**National Institute for Health and Care Excellence**

**Quality Standards Advisory Committee meeting**

**Date:** Thursday 17 October 2024

**Hybrid meeting**

**Venue:** NICE Manchester office, in the Bollin and via Zoom

**Topic:** Ovarian cancer update - review of stakeholder feedback

**Minutes:** FINAL

**Quoracy:** The meeting was quorate.

**Attendees**

**Quality Standards Advisory Committee**

Rebecca Payne [Chair], Anica Alvarez Nishio [Vice-chair], Mark Temple, Louis Savage [LS], Steve Hajioff [SH], Ruth Studley [RS], Kashif Siddiqui, Umesh Chauhan, Kultar Singh Garcha [Virtual], Keith Lowe

**Specialist committee members:**

Rebecca Bowen [Virtual], Tracie Miles [Virtual], Susan Freeman [Virtual], Lucy Side [Virtual], Pubudu N J Pathiraja [Virtual], Fiona Robb [Virtual]

**NICE staff:**

Mark Minchin, Christine Harris, Rachel Gick [RG], Nicola Greenway, Christina Barnes [Minutes], Adam Storrow [Virtual]

**NICE observers:**

None.

**Apologies**

Standing committee members: Dominika Froehlich-Jeziorek, Nadim Fazlani, Murugesan Raja, Devina Maru, Esabel Chabata, Shorai Dzirambe, Peter Hoskin, Mariana Gaspar Fonseca, Jane Dalton, Tim Cooper, Saran Evans

Specialist committee member apologies: Ranjit Manchanda, Jan Van Der Meulen

1. **Welcome, introductions objectives of the meeting**

The chair welcomed the attendees and public observers, and the quality standards advisory committee (QSAC) members introduced themselves. The chair informed the committee of the apologies and outlined the objectives of the meeting, which was to review stakeholder feedback on the draft quality standard.

RS asked for her job title to be updated on the agenda to the Director of Population Transformation at the Office of National Statistics.

1. **Confirmation of matter under discussion and declarations of interest**

The chair confirmed that, for the purpose of managing conflicts of interest, the matter under discussion was ovarian cancer update: specifically,

* Discussion about risk-reducing surgery
* CA125 blood test – age specific thresholds – placeholder statement
* Panel germline genetic testing for high-grade epithelial ovarian cancer
* Tumour testing for stage 3 or 4 high-grade epithelial ovarian cancer
* Treatment of high-risk stage 1 or stage 2 to 4 (inclusive) ovarian cancer.

The chair asked standing QSAC members and specialist committee members to declare any interests additional to those that were already circulated or any interests specifically related to the matters under discussion.

* SH highlighted that he was the chair for NG12 suspected cancer guideline, which is included as source guidance for this quality standard.
* LS declared that he is co-authoring the British Geriatrics Society (BGS) Position Statement of Assisted Dying/Physician-Assisted Suicide.  He declared he is a peer-reviewer for BMJ Case Reports Journal.
1. **Minutes from the last meeting**

The committee reviewed the minutes of the last QSAC 2 meeting held on 10 September 2024 and confirmed them as an accurate record.

1. **Recap of prioritisation meeting and discussion of stakeholder feedback**

RG provided a recap of the areas for quality improvement prioritised at the first QSAC meeting for potential inclusion in the ovarian cancer update draft quality standard. This included:

* Recognition and diagnosis (excl. familial and genetic risk)
* Safety netting & referral onto non-specific symptoms pathways
* Identifying and managing familial & genetic risk
* Treatment planning & management
* Information and support

RG summarised the significant themes from the stakeholder comments received on the ovarian cancer update draft quality standard and referred the committee to the full set of stakeholder comments provided in the papers.

**General**

* General support of the QS and agreement with the areas of the quality statements
* Suggestion to reference the International Federation of Gynaecology and Obstetrics FIGO) system and use inclusive language in the statements
* Concerns were raised that the initial resource and service development to standardise measurement to support data collection, overall resource impact, and concern that statements on genetic testing may not apply in Wales.

**Equality and health Inequalities**

The committee discussed the NICE approach for addressing health inequalities for those with learning disabilities, neurodiversity, or both, and the strategies for supporting these population groups. The committee discussed wider systemic issues around the impact of socioeconomic status and deprivation on outcomes. It was suggested that more general equality issues could be captured and considered as part of the more general patient experience quality standard as this would allow quality standards on specific topics to focus only on topic-specific areas.

The committee discussed the BGCS comment around using gender-inclusive language and noted the importance of both including women and not excluding trans men. The committee suggested using the term women and people with ovaries. A specialist committee member noted the emotive aspects of language for women who may have had ovaries removed. The NICE team agreed to check the current NICE style guide around gender neutral language with the editors.

**ACTION**

* **NICE team to check the use of language with the NICE editors**
* **NICE team to look into whether statements on genetic testing would apply in Wales.**

**Discussion and agreement of amendments required to quality statements**

### **Draft statement 1: Adults with a total lifetime risk of 5% or more of developing ovarian cancer have a discussion about risk-reducing surgery. [new 2025]**

The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard, with the following amendments and issues to be explored by the NICE team:

The committee discussed measurability of this statement at length, including whether it is possible to identify the denominator population and whether this information is recorded.

Committee members highlighted that not all hospitals collect data in the same way and recognised this could represent an additional burden to services. It was noted that data would be collected in clinics and could be found if it is looked for appropriately, but there is no dedicated resource for this.

The committee discussed the statement’s population. The NICE team highlighted that the intention of the statement is not identification of those meeting the risk threshold but instead focuses on those people already known to services who have a 5% or more lifetime risk. The committee felt it would be more straightforward to identify those with a genetic variant as a subset, as those with markers are consistently coded; however, there is inconsistency in coding risk due to family history. The committee noted the difficulty in collecting data on the whole population and suggested that the statement could focus on genetic testing. The committee however were not aware whether genetic diagnoses are consistently recorded, but established they are often not recorded in a patient’s electronic medical record.

The committee noted there are SNOMED codes for BRCA genes associated with other forms of cancer. An issue around standardising coding in general practice was noted; the committee suggested that the code would need to be sent in the discharge letter. Currently the committee agreed this statement would be difficult to measure, however members highlighted ongoing work in this area that would support the measurability of the statement. They felt including this statement in the quality standard could support and guide work in this work.

The committee discussed where the responsibility lies for implementing this quality standard. It was agreed that primary care is not responsible; the relevant services are secondary and tertiary care.

The NICE team suggested an additional measure, or information in the audience descriptors, could be explored in relation to coding genetic risk through national data collection. The focus of the statement should remain - risk-reducing surgery. The statement should also cross-reference NICE NG241 to explain how lifetime risk is calculated.

The committee concluded it would be difficult to include ages in the statement because risk varies by age and increases over time.

**ACTION**

* **NICE team to keep statement as worded.**
* **NICE team to explore adding an additional measure or information in audience descriptors on how to use the existing measure to support coding.**
* **NICE team to cross-reference NICE guideline NG241 on how to calculate risk.**
* **NICE team to ensure ‘variant’ is used rather than ‘mutations’.**
* **SCMs to check examples of services in the audience descriptors to clarify that the statement is relevant to genetic and specialist gynaecological services, and not to primary care.**

### **Draft statement 2: Placeholder statement on CA125 blood test – age specific thresholds: a recent** [**review of recommendations on the recognition of suspected ovarian cancer in NICE’s guideline on suspected cancer: recognition and referral**](https://www.nice.org.uk/guidance/ng12/resources/2024-exceptional-surveillance-of-suspected-cancer-recognition-and-referral-nice-guideline-ng12-13431994093/chapter/Surveillance-proposal?tab=evidence) **has identified that recommendations on thresholds for referral following CA125 testing should be updated. This placeholder statement will be reviewed following publication of the updated NICE guideline recommendations.**

The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard. It was agreed that the wording of placeholder statement should remain unchanged.

**ACTION**

* **Progress placeholder statement with no changes to the wording**

### **Draft statement 3: Adults with a new diagnosis of high-grade epithelial ovarian cancer have panel germline testing. [new 2025]**

The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard.

RG advised the committee that the comments raised by stakeholders for statement 3 may also apply to statement 4.

Stakeholders generally supported the statement. They also highlighted targeted outreach and education programmes, to help increase uptake of genetic testing among adults from ethnic minority backgrounds, as an equity and health inequalities issue.

The committee discussed stakeholder comments that the statement doesn’t align with the NHS England genomic test directory, noting that mucinous ovarian cancer, a form of high-grade epithelial ovarian cancer, is not included within the directory for ovarian cancer, and is unlikely to be so. The committee noted the stakeholder comments and agreed to amend the statement wording to remove the mucinous subtype.

Stakeholders expressed concern about using existing mechanisms for data collection, including collecting data on ethnicity. The committee discussed collecting ethnicity data and stated that it is not well or consistently coded across the NHS. However, a committee member also highlighted that ethnicity data is routinely recorded within genomics data. The committee noted that identifying unwarranted variation is important, and recognised that quality standards can help address variation.

A standing committee member asked for clarity about the different between the purpose of the testing in statements 3 and 4 and if there was evidence of differences in uptake by ethnicity. A specialist committee member outlined the genetic testing and treatment pathway, including why a blood test is carried out for germline testing. The latter would be more important to family members. They also outlined the DEMO project which looked at whether genetic testing was offered, and that people from ethnic minority backgrounds are less likely to take up the offer (consent being required for ovarian cancer). It was also noted that resources to explain testing, including information in different formats, and translated materials, had been produced as part of this project. It was also noted that tests differed between centres, and that for panel germline testing the DEMO project had showed viability in uptake by ethnicity.

A committee member highlighted that the National Disease Registration Service (NDRS) dataset will include ethnicity data and be compatible with data in the cancer registry dataset so it will be possible to get detailed data. The committee therefore agreed it was important to retain reference to the measures being broken down by ethnicity.

The committee discussed the importance of testing to guide treatment. It was noted this is more important in cases of advanced ovarian cancer. At earlier stages it can affect a person’s risk of developing other cancers; it was agreed that germline testing is not always relevant to treatment. It is useful for risk-reducing surgery and in this sense can affect later treatment. The committee heard that tumor testing alone can miss a variant that germline testing would pick up. The committee noted that maintenance treatment in advanced ovarian cancer is restricted and genetic variants need to be known so that the appropriate treatment can be decided upon. The rationale for these tests is therefore important. Specialist committee members agreed to review rationale section of statements 3 and 4 when the draft quality standard is circulated for comment.

A committee member asked, given that consent is needed for this testing, whether this should be an ‘offer’ statement. A specialist committee member also highlighted that data will be collected on the ‘offer’ via ‘mainstream’ genetic testing in gynaecology services, so the data can be collected.

**ACTION**

* **Progress statement**
* **NICE team to retain reference to breaking down take-up data by ethnicity.**
* **NICE team to outline why the 2 tests are important and SCMs to review the rationale of statements 3 and 4 to ensure the focus is correct.**
* **NICE team to remove the definition of high-grade epithelial ovarian cancer**
* **NICE team to amend statement wording to align with the test directory, to refer to ‘non-mucinous high-grade epithelial ovarian cancer’.**
* **NICE team to change statement wording to ‘offer’, and measure both offer and receipt.**

### **Draft statement 4: Adults with a new diagnosis of stage 3 or 4 high-grade epithelial ovarian cancer have tumour testing. [new 2025]**

The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard.

The committee noted the importance of this statement as patients should be offered a biopsy as part of the diagnostic process.

**ACTION**

* **NICE team to align with statement 3 and exclude non-mucinous and refer to ‘offer’**
* **NICE team to retain reference to breaking down take-up data by ethnicity.**

### **Draft statement 5: Adults who have high-risk stage 1 ovarian cancer, or stage 2 to 4 inclusive ovarian cancer, have both surgery and chemotherapy. [new 2025]**

The committee agreed that as there was some support for the statement from stakeholders, although some concerns were raised.

The committee discussed the potential for exclusions from the numerator and denominator such as patients who decline or who are not fit for this treatment modality, so that centres aren’t ‘penalised’ for patients who don’t want this form of treatment or where it is not appropriate. Specialist members highlighted that having surgery and chemotherapy is generally optimal in terms of outcomes.

The committee discussed whether the statement could focus on a specific population. The committee felt however that the key question is who shouldn’t have surgery and chemotherapy; there is dependency on the timing of presentation, who they see and where they are seen.

The committee discussed the importance of the multidisciplinary team (MDT)’s discussion of possible treatment options. It was highlighted that chemotherapy can be used both for treatment and palliative care. Decisions around surgery are more complicated and there may be valid reasons why it is not offered.

The committee considered alternative wording for the statement: ‘adults who have high-risk stage 1 or stages 2 to 4 ovarian cancer are discussed in a gynecology MDT and are considered for both surgery and chemotherapy’. A specialist committee member highlighted that it was important that the MDT included the relevant healthcare professionals to support discussion.

It was queried whether the concepts were linked closely enough to support the amended approach. The committee noted that although having the MDT discussion could be measured it did not address whether the relevant/appropriate topics were discussed. The NICE team suggested the focus of the statement could be changed to focus on the MDT discussion and outcomes added, on receipt of surgery, chemotherapy or both. The committee agreed that this approach would be useful for supporting the change of focus.

**ACTION**

* **NICE team to amend statement wording to change the focus of the statement to MDT discussion**
* **NICE team to add outcome measures on receipt of surgery, chemotherapy, and surgery and chemotherapy.**
1. **Additional quality improvement areas suggested by stakeholders at consultation**

The following areas were not progressed for inclusion in the final quality standard as the committee agreed that they were not a priority in relation to the five quality improvement areas already included:

Access to holistic services

Imaging

Additional guidance/updated recommendations/research

People’s experience

Prerehabilitation

1. **Resource impact**

The committee considered the resource impact of the quality standard.

1. **Equality and Diversity**

RG provided an outline of the quality and diversity considerations included so far and requested that the committee submit suggestions when the quality standard is sent to them for review, reiterating that the areas must be specific to the quality standard topic.

1. **Any other business**
* **Next steps**

RG confirmed that the draft quality standard and EHIA will be sent to committee members for review on 4 November 2024 until 11 November 2024. The quality standard is expected to publish in February 2025.

The chair gave a huge thank you to all the standing committee members and specialist committee members for their attendance and valuable input into the meeting discussions.

* **Next QSAC meeting**

Thursday 28 November 2024 – Cardiovascular risk assessment and lipid modification

**Close of meeting**