NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE Centre for Guidelines

Equality and health inequalities assessment (EHIA)

Ovarian cancer (update)

The considerations and potential impact on equality and health inequalities have been considered throughout the quality standard development, process according to the principles of the NICE equality policy and those outlined in Quality Standards process guide.

STAGE 1. Topic engagement

Date of completion: 28/11/2023

1.1 What approaches have been used to identify potential equality and health inequalities issues during development of the topic engagement proforma?
Reviewed the EIA for NICE's quality standard on ovarian cancer, QS18 (2012). Reviewed the EIAs for the source guidelines: ovarian cancer: recognition and initial management. NICE guideline CG122 (2011, last updated 2023) and ovarian cancer: genetic and familial risk. NICE guideline in development (publication expected March 2024). Reviewed 4-year surveillance review consultation proposal (2015) and surveillance report - exceptional review (2017) for CG122. Reviewed EIAs for a selection of health technology guidance since publication of CG122, that are within the proposed scope of the quality standard. Reviewed reports from the Ovarian Cancer Audit Feasibility Pilot (England, jointly funded by the British Gynaecological Cancer Society, Target Ovarian Cancer and Ovarian Cancer Action). Reviewed results of the scoping search provided by a NICE information specialist.

1.2 What potential equality and health inequalities issues have been identified during development of the topic engagement proforma?
Gender-neutral language • Language around gender used in non-NICE sources is retained below. • Otherwise, as per the draft NICE: genetic and familial risk guideline, 'people' refers to: Women, trans men, non-binary people with some or all of female reproductive organs: ovaries, fallopian tubes and/or a uterus unless specified otherwise. *1. Protected characteristics outlined in the Equality Act 2010* Age: There is variation in treatment options offered to older age groups (ovarian cancer audit feasibility pilot, fifth report (2019)): - Women aged over 79 years at diagnosis were the least likely to receive any treatment, with 58.0% (n=618) receiving neither chemotherapy nor surgery.

- Use of chemotherapy without surgery increased with age: 21.9% (n=233) in patients aged over 79 compared to 6.2% (n=10) in patients aged under 30.

- The likelihood of older age cohorts receiving surgery was lower after accounting for stage and morphology. Other factors may include comorbidities not captured by the comorbidity index used. It was also noted that research is needed to clarify the reasons for diagnoses in older age groups having a lower probability of surgery.

Gender reassignment and sexual orientation: There is evidence that trans and non-binary communities face healthcare discrimination (Ovacome accessed 4/12/23)

Race: A number of populations have a higher risk of having a founder pathogenic variant associated with familial ovarian cancer, of which healthcare professionals need to be aware so that they can identify people who should be referred for genetic testing and counselling, regardless of the geographical location of the service:

- Ashkenazi Jewish people (1 in 40 compared to 1 in 250 in the UK general population) and Sephardi Jewish people (1 in 140 compared to 1 in 250 in the UK general population (NHS Jewish BRCA testing programme).

- Greater London accounts for 53.6% of the total Jewish population of England and Wales, with 145,466 of the Jewish population living in the capital (The Institute for Jewish Policy Research (2022)).

Sex: Men, trans women and non-binary people with male reproductive organs may not come forward for genetic testing because they do not realise that they can carry a pathogenic variant associated with ovarian cancer putting them at risk of developing other cancers.

Religion or belief: no issues identified.

2) *Socioeconomic status and deprivation (for example, variation by area deprivation such as Index of Multiple Deprivation, National Statistics Socio-economic Classification, employment status, income)*

Deprivation: Deprivation is associated with increased mortality. Adjusted mortality rates show that mortality risk increased with a more deprived deprivation quintile. Patients within the most deprived quintile had a 50% higher risk of mortality within 2 months from diagnosis and 40% higher risk of mortality within 2 to 6 months from diagnosis when compared to patients in the least deprived quintile. (ovarian cancer audit feasibility pilot, third report (2022)).

3) *Geographical area variation (for example, geographical differences in epidemiology or service provision- urban/rural, coastal, north/south)*

Regional variation between sub-ICB or cancer alliance geographies has been identified in the following areas:

- Incidence rates vary across both sub-ICB and cancer alliance: this may relate to clusters of ethnicities with higher genetic predisposition factors such as BRCA gene mutations.
- Mortality rates: age standardised mortality rates vary by sub-ICB from 8.7 to 18.3 per 100,000 person-years.
- Survival rates: One-year net survival for the 21 Cancer Alliances varied between 60.9% and 75.8%, five year net survival varied between 27.8% and 47.5 Poor one-year survival associated with diagnosis at late stage whereas five-year survival is more likely to reflect the quality of treatment.
- Variation in the stage of diagnosis at sub-ICB level. The proportion of tumours diagnosed at stage 1 ranged from 16.1% to 38.4% across the 106 sub-ICBs.

Treatment options, in particular, surgical resection rates across cancer alliances.

(ovarian cancer audit feasibility pilot, fifth report).

Variation in access to genetic, fertility and menopause services due to geographical factors (EIA3).

4) *Inclusion health and vulnerable groups (for example, vulnerable migrants, people experiencing homelessness, people in contact with the criminal justice system, sex workers, Gypsy, Roma and Traveller communities, young people leaving care and victims of trafficking).* None identified.

1.3 How can the identified equality and health inequalities issues be further explored and considered at this stage of the development process?

Data on variation by deprivation and geographical area will be highlighted in the introduction and current practice section of the committee briefing paper (if relevant quality improvement area is suggested at topic engagement) for discussion at the Quality Standard Advisory Committee (QSAC) when prioritising key areas for quality improvement. A representative from the National Audit for Ovarian Cancer has also been invited to the meeting to provide further insight about the inequalities data.

The following areas could be addressed by potential quality statements and/or the equality and diversity section, if prioritised for development:

- Age: Inequalities on age will need to be explored further with committee members and considered if a statement on treatment options is prioritised.

- Gender reassignment and sexual orientation: the guideline includes draft recommendations on training and information available for healthcare professionals on equality and inclusiveness issues that could be considered for relevant statements.

- Sex: The guideline includes draft recommendations on training and information on inclusiveness issues and raising awareness that men and people with male reproductive organs can have a genetic risk of a pathogenic variant associated with ovarian cancer and other cancers. This could be considered if a statement on genetic testing was prioritised.

- Race: The guideline includes a draft recommendation on at risk-populations for genetic counselling and testing including populations with a higher risk of having a founder pathogenic variant associated with familial ovarian cancer. This could be considered if a statement on genetic testing was prioritised.

Further consideration of these, and any additional equality and health inequality issues raised during development of the quality standard, will take place following topic engagement with stakeholders, at the QSAC and throughout development of the quality standard.

1.4 Do you have representation from stakeholder groups that can help to explore equality and health inequalities issues during the topic engagement process including groups who are known to be affected by these issues? If not, what plans are in place to address gaps in the stakeholder list?
The stakeholder list includes key patient groups identified within the QS team and in discussion with the Public Involvement Programme (PIP). 4 key patient stakeholder organisations were identified: Target Ovarian Cancer, Ovarian Cancer Action, Eve Appeal and Ovacome. A lay member with lived experience has been appointed as a specialist committee member.

1.5 How will the views and experiences of those affected by equality and health inequalities issues be meaningfully included in the quality standard development process going forward?
We will provide additional detail in the briefing paper where these issues relate to stakeholder suggestions or should be considered in their own right. A representative from the National Audit for Ovarian Cancer has been recruited as a topic expert, to join the QSAC, to provide expertise on data collection and measurement. We expect this would include expertise on data relating to inequalities raised in the reports for the ovarian cancer feasibility audit. A lay member with lived experience will input into the QS throughout development. We will work with key patient stakeholders, and actively chase these organisations for a response if needed, to ensure their views are also presented to the committee.

1.6 Has it been proposed to exclude any population groups from coverage by the quality standard? If yes, could these exclusions further impact on people affected by any equality and health inequalities issues identified?
It is anticipated that the quality standard for ovarian cancer will not cover the care of children and young people (younger than 18 years). This is because ovarian cancer incidence is strongly related to age, with the highest incidence rates being in older people (Cancer Research UK (2021) ovarian cancer, statistics on incidence by age). There is a published quality standard on the care of children and young people with cancer (QS55). Risk management and decision-making support for people with male reproductive organs who have, or are at risk of having, a pathogenic variant associated with ovarian cancer is not included in the guideline. This is because they are not at risk of developing ovarian cancer, and the decisions that they would have to make are different.

Completed by lead analyst: Rachel Gick
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Approved by NICE quality assurance lead: Mark Minchin
Date: 04/12/2023

STAGE 2. Consultation

Date of completion: 05/08/2024

2.1 How inclusive was the topic engagement process in terms of response from stakeholders who may experience inequalities related to the topic (identified in 1.2)?
16 stakeholders (including specialist committee members, 1 of whom was a lay member with lived experience) responded to topic engagement. 3 ovarian cancer charities responded. 10 stakeholders raised health inequality issues which were specific to the topic or where applicable to other conditions, referenced data on ovarian cancer. The PIP topic advisor had no comments at this stage.

2.2 From the topic engagement exercise and the committee of considerations thereof, what were the main equality and health inequalities issues identified?
1) Protected characteristics outlined in the Equality Act 2010 Age: The impact of age on treatment was highlighted by multiple stakeholders. Findings from the ovarian cancer audit feasibility pilot, fifth report (2023) around variation in treatment among age groups were noted: adults aged over 79 were the least likely of all age groups (15 to 99) to receive neither surgery or chemotherapy (58% of this age group received no treatment). They were also, compared to younger age groups, the least likely to receive any surgery (9.6% of this age group). Adults aged over 69 were the most likely of all age groups to be treated by chemotherapy alone. This variation may be explained by a range of factors such as patient choice and comorbidities not captured by the index used. Stakeholders also commented on the potential impact of comorbidities (greater prevalence in older age groups) on outcomes, specifically, morbidity and 1-year survival. The briefing paper also explored the impact of comorbidity (see section 1.2), noting that comorbidity at diagnosis was associated with an increased likelihood of not receiving any treatment (ovarian cancer audit feasibility pilot, fifth report (2023)). Ovarian Cancer Action highlighted the Equality spotlight report: Age (IMPROVE policy report) which noted that older age is associated with delayed access to tests requiring referral from primary care and diagnosis through emergency routes. Stakeholders suggested that CA125 thresholds should reflect that a CA125 above 35 UI/ml (the threshold for referral for an ultrasound) has a significantly higher predictive value in women aged over 50 (15.2%) compared to women aged under 50 (3.4%).

Disability / Gender reassignment / Religion and belief / Sex / Sexual orientation: None identified by stakeholders or committee.

Pregnancy and maternity: No issues raised by stakeholders or committee. However, EIA3, for NG241 noted that fertility needs to be taken into account when prophylactic (risk-reducing) surgery is being considered and that reproductive choices and wish to complete their family are highlighted in recommendations around risk-reducing surgery, so that adults can make informed decisions about surgery.

Race: The following issues were raised by stakeholders:

- A stakeholder highlighted the findings of Demonstration of Improvement for Molecular Ovarian Cancer Testing (DEMO) which suggested that rates of genetic testing may be lower among adults from non-White ethnic backgrounds. Findings noted a trend towards lower take-up of germline genetic testing among adults from a Black ethnic background, based on findings from a study conducted in Birmingham.

- A stakeholder supported identification, at the topic engagement stage, of the increased risk of pathogenic variants within Ashkenazi and Sephardic Jewish populations (section 1.2).

2) Socioeconomic status and deprivation (for example, variation by area deprivation such as Index of Multiple Deprivation, National Statistics Socio-economic Classification, employment status, income)

A stakeholder supported impact of deprivation on outcomes being identified at topic engagement (section 1.2).

3) Geographical area variation (for example, geographical differences in epidemiology or service provision- urban/rural, coastal, north/south)

Multiple stakeholders highlighted variation in service delivery across the care pathway; a number of these issues had been noted in EHIA section 1.2. Unless stated otherwise the source of data is the ovarian cancer audit feasibility pilot.

Recognition & diagnosis:

- Variation in incidence of ovarian cancer, at sub-integrated care board (ICB) and cancer alliance levels.

- Variation in the proportion of cases diagnosed at stage 1 at sub-ICB level (ranged from 16.1% to 38.4%). Conversely, variation in 1-year net survival across cancer alliances (between 60.9% and 75.8%); poor 1-year survival was associated with late-stage diagnosis.

- Regional variation in:
    - CA125 testing and ultrasounds; stakeholders noted that simultaneous CA125 testing and ultrasound is offered in some locations.
    - opportunities for diagnosis (access to sonography and a skilled sonographer and radiology workforce).

Genetic testing, identifying and managing familial and genetic risk:

- Stakeholders noted variation in access to genetic testing, including to 'standard of care' germline (testing for BRCA1 and BRCA2 pathogenic variants) and tumour testing (for homologous repair deficiency syndrome – HRD). Stakeholders highlighted Target Ovarian Cancer's Pathfinder 2022: Faster, further and fairer report (Pathfinder 2022) and the DEMO report.

Treatment:

- Stakeholders highlighted variation in access to surgery, noting that the ovarian cancer audit feasibility pilot highlighted that 1 in 5 women received no treatment at all (fifth report, 2023).

- The probability of receiving primary surgery with chemotherapy, versus chemotherapy before interval debulking surgery was 49.6% (based on analysis of stage 2 to 4 tumours).

- Rates of surgical resection varied between cancer alliances (stage 2 to 4). A stakeholder felt that access to maximal cytoreductive surgery is associated with improved 5-year survival rates, noting that it is not performed at all centres.

- Variation in 5-year survival and mortality across cancer alliances (ranged from 28.6% to 49.6%).

- Higher short-term mortality rates (between 2 to 6 months, following adjustment) was also explored in sections 2.3 and 4.4 (current practice) of the briefing paper. Data on short-term mortality highlighted a trend of higher short-term mortality in patients diagnosed in an NHS secondary care trust that did not house a specialist gynaecological cancer centre compared to trusts that did, as noted in the third report of the ovarian cancer audit feasibility pilot (2021).

4) Inclusion health and vulnerable groups (for example, vulnerable migrants, people experiencing homelessness, people in contact with the criminal justice system, sex workers, Gypsy, Roma and Traveller communities, young people leaving care and victims of trafficking)

None identified by stakeholders or committee.

Please also state if there were any gaps in the guideline recommendations for any particular groups within each of the dimensions above which were highlighted by committee.
None identified.

2.3 How have the committee's considerations of equality and health inequalities issues identified in 1.2 and 2.2 been reflected in the quality standard?

1) Protected characteristics outlined in the Equality Act 2010:

Age: Equality issues on variation of treatment by age were highlighted in the briefing paper for the committee to consider. A statement on all adults receiving treatment, of which surgery is one, was prioritised (statement 5). The measures section highlights that services may wish to compare access to treatment by age and comorbidity, comorbidity being more prevalent in older age groups, in order to identify unwarranted variation.

Delays in diagnostic tests for older people and CA125 thresholds: The quality standard includes a placeholder statement (statement 2) on CA125 testing. Equality issues related to this area therefore have not been addressed and will be highlighted when this placeholder is reviewed.

Disability*:* No issues identified by stakeholders or committee.

Gender reassignment:

- Healthcare discrimination in trans and non-binary communities: this issue was not raised in engagement responses or raised by the committee. A statement to address healthcare discrimination was not prioritised.
- Gender-neutral language: the presentation to committee included a slide on how inclusive language was to be approached, noting that NICE's guideline on ovarian cancer: recognition and initial management CG122 (published 2011) does not use inclusive language. The quality standard uses gender-neutral language in line within NG241, published in March 2024.

Race*:*

Statements 3 and 4 focus on genetic testing. Variation in take-up of genetic testing by ethnicity, based on regional data, was highlighted by stakeholders (DEMO project). The project evaluation noted a trend towards a lower test rate in patients from a Black ethnic background at the Pan-Birmingham Gynaecological Cancer Centre and this was noted in the briefing paper. At committee review, it was noted that variation in take-up of tumour testing by ethnicity had also been investigated. The measures sections of both statements therefore highlight that services may want to compare take-up of each form of testing adults by ethnicity, in line with local needs.

- Increased risk of pathogenic variants among Ashkenazi and Sephardic Jewish people: this suggestion was highlighted in the briefing paper. A statement on genetic testing in populations with a founder pathogenic variant was not prioritised.

Sex: A statement on genetic testing for adults registered male at birth, who may be at risk of carrying a pathogenic variant but who cannot develop ovarian cancer, was not prioritised.

Pregnancy and maternity: Statement 1 focuses on discussion with adults considering risk-reducing surgery. The statement rationale highlights that whether an adult has completed their family or plans to conceive naturally is a key element. The surgery should only be offered to those who have completed their family or do not plan to conceive naturally (and reach the 5% lifetime risk threshold). Other discussion topics include discussion of menopause; this and others are listed in the definitions section. The importance of discussion in relation to shared and informed decision making is highlighted throughout. An outcome on satisfaction with the decision-making process when considering risk-reducing surgery was explored at committee review, but no existing data sources were identified so this could not be progressed.

Statement 5 highlights that conservative (fertility-preserving) surgery may be an option. The optimum surgical procedure depends on the type, stage and grade of the tumour.

Sexual orientation: No issues identified by stakeholders or committee.

Religion or belief: No issues identified by stakeholders or committee.

2) *Socioeconomic status and deprivation (for example, variation by area deprivation such as Index of Multiple Deprivation, National Statistics Socio-economic Classification, employment status, income)*

Data on survival and mortality rates by deprivation was included in the briefing paper. Statement 5 aims to increase access to both treatment modalities for all adults diagnosed with ovarian cancer. 5-year survival and mortality were considered as outcomes but they were not supported by the evidence base. Rates of disease recurrence was also considered but a data source with published data for ovarian cancer alone and showing deprivation data were not identified. Further, the process measures alone support measuring access to treatment in all groups.

No data was identified regarding impact of deprivation on morbidity and so this was not explored further.

3) Geographical area variation:

- Variation in incidence of ovarian cancer, at sub-integrated care board (ICB) and cancer alliance geographies: The extent of reduction of incidence in localities may reflect in part on prevalence of adults with an increased risk of ovarian cancer due to pathogenic variants. Variation in the proportion of cases diagnosed at stage 1 and in 1-year net survival rates were presented in the briefing paper, which also noted that 1-year survival rates were linked to aspects of diagnosis, with higher rates associated with improved recognition and diagnostic pathways.

  Incidence of ovarian cancer was considered as an outcome for statement 1 but this was not supported by the evidence reviews.

  A placeholder statement (statement 2) on CA125 blood testing was progressed for the quality standard: equality issues related to diagnosis have not been addressed and will be highlighted when this placeholder is reviewed.

- Variation in access to genetic testing: A statement on genetic testing was prioritised with the intention to help support equitable access to 'standard of care' germline and tumour testing for adults newly diagnosed with high-grade epithelial ovarian cancer (tumour testing is for stage 3 or 4 only).

- Variation in access to fertility, genetics and menopause services: A statement on access to fertility or menopause services (or both) was not prioritised.

- Variation in treatment; lack of treatment in around 20% of cases, variation in resection rates (stage 2 to 4 inclusive), access to maximal cytoreductive surgery. These were explored in the briefing paper. Statement 5 was prioritised to ensure that all adults are offered both chemotherapy and surgery. Audience descriptors also highlight that referral pathways should be in place to ensure that adults are referred to a specialist gynaecological centre for surgery. Access to maximal cytoreductive surgery is highlighted as one of the approaches which may be used for surgical treatment for adults with stage 2 to 4 inclusive ovarian cancer in the definitions section.

- Variation in survival (5-year net) and mortality rates (including short-term mortality rates): These outcomes were explored in the briefing paper. 5-year survival was explored as a potential outcome for statement 5 but this was not supported by the evidence reviews.

2.4 Could any draft quality statements potentially increase inequalities?
The draft quality statements do not make it more difficult in practice for a specific group to access services compared to other groups.

2.5 Based on the equality and health inequalities issues identified in 1.2 and 2.2, do you have representation from relevant stakeholder groups for the quality standard consultation process, including groups who are known to be affected by these issues? If not, what plans are in place to ensure relevant stakeholders are represented and included?
We identified 3 ovarian cancer charities as key stakeholders. We will work with them to obtain responses at consultation.

2.6 What questions will you ask at the stakeholder consultation about the impact of the quality standard on equality and health inequalities?
For this consultation of an overarching question on the EHIA and equality and diversity considerations sections in statements (question 4) has been included as a pilot: Please provide your comments on the equality and health inequalities assessment (EHIA) and the equality and diversity considerations section for each quality statement. Please confirm any issues that have been missed and how they can be addressed by health care services and practitioners. Draft quality standards includes the following question: Can data for the proposed quality measures be collected locally? Please include in your answer any data sources that can be used or reasons why data cannot be collected. Regarding data collection for statement 3: Please state whether data can be collected to support monitoring take-up of panel germline testing by ethnicity (question for consultation 5). Regarding data collection for statement 4: Please state whether data can be collected to support monitoring take-up of tumour testing by ethnicity (question for consultation 6). Regarding data collection for statement 5: Please state whether data can be collected to support monitoring the measures by age and comorbidity (question for consultation 7).

Completed by lead analyst: Rachel Gick

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Reviewed by committee chair

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Approved by NICE quality assurance lead:

Mark Minchin

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