



2021 exceptional surveillance of endometriosis: diagnosis and management (NICE guideline NG73)

Surveillance report

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Surveillance decision

We propose not to update the [NICE guideline on endometriosis: diagnosis and management](#). We will, however, make an editorial amendment to the [section on referral for women with suspected or confirmed endometriosis](#) to highlight that women with endometriosis outside the pelvic cavity should be referred to a specialist endometriosis centre.

Exceptional surveillance review summary

Reason for considering this area

An enquirer contacted us to ask if we would consider providing NICE guidance on thoracic endometriosis to help improve the care of women with endometriosis. They cited the [All Party Parliamentary Group inquiry report on endometriosis](#), which sets out a number of issues with endometriosis care in the UK.

Methods

To review the impact of this enquiry on NICE guidance we took the following approach:

- Considered the information submitted by the enquirer.
- Considered the development of the NICE guideline on endometriosis.
- Discussed the issues raised with the NICE technical adviser.
- Considered clinical adviser and topic expert advice.

It was concluded that full updated literature searches were not needed because the information we obtained was enough to establish whether an update to the guideline was needed.

For further information, see [ensuring that published guidelines are current and accurate in developing NICE guidelines: the manual](#).

Information considered in this exceptional surveillance review

How the guideline was developed

The NICE guideline does not currently cover endometriosis outside the pelvis. It was excluded during scoping as it was considered very rare (<1% of cases of endometriosis).

Previous surveillance

The guideline has never undergone surveillance.

New intelligence and evidence

In particular, the All Party Parliamentary Group inquiry report, specifically calls for NICE "to ensure that care pathways for those with endometriosis outside the pelvic cavity are developed and implemented, starting with thoracic endometriosis." Qualitative accounts of long delays in diagnosis are provided in the report, particularly for endometriosis outside the pelvic cavity. The report urges the development of pathways for care for those with endometriosis outside the pelvis, starting with thoracic endometriosis.

Views of topic experts

Four topic experts were contacted for their views on whether there would be sufficient evidence upon which to develop recommendations on thoracic endometriosis and the rarity of the condition. Two experts replied and explained that currently the evidence base is insufficient to develop recommendations on how to best diagnose and manage endometriosis outside the pelvis.

One expert explained that thoracic endometriosis is likely an under-diagnosed condition and that the true prevalence is unknown. However, based on extrapolation of a national survey of British gynaecological endoscopists ([Hirsch et al. 2021](#)), the expert estimated that there are likely to be 245 to 545 cases of thoracic endometriosis requiring intervention in the UK annually. The expert went on to describe how thoracic endometriosis is a specialised area which requires multidisciplinary care involving gynaecologists, cardiothoracic surgeons, upper gastrointestinal surgeons, radiologists and anaesthetists. They highlighted that the All Party Parliamentary Group inquiry report and

national survey of British gynaecological endoscopists found that centralising the care of women with thoracic endometriosis was likely to improve clinical outcomes by allowing higher caseloads within a few specific units leading to greater experience and acquisition of expertise. Concentrating care in this way would also likely facilitate research into the safety and effectiveness of treatments and longer-term prognosis.

How we will address this issue

The NICE guideline does not currently cover thoracic endometriosis as it was excluded at scoping due to the rarity of the condition. An enquirer has subsequently highlighted this as a gap in the guideline, which may be contributing to the late diagnosis of endometriosis outside the pelvis and difficulties in women accessing prompt treatment and care.

Feedback from topic experts explained that there is currently no evidence upon which to base recommendations on how to best diagnose and manage endometriosis outside the pelvis, including thoracic endometriosis. The experts explained that treatment in specialist centres may improve patient outcomes and facilitate evidence generation on how to manage endometriosis outside the pelvis.

As such we will make an editorial amendment to the [section on referral for women with suspected or confirmed endometriosis](#) to highlight that women with endometriosis outside the pelvic cavity should be referred to a specialist endometriosis centre.

This issue will also be added to the issue log for this NICE guideline for consideration in future surveillance once the evidence base matures. The [NICE 5-year strategy](#) is currently prioritising which parts of the guideline portfolio will be actively maintained and updated. Given the lack of evidence on how to best diagnose and manage endometriosis outside the pelvis and the small population size, it is unlikely that this topic fits the direction of the NICE strategy.

Equalities

None noted.

Overall decision

We propose not to update the NICE guideline but will make an editorial amendment to

highlight that women with endometriosis outside the pelvic cavity should be referred to a specialist endometriosis centre.

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