**NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE**

# NICE guidelines

## Equality impact assessment

# Ovarian cancer: identifying and managing familial and genetic risk

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)**

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| 1.1 Is the proposed primary focus of the guideline a population with a specific communication or engagement need, related to disability, age, or other equality consideration? N<br><br>If so, what is it and what action might be taken by NICE or the developer to meet this need? (For example, adjustments to committee processes, additional forms of consultation.) |
| The primary focus of the guideline is not on a population with a specific communication or engagement need. |

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| 1.2 Have any potential equality issues been identified during the check for an update or during development of the draft scope, and, if so, what are they? |
| • Age<br>  ○ Women who decide to have prophylactic surgery would not be fertile at a younger age and considerations need to be given to this group.<br>• Disability<br>  ○ Women with disabilities (physical and cognitive) generally have more difficulties having access to services and need support. |

- Gender reassignment
    - Trans people (in this case particularly trans men) and non-binary people may be disadvantaged in relation to access to services (including access to testing).
- Pregnancy and maternity
    - Fertility needs to be taken into account when prophylactic surgery is being considered.
- Race
    - Rate of familial breast and ovarian cancer is higher in Ashkenazi Jewish ethnicity which may lead to inequalities in testing.
- Religion or belief

None identified

- Sex
    - Men may face inequality in testing if they want to know whether their children may be at increased risk of ovarian cancer.
- Sexual orientation

None identified

- Socio-economic factors
    - For most cancer types, incidence rates in females and males in England are higher in the most deprived quintile compared with the least (2013-2017). There are some exceptions where incidence rates are higher in the least deprived quintile, including female breast, prostate, and melanoma skin cancers.
    - Cancer deaths in England are more common in people living in the most deprived areas.
    - There are inequalities relating to socioeconomic factors in access to genetic testing.
- Other definable characteristics (these are examples):
    - The guideline will look at geographical factors in access to genetic testing and access to fertility and menopause services.
    - People for whom English is not their first language or who have other communication needs.

| 1.3 What is the preliminary view on the extent to which these potential equality issues need addressing by the Committee? |
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| For groups where equality issues have been identified (box 1.2) the committee will consider whether data should be analysed separately and whether separate recommendations are required on a case-by-case basis to promote equality. |

Completed by Developer: Katharina Dworzynski

Date: 10th November 2021

Approved by NICE quality assurance lead: Simon Ellis

Date: 12th November 2021

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

| 2.1 Have any potential equality issues been identified during consultation, and, if so, what are they? |
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| • Inclusive language related to the trans community was raised. It was suggested that the term "female pelvic organs" would be better changed to "people who have ovaries/fallopian/uterus" for example to avoid gender-loaded language.<br>• It was also raised in the same that there ought to be consideration of personalised risk for the non-binary/trans community not only in terms of barriers to health care etc but potential differences in risk levels.<br>• A comment was made that there needs to be a more explicit acknowledgement of the dearth of research in relation to non-Caucasian populations and the limitation that this places on current risk-assessment |

| 2.2 Have any changes to the scope been made as a result of consultation to highlight potential equality issues? |
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In relation to the first point in box 2.1, the preamble to the guideline was rephrased from:

‘This scope uses the term 'women' throughout, but this should be taken to include those who do not identify as women but who have female pelvic organs.’

To:

‘This scope uses the term 'women' throughout, but this should be taken to include anyone born with some or all of the following organs: ovaries; fallopian tubes; and uterus.’

In response to the second bullet in box 2.1, no change was made because whether or not there are risk differences will be part of an evidence review rather than it being a fact that we could comment on before this matter has been reviewed.

Ethnicity has been added to the ‘Equality considerations’ section in the scope (in response to the issue raised in bullet point 3 in box 2.1). The GC will have the opportunity to make recommendations for further research in the guideline (which could be in non-Caucasian populations).

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| 2.3 Have any of the changes made led to a change in the primary focus of the guideline which would require consideration of a specific communication or engagement need, related to disability, age, or other equality consideration?<br><br>If so, what is it and what action might be taken by NICE or the developer to meet this need? (For example, adjustments to committee processes, additional forms of consultation) |
| No such changes have been made. |

Updated by Developer: Katharina Dworzynski

Date :3rd February 2022

Approved by NICE quality assurance lead: Simon Ellis

Date: 4th February 2022

**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? |
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| • Age<br><br>Whilst the committee recommended risk-reducing surgery (which the evidence showed to be the most effective and cost effective risk management strategy), they addressed issues related to age in the following ways:<br><br>o The committee recommended surgery only if the person has completed their family or wants to conceive naturally, depends also on the lifetime risk level and the timing which would be no earlier than the age that risk significantly increases (taking into account the particular pathogenic variant associated with an increased risk of ovarian cancer).<br><br>o They emphasised that people should receive information about reproductive choices and about risk-reducing surgery and the consequences of this.<br><br>o Psychological factors should be taken into account in the decision-making process and the available psychological support services should be discussed.<br><br>o Specialist menopause counselling should be offered before and after surgery.<br><br>• Disability<br><br>No evidence was identified in relation to this, but the committee addressed this by recommending that commissioners and service providers should ensure that there is training and information available for healthcare professionals on equality and inclusiveness issues that could improve access to ovarian cancer services, for example, for people who are from under-represented or underserved communities who may need more support to access services (for example, people who are physically disabled, people with neurodevelopmental conditions or a learning disability, people from Black, Asian and minority ethnic backgrounds and people who are LGBTQ+).<br><br>• Gender reassignment |

| 3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how? |
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| No evidence was identified for trans people. The following actions were taken:<br>o The wording of NICE guidelines has evolved to be more inclusive to trans and non-binary people. It is made clear throughout which recommendations apply to which apply to any of the following groups: women, men, trans people and non-binary people. This varies from section to section. Neutral language 'person' or 'people' is used wherever the context would make it clear enough who this would apply to.<br>o Further to this they also emphasised that there is training and information available for healthcare professionals to improve access for people who may not come forward for testing because they do not realise that they may be at risk of having a pathogenic variant associated with ovarian cancer (for example, men, trans women and non-binary people with male reproductive organs).<br>• Pregnancy and maternity<br>Peoples' reproductive choices and wish to complete their family are highlighted in several recommendations (in the context of risk-reducing surgery) so that people can make informed decisions about pregnancy and maternity.<br>• Race<br>An evidence review was conducted to assess the prevalence of pathogenic variants in different populations so it can be established where risks levels are high enough to offer genetic testing to the whole population. This would help more people to access genetic counselling and genetic testing. This would be offered to the Ashkenazi Jewish, the Sephardi Jewish and the Greenlandic population.<br>• Sex<br>The guideline aims to raise awareness that men, trans women and non-binary people with male reproductive organs may not come forward for testing because they do not realise that they may be at risk. The draft guideline also recommends to offer testing to men either as a family member of someone identified as having a pathogenic variant or if they are identified as reaching a threshold of risk of having a pathogenic variant even if they cannot develop ovarian cancer themselves. This will make more men, trans women and non-binary people with male reproductive organs |

| 3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how? |
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| eligible for testing.<br><br>• Socioeconomic factors<br><br>No evidence was identified for people from different socio-economic backgrounds or people specifically from deprived background. The draft guidance ensures that all people meeting a risk threshold are offered testing regardless of their socio-economic background. This will make genetic testing accessible to more people including those who may not be able to afford direct-to-consumer tests.<br><br>It also recommends that that services are easy to access (for example, by offering online appointments) and welcoming for everyone which it is hoped will increase uptake for people from all backgrounds.<br><br>• Other definable characteristics<br><br>o Geographical factors in access to genetic testing and access to fertility and menopause services: the committee drafted guidance related to organisation of services which would standardise services throughout England and Wales and should therefore improve access to genetic testing. They also made a specific recommendation that familial ovarian cancer multidisciplinary team should have established relationships with, and timely access to other specialist services including fertility and menopause services.<br><br>o People for whom English is not their first language or who have other communication needs: the guideline recommends that healthcare professionals ensure that information and support is relevant to the person's circumstances is tailored to the person's needs, for example, is in an accessible format or available in a different language. The guideline also mentions the need to improve access for people with neurodevelopmental conditions or a learning disability and these could include making adjustments to the language that is used and how information is communicated. The draft guideline also cross-refers to NICE's guideline on patient experience in adult NHS services, NICE's guideline on people's experience in adult social care services and NICE's guideline on shared decision making. These guidelines include numerous recommendations aimed to improve communication with the person and making adjustments to the language used (particular technical specialist language) or the need for an interpreter for someone who does not speak |

| 3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how? |
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| or understand English.<br><br>• Research recommendations<br><br>To encourage further research the research recommendations state that there is a particular research gap in people born with some or all of the following organs: ovaries; fallopian tubes; and uterus who do not identify as women. Or people with protected characteristics. |

| 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? |
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| • Sexual orientation: Whilst this was not identified during scoping the committee discussed that people who are LGBT+ can be 'under-represented or underserved communities' and recommended that there is training and information available for healthcare professionals on equality and inclusiveness issues that could improve access to services.<br><br>• Combination of age and sex in relation to thresholds for genetic testing: The economic model showed different threshold levels divided by age and sex. The committee were mindful that this could be perceived as making it more difficult for some groups of people to access genetic counselling and testing than others (see box 3.4 below). |

| 3.3 Have the Committee's considerations of equality issues been described in the guideline for consultation, and, if so, where? |
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| The committees discussions have been summarised in the rationale sections of the guideline with further details of discussions in the 'committee's discussion and interpretation of the evidence' sections of the relevant evidence reviews. |

| 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? |
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| The draft recommendations aim to provide more access to services rather than making it more difficult for certain groups. However, the committee were mindful that the risk thresholds that are divided by age and sex could be perceived as making it more difficult for specific groups to access services. The current risk threshold is 10% for all and this is still a level at which testing is recommended in the draft guideline. However, there are now lower thresholds than 10% recommended for women in the age range of 30 to 69 and men in the age range from 30 to 39. All of these have improved access to services compared to current practice. The committee decided that different thresholds have the most advantageous risk to benefit ratio because level of risk varies according to age and only women, trans men and non-binary people with female reproductive organs can develop ovarian cancer whereas everyone can pass pathogenic variants on to their children (for example risks of surgery are higher in people over 70 which justifies a higher risk threshold because it would provide a better balance between benefits and risks). Therefore, the committee were satisfied that rather than disadvantaging particular groups, it would improve equity of access to services and optimise the balance between different risk levels and potentially beneficial outcomes. |

| 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? |
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| No, the draft recommendations would improve services for people with disabilities. |

| 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? |
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| The committee's discussion around different thresholds by age and sex is summarised in the 'committee's discussion and interpretation of the evidence' section of evidence review F. |

Completed by Developer: Katharina Dworzynski

Date: 20 July 2023

Approved by NICE quality assurance lead: Simon Ellis

Date: 01 August 2023

**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?

**Disability**

- It was raised by 1 stakeholder that the guideline should refer to making reasonable adjustments.

Making reasonable adjustments as required by the Equality Act 2010 is a statutory requirement and so this requirement would not be repeated in each individual NICE guideline. Therefore, the stakeholder comment did not result in a change to the document.

- A stakeholder referred to the annual LeDeR report which relates to the lives and deaths of people with a learning disability.

The annual LeDeR report relates to the lives and deaths of people with a learning disability in general, including deaths related to cancer in female reproductive organs, but does not reflect situations where there is a person at risk of having a pathogenic variant. The report therefore does not specifically apply to this guideline and no change was made based on it.

**Gender reassignment**

- Inclusive language related to, for example reproductive organs
    - A stakeholder would have liked the wording 'gynaecological organs' rather than 'female reproductive organs'. Female reproductive organs is considered to be less 'medical' terminology than 'gynaecological' so is easier for lay people to understand. There is also no clear English equivalent of 'gynaecological' organs for male reproductive organs so the decision was to adopt 'female reproductive organs'. In accordance with NICE style and for consistency with other guidelines the wording 'female reproductive organs was retained. We have raised this stakeholder's concern with NICE style guide team for future consideration.
    - In one of the tables the column headings were entitled 'female' and 'male'. It was raised by a stakeholder that it is not clear whether this is by gender or sex. The committee have added all groups that this could apply to for each of the column headings, for example women, trans men and non-binary people registered female at birth.
    - It was queried whether the phrasing 'This recommendation is for women, trans men and non-binary people with some or all of the following female reproductive organs: ovaries, fallopian tubes and/or a uterus' means that the organs would need to be in situ (because people could have had them removed as part of gender affirming care). Based on this comment the

| 4.1 Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed them? |
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| committee reviewed the wording and revised it to ‘‘This recommendation is for women, trans men and non-binary people born with any female reproductive organs (ovaries, fallopian tubes, uterus)’. Other similar sentences were reworded accordingly.<br>○ The title of one of the evidence reviews was ‘evidence review I: carrier probability – women with ovarian cancer’ and it was queried whether this was due to the fact that only women were included in the research. This was changed to ‘evidence review I: carrier probability –people with ovarian cancer’ because the evidence review was looking for evidence related to anyone with ovarian cancer (only studies with women were identified).<br>• Risk-reducing surgery and surgery as part of gender affirming care<br>○ It was highlighted by a stakeholder that people may undertake surgeries that are risk reducing as part of their gender affirming care and asked for considerations related to this to be added to the guideline. This was discussed with the committee who agreed that people can consider having the surgery that is most suitable for them with respect to gender affirming care as long as that is the reason for undertaking the surgery. So, anyone who is high risk may have surgery at a younger age if that is appropriate and advised by the specialist for gender affirming care. That is the context for having the procedure at that time point and that stands independent of risk reduction. The rationale for earlier surgery cannot be risk reduction as the risk is not high enough to reduce at that time point. So that cannot be the justification. An explanation was added to the ‘benefits and harms' section of evidence review N to clarify that this would therefore be outside the scope of this guideline.<br>• Acceptability of management options, endometrial biopsy and HRT<br>○ It was noted by a stakeholder that an endometrial biopsy may not be acceptable to those who experience gender dysphoria and that standard HRT is also unlikely to be acceptable to trans men and non-binary people. Having an endometrial biopsy and being offered HRT is in the person’s best interest because of the potential serious adverse consequences (such as not identifying asymptomatic cancer or cardiovascular protection).<br>• Research recommendation<br>○ It was suggested that the impact of familial ovarian cancer on trans men and non-binary people, and the experience of this population within genetics services be included as a topic further research. However, there was no evidence review conducted on the topic of ‘impact of familial ovarian cancer and experience of services’ and therefore the committee |

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| 4.1 Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed them? |
| could not add a research recommendation to the guideline.<br><br>**Other definable characteristics**<br><br>**Communication and comprehension difficulties**<br>It was raised by a stakeholder that a reference to the importance of communication should be made. The committee agree that people need to be communicated with in an appropriate way and given information in an appropriate format. Further detail on communication and treating people as individuals is covered in other NICE guidelines (with a cross reference to then in recommendation 1.2.1) so this information is not repeated in all other NICE guidelines.<br><br>**Geographical inequalities**<br>Several stakeholders commented that there are geographical inequalities in access to services. The guideline aims to improve access to services for all and in all areas. There are challenges that services face, particularly where recommendations change current practice and NICE is producing an implementation plan to support improving access to the recommended services acknowledging that this will be a gradual process.<br><br>**Breast cancer thresholds for genetic testing**<br>It was raised that the thresholds for genetic testing that are recommended in this guideline mean that people with breast cancer would have to meet a much higher threshold for testing and in this way would create inequalities. Updating the model of the breast cancer guideline is outside the scope of this guideline, but the topic was highlighted within NICE as a potential issue for the breast cancer guideline update that is currently underway. |

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| 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? |
| No, the draft recommendations would improve access to services. |

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| 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 |

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| of something that is a consequence of the disability? |
| No, the draft recommendations would improve services for people with disabilities. |

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| 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? |
| There was nothing identified in question 4.2 so this question is not applicable. |

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| 4.5 Have the Committee's considerations of equality issues been described in the final guideline, and, if so, where? |
| In relation to changes made to the guideline based on stakeholder comments, considerations related to gender affirming surgery have been captured in 'the committee's discussions and interpretation of the evidence section' of evidence review N.<br><br>Some changes to wording were made for reasons of inclusive language. This does not require a rationale in another section of the guideline because it clarifies the groups that the sections applied to more clearly and inclusively.<br><br>Challenges to services had already been discussed in impact sections of the guideline before consultation. These were reviewed and wherever necessary strengthened to address the issue of geographical inequalities in access to services. |

Updated by Developer: Katharina Dworzynski

Date: 12 December 2023

Approved by NICE quality assurance lead: Nick O'Callaghan-Staples

Date: 06 February 2024