

**A systematic review of people's
experiences of breast screening:
a rich and diverse picture**

A summary

September 2021

1. Introduction

Public Health Commissioning NHS England and Improvement (NHSEI) South East commissioned Wessex Voices to undertake a unique systematic literature review of people's¹ experiences of breast screening. The review consolidates this significant body of evidence, painting a vivid picture of how people from diverse backgrounds experience and view aspects of the screening process. The intelligence gleaned should be used to inform the recovery of breast screening services, as well as influence evidence-based improvements to existing services.

The review findings are themed into five sections, namely:

- those that affect people's attitudes to breast screening
- on the invitation process
- on appointment times and location
- concerning the screening appointment itself
- about results

All themes emerging from this evidence highlight that providing equitable access to screening and additional personalisation of the process would be beneficial in helping to increase uptake, reduce inequalities, and improve existing processes.

This summary provides highlights from the findings and recommendations, drawn from the literature, for all stakeholders to actively consider acting on.

We would however encourage you to read the [whole review](#) for more detailed findings and examples of good practice to support the recommendations. It also contains more contextual and other useful information. A full set of references (as numbered in brackets) can be found in the review.

¹ <https://www.nhs.uk/conditions/breast-cancer-screening/when-its-offered/> and <https://www.gov.uk/government/publications/nhs-population-screening-information-for-transgender-people/nhs-population-screening-information-for-trans-people>

2. Summary of findings

2.1 People's attitudes to breast screening

...there is all sorts of lumps and bumps about there, so what is unusual? Are we looking for a hard pea? Are we looking for a soft bruisy type thing? What are we looking for? Basically, I would have absolutely no idea. [58]

The starting point for whether people are open to breast screening is awareness of their breast health generally. Many are unfamiliar and would welcome more advice and guidance around checking their breasts and screening. Factors that affect attitudes to breast screening are people's:

- Awareness and confidence around breast checks and general health
- Understanding the risk of breast cancer
- Expectations of the screening programme
- Understanding of what screening is and does
- The personal nature of the screening
- Attitudes and the age of carers/relatives of people with learning disabilities
- People's specific religious or cultural beliefs
- Fear and anxiety
- Lesbian, Gay, Bisexual, and Transgender people's experiences of prejudice and awareness
- Confidence in, or the fear of, the results
- Harm caused by screening

These issues vary between different groups of people - according to, for example, their age, family history, learning disability, understanding of English, familiarity with UK health services etc. These are however key to whether people will attend or not. The reassurance that breast screening can provide is a motivating factor for some, which if they have a good experience of the process usually means that it will become a regular part of their health care.

2.2 The invitation process

I think you should be more honest and say it is a bit uncomfortable, won't take long, we will take as little time as possible, be really nice to you and make you feel that your privacy is going to be well respected...I am quite a frightened person...if they gave you perhaps more information in the beginning...[it] might entice me to go. [58]

We reviewed people's expectations and understanding of the breast screening invitation: how it is formulated, who is included, and the information detailed within it. People receiving an invitation for the first time may have more concerns than those who have been before, so could welcome more advice and guidance. How the invite is received and understood varies between people, and there needs to be a way to address the questions and concerns that it might raise.

The following issues emerged from the literature in relation to the invitation process:

- Concern that a range vulnerable groups, including people with a learning disability and Transgender people, will not be invited
- Awareness of the access needs of people at invitation
- The tone of invitation
- Personalisation of invitation - e.g. to individual communication or health literacy needs
- Understanding the invite
- Providing ways of addressing questions and concerns
- The need for reminders
- The impact of COVID-19 pandemic on being invited for screening
- Missed invitations to screening in 2018

Again, at this very initial stage of the screening process these will impact on whether or not people take it up.

2.3 Appointment times and location

Missed an appointment once - cancelled it as my mother was dying - when I asked for another one they said I wouldn't be back in for another 3 years!!! The whole system needs to work. [63]

Key findings are the importance of:

- The offer and flexibility of appointment times
- Location of the screening facility
- Disability access to the facility
- Environment of screening location

People's expectations of the booking process concern the ease and speed of booking and rebooking appointments - important due to the nature of a busy lifestyle and the need to juggle numerous work and home commitments. There is limited flexibility in the current system. The location and environment of the actual screening can also impact on the user experience prior to and during the appointment and on attendance. These factors might also influence whether someone chooses to go the next time they are invited. Again, different groups of people experiences vary in relation to these areas.

2.4 The appointment itself

I found it very unpersonal. It was strange as nobody really said anything you were just ushered into a cubicle and then into a room for the screening. I wanted to ask some questions about the screening and how to prevent getting breast cancer but the staff were very off hand and clearly didn't want to talk to me. My advice would be don't expect anything except going into the van and being put into the machine. [97]

The following need consideration in relation to the experience of the screening appointment itself:

- Treating people with dignity and respect
- Ensuring effective communication
- The gender of healthcare professionals (HCPS) and the environment
- Disability access
- Support for people with learning disabilities
- Staff awareness and training
- The need to obtain ongoing patient feedback

People's expectations include being treated with dignity and respect. This might include their views on the gender of the HCPs that they encounter. Particular user groups have specific needs in relation to the appointment and what support can be offered to them. HCP training needs to cover this effectively. Obtaining and using feedback from attendees is also recommended for ongoing service improvement.

2.5 Breast screening results

She returned from holiday at the weekend to find a letter asking her to contact the hospital as a result of her breast examination. The letter appeared to contain no more information and she spent the weekend "frightened as hell". [58]

Three key factors were highlighted in relation to providing people's results:

- Speed of results
- Wording of the results letter
- How results are received

People's worries about the results or need for reassurance means that the speed and clarity of the information are tantamount. Meeting timescales for results is crucial, as are the accuracy, the wording and details of the results themselves.

3. Conclusion

Providing equitable access to screening should be seen as a priority. Many of the review findings suggest further personalisation, to reflect people's experiences according to their age, protected characteristics and other demographics, would benefit the whole screening process. This would improve people's awareness and understanding of breast health and screening, as well as improved experiences of screening. In turn this could enhance uptake, especially with groups where there is currently low take up.

How best to do this, as highlighted by the evidence, are set out in the [recommendations section](#). This includes where further insight needs to be gathered from groups of people where the literature is sparse or non-existent.

On the concluding note, it is worth remembering that so many moments associated with the entire process of breast screening can have positive or negative longer-term implications, based upon a single personal experience. Having these personal examinations can make people feel tense and vulnerable. Simple things like a warm welcome and helping people to relax makes a real difference, but so too is responding sensitively when they express discomfort.

4. Recommendations

Recommendations drawn from the literature review are summarised below for active consideration by the respective stakeholders. Page numbers are included in brackets to allow quicker reference to the underpinning rationale in the body of review for each recommendation.

NHSE/I National Breast Screening Programme

1. Consider the use of social media influencers and mainstream media to raise awareness of breast health, checks and screening (page 8, 9)

2. Review existing breast screening and breast checking promotional material, and ensure any new communication:
 - 2.1 Is accessible to the needs of specific groups by co-producing and tailoring messaging according to needs of culturally diverse groups (p 14)
 - 2.2 Includes targeted information for those with poor uptake or attending for the first time and with details of the whole process (p16-17)
 - 2.3 Avoids jargon, uses plain English, is available in alternative formats, such as Easy Read, other languages, large print, and is easily available online (p 10, 18,19, 20, 38)
 - 2.4 Raises awareness that breast screening is for anyone between the ages of 50 and 74 who has breasts or breast tissue (p 29, 35)
 - 2.5 Has consistent, accurate and inclusive information for transgender and non-binary people on the [NHS](#) website (rather than separately on the Public Health England website) (p 29)
 - 2.6 Includes reassurance and the benefits of early detection to address the fear of receiving bad news and harm caused by screening (p 32, 33)
 - 2.7 Explains why the NHS uses this type of test for screening rather than other types that people may be aware of or have experienced (p 15)

3. Revisit and revise invitation letter templates to ensure that the tone is appropriate (to reduce anxiety), in conjunction with Screening Quality Assurance Service (SQAS); including realistic timeline of when results will be available (p 37, 63)
4. Advise breast screening providers on adapting screening intervals based on family history and any previous health issues or risks in specific circumstances, in conjunction with SQAS (p 25, 31)
5. Provide advice to breast screening providers on mitigating risks if no breast screening options are accessible to an individual and consider the viability of alternative testing options, for example ultrasound (p 49)
6. Revisit the wording and information included in results letter template to ensure these do not increase anxiety in recipients (p 63)

Public Health commissioning and Screening and Immunisation Teams (SITs)

7. Review and update training requirements for breast screening providers, such as disability awareness, equality and cultural competency training (p 55, 59)
8. Ensure up-to-date information, guidelines and good practice around meeting people's specific needs are available to breast screening providers, for example for disabled people; PWLD; Lesbian, Gay, Bisexual, Trans and Questioning people; Black, Asian and minority ethnic groups; or people whose anxiety/ psychological issues may affect their willingness to go for screening (p 17,18)
9. Undertake further engagement work with vulnerable groups including people with poor mental health, refugees, asylum seekers, sex workers, prisoners, homeless where evidence is sparse (in association with Cancer Alliances and Local Authorities) (p 11, 34)

Cancer Alliances

10. Promote conversations about the positives of going for screening both through peer-to-peer discussions, and with healthcare professionals (p 11, 20)
11. Harness the power of communities by engaging and collaborating with them, and specifically with local seldom heard, minority and religious communities to help build trust and relationships, including with Muslim scholars to use religious text in support of ‘taking care of yourself to prevent disease’ (p 27)
12. Undertake further engagement work with vulnerable groups including people with poor mental health, refugees, asylum seekers, sex workers, prisoners, homeless where research literature is sparse (in association with SITs and local authorities) (p 11, 34)

Breast Screening Providers *(with advice and guidance from the National Team, SITs and SQAS as appropriate)*

Improvements should be considered at the different stages of the screening process managed by breast screening providers in the following ways:

13. Communications and promotional material
 - 13.1 Allow people to choose their communication preferences (Easy Read, large print, language preference, translations) and access requirements, record it, and ensure it is used to meet people’s needs (p 19, 36)
 - 13.2 Provide reassurance to people worried about accessing screening during Covid-19 (p 26)
 - 13.3 Share existing simple, accessible national resources about the entire screening process to better prepare and reassure people with what to expect (p 39)
 - 13.4 Ensure messages include the benefits of early detection to address the fear of receiving bad news (p 20, 25, 33)

14. Invitation Process

- 13.1 Ensure the timeline for results detailed in the invitation letter reflect the reality of when they are sent out e.g. if any delays due to Covid-19 (p 63)
- 13.2 Correspond using peoples' preferred method and ensure people's access needs have been considered (p 36, 37)
- 13.3 Encourage people to request translations and /or an interpreter to their appointment (p 19)
- 13.4 Ensure a map or an online link to adequate directions/ picture-based maps to the screening location is provided with the invitation letter (p 48)
- 13.5 Communicate any access issues of screening locations and advise on alternative sites (p 48)
- 13.6 Allow people to bring someone with them to support their access to screening. Where necessary, review any restrictions or practicalities that would prevent this (e.g. due to space and gender) (p 40)
- 13.7 Offer preferred gender healthcare professionals wherever possible. Where this is not possible, make sure people understand this before they come (p 55)
- 13.8 Consider text messaging reminders using guidance on content and phrasing to remind people about their appointments based on their communication preference (p 40-42)
- 13.9 Offer ways for people to ask questions or raise concerns during the invitation process (p 39)

15. Booking process

- 15.1 Evaluate the 'Open Invitation' approach and hybrid model used by some breast screening providers during the pandemic. Consider whether this could potentially be used in the longer term to make the system more flexible for appointment booking rather than distributing pre-arranged locations, dates, and times (p 45)
- 15.2 Consider alternative booking mechanisms e.g. for people who live in one area who may need to book in another, near work (p 46, 48)
- 15.3 Follow up on reported rebooking difficulties and consider providing occasional evening and weekend appointments in the long term (p 46)

16. Appointment

- 16.1 Discuss the process and what to expect when women arrive for their appointments, even if they have read the leaflet previously sent (p 54)
- 16.2 Review current screening environments being offered for their inclusiveness (p 50)
- 16.3 Investigate ways of making disability access easier during the screening, such as where feasible providing machines which allow for seated screening (p 56)
- 16.4 Consider the provision of specialist staff to help PWLD throughout the screening process and to include accompanying them (p 10, 57)
- 16.5 Offer educational and/or short (video) demonstrations about a self-examination as part of the screening appointment (p 9)
- 16.6 Treat people with dignity, respect and inclusivity as having these personal examinations can make people feel tense and vulnerable (p 53)

17. Results (p 62-63)

- 17.1 Ensure results are conveyed in a timely and clear way
- 17.2 Investigate ways to speed up the communication of results
- 17.3 Investigate reported delays with receiving results

18. Staff training

- 18.1 Review effective communication training techniques for staff (p55)
- 18.2 Ensure teams undertake disability awareness and cultural competency training (p 60)

19. Ongoing patient feedback

- 19.1 Explore ways of gathering and analysing ongoing patient feedback to inform service improvements (p 61)

20. Acknowledgements

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21. Contact us

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