NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

Endometriosis: diagnosis and management

Short title

Endometriosis

Topic

The Department of Health in England has asked NICE to develop a guideline on the diagnosis and management of endometriosis.

Who the guideline is for

- practitioners in endometriosis
- healthcare professionals in secondary care
- healthcare professionals in primary care
- providers of endometriosis services
- commissioners of endometriosis services.
- women with endometriosis, their families and carers and the public.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government, and Northern Ireland Executive.

Equality considerations

NICE has carried out an equality impact assessment [link in final version] during scoping. The assessment:

- lists equality issues identified, and how they have been addressed
- explains why any groups are excluded from the scope, if this was done.

1 What the guideline is about

1.1 Who is the focus?

Groups that will be covered

- Women and adolescents with endometriosis or suspected endometriosis.
- Women and adolescents with recurrent symptoms of endometriosis.
- Women and adolescents with asymptomatic endometriosis discovered incidentally.

Groups that will not be covered

- Women with endometriosis occurring outside the pelvis.
- Postmenopausal women.

1.2 Settings

Settings that will be covered

- All settings in which NHS-commissioned healthcare is provided.

1.3 Activities, services or aspects of care

Key areas that will be covered

1. Signs and symptoms of endometriosis at the time of presentation.
2. How and when to monitor and refer for complications and disease progression.
3. Use of diagnostic tests including imaging, biomarkers and surgical diagnosis.
4. Use of staging systems to guide treatment decisions.
5. Timing of interventions.
6. Pharmacological and surgical treatments including analgesics, hormonal medical treatments, ablation, excision and hysterectomy.

   Note that guideline recommendations will normally fall within licensed indications; exceptionally, and only if clearly supported by evidence, use outside a licensed indication may be recommended. The guideline will

assume that prescribers will use a drug's summary of product characteristics to inform decisions made with individual patients.

7 Combinations of treatments.

8 Non-medical management specific to pain (for example acupuncture).

9 Use of specialist services to deliver care.

10 Information and support for women with endometriosis.

Areas that will not be covered

1 Investigation of fertility problems related to endometriosis.

2 Care during pregnancy for women with endometriosis.

3 Management of menopausal symptoms related to surgical treatment of endometriosis.

4 Treatment specific to adenomyosis in isolation.

1.4 Economic aspects

We will take economic aspects into account when making recommendations. We will develop an economic plan that states for each review question (or key area in the scope) whether economic considerations are relevant, and if so whether this is an area that should be prioritised for economic modelling and analysis. We will review the economic evidence and carry out economic analyses, using an NHS perspective, as appropriate.

1.5 Key issues and questions

While writing this scope, we have identified the following key issues, and key questions related to them:

1 Clinical manifestations of endometriosis

- What are the symptoms and signs of endometriosis at the time of presentation?

2 Monitoring and referral

- How and when should endometriosis be monitored for disease progression and complications, including:
  - ◊ pain
  - ◊ bowel involvement

- ◊ bladder and ureter involvement?

3 Using diagnostic tests

- What is the accuracy of the following tests in diagnosing endometriosis:
  - ◊ imaging
  - ◊ biomarkers
  - ◊ surgical diagnosis
  - ◊ endometrial biopsy?
- Should a surgical diagnosis include histological confirmation?

4 Using staging systems to guide treatment decisions

- What is the effectiveness of staging systems in guiding the treatment of endometriosis?

5 Timing of interventions

- Does early laparoscopy and treatment improve outcomes?

6 Pharmacological and surgical treatments

- What is the effectiveness of the following treatments for endometriosis, including recurrent and asymptomatic endometriosis:
  - ◊ analgesics
  - ◊ neuro-modulators
  - ◊ hormonal medical treatments
  - ◊ ablation
  - ◊ excision
  - ◊ hysterectomy, with or without oophorectomy?

7 Combinations of treatments

- What is the effectiveness of pharmacological therapy before or after surgery compared with surgery alone?

8 Non-medical management specific to pain

- What is the effectiveness of non-medical therapies (for example acupuncture) for managing pain associated with endometriosis?

9 Using specialist services to deliver care

- What is the clinical and cost effectiveness of specialist endometriosis services?

10 Information and support
- What information and support do women with endometriosis and their families and carers need?

The key questions may be used to develop more detailed review questions, which guide the systematic review of the literature.

1.6 Main outcomes

The main outcomes that will be considered when searching for and assessing the evidence are:

1 pain
2 health related quality of life
3 activities of daily living
4 complications of treatment
5 recurrence of endometriosis
6 admission to hospital
7 fertility.

2 Links with other NICE guidance and NICE Pathways

2.1 NICE guidance

NICE guidance that will be updated by this guideline

- Fertility (2013) NICE guideline CG156. Recommendations 1.7.1.1-1.7.2.4.

Updating of recommendations is provisional and is subject to approval and consultation with Fertility guideline stakeholders.

NICE guidance that will be incorporated unchanged in this guideline

- Laparoscopic helium plasma coagulation for the treatment of endometriosis (2006) NICE interventional procedure guidance 171.

NICE guidance about the experience of people using NHS services

NICE has produced the following guidance on the experience of people using the NHS. This guideline will not include additional recommendations on these topics unless there are specific issues related to endometriosis:

- Patient experience in adult NHS services (2012) NICE guideline CG138
- Medicines adherence (2009) NICE guideline CG76

NICE guidance in development that is closely related to this guideline

NICE is currently developing the following guidance that is closely related to this guideline:

- Menopause NICE guideline. Publication expected October 2015.

2.2 NICE Pathways

When this guideline is published, the recommendations will be added to NICE Pathways. NICE Pathways bring together all related NICE guidance and associated products on a topic in an interactive topic-based flow chart.

Other relevant NICE guidance will also be added to the NICE Pathway, including:

- Long-acting reversible contraception (update) (2014) NICE guideline CG30
- Depression in adults with a chronic physical health problem (2009) NICE guideline CG91
- Heavy menstrual bleeding (2007) NICE guideline CG44
- Laparoscopic techniques for hysterectomy (2007) NICE interventional procedure guidance 239
- Laparoscopic uterine nerve ablation (LUNA) for chronic pelvic pain (2007) NICE interventional procedure guidance 234

3 Context

3.1 Key facts and figures

Endometriosis is one of the most common gynaecological diseases needing treatment, although its exact cause is unknown. It is defined as the extrauterine growth of endometrial tissue. The main cause is thought to be metaplasia of the coelomic cells or the implantation of endometrial fragments which reach the pelvic cavity by retrograde menstruation.

Endometriosis is mainly a disease of the reproductive years, but has been described in postmenopausal women. Delaying childbearing, either by choice or because of subfertility, may be a risk factor for endometriosis. The risk of developing the disease corresponds with the cumulative menstruation (menstrual frequency and volume over time). Women with shorter menstrual cycles (less than 27 days) and longer duration of flow (more than 7 days) are twice as likely to develop endometriosis than those with longer cycles.

The prevalence of endometriosis in the population is uncertain. Information to date is based on prevalence studies of women presenting with one of several symptoms needing laparoscopy, for example, pelvic pain, dysmenorrhoea and subfertility. A diagnosis is made by observing lesions, either by laparoscopy or laparotomy, and until a simple screening test is developed, the true prevalence will remain unknown.

There is limited published literature describing the natural history of endometriosis. This is because, before the introduction of laparoscopy, only symptomatic disease was treated and the symptoms were used to define disease progression and the effectiveness of treatment. Using laparoscopy, it is possible to visualise and record the effects of treatment on the disease.

Delayed diagnosis is a significant problem for women with endometriosis. Patient self-help groups emphasise how often healthcare professionals delay making a diagnosis, often because they do not consider endometriosis as a possibility. Studies suggest that there may be a 4–10-year delay between first presentation and diagnosis. Many women think that the delay in diagnosis

leads to increased personal suffering, prolonged ill health and a disease state that is more difficult to treat. Many women with endometriosis believe that delays in diagnosis are because GPs fail to recognise the significance of symptoms and think that women are ‘over-reacting’.

Endometriosis is associated with lower quality of life. A study reported that the diagnosis of endometriosis was associated with more sick days, work disturbances because of symptoms and low work ability. Tiredness, frequent pain, a higher daily pain level, a higher number of sick days and feeling depressed at work were associated with low work ability. Endometriosis is also an important cause of subfertility and this can also have a significant effect on quality of life.

3.2 Current practice

Women with endometriosis typically present to GPs with pain, and may then be referred to secondary care for diagnosis and management. Some women may present to fertility services.

Diagnosis is mainly by laparoscopic visualisation of the pelvis, but other less invasive methods may be used, including ultrasound and MRI scanning. Investigations are chosen on the basis of the woman's symptoms.

Management options for endometriosis include pharmacological, surgical and non-medical treatments. Endometriosis is an oestrogen-dependent disease and most drug treatments for endometriosis work by suppressing menstruation and are contraceptive. Surgical treatment aims to ablate or excise deposits of endometrial tissue. The choice of treatment depends on the woman’s priorities in terms of management of pain or fertility.

Surgical treatment is carried out in specialist endometriosis centres which incorporate a multidisciplinary team including urologists, pain management specialists and endometriosis specialist nurses. There are a limited number of specialist centres in the UK and as a result there is variation in the level of care that women experience in different geographical areas.

Endometriosis is a chronic condition affecting women throughout their reproductive lives. Women's priorities and preferences may change over time and management strategies should change to reflect this. Regular follow-up and monitoring is needed to ensure optimal care but this does not always happen outside specialist endometriosis centres.

Earlier diagnosis and cost-effective treatment of endometriosis may improve quality of life and productivity in the workplace, reduce healthcare cost, and consequently reduce total cost to patients and society.

3.3 Policy, legislation, regulation and commissioning

Legislation, regulation and guidance

The European Society of Human Reproduction and Embryology (ESHRE) has produced guidance on the management of women with endometriosis, endorsed in the UK by the Royal College of Obstetricians and Gynaecologists. The NICE guideline will consider similar areas to the ESHRE guideline but in the context of NHS-commissioned healthcare, and will include consideration of cost as well as clinical effectiveness.

Commissioning

Managing severe endometriosis is typically surgical and commonly by hysterectomy (24.7% of cases). NHS England has published a service specification for providing services for severe endometriosis: complex gynaecological services – severe endometriosis. This endorses the British Society for Gynaecological Endoscopy accreditation criteria for endometriosis centres.

4 Further information

This is the draft scope for consultation with registered stakeholders. The consultation dates are 20 March to 21 April 2015.

The guideline is expected to be published in May 2017.

You can follow progress of the guideline.

Our website has information about how NICE guidelines are developed.

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