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 <u>Developing NICE guidelines: the manual</u>.

This EHIA relates to:

Early and locally advanced breast cancer [NG101]

Section 1.10 Radiotherapy – Dose fractionation

STAGE 2. Informing the scope

(to be completed by the Developer, and submitted with the draft scope for consultation, if this is 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 the views of the topic experts detailed in the <u>2022 exceptional surveillance review</u> together with the health inequalities raised by committee members during scoping and the information contained in the breast cancer health inequalities briefing. 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 a reduced ability to travel to appointments and they need support to travel to receive radiotherapy. Older people may have additional needs which need to be addressed before starting radiotherapy, such as help with caring responsibilities or help for themselves with practical issues such as shopping, washing or dressing. Older people may have other comorbidities (for example arthritis) affecting shoulder movement which in turn could make radiotherapy difficult. Older people may have reduced independence due to age and age-associated issues and radiotherapy may affect 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.

Data from the NHS shows that women with breast cancer who are 70 years and over are less likely to have radiotherapy (in combination with chemotherapy and/or tumour resection) compared to younger women. One reason for this could be that people in this age group with low risk disease may be eligible for selective avoidance of radiotherapy and may choose not to have radiotherapy Therefore, this data may not always reflect a health equalities issue.

b. Disability

People with physical or learning disabilities, including those with dementia may have difficulties accessing healthcare. They may need support to understand radiotherapy regimens and to travel to and receive radiotherapy. 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 treatment. 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 who have sensory disabilities may need additional support when using leaflets or written information about radiotherapy regimens, such as having information provided in easy read format.

People from neurodiverse populations (for example, people with autism) may need additional support to ensure that they are able to participate fully in making decisions about their treatment.

People with mental health problems (for example, anxiety, depression) may need additional support in completing radiotherapy regimens because they may find it difficult to engage in breast cancer services due to psychological symptoms, such as anxiety about leaving the house (agoraphobia) or being in the treatment room alone for radiotherapy. People with claustrophobia may also be affected if the treatment rooms are small.

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 may only have images of women). They may be more reluctant to interact with services providing radiotherapy leading to poorer outcomes.

d. Pregnancy and maternity

Radiotherapy is contraindicated for people who are pregnant and so they will not be able to receive this treatment. People who have given birth recently and who are in the first year after giving birth have additional needs such as being able to lift, breastfeed and care for their babies.

e. Race

Non-English speakers may need additional support so that they are able to understand radiotherapy regimens. This may require the use of translators. In addition, any written information about radiotherapy regimens 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.

Some people with darker skin may be concerned or more reluctant to engage in treatment because of concerns about the potential hyperpigmentation effects of radiotherapy.

f. Religion or belief

Some people may be from certain religions (or cultural interpretations of religions) where being naked (from the waist upwards) in public settings /outside of their home may not be acceptable or they may prefer to receive this type of radiotherapy by a healthcare professional of the same sex.

People from religions and cultures where the marking of skin is not acceptable may be concerned about the tattooing necessary for radiotherapy, and potentially less likely to engage with services.

g. Sex

Breast cancer is a disease that mainly affects women. About 1% of breast cancer cases in the UK are in men. Men and people who do not identify as women and are diagnosed with breast cancer could feel excluded during radiotherapy. Because breast cancer is typically associated with women (for example, men would like gender-specific information on side effects of treatments, such as chest hair loss after radiotherapy), they may be more reluctant to interact with services providing radiotherapy, which may lead to poorer outcomes.

- h. Sexual orientation None identified
- i. Marriage/civil partnership None identified.
- 2) Socioeconomic status and deprivation

Groups of people who are on a low income, only able to get statutory sick pay may be more likely to want or accept a shorter treatment regime which may have a risk of negative long-term effects. The long-term effects of this are being evaluated in the FAST-Forward trial and have not been reported yet.

Groups of people who have low levels of health literacy may need additional support to ensure that they are able to understand the benefits and risks associated with different radiotherapy regimens.

People on lower incomes may find it harder to take time off work (either to attend radiotherapy appointments or to take time off work if they feel unwell from radiotherapy). They may be on zero hours contracts, for example, and lose income if they turn down shifts or only have access to statutory sick pay. The cost of travel to multiple radiotherapy sessions may also be an issue for this group

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 radiotherapy. 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 on lower incomes or who live in deprived areas may have reduced ability to access information about radiotherapy regimens online due a lack of data or computer access which may make it harder for them to engage with treatment or make informed decisions between different treatment options.

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 who have low levels of literacy may need to be given additional support to read leaflets or written information about radiotherapy regimens. They may need to be provided with information orally instead.

3) Geographical area variation

Access to radiotherapy may vary with geographical location due to:

- radiotherapy equipment being located in specialised facilities, which are more likely to be found in larger urban hospitals rather than rural areas. There may also be different levels of experience and training of the available healthcare staff outside of centres of excellence or a lack of qualified radiographers and clinical/radiation oncologists and other relevant staff.
- the reduced ability of certain groups of people to travel to where radiotherapy is available. People living in rural areas, those who lack transport or are older or poorer may be most affected.

4) Inclusion health and vulnerable groups

People who have experienced past sexual or domestic abuse may be reluctant to engage with radiotherapy 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 or who have carer's responsibilities (including parents or carers of young children) may be particularly adversely affected by side effects from radiotherapy (such as fatigue, pain and restricted shoulder movement). They may also have problems with childcare if they have to attend multiple radiotherapy sessions. Some of the people with active or physical jobs may come from groups where jobs may have temporary contracts and a less stable income.

People in prison may have problems with accessing radiotherapy, for example if there are prison staff shortages to accompany them to appointments.

People experiencing homelessness appear to present for diagnoses at later stages and will have poorer prognoses in view of this. They may have more treatment interruptions due missed appointments and therefore a shorter course of radiotherapy may be of benefit to them. However, this approach may be associated with a risk of negative long-term effects. The long-term effects of this are being evaluated in the FAST-Forward trial and have not been reported yet.

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 to address the issues in section 2.2. These could include:

- Referring to NICE's guidelines on making decisions about care (for example, <u>Shared decision making</u> [NG197] and <u>Patient experience in adult NHS services</u>: <u>improving the experience of care for people using adult NHS services</u> [CG 138])
- Referring to NICE's guideline on <u>Workplace health: management practices</u> [NG13]
- Different formats and delivery of material (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

- Other methods of accessing radiotherapy may need to be considered (for example, tailoring service opening hours and locations to meet people's needs), or providing accommodation for people who live far from radiotherapy services
- 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. Gender neutral information and information for people of different genders

We will refer 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.

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 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?

There are no exclusion criteria in the scope or protocol.

Completed by developer: Marie Harrisingh

Date: 24/11/2022

Approved by committee chair: Adam Firth

Date: 18/01/2023

Approved by NICE quality assurance lead: Kate Kelley

Date: 01/02/2023

STAGE 4. Development of guideline or topic area for update

(to be completed by the developer before consultation on the draft guideline or update)

Early and locally advanced breast cancer

Date of completion: 08/02/2023

Focus of guideline or update: Radiotherapy - dose fractionation

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.
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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 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 discussed that people's individual needs should be considered to inform further decisions regarding radiotherapy treatment for breast cancer. These discussions were considered when the committee drafted the recommendation for people where the 26 Gy in 5 fraction regimen may not be suitable. They decided to highlight that 40 Gy in 15 fractions may be more acceptable for some people, such as those who experience high levels of fatigue. Although fatigue was given as an example, the committee did not specify other reasons where the 15 fraction regimen may be more suitable, as they were aware that this may vary depending on individual circumstances. Instead, this is a decision that should be based on discussions between a patient and the clinician.

The committee also highlighted how the barriers to people attending radiotherapy appointments revolve around extended treatment duration and accessibility. For example, people may find it difficult to attend multiple appointments due to other commitments such as carer responsibilities and work responsibilities. Costs of travel to treatment are also higher when multiple appointments are needed, particularly for people who live far from their nearest radiotherapy centre, and this may be a barrier to treatment for some people. A shorter treatment duration would therefore be beneficial for many people with breast cancer and make treatment more accessible for a wider range of people.

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?

Two research recommendations were made to address groups of people where there is a lack of evidence about the effectiveness of different hypofractionation regimens. No

research recommendations were made that specifically addressed the health inequalities issues identified.

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?

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: 08/03/2023

Approved by committee chair: Adam Firth

Date: 08/03/2023

Approved by NICE quality assurance lead: Kate Kelley

Date: 08/03/2023

STAGE 5. Revisions and final guideline or update

Early and locally advanced breast cancer

Date of completion: 05/04/2023

Focus of guideline or update: Radiotherapy – dose fractionation

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 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.

Five of these stakeholder groups responded during consultation. Comments included agreement about the proposed recommendations, queries about who would be offered each regimen and equality considerations in relation to access to services. 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, people with learning disabilities were identified as a group who may need additional support to understand radiotherapy regimens and to travel to radiotherapy centres. Feedback from stakeholders during consultation also highlighted that people with moderate or severe learning difficulties may not be offered radiotherapy as it is not possible for their carers to be with them while radiotherapy is taking place.

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.

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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 status and deprivation No further potential issues were identified.
- Geographical area variation
 No further potential issues were identified.
- 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?

No changes to the recommendations that impacted the equality and health inequalities issues were made.

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?

The committee discussed the points raised by stakeholders about how people who have moderate to severe learning difficulties may not be offered radiotherapy. In the committee's experience, many people with learning difficulties can be offered radiotherapy, as they can be provided with additional information and coaching about what will happen before radiotherapy begins. The committee noted that this should be considered as part of a multidisciplinary team discussion and risk assessment about how practical and tolerable radiotherapy may be for that person.

The committee highlighted that the new recommendations may benefit people who have learning difficulties and are offered radiotherapy, as they can be offered a shorter treatment duration and reduced number of appointments. This reduces the amount of time that they spend having radiotherapy, potentially making it a less stressful experience.

5.5Please 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 relate to access to radiotherapy treatment centres and the ability and availability of patients to attend several appointments. The evidence supports the use of the 26 Gy in 5 fractions regimen as it has comparable effects to higher fraction regimens for most groups of people. Furthermore, the 26 Gy in 5 fractions regimen reduces treatment duration for patients, and as such, it may improve some barriers to access because people have to attend fewer appointments.

Completed by developer: Clare Dadswell

Date: 08/05/2023

Approved by committee chair: Adam Firth

Date: 09/05/2023

Approved by NICE quality assurance lead: Kate Kelley

Date: 10/05/2023