NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE guidelines

Equality and health inequalities assessment (EHIA)

Early and locally advanced breast cancer

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 the Promoting Equality, Reducing Health Inequalities guidance support document.

This EHIA relates to:

Complications of local treatment. Arm mobility

STAGE 2. Informing the scope

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 the views of the topic experts detailed in the 2022 exceptional surveillance review together with the health inequalities raised by committee members during scoping. Equality issues that were identified during the scoping and development of the 2018 update to 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 As people get older they may face difficulties engaging in and accessing healthcare, reasons for this include increasing frailty, reduced physical activity and conditions of old age. They may also be resident in a care home or rely on carers to help them access therapy and some older people have little access to social and practical support. These factors may result in reduced ability to travel to physiotherapy, reduced access or ability to use technology that provides online information about prehabilitation and rehabilitation care. Older people are more likely to have underlying arm and shoulder age-related changes impacting on their independence, surgery and radiotherapy can make these changes worse affecting their independence further. In addition, older people may have caring responsibilities for partners or grandchildren and delay or cancel their treatment due to these responsibilities. b. Disability People with physical or learning disabilities, including those with dementia may have difficulties accessing healthcare. They may need support to decide between treatment options, travelling to appointments and receiving physiotherapy or exercise. People with physical or learning disabilities may be resident in care homes or in supported living facilities and rely on carers to facilitate access to therapy or help them carry out exercises at home. In

addition, they may be unable to access online content about exercise or exercise classes or to read and understand written information without support.

People from neurodiverse populations (for example, people who have autism) may find it harder to understand information leaflets or written or verbal instructions about physiotherapy or exercise strategies. They may need this information presenting in a different manner, and they may need additional support to carry out the exercises.

People with mental health problems (for example, anxiety, depression) may find it difficult to engage in breast cancer prehabilitation or rehabilitation due to psychological symptoms (for example, having reduced or no motivation).

People with chronic conditions such as myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS) may find it difficult when their symptoms are worse to follow breast cancer prehabilitation or rehabilitation strategies due to fatigue and reduced ability to concentrate.

c. Gender reassignment
Trans people or people who are non-binary, may be diagnosed with breast cancer. Trans people or non-binary people may feel excluded because breast cancer mainly affects women (for example, information leaflets about exercises after breast cancer surgery may only have images of women). They may therefore be more reluctant to interact with services providing prehabilitation or rehabilitation, leading to poorer outcomes.

d. Pregnancy and maternity
People who have given birth recently and who are in the first year after giving birth are likely to have specific mobility needs such as being able to lift, hold, breastfeed and care for their babies.

e. Race
Non-English speakers may be unable to understand information provided about the treatment options and be unable to follow written or verbal instructions about how to carry out prehabilitation or rehabilitation exercises. This could prevent non-English speakers accessing this therapy and lead to worse arm mobility outcomes. This may require the use of translators. In addition, any written information would ideally be provided in their preferred language. In addition people from non- white groups may present with later stage cancers and require more extensive treatment.

f. Religion or belief
People from some religions may only be allowed to engage in this type of physiotherapy from a healthcare professional of the same sex. In some religions, there may be cultural restrictions around carrying out certain types of

exercise in public spaces. If this is not taken into account, this could reduce the uptake of prehabilitation or rehabilitation and lead to worse arm mobility outcomes.

g. Sex
Although breast cancer is a disease that mainly affects women, about 1% of breast cancer cases in the UK are in men. Because breast cancer is normally associated with women information leaflets about exercises may only have images of women. This may lead men and people who do not identify as women who have breast cancer to feel excluded, and as a result they may be more reluctant to interact with services providing prehabilitation or rehabilitation, leading to poorer outcomes.

h. Sexual orientation
None identified

2) Socioeconomic status and deprivation

Literacy and health literacy entail people's knowledge, motivation, and competence to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention, and health promotion to maintain or improve quality of life during their life course. This may result in people from deprived groups presenting with later stage cancers and requiring more extensive treatment. In addition people with low levels of literacy and health literacy may find it harder to understand the treatment options that are available to them.

People on lower incomes may find it harder to take time off work to attend physiotherapy appointments, for example if they are on zero hours contracts or only have access to statutory sick pay . People on lower incomes or who live in areas of deprivation may have reduced ability to access information about post-surgery and post-radiotherapy exercise online due a lack of data or online access.

People on lower incomes may not be able to afford specific breast prostheses or mastectomy bras for sports and exercise. This may discourage them from participating in these exercises and lead to worse outcomes for them.

3) Geographical area variation

Access to treatments may vary with geographical location due to:

- differences in treatment availability, which may also be linked to different levels of experience and training of the available healthcare staff outside of centres of excellence, which are often located in big cities.

- the reduced ability of certain groups of people to travel to where treatment is available, including people living in rural areas and those who lack access to transport.

4) Inclusion health and vulnerable groups

People who have experienced certain types of abuse, such as sexual or domestic abuse, may be reluctant to engage with healthcare services if they do not have options about whether they are treated by a male or female member of staff.

People who have active or physical jobs that require a certain amount of arm movement or who have carer's responsibilities may be particularly adversely affected by arm and shoulder problems. Some of the people with active or physical jobs or roles or those who only have access to statutory sick pay may find it harder to take time off work.

People in prison, secure units or other settings where they have restricted movement may be less able to physically access physiotherapy/ exercise sessions or training.

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

Specific recommendations or research recommendations may need to be made for the groups discussed in section 2.1.

These 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 NICE's guideline on Workplace health: management practices [NG13]

- Referring to 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 genders
- Support with accessing services
- Tailoring the type of exercise/ physiotherapy intervention and the mode of delivery to meet individual needs (e.g., face to face, group or virtual) and potentially providing additional support to carry out the exercises.
- Ensuring culturally appropriate care, such as acknowledging why treatment by a healthcare professional of a specific sex is required and accommodating this request if there is staff availability.

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 can people/groups affected by equality and health inequalities issues be meaningfully included in the guideline development process going forward?
Lay members from different populations who have lived experience of breast cancer and radiotherapy will be included 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 register as stakeholders, these groups are encouraged to register as stakeholders.

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?
Not Applicable. No population groups have been excluded from the scope.

Completed by developer: Clare Dadswell

Date: 5 October 2022

Approved by committee chair: Adam Firth

Date: 11 January 2023

Approved by NICE quality assurance lead: Kate Kelley

Date: 30 January 2023

STAGE 4. Development of guideline or topic area for update

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 *a. Age* No further potential issues were identified. *b. Disability* The committee noted that there might be some people who may have vision and or hearing problems or may not have access to technology to receive virtual support. The committee also highlighted that face to face physiotherapy may be more beneficial for people with complex needs or those at higher risk (for example people with disabilities, neurodiverse people, those who experience physical difficulties with recovery or rehabilitation) because they might need specific instructions and feedback. *c. Gender reassignment* No further potential issues were identified. *d. Pregnancy and maternity* No further potential issues were identified. *e. Race* Non-English speakers may need additional support so that they are able to understand instructions on functional exercises. *f. Religion or belief* No further potential issues were identified. *g. Sex* All of the evidence was for women, with no male participants in the included studies. *h. Sexual orientation* No further potential issues were identified. *i. Marriage/civil partnership* No further potential issues were identified. *2) Socioeconomic status and 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.

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 equality and health inequalities issues is included in the evidence review (in the section on the committee's discussion of the evidence) and the rationale section of the guideline. The committee noted that all of the evidence was for women, with no male participants in the included studies. Therefore, the committee could not be certain whether the effectiveness of different interventions would differ for men and women. However, while the content of information may need to differ for each gender, the most effective methods of providing physiotherapy or exercise rehabilitation were not expected to differ greatly and so the committee did not think that the recommendation would cause equality issues for men who have had breast cancer. The committee discussed that people's individual needs should be taken into account to inform further decisions on treatment for people having surgery or radiotherapy for breast cancer treatment. These discussions were taken into account when the committee drafted recommendations. Specifically recommendation 1.12.6 which is about instructions on functional exercises. These instructions should be available in different formats to be accessible to people with different needs (formats could include written instructions, easy read, different languages, audio translation, video, large print, signing, or Braille). Recommendation 1.12.10 which is about supervised support. The committee agreed that this should also be available in different formats (for example face to face, virtual, individual or group), to be tailored to individual needs and to ensure access by all patients. The format of supervised support and the number of sessions should be decided based on each person's needs and wishes.

4.3 Could any draft recommendations potentially increase inequalities?
No. The committee made the recommendations with the intention of increasing access and accessibility of the intervention. This includes ensuring the content of information is in an accessible format, and that people are offered different ways to access support, such as either face-to-face or virtually.

4.4 How has the committee's considerations of equality and health inequalities issues identified in 2.2 and 4.1 been reflected in the development of any research recommendations?
The committee noted that there was no evidence on outcomes for different population subgroups, such as people from minority ethnic family backgrounds, disabled people and neurodiverse people. They added these populations as subgroups in 2 research recommendations that were made to cover this gap in the evidence.

4.5 Based on the equality and health inequalities issues identified in 2.2 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 signed up 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?
No specific questions will be asked, but we will ensure that any comments from relevant stakeholders are considered and discussed with the committee, and changes will be made where necessary. We are also asking for feedback on the health inequalities briefing that has been developed for breast cancer.

Completed by developer: Clare Dadswell

Date: 31/01/23

Approved by committee chair: Adam Firth

Date: 01/02/23

Approved by NICE quality assurance lead: Kate Kelley

Date: 01/02/23

STAGE 5. Revisions and final guideline or update

Early and locally advanced breast cancer

Date of completion: 03/03/2023

Focus of guideline or update: Complications of local treatment. Arm mobility

5.1 How inclusive was the consultation process on the draft guideline in terms of response from groups (identified in box 2.2 and 4.1) who may experience inequalities related to the topic?
[Please provide a summary of relevant stakeholders that were invited to respond to the consultation (and the type of organisation, if known), whether they did respond, and the quality of their response] *[Please detail any discussions with the Public Involvement Programme]* The NICE Public Involvement Programme helped to identify relevant stakeholders and the final stakeholder list was reviewed by Public Involvement Programme colleagues 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 • equalities groups. Seven of these stakeholder groups responded during consultation. Comments included agreement about the proposed recommendations, queries about who would deliver services or equality considerations in relation to access to services, and suggestions for edits to the proposed recommendations. All comments were addressed and discussed with the committee 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 outlined in the Equality Act 2010*

   a. *Age*
   No further potential issues were identified.

   b. *Disability*
   No further potential issues were identified.

   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 (for example, variation by area deprivation such as Index of Multiple Deprivation, National Statistics Socio-economic Classification, employment status, income)*
   Stakeholders agreed that interventions delivered virtually may help to reduce health inequalities and address access options for people where other interventions are not locally available. They also noted that deprivation can have an impact on people being able to access virtual content. This includes issues with affordability of data and access to suitable devices.

3) *Geographical area variation (for example, geographical differences in epidemiology or service provision- urban/rural, coastal, north/south)*
   Stakeholders agreed that interventions delivered virtually may help to reduce health inequalities and address access options for people where other interventions are not locally available. They also noted that geography can have an impact on people being able to access virtual content. This includes geographical issues with poor connectivity in rural communities.

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)*

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 committee amended 2 recommendations to make it easier for people to access supervised support services to perform upper limb exercises. One recommendation was amended to make it clearer that supervised support should be considered for people who have not been assessed as being at high risk of developing shoulder problems but who may still benefit from this type of support (for example, people with learning or sensory disabilities, people having other commonly performed adjunct surgeries, people having side effects from additional cancer treatments). The committee updated another recommendation to highlight that a person's circumstances should be taken into account to tailor the supervised support (for example, mental health and learning needs). Research recommendations were amended based on stakeholders' comments including a bullet point of people with learning disabilities or cognitive impairment, or physical disabilities, or both who often experience access issues and a lack of education resources adapted to their specific needs such as understanding the different formats of interventions to reduce arm and shoulder problems after breast cancer surgery or radiotherapy.

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?

Stakeholders raised problems with digital exclusion and the impact that deprivation and geographical issues can have on people's ability to access virtual content. The committee recommended that supervised support should be tailored to the person's needs and preferences. The rationale and discussion have been expanded to clarify that face to face support should be available for those who have problems accessing virtual support. Research recommendations were amended based on stakeholders' comments including a bullet point of people with learning disabilities or cognitive impairment, or physical disabilities, or both who often experience access issues and a lack of education resources adapted to their specific needs such as understanding the different formats of interventions to reduce arm and shoulder problems after breast cancer surgery or radiotherapy.

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 relate to people's experience around access and lack of support tailored to their specific needs when doing upper limb exercises. The recommendations include guidance on providing information in different formats to be accessible to people with different needs. They also highlight the need to provide different options for supervised support, such as virtual or face-to-face support. This should improve people's ability to be able to benefit from these recommendations.

Completed by developer: Clare Dadswell

Date: 09/03/2023

Approved by committee chair: Adam Firth

Date: 22/03/2023

Approved by NICE quality assurance lead: Kate Kelley

Date: 23/03/2023

STAGE 6. After guidance executive amendments

Early and locally advanced breast cancer

Date of completion: 28/03/2023

Focus of guideline or update: Complications of local treatment. Arm mobility

6.1 Outline any amendments related to equality and health inequalities issues suggested by guidance executive and what the outcome was.
No amendments were requested by GE.

Completed by developer: Marie Harrisingh

Date: 28/03/2023

Approved by committee chair: Adam Firth

Date: 29/03/2023

Approved by NICE quality assurance lead: Kate Kelley

Date: 28/03/2023