

Endometriosis: Reviewer Assessment Form NEW

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") who have their initial diagnosis confirmed by laparoscopic surgery.

Exclusions:

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

This study was commissioned by The Healthcare Quality Improvement Partnership (HQIP) as part of the Clinical Outcome Review Programme into Medical & Surgical care.

B. Case reviewer details

1a. Date of case reviewer meeting

1b. Case Reviewer initials

1c. Was a completed Clinician questionnaire available for this case review?

Yes

No

C. Patient details

The index admission for this study refers to the first admission during the study period (1st February 2018 - 31st July 2020) for a laparoscopy (or other surgery) for endometriosis. The dates of the index admission for this patient are shown on the previous "assignments" screen of the portal.

In some cases the index admission will be the admission when the patient first had a laparoscopy and was first diagnosed with endometriosis, for other patients it will represent a subsequent admission to hospital for laparoscopy (or other surgery) for endometriosis

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 screen)*

 years

Unknown

Value should be between 18 and 120

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?

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

In your opinion, did this impact on the care the patient received throughout the pathway?

- Yes No Unknown

3d. If answered "Yes" to [3c] then:

If So, please provide details:

4a. Did the patient present with any co-morbidities?

- Yes No Unknown

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

Please list any co-morbidities:

Answers may be multiple, please select all that apply

- | | |
|--|--|
| <input type="checkbox"/> Uterine fibroids | <input type="checkbox"/> Migraines |
| <input type="checkbox"/> Irritable bowel syndrome | <input type="checkbox"/> Interstitial cystitis |
| <input type="checkbox"/> Rheumatoid arthritis | <input type="checkbox"/> Psoriatic arthritis |
| <input type="checkbox"/> Osteoarthritis | <input type="checkbox"/> Dyschezia |
| <input type="checkbox"/> Painful bladder syndrome | <input type="checkbox"/> Adenomyosis |
| <input type="checkbox"/> Back pain | <input type="checkbox"/> Chronic widespread pain |
| <input type="checkbox"/> Autoimmune disease | <input type="checkbox"/> Fibromyalgia |
| <input type="checkbox"/> Chronic fatigue syndrome / ME | <input type="checkbox"/> Ovarian cancer |
| <input type="checkbox"/> Cancer of the reproductive organs | <input type="checkbox"/> Early natural menopause |
| <input type="checkbox"/> Ovarian cysts | |

Please specify any additional options here...

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

In your opinion, did the patient's co-morbidities impact on the quality of care provided throughout the pathway?

- Yes No Unknown

4d. If answered "Yes" to [4c] then:

Please provide details:

1a. In the case notes, is there ANY information about the initial diagnosis of endometriosis?

The diagnosis may have been during the index admission or may have happened prior to this. If the patient was not diagnosed with endometriosis during the index admission and there is NO information available to answer questions about the initial diagnosis of endometriosis, please proceed to the next section

- Yes No

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

Please select all those who saw the patient in relation to their symptoms prior to diagnosis with endometriosis:

- 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**1c. If answered "Yes" to [1a] and "General practitioner" 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

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

Please indicate the symptoms that the patient first presented 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"/> Pain on defecation (dyschezia) |
| <input type="checkbox"/> Bowel symptoms | <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...

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

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

- Yes No Insufficient data

3b. If answered "No" to [3a] then:

If no, in your opinion, should they have?

- Yes No Unknown

**4a. If answered "Yes" to [1a] and "General practitioner" to [1b] then:
Prior to the first referral to gynaecology in relation to the symptoms of endometriosis,
did the GP prescribe any medications to manage the symptoms?**

- Yes No Unknown

**4b. If answered "Yes" to [4a] then:
Which type of medications were prescribed?**

- Hormonal treatment Pain medication Tranexamic acid

Please specify any additional options here...

**4c. If answered "Yes" to [4a] then:
In your opinion, in primary care, was there adequate review of all medications prescribed
regarding their effectiveness and management of any side effects**

- Yes No Unknown

**4d. If answered "No" to [4c] then:
If no, please provide details**

Referral to gynaecology

**5a. If answered "Yes" to [1a] then:
Date of first referral to gynaecology**
If complete date is unknown, please see Question 5b

Unknown

**5b. If answered "Yes" to [1a] then:
If exact date unknown, if possible, could you estimate the month and year of the first
referral to gynaecology?**

**6a. If answered "Yes" to [1a] then:
In your opinion, was there any room for improvement in the referral letter to
gynaecology?**

- Yes
 No
 Insufficient data to comment (referral letter not available)
 Not applicable

**6b. If answered "Yes" to [6a] then:
Please provide details as to what was missing from the referral letter:**

**7a. If answered "Yes" to [1a] then:
In your opinion, was there a delay in the initial referral to gynaecology?**

Yes No Unknown

**7b. If answered "Yes" to [1a] and "Yes" to [7a] then:
Please provide details**

**7c. If answered "Yes" to [7a] then:
In your opinion, did this impact on the quality of care provided?**

Yes No Unknown

**8a. If answered "Yes" to [1a] then:
Did the referral to gynaecology include a working diagnosis that mentioned
endometriosis?**

Yes No Unknown

**8b. If answered "Yes" to [1a] and "Yes" to [8a] 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...

**9a. If answered "Yes" to [1a] then:
Was the patient referred to a specialist (e.g. British Society for Gynaecological
Endoscopy (BSGE) endometriosis centre.**

Yes No Unknown

**9b. If answered "Yes" to [1a] and "Yes" to [11a] then:
Did the patient have contact with a endometriosis nurse specialist, prior to diagnosis?**

Yes No Unknown

9c. If answered "No" to [11a] then:

In your opinion, should the patient have been referred to a specialist endometriosis centre?

- Yes No Unknown

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

Please provide details on how this impacted the quality of care provided

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

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

Unknown

11. If answered "Yes" to [1a] 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...

12. If answered "Yes" to [1a] and "Abdominal examination" or "Pelvic examination" to [11] 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...

13a. If answered "Yes" to [1a] then:

Were there any other investigations that should have been carried out prior to diagnosis but were not?

- Yes No Unknown

**13b.If answered "Yes" to [1a] and "Yes" to [13a] then:
Please provide details of any other investigations that should have been carried out:**

**14a.If answered "Yes" to [1a] then:
Was the patient's care discussed as part of an MDT meeting?**

- Yes No Unknown

**14b.If answered "No" to [14a] then:
If not discussed at an MDT meeting, in your opinion, should it have been?**

- Yes No Unknown

Non-gynaecological pathway

**15a.If answered "Yes" to [1a] then:
At any time, was this patient referred to a non-gynaecological specialty pathway for management of endometriosis symptoms?**

- Yes No Unknown

**15b.If answered "Yes" to [1a] and "Yes" to [15a] then:
Did the patient subsequently undergo any non-gynaecological, endometriosis related, treatment/investigations?**

- Yes No Unknown

**15c.If answered "Yes" to [15a] then:
In your opinion, was the diagnosis of Endometriosis delayed because of this?**

- Yes No Unknown

**15d.If answered "Yes" to [15a] then:
Was there any room for improvement in the non-gynaecological pathway?**

- Yes No Unknown

**15e.If answered "Yes" to [15d] then:
Please give details**

Imaging

**16. If answered "Yes" to [1a] then:
Prior to diagnosis, was the patient referred for imaging in relation to their symptoms of endometriosis?**

- Yes No Unknown

**17a. If answered "Yes" to [16] then:
Prior to diagnosis of endometriosis, was the patient referred for an ultrasound (USS) relating to the symptoms of endometriosis?**

- Yes No Unknown

**17b. If answered "Yes" to [17a] then:
Who first referred the patient for an ultrasound scan, 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 [17a] then:
What date was the patient first referred for an USS?**

If complete date is unknown, please see Question 17b.

Unknown

**18b. If answered "Yes" to [17a] then:
If the exact date of the USS is not known, if possible please estimate the month and year:**

**19. If answered "Yes" to [17a] 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...

**20a. If answered "Yes" to [16] then:
Prior to diagnosis, was the patient referred for any MRI scans?**

- Yes No Unknown

**20b. If answered "Yes" to [20a] then:
What was the date of the MRI scan?**

If complete date is unknown, please see Question 19c.

**20c. If answered "Yes" to [20a] then:
If the exact date of the MRI is not known, if possible please estimate the month and year:**

**21. If answered "Yes" to [1a] then:
Were the results of the imaging shared with the patient's GP?**

- Yes No Unknown

**22. If answered "Yes" to [16] then:
Was evidence of endometriosis seen on the imaging?**

- Yes No Unknown
-

**23a. If answered "Yes" to [16] then:
In your opinion, was there any room for improvement in the imaging carried out for this patient?**

- Yes No Unknown

**23b. If answered "Yes" to [23a] then:
If yes, please select which aspects could have been improved:**

Answers may be multiple- additional information can be put in the "other" box

- Timing of scans - eg. delays Reporting of scans Communication of results
 Type of scan performed Interpretation of results

Please specify any additional options here...

E. First diagnosis of endometriosis

1. Date of diagnosis

Please include dates in DD/MM/YYYY format. If the date is not known, if possible 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 suspected deep endometriosis involving the bowel, bladder or ureter?

- Yes No Unknown

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

- Yes No Unknown

5. 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...

6. In your opinion, were the risks/ benefits of the procedure adequately explained to the patient?

- Yes No Unknown

7a. In your opinion, was there any room for improvement in the consent process?

- Yes No Insufficient data to comment

**7b. If answered "Yes" to [7a] then:
Please provide details to illustrate this:**

8. In your opinion, was the specialty and grade of the operating clinician appropriate?

Yes No Unknown

9a. Is the operation note included in the case note record?

Yes No

**9b. If answered "Yes" to [9a] then:
In your opinion, is there anything missing from the operation note?**

Yes No Unknown

**9c. If answered "Yes" to [9b] then:
Please provide details:**

10a. Were there any complications of the procedure?

Yes No Unknown

**10b. If answered "Yes" to [10a] then:
Please provide details of any complications of the procedure:**

**10c. If answered "Yes" to [10a] then:
In your opinion, could this have been avoided?**

Yes No Unknown

11a. Was the patient referred to a specialist (e.g. British Society for Gynaecological Endoscopy (BSGE) endometriosis centre.

- Yes No Unknown

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

Date of referral to specialist endometriosis (BSGE) centre?

Unknown

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

If exact date of referral to specialist endometriosis service is unknown, if possible, could you estimate the month and year?

Please include dates in DD/MM/YYYY format.

12. 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. 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:

What was the reason/s for this delay?

- | | |
|--|--|
| <input type="checkbox"/> Patient factors | <input type="checkbox"/> Disease factors |
| <input type="checkbox"/> COVID-19 pandemic | <input type="checkbox"/> Delay in referral from primary care |
| <input type="checkbox"/> Delay in gynaecologist referral for surgery | <input type="checkbox"/> Staffing |
| <input type="checkbox"/> Bed availability | <input type="checkbox"/> Other organisational factors |

Please specify any additional options here...

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

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

- Yes No Unknown

**14d.If answered "Yes" to [14c] then:
Please provide details:**

**14e.If answered "Yes" to [14a] then:
In your opinion, did the delay have an impact on the outcome for the patient?**

Yes No Unknown

**14f. If answered "Yes" to [14e] then:
Please provide further details**

15a.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

- | | |
|---|---|
| <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...

16a.In your opinion, was there any room for improvement in the perioperative care and/ or diagnosis of endometriosis for this patient?

Yes No Unknown

**16b.If answered "Yes" to [16a] then:
Please give further details:**

F. Medications

1a. Were any hormonal treatments prescribed to manage the symptoms of endometriosis?

- Yes No Unknown

1b. 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...

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

Date first prescribed?

If complete date is unknown, please see Question 1d.

- Unknown

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

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

Please include dates in DD/MM/YYYY format

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

Date first reviewed?

If complete date is unknown, please see Question 2a.

- Unknown

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

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

Please include dates in DD/MM/YYYY format

3. 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 (+/- addback HRT)
 Unknown

Please specify any additional options here...

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

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

- Patient was already on an alternative successful treatment
- Patient refusal
- 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...

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

Was the hormonal treatment stopped at any time?

- Yes No Unknown

5b. If answered "Yes" to [1a] and "Yes" to [5a] 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

5c. If answered "Yes" to [1a] and "Yes" to [5a] 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

Please specify any additional options here...

6. Was pain medication prescribed at any time?

- Yes No Unknown

If not listed above, please specify here...

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

Who prescribed the pain medication?

- General practitioner Gynaecologist

Please specify any additional options here...

8. If answered "Yes" to [6] 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
- GnRH agonist
- Add-back HRT
- Unknown

Please specify any additional options here...

**9. If answered "Yes" to [6] then:
Was the prescribed pain medication well tolerated?**

- Yes No Unknown
-

10a. 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

**10b. If answered "Yes" to [10a] then:
Please give further details:**

11a. Were there any side effects recorded from any of the medications prescribed for the symptoms of endometriosis?

- Yes No Unknown

**11b. If answered "Yes" to [11a] then:
Please provide details of the side effects**

12a. Did the gynaecologist review the medication plan for this patient?

- Yes No Unknown

**12b. If answered "Yes" to [12a] then:
Please provide details:**

13a. In your opinion, was there adequate review of the medication plan for this patient?

Yes

No

Unknown

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

14a. In your opinion was there any room for improvement in the management of any medications prescribed throughout the pathway of care for this patient?

Yes

No

Unknown

**14b. If answered "Yes" to [14a] then:
If yes, 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 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 first 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?

- YES- Endometriosis was diagnosed during the index admission and Sections C &D have already been completed
- NO- Endometriosis was diagnosed during a different admission to the index

Pre-admission

1b. If answered "NO- Endometriosis was diagnosed during a different admission to the index" 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 during a different admission to the index" 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)?

If complete date is unknown, please see Question 2a.

Unknown

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

If exact date unknown, if possible could you estimate the month and year of the first referral to gynaecology?

Please provide date in DD/MM/YYYY format

3a. If answered "NO- Endometriosis was diagnosed during a different admission to the index" 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 that occurred during the index admission.

Unknown

3b. If answered "NO- Endometriosis was diagnosed during a different admission to the index" 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?

Please include dates in DD/MM/YYYY format

4a. If answered "NO- Endometriosis was diagnosed during a different admission to the index to [1a] then:

In your opinion, was there any room for improvement in the care provided to the patient prior to the index admission (from the presentation with symptoms of endometriosis)

- Yes No Unknown

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

Please select from the following aspects of care that could have been improved?

Please select all that apply, further information can be entered in the "other" box

- | | |
|--|---|
| <input type="checkbox"/> GP examination | <input type="checkbox"/> GP treatment plan |
| <input type="checkbox"/> GP referral to gynaecology | <input type="checkbox"/> Referral to supporting services |
| <input type="checkbox"/> Management of medications | <input type="checkbox"/> Detail on referral letter |
| <input type="checkbox"/> Timing of gynaecology appointment | <input type="checkbox"/> Gynaecologist examinations |
| <input type="checkbox"/> Referral for imaging | <input type="checkbox"/> Involvement of other specialties |
| <input type="checkbox"/> MDT | <input type="checkbox"/> Decision for surgery |
| <input type="checkbox"/> Fertility care | |

Please specify any additional options here...

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

In your opinion, did this impact on the quality of care provided?

- Yes No Unknown

5a. If answered "NO- Endometriosis was diagnosed during a different admission to the index 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.

- | | |
|---|---|
| <input type="checkbox"/> Abdominal examination | <input type="checkbox"/> Pelvic examination |
| <input type="checkbox"/> No examinations were carried out | |

Please specify any additional options here...

5b. If answered "Abdominal examination" or "Pelvic examination" to [5a] then:

Did the examinations identify:

Answers may be multiple, please select all that apply

- | | |
|---|--|
| <input type="checkbox"/> Abdominal mass | <input type="checkbox"/> Adnexal mass |
| <input type="checkbox"/> Lower abdominal tenderness | <input type="checkbox"/> Fixed tender retroverted uterus |
| <input type="checkbox"/> Pelvic floor tenderness | <input type="checkbox"/> Unknown |

Please specify any additional options here...

5c. If answered "NO- Endometriosis was diagnosed during a different admission to the index to [1a] then:

Were there any examinations/ investigations not performed that should have been?

- Yes No Unknown

**5d. If answered "Yes" to [5c] then:
Please give details:**

Imaging

**6a. If answered "NO- Endometriosis was dignosed during a different admission to the index" to [1a] then:
Prior to the referral for the laparoscopy during the index admission, was any imaging carried out?**

Yes No Unknown

**6b. If answered "Yes" to [6a] 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...

**7a. If answered "Yes" to [6a] then:
What was the most recent date that imaging was carried out prior to the laparoscopy performed during the index admission?**

 Unknown

**7b. If answered "Yes" to [6a] 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

**8a. If answered "Yes" to [6a] then:
In your opinion, was there any room for improvement in the imaging carried out for this patient?**

Yes No Unknown

**8b. If answered "Yes" to [8a] then:
If yes, please select which aspects of imaging could have been improved:**

Timing of scans - eg. delays
 Reporting of scans
 Type of scan performed
 Interpretation of results
 Interpretation of results Communication of results of ima

Please specify any additional options here...

Decision-making

9a. If answered "NO- Endometriosis was dignosed during a different admission to the index to [1a] then:

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

If complete date is unknown, please see Question 8a

Unknown

9b. If answered "NO- Endometriosis was dignosed during a different admission to the index to [1a] then:

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

Please include dates in DD/MM/YYYY format

9c. If answered "NO- Endometriosis was dignosed during a different admission to the index to [1a] then:

In your opinion, was the referral delayed?

Yes

No

Unknown

10a.If answered "NO- Endometriosis was dignosed during a different admission to the index to [1a] then:

Is there evidence that the patient was formally discussed at a complex endometriosis MDT?

Yes

No

Unknown

10b.If answered "No" to [10a] then:

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

Yes

No

Unknown

11a.If answered "NO- Endometriosis was dignosed during a different admission to the index to [1a] then:

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

Not Applicable Unknown

11b.If answered "NO- Endometriosis was dignosed during a different admission to the index to [1a] then:

In your opinion, were the risks/ benefits adequately discussed with the patient

Yes

No

Unknown

Surgery

12. If answered "NO- Endometriosis was dignosed during a different admission to the index to [1a] then:

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

Unknown

**13. If answered "NO- Endometriosis was dignosed during a different admission to the index" to [1a] then:
What procedure was performed?**

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

If not listed above, please specify here...

**14. If answered "NO- Endometriosis was dignosed during a different admission to the index" to [1a] then:
In your opinion, was the specialty and grade of the operating clinician appropriate?**

- Yes No Unknown

**15a.If answered "NO- Endometriosis was dignosed during a different admission to the index" to [1a] then:
Is the operation note included in the case note record?**

- Yes No Unknown

**15b.If answered "Yes" to [15a] then:
In your opinion, is there anything missing from the operation note?**

- Yes No Unknown

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

**16a.If answered "NO- Endometriosis was dignosed during a different admission to the index" to [1a] then:
Were any other procedures undertaken?**

- Yes No Unknown

**16b.If answered "Yes" to [16a] then:
Please give details of any other procedures performed:**

**17. If answered "NO- Endometriosis was dignosed during a different admission to the index" to [1a] then:
Was there any residual endometriosis noted at the end of the surgery?**

- Yes No Not documented

**18a.If answered "NO- Endometriosis was dignosed during a different admission to the index" to [1a] then:
Was the laparoscopy delayed?**

- Yes No Unknown

**18b.If answered "Yes" to [18a] 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...

**18c.If answered "Yes" to [18a] then:
What was the impact of the delay in laparoscopy?**

or other surgery for endometriosis

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

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

- Yes No Unknown

**19b.If answered "Yes" to [19a] then:
Please give further detail:**

**19c.If answered "Yes" to [19a] then:
In your opinion, were the complication/s avoidable?**

- Yes No Unknown

**19d.If answered "Yes" to [19a] then:
In your opinion, were the complication/s well managed?**

- Yes No Unknown

Discharge/ Follow-up from index admission

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

Date of patients discharge

Unknown

21. If answered "NO- Endometriosis was diagnosed during a different admission to the index" to [1a] then:

Is there a discharge summary available in the notes for this patient's hospital admission when they first had a laparoscopy (or other surgery) for endometriosis)?

Yes No Unknown

22. If answered "Yes" to [21] 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...

23a. If answered "Yes" to [21] then:

In your opinion, was anything missing from the discharge summary?

Yes No Unknown

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

Please provide detail:

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

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

Yes No Unknown

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

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

Yes No Unknown

26a. If answered "YES- Endometriosis was diagnosed during the index admission and Sections C & D have already been completed in relation to this" or "NO- Endometriosis was diagnosed during a different admission to the index" to [1a] then:

Was a management/ care plan put in place?

Yes No Unknown

**26b.If answered "Yes" to [26a] then:
Please provide details of the care plan:**

**27a.If answered "NO- Endometriosis was dignosed during a different admission to the index" to [1a] then:
Following discharge after the laparoscopy performed, during the index admission, was the patient seen in a follow-up clinic?**

- Yes No Unknown

**27b.If answered "Yes" to [27a] then:
Who were the follow-up appointments with?**

- | | |
|--|--|
| <input type="radio"/> Gynaecologist | <input type="radio"/> The operating surgeon |
| <input type="radio"/> General practitioner | <input type="radio"/> Endometriosis nurse specialist |
| <input type="radio"/> Physiotherapist | <input type="radio"/> Gastroenterologist |
| <input type="radio"/> Fertility specialist | <input type="radio"/> Pain specialist |
| <input type="radio"/> Mental health services | |

If not listed above, please specify here...

**27c.If answered "NO- Endometriosis was dignosed during a different admission to the index" to [1a] then:
Were there any follow-up appointments that should have been made but were not?
*Following the index admission***

- Yes No Unknown

**27d.If answered "Yes" to [27c] then:
Please provide details:**

**28a.If answered "NO- Endometriosis was dignosed during a different admission to the index" to [1a] then:
Was the patient readmitted to hospital within 30 days of discharge?**

- Yes No Unknown

**28b.If answered "Yes" to [28a] then:
Please provide details of the readmission to hospital:**

**28c. If answered "Yes" to [28a] then:
In your opinion, was this avoidable?**

Yes

No

Unknown

H. Referral to supporting services

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

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"/> Physiotherapy specialist in endometriosis |
| <input type="checkbox"/> Dietitian | <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"/> Pain clinic | <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. Was the patient referred to mental health services at any time in relation to their symptoms of endometriosis?

- Yes, a timely referral was made
 Yes, but the referral was delayed
 No, a referral was not made to mental health services
 Unknown

2d. If answered "No, a referral was not made to mental health services" to [2c] then: If not referred to mental health services, in your opinion, would this patient have benefitted from a referral?

- Yes No Unknown

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

- Yes No Unknown

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

- Yes No Unknown

If not listed above, please specify here...

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

Please provide details:

4c. If answered "No" to [4a] then:

In your opinion, should this patient have been referred to a pain clinic?

- Yes No Unknown

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**

5c. Was there any room for improvement in fertility treatment

- Yes No Unkown

6a. 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

**6b. If answered "Yes" to [6a] then:
Please give details on which aspect of the patient's care?**

I. Ongoing care and subsequent re-admissions

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

- Yes No Unknown

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

When did the patient experience a recurrence of endometriosis symptoms?

Please use DD/MM/YYYY format. If exact date is not known, if possible, please include month and year. If multiple episodes, please include any recorded dates of onset.

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

How was the patient's care managed?

Answers may be multiple, please select all that apply

- GP prescribed hormonal treatment then referred to gynaecology
- GP referred to gynaecology for further investigation
- GP referred to endometriosis specialist surgeon
- Patient contacted gynaecologist directly
- Patient contacted endometriosis specialist
- Patient attended A&E or ambulatory care
- GP referred patient to chronic pain clinic
- GP referred patient to mental health services
- GP referred patient to fertility services
- GP referred patient for physiotherapy
- Patient referred to independent provider
- Gynaecologist referred patient to mental health services
- Gynaecologist referred patient to fertility services
- Gynaecologist referred patient to physiotherapy

Please specify any additional options here...

2a. 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

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

3a. If answered "Yes" to [2a] then:

Were there any complications from any of the surgeries?

- Yes No Unknown

3b. If answered "Yes" to [3a] and "Yes" to [2a] then:

Please give further details:

Please provide details of any complications, the outcomes and the dates

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 [1a] and "Yes" to [4a] then:

Please provide further details:

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

Has the patient been re-admitted to hospital for any reason other than laparoscopy, or surgery related to the diagnosis or treatment of endometriosis, since the initial (diagnostic) laparoscopy?

- 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 from the following Patient Reported Outcome Measures (PROMs) that were recorded for this patient post-discharge?

- | | | | |
|---|--|---|--|
| <input type="checkbox"/> Functional outcome | <input type="checkbox"/> Complication | <input type="checkbox"/> Return to work | <input type="checkbox"/> Pain/ discomfort |
| <input type="checkbox"/> Personal care | <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...

7a. Was there any room for improvement in the care provided since the index admission?

- Yes No Unknown

7b. If answered "Yes" to [7a] then:

Please indicate any aspects of care since the index admission that could have been improved:

- Referral to secondary care
- Medications management
- Fertility treatment
- Holistic care referrals
- Communication of details of patient's care between healthcare providers
- Communication of information to the patient
- Delay in imaging
- Delay in laparoscopy
- Complications of laparoscopy
- Follow-up care

Please specify any additional options here...

7c. If answered "Yes" to [7a] then:

Please provide any further details

1a. Please rate the overall quality of care using the grading system provided:

- Good Practice
- Room for improvement in clinical aspects of care
- Room for improvement in organisational aspects of care
- Room for improvement in both clinical and organisational aspects of care
- Less than satisfactory

1b. If answered "Good Practice", "Room for improvement in clinical aspects of care", "Room for improvement in organisational aspects of care", "Room for improvement in both clinical and organisational aspects of care" or "Less than satisfactory" to [1a] then: Please highlight the reasons why you graded the care in this way :

1c. Are there any themes/ issues from this case you feel should be highlighted in the final report?

- Yes No

1d. If answered "Yes" to [1c] then:

If Yes Please summarize any themes for the report:

1e. Do you think we should use this case as an illustrative vignette/ case study in the report?

- Yes No

Cause for concern

Occasionally NCEPOD will refer cases that have been identified as 'LESS THAN SATISFACTORY' when it is felt that further feedback to the Trust/ Health Board concerned is warranted. This is usually due to an area of concern to the hospital or clinician involved, and not for issues highlighted across the body of case notes.

This process has been agreed by the NCEPOD Steering Group and the GMC. The medical director of the Trust/ Health Board is written to by the Chief Executive of NCEPOD explaining our concerns. This process has been in operation for 10 years and the responses received have always been positive

1f. Do you feel that this case should be considered for such action?

- Yes No