

National Institute for Health and Care Excellence
Familial Ovarian Cancer
Stakeholder Scoping Workshop
Tuesday 26 October 2021

Presentations
<p>The group were welcomed to the meeting and informed about the purpose of the day. The Stakeholder Scoping Workshop is an opportunity for stakeholders to review the early draft scope and give their input into whether it is appropriate.</p> <p>The group received presentations about NICE's work, the guideline development process and the role of the guideline committee. The Topic advisor of the committee also presented the key elements of the draft scope and the Chair of the committee presented some general points for discussion.</p> <p>Following questions, the stakeholder representatives had a structured discussion around the key issues.</p> <p>After the introductory presentations, the following issues were noted:</p> <ul style="list-style-type: none">• A stakeholder raised the issue of terminology around familial versus hereditary ovarian cancer. It was suggested that this could feature in the facilitated group discussions.
Scope
General comments
<ul style="list-style-type: none">• The general impression of the scope was positive and the stakeholders thought that it covered the key areas which require guidance. They made specific comments and suggestions for potential changes in the specific sections below.
Section 2 Equality considerations
<p>The topic of equality considerations was discussed and suggestions were made. The following process could be considered to promote equality:</p> <ul style="list-style-type: none">• It was raised that there are inequalities in access to menopause and fertility services.• Where trans people were already mentioned it was suggested that non-binary people should be added since there may also be inequalities in access to services.• It was raised that men may also want access to be tested to know whether they could pass risk on to their children.
Section 3.1 Setting

There was agreement that the suggested settings in the scope were correct.

Section 3.2 Who is the focus

The following issues related to the population ('Groups that will be covered') of the guideline were highlighted:

- Some groups suggested that Lynch Syndrome was singled out in some of the bullet points.
- There was a discussion about a number of populations with a potentially higher likelihood of developing familial ovarian cancer and whether the Ashkenazi Jewish population should be specifically mentioned in the scope.

The following issues related to the population ('Groups that will not be covered') of the guideline were highlighted:

- Some stakeholders did not agree with the groups listed in this section. It was discussed that rarely, sex cord stromal tumours could arise as a result of Peutz-Jeghers syndrome.
- It was also suggested that some germ cell tumours and low grade serous ovarian cancer, even though rare, should not be excluded.

Section 3.3 Key areas that will be covered

The Stakeholders agreed that the key areas covered some of the important topics that the guideline would need to cover (for more detail see notes related to draft questions in section 3.5 below).

Section 3.3 Areas that will not be covered

Stakeholders agreed that this section was correct.

Section 3.4 Economic aspects

Stakeholders suggested that risk reducing surgery, issues related to pre-menopause, risk thresholds for genetic testing and surveillance would be economic priorities when the guideline is being developed.

Section 3.5 Key issues and draft questions

Stakeholders agreed that the questions addressed the key issues and focused on areas where the guideline could make a positive impact, but they made some general additional comments and suggestions related to:

- Individual and family support: Questions were raised whether specialist genetic counselling would be included and if so there needed to be a distinction between genetic counselling and the role of the genetic counsellor. It was also stated that it was important to distinguish women with familial ovarian cancer from women at increased risk of ovarian cancer because their information and support needs would differ.
- Risk prediction or assessment methods for familial ovarian cancer: Stakeholders suggested/highlighted the following:
 - Giving information to people about risk is important – there are challenges in making information about risk accessible and the way that such information is presented clearly and understandably will need to be considered.
 - It was also raised that the identification of risk in community settings can be difficult. It is often not clearly known whether there is a family history that could be relevant for ovarian cancer risk. So community healthcare professionals may miss people who may be eligible for testing. It was queried whether more could be done to proactively seek out people who ought to be offered a test.
- Risk thresholds for genetic testing: Stakeholders commented that care should be taken when considering the overlap with other guidance, such as familial breast cancer. It was highlighted that breast cancer without ovarian cancer is covered in the familial breast cancer guideline and a cross reference to this is needed since some of the same genes that increase risks for breast cancer would also increase the risk of ovarian cancer. It was also mentioned that risk factors other than genetic risks should be considered.
- Genetic testing for familial ovarian cancer: Stakeholders outlined that they thought that polygenic risk score or polygenic gene testing was not specifically referred to. Stakeholders also suggested that the guideline would need input of clinical geneticists for this section.
- Familial ovarian cancer surveillance: Stakeholders suggested that it was important to ask end-users what they would consider to be the important outcome of surveillance, so that it is not only restricted to the outcome of cancer specific survival.
- Primary preventative medication: It was outlined that it was key to have safety of medications in this section. A stakeholder suggested to include lifestyle advice to reduce the risk of ovarian cancer, for example diet but it was noted by others that this is already covered in existing guidance.
- Risk reducing surgery: Stakeholders agreed that this is a key issue and the questions are very important. It was outlined that it is important to state within this section who should and should not have certain surgeries, at what age and to what extent.

Other comments

- Stakeholders also outlined that fertility should be included as a separate topic.

- Stakeholders also agreed that the terminology around ‘familial’ is difficult. Some options were suggested such as ‘increased risk’, ‘hereditary’ or ‘increased genetic risk’ but none were unanimously settled on.

Section 3.6 Main outcomes

Overall, the stakeholders were satisfied with the outcomes suggested. In addition to those stated, it was suggested that the psychological impact should also be specifically considered as an important outcome.

Guideline committee composition

Stakeholders made the following suggestions for the proposed members of the committee:

- 3 clinical geneticists
- 2 GPs
- Split consultant gynaecologists with an interest in fertility and menopause into 2 separate roles
- Whether the clinical nurse specialist should be an oncologist specialist nurse
- Histopathologist to be a core member not co-opted
- 1 breast specialist and 1 bowel specialist to be added as co-opted members
- 3 x lay members
- It was suggested that the committee should not be mainly London based but should also include representation from people from centres in areas that may be less well resourced.