a] then:
Please provide details of imaging**

**6c. If answered "Other surgical procedure" to [6a] then:
Please provide details of other surgical procedure**

7. If answered "Yes" to [5] and "Laparoscopy", "Biopsy" or "Other surgical procedure" to [6a] then:

What procedure was performed when endometriosis was first diagnosed?

- | | |
|---|--|
| <input type="checkbox"/> Laparoscopic ablation | <input type="checkbox"/> Laparoscopic excision |
| <input type="checkbox"/> Laparoscopic ablation and excision | <input type="checkbox"/> Other laparoscopy |
| <input type="checkbox"/> Hysterectomy | <input type="checkbox"/> Unknown |

Please specify any additional options here...

8. If answered "Yes" to [5] and "Laparoscopy", "Biopsy" or "Other surgical procedure" to [6a] then:

When was consent taken for the laparoscopy (or other surgical procedure) that was carried out during the admission when endometriosis was first diagnosed?

Unknown

9. If answered "Yes" to [5] then:

Were the risks and benefits of surgery discussed with the patient?

- Yes No Unknown

10. If answered "Yes" to [5] then:

What was the specialty of the operating surgeon?

- Gynaecology General surgery Colorectal surgery Urology
 Unknown

If not listed above, please specify here...

11a. If answered "Yes" to [5] and "Laparoscopy", "Biopsy" or "Other surgical procedure" to [6a] then:

Were there any complications of the procedure?

- Yes No Unknown

11b. If answered "Yes" to [11a] then:

Please provide details of any complications of the procedure:

12. If answered "Yes" to [5] then:

What was the patient's stage of endometriosis at the time of diagnosis?

- Minimal (Stage I) Mild (Stage II) Moderate (Stage III)
 Severe (Stage IV) Not recorded

If not listed above, please specify here...

13a.If answered "Yes" to [5] then:

Following diagnosis, were any other specialties involved in the care of this patient?

- Yes No Unknown

13b.If answered "Yes" to [13a] then:

Please give further details:

14a.In your opinion, was there a delay in the initial diagnosis of endometriosis?

- Yes No Unknown

14b.If answered "Yes" to [14a] then:

Please provide further details

14c.If answered "Yes" to [14a] then:

In your opinion, did the delay lead to a worsening of symptoms?

- Yes No Unknown

15a.If answered "Yes" to [5] then:

Following the admission when endometriosis was first diagnosed, were any follow-up appointments arranged?

- Yes No Unknown

15b.If answered "Yes" to [15a] then:

Who were the follow-up appointment/s with?

Answers may be multiple, please select all that apply

- | | |
|---|---|
| <input type="checkbox"/> Gynaecologist | <input type="checkbox"/> Operating surgeon |
| <input type="checkbox"/> General practitioner | <input type="checkbox"/> Endometriosis nurse specialist |
| <input type="checkbox"/> Physiotherapist | <input type="checkbox"/> Gastroenterologist |
| <input type="checkbox"/> Fertility specialist | <input type="checkbox"/> Pain specialist |
| <input type="checkbox"/> Mental health specialist | |

Please specify any additional options here...

16. If answered "Yes" to [5] then:

Was the discharge summary shared with:

Answers may be multiple, please select all that apply

- The General Practitioner
 The Patient
 Another provider (if care was shared between providers)
 Unknown

Please specify any additional options here...

17a.If answered "Yes" to [5] then:

Was a management/ care plan put in place following diagnosis?

- Yes No Unknown

17b.If answered "Yes" to [17a] then:

Please provide details of the management care plan

18a.If answered "Yes" to [5] then:

Following the admission to hospital when endometriosis was first diagnosed, was the patient re-admitted to hospital within 30 days of discharge?

- Yes No Unknown Not applicable

18b.If answered "Yes" to [18a] then:

Please provide details of the readmission to hospital:

E. Medications

1a. At any time, were any hormonal treatments prescribed to manage the symptoms of endometriosis?

- Yes No Unknown

1b. If answered "Yes" to [1a] then:

Please select the hormonal treatments that were prescribed:

Answers may be multiple, please select all that apply

- Combined hormonal contraception
- Contraceptive patch
- Oral progestogen
- Levonorgestrel releasing intrauterine system
- Nexplanon
- Depo-Provera injection
- Gonadotrophin releasing hormone agonist (+/- add-back hormone replacement therapy (HRT))

Please specify any additional options here...

2. If answered "Yes" to [1a] then:

Who prescribed hormonal treatments?

Answers may be multiple, please select all that apply

- The general practitioner
- The gynaecologist
- Endometriosis nurse specialist
- Unknown

Please specify any additional options here...

3a. If answered "Yes" to [1a] then:

What date was the hormone treatment first prescribed?

Unknown

3b. If answered "Yes" to [1a] then:

If the exact date of prescription is not known, if possible please estimate the month and year:

4a. If answered "Yes" to [1a] then:

What date was the prescription of the hormone treatment first reviewed?

Unknown

4b. If answered "Yes" to [1a] then:

If the exact date of review is not known, if possible please estimate the month and year:

5. If answered "No" to [1a] then:

If hormonal treatment was not prescribed, please indicate the reasons why:

Answers may be multiple, please select all that apply

- Patient was already on an alternative successful treatment
- Patient choice
- Associated risks of hormonal treatments were too great for this patient
- Treatment was not previously effective
- Symptoms resolved without treatment
- Patient was trying to conceive
- Unknown

Please specify any additional options here...

6. If answered "Yes" to [1a] then:

Was the hormonal treatment stopped at any time?

- Yes No Unknown

7. If answered "Yes" to [6] then:

When was the prescription of hormonal treatment stopped?

Please provide date in DD/MM/YYYY format. If full date not known, please estimate month and year

8. If answered "Yes" to [6] then:

What was the reason for stopping the prescribing of hormonal treatment?

Answers may be multiple, please select all that apply

- Lack of efficacy
- Side effects of treatment
- Potential risks of treatment
- Patient trying to conceive
- Patient's wishes
- Unknown

Please specify any additional options here...

9. Was pain medication prescribed at any time to alleviate the symptoms of endometriosis?

- Yes No Unknown

10. If answered "Yes" to [9] then:

Who prescribed the pain medication?

- General practitioner
- Gynaecologist

Please specify any additional options here...

11. If answered "Yes" to [9] then:

Please indicate all pain medications that were prescribed:

Answers may be multiple, please select all that apply

- Opioids
- NSAIDs
- Gabapentin
- Pregabalin
- Amitriptyline
- Nortriptyline
- Imipramine
- Duloxetine
- Unknown

Please specify any additional options here...

**12. If answered "Yes" to [9] then:
Was the prescribed pain medication well tolerated?**

- Yes No Unknown
-

13. Was 'add-back HRT' also prescribed?

- Yes No Unknown
-

14. Was the patient offered GnRH agonists to reduce endometriosis-associated pain?

- Yes No Unknown
-

15a. Other than hormonal treatment or pain medication, was the patient prescribed any other medications for the treatment of the symptoms of endometriosis?

- Yes No Unknown

**15b. If answered "Yes" to [15a] then:
Please give further details:**

16a. Were there any side effects recorded from any of the medication prescribed for the symptoms of endometriosis?

- Yes No Unknown

**16b. If answered "Yes" to [16a] then:
Please provide details of the side effects**

17a. Did the gynaecologist review the medication plan for this patient?

- Yes No Unknown

**17b.If answered "Yes" or "No" to [17a] then:
Please provide details:**

This section is about the events leading up to, during and following the "index admission". This is the first recorded admission to hospital for a laparoscopy (or other surgery for endometriosis) during the study period (01/02/2018- 31/07/2020) for endometriosis (dates of admission / discharge are indicated on the previous "assignments" screen of the questionnaire portal)

If the index admission was for the laparoscopy* when the patient was first formally diagnosed with endometriosis and you have already fully completed sections C and D in relation to this admission, then you do not need to complete this section

1a. Please confirm whether endometriosis was first diagnosed during the index admission* and if so, that sections C & D of this questionnaire have been fully completed in relation to this admission?

see definitions

- YES: Endometriosis was diagnosed during the index admission and sections C and D have been completed
- NO: Endometriosis was diagnosed at a different admission to the index admission
- Unknown

Pre-admission

1b. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:

Please indicate the referral route for the index admission for laparoscopy

- GP referral to gynaecologist
- Referral from gynaecologist following clinic attendance
- Emergency department attendance
- Referral to gynaecology from other specialty
- Unknown

Please specify any additional options here...

2a. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:

Regarding the laparoscopy* that occurred during the index admission, what was the date that the patient was first referred to the gynaecologist (e.g. from primary care or another specialty)?

**or other surgery for endometriosis*

Unknown

2b. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:

If exact date unknown, if possible please estimate the month and year the patient was first referred to the gynaecologist (e.g. from primary care or another specialty)?

in relation to the laparoscopy that occurred during the index admission*

3a. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:

Please give the date that the patient was first seen in the gynaecology clinic regarding their symptoms of endometriosis:

In relation to the laparoscopy (or other surgery for endometriosis) that occurred during the index admission.

Unknown

3b. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:

If exact date unknown, if possible could you estimate the month and year the patient was first seen in the gynaecology clinic?

**4a. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:
Please indicate the examinations undertaken by the gynaecologist, for the symptoms of endometriosis:**

Answers may be multiple, please select all that apply.

- Abdominal examination Pelvic examination
 No examinations were carried out

Please specify any additional options here...

**4b. If answered "Abdominal examination" or "Pelvic examination" to [4a] then:
Did the examinations identify:**

Answers may be multiple, please select all that apply

- Abdominal mass Adnexal mass
 Lower abdominal tenderness Fixed tender retroverted uterus
 Pelvic floor tenderness Unknown

Please specify any additional options here...

Imaging

**5a. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:
Prior to the laparoscopy* that occurred during the index admission, was any imaging carried out?**

**or other listed surgery for endometriosis*

- Yes No Unknown

**5b. If answered "Yes" to [5a] then:
What imaging was carried out?**

Answers may be multiple, please select all that apply

- Ultrasound scan (USS) Magnetic resonance imaging (MRI) scan
 Unknown

Please specify any additional options here...

**6a. If answered "Yes" to [5a] then:
What was the most recent date that imaging was carried out prior to the laparoscopy performed during the index admission?**

Unknown

**6b. If answered "Yes" to [5a] then:
If the exact date of the most recent imaging is not known, if possible please estimate the month and year:**

Please include dates in DD/MM/YYYY format

**7. If answered "Yes" to [5a] then:
Were the scans interpreted by healthcare professional/s with specialist expertise in gynaecological imaging?**

- Yes No Unknown

8a. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:

What was the date of referral for the laparoscopy that occurred during the index admission?

Unknown

8b. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:

If the exact date of the referral for the laparoscopy is not known, if possible please estimate the month and year:

Decision making

9a. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:

Is there evidence that the patient was formally discussed at a complex endometriosis Multi Disciplinary Team (MDT) meeting?

Yes No Unknown

9b. If answered "No" to [9a] then:

If the patient was NOT discussed as part of an MDT, in your opinion, should they have been?

Yes No Unknown

9c. If answered "Yes" to [9a] then:

Did the MDT result in a change in treatment plan for the patient?

Yes No Unknown

9d. If answered "Yes" to [9a] then:

Which specialties were present at the MDT meeting?

Answers may be multiple, please select all that apply

- | | |
|--|---|
| <input type="checkbox"/> Urologist | <input type="checkbox"/> Colorectal surgeon |
| <input type="checkbox"/> Other surgeon | <input type="checkbox"/> Endometriosis nurse specialist |
| <input type="checkbox"/> Other nurse | <input type="checkbox"/> Anaesthesia |
| <input type="checkbox"/> Physiotherapy | <input type="checkbox"/> Unable to answer |
| <input type="checkbox"/> Reproductive medicine | <input type="checkbox"/> Pharmacy |
| <input type="checkbox"/> Radiology | |

Please specify any additional options here...

10. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:

When was consent taken for the laparoscopy* that was carried out during the index admission?

*(*or other surgery to treat endometriosis)*

Not Applicable Unknown

11. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:

Were the risks/ benefits of surgery discussed with the patient?

Yes No Unknown

Admission for laparoscopy

**12. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:
What was the date of the laparoscopy that occurred during the index admission?**

Unknown

**13a. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:
What procedure was performed?**

- Laparoscopic ablation Laparoscopic excision
 Laparoscopic excision and ablation Hysterectomy
 Unknown

If not listed above, please specify here...

**13b. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:
What procedure was performed during the index admission?**

- Laparoscopic ablation Laparoscopic excision
 Laparoscopic ablation and excision Hysterectomy
 Unknown

Please specify any additional options here...

**14. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:
What was the specialty of the clinician performing the procedure?**

- Obstetrics and gynaecology General surgery Colorectal surgery
 Urology

If not listed above, please specify here...

**15a. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:
Were any other procedures undertaken?**

- Yes No Unknown

**15b. If answered "Yes" to [15a] then:
Please give details of any other procedures performed:**

**16. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:
Was there any residual endometriosis noted at the end of the surgery?**

- Yes No Unknown

17a.If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:

In your opinion, was the laparoscopy* delayed?

(*or other surgery to treat endometriosis)

- Yes No Unknown

17b.If answered "Yes" to [17a] then:

What was the reason/s for this delay?

Answers may be multiple, please select all that apply

- | | |
|---|---|
| <input type="checkbox"/> Patient decision | <input type="checkbox"/> Clinical reasons |
| <input type="checkbox"/> Organisational factors | <input type="checkbox"/> COVID-19 pandemic |
| <input type="checkbox"/> GP referral to gynaecology | <input type="checkbox"/> Delay in decision of gynaecologist |
| <input type="checkbox"/> Delay in imaging/ investigations | <input type="checkbox"/> Theatre availability |
| <input type="checkbox"/> Surgeon availability | <input type="checkbox"/> Availability of other staff |
| <input type="checkbox"/> Unknown | |

Please specify any additional options here...

17c.If answered "Yes" to [17a] then:

In your opinion, did the patient's symptoms worsen during this time?

- Yes No Unknown

18a.If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:

Were there any complications from the laparoscopy* performed during the index admission?

(*or other surgery to treat endometriosis)

- Yes No Unknown

18b.If answered "Yes" to [18a] then:

Please give further detail:

Discharge/ Follow-up from index admission

19. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:

Date of patients discharge

- Unknown

20. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:

Is there a discharge summary available in the notes for the index admission?

This is the first recorded admission to hospital for a laparoscopy during the study period (01/02/2018- 31/07/2020) for endometriosis (dates of admission / discharge are indicated on the previous "assignments" screen of the questionnaire portal

- Yes No Unknown

21. If answered "Yes" to [20] then:

Does the discharge summary have any of the following information:

Answers may be multiple, please select all that apply

- Documented diagnosis of endometriosis
- Details of the procedure/s performed
- Follow-up appointments
- No discharge summary available
- Reason for procedure
- Details of medications
- Details of onward referrals to supporting services
- Details of possible complications
- Details of treatment plan
- Details of readmission plan / who to contact if symptoms return

Please specify any additional options here...

22. If answered "Yes" to [20] then:

Was information provided on the discharge summary of who to contact if the patient has any concerns?

- Yes No Unknown

23a. If answered "Yes" to [20] then:

Was a copy of the discharge summary sent to the patients GP practice?

- Yes No Unknown

23b. If answered "Yes" to [20] then:

Was a copy of the discharge summary shared with the patient?

- Yes No Unknown

24a. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:

Was a management/ care plan put in place?

- Yes No Unknown

24b. If answered "Yes" to [24a] then:

Please provide details of the care plan:

25a. If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:

Following discharge after the laparoscopy performed during the index admission, was the patient seen by the gynaecologist in a follow-up clinic?

- Yes No Unknown

25b.If answered "Yes" to [20] then:

Please indicate any other follow-up appointments that were made?

- | | |
|---|---|
| <input type="checkbox"/> Gynaecologist | <input type="checkbox"/> Operating surgeon |
| <input type="checkbox"/> General surgeon | <input type="checkbox"/> Colorectal surgeon |
| <input type="checkbox"/> Urologist | <input type="checkbox"/> General Practitioner |
| <input type="checkbox"/> Endometriosis nurse specialist | <input type="checkbox"/> Reproductive medicine consultant |
| <input type="checkbox"/> Pain specialist | <input type="checkbox"/> Clinical psychologist |
| <input type="checkbox"/> Physiotherapist | |

Please specify any additional options here...

26a.If answered "NO: Endometriosis was diagnosed at a different admission to the index admission" or "Unknown" to [1a] then:

Was the patient readmitted to hospital within 30 days of discharge?

- Yes No Unknown

26b.If answered "Yes" to [26a] then:

Please provide details of the readmission to hospital:

G. Referral to supporting services

1. Please indicate, where evidenced in the notes, the relevant supporting services that this patient was referred to (at any time during the care pathway) :

In relation to the care of endometriosis. Answers may be multiple, please select all that apply

- | | |
|--|--|
| <input type="checkbox"/> Mental health services | <input type="checkbox"/> Clinical psychologist |
| <input type="checkbox"/> Endometriosis nurse-led clinic | <input type="checkbox"/> Physiotherapist |
| <input type="checkbox"/> Physiotherapy specialist in endometriosis | <input type="checkbox"/> Urology |
| <input type="checkbox"/> Colorectal surgery | <input type="checkbox"/> Other surgery |
| <input type="checkbox"/> Gastroenterology | <input type="checkbox"/> Fertility services |
| <input type="checkbox"/> Sexual health | <input type="checkbox"/> Pain clinic |
| <input type="checkbox"/> Dietitian | <input type="checkbox"/> None of these |
| <input type="checkbox"/> Unknown | |

Please specify any additional options here...

2a. At any time, was this patient screened with a mental health assessment?

- Yes No Unknown

2b. If answered "Yes" to [2a] then:

Please provide details of who undertook the mental health assessment/ screening?

- | | |
|---|---|
| <input type="checkbox"/> Endometriosis nurse specialist | <input type="checkbox"/> General Practitioner |
| <input type="checkbox"/> Gynaecology consultant | <input type="checkbox"/> Clinical psychologist |
| <input type="checkbox"/> Liaison psychiatrist | <input type="checkbox"/> Registered Mental Health nurse |

Please specify any additional options here...

2c. If answered "Yes" to [2a] then:

Was the patient referred to a clinical psychologist at any time in relation to their symptoms of endometriosis?

- Yes No Unknown

3. Is there any evidence that the patient was sign-posted to information about endometriosis e.g. information from Endometriosis UK

This could be in the form of an information leaflet or verbal, but documented in the case notes.

- Yes No Unknown

4a. At any time, was the patient referred to a specialist pelvic pain clinic?

- Yes No Unknown

4b. If answered "Yes" to [4a] then:

Please provide details:

5a. Was this patient referred for the treatment of infertility, associated with endometriosis?

- Yes No Unknown

5b. If answered "Yes" to [5a] then:

Please provide details of referral to fertility specialist

6a. In your opinion, were there any services that the patient was not referred to that could have benefitted them?

- Yes No Unknown

**6b. If answered "Yes" to [6a] then:
Please provide details:**

**6c. If answered "Yes" to [6a] then:
In your opinion, did failure to refer to any specific specialty/service result in this patient receiving less than best practice care?**

- Yes No Unknown

**6d. If answered "Yes" to [6c] then:
Please provide further details:**

7a. In your opinion, was there a delay in the patient being assessed/ treated by any of the supporting services regarding their endometriosis care?

- Yes No Unknown

**7b. If answered "Yes" to [7a] then:
Please provide details on how the delay in appointment/s with supporting services impacted on the patient:**

H. Ongoing care and subsequent re-admissions

1a. Following the index admission did the patient have a subsequent recurrence (or persistence) of endometriosis symptoms?

- Yes No Unknown

1b. If answered "Yes" to [1a] then:

Please write the date(s) when the patient first presented with recurrence of endometriosis symptoms following the index admission:

Please use DD/MM/YYYY format. If exact date(s) not known, if possible, please include month and year. If there have been multiple episodes, please include each recorded date when the patient first presented to a healthcare professional with recurrent symptoms of endometriosis

2. If answered "Yes" to [1a] then:

Where did the patient first present with the onset of recurrent endometriosis symptoms?

If there were multiple episodes, please refer to the first recurrence following the index admission

- General practitioner Out-patient /follow-up gynaecology clinic
 Emergency department

If not listed above, please specify here...

3a. If answered "Yes" to [1a] then:

Has the patient had any subsequent re-admissions to hospital for laparoscopy, (or other surgery) for the treatment of endometriosis?

- Yes No Unknown

3b. If answered "Yes" to [3a] then:

Please provide details (including dates and procedures performed):

Please provide dates of admission and discharge and the route of admission, procedure/s performed and findings for each admission to hospital

4a. If answered "Yes" to [1a] then:

In your opinion, were there any delays in the patient being investigated and treated for the recurrence of endometriosis symptoms?

- Yes No Unknown

4b. If answered "Yes" to [4a] then:

Please provide further details:

5a. If answered "Yes" to [1a] then:

Has the patient been re-admitted to hospital for treatment of recurrent endometriosis symptoms (other than for surgery) since the index admission?

- Yes No Unknown

5b. If answered "Yes" to [5a] then:

What was the reason for the re-admission/s?

Please list the reason for each re-admission, plus the dates of admission/discharge

6. Please select any of the following outcome measures that were recorded for this patient at any time following the index admission?

Answers may be multiple, please select all that apply

- | | | | |
|---|--|---|--|
| <input type="checkbox"/> Functional outcome | <input type="checkbox"/> Return to work | <input type="checkbox"/> Pain/ discomfort | <input type="checkbox"/> Usual activities |
| <input type="checkbox"/> Quality of life | <input type="checkbox"/> Sexual function | <input type="checkbox"/> Digestive function | <input type="checkbox"/> Fatigue |
| <input type="checkbox"/> Urinary function | <input type="checkbox"/> Depression/ Anxiety | <input type="checkbox"/> Unknown | <input type="checkbox"/> None of the above |

Please specify any additional options here...

7. Please use this box to highlight any other areas where you feel that there was good practice and any areas where you feel with hindsight that the care could have been improved:

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE

Your answers will contribute to the data that will form the report and the recommendations, due for release in Spring 2024.