NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE guidelines

Equality impact assessment

Endometriosis – diagnosis

The impact on equality has been assessed during guidance development according to the principles of the NICE equality policy.

1.0 Checking for updates and scope: before scope consultation (to be completed by the Developer and submitted with the draft scope for consultation)

No scoping phase was carried out for this update.

2.0 Checking for updates and scope: after consultation (to be completed by the Developer and submitted with the revised scope)

No scope consultation was carried out for this update.

3.0 Guideline development: before consultation (to be completed by the Developer before consultation on the draft guideline)

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

No scoping phase was carried out for this update. The following equality issues were identified in the surveillance report:

Age

There are difficulties in diagnosing endometriosis in adolescents and there is a lack of suitable services to refer adolescents with suspected or confirmed endometriosis.

Ethnicity

The 2020 All-Party Parliamentary Group (APPG) enquiry on endometriosis 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.

Sexual orientation and gender identity

There are assumptions made about fertility and same sex couples, and people with endometriosis who do not identify themselves as women.

The equality issues identified above (age-adolescents, ethnicity, sexual orientation, gender identity) were included within the population covered by the reviews, and where appropriate were considered as subgroups by the committee in the case of heterogeneity in the evidence.

3.2 Have any **other** potential equality issues (in addition to those identified during the scoping process) been identified, and, if so, how has the Committee addressed them?

No other additional equality issues were identified by the committee.

3.3 Have the Committee's considerations of equality issues been described in the guideline for consultation, and, if so, where?

Age

The committee agreed that age was not a relevant factor to take into consideration for the diagnosis of endometriosis as the use of diagnostic tools would be the same for younger and older people, so age was not included as a sub-group or discussed in the evidence reviews.

Ethnicity

Ethnicity was included as a sub-group in the event of heterogeneity for the reviews on diagnosis, but no evidence of diagnostic differences by ethnicity were available in the evidence, so ethnicity was not included as a sub-group or discussed in the evidence reviews, and it was not possible to make separate recommendations for this group.

Sexual orientation and gender identity

The committee did not consider that sexual orientation would have an impact on the diagnosis of endometriosis where fertility is a priority, as the treatment of endometriosis to improve fertility would be the same in people of any sexual orientation. The language in the new and amended recommendations was updated to be more inclusive of people who do not identify as women but who may have endometriosis.

3.4 Do the preliminary recommendations make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

No, the preliminary recommendations do not make it more difficult in practice for a specific group to access services compared with other groups.

3.5 Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

No, there is not the potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability.

3.6 Are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in box 3.4, or otherwise fulfil NICE's obligation to advance equality?

No barriers identified in box 3.4.

Completed by Developer: Hilary Eadon

Date: 28 February 2024

Approved by NICE quality assurance lead: Clifford Middleton

Date: 06 March 2024

4.0 Final guideline (to be completed by the Developer before GE consideration of final guideline)

- 4.1 Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed them?
- Age stakeholders questioned why post-menopausal women were excluded from the guideline. This decision had been made at the scoping stage of the original guideline in 2015, based on the fact that the treatment of endometriosis in post-menopausal women was expected to be covered in the menopause guideline. As this topic was not included in the menopause guideline this has now been identified as a gap in the endometriosis guideline and so this topic has been passed to surveillance for consideration when future updates are planned.
- Disability stakeholders commented that disabled people may face communication barriers when discussing treatment options for endometriosis. The committee noted this but were aware that the need to make reasonable adjustments for people with autism or learning disabilities is a statutory requirement under the Equality Act 2010 and so this is not stated in all individual NICE guidelines. Stakeholders also commented that the limited number of specialist endometriosis services meant that people may need to travel long distances to access specialist treatment and that this may be a particular problem for people with disabilities. The committee agreed that this could be an issue but were not aware of changes to the recommendations that they were able to make that would help address this.
- Race A stakeholder shared evidence suggesting that some people from certain
 ethnic groups are more likely to have their pain dismissed. The committee agreed
 this may be a concern and added a new recommendation (based on one that had
 been developed for the NICE guideline on Intrapartum care) to raise awareness
 of the need to take diversity issues into consideration when assessing pain
 symptoms.
- Geographical location: rural areas stakeholders commented that people living
 in rural areas would find it more difficult to access specialist endometriosis
 services, as these were normally based in large hospitals in urban areas. The
 committee agreed that this could be an issue but were not aware of changes to
 the recommendations that they were able to make that would help address this.

4.2 If the recommendations have changed after consultation, are there any recommendations that make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

None of the changes to the recommendations made after consultation have made it more difficult in practice for a specific group to access services compared with other groups.

4.3 If the recommendations have changed after consultation, is there potential for the recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

None of the changes to the recommendations made after consultation have an adverse impact on people with disabilities.

4.4 If the recommendations have changed after consultation, are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in question 4.2, or otherwise fulfil NICE's obligations to advance equality?

Barriers were not identified in 4.2.

4.5 Have the Committee's considerations of equality issues been described in the final guideline, and, if so, where?

The inclusion of the new recommendation on pain perception has been described in the rationale section of the guideline and the committee's discussion of the evidence in the evidence review. **Updated by Developer:** Hilary Eadon

Date: 20 June 2024

Approved by NICE quality assurance lead: Sara Buckner

Date: 22 October 2024