NICE National Institute for Health and Care Excellence

2022 surveillance of endometriosis: diagnosis and management (NICE guideline NG73)

Surveillance report

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Surveillance decision

We will update the sections on diagnosing endometriosis, surgical management and surgical management if fertility is a priority in NICE's guideline on endometriosis. The topic of mental wellbeing and support for people with suspected or confirmed endometriosis will be further explored during scoping of the update.

Reason for the decision

New evidence was identified that may impact on the diagnosis of endometriosis, specifically with respect to imaging modality.

Evidence in areas not currently addressed in the guideline was also found on surgical management (pain management immediately post-surgery), and interventions when fertility is a priority. These will warrant an update.

Although there was insufficient new evidence found, intelligence gathered suggests that mental wellbeing and support are important for patients and would be valued in this area. This topic may benefit from further consideration during scoping of the update, with input from stakeholders, to explore the best way to address any unmet need.

Despite there being a recommendation for research for pain management programmes, there remains insufficient new evidence to trigger an update in this topic area. NICE will explore further research opportunities for this with the National Institute for Health and Care Research (NIHR).

We did not find sufficient evidence in other topic areas to signal the need to update other sections of the guideline.

Overview of 2022 surveillance methods

NICE's surveillance team checked whether recommendations in the guideline remain up to date.

The surveillance process consisted of:

- Feedback from topic experts and patient groups via a questionnaire.
- A search for new or updated Cochrane reviews and national policy.
- Consideration of evidence from previous surveillance.
- Examining related NICE guidance, quality standards and NIHR signals.
- A search for ongoing research.
- Examining the NICE event tracker for relevant ongoing and published events.
- Literature searches to identify relevant evidence.
- Assessing the new evidence against current recommendations to determine whether or not to update sections of the guideline, or the whole guideline.

For further details about the process and the possible update decisions that are available, see ensuring that published guidelines are current and accurate in developing NICE guidelines: the manual.

Focused literature searches and selection strategies

Published literature search strategies

The initial intelligence gathering process identified that only focused literature searches on selected sections of the guideline were needed.

We searched for new evidence published from November 2016 to May 2022 related to diagnosing endometriosis and interventions for the treatment of endometriosis (including pharmacological treatments, non-pharmacological treatments, and surgical interventions).

In addition, we also searched for evidence on gaps identified during the intelligence gathering process on interventions to improve mental wellbeing and support for women with endometriosis and endometriosis outside the pelvis.

Selecting relevant studies

We applied the same inclusion criteria as in the review protocols of the guideline, with the following additional criteria:

- For diagnostic accuracy studies, we only included studies with sample sizes larger than 50 participants.
- For pharmacological interventions, we included additional interventions, which have become available in the UK for endometriosis since the guideline published, such as dienogest. We have retained the inclusion of any agents without UK marketing authorisation, which the current guideline had included for the purpose of comparison or inference on the action of a pharmacological class.
- For the newly identified gaps (mental wellbeing and support and endometriosis outside the pelvis), we have also included evidence from observational studies, rather than just limiting to randomised controlled trials (RCTs).

Evidence considered in surveillance

Published evidence found through focused searches

From a total of 3,313 abstracts found in the search, we included a total of 64 publications of 60 studies. These studies covered the following:

- Section 1.5 on diagnosing endometriosis: 7 systematic reviews (SR) and 11 diagnostic accuracy studies.

- Interventions for endometriosis:
  - Section 1.8 on pharmacological interventions: 3 SR or network meta-analysis and 9 RCTs.
  - Section 1.9 on non-pharmacological interventions: 1 SR and 3 RCTs.
  - Section 1.10 on surgical intervention: 6 SR and 9 RCTs.
  - Section 1:10 on combination of surgical and pharmacological interventions: 2 SRs and 8 RCTs.
  - Section 1.11 on interventions when fertility is a priority: 1 additional RCT on top of 1 SR and 2 RCTs already included in other sections.
- Mental wellbeing and support (new topic): 1 RCT.
- Endometriosis outside the pelvis: No new evidence.

The abstracts found suggest that new evidence is likely to change recommendations in section 1.5 on diagnosing endometriosis, section 1.10 on surgical management - pain management immediately post-surgery and section 1.11 on surgical management when fertility is a priority.

See appendix A for details of all evidence considered, and references.

Intelligence gathered during surveillance

Views of topic experts

We considered the views of topic experts who were recruited to the NICE Centre for Guidelines Expert Advisers Panel to represent their specialty. For this surveillance review, topic experts completed a questionnaire about developments in evidence, policy and services related to the guideline.

We received 5 questionnaire responses from topic experts, including: a general practitioner, a consultant gynaecologist, a consultant nurse with a special interest in gynaecology, a consultant obstetrician and gynaecologist. A questionnaire response was also received from a patient group.

Two topic experts thought the guideline didn't need updating, while 3 thought it did due to new drugs and treatment options being available, and to cover the gap of extra-pelvic endometriosis. The patient group also thought it needed updating to investigate non-pharmacological pain management, delay in diagnosis, endometriosis outside the pelvis and mental wellbeing and support for people with endometriosis.

Implementation of the guideline

A topic expert stated that the main barriers to implementation are funding to support staffing in endometriosis centres and funding to support a clinical network for endometriosis.

A patient group said they have not seen evidence on services being commissioned as recommended in the guideline, and do not believe the guideline has been fully implemented in the UK. They stated there is a lack of clarity on competencies for a 'gynaecologist with expertise in diagnosing and managing endometriosis, including training and skills in laparoscopic surgery' (recommendation 1.1.3). They also noted that there is a health systems issue in relation to measuring and meeting the demand for endometriosis care in secondary and tertiary care, and an issue around proper workforce planning. They highlighted Endometriosis UK's analysis of endometriosis service provision in Scotland (January 2022), which made 4 key recommendations:

- Implementing NICE's guideline and quality standards on endometriosis across Scotland; the research found that this base level of care 'is not currently being met'.
- Facilitating relationship development between healthcare services through Managed Clinical Networks to allow for smoother referrals.
- Increasing education at primary and secondary care levels, with the analysis showing both GPs and non-specialist gynaecologists needing more education on the condition.
- Investing in endometriosis awareness through a public health campaign, as well as improved menstrual wellbeing education in schools and educating school nurses.

Ongoing research

We checked for relevant ongoing research; of the ongoing studies identified, 5 studies were assessed as having the potential to change recommendations. Therefore, we plan to regularly check whether these studies have published results and evaluate the impact of

them on current recommendations as quickly as possible. These studies are:

- ISRCTN13298303: Investigation of the diagnostic accuracy of a new blood test for endometriosis, compared with the current gold standard surgery for diagnosis
- ISRCTN48609976: Comparing gonadotrophin-releasing hormone analogues with repeat laparoscopic surgery for the treatment of recurrent pain following surgery for endometriosis
- ISRCTN27244948: ESPriT2 – a multicentre clinical trial to determine whether surgical removal of superficial peritoneal endometriosis improves pain symptoms and quality of life
- ISRCTN94462049: Comparing medical management with laparoscopic surgery for the treatment of deep endometriosis
- ISRCTN11469394: Ovarian function after the use of various hemostatic techniques during treatment for endometrioma.

Equalities

Several equalities issues were identified through this review. Firstly, there is a lack of suitable services to refer adolescents with suspected or confirmed endometriosis, and there are difficulties in diagnosing endometriosis in adolescents. Secondly, the All-Party Parliamentary Group (APPG) enquiry on endometriosis in 2020 found black women with endometriosis were often being misdiagnosed with fibroids. The APPG also recognised the additional complexities and barriers that those from black, Asian and minority ethnic communities may face in talking about menstrual health and accessing support. Equality issues were also raised around assumptions made about fertility and same sex couples, and people with endometriosis who do not identify themselves as women.

Overall decision

After considering all new evidence and other intelligence identified, we decided that there is sufficient new evidence to support an update of recommendations related to diagnosis of endometriosis, surgical management of endometriosis, and surgical management of endometriosis when fertility is a priority.

Intelligence gathered suggests that non-pharmacological pain management options are

important to patients. This category of interventions includes a wide variety of options ranging from a pain management programme, lifestyle modifications to physiotherapy. In the current guideline, there was insufficient evidence to recommend any non-pharmacological interventions. Although recommendations for research were made for lifestyle interventions and pain management programmes, there remains insufficient new evidence to trigger an update in this topic area. NICE will explore further research opportunities for this with the NIHR.

Although intelligence gathered had identified a need for addressing mental wellbeing and support for women with endometriosis, and endometriosis in the area outside the pelvis, we did not find evidence that would support specific recommendations in these areas. The current guideline already has recommendations about referring patients with suspected endometriosis outside the pelvis to specialist care, and providing information and support for people with suspected, or confirmed endometriosis. We will explore the development of recommendations for research for endometriosis outside the pelvis, to help in generating more research in these areas. We will, also further consider mental wellbeing and support during scoping of the update.

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