

# Endometriosis: Organisational Questionnaire

## A. Introduction

**Please complete one organisational questionnaire for each hospital in your Trust/Health Board that treats patients with Endometriosis**

### **What is this study about:**

This study will look at the care provided to patients aged 18 and over, with a diagnosis of endometriosis. The clinical review part of the study is reviewing remediable factors in the quality of care provided across the whole care pathway. The organisational questionnaire is looking at the organisational structures in place to provide care to patients with endometriosis, and where there may be room for improvement in the service.

### **Who should complete this questionnaire:**

This questionnaire has been designed to collect data on the organisational structures surrounding the care provided to patients with endometriosis .

It should be completed for hospitals where patients with endometriosis might be treated (surgically or medically). One questionnaire should be completed for each hospital within a Trust/Health board.

It should be completed by or with input from, clinicians(s) that provide care to this group of patients. This is likely to include the Clinical Lead for specialist endometriosis service (if there is one) and/ or the Lead in Gynaecology with input from Colorectal and General surgery, Radiology and Endometriosis Clinical Nurse Specialists.

### **Questions or help:**

A list of definitions can be found here:

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

Further information regarding this study can be found here: <https://www.ncepod.org.uk/endometriosis.html>

If you have any queries about the study or this questionnaire, please contact:

[endometriosis@ncepod.org.uk](mailto:endometriosis@ncepod.org.uk) or

telephone 020 7251 9060.

### **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: diagnosis and management of 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.

Development of a new service specification for paediatric cancer services, 2019- 'on the right course' 2018

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

## B. Organisation Details

### 1. Who has overseen completion of this questionnaire?

Answers may be multiple, please select all that apply

- |  |  |
|--|--|
| <input type="checkbox"/> Gynaecologist   | <input type="checkbox"/> Endometriosis Nurse Specialist              |
| <input type="checkbox"/> General surgeon | <input type="checkbox"/> Colorectal surgeon                          |
| <input type="checkbox"/> Other surgeon   | <input type="checkbox"/> Urologist                                   |
| <input type="checkbox"/> Administrator   | <input type="checkbox"/> Clinical effectiveness/ clinical governance |

Please specify any additional options here...

### 2a. Name of organisation:

Name of Trust/ health board/ parent organisation:

### 2b. Name of hospital:

### 3. Type of hospital:

please select the option that best describes this hospital, please use the text box for additional responses

- NHS Secondary/ Acute care hospital (part of Trust/ Health board)  
 NHS Stand alone tertiary care centre  
 Independent hospital - ward in other hospital  
 Independent hospital - standalone

If not listed above, please specify here...

### 4a. Is this hospital a registered specialist BSGE (British Society for Gynaecological Endoscopy) centre?

\*Please see list of definitions

- Yes  
 No  
 No, but this hospital is a "provisional BSGE centre"  
 Unknown

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

When did this hospital attain registration as a BSGE specialist endometriosis centre?

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

If No, Are there current plans to attain BSGE specialist centre accreditation?

- Yes                       No                       Unknown

### 4d. Does this hospital have a NHS commissioned specialist service for severe endometriosis?

- Yes                       No                       Unknown

### 5a. If answered "Yes" to [4d] then:

When did this hospital become a NHS-commissioned specialist endometriosis centre?

**5b. If answered "No" to [4d] then:**

**If No, are there any current plans to attain status as an NHS commissioned specialist endometriosis centre?**

- Yes  No  Unknown
- 

**6a. If answered "Independent hospital - ward in other hospital" or "Independent hospital - standalone" to [3] then:**

**Are patients referred to this hospital for surgical procedures for endometriosis as part of a contract with the local NHS provider?**

- Yes  No  Unknown

**6b. If answered "Independent hospital - ward in other hospital" or "Independent hospital - standalone" to [3] then:**

**Please select the statements that apply to this hospital:**

*Please write any other comments about the relationship with the NHS provider in the free text box*

- Self referrals for surgery for endometriosis are accepted by this hospital
- Medical treatment for endometriosis is provided at this hospital
- This hospital is able to share patients case notes, results, image reporting etc. with the local NHS provider
- There are opportunities for shared learning with the local NHS provider
- Discharge summaries are shared with the patient's GP (with the patient's consent)
- Holistic care for endometriosis patients is provided at this hospital

Please specify any additional options here...

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**7. Does this hospital have an Emergency Department? (ED)**

- Yes  No  Unknown
- 

**8. Does this hospital provide higher level (2/3) care on-site?**

- Yes  No  Unknown
- 

**9. Is there a post-anesthesia care unit (PACU) on-site at this hospital?**

- Yes  No  Unknown

C. The endometriosis service

**1. Are dedicated consultant-led endometriosis clinics held at this hospital?**

- Yes                       No                       Unknown

**2. Please indicate all the healthcare professionals who comprise the multidisciplinary team that treats patients with endometriosis at this hospital:**

*Answers may be multiple, please select all that apply*

- |  |   |
|--|---|
| <input type="checkbox"/> Gynaecologist                           | <input type="checkbox"/> Colorectal surgeon               |
| <input type="checkbox"/> General surgeon                         | <input type="checkbox"/> Urologist                        |
| <input type="checkbox"/> Endometriosis clinical nurse specialist | <input type="checkbox"/> Gynaecology specialist nurse     |
| <input type="checkbox"/> Physiotherapist                         | <input type="checkbox"/> Reproductive medicine specialist |
| <input type="checkbox"/> Radiologist                             | <input type="checkbox"/> Pain specialist                  |
| <input type="checkbox"/> Histopathologist                        | <input type="checkbox"/> Pharmacist                       |
| <input type="checkbox"/> Psychologist                            | <input type="checkbox"/> General nurse                    |
| <input type="checkbox"/> Dietitian                               | <input type="checkbox"/> Occupational therapist           |

Please specify any additional options here...

**3. How many WTE consultant gynaecologists see patients in the endometriosis service?**

  Unknown

**4a. If answered "Endometriosis clinical nurse specialist" to [2] then:  
How many WTE Endometriosis Clinical Nurse Specialists are employed as part of this service?**

  Not Applicable  Unknown

**4b. If answered "Endometriosis clinical nurse specialist" to [2] then:  
How many are dedicated to the care of endometriosis patients?**

  Not Applicable  Unknown

**4c. If answered "Endometriosis clinical nurse specialist" to [2] then:  
Will every registered patient diagnosed with endometriosis be seen by an endometriosis clinical nurse specialist?**

- Yes                       No                       Unknown

**4d. If answered "No" to [4c] then:  
If not, which patients are seen by a endometriosis clinical nurse specialist?**

*Answers may be multiple, please select all that apply*

- |  |   |
|--|---|
| <input type="checkbox"/> Patients with severe disease                | <input type="checkbox"/> Patients with deep, infiltrating endometriosis |
| <input type="checkbox"/> Patients with recto-vaginal endometriosis   | <input type="checkbox"/> Complex patients with co-morbidities           |
| <input type="checkbox"/> Patients with recurrent/ persistent disease | <input type="checkbox"/> Not clearly defined                            |

Please specify any additional options here...

**5. If answered "Colorectal surgeon" to [2] then:  
How many WTE colorectal surgeons are employed as part of this service?**

  Not Applicable  Unknown

**6a. If answered "Pain specialist" to [2] then:  
How many WTE pain management specialists are employed as part of this service?**

Not Applicable  Unknown

**6b. If there is no pain management specialist employed as part of this service, is there a defined pathway for referral to pain services?**

Yes  No  Unknown  Not Applicable

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**7a. If answered "Reproductive medicine specialist" to [2] then:  
How many WTE fertility specialists are employed as part of this service?**

Not Applicable  Unknown

**7b. If there is no fertility specialist employed as part of this service, is there a defined pathway for referral to fertility services?**

Yes  No  Unknown  Not Applicable

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**8. If answered "Pharmacist" to [2] then:  
How many WTE dedicated pharmacists are employed as part of this service?**

Not Applicable  Unknown

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**9a. If answered "Physiotherapist" to [2] then:  
How many WTE dedicated physiotherapists are employed as part of this service?**

Not Applicable  Unknown

**9b. If there is not a physiotherapist in clinic, is there a defined pathway to physiotherapy services?**

Yes  No  Unknown  Not Applicable

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**10a. If answered "Psychologist" to [2] then:  
How many WTE dedicated psychologists are employed as part of this service?**

Not Applicable  Unknown

**10b. If there is not a clinical psychologist in clinic, is there a defined pathway to psychological services?**

Yes  No  Unknown  Not Applicable

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**11. If answered "Radiologist" to [2] then:  
How many WTE radiologists are employed as part of this service?**

Not Applicable  Unknown

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### Imaging

**12a. At this service, do patients with endometriosis have access to:**

*Answers may be multiple, please select all that apply*

- |   |   |
|---|---|
| <input type="checkbox"/> Ultrasound scan (USS)            | <input type="checkbox"/> Specialist endometriosis USS |
| <input type="checkbox"/> Magnetic resonance imaging (MRI) | <input type="checkbox"/> None of the above            |
| <input type="checkbox"/> Unknown                          |   |

Please specify any additional options here...

**12b.If answered "Ultrasound scan (USS)" to [12a] then:  
Is access to USS:**

- On-site
- At a different site (private clinic)
- Unknown
- At a different site (within the same Trust)
- At a different NHS hospital Trust

If not listed above, please specify here...

**12c.If answered "Magnetic resonance imaging (MRI)" to [12a] then:  
Is access to MRI scans:**

- On-site
- At a different site (private clinic)
- Unknown
- At a different site (within the same Trust)
- At a different NHS hospital Trust

If not listed above, please specify here...

**13a.If answered "Ultrasound scan (USS)" to [12a] then:  
What is the average waiting time for an ultrasound scan (USS)?**

*From referral to scan*

 Weeks  Not Applicable  Unknown

**13b.If answered "Magnetic resonance imaging (MRI)" to [12a] then:  
What is the average waiting time for a magnetic resonance imaging (MRI) scan?**

*From referral to scan*

 Weeks  Not Applicable  Unknown

**13c. Is there an aspirational maximum waiting time from referral to scan?**

*E.g. Patients should wait no more than X weeks for a scan. This can refer to either MRI or USS*

- Yes
- No
- Unknown
- Not Applicable

**13d.If answered "Yes" to [13c] then:  
What is it?**

### Surgical services

**14. How many operating hours per week are dedicated to the endometriosis service?**

  Not Applicable  Unknown

**15. As standard, is the following equipment available in order to undertake complex laparoscopic surgery:**

*Answers may be multiple, please select all that apply*

- Integrated laparoscopic theatre(s)
- High definition camera stacks
- Multiple monitors
- Adjustable screens
- Laparoscopic instrumentation for tissue sealing and dissection

Please specify any additional options here...

**16. Relating to surgery for endometriosis performed at your hospital, is a record kept of:**

*Answers may be multiple, please select all that apply*

- Details of surgical procedures carried out for the treatment of endometriosis
- Cancelled/ delayed/ postponed procedures
- Acute surgical complications
- Late surgical complications
- The number of procedures performed by each surgeon
- Patient recorded outcome measures (PROMS)
- None of the above
- Unknown

Please specify any additional options here...

**17. How long is the average waiting time for a routine laparoscopy at this hospital?**

*from decision to operate to surgery taking place*

weeks

- Not Applicable  Unknown

**18. How many of the surgeons employed at this hospital are able to treat rectovaginal endometriosis\*?**

*\*defined as requiring dissection of the para-rectal space*

- Not Applicable  Unknown

**19. Are cases of rectovaginal endometriosis entered on to a database for patient follow-up?**

*defined as requiring dissection of the pararectal space*

- Yes  No  Unknown

**Audit/ QI / Data collection**

**20. Is there a coder dedicated to gynaecology?**

- Yes  No  Unknown  Not Applicable

**21. Are there any active local audits on endometriosis?**

- Yes  No  Unknown  Not Applicable

**22a. Is there currently any quality improvement work within the endometriosis service?**

- Yes  No  Unknown  Not Applicable

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

**Please provide details of any improvement work carried out locally:**

**23a. Would you describe this hospital/ Trust as "research active" with respect to the care of patients with endometriosis?**

- Yes  No  Unknown

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

**Please provide examples:**



**24a. Is any post-graduate training in the symptoms / treatment pathway for endometriosis provided locally?**

- Yes                       No                       Unknown

**24b. If answered "Yes" to [24a] then:  
Please provide details:**

**24c. If answered "Yes" to [24a] then:  
Which healthcare professionals can receive training in the care of patients with endometriosis:**

*Answers may be multiple, please select all that apply*

- |   |   |
|---|---|
| <input type="checkbox"/> Gynaecologists       | <input type="checkbox"/> Endometriosis clinical nurse specialists |
| <input type="checkbox"/> Other nursing staff  | <input type="checkbox"/> Other medical staff                      |
| <input type="checkbox"/> Other surgical staff | <input type="checkbox"/> Ancillary healthcare professionals       |

Please specify any additional options here...

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**25a. Are procedures carried out for the treatment of endometriosis recorded on a registry/ database?**

- Yes                       No                       Unknown

**25b. If answered "Yes" to [25a] then:  
Please provide details:**

D. Multi-disciplinary team meetings

**1. Are regular endometriosis multi-disciplinary team (MDT) meetings held at this hospital?**

- Yes                       No                       Unknown                       Not Applicable

**2. If answered "Yes" to [1] then:  
How often does the MDT take place?**

- Weekly                       Fortnightly                       Monthly                       Quarterly  
 Half Yearly                       Ad hoc                       Unknown

If not listed above, please specify here...

**3. If answered "Yes" to [1] then:  
Which patients are routinely discussed at the MDT?**

*Answers may be multiple, please select all that apply*

- All registered endometriosis patients  
 All newly diagnosed patients  
 Patients awaiting surgery  
 Deep endometriosis patients  
 Severe endometriosis patients  
 Patients with recto-vaginal endometriosis  
 Complex endometriosis patients  
 Patients with endometriosis outside the pelvic cavity  
 Patients with multiple co-morbidities  
 Unknown

Please specify any additional options here...

**4. If answered "Yes" to [1] then:  
Who would routinely attend the MDT meeting?**

*Answers may be multiple, please select all that apply (for those indicated with a "\*", if the nature of the presentation necessitated)*

- Gynaecologist  
 Gynaecologist with special interest in endometriosis  
 Gynaecology nurse specialist  
 Clinical nurse specialist in endometriosis  
 Psychologist  
 Physiotherapist  
 Pain team/ pain specialist\*  
 Pain specialist  
 Radiologist  
 Pharmacist  
 Reproductive medicine/ fertility specialist\*  
 General practitioner  
 Urologist  
 Colorectal surgeon\*  
 Other surgeon\*  
 Senior fellow  
 Administrative staff  
 Unknown

Please specify any additional options here...

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**5. If answered "Yes" to [1] then:  
Is there an MDT coordinator?**

Yes

No

Unknown

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**6. If answered "Yes" to [1] then:  
Are the MDT meeting outputs routinely:**

*Answers may be multiple, please select all that apply,*

Documented in the patient notes

Made available to all members of the MDT

Fed back to the patient

Fed back to the General Practitioner

None of these

Please specify any additional options here...

E. Pathways/ policies/ guidelines for the care of patients with endometriosis

**1a. Does this hospital have an overarching policy/ pathway/ guideline for the care of patients with endometriosis?**

- Yes  No  Unknown  Not Applicable

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

**Is this in line with:**

*Answers may be multiple, please select all that apply*

- NICE guideline [NG73]  BSGE guidance  
 Based on other guidance (Please specify below)  
 Unknown

Please specify any additional options here...

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

**Is this audited?**

- Yes  No  Unknown  Not Applicable

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

**How frequently is this audited?**

- Monthly  Quarterly  Bi-annually  Annually  
 Ad hoc  Continuously  Unknown

If not listed above, please specify here...

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**Triage and referrals to gynaecology/ endometriosis service**

**2a. Do you take referrals from:**

*Please select all that apply, answers may be multiple*

- Emergency Department  
 Other secondary care departments (this hospital/Trust)  
 Other NHS providers (please specify below)  
 Specialist community gynaecology services  
 Independent hospitals  
 General Practitioner  
 Private practice  
 Self-referral  
 Unknown

Please specify any additional options here...

**2b. If answered "Other secondary care departments (this hospital/Trust)" to [2a] then:  
Please specify which departments have referred patients to the service during the last year (01/01/2022-31/12/2022)**

*Answers may be multiple, please select all that apply*

- Acute medicine  General medicine  General Surgery  
 Colorectal surgery  Gastroenterology  Cardiology  
 Cardiac Surgery  Respiratory medicine  Oncology  
 Urology

Please specify any additional options here...

**3. Is there threshold criteria for a patient referral to be accepted for treatment at this hospital?**

- Yes  No  Unknown
- 

**4. If answered "Yes" to [3] then:**

**What are the referral criteria at your service, for a patient to be treated at this hospital for endometriosis?**

*Please select all that apply, answers may be multiple.*

- Adult women (aged 18 and older)
- Pelvic signs of endometriosis
- Severe, persistent or recurrent symptoms of endometriosis
- Initial management not effective, not tolerated or is contraindicated
- Suspected or confirmed deep endometriosis involving the bowel, bladder or ureter
- Irregular or heavy period in a woman of any age with a structurally abnormal uterus
- Dysmenorrhoea despite three month's drug treatment
- Unscheduled vaginal bleeding interfering with quality of life
- Infertility
- Deep endometriosis
- Complex patient with multiple co-morbidities
- Endometriosis outside the pelvic cavity
- Unknown

Please specify any additional options here...

**5a. If answered "Yes" to [3] then:**

**If this hospital has a specialist (BSGE accredited/ NHS-commissioned) endometriosis service, does this hospital also accept referrals for patients with endometriosis to be treated outside of the specialist service (eg in gynaecology)?**

- Yes  
 No  
 Unknown  
 Not applicable - no specialist service at this hospital

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

**If so, which patients with endometriosis to be treated outside of the specialist endometriosis service?**

*Answers may be multiple, please select all that apply*

- Mild disease responding to treatment
- Mild symptoms
- Not formally diagnosed with endometriosis
- Significant pelvic pain related to cycle interfering with quality of life
- Endometriosis treated with medication

Please specify any additional options here...

**6. Who triages the referrals of endometriosis patients at this hospital**

- Administrative staff
- Endometriosis clinical nurse specialist
- Gynaecology nurse specialist
- Consultant gynaecologist (endometriosis specialist)
- Consultant gynaecologist
- Trainee gynaecologist
- Other nurse

Please specify any additional options here...

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**Initial clinic appointment**

**7. For endometriosis patients whose referral is accepted, as standard, who is the initial outpatient clinic appointment with?**

- Consultant gynaecologist
- Endometriosis nurse specialist
- Trainee gynaecologist
- Unknown

If not listed above, please specify here...

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**8a. Which of the following routinely take place at this hospital at the initial gynaecology clinic appointment (eg. outpatient clinic appointment)**

*Answers may be multiple, please select all that apply*

- Review of current symptoms of endometriosis
- Quality of life questionnaire
- Review of any previous imaging
- Referral for USS (if not done previously)
- Referral for MRI (if required)
- Pelvic/ Abdominal examination (if not done previously)
- Written information given about endometriosis
- Outline of possible treatment options, benefits and risks of different treatments
- Fertility needs assessed
- Psychological screening
- Referral to peer support group
- Referral to counselling (if needed)
- Referral to pain clinic (if required)
- Referral to fertility services (if required)
- Referral to gynaecology consultant-led endometriosis clinic for surgery (if required)
- Unknown

Please specify any additional options here...

**8b. If answered "Quality of life questionnaire" to [8a] then:  
Please give details of the quality of life questionnaire completed:**

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**9. If answered "Psychological screening" to [8a] then:  
What psychological screening tool is used?**

**10a.If answered "Quality of life questionnaire" to [8a] then:  
Is this quality of life questionnaire linked to any PROMs?**

- Yes  No  Unknown

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

**11. Would the initial clinic appointment be:**

*Answers may be multiple, please select all that apply*

- In person at an outpatient clinic  Telephone consultation  
 Video call consultation  Unknown

Please specify any additional options here...

**12. What is the average waiting time in this hospital for a Gynaecology outpatient appointment?**

*Please estimate, if exact average is unknown*

 weeks  Unknown

**13. If answered "Endometriosis nurse specialist" or "Trainee gynaecologist" to [7] then:  
If the initial consultation was not with a consultant gynaecologist, are patients reviewed in a consultant-led endometriosis clinic?**

- Yes  No  Unknown

#### Information/ support provided to patients

**14a.Is it stated as hospital policy/ in local guidance that, all patients with suspected/ diagnosed endometriosis are provided with information about their condition?**

- Yes  No  Unknown  Not Applicable

**14b.If answered "Yes" to [14a] then:  
How is this information provided to patients?**

*Answers may be multiple, please select all that apply*

- Printed leaflet given  
 Directed to on-line information provided by this hospital/ organisation  
 Directed to NHS website  
 Directed to website dedicated to endometriosis eg EndoUK  
 Verbally by the healthcare professional  
 Unknown

Please specify any additional options here...

**15a.Are patients directed to an endometriosis patient support group?**

- Yes  No  Unknown  Not Applicable

**15b.If answered "Yes" to [15a] then:  
Is this run in this hospital?**

- Yes  No  Unknown  Not Applicable

#### Referral for Imaging

**16. Is it policy/ part of a local guideline that all patients with suspected endometriosis are referred for imaging:**

- Yes  No  Unknown  
 NA- no guideline for this

**17. At this service, are USS used to confirm diagnosis of endometriosis?**

- Yes  No  Unknown

**18. At this service, is an MRI used to confirm diagnosis of endometriosis?**

- Yes  No  Unknown

**Treatment**

**19a. Is there a hospital policy/ guideline on the prescription/ review of hormonal medications/ treatments for patients with endometriosis?**

- Yes  No  Unknown

**19b. If answered "Yes" to [19a] then:**

**Does it address the following:**

*Please select all that apply, answers may be multiple*

- Consideration of side effects and contraindications
- Consideration of the patient's fertility status
- Regular review to assess efficacy and/ or any side effects of the treatment
- Patient's wishes

Please specify any additional options here...

**20. Is there any guidance as to which patients should be referred for surgery?**

- Yes  No  Unknown

**21. Who can make the decision to refer a patient for a surgical procedure for endometriosis?**

- Consultant gynaecologist
- Endometriosis nurse specialist
- The patient
- Trainee gynaecologist

Please specify any additional options here...

**22a. Is there hospital policy/ guidance around surgical treatment for patients with endometriosis?**

- Yes  No  Unknown



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

**Does guidance/ policy for surgery for patients with endometriosis cover any of the following aspects of care:**

*please select all that apply, answers may be multiple*

- guidance on the choice of procedure
- guidance on the maximum time on a waiting list for surgery
- guidance on providing patients with comprehensive information on the risks and benefits of surgery
- use of a 2-stage consent process
- adequate preassessment
- consideration of patient's fertility
- data collection regarding procedures completed
- consideration of the patient's choice/ wishes
- handover to the nursing staff
- follow-up with the operating surgeon

Please specify any additional options here...

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**Discharge / Follow-up/ ongoing care**

**23. Is there a policy/ guidance that following surgery for endometriosis, the patient's discharge summary should be shared with the patient's GP within 48 hours?**

- Yes                       No                       Unknown

**24. Is there a policy/ guidance that following surgery for endometriosis, the patient's discharge summary should be shared with the patient?**

- Yes                       No                       Unknown

**25. For patients who have been admitted to hospital for surgery for endometriosis, would an assessment of ongoing care needs be made at discharge?**

- Yes                       No                       Unknown

**26. Please select from the following onward referrals that can be made for patients with endometriosis following discharge from hospital:**

*Answers may be multiple, please select all that apply*

- |  |  |
|--|--|
| <input type="checkbox"/> Specialist physiotherapy (pelvic pain)    | <input type="checkbox"/> Chronic pain clinic       |
| <input type="checkbox"/> Reproductive medicine/ fertility care     | <input type="checkbox"/> Occupational Therapy      |
| <input type="checkbox"/> Dietetics                                 | <input type="checkbox"/> Physiotherapy             |
| <input type="checkbox"/> Endometriosis nurse specialist-led clinic | <input type="checkbox"/> Social care               |
| <input type="checkbox"/> Local patient peer support group          | <input type="checkbox"/> Colorectal surgery        |
| <input type="checkbox"/> Urology                                   | <input type="checkbox"/> Other specialist services |
| <input type="checkbox"/> Unknown                                   |  |

Please specify any additional options here...

**27. As standard, are patients given any other information on discharge?**

*Answers may be multiple, please select all that apply*

- |  |   |
|--|---|
| <input type="checkbox"/> Written leaflet about endometriosis | <input type="checkbox"/> Information regarding Endometriosis UK |
| <input type="checkbox"/> Information on managing pain        | <input type="checkbox"/> Local support group                    |
| <input type="checkbox"/> No other information given          | <input type="checkbox"/> Unknown                                |

Please specify any additional options here...

28. Do all patients who have a laparoscopy for endometriosis have a follow-up appointment, after discharge?

- Yes                       No                       Unknown

29. If answered "No" to [28] then:

**Which patients would have a routine follow-up appointment at this hospital?**

*Answers may be multiple, please select all that apply*

- Patients with severe disease  
 Patients who have had persistent/ recurring disease  
 Patients with deep/ infiltrating disease  
 Patients with complex needs/ comorbidities  
 Patients who had peri-operative complications  
 None- follow-up appointments are not provided at this hospital

Please specify any additional options here...

30a. Who would the initial follow-up appointment be with?

*Answers may be multiple, please select all that apply*

- Consultant gynaecologist  
 Operating surgeon  
 Trainee gynaecologist  
 Endometriosis nurse specialist  
 Other consultant surgeon  
 Unknown  
 Not applicable - follow-up appointments are not provided at this hospital

Please specify any additional options here...

30b. If answered "Consultant gynaecologist", "Operating surgeon", "Trainee gynaecologist", "Endometriosis nurse specialist", "Other consultant surgeon" or "Unknown" to [30a] then: **How long after discharge does the initial follow-up appointment occur?**

*Please select the answer that fits best, additional free-text options may be submitted*

- within 3 months       within 6 months       within 12 months       Unknown

If not listed above, please specify here...

31a. If answered "Consultant gynaecologist", "Operating surgeon", "Trainee gynaecologist", "Endometriosis nurse specialist", "Other consultant surgeon" or "Unknown" to [30a] then: **Following the initial follow-up appointment, are further follow-up appointments carried out at this hospital for patients who have had a surgical procedure for endometriosis?**

- Yes                       No                       Unknown

31b. If answered "Yes" to [31a] then:

**At what timeframe following discharge do the subsequent follow-up appointments occur?**

*Answers may be multiple, please select all that apply*

- 6 months                       8 months                       12 months                       18 months  
 24 months                       36 months                       Unknown

Please specify any additional options here...

**32. Is Patient initiated follow-up (PIFU) available in your Trust?**

- Yes                       No                       Unknown                       Not Applicable
- 

**33a. Does your service use Patient Reported Outcome Measures (PROMs) to assess the quality of care delivered?**

- Yes                       No                       Unknown

**33b. If answered "Yes" to [33a] then:  
Please provide details**

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**34. On discharge, are patients given contact details of a keyworker (such as the endometriosis clinical nurse specialist) to contact if they have a flare up?**

- Yes                       No                       Unknown
- 

**35. On discharge, which of the following options are patients advised to do, if they encounter a recurrence/ continuation of symptoms of endometriosis?**

*Answers may be multiple, please select all that apply*

- Visit their GP for re-referral
- Contact their named endometriosis nurse specialist directly
- Contact their named consultant gynaecologist consultant directly
- Contact the dedicated endometriosis helpline
- Visit the emergency department
- Unknown

Please specify any additional options here...

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**1a. Did the Covid-19 pandemic disrupt surgical procedures in the endometriosis service?**

- Yes                       No                       Unknown                       Not Applicable

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

**Please state the reasons for disruption:**

*Answers may be multiple, please check all that apply,*

- Loss of clinics                       Operating time                       Staff absences                       Unknown

Please specify any additional options here...

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

**Is the service now back to pre-pandemic working?**

- Yes                       No                       Unknown                       Not Applicable

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**3a. Are there any local examples of good practice with respect to the care of patients with endometriosis that you wish to share?**

- Yes                       No                       Unknown

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

**Please provide details:**

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**4. In your opinion, what are the greatest barriers to delivering best practice / areas of the care pathway for patients with endometriosis that could be improved?**

**5. Please use the box below to add any further comments about the endometriosis service at your hospital**