

# Building a truly accessible, equal, and fair breast screening programme –

A consensus statement on health  
inequalities within breast screening

Working with:



# Consensus statement on health inequalities within breast screening

For decades, routine breast screening has been key to improving early diagnosis and boosting survival rates for breast cancer. But the current screening programme doesn't give everyone who's eligible a fair chance to get screened.

Barriers that prevent eligible people from participating in screening have an outsized impact on those who:

- Live in more deprived areas
- Are from an ethnic minority background
- Are disabled, including people with a learning disability, people with mental health conditions, and people with mobility or sensory impairments
- Are from Gypsy, Roma, and Traveller communities
- Are experiencing homelessness or live in insecure housing
- Are in the LGBT+ community, particularly trans and non-binary people

Existing NHS England guidance on how to improve uptake<sup>1</sup> in specific underserved groups looks at each of these communities and the barriers they face separately. In reality people often do not fit into neat categories and different populations face the same types of challenges when accessing care.

To look at this issue in more depth, Breast Cancer Now held a roundtable meeting bringing together a group of organisations and experts that work to combat health inequalities.

This statement is the result of that discussion, and represents our strong collective view of how breast cancer screening can become a truly inclusive and accessible service. It has been co-developed with invaluable input from and is endorsed by the following organisations:

- Black Women Rising
- Friends, Families and Travellers
- OUTpatients
- Pathway UK
- Queen's Nursing Institute
- Disability Rights UK
- Race Equality Foundation
- South Asian Health Foundation
- Mencap
- Caribbean & African Health Network

We will continue to collaborate with these partners to ensure the solutions set out in this statement are put into action so that inequalities in breast screening access are eliminated.

## An untenable position

The 2010 Equality Act directs NHS services to advance equality of opportunity by:

- Removing or minimising disadvantages
- Taking steps to meet people's needs
- Encouraging participation in activities where it is disproportionately low

But in practice, fair access to breast screening has never been a reality for many people. These underserved groups continue to shoulder the burden of inadequacies in the service. This reality needs to be treated as the urgent problem it is, and solved through concrete change rather than broad well-meaning rhetoric.

## Reframing the conversation

While there has been a growing awareness of health inequalities as an issue, efforts to address them tend to focus on finding ways for healthcare professionals and the underserved groups impacted to overcome barriers, rather than addressing the systemic driving forces of inequity.

Too often when talking about people's health, the language of personal responsibility and empowerment can obscure the fact that services like breast screening are not well equipped to support people who fall outside what is seen as the 'usual patient'.

This can be best encapsulated by one contribution during the roundtable – **“it's the system that needs to change, not the people accessing it”**

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<sup>1</sup>The proportion of eligible women who undergo screening within 6 months of being invited

## **Intersectional and inclusive solutions**

The roundtable identified fundamental limitations that can manifest in different ways but are shared across underserved groups. These limitations are outlined in detail in the next section.

We believe there are opportunities to change the system in ways that are relatively simple but massively impactful, removing barriers to entry for many different populations at the same time through:

### **Listening**

- Integrate relevant existing information within people's health records, including reasonable adjustments and communication needs, into breast screening databases and act upon it
- Establish a process of asking for and noting support needs, reasonable adjustments, or any information people want staff to be aware of ahead of their appointment as part of the booking process
- Proactively ask groups who do not engage with screening to share their concerns and work to counter any myths or misconceptions, for example through community of practice events
- Make services trauma-informed to support people who may find screening especially invasive or uncomfortable

### **Enabling**

- Offer routes into screening that do not depend on primary care records for eligible groups that are frequently left off automatically generated screening lists, for example due to their gender marker or because they are not registered with a GP.
- Provide all screening information and resources in the full range of accessible formats and languages, not just invite and result letters.
- Create more flexible ways for people who have been invited to get screened that fit with their lives and responsibilities where advanced booking is not possible or convenient.
- Require robust collection and assessment of equity data<sup>2</sup> by services, and use insights to evaluate and capture the value of different interventions.

### **Embedding**

- Work with underserved groups to inform the design of screening processes and services, so the system is built with them and their needs in mind.
- Make breast screening a standard issue for relevant healthcare professionals to routinely raise when they come into contact with someone eligible, with an offer to provide information or assist with booking if needed.
- Put in place clear expectations and standards for all services delivering breast screening to meet around inclusivity, and set out mechanisms for accountability to enforce these standards.
- Commit to a process of consistent, ongoing engagement with communities to establish breast screening as a visible and valuable routine service within underserved groups.

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<sup>2</sup>This includes but is not limited to ethnicity, disability, deprivation, religion, gender and sexual orientation

## **Fundamental limitations**

On the surface, the issues different groups experience when trying to access screening appear to be unique and specific. However, our discussion made clear that many of the same underlying factors drive poor engagement and uptake of breast screening services, specifically:

### **Trust**

Whether fuelled by fear, misconceptions, or previous bad experiences, the lack of trust in health services is a core issue for almost all underserved groups. This might be a lack of trust in believing the reasons why screening is being offered or in the service's ability to meet a person's needs, both of which make people reluctant to engage with screening.

### **Fear**

People from some underserved groups are more likely to have an expectation of or previous experience with receiving poor care. Some may have a history of trauma that leads them to avoid anything that could potentially deliver 'bad news'. This, combined with a belief that they wouldn't be able to access good care if diagnosed, stops them taking up screening.

### **Flexibility**

Almost all aspects of the screening process are standardised and don't adapt to an individual's needs easily or automatically. The current default, one-size-fits-all approach puts the burden on people to work around an overly rigid system, and makes screening a more resource intensive, and emotionally draining experience.

### **Accessibility**

Services often have a very narrow understanding of accessibility. For example, mobile screening units can help improve access, but only when the screening site which feels appropriate, is safe and easy to travel to, and can accommodate reasonable adjustments, like step free access. Access barriers are also not limited to physical considerations, but also the informational needs of people visiting a screening unit who may benefit from easy read or diagram-based information.

### **Accountability**

The absence of relevant data or metrics on screening inequity makes it challenging to pinpoint the communities who are most poorly served by the current system and see whether targeted interventions work as intended. Individual services have been given guidance and tools to tackle inequalities, but without dedicated staff, expertise, or investment to do this work, progress is limited.

### **Representation**

When people don't see themselves reflected in the public messaging and discussions around breast cancer, or if breast cancer is a taboo topic in their community, or something that is rarely discussed with friends and family, they can see it as an issue that doesn't affect people 'like them'. Increasing the relevance of breast screening in underserved groups requires more diverse representation in screening materials and for screening services to have a more visible presence in their community.

### **Collaboration**

Previous initiatives and efforts to engage and work with underserved groups to improve uptake have been limited to making small modifications within the current system, instead of building equity and fairness into the standard way the screening programme operates. Without meaningful input into the way services are designed from the ground up, barriers that may not be immediately apparent will persist.

### **Supportive systems**

Thinking about the social determinants of health, there are many common barriers to screening that are not directly related to the health service. The availability of public transport, childcare, eldercare, paid medical leave and safe housing will all determine who can reasonably access breast screening.