NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Equality and health inequalities assessment (EHIA)

Contents

STAGE 2. Informing the scope

Familial breast cancer (NICE guideline CG164)

Date of completion: 12/9/2025

Focus of guideline update: assessing carrier probability and thresholds for referral for genetic testing, predicting the risk of developing breast cancer and risk reducing mastectomy.

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?
A thorough approach was undertaken to understand the breadth of equality and health inequality issues affecting people with a family history of breast cancer. We reviewed the published evidence from a literature search of studies assessing equalities and health inequalities in people with known pathogenic variants in breast cancer predisposition genes or a family history of breast cancer. Other relevant sources of intelligence during the scoping process included the CG164 2017 EIA and NG241 2024 EIA, the 2023 surveillance report and Breast cancer health inequalities briefing. The websites of registered stakeholder charities have also been checked for any information relating to equality and health inequalities issues. We met with committee members in a scoping meeting to discuss the equality and health inequality issues identified from the literature search. We also asked the committee if there were any other issues they were aware of that we should consider during the guideline update.

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?

Age

Although risk of breast cancer generally increases with age, diagnosis of breast cancer at a younger age is more likely in women with pathogenic gene variants associated with breast cancer. Mammographic surveillance may be less informative in younger women as they are more likely to have dense breast tissue, which can interfere with mammographic detection of breast cancer (Sessa et al. 2023). Concerns relating to loss of fertility may also hinder younger people from deciding to undergo risk-reducing bilateral salpingo-oophorectomy. Similarly, some evidence has shown that the time from proband BRCA testing to receipt of BRCA testing by family relatives takes longer in people under 40 years. The authors of the study speculated that this could be as a consequence of oophorectomy only being recommended after women have completed their families meaning that there is less clinical urgency in younger people. However, the time from proband to family relative testing in this study could also have been longer in younger people because they were more likely to be eligible for testing as second- or third-degree relatives, and therefore more time was required to test intervening blood relatives (Martin et al. 2020).

Women who have children and are at moderate and high risk of breast cancer may be more likely to use tamoxifen as a chemo-preventative agent compared to women without children. Interview data suggested that this was because people felt that reducing their breast cancer risk meant they will be healthier for longer and therefore more able to look after their families (Hackett et al. 2018). In studies conducted in Germany and France, younger women and women with children have been shown to have higher psychosocial needs, according to the Psychosocial Aspects of Hereditary Cancer questionnaire, when initiating testing for high cancer risk (Bredart et al. 2008). A possible reason why younger women may have higher psychosocial needs could be that they have fewer established relationships and support systems; this may also pose future challenges when raising genetic status in currently unestablished personal relationships. Younger women may also have potential for higher rates of anxiety and depression if they have recently seen a close relative go through breast cancer diagnosis and treatment, as they will be more aware of the impact of a positive test result. This may be particularly difficult for women who were children or adolescent when they experienced the breast cancer-related death of a close relative. Genetic testing may also not have been available for older relatives when they were in the same stage of life as younger people, meaning that they may not have familial role models to support them during genetic testing. Young women may also experience high levels of anxiety and stress around the decision whether to have risk reducing mastectomy, which has only been offered to much younger women widely in the last 7-10 years. For women in their twenties, the complexity of this decision may be increased by worries about the effects of losing sensation in their breasts/ nipples while they are still developing their sexual identity and the need to make decisions about being able to breast feed in the potentially distant future. In addition, this age group are less likely to have peers with experience of this surgery to speak to. Women with children may

also face added anxiety and feelings of guilt around potentially passing on pathogenic variants to their children.

Younger women and women with children may also have concerns related to the negative effects associated with tamoxifen that are akin to menopausal symptoms (such as fatigue, night sweats, vaginal dryness). Due to the teratogenic nature of tamoxifen, women would also need to stop treatment at least 2 to 3 months before trying to conceive, meaning that additional factors such as contraception would need to be considered. Moreover, there are multiple appointments needed for surveillance and younger people may have difficulties attending these if they have caring commitments (for example childcare or care for older relatives). They may also struggle to attend appointments if there is no flexibility about time of day (for example if they have to pick up children from school or have difficulties getting time off work). These struggles could increase mental strain on the individual and may limit their capacity to be involved with usual social activities that they would otherwise enjoy.

Body image is an important factor to consider for women of all ages as it has psychosocial implications. Younger women may have more options for surgery, but this may not mean that younger women want to opt for these options. Conversely, older women may want more options for surgery, including reconstruction surgery but are limited due to fitness rather than age. These options, or lack thereof, could compound any mental strain and anxiety associated with body perceptions experienced by the individual.

Hormone replacement therapy (HRT) is associated with an increased risk in breast cancer, which is an additional concern for women developing menopausal symptoms during the perimenopause around the age of 50 years. Epidemiological evidence also indicates that high breast cancer risk categories are associated with a greater absolute increase in risk with HRT (Association of Breast Surgery).

Although not always the case, with increasing age some people can experience increasing frailty, reduced physical ability, comorbidities and new disabilities that make it harder for them to travel to appointments and take part in breast cancer care. However, some people may experience similar issues at a younger age, while some older people remain fit and healthy and may have caring responsibilities that make attending appointments challenging instead. With increasing age, hearing and vision can deteriorate and so some older people may need information provided in a suitably accessible manner if they have hearing impairment or visual impairment.

Ethnicity

The rate of familial breast cancer is higher in people with Ashkenazi Jewish ethnicity, which may lead to inequalities if the increased baseline risk of this population is not accounted for in testing criteria. However, evidence has shown that BRCA1/2 testing in

Ashkenazi women has high acceptability (Manchanda et al. 2019). Currently the National Genomic Test Directory includes women with breast cancer and Ashkenazi Jewish ethnicity as an indication for testing. Genetic testing has also been offered to people of Jewish heritage as part of the NHS Jewish BRCA Programme, which has been well publicised and has received high uptake. However, the NHS Jewish BRCA Programme is due to end in October 2025. Prior to the NHS Jewish BRCA Programme, most clinical genetic departments had mechanisms in place to offer foundation mutation testing to people with Ashkenazi Jewish heritage.

Black African women are less likely to go to their population breast screening appointment compared to other communities in the UK. Only 49% of black African women who are invited to population breast screening go to their appointment compared to 67% of white women and 63% of black Caribbean women (Breast Cancer Now). However, it is unclear that these disparities would still be present in people being screened because they are at higher risk of breast cancer due to their family history. Although more deprived and ethnically diverse areas tend to have lower uptake of breast cancer screening, a study of British-Pakistani women from lower socioeconomic backgrounds found that their views towards implementing stratified routine breast screening were positive, and women in this community wanted to know their personal risk of developing breast cancer (Woof et al. 2020).

Evidence has shown that uptake of risk-reducing bilateral salpingo-oophorectomy is significantly lower in black and Asian women with BRCA1/2 pathogenic variants compared to white women with BRCA1/2 pathogenic variants (Hassan et al. 2025). Although black women with breast cancer may be less likely to continue taking hormone therapy to prevent recurrence of breast cancer (Breast Cancer Now), evidence has shown that there is no difference according to ethnicity in reported use of risk-reducing tamoxifen for women at moderate or high risk with no personal history of breast cancer (Hackett et al. 2018).

People from ethnic minority family backgrounds may have additional barriers to receiving healthcare, including different language needs and cultural expectations. People who do not speak English as a first language may have difficulty describing their medical history in English, potentially leading to misclassification of risk. Language barriers may also make it more difficult to access information and discuss and understand risk-reducing options and their associated benefits and harms. British-Pakistani women from lower socioeconomic backgrounds have highlighted additional barriers to determining breast cancer risk, such as limited IT proficiency for completing online risk assessment questionnaires (Woof et al. 2020).

Disability

Fewer disabled people participate in population breast screening because of a range of barriers, including lack of accessibility of screening equipment and screening locations. It

is likely that these issues may still apply for disabled people undergoing screening for increased risk of breast cancer due to their family history, and these issues may be particularly exacerbated in people who need breast MRI surveillance, which takes longer than mammographic surveillance.

It can be harder for healthcare practitioners to gather information about a person's family if they have a learning disability, and this degree of difficulty is dependent upon the extent of the person's disability. People with more severe learning difficulties will be more reliant on their carers throughout genetic testing and counselling, and decisions may need to be made on the person's behalf where it is in their best interests. It can also be difficult for healthcare professionals to assess the extent of a person's learning disability, and this can make it more difficult to determine what additional support a person with a learning disability needs. People with a learning disability may also be less likely to seek advice when needed. There is less uptake of screening in people with learning difficulties, and in 2017/18, only 52.2% of women with a learning disability had been screened for breast cancer, compared to 68% of women without a learning disability (Mencap). It can also be difficult for people with learning disabilities to find suitable information about cancer, as books written for the general adult population can be difficult for them to follow (Cancer Research UK).

A person with a learning disability may have additional information needs and require information to be provided in a manner that addresses these needs to be fully accessible for example easy to read information leaflets or verbal communication. 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. In certain situations, there is also a need for best interest meetings where a multidisciplinary meeting is arranged for specific decisions around the person's care if they lack the mental capacity to make the decision themselves.

Some disabled people may need support to physically access appointments (with travel or accessing buildings) and a lack of availability of carers/ family members may compound this problem. 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 have imaging or treatment.

Some evidence has shown that women with higher HADS-Anxiety scores have higher psychosocial needs when initiating testing for high breast cancer risk (Bredart et al. 2008).

Religion and beliefs

In some religions and cultures, cancer is not openly talked about which prevents family members from seeking further help early on. It may also be the case that for some people, screening contravenes their cultural values of modesty and privacy. Some options for treatment, such as the willingness to access risk reducing options and breast reconstruction, may also be limited/ complicated by cultural and religious factors.

Sex

Around 70% of women with a pathogenic variant in either the BRCA1 or BRCA2 gene with develop breast cancer by the age of 80 (Cancer Research UK). Although lifetime risk of breast cancer is generally below 1% for men carrying a pathogenic mutation in BRCA1, PALB2, and CHEK2, it is between 2 and 8% if they have a BRCA2 mutation (UK CGG). There is less evidence around breast cancer in men, however, it is known that breast cancer is also more likely to occur in men who have higher levels of oestrogen (for example due obesity and liver conditions), gynaecomastia, or Klinefelter syndrome (CoppaFeel, Sessa et al 2023).

Sexual orientation and gender reassignment

Trans people and non-binary people may face barriers to accessing healthcare services (including access to testing). Gender-affirming hormone treatment can impact the risk of breast cancer. The risk of breast cancer in trans women is about three times lower than for women, but is still much higher than for men, as oestrogen therapy can lead to breast tissue growth and an increase in breast cancer risk (OUTpatients). Trans women with a family history of breast cancer may be less likely to be invited for population breast screening where they are assigned male on their medical records. There are also known issues with NHS IT systems, where it is not currently possible to add people who are registered as male on their medical records to the very high risk (VHR) screening programme.

Trans men have a five times lower risk of breast cancer than women, however, the risk of breast cancer in trans men is still higher than for men (OUTpatients). Chest reconstruction in trans men reduces breast cancer risk, but not to the same extent as risk-reducing mastectomy, as some tissue is generally retained in order to construct a masculine chest contour. Additionally, the appropriate screening modality for trans men who have had chest surgery is unclear as mammography is difficult in this population (Giblin et al. 2023).

Evidence from multiple studies has shown that adherence to breast screening is lower in trans people compared to non-trans people. This could be due to anticipated discrimination from healthcare professionals for both trans men and trans women. Trans men may face additional challenges around screening as it is often incongruent with their gender identity and may lead to increased gender dysphoria (Giblin et al. 2023).

Screening uptake in lesbian woman and bisexual women is similar to heterosexual women. However, breast care services may not be adequately inclusive for LGBTQ+ groups. For example, LGBTQ+ groups may be intimidated by heterosexually-oriented cancer support groups, and mastectomy support groups discuss intimacy with partners, which can make it difficult for people who identify as LGBTQ+ to participate.

Pregnancy and maternity

Screening with mammography can be safely performed during pregnancy, however, its effectiveness is reduced as breast density increases during pregnancy and lactation. MRI during pregnancy is not recommended due to the high level of background parenchymal enhancement during pregnancy and lactation (NHS England). Fertility can be a concern for people deciding whether to have risk-reducing bilateral salpingo-oophorectomy. Additionally, chemoprevention agents are not suitable for people during pregnancy. The BNF also states that tamoxifen suppresses lactation and should be avoided during breast feeding unless the potential benefit outweighs the risk (BNF). The effect on their ability to breast feed a baby at that time or in the future can also be a concern for people who undergo mastectomy, especially if it is a bilateral mastectomy where tissues and structures necessary for breast feeding have been removed from both breasts.

Socioeconomic deprivation

The least-deprived groups tend to have a higher incidence of breast cancer. This may be due to factors such as higher rates of alcohol consumption, increased use of menopausal hormone therapy, and oral contraceptives (Slade 2024). It is unclear whether the least deprived groups also have a higher incidence of familial breast cancer.

Poorer outcomes, including increased mortality are observed in more deprived groups. People in deprived groups are less likely to participate in breast screening and are less likely to be referred urgently for assessment of breast symptoms. This can result in a delay in diagnosis. People from deprived groups are more likely to have uncertain work arrangements and higher personal costs when seeking healthcare, which may make participation in screening and treatment more challenging. Transport availability and cost may also be a limiting factor to people from deprived groups attending appointments and as a result altering their treatment options. Women at moderate and high risk of breast cancer in low socioeconomic groups may be aware of fewer breast cancer symptoms compared to high socioeconomic groups (Green et al. 2023). Similarly, there is evidence in women at moderate and high risk of breast cancer showing that people educated to degree level were aware of a higher number of breast cancer symptoms than women who were not educated to degree level (Green et al. 2023).

Evidence has shown that BRCA1/2 testing is significantly higher in less deprived social groups (Martin et al. 2019), and some analyses have shown that time from proband BRCA testing to receipt of BRCA testing by family relatives is quicker in the least deprived quintile compared to the most deprived quintile (Martin et al. 2020). Evidence in

women with BRCA1 and BRCA2 pathogenic variants with a personal history of breast cancer has shown that bilateral salpingo-oophorectomy uptake was higher in women in the least socioeconomically deprived areas compared to the most economically deprived areas (Hassan et al. 2025). However, evidence in women at moderate or high risk with no personal history of breast cancer, has shown that there is no difference in reported use of risk-reducing tamoxifen according to socioeconomic status (Hackett et al.2018).

Geographical area variation

Breast cancer is most common amongst people from white ethnic family backgrounds. Affluent areas in the south where these populations are most prevalent have more breast cancers and breast cancer is least common among people living in deprived areas. Differences in behavioural risk factors such as levels of obesity, alcohol consumption, physical inactivity, and increased menopausal hormone therapy prescribing in different populations may explain some of the geographical variation. NHS Breast Screening Programme (NHSBSB) Statistics shows higher levels of breast cancer screening uptake in more affluent areas so this may explain why people living in affluent areas in the south of England are more likely to have screen-detected rather than symptomatic cancers.

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. 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, for example, there may be variation in the number and type of breast reconstruction surgeries offered in different geographical regions which may impact decisions people make about risk-reducing surgery. Additionally, there is variation in the availability of specialist menopause clinics which may be needed to manage treatment for the menopause in people at increased risk of breast cancer.

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 and familial breast cancer.

People from inclusion health groups such as Gypsy, Roma, Traveller communities, people experiencing homelessness, people in prison and migrants may face barriers to registering with a GP practice and may not be invited for breast screening. They may face financial challenges and may not be able to afford travel costs to attend breast cancer screening or receive cancer care. Migrants may be deterred from seeking care because of NHS charges and fear of medical information and their contact details being shared with immigration enforcement. Migrants, refugees and asylum seekers may have limited knowledge of their family history, which can hinder assessment of breast cancer risk. Conversely, some migrants may know their family history and have the language

skills needed to outline any breast cancer in their family history, but it would prove difficult for health care professionals to confirm this as they do not have health records from the migrant's country of origin. For Gypsy, Roma and Traveller communities, barriers to cancer screening services could include language difficulties, low literacy levels, poor knowledge of the health system, and distrust in authority. They may also move around a lot making it harder for healthcare professionals to access previous imaging results for comparisons between scans. Other groups of people who may be vulnerable include those who are adopted, in state or foster care because they may not know their family history.

In prisons, breast cancer screening is mostly undertaken at the prison itself in a mobile screening unit at an agreed frequency. This should be once every 3 years according to the NHS breast screening programme. However, if a person arrived after the screening unit visit then they may have a to wait until the next visit to be screened irrespective of when their screening would have taken place in a non-prison setting, potentially delaying their diagnosis if they have breast cancer.

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

The aim is that the membership of the committee will represent various perspectives and expertise so that equalities issues are adequately considered throughout the development of the guideline. We will try to make sure that different viewpoints and backgrounds are covered by appointing lay members with different perspectives, expertise and lived experiences of familial breast cancer.

The guideline aims to give special considerations for the subpopulations identified in box 2.2 by taking these groups into consideration when developing review protocols and making recommendations. The committee will consider whether evidence specific to the subpopulations should be sought and whether any data identified should be analysed separately. The committee will consider whether separate recommendations are required for specific subpopulations to promote equity for each topic area.

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?

We plan to have a consultation period for the scope. Engagement with voluntary sector organisations will be key in engaging with people with lived experience of familial breast cancer including people who have undergone and/or have had genetic testing for pathogenic mutations associated with an increased risk of breast cancer. We will work

with the NICE people and communities involvement and engagement (PCIEP) team to encourage representation from stakeholder groups that can help to explore health inequalities. We are not running a stakeholder workshop for this piece of work.

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?
We have recruited lay members in enough time for them to contribute to the final scope of the guideline and to provide input to this document. We will also consider asking specific questions during guideline consultation addressing people with lived experience to ensure we gain as much insight from their perspective as possible. This could potentially be facilitated by having direct contact with voluntary/charity sector organisations who engage with people who have lived experience. Examples of charities include BRCA + chat, Prevent Breast Cancer and Breast Cancer Now. We will liaise with lay members to identify any relevant charities that they might be already engaging with. We also may engage with charities who represent certain groups, such as OUTpatients, where there is a lack of evidence around groups who face particular equality and health inequality issues. In order to facilitate lay members participation in the committee meetings, we will consider offering additional support, depending on their situational needs.

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?
We do not plan to ask any specific questions about health inequalities during 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?
1. Children and young people under the age of 18 years are excluded from the scope of this guideline. Even for people at very high risk of breast cancer due to pathogenic mutations in breast cancer predisposition genes, the youngest age at which surveillance commences is 20 years (in people with a likely pathogenic/pathogenic variant in TP53) according to NHSE guidance on women are very high risk of breast cancer. Similarly, risk-reducing treatment is unlikely to be considered in people under

18 years. Therefore, exclusion of this population of the guideline is unlikely to have an impact on their care.

2. Men will be excluded from recommendations around the risk of developing breast cancer prediction, surveillance and risk reduction strategies. The lifetime risk of developing breast cancer is generally below 1% in men who have a pathogenic variant in a breast cancer predisposition gene (except for BRCA2 where the lifetime risk is between 2 and 8%). Men are not eligible for screening as part of breast screening for very high risk women or population breast screening, and mammography is difficult in this population. It is also unlikely that risk-reducing treatment would be considered in this population. Men are included in recommendations relating to genetic testing, as a positive genetic test would have implications for related family members.

3. Trans women and non-binary people born with male reproductive organs who do not have a personal history of breast cancer, and have not received gender-affirming hormone treatment for 5 or more years, will be excluded from recommendations around risk prediction, surveillance and risk reduction strategies, but will be covered by recommendations relating to genetic testing, as a positive genetic test would have implications for related family members.

Completed by developer: Marie Harrisingh, Topic Lead

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Approved by committee chair: Dr Alison Cameron

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Approved by NICE quality assurance lead: Kate Kelley, Associate Director

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