

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE guidelines

Equality and health inequalities assessment (EHIA)

Advanced breast cancer: diagnosis and management (Partial update)

STAGE 2. Informing the scope

CG81 Advanced breast cancer

Date of completion: 01/11/2024

Focus of guideline or update:

- Platinum containing neoadjuvant chemotherapy regimens
- Imaging assessment
- Monitoring disease status

2.1 What approaches have been used to identify potential equality and health inequalities issues during the check for an update or during development of the draft scope?

This document has been compiled using information taken from the [surveillance stage EHIA](#) that accompanied the [2023 surveillance review](#). Further searches were conducted to identify equality issues specific to this topic and discussions were held with committee members during scoping. Equality issues that were identified in the [NICE health inequalities briefing](#) that accompanies this guideline and information from the [National Audit of Breast Cancer in Older Patients, Annual Report 2022](#) have also been included. (The [National Audit of Metastatic Breast Cancer](#) has yet to release a report.)

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

In the UK, there were around 56,400 new breast cancer cases every year between 2017 to 2019. Almost 24% of all new cases are reported in people aged 75 and older, with highest rates reported in people aged 90 and over ([Breast Cancer Research UK, 2024](#)).

The [NICE health inequalities briefing](#) states that people aged 71 and over, where breast cancer incidence is rising, have worse outcomes for breast cancer and experience many inequalities. This age group is not eligible for screening unless they self-refer or are referred by their GP. They are known to present with more advanced stage disease at diagnosis and are more likely to present with higher-grade tumours compared with younger age groups. This is also supported by data in the [Breast Cancer diagnosis: State of the Nation report 2024](#) that shows that in 2022/23 11.5% of people aged 72 years and older were diagnosed with de novo metastatic disease compared to 4.8% of people aged 18-49 years.

The percentage of women diagnosed with advanced/ metastatic breast cancer at initial presentation increased with age from 3% among women aged 50–69 years to 7% among women aged 70+ years (data from 2014-2019, [National Audit of Breast Cancer in Older Patients, Annual Report 2022](#)). During this time period, 41% of women diagnosed with advanced breast cancer at initial presentation who were aged 50–69 years received chemotherapy within six months of diagnosis, while this was 13% among women aged 70+ years and only 6% for women aged 80+ years ([National Audit of Breast Cancer in Older Patients, Annual Report 2022](#)).

The differences in uptake in chemotherapy could be linked to a number of factors, which may include age discrimination based on conscious or unconscious bias on both the part of clinicians and older people themselves ([Ageism in breast cancer report 2019](#)). In addition, although some older people may be suitable for chemotherapy or other treatments others may not be based on their level of frailty and number/ types of co-morbidities they have. For these latter groups of people there could be an increased risk of treatment related adverse events leading to poor outcomes ([National Audit of Breast Cancer in Older Patients, Annual Report 2022](#)). However, decisions about whether to offer a particular type of treatment should be based on the patient's fitness and ability to benefit from the treatment rather than only their chronological age ([All Party Parliamentary Group on Breast Cancer 2013](#)).

Older people with cognitive impairment or dementia may need support with decision making. Others may need information provided in a suitably accessible manner if they have hearing impairment or visual impairment. Older people may also face a range of barriers to taking up an offer of chemotherapy or to attending scans for

assessment or monitoring purposes. These can include increasing frailty, reduced physical ability, comorbidities and existing or new disabilities that make it harder for them to travel to appointments (see also the section on Disability). They may be resident in a care home or rely on family or carers to help them access chemotherapy and some older people have little access to such social and practical support. This may be particularly problematic for treatment with chemotherapy, which is given in cycles every few weeks. In addition, people who have help with their activities of daily living (such as dressing themselves or preparing food) may require additional support to help them cope with the effects of the chemotherapy.

In contrast, other older people may have caring responsibilities that prevent them from accessing chemotherapy.

Specialist units for older age oncology may support a higher uptake of chemotherapy by older people, but access is inequitable as such services are not available in all areas.

Finally, historically older people with breast cancer have not always been eligible for clinical trials and so there may be less good quality evidence about effective treatment options for them.

Although breast cancer incidence increases with age, some types of breast cancer such as triple negative breast cancer (TNBC) are more likely to affect younger women of childbearing age ([Cancer Research UK 2023](#)). This may explain why survival of people aged 15-39 is lower than for people aged 40-60 ([NICE Health inequalities briefing](#)).

Younger women with breast cancer may face a range of barriers to accessing chemotherapy (see also the section Pregnancy and maternity). Young childless women might not be given adequate information and choices about fertility issues before and after breast cancer treatment, which may adversely affect their decisions about accepting treatment.

Treatment with chemotherapy and monitoring of disease status may involve multiple appointments and younger people may have difficulties with attending these if they have caring commitments (for example childcare or care for older relatives). They may also have difficulties attending appointments if there is no flexibility about the time of day (for example if they have to pick up children from school or if they have problems getting time off work (see also issues listed under Socioeconomic deprivation).

b. Disability

The [Equality Act \(2010\)](#) defines a disabled person as a person with a physical or mental impairment that 'has a substantial and long-term adverse effect' on the person's 'ability to carry out normal day-to-day activities.' For this section we will

include the groups of people covered by the act although we recognise that this includes a wide range of people, some of whom may not consider themselves to be disabled but rather differently abled (such as some neurodivergent people).

The [NICE Health inequalities briefing](#) states that diagnosis of breast cancer can be delayed in women with a learning disability, and evidence shows cancers are often only found when at a more advanced stage than in the general population. This could be because of difficulties in recognising and communicating symptoms, or because changes in behaviour are attributed to the learning disability rather than being seen as a possible sign of physical ill health.

There are a range of barriers to accessing treatment that disabled people with breast cancer may face that could also contribute to their poorer outcomes. One key barrier is related to the communication of information and informed decision making. Information needs to be provided in an accessible manner to everyone to facilitate decision making. Some disabled people have additional information needs and require information to be provided in a manner that addresses these needs to be fully accessible. However, the type of accessible information needs to be tailored to individual requirements as it will vary with the type of disability, while other disabled people may not have additional information needs. For example, people with learning disabilities may require easy read information leaflets or verbal information about chemotherapy. In contrast, people with sensory disabilities (for example, people with visual impairment) may require information presented in Braille and verbally. Some disabled people (for example, people with learning disabilities, dementia or who have more severe forms of autism) may require the support of a carer or advocate to help them to understand what is happening to them and to ensure that the consent that they give is informed, whilst others won't have this need (for example, people who use a wheelchair may not need additional support in this area). As well as having information provided to them in a way they can understand and process, neurodivergent people may also need support to adapt to changes in their routine and with physical examinations.

Some disabled people (such as those with dementia, learning disabilities or physical disabilities that affect mobility) may face difficulties in travelling to a treatment centre to receive treatment or for assessment /monitoring due to its geographical location (for example, if the centre is far away and there is limited or no accessible transport to it). This problem may be compounded if they need to attend multiple and regular appointments (for example, chemotherapy therapy is delivered in cycles of treatment). Disabled people may also be more likely to be living in poverty (see also the section on Socioeconomic status and deprivation). The lack of availability of family, carers or support workers to accompany and support them in their appointments at the treatment centre could also be a barrier to access for some disabled people. Additional preparation and support may also be needed to help

some disabled people, such as those with learning disabilities or neurodivergent people, get used to the treatment environment before they receive therapy.

People with mental health conditions (for example, anxiety or depression) may also need additional support in completing their treatment plans because they may find it difficult to engage in breast cancer services due to their psychological symptoms. In addition, concerns about the effects of treatment on long term fertility may exacerbate people's mental health conditions.

c. Gender reassignment

Trans people or people who are non-binary may face barriers in accessing gender-affirming healthcare. Breast cancer services are mostly used by women and a trans man who attends these services is likely to be surrounded by women for example, in clinic waiting rooms. This could cause a lot of anxiety as they may feel that they are being forced back into or given an unwanted reminder of a gender they believed they had left behind. In addition, the limited availability of healthcare providers experienced in trans healthcare and insufficient training in trans-specific needs can result in delayed diagnosis and inadequate treatment.

People who are undergoing gender transition may have concerns about the impact of chemotherapy treatments on their plans for transition and concerns about the impact of any gender-affirming treatments on any treatments for cancer. However, trans people are poorly represented in clinical trials and as a result there is uncertainty around effective treatment options for them. The effects and suitability of a person for chemotherapy will be affected by the treatment they have had or are having for gender reassignment, particularly if this involves hormone treatment. It may be necessary to liaise with the clinicians managing the gender transition to decide on and co-ordinate suitable treatment.

d. Marriage and civil partnership

No potential issues identified.

e. Pregnancy and maternity

Pregnant women and trans men and non-binary people who are pregnant may be excluded from trials of chemotherapy drugs leading to increased uncertainty about whether and when during pregnancy they are able to safely take these drugs. People taking these drugs may not be able to breastfeed for the duration of treatment. They may also have concerns about the effects of the chemotherapy drugs on fertility and their ability to have more children in the future (see the section on Age above for more information about this topic).

f. Race

As the [NICE Health inequalities briefing](#) states, [Public Health England 2018 guidance on health inequalities](#) shows that there is variation by family background in

late-stage diagnosis (stage 3 or 4). For example, people from Black family backgrounds are more likely to be diagnosed late than people from white family backgrounds. This potentially explains worse outcomes in people from ethnic minority family backgrounds. People identified by routes other than screening are more likely to have advanced-stage breast cancers.

In a study using data from South East England, [Jack et al. 2009](#) found that a higher percentage of people from non-White family backgrounds had metastatic disease at diagnosis, with 17% of people of Pakistani background being the highest, compared to White people (7%). Black Caribbean and Black African women were more likely to receive chemotherapy than White women. They suggested this might be linked to differences in the type of breast cancer that Black Caribbean and Black African women were likely to have and the stage at which their cancer was identified. This study noted that there is an increased rate of triple negative breast cancer in Black women compared to White women. Consistent with this, there is evidence to show that women with breast cancer aged 30 to 46 years old from Pakistani, Black Caribbean and Black African family backgrounds had less favourable tumour characteristics (stage, grade, ER and HER2 status) ([Gathani et al. 2021](#)). They were also more likely to score in the most deprived quintile of the index of multiple deprivation compared to White and Indian women. The evidence was similar for older women (53 to 70 years). These tumour characteristics will affect the type of chemotherapy regimen that is suitable.

Ethnic minority groups in the UK may face disparities in breast cancer care. Factors such as language barriers, cultural beliefs and limited awareness of breast cancer care can influence access to timely diagnosis and treatment. Ethnic minorities may also face biases, stereotypes, and discrimination within the healthcare system.

Ethnic minorities who have limited English proficiency may face challenges in navigating the healthcare system, understanding medical instructions, and making informed decisions about treatment options.

g. Religion or belief

Religious or cultural beliefs can influence treatment decisions, including the acceptance or rejection of treatments for breast cancer. In particular, treatments that impact fertility may not be acceptable in some religions or belief systems. Some people may rely on alternative or complementary therapies which could lead to delays or avoidance of certain treatments. In addition, some people may use specific healthcare practices alongside chemotherapy, such as seeking care from traditional healers, undertaking specific rituals, or employing dietary restrictions that could impact outcomes.

h. Sex

Breast cancer primarily affects women, trans men and non-binary people registered female at birth; however, men, trans women and non-binary people registered male

at birth can also have breast cancer. Men, trans women and non-binary people registered male at birth with breast cancer may face additional challenges in terms of delayed diagnosis and gender biases and a lack of knowledge about suitable treatments for them. People with male breast cancer (breast cancer in men, trans women and non-binary people registered male at birth) are often underrepresented in or excluded from breast cancer clinical trials and are underrepresented in breast cancer guidelines as a result.

The [NICE Health inequalities briefing](#) notes that there is a lack of gender-specific information on breast cancer for men ([Breast Cancer Care, 2011](#)). For example, men would like information about sex-specific chemotherapy side effects.

i. Sexual orientation

No potential issues identified

2) Socioeconomic deprivation

The [NICE Health inequalities briefing](#) states that people from deprived groups are less likely to participate in breast cancer screening and are less likely to be referred urgently for assessment of breast symptoms. This can contribute to a delay in diagnosis and result in a more advanced stage of breast cancer at the time of diagnosis. More advanced stages of breast cancer can mean more intensive combination treatment is needed, including surgery, radiotherapy, and drug therapies including chemotherapy. This is supported by data from the [Breast Cancer diagnosis: State of the Nation report 2024](#) that shows that women from the most deprived areas were more likely to have metastatic breast cancer at initial diagnosis in all age groups, with the differences being most pronounced in the 72 years and older category.

People from lower socioeconomic backgrounds or who are experiencing poverty may face barriers to accessing chemotherapy and to attending appointments for assessment/ monitoring. This could be due to the limited availability of healthcare facilities and long waiting times for treatment in their local areas. Problems with the availability and cost of transport could also adversely affect their ability to attend appointments and alter their choice of treatment. Moreover, some people from lower socioeconomic backgrounds or who are living in poverty may find it difficult to attend multiple appointments for these treatments due to their employment status. These could include people on zero-hour contracts or people who will not be paid if they are absent from work due to medical appointments or sickness, for example. They may also lack suitable support and adjustments from their employers when they return to work, and this could limit their choice of treatment to avoid chemotherapy-related side effects. While these issues may not be confined to people from lower socioeconomic groups and may also be experienced for example, by people who are self-employed, those who are on low incomes may be disproportionately affected.

3) Geographical area variation

[An Inquiry into Geographical Inequalities and Breast Cancer 2018](#) (from the All-Party Parliamentary Group on Breast Cancer) notes that there are problems with the collection of data on the numbers of people being diagnosed with metastatic breast cancer and that this makes it hard for healthcare providers to plan their services to adequately meet the needs of their local populations. (This may be addressed by the [National Audit of Metastatic Breast Cancer](#) when it produces a report.) The cancer taskforce identified several gaps/ variations in services between areas around: access to clinical nurse specialists; whether multidisciplinary teams routinely discuss the treatment of these patients; information provision and whether psychosocial needs are met; and prompt and timely access to palliative care ([An Inquiry into Geographical Inequalities and Breast Cancer 2018](#)). They also note that geographical variation in the level of symptom awareness of GPs can lead to delays in the diagnosis of secondary breast cancer. In England, 21% of women who had primary breast cancer previously and attended their GP with symptoms such as backache and tiredness were treated for another condition before being diagnosed with metastatic breast cancer. However, there is geographical variation with 11% of people in the South West of England being treated for another condition before having a diagnosis of metastatic breast cancer, compared to 29% Yorkshire and Humber.

In certain regions or rural areas specialist breast cancer care facilities may be limited and people may have to travel long distances to access treatment. For example, specialist units for older age oncology are available in some areas of the country but not others. This would be expected to have a particular impact on people who have difficulties in traveling longer distances due to caring responsibilities, a lack of transport, a shortage of money, disabilities or older age. There is evidence to suggest that the extra travel time to treatment centres, costs (for example, on parking and fuel) and inconvenience for rural patients and carers can compound what is already a stressful situation ([Breast Cancer Care 2011](#)). It may also limit their treatment options.

4) Inclusion health and vulnerable groups

'Inclusion health is an umbrella term used to describe people who are socially excluded, who typically experience multiple overlapping risk factors for poor health, such as poverty, violence and complex trauma' ([NHS England](#)). The following groups in this section were identified in relation to health inequalities around access to chemotherapy, and assessment/ monitoring.

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

resources and support services can result in delayed diagnosis and poorer outcomes. This issue may disproportionately affect individuals from lower socioeconomic backgrounds or deprived communities, although people with higher socioeconomic status may also experience this ([Vandraas et al, 2022](#)).

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

Newly arrived migrants may face difficulties with accessing healthcare and may, in some cases, be afraid to use health services because they think they are ineligible or because they think it will alert the authorities and they will be arrested and deported. Migrants who do not have access to free NHS care may have problems in being able to afford breast cancer treatment in general, which could be expensive as reported charges levied range from £40 up to £80,000 ([Doctors of the World 2017](#)). The additional barriers they face can include limited knowledge about the healthcare system, limited availability of culturally and linguistically appropriate healthcare services/resources which can lead to difficulties in navigating the healthcare system in a new country. Moreover, limited knowledge about breast cancer, including screening practices, symptoms, and available treatments, can contribute to delays in diagnosis and treatment for newly arrived migrants. Differences in healthcare systems and practices between the home country and the host country may also contribute to delays in seeking appropriate medical care. Newly arrived migrants may not have a permanent address and therefore they may face similar challenges as people experiencing homelessness (see above). They may also have financial difficulties and be living in poverty (see the section on socioeconomic status and deprivation above for additional challenges that they may face as a result). All of these issues can lead to extremely delayed care-seeking and presentation with advanced breast cancer by emergency routes, resulting in worse outcomes ([NICE health inequalities briefing](#)).

People who are in prison may face difficulties in accessing breast cancer treatment. They may experience delays with being able to seek help and to obtain a diagnosis, which may result in them being diagnosed with more advanced disease and having worse outcomes ([NICE health inequalities briefing](#)). In addition, they may have problems attending multiple rounds of chemotherapy or other treatments due to their incarceration and prison staff availability. This can impact their outcomes and may influence their choice of treatment. They may also have additional complex health needs such as mental health issues and have low levels of health literacy.

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

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

Specific recommendations could include:

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

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?

Registered stakeholders include Breast Cancer Now, Autism in Mind, Cancer Black Care and the Women's Support Network. We have requested input from the People and Communities Involvement and Engagement (PCIEP) Team and the committee about key patient groups and any newly identified groups have been invited to register as stakeholders for this update.

2.5 How will the views and experiences of those affected by equality and health inequalities issues be meaningfully included in the guideline development process going forward?

Lay members who have lived experience of advanced breast cancer will be recruited as part of the committee. They will be involved in committee discussions about the evidence and decisions about recommendations. They will also be asked to discuss how the suggested recommendations fit with their personal experiences.

Groups representing people who experience health inequalities will be able to comment on the guideline during consultation if they are registered as stakeholders. In addition, we will invite groups we identify with the committee and through other intelligence sources to register as stakeholders if they have not already done so.

2.6 If applicable, what questions will you ask at the draft scope stakeholder consultation about the guideline/update and potential impact on equality and health inequalities?

No questions that relate to health inequalities will be asked in the scope consultation.

2.7 Has it been proposed to exclude any population groups from the scope? If yes, how do these exclusions relate to any equality and health inequalities issues identified?

Some population groups are excluded from the scope of this update as the treatments under review are not appropriate for them. None of the groups that have been identified in this document are excluded from the scope of this work. However, certain treatments may not be appropriate for certain groups of people listed in this document.

Completed by developer: Marie Harrisingh

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Approved by committee chair: Adam Firth

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Approved by NICE quality assurance lead: Kate Kelley

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