

# Severe Endometriosis Referral Pathway

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## 1. Introduction and who the guideline applies to:

This guideline is intended for the severe endometriosis referral pathway. This clinical pathway is to be shared with all GPs and gynaecologists in East Midlands as well as endometriosis specialists, colo-rectal surgeons, urologists, pain specialists and endometriosis clinical nurse specialist.

### **Related UHL Documents:**

- [Imaging Referral – Gynaecology UHL Imaging Guideline](#) UHL Trust ref: C57/2015
- [Imaging Reporting - Gynaecology UHL Imaging Guideline](#) UHL Trust ref: C58/2015
- [Hysteroscopy - Ambulatory Hysteroscopic Gynaecology Unit Standard Operating Procedure](#) UHL Gynaecology LocSSIP UHL Trust ref:C16/2020

## 2. Background:

Severe endometriosis for the purpose of this guideline is defined as either deeply infiltrating endometriosis or recto-vaginal endometriosis. Deeply infiltrating endometriosis exists where the disease invades at least 5mm below the tissue surface and can occur in a variety of sites, such as; bladder, pelvic sidewalls, ovaries, pelvic brim, bowel surface and diaphragm. Recto-vaginal endometriosis is endometriosis which involves the recto-vaginal area (recto-vaginal septum, vagina, utero-sacral ligaments, rectum).

There are many classification systems for endometriosis but none are universally accepted. The definition used here would accord with grade 3 and 4 disease used in the revised American fertility Score. (1).

Laparoscopic surgery for deeply infiltrating endometriosis or for recto-vaginal endometriosis is considered to be a specialised service due to its complexity and high risk

of morbidity. The British Society for Gynaecological Endoscopy has established criteria ([Requirements to be a BSGE Accredited Centre - BSGE](#)) for centres carrying out such work and accredits departments that reach its standards. The criteria include:

- Working in a multi-disciplinary team with a named colorectal surgeon and nurse specialist
- Holding a dedicated endometriosis clinic
- Operating on a minimum number of patients with severe endometriosis each year (12 cases of rectovaginal endometriosis which require dissection of the para rectal space)
- Submitting operative and quality of life outcome data to a national database
- Dedicated endometriosis specialist nurse
- Audit their outcomes

These criteria are designed to ensure quality care to women with complex surgical needs to minimise the risk of surgical complication and maximise the opportunity to deliver the best outcomes.

### **3. Referral**

Patients with known severe disease, which has not been adequately treated or has recurred, are likely to be referred by primary care clinicians.

Gynaecologists in secondary care, who identify severe deeply infiltrating endometriosis or recto-vaginal disease at laparoscopy, or open surgery, will refer patients from secondary care to an Endometriosis Clinic.

Laparoscopic images and or video, of suitable quality and format will be included with the referral wherever they are available as this may prevent the need for repeat laparoscopic pelvic survey after referral.

In exceptional cases young women under 18 years may be referred to the service. It is recognised that in the upper age groups 16 - 18 years they can be treated in either a paediatric or adult setting and, where possible should be able to choose, provided appropriate safeguarding and facilities are in place.

#### **3.1 Referral acceptance and exclusion criteria and thresholds**

The service will accept referrals from GPs and secondary care clinicians in Gynaecology, Colorectal surgery and Urology in East Midlands. The service will also accept referrals from other providers, particularly when the referring service is not accredited to undertake the clinical care the patient requires.

The service will accept referrals for patients who meet one of the following criteria:

- Women with a diagnosis of severe endometriosis
- Non-severe endometriosis refractory to treatment

Referrals into the service will be assessed by a named Consultant.

Eligible women will be referred using a defined referral system that can be audited for waiting times.

Appropriate referrals to specialist colleagues will be documented and GP informed of any transfer of care

Exclusions:

- Patients that have pelvic pain but do not have endometriosis.
- Non-severe endometriosis that is responding to treatment.
- Patients with gynaecological cancer; their care is covered in the cancer services specifications

#### **4. Service description/care pathway**

(Also see [appendix 1](#))

Summary of the service provided is explained in the following steps:

- Referral from Primary or secondary care (including detailed clinical information, investigation results and laparoscopic images/video)
- Initial outpatient assessment in specialist endometriosis clinic by endometriosis specialist/nurse, information, counselling and explanation will be given. Primary quality of life questionnaire will be completed.
- Other investigations organised as needed, which may include renal and/or pelvic ultrasound and/or diagnostic laparoscopy
- Multidisciplinary discussion of cases which require colorectal and or urology surgeon input.
- Review appointment with consultant gynaecologist in endometriosis clinic and treatment decision made plus pre-operative preparation organised
- Elective surgical inpatient spell
- Elective outpatient follow-up at three months by consultant and six months by nurse, with PROMs including quality of life assessments at 6, 12 and 24 months post-surgery
- Ideally discharge to secondary, or primary, care after six months follow up, with subsequent PROMs collected in non-face to face consultation
- Management of any complications, morbidity or recurrence as required

#### **5. Recommendations:**

##### **5.1 All women with severe endometriosis who require surgery will have standardised treatment pathway**

(Also see [appendix 1](#))

Access to the standardised treatment pathway will enable;

- Access laparoscopic surgery with skilled appropriately trained laparoscopic surgeons, in line with the criteria used for British Society of Gynaecologic Endoscopy (BSGE) accreditation criteria; [www.bsge.org.uk](http://www.bsge.org.uk)
- Experience MDT assessment and care in line with BSGE guidance
- Have a clear understanding of their entry and exit from the Severe Endometriosis pathway
- Experience integrated pathway where all relevant primary/community/secondary treatment providers are aware of their treatment responsibilities
- Experience treatment to referral waiting times to see consultant that are audited in line with the NHS 18 week RTT targets

##### **5.2 Surgical treatment**

Surgical treatment of endometriosis is best performed using laparoscopic surgery as this enables excellent visualisation of the deep pelvis which facilitates the very delicate surgery required.

In contrast, open surgery often results in incomplete excision of the disease. Incomplete excision will result in inadequate treatment, with failure to resolve symptoms and makes repeat surgery even more difficult.

### 5.3 Patient reported outcome measures

Patient reported outcome measures (PROMs) should be used to assess the individual symptoms and the global quality of life score measured at a single point in time should be used to audit outcome

Comparison from pre-operation to 2 years post operation will be expected to show improvement. These PROMs are built into the core structure of BSGE endometriosis centres and will be audited.

### 6. Auditable Standards:

As per NHS England, the following standards should be audited in line with NHS Outcomes Framework Domains & Indicators

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
<b>Domain 1: Preventing people dying prematurely</b>			
% of cases entered on BSGE database	>70%	% seen recorded in database	Audit to assess reasons for non-compliance
Compliance with BSGE criteria for laparoscopic surgery for severe endometriosis	100%	Reported within national audit reports	Audit to evaluate causation and any change in practice
<b>Domain 2: Enhancing the quality of life of people with long-term conditions</b>			
Quality of life score. Record standard dataset of patient symptoms on national database for audit.	Improvement in median score for >75% of population by at least 20% at 2 years post-surgery	Proportion of patients having surgery for severe endometriosis with symptom questionnaire pre operatively and at 6, 12 and 24 months post-surgery.	Audit of QOL scores for whole patient group and change in surgical practice where appropriate.
<b>Domain 3: Helping people to recover from episodes of ill-health or following injury</b>			
Ensure adequate follow up of surgical cases for severe endometriosis	>75%	Proportion of patients who were followed up for 2 years post-surgery for severe endometriosis	Audit to evaluate causation and remedial action
<b>Domain 4: Ensuring that people have a positive experience of care</b>			
Patient feedback	>50%	Proportion of patient completing anonymous feedback questionnaire at completion of treatment	Audit to evaluate causation and remedial action
Access to operation in timely fashion	>90%	Surgery within 18 weeks of referral to specialist centre	Audit to evaluate causation and remedial action
Adequate preparation for surgery	>90%	Given date for surgery at least 4 weeks in advance	Audit to evaluate causation and remedial action
Limit changes in planned treatment time	<10%	Proportion of patients who have surgery date changed once issued	Audit to evaluate causation and remedial action
<b>Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm</b>			

Surgery performed by appropriately experienced team	100%	Confirmation of two skilled laparoscopic surgeons for all cases	Audit to evaluate causation and remedial action/ loss of service.
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## **7. Supporting References**

1. American Fertility Society. Revised American Fertility Society classification: 1985. Fertil Steril 1985;43:351– 2.
2. NHS Standard Contract for Complex Gynaecology- Severe Endometriosis NHS England e10/s/a gateway reference 01369.
3. Requirements to be a BSGE accredited Centre: <https://bsge.org.uk/requirements-to-be-a-bsge-accredited-centre/>
4. Endometriosis: diagnosis and management. NICE guideline, 6 September 2017, nice.org.uk/guidance/ng73
5. Imaging Referral – Gynaecology UHL Imaging Guideline UHL Trust ref: C57/2015
6. Imaging Reporting - Gynaecology UHL Imaging Guideline UHL Trust ref: C58/2015
7. Hysteroscopy - Ambulatory Hysteroscopic Gynaecology Unit Standard Operating Procedure UHL Gynaecology LocSSIP UHL Trust ref:C16/2020

## **6. Key Words**

Colo-rectal, Deeply infiltrating endometriosis, Pain specialists, Recto-vaginal endometriosis, Urologists

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**The Trust recognises the diversity of the local community it serves. Our aim therefore is to provide a safe environment free from discrimination and treat all individuals fairly with dignity and appropriately according to their needs. As part of its development, this policy and its impact on equality have been reviewed and no detriment was identified.**

<b>CONTACT AND REVIEW DETAILS</b>			
<b>Guideline Lead (Name and Title)</b> Mr Tarek Gelbaya Consultant Gynaecologist		<b>Executive Lead</b> Chief Medical Officer	
<b>Details of Changes made during review:</b>			
<b>Date</b>	<b>Issue Number</b>	<b>Reviewed By</b>	<b>Description Of Changes (If Any)</b>
<b>November 2022</b>	<b>1</b>	<b>Gynaecology Governance group</b>	<b>New document</b>

## Appendix1. Management of severe endometriosis pathway

