

A qualitative study to determine Kuwaiti Women's knowledge of breast cancer and barriers deterring attendance at mammography screening

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ARTICLE INFO

Article history:

Received 12 July 2018

Received in revised form

14 October 2018

Accepted 20 October 2018

Available online 5 November 2018

Keywords:

Breast cancer

Breast cancer screening

Barriers

Attitudes

Qualitative

ABSTRACT

Introduction: Although a Mammography Screening Service (MSS) has been established in Kuwait since 2014, the attendance rate for eligible women is only 4.2% in comparison to 72.1% attendance in the United Kingdom (UK) mammography screening service. The aim of this study was to determine Kuwaiti women's knowledge of breast cancer (BC), their attitudes toward BCS and the reasons for not attending Mammography Screening (MS).

Methods: A pragmatic qualitative methodology was used which included the use of two focus groups conducted at two women only social organisations in Kuwait with a total of 23 women. One focus group was conducted at a social and cultural organisation; the second focus group took place at a social organisation whose primary role is the improvement of literacy through the use of religious scripture. Thematic analysis was applied to the recorded verbal transcripts from each focus group.

Results: Thematic analysis revealed four major themes, accompanied by a series of subthemes (1) knowledge and awareness of BC health, (2) knowledge of MS (3) personal factors, (4) medical provision and social environment.

Conclusion: Findings suggest that participant's knowledge of BC and the decision to attend MS is influenced by a series of factors both personal and external. An increase in the awareness of BC, MS and the process of accessing MSS will enhance the uptake of MS among Kuwaiti women. Furthermore, doctors and health care providers will need to play a significant role in encouraging women to self-refer.

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Introduction

Breast cancer (BC) is the most common cancer affecting women, with some 508,000 women dying of breast cancer per year, worldwide.¹ In Kuwait, the incidence of BC is 38.3% of newly-discovered cancer cases, with a mortality rate of 27.3%.^{2–4} Mammography screening of an eligible population forms part of an early detection system for BC in asymptomatic women.^{5,6} MS programmes have been established in many countries, with the United Kingdom (UK) being the first country to offer mammography screening for asymptomatic women of eligible age.⁷ A similar MSS based on mammography of an eligible population was established in Kuwait in 2014, providing part of an early detection opportunity for women aged forty years plus.⁸ However, the uptake of MS in Kuwait remains very low at only 4.2% compared to the UK uptake of 72.1%.^{8–11}

Literature review

A literature search was conducted using CINAHL, Medline/PubMed, and Google Scholar to include material published in English between 2000 and 2017. The search terms used included screening/breast/cancer/carcinoma/barriers/and mammography (and derivatives of mammography). A total of thirty articles were identified which detailed factors influencing the uptake of screening mammography.

Previous research has attempted to explore barriers which may exist to prevent women from taking up breast screening opportunities and suggests that ethnic background, cultural influences, religion, individual psychology, physician recommendations, support mechanisms and knowledge of breast cancer and the breast cancer screening process may act as potential barriers.^{12–18}

The previous experience of family members and friend appears to have a significant effect on the decision to attend screening mammography.¹⁸ Storytelling and hearsay evidence of the pain and

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discomfort of screening mammography is identified as a significant negative barrier.^{18–25}

Associated with religious beliefs and differing cultural norms, the act of another person handling an intimate body area also poses a potential significant barrier to uptake.^{18,19,26} Further, the act of undressing and exposure to a stranger, breaching codes of modesty may also act as a potential deterrent for particular communities.^{13–15,21,26,27} The cultural structure of preventative mammography screening may require cultural adaptation to meet the needs of cultural health systems based on symptomatic treatment.²⁶

Many countries, including those with recently developed screening mammography rely on women to self-refer for mammography screening.^{27,28} Such self-referral is often challenging within rural communities which demonstrate lower levels of screening mammography attendance.²⁷ This situation is typically associated with lower levels of education and literacy which prevent engagement with publicity and promotional materials which encourage attendance.^{27,28} Self-referral screening mammography may also be challenging in terms of physical accessibility and finding time to attend.^{18,28} The actions of physician's in explaining the procedure of mammography screening and formally recommending attendance at mammography screening determines a positive attitude towards mammography screening.¹⁴

A belief in folk medicine and the concept of Islamic predestination (fatalism) have been identified as having a significant negative impact on a decision to attend for mammography screening.^{12,13} Predestination refers to the concept that personal health has a religious predetermination and pre-empting the existence of disease is to be avoided.²⁶ Myths and hearsay evidence of the cause of breast cancer being related to envy or 'red-eye' may also act as barriers to attending mammography screening.²⁹

The current study aimed to explore women's knowledge of BC and MSS as well as potential barriers which may act in preventing Kuwaiti women from attending MS.

Method

Study design

The aim of the research, in exploring knowledge, attitudes and experiences determined that a qualitative methodology most appropriate.^{30,31} A qualitative approach allows the researcher to gather a rich, in-depth and meaningful understanding of an individual's beliefs and experiences.³² The data gathered in the current study was thus collated using focus groups and within a pragmatic qualitative methodology.^{33,34} Focus groups provide participants a safe environment and the opportunity to discuss and share thoughts and experiences of a subject.³⁵

Participants

Two focus groups were conducted to explore Kuwaiti women's knowledge of BC, attitudes toward MS and reasons for not attending. To represent knowledge and attitudes from a range of perspectives, the focus groups were conducted in two all women social organisations reflecting differing socio-economic, cultural and religious perspectives. One focus group (12 participants) was conducted at a social organisation whose membership take interest in issues relating to health, media, culture and sport (Focus Group 1). The second focus group (11 participants) took place at a social organisation whose role includes the improvement of literacy (Focus Group 2). All participants were of eligible MS age, yet none had previously presented for mammography screening. The age range of participants in group 1 spanned 41–60 years of age and 55–67 years of age in group 2.

Focus group interviews

The focus group interviews were completed during July 2017 and lasted for 90 min for Focus Group 1 and 75 min for Focus Group 2. Both focus groups were conducted through the medium of Arabic and the entire audio content of focus group discussions were digitally recorded for later transcription. The first author supervised the focus groups alone and was unable to also record any non-verbal communications. A topic guide (Appendix B) was used to provide a degree of content structure and comparability to the focus group discussions.^{12,13} The topic subjects were derived from a review of previous literature.^{12,13,36}

The pilot study

Prior to conducting the focus group sessions, the topic guide was used to direct two pilot study focus groups.³⁷ Two pilot focus group studies were conducted using a convenience sample and included participants from a range of socio-economic backgrounds.

Ethics

Ethical approval for the study was provided by Cardiff University Ethics Committee (School of Healthcare Sciences) in June 2016. The two social organisations provided permission for hosting the focus groups and allowing contact of their respective members. Informed consent was also obtained from women who took part in the study.

Data analysis

The process of transcription of the focus group discussions and subsequent thematic analysis was conducted through the medium of Arabic to ensure that any subtleties in language were captured. To maintain anonymity each focus group participant was assigned a unique identifier. Thematic analysis was conducted using an approach developed by Braun and Clarke in which data is processed through six stages of analysis.³⁸ Thematic analysis involved the researcher reviewing the transcripts on multiple occasions in order to initiate the process of coding, followed by the creation of themes and sub-themes (Fig. 1).³⁸

Results and discussion

The results and discussion have been combined in line with the structure of many qualitative studies³⁹

The four major themes included: (1) knowledge and awareness of BC, (2) knowledge of MS, (3) personal factors, (4) medical service provider and social environment.

(1) Knowledge and awareness of breast cancer

Not all participants had equal knowledge of what BC was, and especially of any potential causes of BC. Those participants from focus group two demonstrated an overall lower knowledge of BC, its manifestations and potential causes. Participants in this later group included women of lower socio-economic status who accessed the social organisation to improve their literacy. Such findings are consistent with the reported literature which indicates that knowledge of BC and MSS is often limited among women of lower socio-economic status, poor literacy and rural habitation.^{27,40} Similarly, Lawal et al. (2015) reported that women with a tertiary education had a greater knowledge of breast cancer, were more likely to engage in breast self-examination and to attend for mammography screening, paralleling the responses from focus group one.²⁸

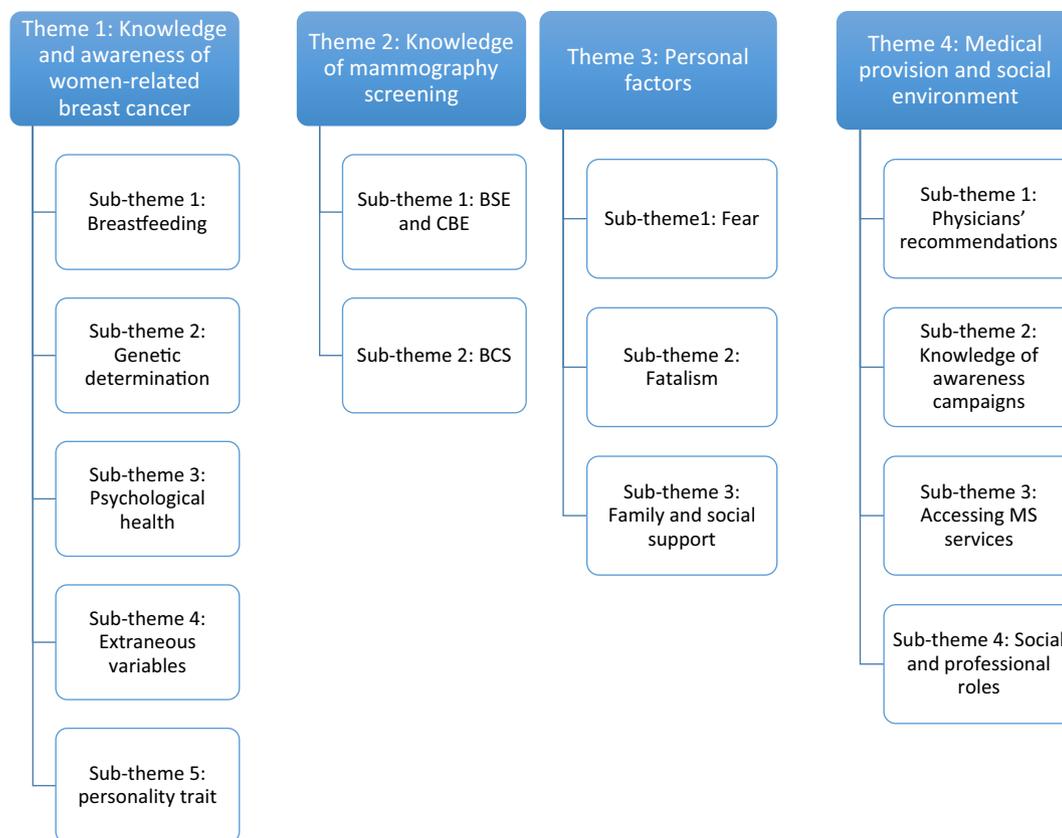


Figure 1. Themes and Sub-themes identified by Thematic Analysis.

Within this general theme of BC knowledge and awareness several sub-themes were identified including:

Breastfeeding

Participants in both focus groups identified the action of breast feeding as a potential preventative action for BC, and would negate any need to attend for MS.

"... breastfeeding is one important way to protect women from developing breast cancer" Participant (P) 8 (Focus group 1)

Not breast feeding and releasing breast milk was identified as a causative agent.

"Breast cancer occurs when the woman does not breastfeed her baby, the milk will be accumulated and ... becomes a tumour". P7 (Focus group 2)

These findings corroborate previous research identifying a failure to breastfeed as a potential cause of cancer and breast disease.^{12,14,16,17,36,41}

Genetic determination

Participants in both focus groups used familial links to reinforce a potential genetic cause of BC.

"... but to develop breast cancer cells the body should have a genetic history" P11 (focus group 1)

"This disease is genetic, my sister died from breast cancer, and my other sister is having chemotherapy now.... I think it is genetic" P8 (Focus group 2)

Such comments regarding the genetic nature of breast cancer have been reflected in the work of Bamidele et al. (2017) who found that despite women being aware of the potential genetic determination of BC, participants still felt that provided they had no symptoms of BC, then they were not at risk of the disease.¹⁷ It was noted from discussions that many of the participants were able to identify maternal links to family members with BC, yet despite this the same participants still remained reluctant to attend MS.

Psychological health

The relationship between stress, anxiety and, in particular, the death of a child, was strongly identified as a potential cause of BC among younger women.

"My aunt lost her son in a car accident, and she developed BC, ... BC is developed after a stressful period". P6 (focus group 1)

"... psychological harm is a reason to develop BC, specially infidelity or having a second wife, or losing a child" P8 (focus group 1)

Psychological factors and stress acting as causative agents were particularly noted in younger women within the focus groups, especially the stress of conceiving a child and fertility issues. Evidence suggests however that there was no evidence for the relationship between breast cancer risk and stressful life events.⁴²

Extraneous variables

Most of the participants in focus group one identified that the pollution resulting from burning oil wells, following the Iraqi invasion of Kuwait in 1990, could be a potential cause of the increase in the number of BC victims in Kuwait.

“... cancer diseases will be widespread among the Kuwaiti population because of the air pollution that resulted from burning 732 oil wells” P6 (focus group 1)

One important environmental factor that was common to women in both focus groups was the belief that screening mammography may be the cause of BC. The findings of this study support earlier research that demonstrates a fear of radiation causing cancer.¹²

“... you will develop BC after the test of breast cancer (mammography) even if you don't have it” P9 (focus group 2)

Cultural determinants of breast cancer included reference to a sedentary lifestyle and poor diet.

“In Kuwait we use cars to go everywhere we do not walk, a reason for developing BC” P7 (Focus group 1)

Again, those participants from both focus groups who claimed to have a healthy diet and followed an active lifestyle felt that this formed a preventative measure against BC and, as such, there was no need to attend for MS.

Personality traits

Individual personality traits were also identified in both focus groups, as a potential cause of BC. Avoiding maleficent behaviour such as being envious, jealous or spiteful and protecting themselves by their religious convictions would act a prevention against developing BC.^{29,43}

“Red eye (envy) and witchcraft are causes of BC” P1 (Focus group 1)

“Red eye was mentioned in the Holy Quran and it could be a reason to develop breast cancer” P2 (Focus group 2)

(2) Knowledge of Breast Cancer Screening

Knowledge of MS itself demonstrated a wide disparity between the two groups, with women in Focus group one having greater knowledge of MS. Indeed, only three women in Focus group one had no knowledge of the MSS programme available in Kuwait. Interestingly, however, women with greater knowledge of MS appeared less keen to attend for screening themselves. Of the women in both focus groups who had no knowledge of MS;

“I don't know anything about breast screening, I thought it is only for sick women to do it” P2 (focus group 2)

“I did not know that there is a screening test. mammography for people who developed BC or have signs of BC” P4 (Focus group 1)

A lack of knowledge of MS was identified as a potential barrier towards self-referral for screening by women of an eligible age. Similarly, Kawar (2013) found that the lack of knowledge about MS acted as a deterrent for many women; the very fact that they did not know what occurred during screening, mixed with piecemeal information from women who

had attended, referring to pressure and discomfort, acted as a barrier to not attending.¹⁵

In describing the process of mammography, most of the participants repeated the words ‘stress’ and ‘pressure’ as an explanation of the MS procedure:

“My friend told me that it is a painful examination, with a pressure on the breast” P2 (focus group 1)

“What I know is that the machine presses each breast” P7 (focus group 2)

Such concern about the pain and discomfort that may be experienced during screening mammography is well documented in literature^{18,20,22,23,25} and is often exaggerated by hearsay and women's talk of previous negative experiences of mammography. Such sharing of negative experience and the resulting fear of an expectation of pain and discomfort has the potential to prevent women from attending^{18,20,22,23,25}

Breast self-examination

During focus group discussion of participant's knowledge of MS, participants also discussed BSE and CBE, which subsequently formed an important sub-theme.

“I do not know how to perform BSE, I just do random touching” P5 (focus group 1)

“I don't know about BSE, I use my hands after the period to search for lumps” P11 (focus group 1)

Although the knowledge of BSE, in general, was higher among focus group 1 participants, more than half in both focus groups had a poor knowledge of how to perform BSE and at what age to perform it. Such poor knowledge of how to perform self-examination correctly has been widely reflected within literature.^{14,17,41,44}

(3) Personal factors

‘Personal factors’ was identified as a major theme preventing individual participants from attending MSS. Fear of discovering BC, fear of having the mammogram itself, fatalism and family history of BC, subsequently formed a series of sub-themes

Fear

Fear was identified as both being afraid of having a mammo-gram and/or the fear of discovering BC. One of the participants showed a lack of trust of the diagnoses of doctors, beside the fear of discovering cancer:

“I am afraid of discovering cancer, I don't trust the accuracy of doctors, they might be wrong” P5 (focus group 1)

“I am afraid of the test itself, it is painful my friend said that she felt her soul went to her breast from the pain” P11 (focus group 2)

Similarly, Davie (2007) found that the fear of what was going to happen during screening mammography as well as disease discovery may both act as potential barriers to attending screening mammography.²⁰ A potential reason for not attending was cited as a lack of trust in the physicians' ability to interpret the imaging. This lack of trust was guided by false positive and false negative results provided in previous medical examinations.

Fatalism

A small number of participants in both focus groups identified fatalism as a barrier to the uptake of MS, identifying that they must accept their directed fate.

“A breast cancer is an affliction from Allah... anything that Allah decides to happen will happen, no matter what we do.” P1 (focus group 2)

“If Allah wants the woman to develop breast cancer, she will develop it” P4 (focus group 2)

While some participants reported their own positive interpretations of fatalism, that Allah directed individuals to take control of their own health, in both social groups there were some women who believed that breast cancer is predetermined and trust in God and reading the holy Quran may act as both a preventative measure and a potential cure.^{13,17,43,44} This strong belief in fatalism has also been reported by Muslim women living outside the Middle East.²⁶

Several participants in focus group 1 stressed that Islam would allow them to uncover intimate body parts for medical examination and that a positive reflection on the concept of fatalism directed them to engage in activities which would preserve health and please Allah:

“If I felt any abnormal symptoms and my doctor advised me to do the breast test I will do it, Allah said: do not throw yourselves into destruction, and do good” P1 (focus group 1)

The concept of having modesty breached during MS and subsequent embarrassment has been widely reported in the literature, yet this was not supported in the current study.^{13,15,46} The reason might be that, in Kuwait, it is recognised that all the screening services are performed by female physicians and health care providers.

Family and social support

Being told of a friend's or family members positive experience of MSS had a significant positive personal impact for some of the participants with a greater tendency to discuss the need for screening and recounting their decision to attend for MS.

“When my sister went to the surgery room to remove the tumour, I saw her doctor and I asked her many questions about BC and she told me about breast screening” P3 (focus group 2)

“I know some friends who attend breast screening every year, some of them said it is painful, but you should go.” P2 (focus group 1)

These findings are consistent with results of a study of Mexican women living in the United States in which women revealed that the positive recommendations of families and friends had a strong influence on their decision to attend for MS.⁴⁷

Any negative testimony of BC care or MS from participant's friends of family members, acted as potential negative barriers to the uptake of MSS.^{13,18,20,22,25,36}

“My friend had a mammography test because she has a lump, she said this the worst test ever, I don't want to do it” P6 (focus group 1)

One participant explained that a very strong family history of cancer in her family had negatively affected her attitude towards attending for MS.

“I have a strong family history of cancer diseases, my brother, my sister, my mother and my father all of them developed cancer. I would not go for screening” P12 (focus group 1)

(4) Medical provision and social environment

The role of the participants' physician in recommending attendance at BCS as well as the accessibility and organisation of MSS formed part of a theme identified as 'medical provision and social environment'.

Physician's recommendations

Despite the fact the physicians have an important role in educating women about the importance of MS and recommending to women the necessity to attend MS, the current study demonstrated that participants felt that physicians are not active in recommending that women attend MSS. This lack of guidance and encouragement to attend acted as a barrier to attend screening opportunities.^{14,36}

“The doctors themselves do not recommend this to women and do not talk to them about breast screening” P3 (focus group 1)

Such lack of physician recommendation to attend screening mammography may allow the development of a role for radiographers in Kuwait, acting as a source of information about mammography screening.²⁵

Knowledge of awareness campaigns

Participants particularly from Focus group 1, identified that they were aware of campaigns aimed at encouraging women to attend for MS, however such campaigns did not appear convincing enough to promote attendance at MSS. Participants in focus group 2 revealed that any awareness campaigns were not suitable for women who could not read or write.

“... they need to educate women who don't read and write ...” P10 (focus group 2)

These findings echo previous studies which indicate that women from rural communities with lower levels of educational attainment and poor literacy who are unable to engage with publicity material, show lower levels of attendance.^{18,27,28}

Accessing breast cancer screening services

Women from both focus groups showed a poor knowledge of the MS programme in current use in Kuwait. Only two participants from the focus group 1 and one participant from the focus group 2 knew how to access screening clinics. Being able to access mammography screening services and identifying a suitable time to attend within a busy lifestyle have been cited as a potential barrier to attendance.¹⁸ Most participants felt that they if they decided to attend for MS that they would simply attend their local hospital facility. None of the participants were aware that women of eligible age could self-refer to MS, or the exact location of MSS clinics in Kuwait.

“If I decide to go for screening, I will go to the gynaecologist and she will give me a request and tell me where to do it” P10 (focus group 1)

Social and professional roles

A busy family, social and/or a professional role were also identified as potential barriers to attending BCS:

“Every day I say tomorrow and then I postpone, I will go, I am planning” P11 (focus group 2)

"I think I am too lazy to go and take an appointment and wait for my turn" P4 (focus group 1)

Similarly, Malhotra, et al.⁴⁷ found that job circumstances and not considering health promotion and disease prevention as primary activities in their daily lives have negatively affected women's attitudes towards breast cancer screening. This suggests a need to offer flexible appointments that would encourage attendance at MS⁴⁸

Quality

Member checking was used to ensure that the transcribed discussions faithfully expressed the opinions and attitudes expressed by participants and thus establish credibility and confirmability.⁴⁹ Dependability or reproducibility of results has been assured by the detailed documentation of the methodology employed.⁴⁹ Transferability has been assured by providing contextual knowledge so allowing comparison to other studies⁵⁰

Conclusion

The discussion within the two focus groups has provided a valuable insight into understanding participant's knowledge of breast cancer and their beliefs and attitudes toward mammography screening. A poor knowledge of breast cancer was identified in both focus groups and this in part was highlighted as a potential barrier to attending breast cancer screening. In addition, personal factors

such as fear of discovering a malignant tumour, fear of mammography, fatalism, and negative experiences of family and friends act as barriers to the uptake of breast cancer screening. The research also highlights the role of physicians in encouraging eligible women to self-refer for MS and the importance of developing appropriate marketing campaigns, dispelling myths of breast cancer screening and encouraging self-referral and attendance.

Conflicts of interest

None declared.

Acknowledgements

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.radi.2018.10.003>.

Appendix B. Topic Guide

Questions	Prompt	Rationale
What do you know about breast cancer? What is breast cancer?	Does anyone have a personal connection with someone who has or has had breast cancer?	Setting the scene Gaining background on knowledge and awareness of breast cancer as a disease Potential for knowledge of breast cancer to influence attitude towards screening
What do you think may be the causes of breast cancer?	Why may you 'get' or develop breast cancer? What have you heard may be the cause of breast cancer? Extraneous variables? Family determinant? Psycho/social causes? Religious/Fatalism/socio-cultural?	knowledge: determining individual participants knowledge of the causes of breast cancer
Can you explain what you understand by the term 'breast screening'? (Mammography Screening) Are you aware of any of the public awareness campaigns for breast cancer screening?	Does anyone know somebody who has attended for breast screening? Did your GP recommend breast cancer screening? Have any of your family or friends been advised to attend screening examinations?	Knowledge: Impact of others experience on individual decision making Knowledge: Potential challenges for those with poor literacy
Questions If you wanted to attend for breast screening would you know how to access a breast screening service?	Prompt If yes, how did you find that information? If no, what do think the problem may be/barrier to access/personnel who may recommend attendance What is the age of breast screening do you think?	Rationale Knowledge: Accessibility to services
Do you know what may happen when you attend for breast screening?	How do you think the 'nurse' or Doctor will take the images?	Knowledge: potential reflection on others/personal experience as a driver or barrier to attend mammography screening
Have any of you friends or family members who have attended breast screening? How was their experience?	Did your friend recommend that you should attend the service? Why? How did they describe the events/experience? What words did they use as descriptors	Knowledge: potential reflection on others/personal experience as a driver or barrier to attend mammography screening
All of you are in the suitable age range for breast screening, are you planning to attend the service? Do you think that receiving extra information about the service and what happens during breast cancer would be useful? And may change your mind to attend?	What are your reasons for attending breast screening? Why may you decide not to attend screening? What could be done to help you make a positive decision to attend? How attending screening could be promoted? What cultural or religious influencers may be used?	Knowledge: personal decision influencers/barriers/ drivers to attending Developing encouragement to attend/future planning/recommendations for service planning
Questions Is there anything else you would like to say about why do you not attend breast screening?	Prompt We are in a safe environment for you to disclose any other reasons for not attending	Rationale Additional material

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