

# **NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE**

## **Equality and health inequalities assessment (EHIA)**

### **Lymphoedema: prevention and management in people with early, locally advanced, and advanced breast cancer (update)**

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 guidelines:

Early and locally advanced breast cancer: diagnosis and management (NG101)

- Section 1.12 Complications of local treatment and menopausal symptoms: Lymphoedema

Advanced breast cancer: diagnosis and treatment (CG81)

- Section 1.5 Managing complications: Lymphoedema.

## 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. As such, both older and younger people may require earlier intervention to manage their lymphoedema.

Younger adults 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.

#### 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.

c) Pregnancy and maternity

For women who are pregnant or breast-feeding, the diagnosis or 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.

d) 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.

e) 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.

f) 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.

g) Sexual orientation

No potential issues identified.

h) 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 risk of negative health outcomes and complications. 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.
- 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).

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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.*