Exploring barriers and facilitators to breast screening uptake among disadvantaged groups and communities in Scotland

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Abbreviations

GP: General Practitioner

NHS: National Health Service

ISD: Information Services Division

SEG: Socio-economic groups

SIMD: Scottish Index of Multiple Deprivation

Glossary

Scottish Index of Multiple Deprivation (SIMD): The Scottish Government's official tool to identify areas of multiple deprivation in Scotland. It incorporates several different aspects of deprivation (multiple-deprivations) and combining them into a single index. Concentrations of deprivation are identified in SIMD at data done level and can be analysed using this small geographical unit. By identifying small areas where there are concentrations of multiple deprivation, the SIMD can be used to target policies and resources at the places with greatest need. The SIMD identifies deprived areas, not deprived individuals.

Quintiles 1 and 2 constitute the most deprived areas.

Socio-economic groups (SEG): These enable the classification and measurement of people of different social grade and income and earnings levels, for market research, targeting, social commentary, lifestyle statistics, and statistical research and analysis. The different classifications are based on the occupation of the head of the household (or chief income earner) and are as follows:

Grade	Social class	Head of household or Chief income earner's occupation
A	Upper middle class	Higher managerial, administrative or professional
B	Middle class	Intermediate managerial, administrative or professional
C1	Lower middle class	Supervisory or clerical and junior managerial, administrative or professional
C2	Skilled working class	Skilled manual workers
D	Working class	Semi and unskilled manual workers
E	Non-working	Casual or lowest grade workers, pensioners, and others who depend on the welfare state for their income

Executive summary

Background

Breast cancer is the most common cancer in women, with about 1000 women dying of breast cancer every year in Scotland. The purpose of breast screening is to reduce the number of women who die from breast cancer by finding cancers in the breasts at an early stage when they are too small to see or feel.

Data by SIMD quintile for Scotland[1] continues to show a clear deprivation gradient from greatest uptake of screening in the least deprived SIMD quintile to the lowest uptake in the most deprived SIMD quintile. The latest data shows that under six in ten women from the most deprived areas attended breast screening, compared with almost eight in ten women living in the least deprived areas. Data also shows that the uptake rate is also lower amongst younger women (aged 50-53 years).

Ministerial approval for a review of the Scottish Breast Screening Programme was granted in June 2019. The review objectives are to:

- review the current Breast Screening Programme in Scotland
- make recommendations on the future delivery of the Programme
- make recommendations on policy direction for the Breast Screening Programme
- develop costed options for service redesign for consideration by NHS Boards and the Scottish Government.

The purpose of this research was to explore the barriers and enablers to breast screening uptake among disadvantaged groups of women who do not attend for breast screening. The findings of the study will form part of a wider public engagement strategy of the Scottish Breast Screening Review and will be used to inform its recommendations.

Method and sample

A qualitative approach was adopted to enable detailed exploration of women's attitudes to, and views of, breast screening. Individual depth interviews were deemed to be the most effective method as it would provide a more comfortable and intimate environment for discussing this sensitive topic.

It was originally intended that these interviews take place face-to-face in the respondent's home. However, due to the COVID-19 outbreak and subsequent lockdown immediately prior to the fieldwork period, this was changed to a telephone interview method. A total of 36 depth interviews were conducted, with each running to around 60 minutes in duration, and conducted by senior

[1] Available at: https://beta.isdscotland.org/find-publications-and-data/conditions-and-diseases/cancer/scottish-breast-screening-programme-statistics/8-october-2019/

researchers. Verbal consent to participate was obtained at the time of recruitment, with a written consent form and details of the project subsequently sent to respondents for their own reference.

All interviews were undertaken in privacy in the respondent's own home, across Health Board areas where minimum uptake standards of 70% were not met in the period 2015/16 to 2017/18: NHS Greater Glasgow & Clyde, NHS Lanarkshire and NHS Lothian and NHS Fife. Urban, semi-urban and rural locations were covered.

The audience of interest to this study was women aged 50-70 living in Scotland's most deprived communities who do not engage with the breast screening programme. Of specific interest were the views of the following groups:

- women aged 50-54 who live in deprived communities
- eligible women who are living in rural deprived communities
- eligible women with a disability living in deprived communities.

Summary of key results

The factors impacting on uptake of breast screening amongst this target audience spanned three key contexts: individual, social and environmental[2], with the extent of influence of each varying across the sample.

Individual factors: Three key areas of misconception about breast cancer and screening were evident: a strong association of the risk of breast cancer with having a family history of the disease, an association of the risk of breast cancer with older women (70+ years), and some sense that breast cancer is less 'hidden' than other cancers, and as such that there was little need to attend for breast screening if self-examination revealed no lumps.

Social factors: Breast screening was not perceived by the majority of this audience as having become normalised. This was due to a perception that neither breast screening nor breast cancer had high salience in their own social context or in the wider media. Furthermore, personal conversations and mutual encouragement to attend for screening appeared to be limited, with some cultural taboos remaining with respect to talking about or exposing their breasts.

Environmental factors: A number of factors relating to the design and delivery of the breast screening service impacted on (regular) uptake and served to reduce the sense of ease of attendance and further bolstered emotional reservations.

Consideration of attendance

A pre-set breast screening appointment encouraged consideration of attendance, with many admitting that they would not proactively make an appointment. Active consideration was largely limited to the first appointment however, with emotional

[2] Based on: Andrew Darnton and David Evans. 2013. Influencing behaviours moving beyond the individual: A technical guide to the ISM tool. The Scottish Government

reactions often driving behaviour in respect of subsequent invitations (usually based on earlier experience).

Barriers to attendance
These encompassed both practical and psychological barriers.

- Screening appointment: time, location, availability
  The unpredictable nature of both work patterns and personal circumstances meant that forward planning to accommodate pre-set appointments could be difficult. Furthermore, many were reluctant to ask for time off work to attend screening appointments as they felt these were not viewed as a priority by their employers.

  In semi-urban and rural areas, the limited availability of appointments in a local venue served to increase the inconvenience of attendance, with travel to other towns adding to the time and cost involved in accessing the screening.

  For women with a disability, travel to a venue which was not local posed a range of additional considerations such as increased anxiety and greater inconveniencing of the individual who would accompany them to the appointment. Consideration of physical access needs and the anxiety caused by a time restricted appointment constituted further barriers for some of these women.

- Screening venue: siting and set-up of mobile units
  Siting of mobile screening units within local supermarket car parks caused emotional discomfort for some. The external branding of the units was perceived to overtly indicate their purpose, with a sense of personal embarrassment further increased by the unit's very public entrance.

  The environment of the mobile units themselves was perceived by many to be sterile and unwelcoming, which together with the minimal personal engagement from staff reported by some, served to increase any existing anxiety.

- Screening procedure: impersonal experience
  The entire experience (pre, during and post the x-ray) was described as functional and detached which served to engender a sense of vulnerability and lack of personal control.

  Some women perceived screening staff attitudes to be uncaring and reported that they were made to feel as if they were making an unnecessary fuss or exaggerating the discomfort.

- Screening procedure: personal discomfort
  Experience of pain during the mammogram and or embarrassment at being naked from the waist up was a strong barrier to attendance.

Conclusions

- Whilst the women in this target audience had high level awareness and understanding of the purpose and process of breast screening, its importance and self-relevance was not acknowledged by a significant proportion of them.

- The inconvenience of appointments presented practical barriers which hindered uptake. The current system for scheduling appointments has a number of drawbacks:
  - Pre-set appointments that are several weeks in the future are often not helpful for this audience who cannot always predict their work or family commitments so far in advance.
  - The inability to schedule appointments out with working times makes attendance difficult for many.
  - There is limited awareness that appointments can be cancelled or rescheduled, and the need to telephone within working hours to do so is inconvenient.
  - Limited appointment time flexibility, particularly in semi-urban and rural locations, leads to appointments not being pursued.

- The location and design of the screening venue can constitute further barriers to uptake:
  - Where the screening venue is not local, travel time, inconvenience or the cost involved can limit access, particularly in semi-urban and rural locations.
  - The accessibility of the mobile units can be an issue for women with restricted mobility, many of whom were not aware that adjustments could be made if requested
  - Attendance at a mobile unit can serve to limit willingness to considered breast screening: perceived to lack discretion from the outside, with the internal environment viewed as sterile, cramped and lacking sufficient privacy.
  - Limited emotional accessibility can also an issue for those attending mobile units as there is no or limited opportunity to be accompanied.

- Psychological concerns constituted a significant barrier for some of the women in this target audience. These related both to the embarrassment and pain experienced during the screening process, but also to perceptions of the impersonal nature of the process, and the lack of empathy and understanding from screening staff. The resulting sense of unacceptability of the experience impacts negatively on preparedness to consider further screening appointments and leads to the spread of adverse stories.

Recommendations

The following is recommended for consideration in helping to increase the uptake of breast screening amongst this target audience:

- Improve the understanding and perceived value of breast screening
  Media campaigns will help to communicate both the value of screening and to provide cultural contextualisation by clarifying the prevalence of breast cancer in Scotland and the populations at risk. There are advantages to employing a variety of channels to help convey the importance of breast screening (e.g. television advertising) and its relevance to this audience (through trusted sources using social media channels for example). The value of screening can be emphasised through GP reinforcement, and normalisation within these communities will be helped by encouraging informal conversations (between both peers and health professionals), for example on social media.

- Increase the convenience of appointments
  Greater flexibility of appointment scheduling and availability would enable better access and uptake. Consideration should be given to a range of service elements: reminder texts or telephone calls which can help to retain screening appointments on the radar, an online appointment cancellation and rebooking system to provide a greater sense of individual control and convenience, and evening and weekend appointments for those who find it hard to adjust weekday commitments or rely on support from others. Increased appointment availability in rural and semi-urban locations would provide some flexibility for women in these areas.

- Increase the user-friendliness of screening venues
  This should be considered at both a practical and an emotional level. Co-location of breast screening services with existing GP or well woman services would facilitate attendance by providing a local, familiar and professional environment, together with more discreet access to the service. At a psychological level, these venues were perceived to be friendlier, with the expectation of a more personalised experience and the opportunity to be accompanied. Larger mobile units with ‘warmer’ waiting areas can also help to provide a more reassuring environment. Better communication of the adjustments that can be made for women with disabilities is key, ideally though personalised invitations.

- Improve the acceptability of breast screening
  There is a need for better engagement with women to demystify the screening process and provide reassurance. This could take the form of informal social support via social media channels, enabling telephone or online support e.g. live chat, peer conversations, and the sharing of positive stories from women who have been screened. Facilitating easy access to concise, straightforward information and honest description e.g. videos of the process would also be helpful. Engagement and empathy during the appointment is vital in encouraging repeat screening. Mammographer

sensitivity and consideration is key, and longer appointment times or (peer) support in the waiting area would enable questions to be asked and reassurance provided. The use of gowns that do not need to be fully removed while the mammogram is being taken would also help in addressing the modesty concerns.

1. Introduction

1.1 Screening and immunisation programmes and policy

Screening tests are offered to groups of the population to identify the risk of certain conditions detrimental to health. They are offered to help people make informed choices about their health and in particular, whether or not they wish to accept the offer of a screening test.

Screening policy in Scotland is set by the Scottish Government Health Directorates on the advice of the UK National Screening Committee and other appropriate bodies. The National Specialist and Screening Services Directorate commissions and co-ordinates various important elements of national screening programmes to ensure consistent, effective, coordinated national screening programmes for the people of Scotland.

1.2 Overview of breast screening in Scotland

Breast cancer is the most common cancer in women, with about 1000 women dying of breast cancer every year in Scotland. The purpose of breast screening is to reduce the number of women who die from breast cancer by finding cancers in the breasts at an early stage when they are too small to see or feel. For every 400 women in Scotland who are screened regularly for ten years, one less woman will die from breast cancer. This means around 130 women are prevented from dying from breast cancer each year in Scotland thanks to breast screening.

The Scottish Breast Screening Programme was established in 1988 and invites all women aged between 50 and 70 years + 364 days for screening every three years. Women aged 71 and above are able to attend for screening through self-referral to their local screening centre at the same intervals. There are six static screening centres in Scotland supported by twenty mobile screening units.

The Programme in Scotland has developed over time due to policy and technology changes, however the way in which it is delivered has largely remained the same since commencement.

All invitations to breast screening are sent via a letter stating an appointment time and location; the letter is accompanied by a patient information leaflet (*Make time for breast screening*[3]) intending to raise awareness and promote informed choice. These are usually sent at least two weeks in advance of the appointment, with the results letter sent within three weeks of the screening. The patient information leaflet is also available to download in English, Albanian, Bulgarian, Farsi, Pashto, Romanian, Slovakian, Polish, Simplified and Traditional Chinese, and Urdu as well as in an Easy Read format at the Public Health Scotland website[3]. Further

[3] Available at: http://www.healthscotland.com/documents/5070.aspx

information for the public about breast screening can also be found on the NHS Inform website.[4]

Alongside this, the Scottish Government's Detect Cancer Early Programme was launched in 2012 with breast being one of three cancer types covered by the social marketing campaign supporting the programme objectives. The breast cancer social marketing activity signed up the well-known Scottish celebrity Elaine C. Smith to front the campaign (her mother had passed away with the disease). She was also involved in a mass awareness campaign in September 2012, highlighting key signs of breast cancer (symptomatic) other than lumps. A breast screening campaign targeting areas with low uptake in the West and South East of Scotland followed in summer 2014. This used regional radio and press ads, supported by a public relations programme and social media activity that included a video showing Elaine having a mammogram to help de-mystify the process.

Due to the Scottish Breast Screening Programme's continued desire to take actions seeking to reduce health inequalities, some of the Detect Cancer Early campaigns have also focused on educating women in the most deprived areas of Scotland about breast screening. This is because, according to PHS data, these women are significantly the least likely to attend breast screening.

1.3 Breast Screening: Uptake and Inequalities in Scotland

Breast screening uptake in Scotland for the period 2015/16 to 2017/18[5] was at 71.2% of all eligible women aged 50-70. During this same period, four NHS Boards failed to meet the minimum acceptable uptake standard of 70%: NHS Greater Glasgow & Clyde (65.8%), NHS Lanarkshire (68.0%), NHS Lothian (69.2%), and NHS Fife (69.7%). Uptake rates have fallen consistently since 2008/09 – 2010/11 when it was 74.9%.

Data by SIMD quintile for Scotland continues to show a clear deprivation gradient from greatest uptake of screening in the least deprived SIMD quintile to the lowest uptake in the most deprived SIMD quintile. The latest data[5] shows that under six in ten women from the most deprived areas attended breast screening, compared with almost eight in ten women living in the least deprived areas.

Data shows that the uptake rate is also lower amongst younger women (aged 50-53 years).

[4] Available at: http://www.nhsinform.co.uk/screening/breast

[5] Available at: https://beta.isdscotland.org/find-publications-and-data/conditions-and-diseases/cancer/scottish-breast-screening-programme-statistics/8-october-2019/

1.4 2019/20 Breast Screening Review

In November 2018, the Scottish Screening Committee suggested a major review of the Scottish Breast Screening Programme was necessary, and it was granted Ministerial approval in June 2019.

The review will take account of previous reviews, recent incidents affecting the programme, current pressures and future options for delivery. The need for significant service redesign is anticipated.

The review objectives are to:

- review the current Breast Screening Programme in Scotland
- make recommendations on the future delivery of the Programme
- make recommendations on policy direction for the Breast Screening Programme
- develop costed options for service redesign for consideration by NHS Boards and the Scottish Government.

An Independent Review Group has been established, with wide membership from key stakeholders, including the third sector, with responsibility for guiding the review, appraising evidence collected and producing the review recommendations.

1.5 The purpose of this research

The purpose of the research was to explore the barriers and enablers to breast screening uptake among disadvantaged groups of women who do not attend for breast screening. The findings of the study will form part of a wider public engagement strategy of the Scottish Breast Screening Review and will be used to inform its recommendations.

1.6 Aims and objectives

The main aims of the research were to explore the barriers and enablers to breast screening uptake among disadvantaged groups of women who do not attend for breast screening, and to provide recommendations to inform the Scottish Breast Screening Review.

The detailed research objectives were to:

- explore women's knowledge and understanding of the breast screening service generally and how it relates to other screening and healthcare decisions they make
- identify whether they considered attending for breast screening when invited and what factors impacted their final decision not to attend
- identify whether there was anything about the time, location or set up of the service that impacted their decision not to participate
- explore what, if anything, would entice them to participate and what, if any, options they feel would improve the breast screening service for them

- explore any other barriers that have impacted their participation in screening
- explore any other enablers that would make them reconsider attending screening
- identify learning on improving uptake to inform the Scottish Breast Screening Review.

1.7 Report structure

The report initially examines the overarching factors impacting breast screening uptake amongst this particular target audience, considering individual, social and environmental elements. It will explore how personal attitudes, together with the social and cultural context and the practical delivery of the breast screening service have influenced inclination to participate in breast screening.

The report then details the extent of consideration of attending for breast screening, and the key issues influencing decision making. The final section details specific barriers to attendance – both practical and emotional – and highlights actions that may help to facilitate consideration.

A discussion of these findings is then provided, followed by conclusions and recommendations.

All reporting is done by exception. This means that specific sample sub-groups are only mentioned if they differ from other related sub-groups. If no mention is made to a specific sample group, the response described is relevant across all sub-groups and there was no difference between them.

The Appendices to the report show all the research material (discussion guide, recruitment questionnaire, participant information sheets, consent forms).

2. Methodology

2.1 Method

A qualitative approach was adopted to enable detailed exploration of women's attitudes to, and views of, breast screening. Individual depth interviews were deemed to be the most effective method as it would provide a more comfortable and intimate environment for discussing this sensitive topic, and enabling a more open discussion of personal motivations, barriers and experiences of participation in the breast screening programme.

Given the need for robustness, the depth method provided the opportunity for evaluating each individual's knowledge of the breast screening programme, how screening decisions are made, what norms and biases play a role, as well as what may facilitate or impede the respondent in this process.

It was originally intended that these interviews take place face-to-face in the respondent's home. However, due to the COVID-19 outbreak and subsequent lockdown immediately prior to the recruitment and fieldwork period, this was changed to a telephone interview method as agreed with the Project Advisory Group. This amended approach was piloted with the first three depth interviews to verify that it would not negatively impact on the quality of the research findings before proceeding with the study. As no undue impact was noted, the telephone method was adopted for the rest of the depth interviews, with those from the pilot included in the final analysis and reporting.

A total of 36 depth interviews were conducted, with each running to around 60 minutes in duration, and conducted by a senior researcher. All interviews were undertaken in privacy in the respondent's own home. Fieldwork was conducted between 25th March and 3rd April 2020.

A discussion guide was used to provide a consistent question format for each of the depth interviews. This can be found in Appendix one.

In order to extend the reach of the research, two consensus building events were originally included within the scope of the project. The aim of these was to provide the opportunity for a wider range of local stakeholders to discuss emerging themes in the findings from the depth interviews and provide additional comment and insight. In the light of the pandemic and a number of other relevant stakeholder events being held, it was decided that the workshops would no longer be required.

2.2 Data collection

2.2.1 Recruitment of qualitative interviews

The qualitative recruitment was conducted on a free-find basis using Scott Porter's network of freelance recruiters who followed agreed and detailed sample criteria, quotas and timings. Experienced recruiters from the specific research locations sourced local respondents who fitted the desired sampling criteria. Twenty-five of the 36 depths were recruited face-to-face as planned prior to the lockdown restrictions due to COVID-19, with the remainder recruited via telephone using snowballing methods. As the decision was taken at the start of the recruitment period to move to a telephone method for the depth interviews, respondents were all recruited on this basis.

The process for the recruitment was as follows:

- At project set-up, the 'invite to research' material was designed and approved by the Project Advisory Group, considering potential literacy issues.
- Recruiters were sent the appropriate documentation and then received a full telephone briefing on the project requirements.
- All screening was done via a recruitment questionnaire devised by Scott Porter and signed off by the Project Advisory Group prior to recruitment starting. This document included all the criteria needed to determine the sample groups and reach quotas. The recruitment questionnaire can be seen in Appendix two.
- As the recruitment was undertaken over the telephone, those who qualified for inclusion and were willing to participate in principle were given verbal details of the project, alongside information on the proposed date, time and location of the interview, and who to contact for further information.
- Consent to participate was also obtained verbally at this time by reading out the statements on the consent form.
- With permission, written details were subsequently sent to respondents. These included a 'Participant Information Sheet', showing full details of the project, a note of the proposed date, time and location of the interview, and who to contact for further information. They were also sent a copy of the consent form for their reference. A copy of the participant information sheet and the consent form can be found in Appendix three.
- All those willing to participate received a phone call or text message a day or so before the interview to check they were still willing to take part.
- Finally, prior to commencing the depth interview, respondents were reminded of the process, including audio recording, confidentiality and data protection, and asked to confirm their consent to participate.

As is customary with qualitative research, all participants were offered an incentive to thank them for their time, receiving £30 via bank transfer following their participation.

2.2.2 Sample

The audience of interest to this study was women aged 50-70 years living in Scotland's most deprived communities who do not engage with the breast screening programme. Of specific interest were the views of the following groups:

- women aged 50-54 who live in deprived communities
- eligible women who live in rural deprived communities
- eligible women with a disability living in deprived communities.

Across these target groups, the following sample variables were applied:

Breast screening participation

All women had been invited to breast screening but had not participated on at least one occasion. In order to ensure relevance and recall, all women had received an invitation in the last 24 months. This included:

- women who had received their first invitation and not attended this appointment
- women who had attended breast screening at some point but who had since decided not to attend any more
- women who had not attended their most recent appointment, but would consider attending in the future
- women who had not attended appointments on multiple occasions.

Age

The sample included women aged 50-70 years, the age bracket for regular breast screening invitation. In order to allow for potentially different emotional needs and attitudes of women across the eligible age spectrum, the sample was split into two narrower age groups: 50-60 years and 61-70 years. The younger age group was further subdivided to permit easy identification of the women aged 50-54 where the uptake rate is lower.

On discussion with the Project Advisory Group, it was decided more women in the younger age groups (50-60 years) should be invited to participate on the basis that older women (who will have received multiple invitations for breast screening) may be less likely not to attend if they have experienced breast screening at least once before.

SIMD profile

The sample was drawn from women living in the most deprived areas of Scotland, SIMD quintiles 1 and 2. As SIMD is an indication of geographic rather than individual deprivation, women in the sample were also verified as being socio economic grades C2, D or E.

Location
Fieldwork was conducted in Health Board areas where minimum uptake standards of 70% were not met in the period 2015/16 to 2017/18: NHS Greater Glasgow & Clyde, NHS Lanarkshire and NHS Lothian and NHS Fife.

The depth interviews were held across a mix of urban, semi-urban and rural locations, with a bias towards those residing in urban population centres. The Scottish Government Urban Rural Classification (2016) was used when selecting appropriate areas. Rural locations for this study were drawn from *'accessible rural areas'* (defined as areas with a population of less than 3,000 people and within a 30-minute drive time of a settlement of 10,000 or more) and *'remote rural areas'* (defined as areas with a population of less than 3,000 people, and with a drive time of over 30 minutes to a settlement of 10,000 or more).

Women with a disability
The latest guidance developed by the Government Statistical Service[6] to classify those who qualify as disabled was adopted. This classification is based on responses to two questions: firstly, whether an individual had any current long-lasting health conditions and illnesses, and secondly the extent to which this has a negative impact on their ability to do normal daily activities. Beyond this, women with a range of physical and sensory disabilities were included.

Exclusion criteria
The following exclusions were applied to the sample:
- any women aged 50+ who had not yet received their first invitation to participate in breast screening
- complete rejecters of breast screening (i.e. those women who say they would never attend breast screening under any circumstances)
- anyone who voluntarily disclosed at recruitment that they are undergoing treatment for breast cancer, or that they were in remission from breast cancer.

The final qualitative sample achieved is shown in Table 1 overleaf.

[6] Measuring disability with European Union (EU) data harmonisation guidance, available at: https://gss.civilservice.gov.uk/policy-store/measuring-disability-with-eu-data/

Table 1: Sample composition

Age	50-60 years	20 depths
	61-70 years	16 depths
Sub-group	55-70 years (core sample)	20 depths
	50-54 years	7 depths
	with a disability	9 depths
Location	urban	21 depths
	semi-urban	10 depths
	rural	5 depths
NHS Board area	Greater Glasgow & Clyde	15 depths
	Lothian	9 depths
	Fife	8 depths
	Lanarkshire	4 depths
TOTAL		**36 depths**

2.3 Method of analysis

Each interview was recorded with the respondent's informed consent. These were either transcribed, or detailed verbatim notes taken by listening back to the recordings. The method of analysis involved interpretation of the data based upon the required output of the study (as defined by the research objectives) and the discussion guide. An informal framework was designed around these and used by each researcher to develop their initial notes which were then used to facilitate thematic and explanatory analysis.

The research team then collectively discussed the outcomes of their respective interviews. The final analysis and interpretation was undertaken by the Lead Researcher, with reference to all the data available.

2.4 Limitations

It should also be noted that participation in studies of a sensitive nature such as this are to some extent self-selecting, with those more open to the subject potentially more likely to agree to participate. This may have impacted on the breadth of representation obtained and consequently on the findings.

Equally, whilst the pilot[7] indicated that the quality of the data obtained was not compromised by the telephone method, it may have limited the range of women prepared to participate.

Given that women were asked to think back to their decision making process and the factors that impacted on their behaviour and attitudes, the accuracy of their recall may be limited somewhat, and the reasons offered post-rationalised or influenced by subsequent emotions.

2.5 Ethics approval

Review of NHS assessment criteria for research ethics confirmed that the study did not require NHS research ethics committee approval, and the study received a favourable opinion from NHS Health Scotland's Research Development Group in February 2020.

[7] A small, three interview pilot was undertaken, and all respondents were informed of the telephone interview method to be adopted at the time of recruitment.

3. Results

The following section of the report details the findings from the qualitative depth interviews. It starts by reporting on the overarching factors impacting uptake of breast screening amongst the target audience of interest, moving on to examine the elements that influence consideration of attendance, before looking at specific barriers and facilitators.

3.1 Overarching factors impacting breast screening uptake

Factors from individual, social and environmental contexts[8] were all found to play a role in driving the behaviour of this audience. Whilst the extent of influence of each varied on an individual level, personal and social 'experience' was often key, with practical barriers providing ready justification for emotional hurdles.

3.1.1 Individual factors

Knowledge and understanding

Knowledge of the particulars of breast screening was found to be high level and to vary greatly between individuals. Whilst there was general consensus that the main purpose of screening was the detection of breast cancer, there was a lack of certainly as to exactly what the mammogram sought to identify: early signs of cancer, lumps, cysts, fatty tissue? All of the women in the sample felt they knew what the process of breast screening involved, although the language used to describe this ranged from 'an x-ray' to more emotive descriptions such as 'clamping your breasts in a machine' with little understanding of why this kind of procedure was required.

Based on their own experience, the majority of the respondents were aware that women were invited to attend for screening from the age of 50, although most were unaware of the upper age limit (some guessing at 65 or 70 years). Most were also unsure as to the frequency of the screening invitation, with mentions ranging from every two to every five years. Those whose attitudes could be described as Pragmatic (see *Attitudes to screening* section on page eleven below) had greater levels of understanding, with most aware that screening was offered every three years.

Three key areas of misconception about breast cancer and screening were evident, particularly amongst those women who were the most reticent about attending for screening. The first related to a strong association of the risk of breast cancer with having a family history of the disease, with the absence of such history reducing the sense of importance or personal relevance of breast screening, and providing an easy rationale for non-attendance.

[8] Based on: Andrew Darnton and David Evans. 2013. Influencing behaviours moving beyond the individual: A technical guide to the ISM tool. The Scottish Government

The second misconception stemmed from an association of the risk of breast cancer with older women (70+ years). In particular, many of the women (in the sample) in their early 50s felt themselves to be at low risk, with a consequent perception of a lack of strong self relevance of breast screening. As such, the arrival of the first invitation to attend for screening can be unexpected and not afforded serious consideration.

Thirdly, there was some sense that breast cancer is less hidden than other cancers, and as such there was no need to attend for breast screening if self-examination revealed no lumps. However, whilst some reported to examine their breasts, they acknowledged that this was not done regularly.

Attitudes to breast screening

For many in this audience, top of mind associations with breast screening did not focus primarily on benefits, but rather on perceived costs, physical discomfort or pain, embarrassment, and the fear of being diagnosed with cancer. As a consequence, it elicited a strong emotional response. Others however, did link it with the benefit of detecting cancer early, although this was largely a rationalised rather than instinctive response.

Only on consideration was there a general acknowledgement that screening (including breast screening) is important in that it can detect cancer earlier and improve chances of recovery.

Mindsets and emotions with respect to breast screening varied across the sample, with three broad attitudinal groups evident. The main characteristics of these groups were as follows:

- Pragmatic group: 'It's just something you have to do'
  These women viewed breast screening as a routine, but not essential, activity. They recognised the potential benefits (early detection, peace of mind) and felt that women in Scotland were fortunate to be offered this opportunity.

  'You get sent a letter and you just go. You don't think about it – it's just like an annual check.' (Female, 66 years, urban)

  This group said they attended for screening when and if they could, but acknowledged that sometimes practical barriers (such as inconvenience or a busy lifestyle) got in the way. Whilst recognising benefits, there was not a strong sense of needing to treat this screening appointment as a priority when it was inconvenient to attend. This attitude tended to be justified by a rationalisation that they were at low risk of breast cancer because they were still young or generally healthy and could self examine their breasts.

- Reluctant group: ‘I feel like I should go but…’
  This group acknowledged the value of screening and appreciated the peace of mind it could bring. However, they tended to characterise those women who chose to regularly attend for screening as being particularly cautious or concerned, or feeling they had a specific reason to attend.

  At a personal level, many expressed a range of emotional concerns, largely relating to the (perceived or experienced) pain and embarrassment of the screening process. Often, these psychological barriers were hidden behind more practical justifications for non-attendance, such as those noted for the Pragmatic group above.

  ‘My immediate feeling is ‘scary’! But I've also got positive feelings… it can save so many people’s lives.’ (Female, 55 years, urban)

- Fearful group: ‘I don’t really want to know…’
  Whilst the women in this group recognised that breast screening could be important, they tended to adopt a head in the sand attitude, not accepting any self-relevance. They characterised women who attended for screening as being confident with their bodies, or as feeling they ‘needed’ to attend (i.e. had found a lump or had a family history of breast cancer).

  They expressed a strong, negative emotional response to the idea of breast screening, unable to see beyond a painful experience and often displaying high levels of anxiety about the process and a potential cancer outcome.

  ‘It really put me off going back, it was so painful and awkward. I had tears in my eyes at the end of it! I know myself I'm being silly and it's not the answer, but it was just so desperately uncomfortable.’ (Female, 60 years, semi-urban)

3.1.2 Social factors

The cultural context in which the screening invitations are considered were a factor in influencing attitudes. Perceived norms with respect to attendance and the extent of identification with the personal relevance of breast screening are likely to be contributing to the lack of priority afforded to this screening.

Whilst there was a wider acceptance of cervical screening as having become more normalised/routine, the majority of the sample did not perceive breast screening in the same way, this being the result of a number of factors:

- The salience of both breast cancer and breast screening was not perceived to be high either in their own social context or in the wider media. Most of the women in the sample talked about not knowing/having heard of anyone who had been diagnosed with, or died from breast cancer, comparing this with other cancers such as cervical (the example of Jade Goody is still remembered).

- There was very little recall of public campaigns (e.g. the Elaine C. Smith campaign[9]) to raise awareness of breast screening or breast cancer, reinforcing a view that it was not see as a priority.
- There was little sense of breast screening being very evident in social media feeds, contributing to a perception of low relevance.

As such it was difficult for many, and particularly the Reluctant and Fearful groups, to recognise the importance, or personal relevance, of breast screening and the potential risks of not being screened.

Personal conversations about breast screening appeared to be limited, particularly amongst older women (55+ years). Anything to do with breasts was perceived to be a private matter, with a degree of embarrassment associated with talking about it with others without any particular cause. A minority of women in the sample had discussed it purely in the context of a family member or friend having been diagnosed with breast cancer.

The 50-54 year old women in the sample were more likely to have discussed breast screening with their friends/sisters, prompted by their surprise at having received their first invitation to attend or by their first experience of attending for breast screening. These conversations were reported to have focused on their anxiety prior to attending and any subsequent distress experienced. Overall, there appeared to be very limited mutual encouragement to attend amongst women in the younger sub-group and their peers.

Additionally, there was perceived to be little community reinforcement or conversation around the topic. For many, there remains a cultural taboo around talking about breasts, with this discomfort extending to exposing their breasts in a 'non-essential' context – this can feel like breaking cultural norms. This is in part linked to the cultural sexualisation of breasts, with women feeling the pressure of judgement with regards how their breasts look. The older women in the sample in particular, spoke about being more reserved when it came to revealing their bodies in front of strangers (including health professionals).

3.1.3 Environmental factors

A number of factors relating to the design and delivery of the breast screening service impacted on (regular) uptake. These served to reduce the sense of ease of attendance and further bolster emotional reservations. The following were the main issues raised:

- the convenience of appointment, including time of the appointment, restricted appointment availability, travel time or distance
- the screening venue, specifically the location of the mobile unit

[9] *Lumps aren't the only sign of cancer* TV ad (2012) and the short film *Introduction to breast screening* (2018) developed as part of the wider Scottish Government's Detect Cancer Early programme.

- the mobile unit set-up, with consequent impact on accessibility, and the comfort of the internal environment.

3.2 Consideration of attending for breast screening

Active consideration of whether or not to attend was largely limited to the first invitation. Initial reactions ranged from acceptance to surprise to shock, with only two of the seven women in the 50-54 years age group subsequently having decided to attend. Their decision was driven by a strong sense of relevance, with one having had a previous cancer scare, and the other conscious of breast cancer in her family (her mother). The latter was the only respondent who had discussed her invitation with someone (her mother).

Of those who decided not to attend, two put this down to the inconvenience of the appointment and the fact it was not perceived to be a priority, two to emotional barriers, and one to concern about over-diagnosis.

Not all of the women who had received their first breast screening invitation had read the letter or booklet[10]. Those who had, had mainly been interested in what they felt to be the key facts (why they were being invited, and the screening process). Two (of the seven) women had sought out more detail online, in particular around the issue of over-diagnosis and seeking out a video of the process.

Others had not read the booklet, their automatic response - whether positive or negative - being driven by existing attitudes and perceptions of breast screening.

Subsequent breast screening invitations tended to be treated in a fairly cursory way: all claimed to have looked at the letter for appointment details but to have considered the booklet to no longer be relevant.

Behaviour with respect to the extent of consideration of the breast screening invitation and the reasons cited for non-attendance varied across the attitudinal groups.

All of the women in the Pragmatic group stated that they had intended to go to the appointment but had subsequently forgotten about it or found it inconvenient. After reading, most had simply put the appointment letter to one side (only one respondent had written it on her calendar) and, with the appointment being sometime in the future with no reminder received, it was forgotten. Being forgotten, the appointment was not cancelled, and not being viewed as a priority, it was not followed up and re-arranged. Two

[10] Evaluation of the letter and booklet was out with the scope of this study.

women for whom the appointment time was/became inconvenient did phone to cancel but didn't re-arrange – again, it was not deemed to be a priority.

At the other end of the spectrum, women in the Fearful group afforded little or no consideration to attending, with this spontaneous rejection often made prior to receipt of invitation and driven by a bad earlier experience, anxiety about the process or fear of the outcome. Whilst some did phone to cancel offering an excuse, others immediately binned the invitation without any real engagement. This group often did not even consider phoning to cancel, or else were afraid to do so in case they are questioned or persuaded to attend.

Amongst the Reluctant group, the reaction to receiving a breast screening invitation was often one of dismay. Whilst most afforded it some level of consideration, this tended to be based on an emotional, rather than a rational weighing up of risks and benefits. Some of the women in this group expressed an initial intention to go, feeling they should, but recall of a negative earlier experience proved to be too strong a barrier to overcome. In such cases, the inconvenience of the appointment time provided a (justifiable) way out, with most not prepared to commit to another appointment if they phoned to cancel. Other women simply pushed the decision to one side, not wanting to actively deal with it and consequently being unlikely to cancel.

Women with a disability expressed similar levels of personal reticence, but also had to consider the practicalities of attendance e.g. reliance on someone else.

The behaviour highlighted above suggests that there are benefits and drawbacks to providing a pre-set breast screening appointment. It can encourage consideration of attendance as many admitted that they would not proactively make an appointment. Whilst some, especially at first invitation, assumed attendance was required, none of the women in this sample felt pressurised to attend. Where the date or time was found to be inconvenient, this provided the more reticent with a ready excuse to not consider further.

Failure to call and cancel inconvenient or unwanted appointments was due to a range of factors. Many of the respondents were unaware that they had the option to change the appointment time (possibly because they did not read the letter carefully). In addition, either the low priority affording the screening or the fear of being questioned or pressurised to attend, often led to a failure to consider telephoning to cancel. Those who had called to cancel or change an appointment had had a largely positive experience, with no sense of being pressurised into rebooking.

Practical barriers were also reported with respect to cancelling and rescheduling appointments: the office hours of the local screening centre can prove limiting for those working full time, and the limited availability of appointments at the local

screening unit or being asked to call their GP in order to reschedule can lead to failure to rebook.

3.3 Specific barriers and facilitators

This section examines in more detail the specific barriers that were reported to be deterring this audience of women from engaging with breast screening services on a regular basis. These barriers cover both practical and psychological factors, and will be described separately below. Actions that might be considered in addressing these barriers were discussed with respondents, initially at a spontaneous level, and then by prompting with possible solutions. The outcome of these discussions is detailed after each barrier has been described.

3.3.1 Practical barriers

The practical barriers cited related to issues pertaining to both the screening appointment and the screening venue.

Appointment time: The pre-set appointments were felt by some to be too far in advance. Many, particularly those with unpredictable shift patterns or zero hours contracts, were not in a position to predict or schedule their work and family commitments several weeks in advance. Others found it difficult, or were reluctant, to request time off work as this would raise a number of issues: the need to make up the time, a sense that it would be frowned upon by their employer, and the potential loss of income. Some women felt that breast screening was not viewed by their employers as a medical essential, whilst others felt embarrassed to ask for time off for this purpose.

> ‘Lots of places will pay you if it’s a hospital appointment, but not for a screening appointment as it’s not hospital.’ (Female, 59 years, semi-urban)

The unpredictable nature of personal circumstances and family commitments also made it difficult for some women to attend future dated appointments e.g. if they were supporting or caring for other family members, had to rely on the availability of others to get to the appointment (esp. those with a disability), or had mental health issues.

With little active forward planning possible, the screening appointment was left to one side as something to be accommodated – if possible - at a later stage. However, for the majority, it was not deemed to be of sufficient importance to be prioritised and was either forgotten or cancelled at late stage.

> ‘I forgot. Had they sent me a reminder, I probably would have went…it just gets shoved to the back of your heid.’ (Female, 55 years, urban)

Whilst there is the flexibility within the service for women to change their appointment time, this was not always noted, lacking sufficient prominence for those who did not read the invitation letter carefully. Additionally, the rescheduling

of appointments for another future date did not necessarily alleviate the related difficulties mentioned above.

> ‘For such a wee thing in my life, it would cause so much hassle.’ (Female, 55 years, urban)

The Pragmatic group (who were inclined to attend for screening if they could) felt that drop-in appointments would provide the kind of flexibility they sought, as it would allow them to more easily fit screening into their normal routine. The Reluctant group felt that the availability of weekend and evening appointments was more likely to be effective in encouraging their attendance, given that without a pre-set appointment they might be unlikely to be prompted to consider screening. They felt that this would provide them with the flexibility to fit the screening appointment around work and caring/family commitments, and make it easier for those with disabilities who needed to arrange support to access the venue.

It was suggested that an online booking system might increase consideration of cancelling unsuitable appointment times and rescheduling to suit personal circumstances. This would not only address the restriction of having to call during office hours, and provide the advantage of ‘anonymity’ and a greater sense of personal control.

Restricted appointment availability or length: This was raised as a barrier primarily in semi-urban and rural locations, but was also mentioned in urban localities where the mobile unit is only in situ for a short period of time, and stemmed from the inconvenience of, or reluctance to travel to another location for screening. This was largely time related, particularly if public transport had to be used, and served to compound the difficulty in fitting in an appointment around work and family commitments. Attempts at rebooking could therefore be thwarted by limited availability of appointment slots at the local site.

> ‘It’s a lot of hassle to get dressed, get on a bus, go there, take it all off, get dressed again, then get back on the bus – I’d be anxious by the time it was all done…it would be simpler if you could go to the GP and walk there – you know where you’re going, what’s there…’ (Female, 63 years, urban)

Some women also reported that they had been unable to rebook when they called to cancel their pre-set appointment. This subsequently resulted in the screening falling off the agenda as most either forgot or did not make a concerted effort to call back.

The length of the appointment slots was felt to add to the stress felt by women who had attended in the past: a sense of being rushed or ‘processed’ rather than treated as an individual. This was reported as a particular barrier for those with a physical disability who felt pressured to just ‘fit in’.

> ‘I take a wee bit longer to do things…I can’t rush like everyone else.’ (Female with a disability, 61 years, semi-urban)

Women in semi-urban and rural locations believed that maximising the opportunity for attendance locally was key. This would involve increasing the availability of appointment slots, including evening and weekend appointments to provide for greater flexibility.

Women with disabilities sought consideration not only of physical needs such as ramps, but also factors such as the timing of their appointment. For example, it was suggested that the first or last appointment of the day, dedicated times when there may be less time pressure, and longer appointment slots would be helpful. It was felt that such considerations (together with clear communication in this regard) would help to provide reassurance and facilitate a better experience.

Travel time/distance: The need to travel to the screening unit constituted a further barrier in semi-urban and rural locations. Depending on the time of the appointment and on the timetable limitations of public transport, women reported that attendance could take up a significant part of their day and require a day or half day off work.

> ‘It’s too difficult to get between towns in a small time span and between the regular things you need to do…I need to go on the bus and it takes an hour and a half.’ (Female, 61 years, rural)

> ‘It’s difficult taking time off work –I work 8 ‘til 8 and they’re short staffed. I would need half a day to travel by bus to the next town…it’s not enough of a priority.’ (Female, 62 years, semi-urban)

For women with a disability, travel to a venue which is not local can pose a range of additional considerations: transportation of equipment such as a wheelchair or oxygen cylinder, increased travel costs if they need to take a taxi, increased anxiety levels, and or the additional time the individual providing support may need to take off work in order to assist. It should be noted that this can sometimes apply as much in urban locations (e.g. travel to Nelson Mandela Place in Glasgow) as in rural.

> ‘I depend on someone taking me as I always have to carry an oxygen cylinder, so they need to think about how people like me can get there easily…it would be good if they could organise pick up and drop off so you don’t need to worry.’ (Female with a disability, 66 years, urban)

It was thought that a more localised service provision would encourage greater consideration of attendance by addressing some of the logistical barriers that complicated the decision process.

Women with a disability felt that this would also help to reduce the complexity of the arrangements that needed to be made and the anxiety associated with this. The provision of transport to the venue for those with mobility difficulties would help to reduce anxiety over travel on public transport or the need for taxis, and may create a greater sense of the importance of breast screening.

Location of mobile screening unit: The location of mobile units can constitute both a facilitator and a barrier. Whilst siting within local supermarket car parks was seen to provide convenience for some, it also engendered some emotional discomfort for others as it was perceived to display a conspicuous indication of purpose on its livery and a very public entrance permitting little discreetness.

> ‘Everyone knows where you’re going if it’s in the car park in Morrison’s…it seems less serious, less important.’ (Female, 56 years, urban)

Concerns over levels of privacy (both inside and from outside looking in) led some to feelings of being exposed.

Whilst the less obviously clinical setting was viewed as an advantage by some, other women perceived it as less professional when compared with a ‘traditional’ medical venue, serving to diminish the perceived value of the screening.

> ‘Like a second rate service.’ (Female, 54 years, rural)

> ‘I really don’t think they should be using these mobile units ‘cos it doesn’t seem professional or private and confidential…like a hospital.’ (Female, 53 years, rural)

The women in this sample felt that the co-location of screening services with GP practices/health centres was not only a good fit, but would begin to normalise breast screening. This stemmed from the familiarity of a known medical environment which was already linked by many with well woman clinics and instinctively associated with a greater degree of discreetness and privacy. This co-location could simply involve the location of mobile screening units within the practice car park, although it was felt that the ideal scenario would be a degree of integration with the practice itself.

Many of the women in the Reluctant group believed that the association with GP services would also serve to provide some emotional reassurance: perceived to be a friendlier, more accessible environment with an expectation of a personalised service, rather than one which is simply functional.

Mobile screening unit set-up: Accessibility was an issue for some women with a physical disability. They cited concerns related to the steps into the mobile unit being steep and not feeling safe, difficulty in standing for extended periods, and

increased levels of anxiety and self-consciousness as a result. There was a lack of awareness that some provision could be made for their needs if they contacted screening service prior to the screening appointment. The more limited space within the mobile unit also presented a barrier for some women with disabilities and for the more anxious (especially older women). The unit was felt to be very confined, and the restriction on being accompanied limited the possibility of emotional or physical support.

> ‘It would be good if you could phone and talk it through with them to make it easy to go.’ (Female with a disability, 57 years, urban)

The environment within the mobile units was perceived by many to be very sterile and unwelcoming which, together with the minimal personal engagement reported by some, served to increase any existing anxiety. A number of the women also mentioned experiencing emotional discomfort when moving from the changing cubicle to the x-ray room past others, or when having to wait in gowns for their turn.

> ‘They seem rushed and stressed, but they’re just trying to do their best.’ (Female, 68 years urban)

> ‘They made us wait, three of us, bras off! That wasn’t great and you feel a bit odd being with people with no bra on.’ (Female, 69 years, urban)

> ‘No one speaks in the waiting area – you just stare at each other with fear on your face!’ (Female, 63 years, urban)

Women with disabilities believed that greater clarity should be provided on the support/service adjustments that can be made for them. They felt that this should be made evident in the invitation letter, either by ensuring good stand-out within the standard invitation, or ideally by developing tailored invitations. Providing the option for women to have the mammogram while seated was perceived to be an important consideration in facilitating a more comfortable experience for those who had difficulty standing still for a period of time.

With respect to the environment of the mobile screening units, the value of a friendlier, more comfortable waiting area was felt to be vitally important to help calm some of the anxiety experienced by women waiting for their appointment. Women also sought greater levels of privacy, for example when moving to and from the x-ray room (e.g. a curtained off changing area in x-ray room itself) and not having to wait with others while only wearing their gown.

Space in the waiting area to allow for individuals to be accompanied to the appointment would help with anxiety levels prior to screening. Some women with disabilities also sought the space to sit and compose themselves after the screening.

3.3.2 Psychological barriers

For many of the women in the sample, the psychological barriers to be overcome presented significantly greater obstacles than the practical ones.

Screening procedure: The breast screening service was widely perceived to be very impersonal. It was described as a 'conveyor belt' approach, engendering a sense of being processed rather than being treated as individuals. The entire experience (pre, during and post the x-ray) was described as functional and detached which can result in a sense of vulnerability and a lack of control.

> 'It feels a bit robotic – stand in line to go on the conveyor belt kind of thing.' (Female, 62 years, urban)

> 'It's all too much of a process. The same girls are doing it every day - they probably don't even see the faces so they don't know who you are, and that makes it all about numbers and not about each person.' (Female, 59 years, semi-urban)

Appointment time restrictions added to a sense of being rushed through, with little perceived opportunity to ask questions, for discussion of concerns or the provision of reassurance. Additionally, women felt that they received little encouragement or reinforcement of the value of breast screening.

> 'If the people had been nice, you'd put up with the vans better – they're not nice, but they're ok.' (Female, 69 years, urban)

> 'The staff are very matter of fact, clinical – they don't put you at your ease…they don't explain anything, you need to ask. Even the receptionist isn't friendly.' (Female, 61 years, rural)

> 'They can have someone to explain what will be happening and help reduce your anxiety…so you don't have to sit with everyone all looking terrified!' (Female, 54 years, rural)

Women in the sample believed there that there was the opportunity for staff in the screening centre or unit to better support women who were anxious about the screening process. They felt that there was the scope to diffuse a lot of concerns and reinforce the benefits of screening when women arrived or were waiting for their appointment. This included the chance to ask questions of, and be reassured by, a member of staff (this could be a trained receptionist or volunteer).

The manner and approach of the Mammographer was felt to be crucial to the overall experience. These women sought a more empathetic manner which acknowledged any possible fears rather than dismissing them, with enough time available during the appointment to facilitate such conversation with women who needed to be put more at ease. Importantly, they believed it was essential for the

mammographer to afford more control to the individual being screened by reinforcing the fact that they could ask to pause or stop at any point.

Screening experience: Perceptions of a negative staff attitude impacted strongly on these women's willingness to attend for future screening appointments. A small number of respondents described what they felt to be the mammographer's insensitivity or roughness during their appointment. They perceived their attitude to be uncaring and reported that they had been made to feel as if they were making an unnecessary fuss or exaggerating the discomfort.

> 'You're like a piece of meat!' (Female, 61 years, rural)

> 'I was so anxious and tense…they don't see it, don't ask, don't help or put you at your ease!' (Female with a disability, 57 years, urban)

> 'Remember it's a person who's maybe worried about doing this – you don't know what's going on behind this set of boobs you're processing – just think and ask!' (Female, 59 years, semi-urban)

The pain experienced during the mammogram was a key barrier. This tended to be attributed either to the 'roughness' of the mammographer, their own condition (e.g. fibromyalgia), or to the nature of the process (i.e. the compression needed for the x-ray). In the case of the latter two assumptions, there was little or no expectation that this could be managed or altered in any way, and as such non-attendance was the only way of avoidance.

> 'You go into the main body of the bus and there's a contraption there and they clamp you in it and they keep pressing and pressing and pressing 'til you can't breathe as something digs into your ribs and they're pancake style – oh god it's brutal!' (Female, 60 years, semi-urban)

The embarrassment of standing undressed from the waist up created high levels of anxiety for many of the women in the sample, particularly for older women and those who were very sensitive about their body image. The reassurance of a female mammographer was perceived by these women to offer limited comfort. Some of the older women felt that such exposure of their breasts was completely inappropriate, and pointed to the fact that this was the first and only time they had had to do this in front of a stranger.

> 'It's all about how you feel about yourself. So having put weight on I don't feel good about me and it's hard, I don't want people to see me now.' (Female with a disability, 55 years, urban)

As mentioned above, women sought greater levels of empathy and support from staff in the screening centre. This included the mammographer's acknowledgement of the pain being experienced, and being willing or having the

time to work with women to reduce the discomfort by for example, gradually increasing the compression pressure. Some women thought it would be helpful to be provided with tips on how to minimise the discomfort during the mammogram, for example taking over-the-counter painkillers beforehand, or deep breaths during the procedure.

It was felt that any strategies that might minimise the extent of complete exposure of the breasts and or upper body would go some way to offering comfort for some of these women, for example the provision of a gown or cover-up that allows for one breast to be exposed as necessary.

4. Discussion

4.1 Factors impacting breast screening uptake

Consideration of uptake of the invitation to attend for breast screening is influenced not only by personal attitudes and service features, but by the social and cultural context in which they are received. The low level of priority associated with breast screening is linked with a perception of the invisibility of breast cancer and screening in this audience's social context, both in their immediate community, and in Scotland in general. This stems from a lack of awareness of the prevalence of breast cancer, and a perceived absence of recent mass and social media activity around breast screening. Furthermore, the limited amount of positive private conversations that appears to be taking place around breast screening is reinforcing these perceptions.

This is in contrast to findings of a 2017[11] study which found that women perceived breast cancer to be quite prevalent and to receive a lot of media coverage. At that time, there was also good awareness of the screening programme in Scotland, stemming from recall of the 2012 TV campaign and discussion amongst friends and family. This indicates the importance of retaining the importance of breast screening front of mind through awareness raising and wider media activity.

Misconceptions about the prevalence of breast cancer and the risk for those who consider themselves to be too young or without a family history of the disease, also play a key role in driving perceptions of a lack of self relevance. This highlights a need to further raise awareness and understanding amongst this audience. However, it should be noted that education alone is unlikely to significantly impact on the attitudes of some groups of this audience – this will require reassurance at an emotional level to address negative perceptions or experiences of the pain and embarrassment associated with breast screening.

Specific service related factors also impact on screening uptake and have the potential to limit attendance amongst those who recognise the importance of, or are more open to screening. Addressing these (such as appointment convenience or location of mobile units) can potentially provide quicker wins than overcoming some of the psychological barriers evident in relation to breast screening.

4.2 Barriers to attendance

Barriers reflect those identified by the 2017 research study and those highlighted in the Independent Review of Adult Screening Programmes in England[12] published in 2019. The latter notes factors likely to impact on uptake to include:

[11] NHS Health Scotland. Evaluation of national breast screening materials
[12] NHS England. 2019. Independent Review of Adult Screening Programmes in England. Available at: https://www.england.nhs.uk/wp-content/uploads/2019/02/report-of-the-independent-review-of-adult-screening-programme-in-england.pdf

acceptability, awareness, convenience, accessibility, reminders and endorsements.

In terms of practical barriers, the key issues related to the timing of receipt of the appointment, and the convenience and comfort of attending the venue. These factors should be considered in the context of the work and family circumstances of these disadvantaged audiences. As many of the women in the target audience for this study did not have fixed work schedules or had caring or childcare commitments, pre-set appointments sent several weeks in advance did not serve to provide the opportunity for better planning, but rather resulted in the screening being side lined or dismissed as inconvenient.

The perceived lack of flexibility of appointments (particularly in the context of the lack of priority afforded to breast screening) is a barrier that is potentially easy to address for women who intend to go to their screening appointment (pragmatic groups) but find either the time or the location inconvenient.

The accessibility of the appointment venue, both in terms of locality and siting in public areas such as supermarket car parks, can also create barriers to attendance. This is linked to travel time, particularly in rural and semi-urban areas, but also with regards the time taken to when traveling from and back to work. Siting in supermarket car parks can raise concerns over privacy, and rather than normalising, can serve to reduce the perceived importance and professionalism associated with breast screening.

Emotional barriers play a significant part in deterring uptake of breast screening amongst this audience. Whilst the acceptability of the procedure with respect to the discomfort experienced will be hard to overcome for some of the women in this target audience, there may be ways to mitigate against the most negative experiences. The first encounter is a key influencer in consideration of attendance for subsequent screening appointments, with the screening staff having an important role to play in helping to put women at ease both prior to and during the screening.

The barriers to attendance reported by women with disabilities largely reflected those of others in the sample. Additional barriers for women with limited mobility stemmed from issues of accessibility in respect of travelling to venues and ease of access to, and movement within the mobile units. Communication regarding the adjustments that are available do not appear to be sufficiently prominent to provide reassurance and promote active consideration. These practical barriers can serve to further compound anxiety around self-image and the procedure itself.

4.3 Enabling attendance

It was evident that in the absence of a pre-set appointment, the majority of the women interviewed were unlikely to proactively make a breast screening appointment. It is therefore important that this is retained, but that a more proactive approach to appointment setting be considered by issuing reminders to address the issue of forgotten appointments. This would also provide a further opportunity to reinforce the benefits of screening and the option to cancel or reschedule.

Greater appointment flexibility would be a key facilitator, with near term appointment scheduling, drop-ins and evening and weekend appointments allowing easier accommodation of the screening around regular commitments. Options which afford women a greater level of control in respect of making or rescheduling their appointment (for example via a weblink) would facilitate attendance amongst women who are more inclined to attend if it was convenient to them.

Location of mobile units and or the flexibility to attend at a different venue where possible would address both convenience (e.g. near place of work) and emotional concerns for some women. Bringing mobile units into familiar health environments, such as co-locating them with GP practices or well woman clinics may also serve to better communicate breast screening to be a serious (and routine) aspect of monitoring women's health.

Given the anxiety with which the appointment is approached by many in this audience, a level of personal engagement and empathy can help to ease concerns. Longer appointment slots to enable Mammographers to talk women through the process, greater awareness of privacy needs in the design of the mobile units, gowns which facilitate greater modesty, and consideration of how women could be advised to manage the discomfort, are key considerations.

Setting expectation and easing concerns as far as possible prior to the screening appointment would go some way to encouraging attendance. It should be recognised that many of the women in this target audience were not inclined to read the letter and information booklet in any detail, and as such providing other opportunities for engagement are key, for example through social media platforms. This would provide scope, not only to communicate information and directly answer queries or concerns, but also to encourage peer conversations, support and sharing of experiences.

Digital approaches may also help to provide more immediate and accessible information about the assistance that is available for women with disabilities, and the ability to request support without having to telephone may offer advantages for some. Providing the opportunity to select convenient appointment times, or the provision of transport to the venue for those with mobility difficulties would also

help to reduce the complexity of the arrangements that need to be made and the anxiety associated with this.

5. Conclusions and recommendations

5.1 Conclusions

- Whilst the women in this target audience had high level awareness and understanding of the purpose and process of breast screening, its importance and self-relevance was not acknowledged by a significant proportion of them. This was in part driven by a number of misperceptions: a sense that breast cancer is not very prevalent, an association of risk residing primarily with women with a family history of breast cancer and women over 70 years, and a belief that self-examination can identify any cancer present.

- There are attitudinal differences which distinguish the needs of women in this sample. It may be easier to address the primarily practical service related barriers of those who are more open to recognising the benefits of breast screening than the psychological barriers prevalent amongst the most fearful of women in the sample.

- The inconvenience of appointments presented practical barriers which hindered uptake. The current system for scheduling appointments has a number of drawbacks:
  - Pre-set appointments that are several weeks in the future are often not helpful for this audience who cannot always predict their work or family commitments so far in advance.
  - The inability to schedule appointments out with working times makes attendance difficult for many.
  - There is limited awareness that appointments can be cancelled or rescheduled, and the need to telephone within working hours to do so is inconvenient.
  - Limited appointment time flexibility, particularly in semi-urban and rural locations, leads to appointments not being pursued.

- The location and design of the screening venue can constitute further barriers to uptake:
  - Where the screening venue is not local, travel time, inconvenience or the cost involved can limit access, particularly in semi-urban and rural locations.
  - The accessibility of the mobile units can be an issue for women with restricted mobility, many of whom were not aware that adjustments could be made if requested
  - Attendance at a mobile unit can serve to limit willingness to considered breast screening: perceived to lack discretion from the outside, with the internal environment viewed as sterile, cramped and lacking sufficient privacy.
  - Limited emotional accessibility can also an issue for those attending mobile units as there is no or limited opportunity to be accompanied.

- Psychological concerns constituted a significant barrier for some of the women in this target audience. These related both to the embarrassment and pain experienced during the screening process, but also to perceptions of the impersonal nature of the process, and the lack of empathy and understanding from screening staff. The resulting sense of unacceptability of the experience impacts negatively on preparedness to consider further screening appointments and leads to the spread of adverse stories.

5.2 Recommendations

The following is recommended to help increase the uptake of breast screening amongst this target audience:

- Improve the understanding and perceived value of breast screening
  Media campaigns will help to communicate both the value of screening and to provide cultural contextualisation by clarifying the prevalence of breast cancer in Scotland and the populations at risk. There are advantages to employing a variety of channels to help convey the importance of breast screening (e.g. television advertising) and its relevance to this audience (through trusted sources using social media channels for example). The value of screening can be emphasised through GP reinforcement, and normalisation within these communities will be helped by encouraging informal conversations (between both peers and health professionals), for example on social media.

- Increase the convenience of appointments
  Greater flexibility of appointment scheduling and availability would enable better access and uptake. Consideration should be given to a range of service elements: reminder texts or telephone calls which can help to retain screening appointments on the radar, an online appointment cancellation and rebooking system to provide a greater sense of individual control and convenience, and evening and weekend appointments for those who find it hard to adjust weekday commitments or rely on support from others. Increased appointment availability in rural and semi-urban locations would provide some flexibility for women in these areas.

- Increase the user-friendliness of screening venues
  This should be considered at both a practical and an emotional level. Co-location of breast screening services with existing GP or well woman services would facilitate attendance by providing a local, familiar and professional environment, together with more discreet access to the service. At a psychological level, these venues were perceived to be friendlier, with the expectation of a more personalised experience and the opportunity to be accompanied. Larger mobile units with ‘warmer’ waiting areas can also help to provide a more reassuring environment. Better communication of the adjustments that can be made for women with disabilities is key, ideally though personalised invitations.

- Improve the acceptability of breast screening
  There is a need for better engagement with women to demystify the screening process and provide reassurance. This could take the form of informal social support via social media channels, enabling telephone or online support e.g. live chat, peer conversations, and the sharing of positive stories from women who have been screened. Facilitating easy access to concise, straightforward information and honest description e.g. videos of the process would also be helpful. Engagement and empathy during the appointment is vital in encouraging repeat screening. Mammographer sensitivity and consideration is key, and longer appointment times or (peer) support in the waiting area would enable questions to be asked and reassurance provided. The use of gowns that do not need to be fully removed while the mammogram is being taken would also help in addressing the modesty concerns.

Appendices

Appendix 1: Discussion guide

Job No: 1604

SCOTT PORTER
Research & Marketing

Exploring barriers and facilitators to breast screening uptake among disadvantaged groups and communities in Scotland
Depth discussion guide

19/03/20 final

Note: the guide is designed for all audiences – the moderator will adapt question wording/language and probing by audience, literacy levels etc.

1. Introduction (2 mins)

- Self, Scott Porter, MRS Code of Conduct, confidentiality, audio recording etc
- Purpose of the research*: This research is looking to explore what women think about the breast screening service currently offered in Scotland. I'd like to chat to you about your views and feelings about breast screening, and any ways you think the service could be changed to encourage more women to take up the offer of breast screening.*
- Respondent name, age
- Have you ever been invited to attend for breast screening
  - do you remember roughly how many times you've been invited?
  - and have you ever been to any of the appointments: if so, when was the last time you were screened?

2. Attitudes to and understanding of breast screening (8 mins)

- When you hear 'breast screening', what is your gut reaction?
  - what words, thoughts or feelings come to mind
  - probe fully: how does it make you feel – why do you think you feel like this?
  - *note words used and explore fully: is it associated with drawbacks or benefits etc.*

- Is breast screening something that's talked about amongst your friends/work colleagues or family?
  - if yes: what is it that they say about it/what aspects are discussed? How is it talked about (*do not prompt* - e.g. seriously, jokingly, with concern)
  - if no: why do you think that is (*do not prompt* – e.g. too private/embarrassing, no-one does it)

- Why do you think some women attend for breast screening? *Spontaneous, probe fully but do not prompt*
- What do you think prevents some women from attending for breast screening? *Spontaneous, probe fully but do not prompt*

- Do you think there are any benefits to going for breast screening? What would you say these are?
- Do you think there are any drawbacks to going for breast screening? What would you say these are?

- How much do you feel you personally know about breast screening?
  - spontaneous then probe awareness of: who is invited, how often they are invited, where you go for screening and what is involved, what the screening is looking for

- And have you personally read about or discussed breast screening with anyone?
  - if yes: what did you read/where did you find the information/who did you discuss breast screening with?
  - what prompted you to do this? How did you feel afterwards?
  - if no: why is that?

- How do you feel about health screening generally: important or not really a priority for you?
  - why is that?

- Do you tend to accept your other screening invitations or not?
  - *If yes:* which ones, and why those? (cervical, bowel)
  - what prompts you to go along or not?

- How do you view breast screening in relation to these other screening tests?

3. Consideration of attendance (10 mins)

Those who have been invited for the first time

- Do you remember receiving your invitation to attend a breast screening appointment? Roughly, how long ago was that?
  - what was your reaction to it? How did you feel when you opened the letter? *Explore emotions experienced as well as any practical reactions*

- What did you do when you received the invitation?
  Allow for spontaneous description of actions, then probe fully:
  - did you read the letter?
  - did you look at/read the information booklet that came with the invitation?
    - if yes: how much of it did you read; did it answer any questions you had?
    - if no: why did you decide not to look at this information?
  - did you have any worries or concerns at the time? What were these? Were these answered by the information in the leaflet?
  - did you discuss the contents of the letter or leaflet with anyone?
  - what did you decide to do

Those who have been invited previously

- When was the last time you were invited to a breast screening appointment?
- What was your reaction when you received your most recent invitation?
  - did you open and read the letter? If no, why was that?
  - did you discuss it with anyone?

All

- How much did you actively consider whether or not you would go to your most recent breast screening appointment?
  - would you say you thought about it before coming to a decision, or was it more of an emotional/gut decision?
  - if thought about it:
    - what things did you take into account?
    - did you weigh up the pros and cons? What were these, and which ones where the most important to you?

- How did you feel about getting a pre-set appointment?
  - did this have any effect on your decision (explore practical issues e.g. not convenient, and emotional ones e.g. feeling of being pressurised)
  - did you know you had the option to change the time of the appointment? If known, did you consider this?

If attended last appointment or previously

- What would you say was the main reason you decided to attend your last/previous breast screening appointment(s)
- If first attendance: would you go the next time you are invited – why is that?

If did not attend last appointment

- What would you say was the main reason you decided not to attend your last breast screening appointment

- Did you call to cancel the appointment?
  - if no, why was that? Probe: not aware had to, didn't think about it etc.
  - if yes, how was that received; were you asked if you wanted to organise another appointment time?

4. Barriers to attendance (20 mins)

I'd like to now chat in a bit more detail about your experience of different aspects of the breast screening process and whether you think anything could be changed to make it easier or more comfortable for women to attend

- What were the things that made it difficult for you to attend or (would) put you off attending your screening appointment? *Spontaneous, then prompt with the following if not already covered in discussion above. Then use following technique to establish priority and strength of influence: ask respondent to select cards – or fill in blank ones if own barriers not represented - that reflect the factors that put them off attending and place them in order of importance.*

  - Practical factors
    - time of the appointment
    - location of the screening centre/unit
    - set up of the screening venue e.g. mobile unit in supermarket car park, comfort, accessibility
    - travel to appointments (time/cost/distance)
    - need time off work (difficult/loss of earnings/inability to take time off)
    - childcare (difficult/cost)

- Emotional factors
  - concern/fear
  - embarrassment
  - discomfort/pain
  - negative experience with staff
  - feel fine/no symptoms

5. Enablers to attendance (20 mins)

- Do you feel there are things that the breast screening service can do to make it easier or more comfortable for women to attend their appointment? *Spontaneous, then explore reactions to:*

  - Practical enablers
    - change in the invitation process (e.g. telephone, simplified letter)
    - better awareness (e.g. via community groups)
    - drop-in service
    - weekend/evening appointments
    - design of mobile units (how?)
    - better accessibility (how?)
    - location of screening units
    - co-location with other services e.g. GP practice, pharmacy, community buildings, specialist services (disability)
    - reimbursement for travel to attend the screening appointment
    - childcare facilities
    - other

  - Emotional enablers
    - attitude/behaviour of staff (e.g. friendliness, ease of dealing with disabilities)
    - greater privacy (how?)
    - more time
    - support (if needed when/after receive result)
    - other

6. Overall

- Overall, are there any factors that would encourage you to reconsider attending for breast screening
  - if no: why is that?
  - if yes: which 2 or 3 changes would be most important for you personally?

60 minutes

THANK AND CLOSE

Appendix 2: Recruitment questionnaire

Scott Porter Research & Marketing Ltd
28 Drumsheugh Gardens
Edinburgh
EH3 7RN
Tel: 0131-225-0901

Job No: 1604
March/April 2020
Participant Information Number: ___

Exploring barriers and facilitators to breast screening uptake
Recruitment questionnaire

INTRODUCTION

Good morning / afternoon, my name is .....from Scott Porter Research, an independent research agency. We are currently conducting a research study on behalf of NHS Health Scotland to better understand women's attitudes to attending breast screening. We wish to conduct an informal one-to-one interview to discuss your thoughts about the current breast screening service in more detail. The depth interview would take approximately 60 minutes and if you take part, you will be offered a cash incentive of £30 at the end of the interview to thank you for your time.

This research is being conducted on a strictly confidential and anonymous basis as set out by the Market Research Society Code of Conduct. This means that anything that you say during the interview will be treated confidentially, except in circumstances where there is a serious and immediate concern that you or someone else is at risk of harm. Any comments you make will not be linked to your name.

As we're looking for women from a range of backgrounds and experiences, would you be happy for me to ask you a few more questions to see if the study is suitable for you?

Yes ..... 1 THANK AND CONTINUE TO SCREENER (QA)
No ..... 2 THANK FOR TIME AND CLOSE INTERVIEW

CLASSIFICATION

AGE:
50-54..... 1 QUOTA
55-60..... 2 QUOTA
61-65..... 3 QUOTA
66-70..... 4 QUOTA

SEGMENT:
Core sample..... 1 QUOTA
Women with disability..... 2 QUOTA

ATTENDANCE IN LAST 24 MTHS (Q4):
Did not attend ..... 1 QUOTA
Attended ..... 2 QUOTA

ATTITUDE TO ATT'G NEXT APPT (Q7):
Yes, think they might..... 1
Not sure 2
Probably not..... 3

REASON FOR NON-ATTENDANCE(Q6):
Practical 1
Other 2
Not applicable (attended) 3

NHS HEALTH BOARD AREA:
Fife..... 1 QUOTA
Greater Glasgow & Clyde..... 2 QUOTA
Lanarkshire ..... 3 QUOTA
Lothian ..... 4 QUOTA

LOCALITY:
Urban (city) ..... 1 QUOTA
Semi-urban (town)..... 2 QUOTA
Rural (<3,000 inhabitants) ..... 3 QUOTA

SCREENING:

The first few questions relate to any prior market research attendance:

QA. Have you ever attended a market research focus group or an interview for research purposes?

Yes ..... 1 GO TO QB
No ..... 2 SKIP TO QD

QB. How long ago did you attend a market research discussion / interview?

In the last 6 months ..... 1 THANK AND CLOSE
More than 6 months ago ..... 2 GO TO QC

QC. Do you remember what the discussion was about?

.....
CLOSE IF ON SAME OR SIMILAR SUBJECT

QD. Do you or your family or close friends work in any of the following occupations or any related industries?

Marketing ..... 1 CLOSE
Advertising..... 2 CLOSE
Market Research ..... 3 CLOSE
Design..... 4 CLOSE
Journalism ..... 5 CLOSE
Design..... 6 CLOSE
NHS / Healthcare ..... 7 CLOSE
None of these ..... 8 CONTINUE

MAIN QUESTIONNAIRE:

Q1. Can you please tell me which age group applies to you?

READ OUT:

Under 50 ..... 1 CLOSE
50-54..... 2 QUOTA
55-60..... 3 QUOTA
61-65..... 4 QUOTA
66-70..... 5 QUOTA
71+ ..... 6 CLOSE

Q2. As we are looking for women who live in certain areas could you please tell me your full postcode?

Write in: _____

CHECK AND CODE SIMD

SIMD 3, 4, 5..... 1 CLOSE
SIMD 2..... 2
SIMD 1..... 3

Q3. Can I please just check, what is the occupation of the chief income earner in your household (the person who earns the most)?

Write in: _____

CODE SOCIAL GRADE

ABC1 ..... 1 CLOSE
C2 2
D 3
E 4

ASK ALL

Q4 Do you recall receiving an invitation by post to attend a breast screening appointment <u>within the last 24 months</u>?

Yes ..... 1 CONTINUE TO Q5
No ..... 2 CLOSE
Not sure ..... 3 CLOSE
Refused to answer ..... 4 CLOSE

ALL MUST RECALL RECEIVING INVITATION WITHIN LAST 24 MONTHS

Q5. And did you go on to attend that screening appointment?

Yes ..... 1 SKIP TO Q7
No ..... 2 CONTINUE TO Q6
Can't remember/don't know ..... 3 CLOSE

CHECK QUOTAS

Q6. Was it for PRACTICAL reasons that you didn't attend - for example, you couldn't make the proposed date or time, you had a childcare issue, you couldn't get to the venue, etc or was there some other reason behind your decision?

Practical reason ..... 1 CONTINUE TO Q7
Some other reason ..... 2 CONTINUE TO Q7
Refused to answer ..... 3 CONTINUE TO Q7

AIM FOR A MIX OF PRACTICAL AND SOME OTHER REASON

Q7. Women in Scotland are invited to be screened every three years. As this point in time, would you consider attending an appointment in the future?

Yes, definitely ..... 1 CLOSE
Yes, I think I might ..... 2 SEE INSTRUCTION BELOW
Not sure ..... 3 SEE INSTRUCTION BELOW
Probably not ..... 4 SEE INSTRUCTION BELOW
No, I definitely wouldn't attend ..... 5 CLOSE

***RECRUIT** IF 'YES' AT Q5 **<u>AND</u>** 'NOT SURE'/'PROBABLY NOT' AT Q7*
***CLOSE** IF 'YES' AT Q5 **<u>AND</u>** 'YES, DEFINITELY'/'YES, I THINK I MIGHT' AT Q7*
***RECRUIT** IF 'NO' AT Q5 **<u>AND</u>** 'YES, I THINK I MIGHT'/'NOT SURE'/'PROBABLY NOT' AT Q7.*
***EXCLUDE** ANYONE WHO DEFINITELY WILL ATTEND IN THE FUTURE AND ANY OUTRIGHT REJECTERS.*

For the final couple of questions I need to ask about any health conditions, illnesses or impairments you may have…

Q8. Do you have any physical or mental health conditions or illnesses lasting or expected to last for 12 months or more?

Yes ..... 1 ASK Q9
No. ..... 2 NO DISABILITY - SKIP TO END
Refused to answer..... 3 CLOSE

ASK ONLY THOSE SAYING YES AT Q8 (OTHERS, SKIP TO END)

Q9. Does your condition or illness (do any of your conditions or illnesses) reduce your ability to carry-out day-to-day activities?

Normal day to day activities can include: washing and dressing, household cleaning, cooking, shopping for essentials, using public or private transport, walking a defined distance, climbing stairs, remembering to pay bills, and lifting objects from the ground or a work surface in the kitchen, moderate manual tasks such as gardening, gripping objects such as cutlery and hearing and speaking in a noisy room.

In answering this question, please consider whether you are affected whilst receiving any treatment or medication for your condition or illness and/or whilst using any devices such as a hearing aid, for example.

Yes, a lot ..... 1 WITH DISABILITY – CHECK QUOTA
Yes, a little..... 2 WITH DISABILITY – CHECK QUOTA
Not at all ..... 3 NO DISABILITY – CHECK QUOTA

IF ELIGIBLE: **Thank you very much. I can confirm that you are eligible to take part in the study!**

Now give the respondent the Participant Information Sheet, point out key information. Proceed to the consent page (p5), reading out and completing as instructed. Finally, classify on front page.

FINAL CHECKS: ALL RESPONDENTS:

- should live in a SIMD 1 or 2 area and are SEG C2DE
- should recall receiving an invitation to attend breast screening in the last 24 months
- exclude anyone who says they *definitely wouldn't* attend a breast screening appointment in the future OR anyone who *definitely would at Q7*
- if they did NOT attend their screening appointment, then it's OK if they think they might attend in the future OR they may be unsure about attending in the future or say they probably won't consider attending again. Exclude if they say they definitely would attend the next time.
- if they DID attend screening appointment in the last 24 months, then they must be *unsure* about attending in the future or say they probably *won't consider attending again.* Exclude if they say they definitely would/think they might attend the next time.
- do not ask, but should anyone voluntarily disclose that they are currently undergoing treatment for breast cancer, please exclude them from the research. Please also exclude anyone who discloses they have had breast cancer and are currently in remission.

CONSENT PAGE

READ OUT VERBATIM: With your permission, the research team will be passed the details you have provided me with so that the researcher knows who to meet and where to come to interview you. Also, with your permission, they will need to recontact some of the people who have taken part in the study so they can check I've recruited the right people for the project in the correct manner.

I will therefore need to record your name, address and a contact telephone number. The research company will keep these details for up to 1 month after the end of the project before securely destroying them. Your personal identifiable information will not be passed on or used for any other purpose other than to confirm/assist the interview and for quality control. In line with new data protection laws could you tell me:

	Yes	No
Do you consent to taking part in the depth interview in line with what's been described to you?	1	2
Do you consent to me passing your personal details to Scott Porter for the reasons described above and hence to the data processing associated with this?	1	2
Can you confirm that you have been given a Participant Information Sheet to provide you with additional information and a written consent form for completion?	1	2
Do you consent to Scott Porter contacting you to check that this interview was conducted appropriately at the end of the study?	1	2
Do you consent to me contacting you the day before the interview to confirm the appointment and verify there is no known risk of coronavirus for all parties?	1	2

RESPONDENT DETAILS: ***If consent given above complete:***

Name: .....

Address: .....

..... Postcode: .....

Contact number: .....

INTERVIEW DETAILS:

Date: .....

Time: .....

Location: .....

Interviewer name: .....

RECRUITER DECLARATION: **MUST BE COMPLETED**

I declare this interview has been carried out strictly in accordance with your specification, within th code of conduct, and with a person totally unknown to me. ***I also confirm that the respondent was asked and verbally responded to the consent questions***

Consent taken: On (date): ..... At (time): .....

Interviewer name: .....

Interviewer signature: .....

Signed on (date): ..... At (time): .....

Appendix 3: Participant information sheet and Consent form

SCOTT PORTER
Research & Marketing

NHS
Health
Scotland

Exploring barriers and facilitators to breast screening uptake
Participant Information Sheet v3 11/03/20

Invitation to take part:
We'd like to invite you to take part in our research study. Taking part is entirely up to you, and before you decide whether to take part or not, we would like you to understand why the study is being done and what it would involve. **Please read this information sheet carefully**. Discuss it with others if you wish. If you have any questions, or if anything is unclear, please ask a member of the research team (details are at the end of this document).

Location:		
Date:	**Start time:**	**Finish time:**
Name of recruiter:	**Recruiter's tel:**	
Name of researcher:		
Please remember: *If you usually wear reading glasses, please have them with you when you meet with our researcher.*		
We will 'phone you the day before the interview, to check you are still happy and willing to take part.		

What is the study about?
We are doing this study as we want to find out why women may attend or may not attend the breast screening service which is available to all women in Scotland who are aged between 50 and 70.

Who is organising and funding this study?
This study is being carried out by Scott Porter Research on behalf of NHS Scotland who are funding the study.

Why have I been invited to take part?
You've been asked to take part in the study as you have told us that you have been invited to have a breast screening examination in the last 24 months which you may or may not have attended.

What does taking part involve?
If you agree to take part, you'll be asked to take part in a depth interview. This would be one of 36 which are being held with members of the public across Scotland throughout April 2020.

All interviews are done on a one to one basis with one of our researchers and are very informal in nature. They will last approximately **60 minutes** and will take place at a time and location convenient to you (e.g. your home). If you prefer the interview to be held in a public place, we'll aim to find a suitably private space to make sure no one else can hear what you say.

During the interview you'll be asked to discuss your feelings about, and experience of the breast screening process and how it could be made more accessible or more comfortable for women

to attend. There will be no pressure to answer a question if you do not want to, and you can stop the interview, or leave the study at any time without giving us a reason.

With your permission, we'll audio-record the interview to ensure that the information you provide is accurately documented. Also with your permission, you may be re-contacted by one of the research team within a couple of weeks after your interview for quality control purposes.

Will my taking part in this study be kept confidential?
Yes, all information collected from and or about you will be kept confidential except in circumstances where there is a serious and immediate concern that you or someone else is at risk of harm. If that happens, we are required to report this to the Head of Research Services at NHS Health Scotland who will provide advice on actions to be taken. You will never be identifiable in any study outputs, such as reports or presentations. We may use some direct quotes from what you say in study reports and presentations but where we do this, we will make sure we do not include information that will identify you.

What will happen to the results of this study?
Your anonymous data will be combined with that of other participants and this will be used to produce a presentation and a report to be shared with NHS Health Scotland.

Do I have to take part?
No, it is entirely up to you. Participation is voluntary; you do not have to participate if you do not want to. If you decide to take part, the recruiter will give you this 'Participant Information Sheet' to keep and will check whether you are still happy to take part a day or so before the interview. Then on the day of the interview the researcher will ask you to sign a 'Participant Consent Form' – a document which confirms that you are happy and willing to take part.

What will happen if I don't want to carry on in the study?
Even if you tell our recruiter you want to take part or sign the consent form, you're still free to pull out from the study at any time, either during the interview or even afterwards, without giving a reason and with no negative consequences for you. Be assured, pulling out will have no effect on any care you receive or any services you use, or indeed any care or services you'll be offered in the future.

If you decide you don't want to take part *before* the date and time you are to meet with the researcher, please contact our recruiter (details of which will have been provided). We'd appreciate it if you could give them as much notice as is possible. Should you decide you don't want to take part *during the interview*, simply let the researcher know you'd like to stop. If you decide that you don't want your information to be included in the study *after* you've completed the interview, please contact Alison Miller at Scott Porter Research (contact details page 4). We will not include your data if you pull out during the interview or shortly thereafter, but please note that we will not be able to exclude the information you have provided after it has been combined with that of other people taking part and we will need to keep the information you've already provided. Your rights to access, change or move your information will be limited at this point as we need to manage your information in specific ways for the research to be reliable and accurate.

However, to safeguard your rights, be assured we will use the minimum amount of personally identifiable information possible.

What are the possible benefits of taking part?
The information you provide will be used to ensure that any changes made to the Breast Screening programme in Scotland will meet the needs of the population it is designed to serve. There will be no immediate direct benefit to you should you decide to take part, nor will there be any personal benefit in the level of care you receive. However, to thank you for your time and contribution, you will be offered £30 for taking part. You will receive this in cash at the end of the interview. Please note that for accounting purposes you will be required to acknowledge receipt of the incentive via a written form. This form (containing your name, address and signature) will be securely retained by Scott Porter Research for the required period (currently 7 years from study completion) and then it will be securely destroyed.

What are the possible risks of taking part?
We hope that taking part won't cause you any harm and we've tried to minimise any harmful effects of taking part. You might be asked questions you find difficult to answer, or you might find out information about breast screening that causes you some concern. If this happens, the researcher will check whether you wish to continue. Details have been provided at the end of this document should you wish to find out more or speak to someone else.

Data Protection information
NHS Health Scotland is the Data Controller for the research study, which means that they are responsible for looking after your information and ensuring it is used properly. Information collected from you as part of the study will be processed by Scott Porter Research and their third-party transcribers (who produce written transcripts of recorded interviews). The information collected will only be used for the purposes of this specific study.

Personally identifiable information is used to help NHS Health Scotland conduct research to ultimately improve health, care and services. As a publicly funded organisation, NHS Health Scotland have to ensure that it is in the public interest when they use personally identifiable information from people who agree to take part in research. This means that when you agree to take part in a research study, they will use your data in the ways needed to conduct and analyse the research study. Your data will be processed only so long as is required for this study.

In order to collect and use your personal information as part of this research, there must be a basis in law to do so. The basis used for the research is 'a task in the public interest'. As we will be collecting some data that is defined in the legislation as more sensitive (information about your health), we also need to let you know that we are applying an additional condition in law: that the use of your data is 'necessary for scientific or historical research purposes'.

During the study, your data will be stored in secure, locked cabinets or secure password protected servers for electronic data with access limited to the research team at Scott Porter Research. To safeguard your rights, we will try to minimise the processing of personal data wherever possible. If we are able to anonymise or pseudonymise the personal data you provide, we will do this at the earliest opportunity. This means that personal details such as your name

and contact details will be removed from the data, and a number will instead be assigned to it. That number will then be used whenever transferring your data (e.g. sending the recording of your interview to transcribers) and/or whenever we may need to refer to it. Only the research team, an approved transcriber (both of whom have agreed confidential and secure data storage systems in place) and select individuals in NHS Health Scotland will have access to the data. Once our quality checks have been completed and/or one month following the completion of the project (whichever is the soonest), we securely destroy any information left on the file which may identify you (e.g. recruitment questionnaires and researcher appointment schedules containing your name and contact details). It is a condition of the funding agreement for this research that NHS Health Scotland can request that any data, documents and material relating to the research be returned to them upon completion of the study, or if earlier, upon termination of the agreement. If this occurs, this will be transferred between Scott Porter Research and NHS Health Scotland via an encrypted device. Electronic and hard copy data will be couriered between the two organisations. Data held in long term storage by NHS Health Scotland will be on secure, password protected servers. Any hard copy or paper data will be stored in a locked cabinet with restricted access. Electronic and hard copy data will be kept for a minimum period of 3 years from study completion then securely destroyed.

Who do I contact if I want more support or information about breast screening?
Should you wish to seek further support/advice about breast screening, please either contact your GP practice or phone the **NHS Inform helpline on 0800 22 44 88.** Alternatively, for further information visit: https://www.nhsinform.scot/healthy-living/screening/breast/breast-screening

Contact details
If you have any concerns or questions about taking party in the study, please contact Alison Miller at Scott Porter Research on 0131 225 0901 or email her at: alison@scottporter.co.uk

If you are still concerned or are unhappy about any aspect of the study, please contact the NHS Health Scotland study lead Nuala Healy, Organisational Lead - Screening and Immunisation, nuala.healy@nhs.net or by phone 07717 816 592 / 0131 314 5367

For enquiries about NHS Health Scotland (the Data Controller) data protection practices, you can contact Duncan Robertson, NHS Health Scotland's Senior Policy, Risk and Data Protection Officer by email at Healthscotland-dpo@nhs.net or by phone on 0131 314 5436.

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO). For information on how to make a data protection complaint you can visit their website (https://ico.org.uk/concerns/) or contact their helpline (telephone: 0303 123 1113).

Thank you for taking the time to read this and considering taking part. Please take this sheet away with you.

SCOTT PORTER
Research & Marketing

Exploring barriers and facilitators to breast screening uptake
Participant Consent Form V3 (11/03/20)

NHS Health Scotland

PARTICIPANT COPY (FOR REFERENCE PURPOSES)

Study number: **2019/20 RE007**
Project title: **Exploring barriers and facilitators to breast screening uptake**
Participant ID No:
Name of researcher:

This consent form is to ensure that you understand the nature of this research and have given your consent to participate. Your participation is entirely voluntary, and you are free to change your mind about taking part at any time. Contact the researchers should you wish to do this.

Please read each of the statements below. If you have any questions, please ask a member of the research team at Scott Porter. Please **initial** to confirm that you've done this and only sign the form when you are happy with ALL statements.

Please initial box

	Statement	Initial
1.	I confirm that I have read and understand the participant information sheet dated 11/03/20 (v3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.	
2.	I understand that my participation is voluntary and that I am free to pull out of the study at any time, either during the interview or afterwards (up to the point my information has been combined with that from other people) without giving a reason and without there being any negative consequences. I understand my medical care or legal rights will not be affected.	
3.	I understand that I do not need to answer any questions that I do not wish to.	
4.	I agree to my interview being audio recorded and direct quotes being used.	
5.	I understand that direct quotations from my interview may be used for research purposes (e.g. research presentation, publications and reports) but my identity will not be revealed.	
6.	I give permission for members of the research team to have access to my anonymised responses.	
7.	I understand my anonymised responses may be transferred to NHS Health Scotland at the end of the study and that my responses will be kept confidential, except in circumstances where there is a serious and immediate concern that you or someone else is at risk of harm.	
8.	I give my permission for members of the research team to use my contact details to re-contact me for quality control purposes.	
9.	I agree to take part in the above study.	

Name of Participant	Date	Signature
Name of person taking consent	Date	Signature

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MRS Evidence Matters™
Company Partner

The Market Research Society (MRS) is the professional body for market and social researchers.

This project is being conducted by Scott Porter Research & Marketing Limited. You can verify this by calling MRS Freephone **0800 975 9596** or visiting the MRS Freephone website:
https://www.mrs.org.uk/standards/online-register

Under the MRS Code of Conduct, you have the right:

- To know the purpose of the interview
- To know who is interviewing you: The Interviewer Identity Card gives the interviewer's name, photograph and organisation
- To end the interview at any point
- To know that any personal information provided will only be used for the purposes about which you have been told

www.mrs.org.uk

SCOTT PORTER
Research & Marketing

Exploring barriers and facilitators to breast screening uptake
Participant Consent Form V3 (11/03/20)

NHS Health Scotland

RESEARCHER COPY

Study number: **2019/20 RE007**
Project title: **Exploring barriers and facilitators to breast screening uptake**
Participant ID No:
Name of researcher:

Please read each of the statements below. If you have any questions, please ask a member of the research team at Scott Porter. Please **initial** to confirm that you've done this and only sign the form when you are happy with ALL statements.

This consent form is to ensure that you understand the nature of this research and have given your consent to participate. Your participation is entirely voluntary, and you are free to change your mind about taking part at any time. Just contact the lead researchers should you wish to do this.

Please initial box

	Statement	Initial
1.	I confirm that I have read and understand the participant information sheet dated 11/3/20 (V3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.	
2.	I understand that my participation is voluntary and that I am free to pull out of the study at any time, either during the interview or afterwards (up to the point my information has been combined with that from other people) without giving a reason and without there being any negative consequences. I understand my medical care or legal rights will not be affected.	
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Name of Participant	Date	Signature
Name of person taking consent	Date	Signature

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