A systematic review of people’s experiences of breast screening – A rich and diverse picture

September 2021

Contents

1. Summary

This unique systematic literature review consolidates the significant body of published evidence around people's experiences of breast screening from their many different perspectives. This insight paints a vivid picture about how people from various backgrounds experience and view aspects of the process – from the understanding and beliefs they hold before they attend screening, to their thoughts about and feelings upon receiving the results. The review also helps identify gaps in knowledge and areas where further insight is needed.

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

Recommendations are made based on the evidence collected. They are included throughout the review, with the intention of providing examples of good practice, as well as identifying actions for readers. The recommendations are later summarised in Section 11 for key stakeholders to actively consider for action.

2. Background

Wessex Voices were commissioned by Public Health commissioning, NHS England and Improvement (NHSEI) South East, to conduct a systematic review of breast screening literature. The aims of this were to understand the views of people eligible[1] for breast screening and identify gaps in knowledge and areas where further insight is needed.

---

[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

The objectives were to understand:

1. What works well in breast screening across the whole process from promotional materials and invitations, to the screening appointment and results.
2. What can be improved
3. People's views on:
    - communication throughout the process
    - text messaging (including views on content, acceptability and suitability)
    - why people attend breast screening and what the enablers are
    - why don't people attend, what are the barriers and what can be done to change this

The intelligence gleaned can be used to inform recovery of breast screening services, as well as evidence-based improvements to existing services.

3. Review methodology

Between April and July 2021, Wessex Voices conducted a systematic review of breast screening literature compiled from a variety of sources published since 2000. These included peer-reviewed journals, grey literature, reports from charitable and research organisations, governmental and health departments, and other online sources. A total of 105 sources were reviewed; 83 published between 2011 to 2021 and 18 between 2001 to 2010. Four peer-reviewed articles published before 2000 (also referenced in later articles) are included where insightful.

4. Overview of the findings

This review provides a detailed overview of the whole experience of breast screening. It paints a vivid picture of how many people with different backgrounds experience and view aspects of the process – from the understanding and beliefs they hold before they attend screening to their thoughts about and feelings upon receiving the results.

Where possible, we have used boxed participant quotes to introduce each section and highlight a personal example of the area being discussed. Quotes are verbatim unless minor amendments to punctuation aid legibility.

Findings have been separated into five sections, namely:

- Section 5: those that affect people's attitudes to breast screening
- Section 6: on the invitation process
- Section 7: on appointment times and location
- Section 8: the screening appointment itself
- Section 9: about results

We would encourage you to read the whole document to understand this rich and diverse picture. That said, the document can also be searched in different ways. For example, by groups of people or specific issues.

Use the 'Find' function to do this. Here are some terms you may wish to search by:

- Access (will pick up a variety of accessibility issues)
- African
- Anxiety
- Asylum
- Autism
- Black, Asian and minority ethnic
- British-Pakistani
- Carer
- Chinese
- Family (history of breast cancer)
- First time
- Homeless
- Lesbian (will pick up Gay, Bisexual and Trans issues but also search by Transgender for specific issues)

- Muslim
- Physical disability
- Polish
- Prisoners
- Psychological
- PWLD (people with learning disabilities)
- Roma (will pick up information about Gypsy, Roma and Traveller people)
- Translation
- Young (younger people)

Please note this list is extensive but not exhaustive.

Recommendation boxes are included throughout the review, drawing from people's experiences, good practice and suggested actions taken from the literature. A summary of recommendations, can be found in Section 11.

Appendices have also been included where information falls outside of the main scope of the report but may also be of interest or use to readers:

- *Appendix A* provides UK variations in uptake by region and particular groups
- *Appendix B* reflects the picture in other parts of the world
- *Appendix C* highlights positive descriptions of screenings and first screenings which have been documented during pre- and post-pandemic periods
- *Appendix D* details information on recall and follow up processes
- *Appendix E* provides a full list of references used in this review

A summary of this report can also be found on the Wessex Voices website in the publications section.

5. People's attitudes to breast screening

Section summary: It could be said that 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.

People's expectations and understanding of what the breast screening process is, what it does, and its importance are also vital. These and the other issues identified are key to whether people will take a decision to 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.

5.1 Awareness around breast checks and general health

> *...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]

Women in the Griffiths et al. [33] study reported more confidence in mammography screening than in checking their own breasts:
I always wonder whether I would be doing it properly enough. The confidence and the fact that I hadn't been checking properly and had missed something and totally ignored it, I don't know.

Their study suggests that many women perceived their (at risk) breasts as something external to the self to be submitted to technological surveillance. Screening being peripheral to daily life, something to be endured every three years and then forgotten about. The medicalised 'at risk' breast was 'parked' by women between screenings and bore little relation to the women's embodied experience. The authors suggest that an overreliance on experts making decisions could delay diagnosis; whereas women's self-awareness and confidence in their own agency to detect changes could be beneficial for early detection and treatment.

Previous studies [58] highlight that if self-examination is to be encouraged, not all women know how to do it and not all feel that the screening programme has equipped them with confidence to conduct self-examinations. 'How to examine?' was an area focused on by Boundouki et al. [14], with one participant highlighting that they didn't know a rash was a sign. The variation in signs and symptoms of possible breast cancer according to age and how these may affect presentation to a healthcare professional was also discussed in this study.

Recommendation: Use social media interventions to improve cancer awareness and uptake of screening. [74] Consider use of social media influencers and mainstream media to raise awareness of breast health, checks and screening. Consider different, accessible locations for supplying breast-awareness leaflets.

I watch 'Holby City'… they check it on the big screen, an x-ray and they feel for it [36]

I still think that we should be doing more about breast cancer awareness on the TV ads [14]

Boundouki et al. [14] highlighted different generations will access information differently, e.g., using different media sources. Some felt that social media and celebrity culture could be used to increase cancer awareness. As an example, Katie Claydon watched a TikTok video that taught her how to check her breasts. Thanks to the video, she was detected an abnormal lump, leading to a breast cancer diagnosis [32]. Another example is the use of Facebook Messenger to improve access to booking breast screening appointments [30].

Lack of self-checking help literature was noted in the Manchester Health and Care Commissioning (MHCC) report where a respondent commented that information about what to look out for when self-checking was not accessible [60].

Recommendation: Offer education and/or a short (video) demonstration about a self-examination as part of the screening service [58].

Those working in the breast screening programme noted that they were useful signposts providing information, advice and support [60]:

Working in the breast screening programme, my role as a clinical nurse specialist is to educate the ladies, to be a support aid, to provide information about each step of the process so that they know exactly what is happening … So regardless whether they have an intellectual disability or not … we are the signposts, we are there for information, we provide advice, we provide support.

A study by Hanna [34] of how care staff engaged in cancer prevention and health promotion activities on behalf of people with learning disabilities (PWLD) showed only 10.9% were offered advice about the importance of regular breast screening at least once a month, whilst 33.7% were never offered advice on the importance of regular breast screening. Lack of understanding in this group was highlighted by McIlfatrick et al. [60]:

… also, a lack of understanding of the procedure or of the purpose of the mammogram may be a barrier to the patient in that they really don't understand why they should be coming and don't realise the importance of it.

Recommendation: Consider the needs of specific groups such as PWLD.

Cornwall healthcare professionals (HCPs) have produced a video on what carers can do to help their PWLD (PHE Screening 2017). Suggestions are:

- Talk to them
- Explain what is going to happen
- Use the Easy Read information that is available
- Keep reminding and reassuring them
- Talk to the unit as it is very important to explain to staff about the person that is going to be coming along for their breast screening. Know that it is perfectly OK to ask if that person can go along and have a look first. Do

not be scared of talking to people in the breast screening unit. They are really passionate about their jobs and they want people to go.

The Jiwa et al. [102] study noted women were unaware of cancer risk around diet and 53% were unaware that mammogram screening was affected by breast density.

Recommendation: Raise awareness of breast health and screening as part of messaging around women’s general health and wellbeing from a younger age and throughout their lives.

Work with other campaigns on women’s health to ensure breast health is included. This was also suggested by Boundouki et al. [14] where there was particular concern about educating younger women, when this should take place and how to educate children. This encompassed the role schools in delivering information on breast self-examination, signs, symptoms and modifiable risk factors. In the Jiwa et al. study [102] 91.6% of women believed that breast health should be incorporated as part of the school education curriculum.

At a recent Wessex Cancer Alliance (WCA) public information event, participants highlighted projects like Coppafeel [21] which were aimed at younger people. This breast cancer charity solely focusses on awareness amongst young people, with the aim of instilling the knowledge and tools they need to get to know their bodies.

At the WCA event people also highlighted that they do not look for prevention messaging on cancer related websites, so it would be worth considering where best to put messaging.

Another promotional suggestion [14] concerned providing breast-awareness leaflets in lingerie departments.

5.2 Understanding the risk of breast cancer

Breast cancer runs in my family. Mum, aunt and Nana had it. Nana died of it. They leave it up to me to find out, they don't offer services. I want to be listened to and not shoved to one side and not taken seriously. [60]

I think that's a lovely alternative, it doesn't hurt much, giving a blood sample [14]

People's expectations of the screening programme will vary according to, for example, family history, aging for a PWLD, whether an existing health condition increases risk and experiences of screening in other countries. Providing clarity around this will help people know what they can expect and why they should take up the UK screening programme invitation.

One barrier noted in the MHCC report [60] was a lack of integrated approaches concerning family history:
My non-disabled sister has been getting a mammogram every year since she was 30. I have been told I have to wait until I'm 40 to have one. We have different GPs but live in the same area and have the same level of risk. I have now got a referral to the family history team. They are looking at the family history from scratch, even though my sister volunteered to share the info they already have for her. They are not joining up me and my sister. It feels like a barrier. I don't want to wait until I'm 40. I'm very anxious. It's hard for me to check my breasts. Can't someone help me to check my breasts? [60]

In the Jiwa et al. study [102] most women wanted to know their risk because of a family history of breast cancer (29.2%), a personal history of breast cancer/ previous breast disease (11.5%), or they were undecided between wanting to know their risk and concern that it would cause undue anxiety - especially if there was no acceptable treatment (4.3%). Respondents who wanted to know did so to proactively manage their health; particularly since they had family members or friends who had breast cancer or had died from it at a relatively early age. The systematic review by Román et al. [84] shows that there is currently no conclusive evidence to identify the most advisable personalisation strategies. Their results suggest the need for additional studies that also assess acceptability, feasibility, and the legal and ethical aspects of personalised screening strategies.

There was also discussion about screening age and the lack of understanding behind why ages are targeted [14]:
what age truly is too young? They all need to know about this…

Similarly, in the Jiwa et al. study [102] some comments focused on wanting to reduce the age of screening, drawing on personal experiences of participant breast cancer diagnoses and comparisons to breast screening pathways in other countries.

Crook et al. [22] detail that women with neurofibromatosis type 1 (NF1) have an increased risk of developing early breast cancer with a poorer prognosis compared to the general population. Therefore, international management guidelines recommend regular screening in women with NF1 starting from 30 to 35 years.

Due to the complexity of health issues that PWLD face their bodies age differently. This needs to be taken into consideration when developing screening programmes. One carer in the Brent Council report [16] explained that she looked after someone with a chronological age of 53, mental age of 5 and the body of a 70-year-old. However, she didn’t qualify for screening as the programme was for the over 60s.

Gorman and Porteous [31] highlighted that the information needs of women who come from a country, such as Poland, with their own screening programmes are different to those of women from countries with no screening programmes. With the arrival of new European migrants, the dual use of screening programmes had not been highlighted before. They explained that Polish women living in Scotland had difficulties accessing the breast screening programme. They were only able to get information from the Scottish Breast Screening Programme (SBSP), which was primarily designed for Scottish women and did not address their specific concerns relating to Polish health culture and their approach to screening. Currently, the SBSP provides a Polish version of its booklet online or on request, but this direct translation of the English language version does not address the topics Polish women wanted to know about. These issues are often about how the programmes compare and relate to each other, with the longer screening interval in the UK a particular concern. With Poland's 2-year screening cycle and many women funding their own annual mammography, Polish women may assume that being screened more frequently is obviously better [31]:

I do something every year in Poland - one year I do mammography, the next cervical screening. Every time when I'm eligible for something here I go but if I miss the date and I'm in Poland I go there (interchangeably). Scottish women have just one option … the good thing is that the screening is for free here.

Amongst Roma people who had experience of screening abroad [20], there was confusion about the timing of screening in the UK. More frequent screening was available in Slovakia to those who had health insurance and women in their early 20s had had mammograms. Because screening in Slovakia was viewed as more comprehensive, some chose to access screening there. These issues were similar in Wessex Voices' engagement with Eastern European women in 2018 [94], with over a third of the women surveyed who attended cervical screening in the UK also attending screening in their own country. Meanwhile 25% did not attend cervical screening appointments in the UK. Reasons included having previously had a bad experience in the UK, the language barrier and feeling more confident in the system in their home country.

A general lack of understanding of the healthcare system, particularly for those who have migrated to the UK from other continents was noted by Hunneybell et al. [44] who detailed how Muslim groups might not understand the concept of healthcare and healthcare systems and in particular the importance of preventative health.

Recommendation: Co-produce messaging with culturally diverse women around the importance of breast checks and for those who have/haven't had them overseas, so that they understand NHS breast screening.

Expectations of different options for testing were also noted in literature. Jiwa et al. [102] found many women were unaware that Nipple Aspirate Fluid (NAF) might be a useful biofluid for future risk prediction, and yet the concept of self-testing of nipple fluid, with either hand massage or a breast pump was well received.

The desirability of other potential forms of screening such as blood tests was also mentioned in another study [14]. Participants also debated about whether genetic screening should be available to all women regardless of risk stratification, at what age it should be offered and wishes that 'a new universal (genetic) test' could be created. The need for clarity about the implications of some gene variants (variant of uncertain significance) was also noted [14]:
I've got concerns … I do have a mutation, it's a random variant it's not a recognised one…

Wessex Voices' report highlighted positive comments about the use of ultrasound. There was a preference expressed for it in some cases [97]:
If it were ultrasound [instead] of mammography (which can be harmful or very confusing) then I would go.

but some expressed preference for screening over ultrasound [97]:
I do ultrasound and I think this screening is better.

Early detection by ultrasound had in one case found a breast tumour [97]:
Thanks to the early detection by the ultrasound test, it was removed early (fortunately it turned out to be mild). Now, despite the old age, 73, I receive regular invitations for the screening and of course I use them.

Recommendation: There are a range of options available as alternatives to breast screening – genetic screening, blood and NAF tests and ultrasound. Explain the type of test and why it is being used in comparison to others somewhere within the invitation might be beneficial in managing expectations, as public awareness of alternative methods grows.

5.3 Expectations of the screening programme

> *If we have a better understanding of what the procedure is and what it entails, people might be more receptive* [5]

Some people do not understand what breast screening entails, as in the Wessex Voices report [97], or why attendance is important [4]. In the Baird et al. [4] review the emphasis of the importance of knowledge was highlighted by all eight studies reporting knowledge as either a barrier or facilitator to breast screening attendance ([5] [6] [7] [10] [27] [47] [73] [92]). Five studies specified unfamiliarity with the screening process as a barrier to attending ([5] [6] [27] [73] [92]).

Some people believe that breast screening is only for symptomatic people [31]:
… and because everything was fine and I've never noticed any symptoms – there was no need for breast screening.

This can also lead to delays in attending, highlighted by a British Chinese woman on Healthtalk.org [35] who was running a family business and said she missed several screening appointments because she was extremely busy with work. When her husband suggested there was no need to attend if she felt fit and well, she decided not to go until she was less busy.

In the Bener et al. [11] study, surveys issued to non-attenders and their health-care providers identified the most prevalent patient-related factors for missing a breast screening appointment was:
inadequate knowledge and understanding of the breast screening test.

In the Boundouki et al. [14] study there was a discussion about public awareness of the need for screening:
if you think …. you can find a lump yourself and screening is just to catch the leftovers you're not going to go.

Factors [97] that would make women feel more comfortable about going to first time breast screening were:

- Knowing what to expect and receiving results in a timely manner
- Needing reassurance and wanting ‘peace of mind’
- Understanding the effectiveness of mammograms and different screening options
- The importance of breast screening awareness from a younger age.

The MHCC report [60] highlighted follow up assistance and information to people who had never attended screening as an enabler to encourage people to attend.

Döbrössy et al. [25] noted that the volume of breast cancer related social media discussion was considerable. The majority of participants were lay individuals as opposed to HCPs or advocacy groups. Lay misunderstandings around the harms and benefits of mammography was mirrored in this content. However, screening sentiment on social media ranged from neutral to positive and was deemed as suitable for offering peer emotional support to participants. Dedicated breast screening websites operated by screening organisers would ensure much needed quality-controlled information. Plus, websites could provide space for reliable question and answer forums, sharing of personal experience, and peer and professional support.

Recommendation: Consider whether a ‘first time’ screening leaflet with enhanced information is appropriate. Consider making this easily available online in addition to having hard copies.

The main barriers presented for Black, Asian and minority ethnic women [4] were a lack of knowledge about what is breast cancer, who is at risk, how to identify it, what the screening programme is, and the treatments available:
I think I've read that women who have never married and had children are more likely to get it. [73]

I think it's an infection … I don't know but it's not something that you can contract [5]

Woof et al. [100] noted that inequity in access continues to be challenging for British-Pakistani women. To mitigate the challenges presented by language difficulties, they recommend that the breast screening service should provide explicit information signposting women to the NHS Translation and Interpretation Service, and should, in addition, involve women in the creation of screening materials.

Recommendation: Share existing simple, accessible resources about the process from start to finish [97], so people feel better prepared and reassured about what to expect:

I was initially anxious but found leaflet helpful.

Read the leaflet that is sent with the appointment- I found that really useful.

Some online resources were identified by Public Health England [75] (p26-30) in their ‘Making reasonable adjustments to cancer screening’ report. The resources related to breast screening include leaflets, factsheets, webpages, videos and apps. The majority are Easy Read, with information for supporters, HCPs and screening services. Public Health Scotland [82] have also made a breast screening video available via their YouTube channel, which includes sign language.

A Communities against Cancer grant has been awarded to a Wessex based project run by Enable Ability. The aim being to produce a ‘What’s it like?’ [98] breast screening journey video for people with autism, based on client feedback [105].

Public Health England [81] issued recommendations based on the Woof et al. [100] study. This included raising awareness of the NHS interpretation and translation service by providing information posters and leaflets about the service in healthcare settings translated into the most commonly spoken languages in the area. They also said that HCPs should be aware of the process for referring patients to the service.

Woof et al. [100] noted in views from British-Pakistani women that community communication was invaluable, whereas NHS materials were deemed inaccessible due to translation incongruences and incomprehensible terminology. It was explained that in the common language spoken by this community i.e. Urdu, clear and direct translations of screening terminology was lacking. The uncertainty over terms such as ‘screening’ and ‘mammogram’ caused some women to inaccurately speculate about what would happen during their appointments. Only two women who had attended screening recalled being able to access information about the breast screening programme. The majority described having no prior knowledge and attended their appointments naive about what it would entail.

Recommendation: Encourage people to request translations and /or an interpreter to accompany them to screening. Also review materials for potentially confusing terminology. It has been suggested that a glossary of screening terminology could be provided, or more common terminology (e.g. ‘X-ray’ or ‘scan’) could be used to reduce conjecture and facilitate understanding [100].

A view on the clarity of the information leaflet and a need for revision was also expressed on Care Opinion [19]:

In 2019 I was called for my first time post-50 mammogram. I thought this would be a straightforward process and an all-clear result. This was not my experience. I have a lobular neoplasia which I have to be screened annually to review. At the initial diagnosis I was left feeling confused as the information leaflet is not clear and very non-specific. It’s either something I don’t need to worry about or could need a bilateral mastectomy. When I pointed this lack of clarity in the leaflet the *nurse told me they hadn't actually read it so couldn't comment. I suggested it might be helpful to people reading the leaflet if it was revised.* (Nov 2020)

Recommendation: Revisit wording of letters and leaflets, including the use of jargon and translations, especially if issues are raised about confusion with the information given.

Recommendation: Make reasonable adjustments for particular groups depending on their knowledge of and understanding about what the screening process is and what it does.

The video produced by HCPs in Cornwall shares several reasons for what stops PWLD attending screening:

- Sending out letters people do not understand
- Sending out letters with lots of words that PWLD struggle with reading
- Fear of the unknown
- Not knowing what is going to happen at their screening
- Stories that other people have told them that might put them off
- Not understanding the importance of going
- Asking people to go along for a test that is not particularly pleasant.

Recommendation: Promote conversations about the positives of going for screening, both peer-to-peer and with HCPs [97]:

I would suggest she reads more information on it particularly good sources such as the Cochrane Review to make up her own mind. If there was a medical history in her family that could be different. I would suggest that it is not as straight forward as the leaflet you get says.

Do what you feel comfortable with but do read up on the subject not just the leaflet you are sent. Also look up how to prevent breast cancer through behaviour choices because this is equally if not more important.

I would recommend she read pros and cons leaflet. If particularly anxious and I could help, I may offer to go with her/ meet for coffee after.

Talking to HCPs was recommended as a way of providing motivation prior to an initial screening [97]:
I would suggest she talk to the department or her GP practice regarding her concerns. If she were a very close friend, I would tell her about my experience.

I'd encourage her to talk about her concerns and to objectively weigh up the pros and cons of going. I'd also encourage her to talk to the experts - either her GP or to call the Macmillan helpline.

The Woof et al. [100] study of views from British-Pakistani women highlighted that family and community dialogue was invaluable for sharing knowledge about breast screening. Women emphasised that by talking to others who had attended screening they gained valuable information about the procedure. They suggested health awareness events across the community, where attention could be given to explaining the screening environment and purpose of screening.

Hunneybell et al. [44] suggested community champions in mosques and religious schools, educating young as well as older people on the signs and symptoms of cancer and the importance of screening. ‘Champions’ was a reoccurring suggestion from the local Muslim community and the leaders of the community centre they worked with.

Forming interpersonal relationships between HCPs and Black, Asian and minority ethnic women, was highlighted by two studies in the Baird et al. [4] systematic review, to encourage screening attendance ([7] [47]). Two other studies identified the positive influence HCPs have on Black, Asian and minority ethnic women’s health seeking behaviour – regarding them valuing and respecting the advice of their GP ([10] [92]).

For PWLD, one GP highlighted that opportunistic discussion was a way of highlighting screening services for this group [60]:

We tend to see people with intellectual disabilities opportunistically mostly … and I think that could be used as an opportunity to check with themselves and their carers that they have actually accessed screening, not only breast but also cervical.

5.4 The personal nature of the screening

I was nervous - who really wants to expose their breasts to strangers?! [97]

...they couldn't hurt you enough [58]

Because breast screening involves removing clothes and exposing breasts our review found a variety of sources - including [63] – as to why this might be a barrier. These ranged from the pain and discomfort of the process to embarrassment about body shape and childhood trauma. Also, the levels of dignity and respect someone is treated with in these circumstances can have an impact on whether they will attend again. In the Manthorpe et al. [58] one woman described the lack of information in the original letter about the need to undress as making her feel:

...shocked and embarrassed because it wasn't what I expected...I remember feeling very uncomfortable being a shy person anyway and they could have explained a little bit more.

The lack of warning about potential discomfort and the threshold of pain and uncomfortableness of the procedure – which might also have an impact on future attendance - were mentioned in a number of studies ([14] [36] [63] [97]). The fourth highest barrier to non-attendance in the Mulvey and Gissing [63] study was a worry that it might be painful (12%):

would always go but one thing that could put me off is the pain during the screening. [63]

Other reflections on the pain of the process included:
…It was very uncomfortable, felt like my breast was going to be ripped off [97]

I found it quite painful once the clamp was tightened and that wasn't really explained that that was going to happen. So, anticipating it for the second breast I clearly tensed up and was then told to relax. I said, 'How?' given the position you are expected to be in, so the nurse came over and put her hands on my shoulders and pushed down which had the desired affect, but I wouldn't say it was relaxing. On balance again I would say go to my friend and just explain what happens, so she is prepared. [97]

...it was particularly painful and I said it was painful but she totally ignored me...I felt particularly distressed when I was walking home and the pain stayed for two days...there was more damage from the actual session. [58]

I don't want my boob squashed to smithereens and they didn't used to have these things in the past so why now? [60]

And I really was literally bent over in pain when I came out. And not everybody finds it painful, some do. So foolishly I said I'm not going back for anymore, and I didn't. [35]

Two respondents in the Mulvey and Gissing [63] study said that previous breast cancer treatment meant screening was either too painful or unnecessary due to double mastectomy. One commented:
due to other medical conditions I found it painful to twist my body onto the machine.

In Manthorpe et al. [58], a Chinese woman accompanying her elderly, non-English speaking mother for a breast examination recollected her mother complained about how cold she felt when undressed. This was because of the time it took her to translate and because the staff were taking time because of her mother's age.

For PWLD the experience is also very difficult. Again in Manthorpe et al. [58], one woman described being treated *"like a piece of meat"*. She also had a physical disability that made standing very painful but despite explaining this to the HCP, she was ignored. She said that she would attend another appointment if invited, but only if the examination was carried out sensitively and she was treated with respect.

For some PWLD, going for mammograms is just too difficult because the procedure is painful and people are required to stand up [16]. This was also highlighted by McIlfatrick et al. [60]:
Some of our patients with intellectual disabilities also have major physical disabilities so they are wheelchair bound or their mobility is not great …

The tactile nature of screening can be an issue, as noted in Taggart et al. [90]:
Some women with autism … tactile defensive issues, the smell, the curtains, the buzzing and the machinery. They just can't cope with it … they can't handle touch.

Woof et al. [100] explored the subjective issues associated with disengagement, including the cultural misalignment of the service. The necessity to reveal breasts to a stranger was a major deterrent to attending breast screening for British-Pakistani women. For Muslim women [44], some declined breast screening due to personal space intrusion. Various reasons were cited:
Genitalia is seen as a very private part of the body, religious rules on dignity of the body, embarrassment, exposure to another person and assumption that a male may carry out the procedure.

In the Baird et al. [4] two studies revealed previous negative experiences with HCPs dissuaded women from engaging with breast screening services ([73] [92]); exacerbated in situations where women felt disrespected:
My GP, he sits like he is getting impatient that I am there, I am watching his body language … and I'm thinking don't worry about it – I'm just wasting your time. [92]

5.5 Fear and anxiety

I can still put myself straight back in that room now [14]

People’s own fears and anxiety can be a barrier to attending screening. This may be because of their own confidence levels, psychological distress due to previous procedures or family history or a more general fear of healthcare settings, including during the COVID-19 pandemic. People may also fear being treated with prejudice.

In Baird et al. [4], for Black, Asian and minority ethnic women emotional barriers were noted as a main cause for decreased access to services. For example, a lack of confidence and expectation anxiety were barriers to attendance [5], with women reporting fear and apprehension regarding screening, self-examination and breast cancer.

In the Ross et al. [85] study of screening uptake for women with mental illness, more than a third of women received one or more prescriptions for psychotropic medication in the three months preceding screening invite, with the odds of attendance in these individuals reduced by 15%. Attendance was particularly low for women prescribed antipsychotics, anxiolytics and hypnotics. People with mental health conditions can be particularly prone to fear and anxiety:
Some women who are called for screening and they can be very disturbed, having poor mental health. It’s a major ordeal going up to the hospital for some women like, so they just refuse. [90]

Montgomery and McCrone [62] suggested that because women who had a history of a previous breast biopsy or a family history of breast cancer had increased psychological distress, nurses should offer additional support.

Recommendation: Raise awareness of psychological barriers that affect people’s access and experience of screening.

Kanani et al. [49] suggested that a more active approach to cancer screening and establishing treatment guidelines for patients with mood disorders may also target inequalities in uptake and utilisation of these services.

Montgomery and McCrone [62] recommended access to a healthcare provider should be ensured in all places where tests occur; concluding that the ultimate goal of nursing practice was to promote a more positive experience. This is needed particularly for higher risk women, so that they may have a quicker return to a prebiopsy psychological state.

In the Manthorpe et al. [58] study, one participant had not responded to at least three invitations to attend breast screening appointments because she had a general fear of hospitals:
...the smells in hospitals and all the things in the paper about these bugs and whatever...

She also had friends who would not attend breast screening appointments because of their fear of hospitals. Noise was another discomforting factor reported [36]:
I can't relax, there's all these noises, I was very nervous. The next time I had it, I was put to sleep to have it done. Will have it again as long as I'm put to sleep.

In the Mulvey and Gissing study [63], the second biggest barrier was worrying about visiting a GP during the pandemic (16%). Concerns have also been noted regarding possible COVID-19 vaccine side effects and their impact on attendance. This has led Public Health England to confirm that there is currently no need for anyone to postpone breast screening appointments following their vaccination [67]. For UK approved vaccines, trials have shown that there is a less than 1% chance of enlarged lymph nodes as a side effect after vaccination.

Recommendation: Raise awareness of the need to regain confidence after COVID-19 pandemic restrictions are lifted and targeted education where necessary.

As services begin to resume, Palmer and Johnson [70] noted that there may be the additional challenge of fostering confidence in the public that it is safe to attend screening – including after vaccination.

5.6 Attitudes and age of carers of people with a learning disability (PWLD)

The older carers would also be of a generation where they missed the self-breast examination move and would not advocate the importance of breast screening. [90]

In some cases, carers might need to be persuaded that it is a good idea for their cared for person to attend otherwise [61]:
The decision could be taken for them [women with LD] by carers and relatives may feel that it's not what they need, that it might cause them distress. So, the decision may not necessarily be taken by the patient themselves.

Motivation to take them and the age of the carer – older carers being sometimes less likely to see the benefit of attending from a generational perspective - were also seen as affecting the decision to go in another study [90].

5.7 Specific religious or cultural beliefs

Most African people don't like to talk about … cancer. They see it as a taboo, in fact, I know a lot of people who do not even say the word cancer [92]

The Baird et al. [4] review of Black, Asian and minority ethnic women noted that the stigma associated with cancer, fear of mastectomy and its marital consequences and deficient support from family and community were screening barriers [5]:
… those of us that … hear that the family that your daughter wants to marry into, they all have cancer, is that not a stigma? … what of the child you are going to have for them if she is a woman, she might have cancer as well…

Hunneybell et al. [44] described some individuals in Muslim communities as having the belief that illness and cancer was a retribution for past actions and that illness was a means of forgiveness - hence not seeking treatment. However, from an Islamic perspective seeking treatment for an illness is encouraged and sometimes mandatory. Two studies highlighted by Baird et al. [4] drew associations between faith and decreased appreciation of preventative medicine, with women describing the development of breast cancer as ‘up to God’ ([5] [73]). These opinions were mitigated [6] by incorporating religious leaders into educational interventions [73]: *There is a connection between our spiritual welfare and our health. If you are well spiritually, then you should be well physically.*

There were differing views amongst Muslim scholars in relation to exposure of sensitive areas (such as the breasts) for screening [44]. The arguments for not allowing this were due to:

- Screening being non-diagnostic (asymptomatic patients) so the rule around exposure being permissible for diagnosis and treatment do not apply to screening.
- The reasons for permissibility are too general and need sound and specific evidence. The evidence needs to show that breast and cervical cancer prevalence is enough to substantiate the 'rule of necessity' for screening. This highlights a need for education and understanding of screening and immunisation relating to prevention, asymptomatic and early diagnosis, as well as religious and ethnically broken-down data in the UK.

Recommendation: Raise awareness of screening programmes and the differences between symptomatic and early diagnosis enabling Muslim scholars to use religion as a platform [44] - i.e. the body has a right over you - to encourage prevention of disease. Also recommended that HCPs needed to engage and collaborate with local minority and religious communities to help build trust and relationships. [44]

5.8 Lesbian, Gay, Bisexual and Trans experiences of prejudice and awareness

Lesbian, Gay, Bisexual and Trans (LGB and T) populations have pre-existing levels of healthcare avoidance [56]. One in seven, including more than a third of trans people, have avoided treatment for fear of prejudice [89]. Not all transgender and nonbinary people will be aware of their need to go to breast screening.
[Also, see later discussion about highly gendered environments and issues around recalling people who have transitioned].

Recommendation: Raise awareness that breast cancer screening is for anyone between the ages of 50 and 74 who has breasts, due to either naturally occurring oestrogen or oestrogen hormone therapy.

Cancer Research UK [18] state that this can include:

- transgender men and nonbinary people assigned female at birth who have not had an operation to remove their breasts (bilateral mastectomy)
- transgender women and nonbinary people assigned male at birth and who have taken feminising hormones
- cisgender women.

There is Public Health England leaflet [80] for transgender people about which screenings they need to attend and this has improved community awareness.

5.9 Confidence in/fear of results

Mammograms actually don't show all forms of cancers……. mammograms aren't wonderful [14]

The limitations of breast screening have been highlighted as a potential barrier to screening. Whilst some women have described how screening had saved the lives of family, friends and colleagues, some were not convinced of the evidence for screening [97] and expressed a desire for other potential forms of screening, such as blood tests [14].

One respondent in Mulvey and Gissing's study [63] also said that a previous screening had missed tumours and that they now felt screening was pointless. Other responses included [95]:
I will now tell you a bit about my journey. My last two mammograms were "dodgy" and each time I was told that it was a cyst. It was not when I found the lump and it was already stage 3 aggressive cancer. I had chemo and radiotherapy I also had a mastectomy, since I have had another mastectomy and a hysterectomy.

Recall because of a false-positive mammogram can cause significant adverse psychological effects [29]. However, for women without a family history of breast cancer these appear to be transient (less than 5 weeks). Screening programmes should ensure that steps are taken to minimise the number of women who are recalled for unnecessary investigations.

A later study [53] concluded that recall for further investigation after mammographic screening was associated with considerable anticipatory anxiety in many women. There was a high prevalence of anxiety in women prior to the recall visit; significant differences in short-term distress depending on the type(s) of examination and information received at the recall visit; and no evidence of increased long-term distress in recalled women with false-positive mammograms. There would therefore be a benefit from procedures and routines minimising the delay in receiving information of definitive results.

Although not affecting her view on attending screening, one participant in the Wessex Voices study [97] mentioned her experience of false-negative outcomes:
I had a false-negative mammogram result in September 2018 and by January 2019 I referred myself to breast screening via GP and was stage 3. The team could see the cancer on the September 2018 image which was a false-negative result at that time.

This was also listed as a reason for not attending their first time invitation by another participant [97].

False-positive screening results affect one in every five women during 10 biennial screening exams [39]. Mulvey and Gissing [63] suggest that the misconception around the accuracy of diagnostic testing and the consequence of false-positives may be a barrier to screening:
Breast screening finds lumps that may not be cancerous and therefore you have to have procedures that you don't need.

False-positive screening results were also listed as a reason for not attending their first time invitation in the Wessex Voices study [97]. The Bond et al. [13] study revealed a wide range of responses to having a false-positive mammogram, from nonchalance to extreme fear. These reactions stem from the potential to believe that one is healthy, which may be challenged by being recalled, as the worst is frequently assumed.

Recommendation: Ensure information on guidelines for screening some people more often based on their results are readily available on all usual screening information sources.

For example, the higher interval breast cancer rate after a false-positive screening suggests that women with a false-positive screening may benefit from being offered another mammographic examination within one year rather than the usual biennial screening [40].

Fear of outcomes was also noted ([63] [97]). This was primarily associated with a fear of cancer [97] as reason for not attending an invitation. Two respondents in the Mulvey and Gissing [63] study said that fear of finding cancer would stop them from booking an appointment. In Condon et al. [20], concerning Gypsy, Roma and Travellers, a minority avoided screening because they feared diagnosis, but experience of cancer within the family was also cited as a motivating factor.

5.10 Harm caused by screening

I know that there are quite serious side effects of screening and radiation and who knows if it cannot wake up something in your body. [31]

Fears associated with the harm of screening are highlighted including [14]:
squashing of the breast is actually going to damage it and may cause cancer

biopsy …. may carry it…. off all round your body

Three respondents cited that information they had read suggested that the test itself could cause trauma to the breast tissue leading to breast cancer [63]. A woman who had chosen not to attend any screening appointments said that this was because the pressure put on the breast during the examination damaged tissue and that this could cause breast cancer [58]. Concerns about the potential harm of radiation [97] and its potential to cause cancer [31] were also noted.

Screening breasts with implants may cause rupture, however, there is no reliable evidence to support this [72]. To lessen anxiety for women with implants, Parr and Dunmall [72] suggested that women should be made aware that the Eklund technique helps mammographers achieve successful imaging with implants and avoids rupture. Websites providing information on breast screening with implants are not easily accessible, were of poor quality and too difficult to be read by most people. They suggested that this should be improved to help support women make informed decisions relating to breast screening attendance, increase their understanding and lessening their anxiety.

Recommendation: Review whether fear of possible screening outcomes and of harm caused by screening can be reduced and/or clarified in educational materials. Include messages focused on reassurance and the benefits of early detection to address some of these fears. [63]

Improve breast screening information for people with breast implants [72].

5.11 Screening provides reassurance

> *But staff were fab and made me so at ease. Advice would be the awkwardness is a small price to pay for something that might save your life.* [97]

Despite some of the issues previously discussed, the possibility of identifying cancer early was a motivating factor for some [97]:
The chance to have a cancer detected sooner is important. Though the result may not be 100 percent accurate and any advice on how to regularly check yourself is also valuable.

This could provide an element of reassurance and provide a checkpoint to be used for future comparison [97]:
Years later on a "routine" mammogram something was spotted and various biopsies later turned out to be nothing. Had the mammogram been done years earlier they would have seen it was the same thing and no biopsies would have been needed. Saving pain, anxiety and money.

For 15 participants in the Bond et al. [13] study, going for a mammogram every 3 years had become part of their health care routine. It was welcomed and there was a sense of handing responsibility for their health, in some way, over to the NHS. Screening gave peace of mind.

6. The invitation process

Section summary: The second part of the process concerns receiving an invitation to attend a screening (whether for a first time or a subsequent appointment). People receiving an invitation for the first time might have more concerns than those who have been before, so could welcome more advice and guidance offered at this stage.

We reviewed people's expectations and understanding of the breast screening invitation: how it is formulated, who is included and how the information is detailed within the invitation. Consideration was also given to how it is received and understood by the recipient and the questions and concerns that it might raise.

6.1 Concern that vulnerable groups will not be invited

In 2019 Public Health England issued the NHS public health functions agreement 2019-20 Service specification No. 24. for NHS Breast Screening Programme (NHSBSP) [77]. In the Equality section the provider should have procedures in place to identify and support those persons who are considered vulnerable/hard-to-reach, including but not exclusive to, those who are not registered with a GP; homeless people and rough sleepers, asylum seekers, Gypsy, Roma, Traveller groups and sex workers; those in prison; those with mental health problems; those with drug or alcohol harm issues; PWLD, physical disability or communications difficulties. The provider should also comply with safeguarding policies and good practice recommendations for such persons. However, research literature highlighted concerns regarding the access of certain groups to screening.

For example, in the 2006 Birth Companions [12] study, only 10 of 21 eligible female prisoners had ever had a mammogram and 7 of these women were still in prison after 3 months had elapsed. None had had a mammogram during these 3 months of imprisonment.

Similarly, the O'Reilly et al. [69] study provided novel evidence of inequalities in breast screening uptake for women with self-reported poor mental health. 10.7% of women in the cohort reported poor mental health, and in fully adjusted analyses, these individuals were 23% less likely to attend breast screening. This suggests that targeted interventions are required to improve screening uptake in individuals with poor mental health.

Another research study [61] noted that there was a possibility that GPs could potentially be able to block certain PWLD from being invited:
There is a step before the invitations go out whereby the units send out the lists of ladies who are about to be invited to the GPs and they can make comments ... One of our concerns was that GPs were able to say don't invite them [woman with LD].

Recommendation: Link up with members of vulnerable groups where more engagement will be helpful in improving uptake and outcomes.

6.2 Concern that Transgender people will not be invited

Concerns have previously been raised [54] that cancer screening programmes were regularly failing to identify eligible transgender individuals who '*remain susceptible to cancers of reproductive organs that are no longer in alignment with their gender*'.

Kamaruddin [48] noted that there is currently no automated call-recall system because the system is still defined by binary genders – male or female. There also is not a national gender identity data collection, which makes an automated call-recall system for transgender people almost impossible. Until corrected, cancer screening for transgender people remains underreported and underdiagnosed, and the risk of cancer is high. Transgender men might still have breast tissue following a mastectomy, so the risk of breast cancer remains and those who haven't had a mastectomy should be referred to the breast screening service.

6.3 Awareness of access needs at invitation

Breast screening in mobile units, often with stairs & no previous warning. [60]

The most commonly reported barriers raised by participants in the MHCC study [60] were around the inflexibility and inaccessibility of equipment offered at some breast screenings, poor information on options, and access requirements not being communicated or acted upon. These need to be identified and acted upon prior to an invitation being sent and throughout the screening process.

Recommendation: Raise awareness concerning the accessibility of the venue, equipment and environment prior to screening attendance for people with physical impairments. This might help to alleviate any possible issues before the appointment.

MHCC [60] report recommendations are:

- Provide clear, accessible information on each testing centre in a range of formats, on how to get an appointment there.
- Flag up access requirements. Ensuring that the Accessible Information Standard works well enough to highlight people's access requirements in the call up process, so they are not referred to an inaccessible testing unit. Ensuring that accessible parking should be available at all sites.
- Provide an option to contact the centre beforehand, so people can discuss how a person's access requirements can be met whilst also taking an effective image. Also ensuring that people know that they can be in touch in advance to check access.

6.4 Tone of invitation

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]

In the MHCC report [60] enablers/solutions that would help remove or prevent a screening barrier for the invitation letter included providing information about the process and what to expect in a clear way. A respondent wanted honest descriptions of the process, whilst another commented positively on the letter received:

... it was quite a friendly letter using down to earth language. [58]

Recommendation: Revisit and revise invitation letter templates to ensure that the tone of invitation is appropriate.

6.5 Personalisation of invitation

Woof et al. [100] suggested that the NHSBSP and, more broadly, the health service should begin to routinely record the service user's preferred forms of communication, to enable underserved populations to receive tailored health materials.

Recommendation: Look into possibility and potential challenges of recording communication preferences for future tailoring of health materials.

6.6 Understanding the invite

I mean if they have intellectual disabilities and something comes in the post and they are not able to read, they may not even be aware that they have been invited to breast screening… [61]

In the MHCC report [60] highlights that an invitation letter sent in appropriate accessible format, with information about the process and what to expect provided in a clear way, would be an enabler to breast screening.

Literacy issues were mentioned in two studies ([61] [90]). Respondents to the Brent Council report [36] suggested that having correspondence in Easy Read would improve their experience. Whilst some found that they were able to read letters that were not in Easy Read, there was a consensus that good quality information in this format about cancer, invitations for screening, referral and results letters would be beneficial to all PWLD. Although the NHS and Public Health England currently has information about screening available in Easy Read, most respondents had not seen this [36]:

I understand [the letters] but as I'm partially sighted, I'm scared I'll miss the appointment [details]. It needs to be bigger.

We don't get any letters in easy read – we don't get the reasonable adjustments.

Recommendation: Provide information in clear English which meets people's known access requirements. Ensure Easy Read information on screening is made available to groups if required and for letters where appropriate. [60]

Wessex Voices' report [96] concerning a draft GP cervical screening invitation letters highlights some common issues and solutions by seldom heard groups that would encourage people to attend, which are applicable to breast screening.

If reports of inaccessible materials are reported then follow up on this. Also consider alternative methods of communication. For example, in Taggart et al. [90] a range of materials were suggested to educate PWLD including:

a DVD, leaflets, something women focussed using pictures, signs and symbols (Makaton) where necessary. (FG1)

In Baird et al.'s study [4] concerning Black, Asian and minority ethnic women, language was presented as both a facilitator and a barrier with emphasis on the benefits of translated material. This point is highlighted in one Pakistani participant in the Manthorpe et al. [58] study who said that she would have preferred the letter to have been written in Urdu so that she could have understood it herself. In Woof et al. [100], some participants explained that they relied on family members, or women in their community, to explain the letter. For some, asking others to translate caused them to feel burdensome and concerned as to what effect translating private letters (which may contain results) could have on their translators. Especially when the majority of those translating for them were their daughters. Gorman and Porteous [31] noted that to help with communication problems, participants had advocated provision of more written material in the Polish language. They also noted that written communication from the health service is not expected in Poland and therefore English language letters can be easily discarded or misunderstood.

Recommendation: Improve autonomy and confidentiality by offering alternative versions of letters in requested languages (denoted by individual preferences).

6.7 Addressing questions and concerns

Receiving an invitation (especially for the first time) might prompt several questions and concerns from the invitee. In the Kearins et al. [50] study phone calls and home visits, to remind about an upcoming appointment, were welcomed by those who wanted more information about the breast cancer screening process.

Recommendation: Consider methods for addressing queries and concerns during the invitation process [97].

Manthorpe et al. [58] suggested that the effectiveness of being told that a female friend could accompany patients could be investigated as a means of helping women overcome their fear of examinations. This option was discussed with a lesbian woman who was highly discrete about her sexuality but who might have liked to have been accompanied by her partner. She did not take them because she was concerned that the staff would immediately make assumptions about her sexuality which she wanted to keep private. She suggested that such presumptions could be avoided were appointment letters to specifically say that a female friend could accompany patients.

Recommendation: Consider methods of raising awareness on buddying within invitation information. Look at any restrictions in force or practicalities regarding more than one person attending an appointment (e.g. due to space and gender).

6.8 Reminders

Forgetting to go to the appointment was the single most frequently cited reason for not attending screening, accounting for up to nearly a third of missed appointments ([2] [8]). Kerrison et al. [51] noted that interventions which addressed forgetting to go to the appointment, such as reminders, might offer a potential solution for preventing many missed appointments, thereby improving uptake without infringing upon a person's ability to make an informed choice.

Allgood et al. [1] found that postal reminders increased breast screening uptake, and could be practicable to implement. In all, 49.9% of women were randomised to the intervention and 50.1% to the control. In the intervention arm, 68.2% attended within 30 days of the first offered appointment compared with 64.2% in the control arm. This difference was significant ($P<0.001$). The study was not significantly affected by age, socioeconomic status or type of screen (prevalent or incident) but results did differ between the different centres studied.

In Kearins et al. [50], persistent non-attenders were identified in routine screening lists. Phone contact was attempted, or a home visit was made. If the case was not resolved, a second appointment was made, with further phone calls and home visits attempted. Phone calls and home visits resulted in only a moderate increase in screening uptake. The initiative encouraged nervous attendees who were reassured about the screening process. However, more women declined screening than were screened and the initiative made it easier for women to request to be permanently withdrawn from the National Screening Register. Negative comments were recorded from 10 women who were angry at receiving unsolicited phone calls or home visits about screening. Conversely, positive comments were recorded from another 10 who were glad to be reminded about attending.

Kerrison et al. [51] performed a single-blind randomised controlled trial (RCT) to test whether text message (SMS) reminders were effective. Women receiving their first time breast screening invitation were included and randomly assigned to receive either a normal invitation (n=1 118) or a normal invitation plus a text message reminder 48 hours before their appointment took place (n=1 122). Sending women a text message to remind them of the time, date and venue of their first routine appointment significantly increased uptake without exacerbating social health inequalities.

Huf [42] highlighted the importance of the message content within health communications in cancer screening to improve participation rates. Different subgroups of women with common characteristics such as age, level of deprivation or previous exposure to cancer screening affected which message content was most effective in improving cancer screening participation. In the Huf et al. [43] study the final RCT tested the effect of different behaviour message content in text message reminders for timed appointments in the breast screening programme. No significant difference in participation was noticed because of the message content within text message reminders. However, due to logistical barriers encountered during the trial, including a reconfiguration of regional screening services, this study had to be closed early so the sample size was underpowered.

Huf [42] noted that the RCT encountered a different issue regarding access to mobile numbers. The mobile phone number is not currently considered part of a patient’s core contact address. This means that it cannot be shared between the GP practices and screening centres. This is an important distinction as information governance specialists argue that screening is a public health service, that is offered to the public and was not initiated by the screening invitee. Therefore, women who have provided their mobile phone number to their GP for the purpose of their healthcare have not formally consented to it being used by screening services. As a result, it is not currently permitted for them to access the mobile phone numbers stored on a patient's GP practice IT system (as of 2017), although it is in principle and technically possible.

In the absence of the ability to access phone numbers held by GP practices, only women who have previously had contact with the screening centre, (i.e. had previously attended, or were due to attend and had made contact at which point they shared their mobile number) were able to be sent text reminders. Therefore, the women who currently receive text message reminders are women who are already more likely to attend screening. As women are only invited every three years, unless they are deemed high risk, it is possible that the patients who have updated their phone numbers with their GP practice since their last screening appointment have not done so separately with their local breast screening hub. As a result, the current practice within some hubs of sending text reminders in advance of appointments may in fact be disadvantaging women who are first time invitees or women who have been repeatedly invited and have persistently not attended due to personal barriers.

There are also questions concerning wider public opinion of the acceptability of using text reminders in breast cancer screening when women have not provided their phone number directly to the screening service [42]. Also, about the public's opinion of sharing a patient's mobile phone number, which was provided to GP practice with other secondary care organisations within the NHS, as well as preventative services. One option suggested by Huf [42] is to ask GP practices recording these numbers, to inform and consent patients for providing their mobile phone number to all NHS services, or selected services such as the GP practice, secondary care and preventative care (i.e. health promotion that was not initiated by the patient).

Recommendation: Consider different methods of reminding attendees about their appointments – perhaps based on their personal preference for being reminded. Also look at effects of different phrasing dependent on the media being used for reminders.

Public Health England [78] has developed some principles as part of its screening inequalities strategy to support local screening services to make the most effective use of text reminders for screening appointments. When considering text messages be aware that using this method as the sole way of reminding might disadvantage some groups of women.

Be aware of the latest GDPR requirements in terms of legislation and acceptability.

Also consider the gradual decline of people using landlines and the increased regularity with which some people now change their mobile phone and number.

6.9 Impact of COVID-19 pandemic on screening

Mammogram was cancelled, so I'm a little worried in case there is something wrong. [56]

Delays to and cancellations of screening appointments have been noted during the COVID-19 pandemic [19]:
Hi, just thought I'd share it took 4 weeks to the day after my gp app for an appointment letter to come through, and it was for 4 days later. I was very worried during the 4 week wait and found no answers myself regarding wait times etc., so thought I'd share my experience with it. (July 2020)

Whilst the longer-term impact of this might not yet be fully understood [15]:
I was diagnosed just before lockdown. If I didn't have the screening, I would still be unaware of my diagnosis.

Some feedback has shown that since restarting screening, the process has been prioritised so women who were approaching 71 during the pandemic and would have been invited for screening during this time are not being offered screening now. If they notice any symptoms, they are advised to contact their GP [37]. A breast cancer survivor, who has been refused access to a mammogram because she was over 70, said this was an ‘ageist’ policy [9].

6.10 Missed invitations to screening in 2018

On 2 May 2018, the then Secretary of State for Health and Social Care, announced that there had been ‘a serious failure … in the national Breast Screening Programme’ across in England and affecting women who may have missed their final invitation to screening between their 68th and 71st birthdays. He suggested that between 135 and 270 women may have had their lives shortened because of the mistake [41]. The advisory group set up at the time estimated that between 150,000 and 200,000 women were affected by the incident [101].

In their study of the local impact on three screening services to help address this situation, Zelenyanszki et al. [101] found that all services were able to absorb the additional demand, although the smaller service, using two mobile vans, found this more challenging than services with predominantly static sites.

7. Appointment times and location

Section summary: The third part of the process concerns the area of appointment times and the location and environment of the screening.

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 - and the limited flexibility of 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 might choose to go the next time that they are invited. Consideration is also given to issues experienced by particular user groups in relation to these.

7.1 Appointment Times

> *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]

Difficulty making an appointment was highlighted by 5% in Mulvey and Gissing's study [63]. Comments included not being able to easily rebook cancelled appointments and a preference for having a centralised number to ring and arrange an appointment, rather than being given a pre-arranged date and time:
I would rather be given a number to ring and make an appointment. Pre-booking an appointment suggests that women are not working. [63]

Difficulties rebooking were also highlighted elsewhere:
I couldn't go to my original appointment and it took me a lot of phone calls to schedule another appointment but I persevered as I knew it was very important. I was recalled so definitely was important. [97]

A lack of alternative options (sometimes due to cost constraints) was highlighted when people couldn't attend external appointments [60]:
Too ill to attend post cancer mammogram.

or were unable to access equipment due to a physical disability [104]:
When my GP requested that instead I have a more expensive procedure done in order to ensure that I was clear of any breast cancer, we were told by the CCG that it was far too expensive and that they wouldn't sanction it. So, I find myself in my mid 50s unable to access breast screening of any kind. [104]

The need for more flexible appointment arrangements was highlighted in two studies ([31] [63]) and flagged as an enabler/solution in the MHCC report [60]. This would help people who were working and/or domestic or caring constraints.

There were conflicting views and beliefs about attending screening during work time. Opinion was evenly split between those who saw this as no problem and others who were either fearful of taking time off work or who could not arrange cover for their domestic responsibilities [31]:
The problem is that I've got huge difficulties getting there (for screening) – it's just too far. I help my daughter (with kids: 2 & 7 years old) but just have no way of getting there for the time given. I'd find Saturday afternoon best but I'm not sure if that is possible.

There are also issues that have been raised around women being invited to screening near their home address, whereas it would be much more convenient to attend near their place of work to reduce the time needed to attend [94].

Recommendation: Make the system more flexible for appointment booking rather than distributing pre-arranged locations, dates and times. Follow up on reported rebooking difficulties and look at the potential of providing occasional out of hours appointments (on evenings and weekends). Investigate use of central appointment phone numbers.

In Kearins et al. [50], women invited to breast cancer screening were asked to call the screening office if they wished to change the assigned screening appointment. The direct phone calls and home visits undertaken as part of this initiative, to remind about a future appointment, made it easier to change to a more convenient appointment time.

Investigate use of online booking options [95]:
… If you can book it online that might be handy.

To address the backlog to appointments caused by the COVID-19 pandemic, Breast Cancer Now [15] noted that in England, from the end of September 2020 to the end of March 2021, women would be sent an 'Open Invitation' to call and make an appointment for screening rather than via a timed appointment. However, although women may be more likely to attend an appointment they have made, research showed that the number of women making appointments was significantly lower than those attending timed appointments [15]. They recommended that during this period:

- Measures must be taken to mitigate the potential impact by implementing strategies shown to improve uptake, such as appointment reminders and letters from GP practices endorsing screening
- Outcomes must be carefully monitored at a local level and experience shared and reflected upon
- Uptake, including amongst groups already less likely to access breast screening, must be monitored regularly and locally, and measures to mitigate against a decline in uptake implemented
- Open Invitations should only be used for a limited period, as proposed.

Recommendation: Evaluate the success or failure associated with the Open Invitation approach utilised during the pandemic backlog and whether this could be another potential approach used in the longer-term.

7.2 Location of the screening facility

In the MHCC report [60], a participant who required Easy Read information said she didn't know where she was going on the day of her mammogram. The letter didn't say where it would be on the site. She didn't know it would be in a van outside and she spent a lot of time trying to find the right place when she got to the hospital.

Recommendation: Ensure a map or an online link to adequate directions or picture based map to the location of screening is provided with the invite letter.

In the MHCC report [60] suggested the invitation letter should be sent in appropriate accessible format with a picture-based map.

The Manthorpe et al. [58] study included a woman with an anxiety disorder who needed to be taken to the mobile unit by a Community Psychiatric Nurse. Had she not had this service she would have needed to catch two buses to get there. She also had difficulty remembering the location and other details of the screening centre because she was using medication at the time. These difficulties might have made attending an appointment particularly hard for her.

Hunneybell et al. [44] noted that it was felt assumptions are made regarding communities wanting the breast screening van to be accessible within community locations and thus it was being placed regularly in supermarket car parks. It was suggested this was embarrassing not just for Muslim women, but for women of all ethnicities, suggesting locations should be reviewed. Local community centres like the Eden Foundation should be considered as more private places for the van. People with autism have also ignored invitations for screenings at these locations. Enable Ability heard from clients who upon receiving an invite to a screening service in a mobile unit located in a supermarket car park, do not connect the supermarket with their health and so do not attend [105].

Recommendation: Raise awareness of alternative sites which can be visited for breast screening and provide information on alternative methods of having the test, if locations are not suitable for some individuals.

Hunneybell et al. [44] suggested raising awareness for women that there are other sites that can be visited for breast screening – e.g. a hospital site - if they are uncomfortable accessing screening within a community setting.

7.3 Disability access

Screening was in a prefab, up steps, at the back of the hospital. All parking was staff only. Paid parking was at the front - walk from there to hospital, through hospital, out back - maybe 15 minutes for a healthy person, 30 minutes+ for me. [60]

The most commonly reported barriers for disabled people in the MHCC study [60] were access requirements not being communicated or acted upon. Venues with steps and/or stairs and small screening rooms and poor lifts were described. In one case the mobile location could not be used by a wheelchair user. Distance from a parking location was also reported as a difficulty.

Recommendation: Provide information about accessing alternative methods of having the test if possible, e.g. at more accessible units. Ensure good communication with individuals about what would be accessible to them. Provide advice on mitigating risks if it is really the case that no current screening options are accessible and consideration of the viability of alternative testing options, such as ultrasound in some cases. [60]

The MHCC report [60] also contains a contribution from a participant based on their own experience of breast screening, much of which tallies with the barriers identified in the overall study. The report gives potential suggestions and things to avoid.

Three case studies detailing examples of reasonable adjustments and case studies in breast cancer screening for PWLD are recorded in the Public Health England 'Making reasonable adjustments to cancer screening report' [75]:

- Cornwall and Devon (p31) - additional information on this approach is also available from the PHE Screening blog [79].
- Newcastle upon Tyne (p31).
- Poole Hospital NHS Foundation Trust (p32).

7.4 Environment of screening location

...having it in a caravan in a car park does send out a certain message...you would feel more comfortable in a different setting. [58]

Some screening facilities have been described positively. For example, premises were described as clean and tidy, with good changing facilities and privacy to ask questions [58]. One participant described the standard of the hospital premises as: *clean and comfortable like a five-star hotel*.

Those that were more critical were often those examined in a mobile unit [58]. They said these facilities were basic or cramped, with "*tiny, tiny changing rooms*" and "*just about enough*" privacy and were impossible to have gotten into if someone had mobility problems. One participant said the mobile unit was "*Spartan, no bigger than a caravan*" and implied that the small space compromised the ability of the staff to treat her with dignity and respect, even though she thought that they were doing their best.

In this study [58], a woman who had attended the centre that had a leaking roof also described having to wear a gown open at the back, with her clothes on a basket and sitting in a waiting area adjacent to an open corridor before being examined. The space for undressing was in the same room as the examination machinery. While waiting to be examined she also saw and heard a surgeon dictating letters with his office door open.

Hunneybell et al. [44] suggested improving some of the language used to increase acceptability within the South-Asian community. For example, ensuring the word ‘*Breast*’ was not used on the screening van, as Muslim women would prefer something along the lines of ‘*Local Health Check’*.

The Live Through This report [56] highlights that the overt gendering or ‘pinking’ of breast and gynae cancers can be a barrier for LGBT people seeking information, screening or support. A participant in the Manthorpe et al. [58] study noted that images of women in breast screening services were largely heterosexual. In the Mulvey and Gissing [63] study, a transgender woman felt uncomfortable in the waiting area:
odd looks off others waiting - almost like "what are you doing here”.

Recommendation: Review current screening environments being offered for their inclusiveness.

8. The appointment itself

Section summary: The fourth part of the process concerns the actual screening.

People’s expectations of the screening include being treated with dignity and respect during the process. This might mean considering their views on the gender of the HCPs that they encounter. Consideration is given to issues experienced by particular user groups, in relation to the screening and what support can be offered to them. Whether some HCP training is required for certain aspects of effective communication and support is examined. Obtaining feedback from attendees is also recommended to improve services.

8.1 Being treated with dignity and respect

...I thought this being breast cancer...they would have been really sympathetic and been there for all us girls...but they wasn’t. [58]

You end up walking around a ward of visitors/patients half naked [63]

The screening experience has been described in various studies as impersonal and unwelcoming ([19] [58] [97]). Descriptions included:
I found it very unpersonal. It wasn't 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 had being put into the machine. [97]

it feels like people putting things through the beepers at the supermarket...you felt as if you had been scanned like a bag of sugar... [58]

My Gran has a mammogram yesterday at XXX mobile unit. Was fired with questions in a rude and abrupt manner. This is already a procedure people feel anxious about and staff should be welcoming to patients. (Oct 2020) [19]

No introduction, no 'My name is...' (Aug 2020) [19]

I thought that the nurse or radiographer who took the x-rays was pretty cold. And I don't expect them to be McDonalds "have a nice day" but you had to ask questions rather than information being volunteered. [35]

In the MHCC report [60] a participant was not happy about the way she was touched at the appointment. She said there was a handprint on her breast that lasted all day. She said they did not seem interested in helping when she told their reception about this. She then complained about the member of staff and "*they made her stop working*".

More positively, many other women, irrespective of ethnicity or other factors, praised the staff for their friendliness and care in the Manthorpe et al. [58] study. A typical comment from a woman aged under 50 years who had been referred because of her mother's history of breast cancer was:
They explained the procedures...They were just friendly, they were welcoming, put you at ease, lovely.

For one Pakistani woman her positive experience of breast screening stood out because of her poor experience elsewhere in the health system [58]. Remarking on the friendliness of breast screening staff and them having a *"soft touch"* and being *"softly spoken"*. She concluded about all aspects of her treatment that:
... it exceeded my expectations because I am so used to being knocked about because of my dress and my colour and my looks ... I was quite pleasantly surprised that they were so polite and so caring and that helps a lot when you are a patient.

Accounts of screening described by Gypsy, Roma and Travellers were generally positive and staff were described as kind [20].

Recommendation: Treat people with dignity, respect and inclusivity. Having these personal examinations can make women 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 women express discomfort [94].

In Manthorpe et al. [58] one respondent described radiographers, radio therapists and speech therapists as very different to nurses, in that these HCPs: *...are almost guaranteed to be courteous, professional, sympathetic and pay attention to the patient...I don't think I have ever encountered a surly or indifferent radiotherapist.*

(Be more like) radiographers

8.2 Effective communication practice

Medical staff using jargon. Make it clear according to our ability [36]

The MHCC report [60] state enablers to improving screening experiences as being good communication (in general); sharing information where consent was given; and accessible explanation of clinical decisions (regarding the testing of younger women). Making extra time to talk through concerns and options [60] was also suggested as another solution.

Recommendation: Discuss the process and what to expect when women arrive for their appointments, even if they have read the leaflet previously sent to them. This would help to ensure they feel supported during the process. [97]

In the Brent Council [36] report more support during health-related appointments, including screening, was suggested as improving participant experience.

Respondents suggested that HCPs should clearly explain the procedures, without using jargon, and ensure that the patient understands them.

Recommendation: Review effective communication training techniques for staff. Try to minimise the overuse of medical terminology and jargon.

8.3 Gender of HCPs and the environment

It's embarrassing to be in front of a strange man [73]

The possibility of encountering a male radiographer [4] made some women reluctant to partake and unanimously, across all ethnicities, a female radiographer was shown to be preferable. For British-Pakistani women it was apparent that if they knew that a female radiographer would be performing the mammogram, they would be more inclined to attend [100]. The gender of HCPs was also identified by other studies as a barrier ([5] [60] [73]). Comments included:
My initial screening was with a male consultant - when I said I only wanted to see a female they said I could rebook but would have to wait. As I was already really anxious and didn't want to wait I had to let the male consultant examine me which was awful. [60]

For Muslim women, scholars believe that exposure for medical needs has a basic principle of '*treat by the same gender*' [44].

In another study, a UK participant gave the example of a friend of a friend - a gay male who had lumps in his chest and was the only man attending breast cancer screening. This was an experience that he found very intimidating. He also gave the example of transgender people attending screenings with people of the opposite gender and finding this distressing [17].

Recommendation: Offer preferred gender HCPs wherever possible for sensitive screening [60]. Where this is not possible, make sure people understand that this option is not available before they come.

8.4 Disability access

Breast screening refused because my wife is confined to a wheelchair. [60]

When she was called for her first time check at the age of 50 she couldn't access the machine because she is paralysed - BUT she wasn't offered alternative tests or even a GP's appointment which might have located the lump which doctors now think had been growing for two years. [45]

A total of 2.4% of respondents to a breast cancer survey reported that a physical disability was a barrier to attending screening [63]. This was also reflected elsewhere in literature:
I haven't had breast screening due to not being able to get out. And I don't have anyone to support me. [60]

The accessibility of the equipment used can be a problem for this group, such as inaccessible x-ray machines [60], standard equipment not designed to be used seated [60] and a lack of adjustments:
failure to have the access adjustments in place when I turned up for my appointment; lack of consideration at to how and where I could, and couldn't, move parts of my body e.g. pushed my arm into the position they thought necessary without checking/asking first = pain then and impact lasted 2 days. [60]

As a severely disabled person, when I was called for a breast screening at the hospital here in Swindon I was unable to use it because I couldn't stand up to be properly positioned in the machine. [104]

Recommendation: Investigate ways of making disability access easier, such as where feasible providing machines which allow for seated screening [60].

8.5 Supporting people with learning disabilities (PWLD)

I don't think they [women with LD] would have ever gone through with any of the screening unless that they had the support of someone to communicate on their level and to advocate for them. [61]

PWLD require specific support to have successful screenings. These include resolving issues of consent and carers being allowed to provide support where appropriate or needed. A McIlfatrick et al. [61] study participant noted some patients because of their learning disability would not be able to consent:
…it is how do we advise someone with intellectual disabilities to consent and if they can't consent, which is usually the case, who will consent for them . . . So it's a big area ... the consent issue has to be watertight.

In this study a lack of an available carer was also highlighted as an issue for some PWLD. Carers are often not allowed to go into the screening room with the patient. This can make the screening process distressing for them as the carer can provide reassurance and help with communication [16]. In Taggart et al. [90], this was also noted by a participating Community Intellectual Disability Nurse (CIDN):
We have had the other experience where women with LD haven't cooperated and they have shouted and screamed and it has been very difficult for the breast screening nurses.

Marriott et al. [59] described the role of screening liaison nurses for PWLD employed by Peninsula Community Health (PCH). They noted that although this role had not been formally evaluated (at time of writing in 2015), the emerging data suggested that the role was effective in improving participation and the figures from one of the breast screening centres in PCH demonstrated that a significant impact could be made in just two years.

Recommendation: Consider the provision of specialist staff to help PWLD.

Some resources have been put towards addressing this by creating screening liaison nursing roles in certain areas. These dedicated roles allow HCPs to concentrate on the 5 adult screening programmes and has been effective in Cornwall (PHE Screening 2017).

One group in the Brent Council [36] report suggested the possibility of recruiting for a dedicated learning disability screening nurse to support PWLD throughout the process:
Having a learning disability cancer nurse, someone to contact before and explain give screening support and hold your hand if needed.

CIDNs in Northern Ireland were highlighted [90] as a good source for signposting and support. This ranged from providing pre-appointment information:
Accompanying them to the breast screening clinic, taking them up beforehand and showing them around … and getting leaflets and explaining what the procedure is...

To offering advice to both PWLD and their family members in relation to breast examination and attending screening:
very often families think, oh you know, because they have an ID (intellectual disability) that they don't require the same level of screening that everyone else does. It's about advising them that yes it is very important.

Also providing information and support to the breast screening nurses on topics such as communication. This has helped the breast screening nurses to provide more in-depth support where possible to PWLD, ensuring extra time is given to them and providing reassurance:
I have contacted the breast screening nurses before the women with LD attends, explaining what this person's particular needs will be on a given day and making sure that the nurses are aware of her needs.

8.6 Staff awareness and training

> *Well its like anything, you can always improve on probably everything you are doing … I don't know that as part of your training there is specific training on dealing with people with learning disabilities … it probably would be a good idea for us to undertake some sort of specific training or guidance from even another organisation on ways that we could improve what we are doing.* [61]

The MHCC report [60] recommends that people should be treated with respect and dignity. Disability Equality Training was suggested as a way to help facilitate this. As an example, the report suggests [60] always checking with the person about what works for them before taking any action:
At the last breast screening the staff were much more accommodating and didn't 'pull' my body into the position they wanted it without checking whether I would be able to do that/be caused unnecessary pain.

A respondent to the McIlfatrick et al. [61] study also highlighted specific learning disability training as being useful as a means of improving HCP's practice.

NHS guidelines [66] highlighted that the main issue for people within the transgender group was fear of negative attitudes from screening staff. The main tip for services was to ensure all staff had adequate training. These guidelines also noted that it was important to make sure that staff used the right pronoun when talking to an individual and if in doubt, to ask the individual how they preferred to be addressed. This could help to avoid an experience like this:
I have never been for a sexual health screening. I tried once but the woman at reception asked me if I was a 'man or a woman' in front of a waiting room full of people, it was humiliating. I turned around and walked out of the clinic as fast as I could [55].

Furthermore, NHS guidelines [66] also highlighted that it was important that information was available for both staff and patients about screening and the transgender population. A commonly held perception was that transgender

individuals no longer required screening; this is not necessarily true and can lead to much confusion.
[Also, see earlier discussion about Lesbian, Gay, Bisexual and Trans experiences of prejudice and awareness]

In the Baird et al. [4] systematic review one study identified a reluctance of staff to engage with Black, Asian and minority ethnic women due to feelings of '*cultural incompetence*' and fears of causing offence. Moreover, another study also showed lack of awareness amongst HCPs regarding the specific needs of Black, Asian and minority ethnic women and how best to address them.

Hunneybell et al. [44] recommended in their study of Muslim communities that HCPs needed to understand religious and cultural sensitivities; and secondly appreciate the role religion played in a person's health – highlighting the need for religious and cultural awareness training.

During the COVID-19 pandemic, appropriate use of PPE at a screening was negatively discussed on Care Opinion [19]:
PPE - operator was wearing a mask and gloves. She placed a plastic apron over her neck, however failed to wear it appropriately, it was hanging like a plastic tie.
(Aug 2020)

Finally, Healthtalk.org [35] notes one participant who encountered a younger trainee screener and their behaviour was notably different from other HCPs at previous appointments which caused her anxiety after the appointment. This highlights how even subtle nuances of different behaviour in certain instances can impact on someone:
Well the girl that I had doing mine was a learner, she was a student and she was being very careful and very concerned and when she came out to tell me about mine she came out and said "Thank you very much, your scan was done and it's, and we've got the pictures and you'll be hearing from us." And immediately I was ahh, why, why isn't she talking to me like the other people are being talked to? Why isn't she saying "Everything's all right," da di da, you know, something must

be wrong, there's something wrong. So, then I spent the next period thinking what am I going to hear? What am I going to hear? And, of course, the letter came and everything was clear, so yeah. A lot depends on who you are dealing with…

Recommendation: Review training requirements for staff involved in the screening process such as Disability Equality Training. Make information, guidelines and good practice examples available to staff including raising awareness of issues which might affect particular groups (e.g. people with disabilities, PWLD, Lesbian, Gay, Bisexual and Transgender, and Black, Asian and minority ethnic groups) including some of the examples documented in this report.

For example, Brighton and Sussex Universities NHS Trust were inspired to develop a new breast symptom referral form following feedback from a project stakeholder who challenged their initial Male/Female specific referral forms and highlighted the importance of gender inclusivity moving forward [68].

8.7 Obtaining patient feedback

Obtaining continuous patient feedback on the whole journey of breast screening from start to finish, is an important step in being able to improve aspects of services by reflecting on documented experiences.

Recommendation: Review mechanisms for obtaining patient feedback and whether these could be improved.

Wessex Voices made recommendations to help reduce worries and support higher uptake of first time routine breast screening [97]:

5. Public health commissioners to review how screening providers gather feedback, implementing standard feedback processes across all providers, and to regularly discuss feedback from patients shared after screening with screening providers.

9. Breast screening results

Section summary: The fifth and final part of the process is the results stage. The potential for a possible recall and follow-up is outside the scope of this report but are included in Appendix D.

People's worries about the news they might receive or hope for reassurance means that the speed in receiving information and the clarity of it are very important considerations. Meeting the timescale for results delivery is an important goal, as are the accuracy and wording and details of the results themselves.

9.1 Speed of results

Good thing was to have results at the same time. I am aware this was at the specialist centre and not a mobile unit so probably not always the case [97]

The MHCC report [60] suggest results should be sent in the person's preferred format within standard timescales. Wessex Voices recommends this to help reduce worries and support higher uptake of first time breast screening [97]:
4. Ensure women receive their results in a timely manner to reduce any concerns or fears they may have about the outcome.

Quickness in receiving results was described - face-to-face and by post [97]:
The results are posted promptly and received within a week so there's no need to worry unnecessarily. I'd rather know if there's a problem so that it can be addressed.

Delays to results both pre- and post-pandemic have been recorded. One person in the MHCC report [60] said she had to wait for five months to get the results from her breast screening at Wythenshawe. Another participant went for breast screening and had not had any results. She rang her doctor two weeks before the session and still had not heard anything. This was worrying her [60]. Delays post-pandemic have also been recorded on Care Opinion [19]:

The final straw for me is in relation to the appointment letter. The appointment letter clearly states that I would receive my results in two weeks. It is now 5 weeks later and I've still not received my results. I phoned to enquire and was told that the two weeks related to non-COVID times. When I asked why the letter had not been amended to reflect this? The person on the phone said they would mention it to her manager. (Nov 2020)

Recommendation: Ensure the timeline for results detailed in the invitation are reflecting the actual realities of the time they are being sent out. Investigate any reported delays with receiving results.

9.2 Wording of the results letter

In the Manthorpe et al. [58] study a participant had 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"*. In the event there was not an adverse diagnosis, but she felt that perhaps such letters could be more reassuring.

Recommendation: Revisit results letter wording and information included to reduce anxiety in recipients.

9.3 How results are received

I wouldn't have minded getting a text to say, you know, the results. [14]

The methods of delivering normal result were considered in the Boundouki et al. [14] study, including the potential use of text messages for delivery.

Recommendation: Investigate ways to improve speed of results - such as offering options for mobile text messages, or, immediately if possible and according to people's preferences.

10. Conclusion

Providing equitable access to breast screening should be seen as a priority. Many of our 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, and reduce inequalities.

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.

11. 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)

Appendix A: UK variations in uptake

COVID-19 pandemic impact on programme

The breast screening programme was officially paused in Scotland, Wales and Northern Ireland, and effectively paused in England, in March 2020. Screening is now restarting, although this is happening more quickly in some parts of the UK than others. It is estimated that a significant backlog of nearly a million women requiring screening has built up across the UK during the pause. It is currently unclear how long it will take to catch up. The number of appointments available has been reduced to enable social distancing and infection prevention and control measures (IPC) to be implemented, and these arrangements will need to be kept under review [15]. IPC constraints have currently increased the length of an average screening from 6 to 12 minutes, effectively cutting capacity [87].

Decline in uptake (pre-COVID-19 pandemic)

Breast Cancer Now [15] were concerned that the pandemic could worsen the persistent decline they had seen in uptake of breast screening in recent years. They were particularly concerned about the impact the pandemic would have on groups amongst which uptake was already low, such as women living in deprived areas and some Black, Asian and minority ethnic groups.

Which groups are not attending screening?

It was highlighted in the Boundouki et al. [14] study that there was a need to research which groups were not attending screening,

Which groups present late with breast cancer?

It was also highlighted in the Boundouki et al. [14] study that it would be useful to investigate which groups present late with breast cancer and explore the reasons underlying this.

Improve engagement with hard to reach groups

It was recognised that there was a need to improve engagement with screening by '*hard to reach*' groups such as some ethnic minorities [14]. For context, white British women attended their first time call (67%) and routine recall (78%) invitations most often. Indian women were more likely to attend their first (61%) or routine recall (74%) than Bangladeshi women (43% and 61%, respectively) and Black Caribbean women were more likely than Black African women to attend first call (63% vs 49%, respectively) and routine recall (74% vs 64%, respectively). There was less variation between ethnic groups in some geographical screening areas [46].

The variation in the uptake for women from the same ethnic groups in different geographical areas suggests that collaboration about the successful engagement of services with different communities could improve uptake for all women [46].

London

Uptake of breast cancer screening is defined as the proportion of women invited who attend for screening within 6 months of their invitation. Within England, this has been consistently lower in London than other areas ([46] [65]).

Breast cancer screening uptake in London varies by specific ethnic group for first and subsequent invitations, with White British women being more likely to attend [46].

Attendance has been found to vary between the broad White (British, Irish and White Other), Black (Caribbean, African and Black Other) and Asian (Indian, Pakistani, Bangladeshi and Asian Other) groups within London [83].

The Transforming Cancer Services Team (TCST) has produced a toolkit to reduce inequalities in cancer care and outcomes in London and West Essex which includes breast screening. The strategy underpins delivery of the three agreed London Cancer Priorities for 2019/20 [38].

West Midlands

Uptake of breast cancer screening is lower in some Asian religio-linguistic groups, particularly Muslim women, compared with non-Asian groups in the West Midlands [88].

South East (first time screening)

The national breast screening programme sends an invitation for first time screening within a few years of a woman turning 50. Studies indicate women who attend their first screening are more likely to attend future appointments. Current uptake of women who attend their first screening appointment is 61% for women who live in South East England - below the national target of 70% [97].

South West (first time screening)

Current uptake of women who attend their first screening appointment is 60.3% for South West England - below the national target of 70% [97].

Black, Asian and minority ethnic women

Screening rates for breast cancer are lower amongst ethnic minority women, particularly South Asians (including Bangladeshi, Indian, Pakistani, Sri Lankan, Bhutanese, Maldivian and Nepali populations). Poorer awareness of risk factors for cancer and symptoms, and socio-cultural and practical barriers such as language, contribute to lower cancer screening rates among ethnic minority groups [52].

The de Cuevas et al. [24] systematic review of barriers and enablers to breast and cervical screening noted that South Asian women generally had lower screening rates when compared to women from the countries where they were now living. South Asian women had poorer knowledge of cancer and cancer prevention and experienced more barriers to screening. Cultural practices and assumptions influenced understandings of cancer and prevention, emphasising the importance of their new locations cultures and healthcare systems.

Refugees and asylum seekers

Screening and health promotion programmes tend to have a low uptake among refugee women. In one study only 5% of women aged over 50 had attended breast screening [28].

Gypsy, Roma and Travellers

Participants frequently stated that members of their community (Gypsy, Roma and Travellers) would be unlikely to attend screening, but that they themselves did attend. Older participants described a generational change with younger people being more likely to attend. Some eligible women stated they had had mammograms [20].

People with a learning disability (PWLD)

In 2010 a gap in terms of screening programmes not reaching PWLD was recognised (PHE Screening 2017):
Feedback from women with learning disabilities, health and social care professionals and families and carers, indicates numerous reasons for low levels and a decreasing rate of uptake, including a lack of understand, embarrassment or fear. Whatever the reason for non-attendance, all health and social care professionals, alongside families and carers of women with learning disabilities can play a vital part in helping address this recognised health inequality.

Mental Health

Woodhead et al. [99] noted to tackle health disparities linked to serious mental illness (SMI) status, increasing uptake of cancer screening for women with SMI must be a key element. Their findings indicated the potential benefits of incorporating policies which targeted efforts at encouraging greater screening uptake among women with other markers of severity or risk, beyond SMI status alone. Schizophrenia diagnosis, depot injectable antipsychotic prescription, and illness severity and risk were associated with the lowest odds of uptake of breast screening [100].

In a previous UK study [93], breast screening registrations were linked to mental health service use and no difference in mammography receipt for women known to mental health services was found overall. However, women with a psychosis diagnosis or a history of compulsory treatment had reduced screening receipt. This study focused on mammography and dates from nearly a decade prior to Woodhead et al. [99], suggesting that the situation has not changed markedly over this time.

A participant speculated about the effect on take-up of screening examinations by women with mental health problems who had been exposed to a poor experience of psychiatrists, previously having a male Community Psychiatric Nurse and whether GPs should ensure patients with mental health problems were attending screening appointments [58].

Lesbian, Gay, Bisexual and Transgender People

Screening uptake is lower amongst transgender people in comparison to cisgender women, which will have an impact on diagnosis [55]. It is thought that this is due to fear of negative attitudes towards transgender people in these services [66].

Women prisoners

In 2018 Public Health England issued Gender Specific Standards to Improve Health and Wellbeing for Women in Prison in England [76] which included Standard 1.9: *all eligible women should be offered screening and a physical health check (as per the Physical Health Check in Prisons Programme) within the appropriate interval.*

However, this document acknowledged that currently not all standards were being met. But, implementation of these evidence-based standards was a shared objective for Her Majesty's Prison and Probation Service, NHS England and Public Health England to improve the quality of health services, reduce health inequalities and improve the health and wellbeing of women in prison.

Polish women

Polish reports suggest that while many women opt for annual mammography, many others, particularly in rural areas, remain unscreened and overall uptake is reported at between 31% and 43%.

Uptake of the SBSP in Polish women living in Lothian has been calculated at 47%, a little higher than in Poland but well below the overall Scottish uptake rate of 72.5% (for 2012–15) [31]. However, a notable number of Polish women living in Dorset were strong proponents of going for breast screening, saying that it was a ‘*no-brainer*’ and in Poland, there was information given to women consistently about breast health. Comments from the Wessex Voices study included [97]:
Do you respect your life and life of your family? You won't let you get you and cancer!

My aunt had breast cancer, she was screened that helped her with a quick diagnosis. So it has both breasts and the treatment was quick and effective.

It’s simple - breast screening saves lives.

Better to discover something early when it is possible to have simpler treatment.

It is better to prevent than to treat.

Appendix B: Worldwide

Denmark

Minority ethnic women

The ethnic minority women in the Tatari [91] study believed that cancer screening was only relevant if they had symptoms. They had fragmented knowledge about cancer screening and cancer prevention. Furthermore, they had inadequate language skills in Danish which made it difficult for them to interact with the Danish medical system.

USA

Who does the inviting?

Crump et al. [23] noted that the profession of the HCP making the referral might be a barrier. Women in this study were more likely to keep their mammogram appointments if they were referred by a nurse practitioner or physician's assistant. They suggested that it should be considered that perhaps nurse practitioners or physician's assistants used more effective communication styles than physicians in prompting women to comply with screening recommendations.

Women Sex Workers

Although most women acknowledged the need for mammograms or pap smears, few had had these tests done recently [103].

Improving Uptake in Asian Women and Pacific Islanders

In the United States, Asian Americans and Pacific Islanders have the lowest breast screening rates amongst all ethnic groups. A study from the year 2000 reported that compared with 21% of white women in the same sample, 30% of Asian women (26% Chinese, 21% Japanese, 28% Filipino, 50% Korean, and 68% Asian Indians) had never had a mammogram [57].

Targeting/tailoring resources and groups

Three national Community Network Programs (CNPs) funded by the National Cancer Institute have focused on breast cancer screening interventions as their major research intervention. Each targeted different populations and used participatory research methods to design their intervention tailored to the needs of their respective audience.

The Alameda County Network Program (ACNP) to Reduce Cancer Disparities partnered with community members to design and conduct 2-hour '*Tea Party*' education sessions for Afghan women. The Kansas Community Cancer Disparities Network co-developed and deployed with community members a computerised Healthy Living Kansas (HLK) Breast Health program for rural Latina and American Indian women. The Johns Hopkins Center to Reduce Cancer Disparities employed a train-the-trainer COACH approach, to educate urban African American women about breast cancer [86].

Communication to improve uptake

In 2006, Sharp Health Plan (SHP) conducted a campaign to increase mammography screening for at-risk female members. It consisted of mailing each eligible member an informational mammography postcard with an appointment tracker. Then came an automated phone call reminder. After the mammography campaign, 70% of SHP members sought mammography screening while 30% remained nonadherent. SHP decided to conduct a survey to better understand members' barriers to breast cancer screening. The top three barriers identified were: Mammogram not a priority, knowledge deficit and had a bad experience in the past [71].

Lesbian, Gay, Bisexual and Transgender related

Researchers discovered that, within the hospital system, eligible transgender patients were 70% less likely than cis-gender patients (meaning those whose gender identity matches the sex they were assigned at birth) to be screened for breast cancer [64].

Due to discrimination, patient unease, a lack of provider awareness, and other obstacles such as misgendering (when a transgender person is referred to in a way that does not reflect the gender with which they identify), those cancer screening messages often are never sent, received, or acted upon, with potentially disastrous results [64]:

If you treat a trans guy the same as a cis guy, then you're not going to give him the screenings that his body needs.

Charlie Manzano, a transgender man, says breast clinics often are folded into women's health clinics and include highly gendered pamphlets, documents, and paperwork [64]. Similarly, breast cancer screening can be fraught for both transgender men and women:

Transgender men can feel very uncomfortable because breast cancer screening is something that women undergo, and the whole process is very feminized.

Transgender women, meanwhile, may be uncomfortable due to the potential for confusion about their gender presentation when they check in for a mammogram [64].

This study [64] suggests physicians can further help their transgender patients by asking more questions:

A lot of doctors are scared to ask questions, which is a huge problem.

and instead of shying away from saying certain words:

asking what language we prefer is better than not saying it at all. [64]

United Arab Emirates

Arabic women

HCPs infrequently offered screening examinations and women lacked adequate knowledge about breast cancer screening. Acquired information about barriers to screening may help in the design of effective screening programs for Arabic women [11].

Appendix C: Positive Experiences

of screening (pre COVID-19 pandemic) – disabilities

Adjustable equipment was described positively in the MHCC [60] report:
Excellent practice at hospital - well trained staff and height adjustable chairs to make mammogram easier for wheelchair users- you don't want to fall if your breast is clamped for screening!!

of screening (during COVID-19 pandemic)

A number of positive experiences of screening were highlighted during the COVID-19 pandemic on Care Opinion [19]:
Excellent service, I had a routine referral from my GP and was still seen within 14 days. I expected due to be waiting a lot longer due to COVID-19. Mr Harron was so friendly and reassuring. Very impressed by the whole team and service. (Nov 2020)

I am so pleased that the breast screening service is still working and so efficient despite the virus. Thank you for taking the time. It's still important for us all to check for other issues not just COVID-19. (Jan 2021)

Attended routine breast screening today at Nelson Mandela Place Glasgow. Excellent service felt respected and cared for throughout my appointment. Mammographer Mary was excellent so kind and really explained procedure well. Well done. (Dec 2020)

of first time screening (pre COVID-19 pandemic)

Positive experiences of first screenings (pre COVID-19 pandemic) were described in the Wessex Voices report [97]:
I was very worried about what to expect but the staff were all very sensitive of every patient and our privacy was respected as much as possible.

It was a short appointment. The radiographer was very pleasant and explained the procedure.

of first time screening (during COVID-19 pandemic)

Positive experiences of a first screening were highlighted during the COVID-19 pandemic on Care Opinion [19]:

I attended the mobile breast screening unit on the 4th of February at Earlston health centre in the Borders. The staff were welcoming and friendly. This was my first time and they explained everything well and treated me with respect. Thank you - you are doing a great job. (Feb 2021)

Appendix D: Recall and Follow Up

Recall letter

In the Bond et al. [13] study participants described how they immediately thought the worst when they received a recall letter, believing they had breast cancer, and were very frightened:

It's fear, uh, and then you think, 'ah, it can't be anything' and then you try and disregard it, but it's always there in the back of your mind. . .you're not as invincible as you thought you were. . . I couldn't speak to anybody that had had a recall. . . that made it worse. . . It was just a preying on the mind business, but trying not to think about it and that's how I've tried to be, quite positive, but fail miserably.

Recommendation: Revisit the recall letter wording.

Findings by Austoker and Ong [3] indicated that careful phrasing of the recall letter and extensive information may reduce distress associated with the recall experience. Implications of their study were:

- Women should be prepared for the possibility of a recall in different ways and as often as possible during the first stage of screening.
- A leaflet should be used with the recall letter and the letter should refer to the leaflet.
- All nine topics identified should be mentioned in the recall letter or leaflet, or both. These are -1- Why women had been called back; 2- How to get to the centre; 3- Who could come with them; 4- How to change the appointment; 5- How long the appointment would be; 6- Who they would see at the centre; 7- What tests would be carried out; 8- When the results would be available; 9- How to get more information.
- Key and additional information should be put in the recall letter.
- The most reassuring information should be repeated in the leaflet. The most reassuring information concerning recall was the fact that

assessment was part of routine screening and that most recalled women are found to have normal breasts.

- Special care should be taken with the way in which topics that are sensitive to distressed women are covered: the reason for recall; how to get more information; approximately how long the recall appointment will take.
- The readability of all written information should be enhanced – for example, by using an established readability measure.
- All written information should be tested and evaluated before it is used routinely.

Recall appointment (during COVID-19 pandemic)

Positive experiences of a recall appointment during the COVID-19 pandemic were reported on Care Opinion [19]:

Recall appointment at West of Scotland Breast Screening. Seen by Dr Todd and Dr Dawson. This was a very difficult appointment and both Dr Todd, Dr Dawson and the radiographers treated me with patience and care and made a very stressful appointment much more bearable. (Mar 2021)

Who could tell you the results?

I think some patients are afraid to ask doctors questions and some see that as a barrier [26]

The Eden and Borgen [26] study explored the perceptions of advanced practice radiographers (APRs) who currently give benign biopsy results. There are potential plans to extend their role to deliver malignant outcomes. Increasing pressures on breast screening units are a key driver for APR evolvement. This study identified important enabling factors and challenges concerning role extension in the delivery of breast biopsy results:

Yeah that’s my biggest fear really, is giving the result and them crying.

The apparent suitability of APRs to communicate results may address breast service pressures, with benefit to patients and the radiology profession:
We might be better suited to put it into layman's terms.

When you've done the biopsy and you get to give them their results …it's nice to be able to tell them everything's alright.

especially in mammography you might see them on the van when you do their mammogram, you might come across them in the assessment and then you might do the biopsy. You might then give the results. It's continuity. And there's a rapport that you would get with the patients. And that's all an extension of your advanced practice.

Recommendation: Consider the impact of extending the roles of advanced practice radiographers in relation to breast screening.

Follow-up

Diagnosis/treatment (pre-COVID-19 pandemic)

Positive experiences of diagnosis and treatment (pre-COVID-19 pandemic) were highlighted in the MHCC report [60]:
Mammogram screening picked up that I had breast cancer early so it was effectively dealt with.

Usually positive, last screening was for breast cancer.

A female refugee from Central Africa had breast cancer identified through screening and subsequently underwent a mastectomy. When asked to describe her overall experience of her medical treatment she said: *The experience was good for me because I am still alive. If I hadn't been looked after, cared for, hadn't been attended to and treated then it might have been worse.* (Manthorpe et al. [58])

Diagnosis/treatment (during COVID-19 pandemic)

A number of positive experiences of diagnosis and treatment were highlighted during the COVID-19 pandemic on Care Opinion [19]:
I found a lump in my breast for the first time in April 2020, a few weeks into lockdown. As a nurse, I was concerned but tried to reassure myself. To be sure I made an appointment with my GP who then referred me on to the breast screening unit in AAH. I was seen within two weeks of my initial presentation and throughout the day was treated with care, compassion and the same level of consideration as pre-COVID-19. (Nov 2020)

I went for a routine mammogram when screening resumed late August 2020. I was recalled to breast screening clinic in Nelson Mandela within 2 weeks for further investigation. Was seen by Mr McKirdy the following week & breast cancer diagnosis confirmed…. Options discussed & decisions made on next steps. I cannot thank or praise each & everyone within NHS who looked after me during this time. I have laughed & cried with some of them as they saved my life despite the craziness of a worldwide pandemic. I was always treated as an individual but more importantly, they treated me with respect. God bless them all....not all superheroes wear capes, I know that from first-hand experience x. (Apr 2021)

Appendix E: References

1. Allgood, P.C., Maxwell, A.J., Hudson, S., Offman, J., Hutchison, G., Beattie, C., Tuano-Donnelly, R., Threlfall, A., Summersgill, T., Bellis, L. and Robinson, C., 2016. A randomised trial of the effect of postal reminders on attendance for breast screening. *British Journal of Cancer*, *114*(2), pp.171-176.

2. Aro, A.R., De Koning, H.J., Absetz, P. and Schreck, M., 2001. Two distinct groups of non-attenders in an organized mammography screening program. *Breast Cancer Research and Treatment*, *70*(2), pp.145-153.

3. Austoker, J. and Ong, G., 1994. Written information needs of women who are recalled for further investigation of breast screening: results of a multicentre study. *Journal of Medical Screening*, *1*(4), pp.238-244.

4. Baird J, Yogeswaran G, Oni G, Wilson EE., 2021. What can be done to encourage women from Black, Asian and minority ethnic backgrounds to attend breast screening? A qualitative synthesis of barriers and facilitators. *Public Health*, Jan 6.

5. Bamidele, O., Ali, N., Papadopoulos, C. and Randhawa, G., 2017. Exploring factors contributing to low uptake of the NHS breast cancer screening programme among Black African women in the UK. *Diversity and Equality in Health and Care*.

6. Banning, M., 2011. Perceptions of breast health awareness in Black British women. *European Journal of Oncology Nursing*, *15*(2), pp.173-177.

7. Barter-Godfrey, S. and Taket, A., 2007. Understanding women's breast screening behaviour: A study carried out in South East London, with women aged 50—64 years. *Health Education Journal*, *66*(4), pp.335-346.

8. Baysal, H.Y. and Gozum, S., 2011. Effects of health beliefs about mammography and breast cancer and telephone reminders on re-screening in Turkey. *Asian Pac J Cancer Prev*, *12*(6), pp.1445-50.

9. BBC News. 2020. Coronavirus: Cancer survivor calls mammogram refusal 'ageist'. URL: https://www.bbc.co.uk/news/uk-england-leicestershire-53692885 [accessed 09/06/21]

10. Bell, T., K Branston, L., G Newcombe, R. and R Barton, G., 1999. Interventions to improve uptake of breast screening in inner city Cardiff general practices with ethnic minority lists. *Ethnicity and Health*, *4*(4), pp.277-284.

11. Bener, A., Alwash, R., Miller, C.J., Denic, S. and Dunn, E.V., 2001. Knowledge, attitudes, and practices related to breast cancer screening: a survey of Arabic women. *Journal of Cancer Education*, *16*(4), pp.215-220.

12. Birth Companions. 2006. The Health of Women in Prison Study Findings. URL: https://hubble-live-assets.s3.amazonaws.com/birth-companions/attachment/file/49/Health_of_Women_in_Prison.pdf [accessed 29/04/21]

13. Bond, M., Garside, R. and Hyde, C., 2015. A crisis of visibility: the psychological consequences of false-positive screening mammograms, an interview study. *British Journal of Health Psychology*, *20*(4), pp.792-806.

14. Boundouki, G., Wilson, R., Duxbury, P., Henderson, J., Ballance, L., Wray, J., Appanah, V., Ibrahim, I., Harvey, J. and Kirwan, C.C., 2021. Patient and public priorities for breast cancer research: a qualitative study in the UK. *BMJ Open*, *11*(1), p.e036072.

15. Breast Cancer Now. 2020. Press Play: Getting and Keeping Breast Cancer Service Back on Track. URL: https://breastcancernow.org/sites/default/files/final_breast_cancer_now_press_play_report.pdf [accessed 28/04/21]

16. Brent Council. Undated. Access to health services for people with learning disabilities. URL: http://democracy.brent.gov.uk/documents/s3144/ [accessed 30/04/21]

17. Brighton & Hove LGBT Switchboard. 2018. LGBTQ People affected by cancer report. URL: https://www.switchboard.org.uk/wp-content/uploads/2018/05/LGBTQ-People-affected-by-Cancer-Report-2018.pdf [accessed 30/04/21]

18. Cancer Research UK. 2021. I’m trans or non-binary, does this affect my cancer screening. URL: https://www.cancerresearchuk.org/about-cancer/screening/trans-and-non-binary-cancer-screening [accessed 23/04/21]

19. Care Opinion. 2021. Website. Published comments from 2020 and 2021. URL: https://www.careopinion.org.uk/ [accessed 03/06/21]

20. Condon, L., Curejova, J., Morgan, D.L., Miles, G. and Fenlon, D., 2021. Knowledge and experience of cancer prevention and screening among Gypsies,

Roma and Travellers: a participatory qualitative study. *BMC Public Health*, *21*(1), pp.1-11.

21. Coppafeel, 2021. Home Page. URL: https://coppafeel.org [accessed 25/05/21]

22. Crook, A., Kwa, R., Ephraums, S., Wilding, M., Thiyagarajan, L., Fleming, J., Moore, K. and Berman, Y., 2021. The psychological impact and experience of breast cancer screening in young women with an increased risk of breast cancer due to neurofibromatosis type 1. *Familial Cancer*, pp.1-13.

23. Crump, S.R., Mayberry, R.M., Taylor, B.D., Barefield, K.P. and Thomas, P.E., 2000. Factors related to noncompliance with screening mammogram appointments among low-income African-American women. *Journal of the National Medical Association*, *92*(5), p.237.

24. de Cuevas, R.M.A., Saini, P., Roberts, D., Beaver, K., Chandrashekar, M., Jain, A., Kotas, E., Tahir, N., Ahmed, S. and Brown, S.L., 2018. A systematic review of barriers and enablers to South Asian women's attendance for asymptomatic screening of breast and cervical cancers in emigrant countries. *BMJ Open*, *8*(7), p.e020892.

25. Döbrössy, B., Girasek, E., Susánszky, A., Koncz, Z., Győrffy, Z. and Bognár, V.K., 2020. " Clicks, likes, shares and comments" a systematic review of breast cancer screening discourse in social media. *PloS one*, *15*(4), p.e0231422.

26. Eden, J.K. and Borgen, R., 2021. Exploring the perceptions of advanced practitioner radiographers at a single breast screening unit in extending their role from delivering benign to malignant biopsy results; a preliminary study. *The British Journal of Radiology*, *94*(1117), p.20200423.

27. Forbes, L.J.L., Atkins, L., Thurnham, A., Layburn, J., Haste, F. and Ramirez, A.J., 2011. Breast cancer awareness and barriers to symptomatic presentation among women from different ethnic groups in East London. *British Journal of Cancer*, *105*(10), pp.1474-1479.

28. Gammell, H., Ndahiro, A., Nicholas, N. and Windsor, J., 1993. *Refugees (political asylum seekers): service provision and access to the NHS*. London: College of Health.

29. Gilbert, F.J., Cordiner, C.M., Affleck, I.R., Hood, D.B., Mathieson, D. and Walker, L.G., 1998. Breast screening: the psychological sequelae of false-positive

recall in women with and without a family history of breast cancer. *European Journal of Cancer*, *34*(13), pp.2010-2014.

30. Good Things Foundation. 2018. Using Facebook to improve attendance at screening appointments. URL: https://drive.google.com/file/d/1pASaOsKqsJ5AEdwT3-xAzUbZFlDI4W7K/view [accessed 04/06/21]

31. Gorman, D.R. and Porteous, L.A., 2018. Influences on Polish migrants' breast screening uptake in Lothian, Scotland. *Public Health*, *158*, pp.86-92.

32. Grieveson-Smith, J. 2021. How a simple TikTok video helped a Barnsley woman, 22, discover she had breast cancer. Yorkshire Live. URL: https://www.examinerlive.co.uk/news/local-news/how-simple-tiktok-video-helped-19794665 [accessed 20/05/21]

33. Griffiths, F., Bendelow, G., Green, E. and Palmer, J., 2010. Screening for breast cancer: medicalization, visualization and the embodied experience. *Health*, *14*(6), pp.653-668.

34. Hanna, L.M., Taggart, L. and Cousins, W., 2011. Cancer prevention and health promotion for people with intellectual disabilities: an exploratory study of staff knowledge. *Journal of Intellectual Disability Research*, *55*(3), pp.281-291.

35. Healthtalk.org. 2016. Breast screening section. URL: https://healthtalk.org/breast-screening/overview [accessed 04/06/21]

36. Healthwatch Brent. 2020. Cancer Screening for people with learning disabilities in Brent. January 2020.

37. Healthwatch Northamptonshire. 2020. Restoring Breast Screening Services in the Midlands. August 2020. URL: https://www.healthwatchnorthamptonshire.co.uk/news/2020-08-25/restoring-breast-screening-services-midlands [accessed 09/06/21]

38. Healthy London Partnership. 2021. Cancer Inequalities Toolkit. URL: https://www.healthylondon.org/resource/cancer-inequalities-toolkit/ [accessed 04/06/21]

39. Hofvind, S., Ponti, A., Patnick, J., Ascunce, N., Njor, S., Broeders, M., Giordano, L., Frigerio, A. and Törnberg, S., 2012. False-positive results in mammographic screening for breast cancer in Europe: a literature review and

survey of service screening programmes. *Journal of Medical Screening*, *19*(1_suppl), pp.57-66.

40. Hofvind, S., Sagstad, S., Sebuødegård, S., Chen, Y., Roman, M. and Lee, C.I., 2018. Interval breast cancer rates and histopathologic tumor characteristics after false-positive findings at mammography in a population-based screening program. *Radiology*, *287*(1), pp.58-67.

41. House of Commons Hansard. 2018. Breast cancer screening. London: House of Commons, 2018.

42. Huf, S., 2017. Thesis: The use of behavioural sciences in targeted health messages to improve the participation in cervical and breast screening programmes. Imperial College London.

43. Huf, S., King, D., Judah, G., Fuller, C., Vlaev, I., Cunningham, D. and Darzi, A., 2017. Behavioural text message reminders to improve participation in breast screening: a randomised controlled trial. *The Lancet*, *390*, p.S45.

44. Hunneybell, J., Khan, I. and Winter, N., 2019. Breast and Cervical Cancer Screening in Muslim Communities. June 2019.

45. ITV News. 19 January 2021. Breast screening services to be reviewed after failings exposed by disabled cancer patient. URL: https://www.itv.com/news/calendar/2021-01-19/breast-screening-services-to-be-reviewed-after-failings-exposed-by-disabled-cancer-patient [accessed 01/06/21]

46. Jack, R.H., Møller, H., Robson, T. and Davies, E.A., 2014. Breast cancer screening uptake among women from different ethnic groups in London: a population-based cohort study. *BMJ Open*, *4*(10), p.e005586.

47. Jain, A., Acik-Toprak, N., Serevitch, J. and Nazroo, J., 2012. Inequalities in breast screening uptake among South Asian women in the UK: The role of service providers. *The Nightingale Centre and Genesis Prevention Centre, University Hospital of South Manchester, Manchester, UK 3Manchester Academic Health Sciences Centre, Institute of Cancer Sciences, Manchester, UK.*

48. Kamaruddin, K., 2019. We must improve cancer screening for trans and non-binary people. Pulse magazine. URL: https://www.pulsetoday.co.uk/views/uncategorised/we-must-improve-cancer-screening-for-trans-and-non-binary-people/ [accessed 29/04/21]

49. Kanani, R., Davies, E.A., Hanchett, N. and Jack, R.H., 2016. The association of mood disorders with breast cancer survival: an investigation of linked cancer registration and hospital admission data for South East England. *Psycho-Oncology*, *25*(1), pp.19-27.
50. Kearins, O., Walton, J., O'sullivan, E. and Lawrence, G., 2009. Invitation management initiative to improve uptake of breast cancer screening in an urban UK Primary Care Trust. *Journal of Medical Screening*, *16*(2), pp.81-84.
51. Kerrison, R.S., Shukla, H., Cunningham, D., Oyebode, O. and Friedman, E., 2015. Text-message reminders increase uptake of routine breast screening appointments: a randomised controlled trial in a hard-to-reach population. *British Journal of Cancer*, *112*(6), pp.1005-1010.
52. The Kings Fund. 2021. The health of people from ethnic minority groups in England. URL: https://www.kingsfund.org.uk/publications/health-people-ethnic-minority-groups-england#Cancer [accessed 04/06/21]
53. Lampic, C., Thurfjell, E., Bergh, J. and Sjödén, P.O., 2001. Short-and long-term anxiety and depression in women recalled after breast cancer screening. *European Journal of Cancer*, *37*(4), pp.463-469.
54. Lancet Oncology. 2015. Cancer risk in the transgender community. *Lancet Oncol*, *16*(9), p.999.
55. LGBT Foundation. 2017. Transforming Outcomes.
56. Live Through This. 2020. Cancer & COVID in our Community - Experiences of the coronavirus pandemic from LGBTIQ+ people affected by cancer. August 2020.
57. Lu, M., Moritz, S., Lorenzetti, D., Sykes, L., Straus, S. and Quan, H., 2012. A systematic review of interventions to increase breast and cervical cancer screening uptake among Asian women. *BMC Public Health*, *12*(1), pp.1-16.
58. Manthorpe, J., Hussein, S. and Charles, N., 2008. Women’s experiences and perceptions of the NHS Breast Screening Programme and recommendations for service development. KCL Social Care Workforce Research Unit. URL: https://www.researchgate.net/publication/231705285_Women's_experiences_and_perceptions_of_the_NHS_Breast_Screening_Programme_and_recommendations_for_service_development [accessed 04/05/21]

59. Marriott, A, Turner, S, Ashby, S and Rees, D., 2015. Cancer screening for people with learning disabilities and the role of the screening liaison nurse. *Tizard Learning Disability Review*, *20*(4), pp.239-246

60. MHCC (Manchester Health & Care Commissioning). 2019. Engaging with Disabled People on Experiences of - and. Barriers to - Accessing NHS Screening Programmes. Final Project Report. October 2019 (p13-19). URL: https://www.mhcc.nhs.uk/wp-content/uploads/2020/01/FINAL-_Screening-Report-Final_USE.pdf [accessed 01/06/21]

61. McIlfatrick, S., Taggart, L. and Truesdale-Kennedy, M., 2011. Supporting women with intellectual disabilities to access breast cancer screening: a healthcare professional perspective. *European Journal of Cancer Care*, *20*(3), pp.412-420.

62. Montgomery, M. and McCrone, S.H., 2010. Psychological distress associated with the diagnostic phase for suspected breast cancer: systematic review. *Journal of Advanced Nursing*, *66*(11), pp.2372-2390.

63. Mulvey, M. and Gissing, S., 2021. West Yorkshire and Harrogate Cancer Alliance insight surveys: exploring barriers and perceptions around cancer screening. April 2021.

64. Nelson, B., 2019. A cancer screening crisis for transgender patients. *Cancer Cytopathology*, *127*(7), pp.421-422.

65. NHS. 2011. The NHS Information Centre, Public Health Indicators Team. Breast Screening Programme, England 2009–10. Leeds: The NHS Information Centre, 2011.

66. NHS. 2013. NHS population screening: working with minority or hard to reach groups. URL: https://www.gov.uk/government/publications/nhs-population-screening-equitable-access-tips/nhs-population-screening-working-with-minority-or-hard-to-reach-groups [*N.B. this guidance was withdrawn on 25 April 2019 and replaced by 'Equitable access to screening: statutory duties under Equality Act' guidance*] [accessed 23/04/21]

67. NHS North Cumbria Advice. 2021. Breast screening appointments following COVID vaccination. https://www.ncic.nhs.uk/news/advice-those-attending-breast-screening-appointments-following-covid-vaccination [accessed 28/04/21]

68. NICE Shared Learning Database. 2020. Symptomatic Breast Referral Resource Suite: Enhancing the Suspected Cancer Recognition and Referral Process. URL:

https://www.nice.org.uk/sharedlearning/symptomatic-breast-referral-resource-suite-enhancing-the-suspected-cancer-recognition-and-referral-process [accessed 04/05/21]

69. O'Reilly, D., Ross, E., Maguire, A., Donnelly, M., Mairs, A. and Hall, C., 2019. OP96 Are women with chronic poor mental health less likely to attend breast screening and does this explain the social and geographic variations in uptake? A population-wide record linkage study.

70. Palmer, C. and Johnson, P., 2020. Second phase of NHS response to COVID-19 for cancer services. URL: https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/06/C0511-second-phase-of-nhs-response-to-covid-19-for-cancer-services-letter.pdf [accessed 30/04/21]

71. Parkington, S.R., Faine, N., Nguyen, M.C., Lowry, M.T. and Virginkar, P.A., 2009. Barriers to breast cancer screening in a managed care population. *Managed Care (Langhorne, Pa.)*, *18*(4), pp.34-45.

72. Parr, O. and Dunmall, K., 2018. An evaluation of online information available for women with breast implants aged 47–73 who have been invited to attend the NHS Breast Screening Programme. *Radiography*, *24*(4), pp.315-327.

73. Pfeffer, N., 2004. Screening for breast cancer: candidacy and compliance. *Social Science & Medicine*, *58*(1), pp.151-160.

74. Plackett, R., Kaushal, A., Kassianos, A.P., Cross, A., Lewins, D., Sheringham, J., Waller, J. and von Wagner, C., 2020. Use of social media to promote cancer screening and early diagnosis: Scoping Review. *Journal of Medical Internet Research*, *22*(11), p.e21582.

75. Public Health England. 2015. Making reasonable adjustments to cancer screening. URL: https://www.ndti.org.uk/uploads/files/Updated_reasonable_adjustments_in_cancer_screening_report.pdf [accessed 30/04/21]

76. Public Health England. 2018. Gender Specific Standards to Improve Health and Wellbeing for Women in Prison in England. URL: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/687146/Gender_specific_standards_for_women_in_prison_to_improve_health_and_wellbeing.pdf [accessed 04/06/21]

77. Public Health England. 2019. NHS public health functions agreement 2019-20. Service specification No. 24. NHS Breast Screening Programme. URL: https://www.england.nhs.uk/wp-content/uploads/2017/04/Service-Specification-No.24-Breast_Screening_Programme.pdf [accessed 08/06/21]
78. Public Health England. 2020. Screening text message principles. URL: https://www.gov.uk/government/publications/nhs-population-screening-effective-text-message-use/screening-text-message-principles [accessed 25/05/21]
79. Public Health England Screening. 2017. Women with learning disabilities are least likely to attend breast cancer screening – except in Cornwall. URL: https://phescreening.blog.gov.uk/2017/10/31/women-with-learning-disabilities-are-least-likely-to-attend-breast-cancer-screening-except-in-cornwall/ [accessed 27/04/21]
80. Public Health England Screening. 2018. New PHE Screening leaflet for trans and non-binary people has improved awareness. URL: https://phescreening.blog.gov.uk/2018/01/24/new-phe-screening-leaflet-for-trans-and-non-binary-people-has-improved-awareness/ [accessed30/04/21]
81. Public Health England Screening. 2020. Making breast screening more accessible: views from British-Pakistani women. URL: https://phescreening.blog.gov.uk/2020/02/19/breast-screening-accessible-british-pakistani/ [accessed 03/06/21]
82. Public Health Scotland. 2018. Make time for breast screening (BSL). URL: https://youtu.be/RU4mrLmA38s [accessed 01/06/21]
83. Renshaw, C., Jack, R.H., Dixon, S., Møller, H. and Davies, E.A., 2010. Estimating attendance for breast cancer screening in ethnic groups in London. *BMC Public Health*, *10*(1), pp.1-8.
84. Román, M., Sala, M., Domingo, L., Posso, M., Louro, J. and Castells, X., 2019. Personalized breast cancer screening strategies: A systematic review and quality assessment. *PloS one*, *14*(12), p.e0226352.
85. Ross, E., Maguire, A., Mairs, A., Hall, C., Donnelly, M.J. and O'Reilly, D.P., 2021. Disparities in Breast Cancer Screening Uptake for Women With Mental Illness in the United Kingdom. *American Journal of Preventive Medicine*, *60*(3), pp.e123-e130.
86. Shirazi, M., Engelman, K.K., Mbah, O., Shirazi, A., Robbins, I., Bowie, J.,

Popal, R., Wahwasuck, A., Whalen-White, D., Greiner, A. and Dobs, A., 2015. Targeting and tailoring health communications in breast screening interventions. *Progress in community health partnerships: Research, Education, and Action*, *9*(2), pp.83-89.

87. South East London CCG. 2020. Breast Cancer Screening recovery services. URL: https://selondonccg.nhs.uk/wp-content/uploads/2020/11/Breast-screening-new-tel-no.pdf [accessed 04/06/21]

88. Szczepura, A., Price, C. and Gumber, A., 2008. Breast and bowel cancer screening uptake patterns over 15 years for UK south Asian ethnic minority populations, corrected for differences in socio-demographic characteristics. *BMC Public Health*, *8*(1), pp.1-15.

89. Stonewall. 2018. LGBT in Britain: Health Report. URL: https://www.stonewall.org.uk/lgbt-britain-health [accessed 30/04/21]

90. Taggart, L., Truesdale-Kennedy, M. and McIlfatrick, S., 2011. The role of community nurses and residential staff in supporting women with intellectual disability to access breast screening services. *Journal of Intellectual Disability Research*, *55*(1), pp.41-52.

91. Tatari, C.R., Andersen, B., Brogaard, T., Badre-Esfahani, S.K., Jaafar, N. and Kirkegaard, P., 2020. Perceptions about cancer and barriers towards cancer screening among ethnic minority women in a deprived area in Denmark-a qualitative study. *BMC Public Health*, *20*(1), pp.1-10.

92. Thomas, V.N., Saleem, T. and Abraham, R., 2005. Barriers to effective uptake of cancer screening among Black and minority ethnic groups. *International Journal of Palliative Nursing*, *11*(11), pp.562-571.

93. Werneke, U., Horn, O., Maryon-Davis, A., Wessely, S., Donnan, S. and McPherson, K., 2006. Uptake of screening for breast cancer in patients with mental health problems. *Journal of Epidemiology & Community Health*, *60*(7), pp.600-605.

94. Wessex Voices. 2018. Cervical Screening and Eastern European Women Report. 2018. URL: https://www.wessexvoices.org/uploads/9/2/1/6/92161062/ee_cervical_screen_background.pdf [accessed 01/06/21]

95

95. Wessex Voices. 2019a. Why don't women go? Wessex Voices' findings about why women over 50 years old experience barriers to cervical and breast screening. 2019. URL: https://www.wessexvoices.org/uploads/9/2/1/6/92161062/why_dont_women_go.pdf [accessed 28/04/21]
96. Wessex Voices. 2019b. Feedback from seldom heard groups on the final GP cervical screening invitation letter. URL: https://www.wessexvoices.org/uploads/9/2/1/6/92161062/engagement_report_cervical_screening_3rd_letter_from_gp_101219.pdf [accessed 03/06/21]
97. Wessex Voices. 2020. Making the Right Decision: What Matters to Women About First Time Breast Screening. April 2020. URL: https://www.wessexvoices.org/uploads/9/2/1/6/92161062/making_the_right_decision_breast_screening_report_final.pdf [accessed 28/04/21]
98. What's it like? 2021. Website. URL: https://www.whatsitlike.co.uk/ [accessed 03/06/21]
99. Woodhead, C., Cunningham, R., Ashworth, M., Barley, E., Stewart, R.J. and Henderson, M.J., 2016. Cervical and breast cancer screening uptake among women with serious mental illness: a data linkage study. *BMC Cancer*, *16*(1), pp.1-9.
100. Woof, V.G., Ruane, H., Ulph, F., French, D.P., Qureshi, N., Khan, N., Evans, D.G., Donnelly, L.S., 2020. Engagement barriers and service inequities in the NHS Breast Screening Programme: Views from British-Pakistani women. *Journal of Medical Screening*, *27*(3), pp.130-7.
101. Zelenyanszki, C., McAvinchey, R. and Hudson, S., 2021. The National Patient Notification Exercise: How well did local breast screening services cope with the additional workload? *Journal of Medical Screening*, *28*(2), pp.177-184.
{References added after 11/06/21}
102. Jiwa, N., Takats, Z., Leff, D.R. and Sutton, C., 2021. Breast health screening: a UK-wide questionnaire. *BMJ Nutrition, Prevention & Health*, pp.bmjnph-2021.
103. Baker, L.M., Case, P. and Policicchio, D.L., 2003. General health problems of inner-city sex workers: A pilot study. *Journal of the Medical Library Association*, *91*(1), p.67.
104. Healthwatch Swindon. 2020. Patient Feedback.
105. Enable Ability. 2021. Client Feedback.

Acknowledgements

Wessex Voices would like to thank all the people and organisations who provided us with information or spoke to us as part of our research for this literature review.

We would also like to say a very big thank you to Dr Andy Pulman for his efforts in tracking down a huge array of sources and carrying out this unique review of breast screening.

Contact us

For more information about this report or our findings please contact:
Sue Newell from Wessex Voices on Sue.Newell@helpandcare.org.uk or 07595 424198.