

Equality Impact Assessment Report

Breast Screening Standards Project

December 2018

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Contents

1. Introduction	4
2. Aim/purpose of the breast screening standards.....	6
3. Assessment of impact	8
4. Recommendations for change	15
5. Who carried out the impact assessment?.....	16
6. Contact information	16
References	17

1. Introduction

Healthcare Improvement Scotland is required to assess the impact of applying a proposed or revised policy against the needs of the general equality duty. This duty requires that all reasonable effort should be made to:

- eliminate unlawful discrimination, harassment and victimisation and any other conduct prohibited by the Equality Act 2010
- advance equality of opportunity between people who share a protected characteristic and people who do not share it, and
- foster good relations between people who share a protected characteristic and people who do not share it.

The relevant protected characteristics are:

- age
- disability
- gender reassignment
- pregnancy and maternity
- race
- religion and belief
- sex
- sexual orientation, and
- marriage and civil partnership (relates to the elimination of discrimination only).

The recommendations made in this report aim to improve equality and help meet the specific needs of people with relevant protected characteristics.

This impact assessment is also influenced by possible health inequalities that may affect the development, implementation and outcomes of the breast screening standards.

Health inequality is defined as unjust and avoidable differences in people's health across the population and between specific population groups¹. These arise as a consequence of inequitable distribution of income, wealth and power. They are influenced by factors that include access to education and employment, the physical environment in which people live, and connected feelings of empowerment and efficacy.

These influences are affected by individual circumstances. They are often defined by whether or not a population is more or less likely to act in a particular way, or has greater or lesser access to information and services than a comparable group. Disparity between groups on issues such as access to good quality housing, the rates at which people smoke, drink, and take regular exercise, all affect the likelihood of positive or negative health outcomes.

¹ <http://www.healthscotland.scot/health-inequalities/what-are-health-inequalities>

2. Aim/purpose of the breast screening standards

The aim and purpose of these standards is to support territorial NHS boards to assess the quality of breast screening and encourage service improvement.

The standards apply to the following areas:

- leadership and governance
- information and support
- call and recall
- the screening process
- recall for assessment
- surgical referral, and
- detection rates.

Clinical Standards for Breast Screening, published in 2002, were identified for revision by Healthcare Improvement Scotland in 2016. They are intended to complement existing standards and guidelines and should be read alongside relevant legislation²⁻³, including:

- Healthcare Improvement Scotland 2008
http://www.healthcareimprovementscotland.org/our_work/cancer_care_improvement/programme_resources/standards_for_cancer_services.aspx
- IRR17 The Ionising Radiations Regulations 2017
<http://www.legislation.gov.uk/uksi/2017/1075/contents/made>
- NHSScotland 2016
http://www.healthcareimprovementscotland.org/our_work/cancer_care_improvement/cancer_qpis/quality_performance_indicators.aspx

² Public Health England. NHS Breast Screening Programme: Consolidated Standards. 2017 [cited 2017 Oct 10]; Available from: <https://www.gov.uk/government/publications/breast-screening-consolidated-programme-standards>.

³ NHSScotland. Breast Cancer: Clinical Quality Performance Indicators. 2016 [cited 2017 Oct 10]; Available from: http://www.healthcareimprovementscotland.org/our_work/cancer_care_improvement/cancer_qpis/quality_performance_indicators.aspx.

- Public Health England 2017
<https://www.gov.uk/government/publications/breast-screening-consolidated-programme-standards>

Breast screening aims to reduce the number of deaths from breast cancer through early detection and treatment. The Scottish Breast Screening Programme is a population-based service which aims to help early detection.

Breast cancers are more prevalent after the age of 50 compared with younger women. Eligible people are offered screening every 3 years between the ages of 50 and 70. Those over the age of 71 are able to access screening through self-referral. Women who have had a bilateral mastectomy do not require breast screening.

NHSScotland's territorial boards are responsible for ensuring women are invited for breast screening. The service is delivered by six screening centres and a number of mobile screening units.

Screening is supported through the Scottish Government *Detect Cancer Early* programme and the UK National Screening Committee. The Scottish Government programme aims to improve cancer outcomes through data collection, monitoring and promoting public awareness. The UK National Screening Committee (UK NSC) sets policy for the UK's four nations. Revised breast screening standards reflect the influence of Scottish and UK policies, including the *NHS Breast Screening Programme Consolidated Standards* (Public Health England 2017).

3. Assessment of impact

It is expected that the revised breast screening standards will positively affect health outcomes for eligible women across Scotland. This impact assessment considers the potential effects the standards will have on people with the following relevant protected characteristics:

Age

Breast screening in Scotland is routinely offered to all women between the ages of 50 until their 71st birthday, in compliance with recommendations given by the UK NSC (Public Health England 2017). Women in this age range receive invitations to screening every 3 years. Those 71 and older receive screening only through self-referral: woman who have had a bilateral mastectomy do not require breast screening regardless of age.

Women below the age of 50, without a family history of breast cancer, are not routinely invited for screening. This is because mammograms have limited effectiveness in identifying cancers in pre-menopausal women. The density of young women's breasts compared with those of women aged 50 years and above makes effective imaging harder to achieve. High risk younger women under the age of 50 are often added to a surveillance group, where they receive frequent screening. Women in this group are more likely to be offered a Magnetic Resonance Imaging (MRI) scan rather than a mammogram, as these are more effective in identifying cancers in younger women.

The risk of developing breast cancer increases with age, with a third of all breast cancers occurring in women over 70 years of age⁴. It is, therefore, important that women are made aware that self-referral is available every 3 years for all women over the age of 71.

Disability

Women with physical or hidden impairments and those with learning difficulties may face barriers to effective breast screening. Studies show that uptake of

⁴ Public Health England - NHS Breast Screening Programme, Over 70? You can still have breast screening if you choose – January 2007, updated May 2018: <https://www.london-breastscreening.org.uk/files/BSP06-Over-70-breast-screening.pdf>

screening invitations may be negatively affected by impairment type and associated health inequality.

People with learning impairments have, in general terms, been identified as experiencing more health problems than the general population, yet they experience poor access to health services (Disability Rights Commission [2006]. Equal Treatment: Closing the Gap).

It has also been evidenced that approximately 50% of people with learning impairments have difficulty communicating (Stokes and Clift 2012). These communication difficulties can act as a barrier in a clinical setting. Equality of access and understanding may be negatively affected if the screening process is rushed or is not explained to disabled people in ways which are accessible.

It is suggested that the uptake of screening amongst people with learning difficulties can be influenced by factors such as physical access, the values and prejudices of medical staff, and a disabled person's response to unfamiliar people and environments. Those who may have had past negative experiences interacting with clinical services may be dissuaded from engaging with screening, and in some cases, a learning impairment may limit the level of understanding a person has about their body⁵. Access to screening for physical and learning impaired women may also be affected by living circumstances, the consequence being that they may not be invited for routine screening.

Barriers beyond this have, at an international level, been suggested to include physical and structural access, as well as the process of breast screening. A small Australian case study research project (Peters and Cotton 2016) highlights inaccessible venues and screening equipment as having a negative impact on the uptake of screening amongst some physically impaired women. The Scottish environment appears to recognise these barriers as being influencing factors on uptake of screening services. NHSScotland provides publicly available information about its screening venues and mobile units, giving details of adjustments that can be made for women with physical impairments. The screening process is routinely carried out by female clinical staff who ensure that all women are given time to ask questions⁶.

⁵ Stokes.A, and Clift. J. (2012).Supporting people with learning disabilities who have a cancer diagnosis. Lancashire Care NHS Foundation Trust.

⁶ <https://www.nhsinform.scot/healthy-living/screening/breast/breast-screening>

Gender reassignment

Transgender people are more likely to encounter barriers to general health care arising from issues of social stigma, perceived and real negative perceptions of medical staff and associated psychological distress. Evidence shows that transgender people can often be made to feel like they are an inferior part of society as a consequence of the expressed or implied behaviours of others (Phillips, Fein-Zachary et al. 2014). This may lead to transgender people failing to disclose their gender identity when engaging with medical services.

Transgender women – male to female (MTF) – often receive hormone treatment as part of their transition process. The prolonged use of some hormones has anecdotally been suggested as a contributing factor in an increased risk of breast cancer, similar to natal post-menopausal women⁷⁻⁸.

Transgender men – female to male (FTM) – aged 50 to 70 should receive routine invitations to breast screening if they have not undergone breast reconstruction surgery or have remaining breast tissue. Transgender women (MTF) who have a history of hormone therapy should similarly be invited to routine screening between the ages of 50 and 70. This is because of an associated increased risk of developing cancer (Public Health England 2017).

Transgender people should be encouraged to attend screening and discuss any issues with their GP. This is more likely to be achieved if they feel confident that they will not be judged and discriminated against by medical staff. The potential for many transgender people not to receive an invitation to screening may, however, remain quite high in comparison with non-transgender people. This can often be a consequence of transgender people not being accurately recorded on NHS databases.

People living in Scotland are assigned a Community Health Index (CHI) number. This is a record of an individual's date of birth, gender identification and is a unique identifier. It enables NHSScotland to identify who should be invited for routine screening. Currently the ninth digit of the CHI number is always even for

⁷ Coleman E, Bocking W, Botzer M, et al. Standards of care for the health of transsexual, trans-gender, and gender-nonconforming people, version 7: <https://www.ajronline.org/doi/10.2214/AJR.13.10810>

⁸ Rossouw JE, Anderson GL, Prentice RL, et al.; Writing Group for the Women's Health Initiative Investigators. Risks and benefits of estrogen plus progestin in healthy postmenopausal women: principal results from the Women's Health Initiative randomized controlled trial: <https://www.ajronline.org/doi/10.2214/AJR.13.10810>

people assigned as female and odd for people assigned as male. Transgender men (FTM) may not receive invitations to screening if they changed their CHI number to reflect their post-transition gender before 14 June 2015⁹. Those who transitioned after this date will automatically be invited for breast screening. There is, therefore, potentially a number of people who have not received invitations to screening. Transgender people may benefit from greater engagement which sensitively highlights the risks of not having an up-to-date CHI number. This should be done in a context of dignity, respect, choice and control.

Pregnancy and maternity

Pregnancy has been shown to influence positive and negative rates of breast cancer. The likelihood of developing breast cancer correlates to a woman's exposure to particular hormones, namely oestrogen and progesterone. Women who have had long term exposure to these cell stimulating hormones are at greater risk of developing breast cancer than those who have had less exposure. The production of these hormones relates to a range of reproductive factors. Those who become pregnant at a late age, or have never given birth will have greater lifetime exposure and, as a consequence, they are more likely to develop breast cancer than women who give birth below the age of 30 (Kelsey JL, Gammon MD, John EM, 1993).

The likelihood of developing breast cancer throughout their lifetime is further decreased in women who have had multiple births. Women who have given birth to five or more children have, in some cases, been shown to have half the rate of breast cancer compared to women who have never given birth (Lambe M, Hsieh CC, Chan HW, et al., 1996). Mothers who chose long-term breast feeding have also been shown to have lower instances of breast cancer (Ma H, Bernstein L, Pike MC, Ursin G. 2006).

Hormone production can, in rare cases, lead to the development of cancer during pregnancy. This can be difficult for women to identify, as breast tissue naturally changes at this time, making it harder than normal for women to self-examine their breasts. Women should be made aware of this possibility and be encouraged to seek medical advice should they discover any abnormalities.

⁹ <https://www.nhsinform.scot/healthy-living/screening/screening-information-for-the-transgender-community> d

Race

The level of screening uptake amongst minority ethnic people has historically been low compared to the general UK population. Barriers that negatively affect uptake have been shown to include poor knowledge, health and cultural beliefs. Language barriers and attitudes of clinical staff are also recognised as influencing factors, along with the wrongly held belief amongst many minority ethnic women that they are unable to specify the preferred sex of screening staff (Thomas et al, 2005). This lack of knowledge and poor clinical communication has been suggested to have a negative impact on screening uptake amongst many ethnic groups (Patnick, 2007).

Asian women who speak, but do not read, Urdu or Punjabi are amongst some of the groups least likely to engage with screening services. These women may receive screening invitations in an inaccessible format that acts as a barrier to effective screening uptake (Isaacs, 2008). This is an example of how unresponsive communication methods can have a negative impact on access to clinical services amongst some ethnic groups.

Gypsy/Traveller women, similar to many women in the Asian community, can also have limited access to breast screening services. The barriers which they might face include racism, differing cultural beliefs amongst those in the community and clinical staff, inadequate service provision and lack of a postal address (Atterbury, 2010).

Gypsy/Traveller women may often be adversely affected by a GP's unwillingness to visit campsites and communication difficulties between those in the community and medical staff. The culture within the community often does not promote knowledge and understanding of health services, resulting in a lack of engagement. This barrier is compounded by low levels of literacy within many Gypsy/Traveller communities and the belief that screening will be carried out by a man – something which is commonly culturally unacceptable.

Race and associated cultural norms can potentially also affect diagnosis and likely survival from breast cancer. Women in black ethnic groups are more likely than white women to be diagnosed with breast cancer at an advanced stage. This has been suggested to reflect low cancer awareness within black ethnic

groups, resulting in women within these groups taking longer to seek medical advice or access screening compared to white women¹⁰.

Religion or belief

Church attendance and strong religious commitment has anecdotally been linked to increased uptake of screening services (O'Reilly, D et al, 2013). Women who regularly attend church have been shown to be more influenced by preventative actions than those who do not. This can result in greater inclination to self-examine and attend breast screening. Levels of screening uptake amongst Jewish and Christian communities can vary dependent on denomination. Uptake within groups of women who are not affiliated with specific religions, but who have had past affiliation, are also high compared to those who have no current or past religious commitment.

Studies have highlighted that discrimination within healthcare systems, as opposed to wider societal discrimination may limit access to repeated breast screening within certain religious communities. The Islamic community in particular may limit its access to screening because of potentially discriminatory practices within health services, rather than because of commonly considered barriers of modesty¹¹⁻¹². This is further supported by evidence that Muslim women may be willing to attend initial screening, overcoming barriers of modesty, but they are less likely to attend repeat screening if direct or indirect discrimination exists within the healthcare system.

Sex

The breast screening standards are for all eligible women: those routinely invited to screening between 50 years of age and their 71st birthday. The standards also apply to older women above the age of 71 who request screening.

¹⁰ <https://www.kcl.ac.uk/nursing/research/nuru/research-programme/Carequalityandoutcomes/Barriers-to-early-presentation-and-diagnosis-with-breast-cancer.aspx>

¹¹ Padela AI, et al. Religious values and healthcare accommodations: voices from the American Muslim community. *J Gen Intern Med.* 2012; 27(6):708–15.

¹² Rashidi A, Rajaram SS. Culture care conflicts among Asian-Islamic immigrant women in US hospitals. *Holist Nurs Pract.* 2001; 16(1):55–64.

Sexual orientation

Evidence from a number of third sector organisations that represent the interests of LGBT+ people shows that they are more likely to experience greater healthcare inequality. They are also more likely to experience higher rates of mental and physical health problems, and face barriers to effective and equitable healthcare.

Evidence also shows that lesbian and bisexual women could be more likely to develop breast cancer, but are less likely to regularly self-examine their breasts for abnormalities (Fish and Wilkinson, 2003). This increased likelihood of developing breast cancer has been suggested to be linked to the fact that lesbian and bisexual women may not have children, or are more likely to delay childbirth to beyond the age of 30. Evidence of higher rates of drinking within the LGBT community and a greater tendency to be overweight have historically also been suggested to potentially be influencing factors.

Based on the evidence available, it would appear that the motivations for lesbian and bisexual women to engage in regular self-examination can differ from those of heterosexual women. Those in the latter group seem to be more likely to be driven by a preventative approach to breast cancer, whereas those in the former are more influenced by their own breast problems, or those of friends. Family history of breast cancer and other risk factors have also been identified as motivational influences on whether or not lesbian and bisexual women self-examine. A lack of routine checking may account for increased occurrence of breast cancer amongst lesbian and bisexual women, as opposed to historically presumed causes. Infrequent self-examination may mean that abnormalities are discovered at a later stage.

Some lesbian and bisexual women may resist frequent contact with medical professionals because of previous negative experiences, or because of a reluctance to discuss their sexual orientation or because of a fear of possible negative attitudes amongst health workers.

4. Recommendations for change

Recommendations are informed by the evidence detailed in Section 3.

Recommendation 1 – Consider engaging with women of varying ages, including women within the invitation range and women over 70, during the consultation phase of the breast screening standards. Try to ensure diversity across the age range, taking steps to specifically include minority ethnic women, LGBT+ groups and groups of women perceived to be at a higher risk.

Recommendation 2 – Consider engaging with disabled women who have a range of hidden, physical and learning impairments. Engagement with people who represent the interests of disabled people should also be considered, including but not limited to, personal assistants, carers and third sector organisations that represent their interests.

Recommendation 3 – Consider engaging with transgender people and consider how transgender people are acknowledged within the standards, ensuring that all terminology used is respectful and appropriate.

Recommendation 4 – Consider how the standards can support an improved experience for lesbian and bisexual women, based on the evidence gathered.

Recommendation 5 – Consider if it is within the scope of the standards to address potential issues identified relating to an improved experience for women who are pregnant.

Recommendation 6 – Consider how the standards can support an improved experience for minority ethnic people and how potential barriers to accessing services might be addressed.

Recommendation 7 – Consider the involvement of a range of religious groups during the consultation process.

Recommendation 8 – Consider the evidence gathered and how potential barriers to accessing services for those groups already identified, may also impact people who are homeless, people on low incomes, asylum seekers and refugees.

5. Who carried out the impact assessment?

The impact assessment of breast screening services was carried out by:

EQIA completed by – Allan Barr

EQIA reviewed by – Donna O'Rourke

6. Contact information

If you have any comments or questions about this report, or if you would like us to consider producing this report in an alternative format, please contact our Equality and Diversity Advisor:

Mario Medina
Healthcare Improvement Scotland
Delta House
50 West Nile Street
Glasgow
G1 2NP

Phone: 0141 225 6871

Email: mario.medina@nhs.net

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or email contactpublicinvolvement.his@nhs.net

Healthcare Improvement Scotland

Edinburgh Office

Gyle Square

1 South Gyle Crescent

Edinburgh

EH12 9EB

0131 623 4300

Glasgow Office

Delta House

50 West Nile Street

Glasgow

G1 2NP

0141 225 6999

www.healthcareimprovementscotland.org