NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE guidelines

Equality and health inequalities assessment (EHIA) template

Early and locally advanced breast cancer: diagnosis and management

The considerations and potential impact on equality and health inequalities have been considered throughout the guidance development, maintenance and update process according to the principles of the NICE equality policy and those outlined in Developing NICE guidelines: the manual.

This EHIA relates to:

Early and locally advanced breast cancer [NG101]

Section 1.3 Surgery to the breast.

STAGE 2. Informing the scope

NG101 Early and locally advanced breast cancer

Date of completion: 04/09/2023

Focus of guideline or update: Further surgery after breast conserving surgery based on tissue margins

For short updates where there is no scoping workshop or scope consultation, questions relating to these in stage 2 can be noted ‘not applicable’.

2.1 What approaches have been used to identify potential equality and health inequalities issues during the check for an update or during development of the draft scope?
This document has been compiled using information taken from the surveillance stage EHIA that accompanied the 2023 surveillance review. Further searches were conducted to identify equality issues specific to this topic and discussions were held with committee members during scoping. Equality issues that were identified during the scoping and development of the 2018 update and the health inequalities briefing that accompanies this guideline have also been considered. No scoping workshop was carried out.

2.2 What potential equality and health inequalities issues have been identified during the check for an update or during development of the draft scope?
1. Protected characteristics a) Age Older people (for example those over 65 years) can face challenges in accessing and tolerating breast surgery. They may have pre-existing comorbidities that limit treatment options they can take or that increase the risk of surgical complications. They may have difficulties in travelling to multiple appointments for surgery assessments and follow up because they require support from a family member or carer or alternatively, they may have caring commitments of their own for other people. There may also be certain misconceptions about the benefits of surgery in older age and as such, older people may not be offered surgical treatment.

Younger people could have difficulties attending multiple appointments for surgery assessments and follow up if they have caring commitments (for example childcare or care for older relatives). They may also have difficulties attending these appointments if there is no flexibility about the time of day (for example if they have to pick up children from school). In addition, younger women may have more dense breast tissue and standard mammography and ultrasound may not be as accurate in predicting extent of disease.

People at extremes of age (younger and older people with breast cancer) are often not included in clinical trials and so there is likely to be much less good quality evidence for these groups.

b) Disability

People with disabilities (including neurodiversity) may face challenges with accessing information and resources regarding surgery and post-surgery treatment plans and this could impact their choice of care. For example, people with severe learning disabilities may require accessible information leaflets or written and verbal instructions about surgery and follow-up. They may require the support of a carer or advocate to help them to understand what is happening to them and to ensure that the consent that they give is informed. Additional preparation may be needed to help some people get used to the surgical environment before they have the operation.

Furthermore, people with disabilities may also face barriers to accessing appointments for surgery and follow-up. This could be because of problems with the practicalities of accessing a treatment centre due to its geographical location (for example, distance and difficulties with transport to the centre), multiple appointments being required, and/or the availability of carers or support workers to accompany and support them in their appointments at the treatment centre.

People with hidden disabilities (for example hearing problems) may need to be provided with reasonable adjustments to be able to fully participate in making decision about their treatment options.

People with physical disabilities who have multiple surgeries may be less able to use independence aids that they rely on while they recover from the surgery. For example, people who use wheelchairs or who need to use arm and shoulder strength to transition to and from the toilet won’t be able to do so easily for a time after surgery, and may need additional support.

c) Gender reassignment

Trans people or people who are non-binary may face barriers in accessing gender-affirming healthcare, including breast cancer screening and surgical services. Breast cancer services are women centred and a trans man who attends these services is

likely to be surrounded by women for example, in clinic waiting rooms. This could cause a lot of anxiety as they may feel that they are being forced back into or given an unwanted reminder of a gender they believed they had left behind.

Limited availability of healthcare providers experienced in transgender healthcare and insufficient training in transgender-specific needs can result in delayed diagnosis and inadequate treatment. Moreover, trans people who are undergoing hormone therapy, including oestrogen or testosterone, are known to have altered levels of risk for developing breast cancer (higher for trans women compared to cis men and lower for trans men compared to cis women respectively). Hormone therapy alters breast tissue structure and density and may affect decisions around surgical and other treatments. Trans men may be less likely to want breast conserving surgery, depending on their individual circumstances.

Trans women may have different breast tissue (for example depending on whether they have had surgically constructed or if they have taken hormone therapy) to cis women and may require different approaches to breast conserving surgery. However, there is expected to be a lack of evidence about surgical margins for trans women.

d) Pregnancy and maternity

Breast cancer symptoms in pregnant or breastfeeding women can be mistaken for normal changes related to pregnancy or lactation. As a result, there may be delays in diagnosis, leading to more advanced stages of cancer at the time of surgery for pregnant or breast-feeding women. Radiotherapy is not delivered to pregnant women and so this component of the treatment following breast conserving surgery may be delivered in a delayed timeframe. There is expected to be a lack of evidence about surgical margins for pregnant women.

For breastfeeding women, breast cancer surgery may impact their ability to continue breastfeeding. Access to lactation support, guidance, and resources can vary, affecting the woman's ability to make informed decisions about breastfeeding continuation or weaning. Concerns about the impact of surgery, anaesthesia, or adjuvant therapies on the pregnancy or breastfeeding relationship may influence treatment choices for some people.

Pregnant or breastfeeding women may face additional challenges in cases where there is a lack of coordination between delivery and obstetric care and their breast cancer surgery. This could be particularly difficult if the care is provided at different hospitals.

Diagnostic MRIs are less likely to be carried out on pregnant women because of the potential risk of the gadolinium contrast to the baby. This could affect the surgical margins that are achieved in a small number of cases as MRI is not generally required.

In addition, cosmetic outcomes may be unpredictable in pregnant or breastfeeding women.

e) Race

Ethnic minority groups in the UK may face disparities in breast cancer care. Factors such as language barriers, cultural beliefs and limited awareness of breast cancer care can influence access to timely diagnosis and surgical treatment. Ethnic minorities may also face biases, stereotypes, and discrimination within the healthcare system. However, a recent study suggests that, regardless of ethnicity, the surgical management of early breast cancer is similar in all women.

Ethnic minorities who have limited English proficiency may face challenges in navigating the healthcare system, understanding medical instructions, and making informed decisions about surgical interventions which can impact their treatment options and outcomes.

f) Religion or belief

Religious or cultural beliefs can influence treatment decisions, including the acceptance or rejection of surgical interventions for breast cancer. Some people may rely on alternative or complementary therapies based on religious or cultural practices, which could lead to delays or avoidance of surgery or appropriate postoperative care. In addition, some people may use specific healthcare practices alongside surgery, such as seeking care from traditional healers, undertaking specific rituals, or employing dietary restrictions that could impact surgical outcomes.

g) Sex

Breast cancer primarily affects women; however, men can also have breast cancer. Men with breast cancer may face additional challenges in terms of delayed diagnosis, limited awareness and gender biases which may pose challenges with appropriate treatment and follow-up.

For example, breast reconstruction options may not be available or discussed as frequently for men compared to women, leading to disparities in surgical choices and psychosocial outcomes. The impact of breast cancer surgery on body image, self-esteem, and gender identity can also be significant for men, and may influence their treatment choices.

Breast cancer information is usually written in a female centric language. This may result in men being more reluctant to interact with breast cancer care services, which may lead to poorer outcomes.

However, breast conserving surgery is not usually carried out on men.

h) Sexual orientation

No potential issues identified.

i) Marriage/civil partnership

No potential issues identified.

2) Socioeconomic status and deprivation

People from lower socioeconomic backgrounds or who are experiencing poverty may face barriers to accessing breast cancer surgery and adequate postoperative follow-up. This could be due to the limited availability of healthcare facilities and long wait times for appointments and treatment in certain areas. Moreover, some people from lower socioeconomic backgrounds or living in poverty may find it difficult to attend multiple appointments for surgery and pre- or post- operative assessments due to work responsibilities and their employment status. These could include people on zero-hour contracts or people who will not be paid if they are absent from work due to medical appointments or sickness, for example. Problems with the availability and cost of transport could also adversely affect their ability to attend appointments or alter their choice of the type of surgery. They may also not be able to afford to buy appropriate post-surgery bras which may have an impact on physical and cosmetic recovery (the appearance of the breast) and on pain levels.

3) Geographical area variation

In certain regions or rural areas, access to specialised breast cancer care, including breast surgery and post-operative treatment may be limited. As such, a lack of proximity to healthcare facilities equipped with the necessary resources and expertise could lead to delays in treatment and follow-up as well as longer travel times which could exacerbate disparities in surgical care. This would also be expected to have a particular impact on people who have difficulties in traveling longer distances due to caring responsibilities, a lack of transport, a shortage of money, disabilities or age. In addition, some patients living in rural areas may choose to have a mastectomy instead of breast conserving surgery as they do not wish to or find it difficult to travel to receive radiotherapy afterwards (which is required in most cases of breast conserving surgery).

4) Inclusion health and vulnerable groups

Inclusion health is an umbrella term. The following groups in this section were identified in relation to health inequalities and further surgery after breast conserving surgery.

Health literacy is the ability to obtain, read, understand, and use healthcare information in order to make appropriate health decisions and follow instructions for treatment. People with low levels of health literacy and awareness about breast cancer symptoms may face barriers to being diagnosed and with being able to manage their breast cancer. For

example, the lack of access to health education, language barriers, and limited knowledge about breast cancer symptoms, available resources and support services can result in delayed diagnosis and poorer surgical outcomes. This issue may disproportionately affect individuals from lower socioeconomic backgrounds or deprived communities, although people with higher socioeconomic status may also experience this.

People experiencing homelessness can face many challenges to accessing breast cancer surgery and treatment. These people may experience delays with diagnosis and treatment, have problems travelling to appointments, and limited access to postoperative support and rehabilitation services, such as physical therapy and counselling. This can impact their recovery, functional outcomes, and overall well-being after breast cancer surgery. They may also have low levels of health literacy and additional complex health needs.

Newly arrived migrants may face difficulties with accessing healthcare and may, in some cases, be afraid to use health services because they think they are ineligible or because they think it will alert the authorities and they will be arrested and deported. The additional barriers they face can include limited knowledge about the healthcare system, limited availability of culturally and linguistically appropriate healthcare services/resources which can lead to difficulties in navigating the healthcare system in a new country. Moreover, limited knowledge about breast cancer, including screening practices, symptoms, and available treatments, can contribute to delays in diagnosis and treatment for newly arrived migrants. Differences in healthcare systems and practices between the home country and the host country may also contribute to delays in seeking appropriate medical care. Newly arrived migrants may not have a permanent address and therefore they may face similar challenges as people experiencing homelessness (see above). They may also have financial difficulties and be living in poverty (see the section on socioeconomic status and deprivation above for additional challenges that they may face as a result).

People who are in prison may face difficulties in accessing breast cancer surgery and treatment. They may experience delays with diagnosis and treatment, have problems attending appointments and postoperative support and rehabilitation services due to their incarceration and prison staff availability. This can impact their outcomes after breast cancer surgery and may influence their choice about the type of surgery they have. They may also have additional complex health needs such as mental health issues and have low levels of health literacy.

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

The guideline update aims to give special considerations for the subpopulations identified in box 2.2 by taking these groups into consideration when developing the review protocol and making recommendations. The committee will consider whether evidence specific to the subpopulations should be sought and whether data should be analysed separately.

Specific recommendations could include:

- Referring to NICE's guidelines on making decisions about care (for example, Shared decision making [NG197] and Patient experience in adult NHS services: improving the experience of care for people using adult NHS services [CG 138]
- Referring to the Accessible Information Standard which aims to make sure that people who have a disability, impairment or sensory loss get information that they can access and understand, and any communication support that they need from health and care services.
- Different formats and delivery of information (for example, leaflets and written information which can include easy read format and braille; videos and graphics) and providing information in different languages and/ or using translators to facilitate understanding of spoken information or instructions.
- Gender neutral information and information for people of different gender identities.
- Support with accessing services.
- Ensuring culturally appropriate care, such as acknowledging why treatment by a healthcare professional of a specific gender is required and accommodating this request if there is staff availability.
- Recommendations aimed at improving the quality of breast cancer care.

2.4 Do you have representation from stakeholder groups that can help to explore equality and health inequalities issues during the consultation 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?
Not applicable as no scope consultation is being held for this update.

2.5 How will the views and experiences of those affected by equality and health inequalities issues be meaningfully included in the guideline development process going forward?
Lay members who have lived experience of breast cancer and breast conserving surgery have been recruited as part of the committee. They will be involved in committee discussions about the evidence and decisions about recommendations. They will also be asked to discuss how the suggested recommendations fit with their personal experiences. Groups representing people who experience health inequalities will be able to comment on the guideline during consultation if they are registered as stakeholders. In addition we will invite groups we identify with the committee and through other intelligence sources to register as stakeholders if they have not already done so.

2.6 If applicable, what questions will you ask at the draft scope stakeholder consultation about the guideline/update and potential impact on equality and health inequalities?
Not applicable as no scope consultation is being held for this update.

2.7 Has it been proposed to exclude any population groups from the scope? If yes, how do these exclusions relate to any equality and health inequalities issues identified?
Some population groups are excluded from the scope of this update. However, none of the groups that have been identified in this document are excluded from the scope of this work.

Completed by developer: Omnia Bilal, Yolanda Martinez and Marie Harrisingh
Date 04/09/2023

Approved by committee: chair Adam Firth
Date 12/9/23

Approved by NICE quality assurance lead: Kate Kelley
Date 7/9/23

STAGE 4. Development of guideline or topic area for update

NG101 Early and locally advanced breast cancer

Date of completion: 10/11/2023

Focus of guideline or update: Further surgery after breast conserving surgery based on tissue margins

4.1 From the evidence syntheses and the committee's considerations thereof, what were the main equality and health inequalities issues identified? Were any **further** potential issues identified (in addition to those identified during the scoping process) or any gaps in the evidence for any particular group?
1) Protected characteristics No further potential issues were identified. 2) Socioeconomic status and deprivation No further potential issues were identified. 3) Geographical area variation The committee noted that there could be limitations with access to oncoplastic techniques. Oncoplastic surgery may not be available in some areas, and this could affect a person's decision about further surgery if they have concerns about post-surgery cosmesis. 4) Inclusion health and vulnerable groups No further potential issues were identified.

4.2 How have the committee's considerations of equality and health inequalities issues identified in 2.2, 3.2 and 4.1 been reflected in the guideline or update and any draft recommendations?
The committee's discussion on these issues is included in the evidence review (in the section on the committee's discussion of the evidence). The committee made a recommendation for a shared decision around whether to have further surgery for radial margins of less than 1mm for people with invasive breast cancer with or without DCIS or 2mm for people with DCIS without invasive cancer. They took care to include the person's preferences, which would be expected to facilitate a discussion of any equality issues that might impact on the individual's decision whether to have further surgery, as well as clinical factors. To facilitate this discussion they included cross references to the following: enabling patients to actively participate in their care in the NICE guideline on patient experience in adult NHS services, and communicating risks, benefits and consequences in the NICE guideline on shared decision making.

4.3 Could any draft recommendations potentially increase inequalities?
No

4.4 How has the committee's considerations of equality and health inequalities issues identified in 2.2, 3.2 and 4.1 been reflected in the development of any research recommendations?
No research recommendations were made.

4.5 Based on the equality and health inequalities issues identified in 2.2, 3.2 and 4.1, do you have representation from relevant stakeholder groups for the guideline or update 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?
Due to the large number of potential groups involved we plan to try to engage with people from relevant groups during consultation. We have a number of organisations registered for consultation who we will ask for feedback on our recommendations.

4.6 What questions will you ask at the stakeholder consultation about the impact of the guideline or update on equality and health inequalities?

We are going to ask the stakeholders if they are aware of any measures that have helped to address the health inequalities raised in the EHIA. We will ensure that any equalities related comments are discussed with the committee, and changes will be made to the recommendations, evidence review discussion or rationale where necessary.

Completed by developers: Yolanda Martinez, Clare Dadswell and Marie Harrisingh
Date: 7/10/23

Approved by committee chair: Adam Firth
Date: 7/11/23

Approved by NICE quality assurance lead: Kate Kelly
Date: 10/11/23

STAGE 5. Revisions and final guideline or update

Early and locally advanced breast cancer

Date of completion: 05/12/2023

Focus of guideline or update: Further surgery to the breast

5.1 How inclusive was the consultation process on the draft guideline in terms of response from groups (identified in box 2.2, 3.2 and 4.1) who may experience inequalities related to the topic?
The NICE Public Involvement Programme helped to identify relevant stakeholders and the final stakeholder list was reviewed by Public Involvement Programme colleagues and the committee to review any potential gaps. Registered stakeholders were invited to respond to the draft guideline during consultation. Stakeholders were from a variety of organisations including: • national patient, carer and voluntary organisations • charities • national organisations representing public health, healthcare and other professionals who provide the activities and services related to the updated guidance in England • local authorities and representative bodies of local government • providers of public health, health and social care in England and Wales, commercial industries which are relevant to the updated guidance • the Department of Health and other relevant Government departments and agencies • research organisations and academic institutions across the UK. Three of these stakeholder groups responded during consultation. Comments included agreement with the proposed recommendations and suggested additions to address inequalities that may be faced by people with learning disabilities. All comments were addressed and will be responded to individually and published on our website.

5.2 Have any **further** equality and health inequalities issues beyond those identified at scoping and during development been raised during the consultation on the draft guideline or update, and, if so, how has the committee considered and addressed them?
1) Protected characteristics a. Age

No further potential issues were identified.

b. Disability
During the scoping phase, it was noted that people who are neurodiverse or who have learning disabilities may need additional support to understand surgery and post-surgery treatment plans and to access treatment. Feedback from a stakeholder during consultation referred to the legal requirement for reasonable adjustments and the Reasonable Adjustment Digital Flag (RADF) and Information standard. This information was added to the evidence review discussion. In addition, the recommendations were amended to include consideration of people's circumstances and needs as part of the decision-making process, as well as their preferences. The same stakeholder also drew our attention to the LeDeR report on Learning from lives and deaths: people with a learning disability and autistic people. In response we have added information about the impact of having a learning disability on the survival of people with breast cancer to the health inequalities briefing that accompanies this work.

c. Gender reassignment
No further potential issues were identified.

d. Pregnancy and maternity
No further potential issues were identified.

e. Race
No further potential issues were identified.

f. Religion or belief
No further potential issues were identified.

g. Sex
No further potential issues were identified.

h. Sexual orientation
No further potential issues were identified.

i. Marriage/civil partnership
No further potential issues were identified.

2) Socioeconomic deprivation
No further potential issues were identified.

3) Geographical area variation
No further potential issues were identified.

4) Inclusion health and vulnerable groups
   No further potential issues were identified.

5.3 If any recommendations have changed after consultation, how could these changes impact on equality and health inequalities issues?
The changes to the recommendations detailed above were intended to help ensure that the realities of patients' lives are taken into account and that any barriers to particular treatment options are identified and addressed, where possible. By doing this the committee hoped to reduce the impact of some health inequalities on patients' treatment journeys and increase their choices.

5.4 Following the consultation on the draft guideline and response to questions 4.1 and 5.2, have there been any further committee considerations of equality and health inequalities issues across the four dimensions that have been reflected in the final guideline?
No further equality and health inequalities issues were identified by the committee at this stage and their actions in response to the stakeholder comments are covered in section 5.2b above and in the 'Other factors the committee took into account' section of the committee discussion in the evidence review.

5.5 Please provide a summary of the key equality and health inequalities issues that should be highlighted in the guidance executive report before sign-off of the final guideline or update
Key issues considered in this update related to the importance of: • communication of information in a way that is accessible for people with a range of needs (including those with low health literacy, people who have severe learning disabilities, people who are neurodiverse). • taking people's circumstances, needs and preferences into account when discussing surgery to the breast and post-surgery treatment plans. Recommendations were included that refer to the sections on communication in the NICE guidelines on patient experience in adult NHS services (CG138) and shared decision making NICE guideline (NG197). In addition, the shared decision about whether to have further surgery includes consideration of people's circumstances, needs and preferences.

Completed by developer: Yolanda Martinez and Marie Harrisingh

Date: 13/12/2023

Approved by committee chair:

Date: Adam Firth 18/12/23

Approved by NICE quality assurance lead:

Date: Kate Kelly 3/1/24