NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Equality and health inequalities assessment (EHIA)

STAGE 2. Informing the scope

NG101 Early and locally advanced breast cancer: diagnosis and management

CG81 Advanced breast cancer: diagnosis and treatment

Date of completion: 03 January 2024

Focus of guideline or update: Preventing and managing lymphoedema in people with breast cancer

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 these topics and discussions were held with committee members during scoping. Equality issues that were identified during the scoping and development of the 2009 update and 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 There is evidence to suggest that older people with breast cancer may experience disparities in accessing support services for their breast cancer. This may be because of factors such as delayed diagnosis, variable access to some treatment services (for example, reduced treatment times, limited access to exercise and physiotherapy services) and communication barriers. Moreover, older people may have existing comorbidities and conditions like arthritis, which can impact the management of their lymphoedema. For example, older people with arthritis may face difficulties with applying compression garments or exercising. As such, older

people may require further discussions and support from the clinical team to ensure that they are aware of the options available to them for managing their lymphoedema.

Furthermore, there is evidence to suggest that despite older age being a risk factor for lymphoedema and impaired arm function, younger people may notice and report on their lymphoedema more than older people.

Younger and older people may also struggle with attending multiple appointments due to childcare or other caring commitments, especially if appointments lack flexibility. Younger women also tend to have denser breast tissue, as such standard mammography and ultrasound may not be as accurate in diagnosing and determining the extent of breast cancer. This is one of the factors that may lead to a delay in diagnosing breast cancer in younger women and delayed diagnosis or advanced disease, are risk factors for developing lymphoedema.

Lastly, both older and younger groups are often excluded from clinical trials, as such, it is likely that less good quality evidence is available for these groups.

b) Disability

Some people with disabilities may face challenges with accessing information and resources regarding lymphoedema. As such, this may impact their wellbeing. For example, people with severe learning disabilities may require accessible information leaflets or written and verbal instructions on preventing and managing lymphoedema related to their breast cancer.

Furthermore, people with disabilities may also face barriers to accessing appointments for lymphoedema treatment. This can be due to the practicalities of accessing a treatment centre such as the geographical location (for example difficulties with travelling to the centre), the availability of carers or appointments with specialist clinicians at the treatment centre. Additional preparation may also be needed to help some people make informed choices about their treatment. For example, people with severe learning or motor disabilities may need time to familiarise and adjust to the surgical setting before they receive a surgical intervention to manage their lymphoedema. As such, it is important to consider and involve people with disabilities in discussions surrounding their care so that, the best therapy that accommodates for their specific needs is identified.

c) Gender reassignment

Trans people or people who are non-binary may face challenges in accessing gender-affirming healthcare in the context of breast cancer, as well as lymphoedema prevention and treatment. Limited availability of healthcare providers experienced in transgender healthcare and insufficient clinician training in transgender-specific needs can result in delayed diagnosis and inadequate treatment and access to services for trans people or people who are non-binary.

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.

d) Pregnancy and maternity

For women who are pregnant or breast-feeding, the diagnosis or prevention and management of their breast cancer and lymphoedema may impact their psychological wellbeing and quality of life. Furthermore, pregnant or breast-feeding women may have limited access to lymphoedema management services due to difficulties of travelling to the appointment, the availability of appointments or the suitability of different lymphoedema services to their needs. Thus, women who are pregnant or breast-feeding may have limited lymphoedema treatment options available to them.

There is evidence to suggest that maternity-related concerns (for example, increased blood volume and fluid retention, hormonal changes that impact blood and lymph vessels and altered immune responses such as increased risk of infections) may exacerbate lymphoedema in pregnant women with breast cancer. As such, special considerations need to be made to prevent and manage lymphoedema in pregnant women and this may alter treatment options offered to them. For example, as the body changes during pregnancy, compression garments may need to be refitted to ensure proper pressure and avoid restricting blood flow.

e) Race

There is evidence to suggest that Black people have an increased risk of developing breast cancer-related lymphoedema.

Ethnic minority groups in the UK may face disparities in accessing lymphoedema treatment services for breast cancer. Factors such as language barriers and cultural beliefs can influence access to timely diagnosis and treatment.

Ethnic minority groups may also face disparities with the availability of limited treatment options that suit their needs. For example, compression garments for lymphoedema are available in limited shades, with fewer options available for people with darker skin tones.

f) Religion or belief

Religious or cultural beliefs can influence treatment decisions, including the acceptance or rejection of some lymphoedema management options for breast cancer. For example, some people may prefer for their treatment practitioner to be of the same sex, which may limit the treatment options available to them.

Some people may rely on alternative or complementary therapies based on religious or cultural practices, which can lead to delays or avoidance of recommended therapies or available NHS support. In addition, some people use specific healthcare practices alongside conventional medicine, such as seeking care from traditional healers, undertaking specific rituals, or employing dietary restrictions that could impact their willingness to partake in other lymphoedema management strategies.

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 the management of breast cancer-related lymphoedema. Because breast cancer is typically associated with women (for example, men would like gender-specific information on side effects of treatments), this factor can be significant for men and may influence their treatment choices. this is because they may be more reluctant to interact with breast cancer-related lymphoedema services, which may lead to poorer outcomes.

Men with breast cancer may face additional challenges such as delayed diagnosis, treatment, and inappropriate follow-up and lymphoedema management. For example, breast cancer treatment may be less discussed or available for men compared to women, leading to disparities in treatment.

h) Sexual orientation

No potential issues identified.

i) Marriage and civil partnership

Marriage and civil partnership often confer health benefits for people with breast cancer. For example, breast cancer patients who are married and stay married after their breast cancer have a better prognosis and quality of life compared to patients who become/are single, divorced or widowed.

However, there is evidence to suggest that unmarried individuals with breast cancer (including people who are widowed or divorced) may be at a high risker risk of negative health outcomes and complications as they may have less support . As such, these patients may require further support throughout their breast cancer diagnosis and treatment to improve their outcomes.

2) Socioeconomic status and deprivation

People from lower socioeconomic backgrounds may face barriers to accessing treatment for their breast cancer-related lymphoedema. This can be because of limited availability of healthcare facilities in certain areas, long wait times for appointments and treatment in these areas, and problems with the availability and cost of transport to appointments.

Moreover, people from lower socioeconomic backgrounds may find it difficult to attend multiple appointments depending on the type of lymphoedema treatment options offered. This may be due to work responsibilities and their employment status (for example self-employed people, people on zero-hour contracts or people who will not be paid if they are absent from work due to medical appointments or sickness).

People experiencing poverty or homelessness may face challenges accessing treatment for their breast cancer related lymphoedema. For example, these people may have 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 treatment or diagnosis.

3) Geographical area variation

Access to specialised breast cancer care, including lymphoedema management services, may be limited in some areas throughout the UK. As such, lack of proximity to healthcare facilities equipped with the necessary resources and expertise can lead to delays in treatment and follow-up as well as longer travel times which can exacerbate disparities in their treatment outcomes and quality of life.

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 identification and management of lymphoedema in people with breast cancer.

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 and treatment complications may face barriers with diagnosis and management of these symptoms. For example, the lack of access to health education, language barriers, and limited knowledge about lymphoedema services and resources can result in delayed diagnosis and poorer lymphoedema management. This issue may disproportionately affect individuals from lower socioeconomic backgrounds or deprived communities, although people with higher socioeconomic status may also experience this.

Newly arrived migrants may face difficulties with accessing healthcare. The 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. This can also mean that they face challenges with navigating the healthcare system and making informed decisions about their healthcare.

Moreover, limited knowledge about breast cancer, including screening practices, symptoms, and available treatments, can contribute to delays in accessing lymphoedema management 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 and support.

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 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 genders. For example, transgender or non-binary
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- Support with accessing services.

- Ensuring culturally appropriate care (for example, acknowledging why treatment by a healthcare professional of a specific gender is required and accommodating this request if there is staff availability, as well as, the use of culturally appropriate garments and cosmetics).

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 lymphoedema support services 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 are registered as stakeholders, and we will invite the groups we identify with committee and other input 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?
Not applicable as no population groups were excluded.

Completed by developer: Omnia Bilal

Date: 05/03/2024

Approved by committee chair: Rakesh Heer

Date: 06/03/2024

Approved by NICE quality assurance lead: Kate Kelly

Date: 5/3/2024

STAGE 3. Finalising the scope

NG101 Early and locally advanced breast cancer: diagnosis and management

CG81 Advanced breast cancer: diagnosis and treatment

Date of completion: 18 January 2024

Focus of guideline or update: Preventing and managing lymphoedema in people with breast cancer

3.1 How inclusive was the consultation process in terms of response from stakeholders who may experience inequalities related to the topic (identified in 2.2)?
NA – no scope consultation.

3.2 Have any additional equality and health inequalities issues been identified during consultation? If so, what were they and what potential solutions/changes were suggested by stakeholders to address them?
NA – no scope consultation.

3.3 Have any changes been made to the scope as a result of the consultation and equality and health inequalities issues identified in 2.2 and 3.2? Were any other changes made to the scope that may impact on equality and health inequalities?
NA – no scope consultation.

STAGE 4. Development of guideline or topic area for update

NG101 Early and locally advanced breast cancer: diagnosis and management

CG81 Advanced breast cancer: diagnosis and treatment

Date of completion: 09 May 2024

Focus of guideline or update: Preventing and managing lymphoedema in people with breast cancer.

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?

2) Protected characteristics

a) Age

No further issues identified.

b) Disability

No further issues identified.

c) Gender reassignment

No further issues identified.

d) Pregnancy and maternity

No further issues identified.

e) Race

No further issues identified.

f) Religion or belief

No further issues identified.

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.

h) Sexual orientation

No further issues identified.

i) Marriage and civil partnership

No further issues identified.

2) Socioeconomic status and deprivation

The committee discussed that for people who prefer Kinesio-taping for their lymphoedema, it can incur an extra cost as most people will be expected to buy their own Kinesio-tape. This potential cost may hinder people from lower socioeconomic backgrounds from accessing Kinesio-taping and exacerbate inequalities.

3) Geographical area variation

The committee previously acknowledged that there was geographical variation in lymphoedema centres and their services. As such, there may be longer travel times or wait times for accessing these services, which may exacerbate disparities in treatment for people in these areas.

4) Inclusion health and vulnerable groups

The committee noted that in their experience ordering made-to-measure compression garments from suppliers can be a complicated process due to the codes required to order them and their availability. This can potentially exacerbate health inequalities for some people with low levels of health literacy or awareness about lymphoedema and services available to them.

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 (see section on the committee’s discussion of the evidence) and the rationale section of the guideline. The committee discussed that in the recommendation for people who are being offered Kinesio-taping, this may be paid for privately and therefore incur additional costs for people. This potential cost may hinder people from lower socioeconomic backgrounds from accessing Kinesio-taping and exacerbate inequalities. These discussions were considered when the committee drafted the recommendations and the committee noted that in their experience, the provision of kinesio-taping varies, and some physiotherapists may provide the tape for their patients.

4.3 Could any draft recommendations potentially increase inequalities?

No recommendations that may potentially increase health inequalities were drafted. The recommendations that were drafted all included stipulations that can mitigate for any health inequalities. For example, for recommendations on the provision of information to lymphoedema patients, the use of different formats for providing the information (written or online) is highlighted.

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?

The committee discussed that in all the included evidence in this review, all the participants were women. As such, the committee were concerned with the generalisability of the evidence for men and considered this when drafting the recommendations. The committee acknowledged that breast cancer in men is uncommon, however when drafting research recommendations, they identified men and non-binary people as a subgroup of interest for further research.

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?
Yes, the committee included lay members with lived experienced with lymphoedema and socio-economic deprivation. They have considered the health inequalities issues such as socio-economic deprivation identified in the review.

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 registered stakeholders covering the different health inequalities issues identified in earlier sections considered and discussed with the committee, and changes will be made where necessary.

Completed by developer: OMNIA BILAL

Date: 08/07/2024

Approved by committee chair: Rakesh Heer

Date: 03/09/2024

Approved by NICE quality assurance lead: Kate Kelley

Date: 02/09/24

STAGE 5. Revisions and final guideline or update

(to be completed by the developer before guidance executive considers the final guideline or update)

NG101 Early and locally advanced breast cancer: diagnosis and management

CG81 Advanced breast cancer: diagnosis and treatment

Date of completion: [12/11/24]

Focus of guideline or update: Preventing and managing lymphoedema in people with breast cancer.

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?
There were 61 stakeholders that were invited to consultation. These consisted of various types of organisations including those that represent people who have experience of breast cancer or lymphoedema. Only 8 stakeholders responded of which 3 were representatives of people experiencing the condition (Lymphoedema Support Network, Lymphoedema Network Northern Ireland and Breast Cancer Now.

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?

Stakeholders NHS England responded to the guideline with comments on the impact of lymphedema symptoms on darker skin. They highlight that it can be difficult to identify skin changes in darker skin and that this information is often missed out of patient information which can make self-monitoring more challenging. The committee were aware of support materials such as infographics to help identify changes in darker skin which can be included as part of the information sharing with people lymphoedema when they are referred to the lymphoedema specialist services. Stakeholders have also highlighted that recommendations should include advice for those unable to self-monitor for example people with learning disabilities or dementia. Whilst the committee did not make lymphoedema-specific recommendations to address these, these issues were discussed by the committee and added to the relevant evidence reviews. They were aware of NICE guidance on patient experience which provides recommendations on how to consider the person’s needs to ensure they are able to participate as fully as possible in consultations and care. This guidance is referenced throughout the guideline.

5.3 If any recommendations have changed after consultation, how could these changes impact on equality and health inequalities issues?

The recommendation on lymphoedema education to discuss lymphoedema and possible management options (for example, conservative management, surgical options) treatment. The committee were aware that availability of treatment options for lymphoedema varies, particularly surgery. However, by not including surgery in the guideline access to surgery may become even more limited, potentially exacerbating health inequalities. The committee also previously made research recommendations for surgery, so the addition of surgery to this recommendation will further enable the possibility for research to be carried out.

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?

Nothing in addition to the above considerations.

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

Socioeconomic Barriers, Kinesio-taping costs create potential treatment disparities as people are required to pay for it privately and a variable lymphoedema service provision across regions for specialist care and surgery.

Completed by developer: Ahmed Yosef

Date: 09/12/2024

Approved by committee chair: Rakesh Heer

Date: 12/12/2024

Approved by NICE quality assurance lead: Sharon Swain

Date: 09/12/2024