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LIST OF ABBREVIATIONS

ARR  Absolute Risk Reduction
AMI  Australasian Medical Index
AHMAC  Australian Health Ministers’ Advisory Council
APAIS  Australian Public Affairs Information Service
BSA  BreastScreen Australia
EAC  Evaluation Advisory Committee
BCNA  Breast Cancer Network of Australia
CALD  Culturally and Linguistically Diverse
CINALH  Current Index to Nursing and Allied Health Literature
CIRCA  Cultural and Indigenous Research Centre Australia
DCIS  Ductal Carcinoma In Situ
GPs  General Practitioners
IPTAS  Isolated Patients’ Transport and Accommodation Service
IQCA  Interviewer Quality Control Australia
NSW  New South Wales
NT  Northern Territory
RCTs  Randomised controlled trials
RRR  Relative Risk Reduction
RRMAs  Rural, Remote and Metropolitan Areas
Qld  Queensland
SA  South Australia
Tas  Tasmania
WA  Western Australia
Vic  Victoria
# GLOSSARY OF TERMS

<table>
<thead>
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<th>Term</th>
<th>Definition</th>
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<tr>
<td>Accessibility</td>
<td>Level of ease with which women can participate in Program.</td>
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<tr>
<td>Acceptability</td>
<td>Level of satisfaction with the Program among women and/or health professionals.</td>
</tr>
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<td>Active Barriers</td>
<td>A term used in this report to segment women with stridently argued reasons for why they do not participate in mammographic screening. This is in contrast to women with ‘passive barriers’ who simply have low awareness or low motivation to attend (see below).</td>
</tr>
<tr>
<td>Assessment centres/services</td>
<td>BreastScreen Australia services that assess women who have been recalled for further investigation following an initial mammogram.</td>
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<tr>
<td>Availability</td>
<td>Perceptions of whether or not women could theoretically use service.</td>
</tr>
<tr>
<td>Diagnosed and treated</td>
<td>Women who self-report a history of diagnosis of breast cancer as a result of screening and have subsequently been treated.</td>
</tr>
<tr>
<td>EAC project sponsors</td>
<td>Each evaluation project is ‘sponsored’ by up to four members of the EAC. The sponsor role included active involvement in the development of the project and input at key decision points.</td>
</tr>
<tr>
<td>Eligible audience/eligible women</td>
<td>Women aged 40 to 49 and 70+ years who are eligible for free screening through BreastScreen Australia but are not actively targeted by the BreastScreen Australia Program via its communications. NB: see ‘target audience’ below.</td>
</tr>
<tr>
<td>Interval cancers</td>
<td>Breast cancer that is diagnosed in between routine two-yearly screening events, either due to the cancer not having been detected via mammography or to the cancer developing subsequent to the screening mammogram.</td>
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<tr>
<td>Lapsed screeners</td>
<td>Women who self-report having had a mammogram for screening rather than diagnostic purposes in the past, but not in the last two and a half years.</td>
</tr>
<tr>
<td>Never screeners</td>
<td>Women in the eligible age range who self-report never having had a mammogram.</td>
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<tr>
<td>Mobile services</td>
<td>BreastScreen Australia services that are not stationed in one place but move around between locations. The length of time they spend in a given area is determined by the size of the local population and varies from a few days to several months (also described by respondents as ‘buses’ or ‘vans’).</td>
</tr>
<tr>
<td>Term</td>
<td>Description</td>
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<td><strong>Passive Barriers</strong></td>
<td>A term used in this report to segment women whose reasons for not participating in mammographic screening are based on low awareness of the Program or low motivation to attend screening rather than on strongly held beliefs about screening. This is in contrast to those with ‘active barriers’ (see above)</td>
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<td><strong>Proactive GPs</strong></td>
<td>General practitioners who claimed to actively raise the subject of breast cancer screening with female patients and who felt that it was their responsibility to raise awareness of screening, motivate women to attend and answer questions about the procedure and Program.</td>
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<tr>
<td><strong>Reactive GPs</strong></td>
<td>General practitioners who were unlikely to raise the topic of breast cancer screening with patients unless asked. They accepted and endorsed screening mammography but often did not feel it was their role to raise the subject or remind their patient about it.</td>
</tr>
<tr>
<td><strong>Recalled</strong></td>
<td>Women who following a screening mammogram self-report being recalled for further assessment, but subsequently found not to have breast cancer.</td>
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<tr>
<td><strong>Regular screeners</strong></td>
<td>Women who have had a mammogram for screening rather than diagnostic purposes in the last two years.</td>
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<tr>
<td><strong>Static services</strong></td>
<td>BreastScreen Australia services in fixed locations offering year-round screening.</td>
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<tr>
<td><strong>Target audience / target women</strong></td>
<td>Women aged 50 to 69 who are actively targeted by the BreastScreen Australia Program via its communications.</td>
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NOTES ON THIS REPORT

NOTE ON REFERENCING

Two styles of referencing are used in this report. Abstracts that form part of the literature review are referred to by a number in brackets. The abstracts can be found in Appendix A. Articles and data that have informed research design, analysis and interpretation but which did not form part of the review are referenced using footnotes.

References to specific studies have not been included in the executive summary of the literature review in order to not break the flow of the discussion. Each of the studies referred to is included with full referencing in relevant sections of this document.

LITERATURE REVIEW

The literature review was intended to provide a concise summary of the literature found to inform the subsequent Participation Qualitative Research for the BreastScreen Australia evaluation. It was not intended to provide a full academic exploration of all the issues in regards to the BreastScreen Australia Program. Rather, it focused on providing a summary of the analysis and implications for the subsequent qualitative research. As such, it provided the key findings from the literature that relate to evaluation questions from the perspective of the eligible and target audiences (women aged 40 years and over). From this exercise, knowledge gaps, insights and hypotheses were further investigated in the qualitative research, as were any implications for the proposed sample design and discussion structure for the qualitative stage.

QUALITATIVE RESEARCH

Qualitative research deals with relatively small numbers of subjects and explores their in-depth motivations, attitudes, feelings and behaviour. The exchange of views and experiences among participants is relatively free flowing and open, and as a result often provides very rich data that can be broadly representative of the range of views held by the population at large.

The findings however are not based on statistics: they are interpretive in nature, and are based on the experience and expertise of the researchers as they analyse the discussions. While broadly representative of the population at large, they cannot be assigned to a proportion of the population.
RESEARCHERS

Blue Moon Research & Planning, in partnership with Cultural and Indigenous Research Centre Australia (CIRCA), were commissioned to conduct the literature review and Participation Qualitative Research. CIRCA conducted all group discussions with Indigenous women and women from non-English speaking backgrounds and contributed to the analysis of the literature.

ACKNOWLEDGEMENTS

The researchers and Department of Health and Ageing would like to thank the Breast Cancer Network of Australia (BCNA) and BreastScreen Tasmania for their assistance in recruiting some respondents for this research. The nature of their involvement is discussed in section 5.9. We would also like to thank the project sponsors for their input and feedback throughout the process.
1. EXECUTIVE SUMMARY

1.1 BACKGROUND TO THE RESEARCH

BreastScreen Australia was established in 1991. The Australian Health Ministers’ Advisory Council (AHMAC), supported by all the States and Territories, has provided agreement and funding for a comprehensive evaluation of BreastScreen Australia to be overseen by a committee of Australian and international experts. The BreastScreen Australia Evaluation Advisory Committee (EAC) has developed an evaluation plan that will examine the policy as well as the Program’s impact, effectiveness and efficiency.

As part of this broader evaluation, the Participation Qualitative Research sought to explore target and eligible women’s perceptions of BreastScreen Australia, as well as the views of health professionals on the Program. The study was intended to help answer seven of the evaluation questions. The research objectives can be summarised into three broad areas: to understand barriers to, and facilitators of, participation in the Program; to explore perceptions of alternative mammography services and the implications of this for BreastScreen Australia; and to explore the extent to which women understand and are fully informed about the risks and benefits of screening when they make a decision to participate. The impact of BreastScreen Australia communications and media information were also explored in order to address each of these aims.

1.2 RESEARCH OVERVIEW

The research consisted of a literature review followed by an extensive program of qualitative research.

Literature review

Given the amount of research and communication activity that has already been undertaken by both the Australian Government and each state and territory’s BreastScreen Australia services, the qualitative research was preceded by a limited review of relevant grey literature and published articles. This had the aim of identifying key themes and insights, information gaps and determining any implications for the research design. In particular the review was designed to inform the sample structure, qualitative discussion guides and analysis of the subsequent qualitative research.

The Department of Health and Ageing Library, Departmental staff, BreastScreen Australia Program Managers and BreastScreen Australia Recruitment Officers provided seventy-six articles and reports. Blue Moon synthesised the key relevant findings from each into a succinct abstract, before analysing the output.

1 The evaluation questions are listed in section 3.1
Qualitative research

The qualitative research sought to build on the results of the literature review to provide detailed findings on each of the evaluation question topics. The Program consisted of 19 ‘standard size’ group discussions, 13 ‘mini groups’ and 16 in-depth interviews in total. The research was conducted in metropolitan, regional and rural areas across all states and territories in Australia.

The sample included target and eligible women and health professionals. The sample among women included women aged from 40 to 80, a mix of socio-economic backgrounds, women from non-English speaking backgrounds, Indigenous women and women with disabilities. The sample among women was split by usage and experiences of BreastScreen Australia services, and included: regular, lapsed and never screeners; women who had been recalled for further assessment but not diagnosed with cancer; women who had been diagnosed with breast cancer through BreastScreen Australia and subsequently treated; and women who had been diagnosed with cancer in the interval between regular screening events. The sample among health professionals predominantly focused on general practitioners but also included breast physicians, nurse counsellors within the BreastScreen Australia Program and Aboriginal health workers.

Participants were recruited by specialist Interviewer Quality Control Australia (IQCA) accredited recruitment companies, with the assistance of Breast Cancer Network of Australia (BCNA) and Tasmania BreastScreen. BCNA and Tasmania BreastScreen assisted with recruitment of women recalled for assessment but not diagnosed with cancer; women who had been diagnosed with breast cancer through BreastScreen Australia; and women diagnosed with interval cancers.

Analysis and reporting

Analysis was on-going throughout the project as a result of the broad scope of the objectives and the iterative nature of the research program. The approach to analysis was in keeping with international market research industry and social research standards. In the qualitative phase interviewers reviewed tapes or transcripts of the sessions they conducted and analysed the data for key themes and patterns. Researchers conducted a series of analysis sessions with members of the Department and EAC sponsors to discuss findings and their implications for the development of research instruments.

Within the executive summary the findings from the literature review and qualitative research are organised according to the three objectives identified above. The main body of the report is structured by the evaluation questions. The literature review abstracts are referred to throughout the report and are provided in alphabetical order by surname of the first author in Appendix A.

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2 See section 5.4 for the full sample
3 See section 3.2 and the glossary for definitions
1.3 **KEY FINDINGS**

**Barriers to, and facilitators of, participation including availability, accessibility and acceptability**

The literature review identified four key *facilitators* positively influencing women to participate in breast screening: a good appreciation of the benefits of breast screening; a doctors’ recommendation or referral; exposure to communications from BreastScreen Australia, including direct correspondence and mass marketing; and encouragement from family and friends. The qualitative findings supported this. In particular, *regular* screeners tended to see the benefits of screening as outweighing the perceived downsides of participation.

Qualitative findings also provided further detail on specific activities that can be effective in encouraging participation among particular sub-populations with low participation rates. For example, local health workers can have a beneficial impact on screening behaviour among women from sub-populations, such as Indigenous women.

**Barriers to participation** as detailed in this report are split into three categories: those which relate to having a mammogram; those which relate to taking part in screening mammography; and those which relate to the availability, accessibility and acceptability of the BreastScreen Australia service. The literature review indicated that many of the key barriers to participation are not a direct function of the service provided by BreastScreen Australia but relate to factors such as: avoidance of the pain or discomfort involved; fear of results; concerns about the effects of radiation; and low awareness of risk factors for breast cancer.

The qualitative research identified that primary barriers to participation in the Program vary according to attitudes to mammography and breast screening more broadly. Women with *active* barriers have strongly held reasons not to take-up screening. These tend to relate to a mistrust of the procedure due to concerns about the effects of radiation or trauma to the breast and / or an unwillingness to undergo medical interventions in the absence of symptoms. In contrast, many women have *passive* barriers to screening. For these women, the cumulative effect of a wide range of barriers means that the downsides are not outweighed by benefits. The literature review suggested that many of these are not directly related to the BreastScreen Australia Program.

Nevertheless, the qualitative research highlights that several of these factors could be influenced. For example, key misconceptions, such as the lack of awareness of age as a risk factor irrespective of family history and low appreciation of the need for the intervention in the absence of symptoms, could be addressed through national and local communication.

Findings also indicate that women’s perceptions of the discomfort involved can be affected by the extent to which they feel the staff attempt to minimise pain and embarrassment and treat them in a culturally appropriate way. Moreover, women who have *never* experienced mammograms
are sometimes deterred by negative word-of-mouth about the discomfort they can expect to experience, from those who have been screened. It is possible that the impact of this could be minimised by enhancing appreciation of the benefits and reasons to screen.

The literature review also identified that there are barriers relating to the availability, accessibility and acceptability of the BreastScreen Australia service for certain sub-populations. In the literature these are most apparent for: women from non-English speaking backgrounds, especially new arrivals to Australia; Indigenous women; women living in remote areas, especially in the Northern Territory (NT); women with disabilities; and unmarried women. Various issues were highlighted in the literature, including problems with accessing health services and a perceived lack of cultural sensitivity in the services provided by BreastScreen Australia. However, it was not clear from the literature which of these issues are the primary barriers for each of these audiences.

The qualitative research further illuminated barriers to participation in the BreastScreen Australia Program identified in the literature review. The widespread availability of the Program is broadly seen as one of its key strengths. However, some women with disabilities do not have access to screening because they are physically unable to undergo a mammogram. One solution to this suggested in the literature was to screen such women using ultrasounds alone. However, the efficacy of such an approach to screening among asymptomatic women is not supported by clinical evidence.

As expected, access proved to be an important contributory factor leading to the under-representation of women from key sub-populations. Lack of transport was raised as a key issue for women from non-English speaking backgrounds and Indigenous women. Limited opening hours was a barrier for women with inflexible jobs or ‘complex lives’, including many women from lower socio-economic backgrounds. Access to screening at a convenient time and access to assessment services were problematic for women in some remote and rural communities, despite the availability of mobile units in areas that do not have static services. While in practice, access was not a problem for most of the women with disabilities in this sample, findings indicate that some women with impairments may be deterred from attempting to participate because they are not aware appropriate facilities are available.

Levels of satisfaction with BreastScreen Australia services were high overall, including among women who had been recalled and those who had been diagnosed with breast cancer through BreastScreen Australia. There was also a sense among many that the acceptability of the Program has improved over time. However, reports from women and health professionals indicate that service provision can be variable and there are opportunities to raise the levels of acceptability of the service by adopting ‘best practice’ principals nationally.

The literature review identified little information on health professionals’ perceptions of the Program and their referral practices. However, one study in Western Australia (WA) reported 44% of GPs preferred BreastScreen WA over private services and a further 50% with no preference.

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4 For example, see:
This study also indicated that 97% of GPs referred or reminded their patients to have their breasts screened. However, the ‘competing demands of the consultation’ was cited as the key barrier to GPs raising breast screening with patients in the eligible and target population.

GPs in the qualitative research were broadly very supportive of the Program and praised it for being free, available, accessible and acceptable and because GPs are informed of women’s results, despite it being a self-referral service. Proactive GPs felt they had a role in encouraging participation among female patients, while reactive GPs, often older males working in larger bulk-billing practices, admitted they rarely have time to mention breast screening to patients. However, even proactive GPs say they are not able to discuss screening with all women. They attributed this in part to a lack of automated reminders, which means that the topic is not raised routinely. In addition, there were some gaps in GPs’ knowledge about the Program which they felt impaired their ability to promote it effectively. In particular some wanted to know more about the age eligibility criteria. Some, especially male and younger female GPs, also wanted information on the process and procedure of screening, to facilitate discussion with women who are concerned about using BreastScreen Australia for the first time.

The other health professionals, including those who work within and outside the Program, were also positive about BreastScreen Australia overall and identified similar strengths to those mentioned by women and GPs. However, for this group a key weakness of the service was seen as the time taken for women to receive results in remote and regional areas, and lack of assessment services in some parts of the country. Findings among this audience, supported by findings among target and eligible women, also highlighted variability in approaches and protocols between services, for example in terms of the recall process and on informing women about the risk of interval cancers.

**Factors leading to screening outside the Program**

Few studies included in the literature review identified perceptions of private services. One market research report in Victoria identified that women used private services with the expectation of receiving the results on the same day. Another study with GPs found that only 7% preferred private services over BreastScreen Australia. However, GPs who preferred BreastScreen Australia indicated that cost was the main reason not to recommend private services, though there was an expectation among some GPs that the service would be of higher ‘quality’.

The qualitative research found that many women who used private services for screening mammography did so because they had previously undergone diagnostic mammography at a particular clinic and wanted to continue to use this familiar service. Faster results, convenience and the availability of ultrasounds as a routine part of the process and / or the availability of ultrasounds on the same day as the mammogram were also factors. In some cases, women aged 40 to 49 reported using private services because they and / or their GP are not aware that they are eligible for free screening through BreastScreen Australia. In addition, a small number of GPs admitted they encourage women to use private services because they have links with private radiology clinics.
Many women in the qualitative sample felt that the quality of the service provided by BreastScreen Australia would be at least as good, if not better than, that of private radiology services since this is a specialist breast screening service. However, some women believed that private services provide a better quality service, either because they offer routine ultrasounds or because these women assume a paid-for service must be superior to a free service. In particular, women who had experienced an interval cancer following screening tended to express these views, as some had lost confidence in the quality of screening through the Program.

The literature review highlighted the difficulties in identifying whether women have used BreastScreen Australia or private services. Several questions to identify previous screening behaviour were therefore developed for use in the respondent recruitment process and during discussions in the qualitative research. Findings indicated that women in some areas were less likely to be aware of the BreastScreen Australia brand, and hence did not know whether they had used private services or not, whereas in other areas women were much more familiar with the brand. Awareness was lower in some large metropolitan areas where there are a number of services and in jurisdictions where local marketing activity is less intense. Women from Indigenous and non-English speaking backgrounds had particularly low awareness of the brand. This may be due to language barriers or lack of familiarity with Australian health services, although it should be noted that many of the groups among women from these audiences took place in locations where women in the main sample also had low awareness of the BreastScreen Australia brand. In addition, some doctors admitted to referring women to private services for ‘diagnostic’ mammography when they require screening mammography, in order to enable the patient to claim the Medicare rebate. The BreastScreen Australia participation rate may not therefore accurately reflect the proportion of women in the target and eligible populations who undergo regular screening mammograms.

**Understanding of the potential harms and benefits of screening and the ‘informed consent’ debate**

Some studies in the literature review indicated that many women are not currently well informed about risk factors for breast cancer. These indicate that women tend to over-estimate the importance of family history and under-estimate age as a major risk factor. The review indicated that the media, especially women’s magazines, are a key source of information about breast cancer for target and eligible women. These tend to focus on young women with breast cancer, especially celebrities, which contributes to a perception that breast cancer is common among younger women. As a result, women often question why the Program targets women aged 50 – 69.

Three articles in the review indicated that the way in which information about breast screening is framed affects support for screening. The authors of these studies argue that women’s varying perspectives on breast screening when information on the benefits is presented in different ways means they do not fully understand the potential harms and benefits associated with breast screening. However, other studies indicate that regular screeners enjoy the benefit of feeling that they are maintaining their health by taking part in screening.
The qualitative findings supported the literature review in terms of women’s understanding of the risk factors for breast cancer, potential harms associated with breast cancer and the benefits of screening. In addition, the qualitative research sought to gain insight into three issues raised in the literature review, in relation to the ‘informed choice’ debate. These were: the potential for unnecessary anxiety to be caused by recall that does not lead to diagnosis; the risk of interval cancers occurring in between screening; and the possibility of treatment of breast disease that may not progress (such as low-grade ductal carcinoma in situ). Women were asked whether they were aware of any potential harms and discussion of the first two issues were then prompted. Furthermore, women who were recalled, women who were diagnosed through the Program and women who had been diagnosed with interval cancer were asked about their experiences and perceptions of the Program as a result.

Women who had been recalled and not diagnosed reacted in very different ways to the experience. Some said they had been very anxious while others were not particularly concerned. In some cases women had been told that there is a high chance that further assessment will not lead to a breast cancer diagnosis whereas others had not. Importantly, many women and all health professionals felt that this information had the capacity to reduce anxiety levels significantly.

Some women were aware that breast screening does not pick up all cancers and/or that interval cancers may occur in between screens. For a minority, this affected their perceptions of the efficacy of the intervention. However, others appreciated that many medical procedures are not completely failsafe and were happy to continue to screen nevertheless. Some of those who were aware of the issue had heard about this through BreastScreen Australia. In other cases women personally knew people who had experienced interval cancers.

None of the women in the qualitative sample who had experienced interval cancers had delayed reporting symptoms to the doctor when they noticed them. However, some felt they had not been fully aware of the need to be ‘breast aware’ in between screens and felt that this information should be more clearly communicated to all women. Many commented that they had not been interested in reading information on this, or any other, topic when they screened and therefore felt the message should be conveyed more clearly. Suggestions for how this could be achieved included imparting the information verbally or via a single message on a prominently displayed poster.

Health professionals agreed that it is important to convey information on both these issues to women who screen, to minimise anxiety and ensure that symptoms that are noticed following screening are reported. However, there was some confusion about whose role it is to impart this information and at what point in the process women should be provided with this. A standardised approach to communication across jurisdictions could therefore be considered.
None of the women raised concerns about treatment of cancer that may not progress and the health professionals unanimously agreed it would be counterproductive to discuss this with patients at any point in the process. They commonly felt that most women would prefer to be treated whether or not the cancer might have progressed. Moreover, several argued that a ‘wait and see’ approach is not appropriate for breast cancer because no one knows which cancers will progress or how quickly the disease may spread.

1.4 SUMMARY OF CONCLUSIONS

The BreastScreen Australia Program has many strengths and was widely praised by many women and health professionals in the qualitative research because it is broadly available, accessible and acceptable for a large number of women in Australia. In addition, many felt that BreastScreen Australia communications had been effective in encouraging them to participate and informing them about the process. However, several opportunities to improve the Program and enhance participation have been identified and have been grouped under five key issues below.

**Issue 1: Appreciation of the relevance and benefits of screening mammography**

Many Lapsed and never women do not have a good appreciation of the benefits of screening mammography or why screening is important for them personally. Moreover the barriers are often more top-of-mind than the benefits. There is therefore an opportunity to communicate to all women that screening is personally relevant to them, and that the advantages outweigh the downsides.

**Issue 2: Awareness of the Program and the BreastScreen Australia brand**

Findings indicate that there are opportunities to ensure all women are aware of the Program and ideally also the BreastScreen Australia brand. This could be achieved through direct and mass marketing as well as by assisting GPs and other health professionals in routinely discussing the topic with patients.

**Issue 3: Perceived availability and accessibility**

The availability of the Program is widely seen as one of its strengths. However, perceptions of the accessibility of services could be enhanced for some women, for example by communicating with them about transport options or reviewing opening hours for some services. Consideration could also be given to communicating about the reasons for the time taken for results to be delivered, as well as the lack of evidence-based alternatives to mammographic screening for women who are unable to undergo mammograms.
Issue 4: Experience of the service

While many women in the qualitative research were highly satisfied with the service, experiences could be optimised in order to encourage re-screening. This could include ensuring mammography staff are aware of the importance of appearing to minimise discomfort and embarrassment and developing service protocols for women attending screening for the first-time as well as for women from non-English speaking backgrounds, Indigenous women and women with a disability.

Issue 5: Information needs and informed consent

Although most women feel well informed about screening mammography when they participate, not all regular screeners are fully aware of: the process the first time they screen; the low rate of diagnosis among women who are recalled for further investigation through BreastScreen Australia, which can cause unnecessary anxiety; and the importance of reporting symptoms of breast cancer to the GP in between regular screens because of the potential for interval cancers to occur. Findings indicate that raising awareness of all these issues could enhance the degree to which women are fully informed about screening mammography.
2. BACKGROUND TO THE RESEARCH

2.1 OVERVIEW

Breast cancer is responsible for more deaths among women than any other cancer in many countries, including Australia. Results from randomised controlled trials (RCTs) conducted in the US, Canada, UK and Sweden in the 1980s indicated that population level mammographic screening might significantly reduce mortality from the disease, through early detection and treatment\(^5\). BreastScreen Australia is a national screening program that was set up in 1991 following 11 successful pilots across Australia. The BreastScreen Australia Program is managed in each State and Territory, with the Commonwealth taking an overall leadership role in policy direction and funding.

The target population for the Program is asymptomatic women aged 50-69. Women aged 40-49 and 70+ are also eligible for free mammograms through BreastScreen Australia, although they are not targeted by the Program communications or actively invited to attend. BreastScreen Australia has been supported by a series of campaigns at both the national and State level, aimed at driving take-up of the service. Sara Henderson, a pioneering cattle-station owner and motivational speaker, featured in the national campaign from 1995 until her death from breast cancer in 2005. There have been no national campaigns since then, although in 2006 NSW launched a ‘cherry and pea’ television commercial voiced by the former SBS news presenter Mary Kostakidis and in 2007 Queensland launched a campaign featuring Jana Wendt.

In 1991 a target participation rate of 70% of women aged 50-69 screening at two-yearly intervals was set for the Program. This was anticipated to be the rate at which the Program would provide optimal outcomes in terms of reduced mortality. In 2003-04 over 1.6 million women were screened in the Program. Of these, 1.1 million (70%) were in the target age group of 50-69 years. The participation rate among women in Australia in the target age group was 55.6% (i.e. 55.6% women participated two-yearly), with lower participation among some sub-populations, notably women from non-English speaking backgrounds, Indigenous women, and women living in very remote areas (though there is likely to be some overlap between the latter two audiences). Previous qualitative research identified that a spectrum of attitudes to breast screening exists, including active rejection, passive non-participation, passive compliance and active compliance\(^6\).

While the participation rate for BreastScreen Australia is just over half of the target population, in 1997-98\(^7\) an estimated 87.1% of women in NSW aged 50-69 said they had ever had a mammogram. This may be explained by some women who do not participate in the BreastScreen Australia Program receiving mammograms through private radiology services, either for screening or diagnostic purposes. Moreover some women may be lapsed or infrequent screeners. Others make use of the Medicare rebate (either through bulk billed services or patient claiming) available

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\(^6\) Blue Moon (2006), ‘BreastScreen Australia Communication Needs’
for diagnostic mammograms with a doctor’s referral on the basis of family history or suspicion of breast cancer. Research and anecdotal evidence suggest that women may not always know which type of service they have used.

BreastScreen Australia was established in 1991 and in 2006 the Australian Health Minister’s Advisory Council (AHMAC), provided agreement and funding for a comprehensive evaluation of BreastScreen Australia to be overseen by a committee of Australian and international experts. The BreastScreen Australia Evaluation Advisory Committee (EAC) was established to oversee the evaluation.

The evaluation will review BreastScreen Australia policy and identify the impact, effectiveness and efficiency of the Program. Findings will be used to identify directions for the Program into the future. Ten separate projects to address the evaluation objectives will be conducted and these will be synthesised into one report at the end of the process. One of these projects is the Participation Qualitative Research.

2.2 THE NEED FOR RESEARCH

The Participation Qualitative Research was intended to address some of the key evaluation questions relating to perceptions of the Program among eligible and target women and health professionals. This was the only one of the ten projects within the evaluation that sought to canvass the views of these audiences. Findings will feed into the overall evaluation and will be used to provide guidance on how participation rates across the target groups can be improved.

The qualitative study was preceded by a review of existing grey literature and published articles. Blue Moon Research & Planning, in partnership with the Cultural and Indigenous Research Centre Australia (CIRCA), were commissioned by the Australian Government Department of Health and Ageing to conduct the literature review and Participation Qualitative Research. CIRCA conducted all group discussions with Indigenous women, Aboriginal health workers and women from non-English speaking backgrounds.
3. OBJECTIVES

3.1 EVALUATION QUESTIONS

The Australian Health Ministers’ Advisory Council (AHMAC) endorsed the following objectives for the evaluation:

- assess the outcomes delivered by the Program;
- assess the extent to which the Program has achieved its aims and objectives;
- assess the appropriateness, efficiency and effectiveness of the Program;
- assess, and address the ongoing and unresolved issues impacting on the Program; and
- identify opportunities to improve the Program overall.

To achieve its objectives, the evaluation will consist of a range of evaluation projects aimed at assessing:

- health outcomes – the benefits and risks of the Program;
- process outcomes – efficiency of the implementation of the Program; and
- economic outcomes in relation to the cost-utility, cost-benefit and cost-effectiveness of the Program.

The Participation Qualitative Research as a whole was intended to assess the perceived availability, accessibility and acceptability of the BreastScreen Australia Program to women and service providers. Findings will help answer seven of the EAC’s evaluation questions.\(^8\) These are as follows:

- What are the factors that discourage participation? What are the implications of this for the Program?
- To what extent is the Program available and accessible to all eligible women, in particular to sub-populations of women where the participation is lower than the national average?
- To what extent is the Program acceptable to women and other stakeholders (e.g. health professionals)?
- What are the factors contributing to women choosing mammography outside the Program?
- What impact have BreastScreen Australia communication activities had on participation rates?
- What impact has the Program had on breast cancer morbidity?\(^9\)
- Do the current BreastScreen Australia communication mechanisms help women to make an informed choice about screening and re-screening?

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\(^8\) Evaluation questions may be addressed in full or in part by an individual project.
\(^9\) The focus for this research is on women’s understanding of the risks and benefits of screening.
3.2 OVERALL QUALITATIVE RESEARCH OBJECTIVES

Research objectives were developed with the intention of generating insights to help answer the evaluation questions. The overall objectives among target and eligible women were to identify:

- factors that facilitate and discourage participating in screening;
- perceptions of the availability and accessibility of BreastScreen Australia services and how these could be improved;
- views on the acceptability of the Program and opportunities for improvement;
- reasons for choosing private mammography, including views on the quality of services provided by BreastScreen Australia and private services;
- reactions to communications and information on the Program from all sources, including BreastScreen Australia, the media and word-of-mouth;
- women’s understanding of the benefits of participation, including reduced mortality, morbidity and the reassurance gained from an ‘all clear’ result;
- women’s understanding of the risks of participation, including the potential for physical and psychological harm due to further investigations and being recalled for further tests and treatment, and financial costs; and
- the extent to which women feel they make an ‘informed choice’ regarding participation in the Program.

The overall objectives among health professionals were to explore:

- screening referral practices and perceptions of breast screening services among general practitioners;
- communication needs, level of support for, and concerns of health professionals who refer to the Program, such as general practitioners (GPs); and
- Breast physicians’, Aboriginal health workers’ and nurse counsellors’ insights into women’s views on the Program, their understanding of its risks and benefits and the impact on women of being recalled for further tests and treatment.

3.3 LITERATURE REVIEW OBJECTIVES

A limited literature review was conducted to explore existing knowledge and data that was expected to be of assistance in answering the evaluation questions. The review was limited in focus, as there were constraints due to available time and budget. Rather than attempting a full academic exploration of all issues, the review sought to identify key themes, insights, information gaps and hypotheses that could be tested in the subsequent Participation Qualitative Research.

To ensure continuity with the qualitative research, the focus of the review was further limited to studies where the perspectives of women in the target audience on the identified research objectives were discussed.
Specific objectives were to identify from the literature reviewed:

- key themes and insights;
- information gaps and hypotheses for further testing; and
- implications for the design of the Participation Qualitative Research, in terms of appropriate sample structure, design of discussion guide and analysis.

3.4 DETAILED RESEARCH OBJECTIVES

The process of developing objectives

Detailed research objectives within each evaluation question area were developed following the literature review and in consultation with the Department of Health and Ageing (the Department) and the EAC project sponsors\(^\text{10}\). The research team worked closely with the Department and project sponsors throughout the project and conducted the following sessions:

- an analysis workshop to discuss the literature review and implications, with members of the Department and one of the EAC Participation Qualitative Research sponsors;
- a presentation workshop of the literature review findings with members of the Department and project sponsors;
- a teleconference to discuss possible issues that might arise in the research with Program Managers from a range of jurisdictions;
- an analysis session to discuss key findings and implications with members of the Department;
- a presentation of the main qualitative research findings to members of the Department and project sponsors.

The objectives for each evaluation question area are listed below. The headings used correspond to those in the body of this report. Assumptions relating to the terms used and how they have been interpreted for the purposes of analysis are included in the introduction to each section.

It should be noted that there is a degree of cross-over between the issues highlighted in each section. This is because each is intended to refer to all the findings relating to the relevant evaluation question. The executive summary pulls the themes together to provide a coherent overview of the issues.

Factors that facilitate and discourage participation

To explore among women:

- what facilitates participation among regular screeners;
- which barriers are primary reasons for non-participation among lapsed and never screeners;
- whether barriers relate equally to diagnostic mammography for lapsed and never screeners;

\(^{10}\) Each evaluation project is ‘sponsored’ by up to four members of the EAC. The sponsor role included active involvement in the development of the project and input at key decision points.
• which barriers *lapsed* and *never* screeners relate to:
  – having a mammogram;
  – participating in screening mammography;
  – the service provided by BreastScreen Australia;
• how far ‘pain’ or ‘discomfort’ is a primary barrier for *lapsed* and *never* screener and what is being done to mitigate this;
• how women who have been diagnosed with interval cancers feel about screening and BreastScreen Australia as a result of their experiences; and
• how all of these issues differ by sub-populations.

To explore among health professionals:
• whether general practitioners and Aboriginal health workers acknowledge their role in encouraging the take-up of screening;
• barriers to discussing breast screening with patients;
• what target and eligible patients say to them about their experiences; and
• at what age doctors discuss breast screening with their patients and why.

The perceived availability and accessibility of the Program

To explore among women and health professionals:
• awareness of, and knowledge about, the BreastScreen Australia Program;
• perceptions of availability of the Program across audiences, especially in rural and remote communities; and
• how far accessibility (versus acceptability and other barriers) is an issue for:
  – women from lower income groups;
  – women from non-English speaking backgrounds;
  – women in Indigenous communities; and
  – women with disabilities.

The perceived acceptability of the Program

To explore among women:
• broad levels of satisfaction with the Program across Australia and among different sub-populations;
• the impact of perceptions of the service on re-screening;
• the extent to which physical and emotional discomfort are perceived to be minimised within the Program;
• how women who have been recalled for further tests and / or treatment feel about how this was handled;
• how women who have been diagnosed with interval cancers feel about the Program;
• the extent to which the service is, or is expected to be, acceptable to women with disabilities; and
• who influences expectations and perceptions of the acceptability of the service.

To explore among health professionals:
• perceptions of the Program from their perspective; and
• what patients / clients say to them about the Program.

Factors that lead to women choosing screening mammography outside the Program

To explore among women:
• how private services are perceived by women who have used them;
• perceptions of private services among those who have not used them; and
• reasons for using private screening.

To explore among health professionals:
• referral practices of GPs, including exploring referral to private providers; and
• health professionals’ perceptions of private services compared with BreastScreen Australia services.

The impact of BreastScreen Australia communication activities

To explore among women:
• broad responses to BreastScreen Australia communication materials;
• how far awareness and interpretation of communications varies by sub-populations;
• whether expectations of the experience were set prior to having a first mammogram, and the impact of this on perceptions of the service;
• what information women with interval cancers were provided with by BreastScreen Australia about the potential for cancers to occur in-between screening events and how they now feel about this information; and
• whether women from non-English speaking backgrounds have come into contact with language specific materials and whether this affected their perceptions of BreastScreen Australia, or could do so.

To explore among health professionals:
• how they feel about the way in which BreastScreen Australia communicates with them;
• whether they have any other communication needs; and
• how they feel about the information they are provided with from BreastScreen Australia on recalled patients.
Women’s understanding of the risks and benefits of screening

To explore among women:
- perceived risk factors for breast cancer;
- perceptions of the prevalence of breast cancer in Australia; and
- perceived benefits and risks of breast cancer screening;

To explore health professionals’ experiences of women’s perception of:
- the risk factors for breast cancer; and
- the benefits and risks of breast cancer screening.

The extent to which women make an ‘informed choice’

To explore among women:
- the extent to which women from all sub-populations feel they have made an informed decision about whether or not to screen;
- how women who were recalled / diagnosed with cancer / diagnosed with interval cancer felt about the information they were provided with; and
- whether women have heard of ‘informed choice’ and how they feel about this in relation to breast cancer screening.

To explore among health professionals:
- knowledge of the ‘informed choice’ debate and how they feel about this in relation to breast screening, and
- views on the specific issues in the informed choice debate:
  - potential for uncovering illness that would not have progressed;
  - potential for creating unnecessary anxiety over recalls for further tests when cancer is not diagnosed; and
  - potential for interval cancers to occur between screening and the implications of this.
4. LITERATURE REVIEW METHODOLOGY

4.1 APPROACH TO SOURCING DATA

The Department sourced seventy-six relevant articles and unpublished reports in the English language from 2000 onwards. The search was conducted in September 2007. A combination of searching computerised bibliographic databases and collecting information from Program Managers in each jurisdiction was used. Blue Moon also conducted a short search using the internet and computerised bibliographic databases but did not find any additional articles that were relevant to the study. All searches focused on data on women and health professionals’ perceptions, knowledge and behaviour in relation to each of the relevant evaluation questions.

The databases searched were: Medline (health and medicine); Embase (health and medicine); CINAHL; AMI (Australasian Medical Index); APAIS, Business Source Premier; and Catalogue of the Health and Ageing portfolio libraries. The search terms used were: Breast cancer; screening; mammography; BreastScreen; and Australia.

4.2 APPROACH TO DATA MINING

Blue Moon generated a descriptive abstract of each document, detailing the reference, objectives, methods and sample / participants, main results and conclusions of the study. Abstracts can be found as an appendix to this document (Appendix A). These are listed in alphabetical order by author. Throughout this report, abstracts are referred to using a number in brackets. This approach has been adopted (rather than standard referencing systems) to assist the reader in finding relevant abstracts. In addition, each abstract includes a cross reference to the evaluation question(s) that it helps to address.

4.3 ANALYSIS

Once the data was collected, mined and organised into the data summary document, an analysis session was conducted among Blue Moon and CIRCA executives, an EAC sponsor and members of the Department. Each had read all the abstracts and contributed to a discussion on key themes that had emerged and the implications the review had for the Participation Qualitative Research. This was followed by a workshop at which Blue Moon presented the key findings to the Department and the EAC sponsors, which provided an opportunity to conduct further analysis and interpretation of the data. The analysis has been organised into findings relevant to each of the key evaluation questions. Literature review findings precede the qualitative research findings for each question area.
5. QUALITATIVE RESEARCH METHODOLOGY

5.1 OVERVIEW

The methodology, including the sample and discussion content, evolved following the literature review and discussions with members of the Department and BreastScreen Australia Program Managers. A program of 19 ‘standard size’ groups, 13 ‘mini groups’ and 16 in-depth telephone interviews were conducted in total. These represented the target audiences identified in the brief:

1. Target and eligible women, aged 40 and over:
   • from all jurisdictions, including metropolitan, regional, rural and remote areas;
   • from Indigenous communities and non-English speaking backgrounds;
   • who are regular screeners (regular), lapsed screeners (lapsed) and women who had never screened (never);
   • who have been recalled for further assessment of a screen detected abnormality on a subsequent day to the original screen and were not subsequently diagnosed with breast cancer (recalled);
   • who have been recalled for further assessment, were diagnosed with breast cancer as a result of screening and have been treated (diagnosed and treated);
   • who have been diagnosed with breast cancer in-between two-yearly screening events (interval cancers); and
   • who had disabilities that might present access barriers to screening.

2. Health Professionals:
   • general practitioners (GPs);
   • Aboriginal health workers;
   • breast physicians; and
   • nurse counsellors.

5.2 RATIONALE FOR THE METHODOLOGY

Qualitative research was used to allow for a full and detailed identification of the issues. Group discussions were adopted as the primary methodology for this project as, in our extensive experience of conducting research on sensitive subjects, we have found people often feel more comfortable taking part in groups with others who are in a similar situation to them. Moreover, group discussions allow ideas and experiences to be exchanged and provide a conducive environment for the use of projective techniques, which can also be useful when discussing sensitive subjects.

11 Standard groups comprised approximately eight participants and mini-groups approximately four.
12 Refer to glossary for the project definition of these groups of women.
13 Breast physicians are registered medical practitioners with training in the diagnosis and management of benign and malignant breast disease.
Group discussions with general practitioners were conducted as this is a highly cost and time efficient, approach. Individual in-depth interviews were conducted in situations where these were more efficient for the following reasons: because of the location of respondents; in situations where it would have been difficult to gather respondents together; and where there was a need to explore views of people with specific roles in the breast screening process individually, such as with breast physicians and nurse counsellors.

5.3 THE SAMPLE

The sample was as follows:

Table 1: Group discussions among target and eligible women

<table>
<thead>
<tr>
<th>GP</th>
<th>Segment</th>
<th>Screening history</th>
<th>Group size</th>
<th>Age</th>
<th>SES</th>
<th>Location</th>
<th>State</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>General Population (including women from established non-English speaking communities)</td>
<td>Lapsed / Never</td>
<td>Standard-group</td>
<td>50-69</td>
<td>Higher</td>
<td>St. Leonards</td>
<td>NSW</td>
</tr>
<tr>
<td>2</td>
<td>40-59 Lower Adelaide SA</td>
<td></td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>3</td>
<td>45-65 Lower Perth WA</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>50-69 Higher Canberra ACT</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>60-75 Mix Bendigo VIC</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>6</td>
<td>50-69 Mix Maroochydore QLD</td>
<td></td>
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<tr>
<td>7</td>
<td>General Population</td>
<td>Regular (BreastScreen Australia and Private)</td>
<td>Standard-group</td>
<td>50-69</td>
<td>Mix Bendigo VIC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>50-69 Mix Bendigo VIC</td>
<td></td>
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<tr>
<td>9</td>
<td>50-69 Higher St. Leonards NSW</td>
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<tr>
<td>10</td>
<td>60-75 Lower Darwin NT</td>
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<tr>
<td>11</td>
<td>45-65 Mix Perth WA</td>
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</tr>
<tr>
<td>12</td>
<td>Recalled but no treatment required</td>
<td></td>
<td>Mini-group</td>
<td>40-59</td>
<td>Mix St. Leonards NSW</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>45-69 Mix Adelaide SA</td>
<td></td>
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</tr>
<tr>
<td>14</td>
<td>55-75 Mix Bendigo VIC</td>
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<td></td>
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<tr>
<td>15</td>
<td>Diagnosed and treated</td>
<td></td>
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<tr>
<td>16</td>
<td>50-69 Mix Hobart TAS</td>
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<tr>
<td>17</td>
<td>Women with disabilities</td>
<td>Regular, Lapsed, Never</td>
<td></td>
<td>50-69</td>
<td>Mix Melbourne VIC</td>
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</tbody>
</table>

14 Only two respondents attended this group so it was supplemented with telephone in-depth interviews with women living in Melbourne.
### Table 2: Groups discussions among women from non-English speaking backgrounds and Indigenous communities

<table>
<thead>
<tr>
<th>GP</th>
<th>Segment</th>
<th>Screening history</th>
<th>Group size</th>
<th>Age</th>
<th>SES</th>
<th>Location</th>
<th>State</th>
</tr>
</thead>
<tbody>
<tr>
<td>18</td>
<td>Chinese (in Mandarin)</td>
<td>Lapsed / never</td>
<td>50-69</td>
<td>Mix</td>
<td>Sydney</td>
<td>NSW</td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>Lebanese (in Arabic)</td>
<td></td>
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<tr>
<td>20</td>
<td>Iraqi (in Arabic)</td>
<td></td>
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</tr>
<tr>
<td>21</td>
<td>Vietnamese (in Vietnamese)</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>22</td>
<td>Greek (in Greek)</td>
<td></td>
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</tr>
<tr>
<td>23</td>
<td>Indigenous women (in English with assistance from local bi-lingual moderators)</td>
<td>Lapsed / regular</td>
<td>50-69</td>
<td>Mix</td>
<td>Ceduna</td>
<td>SA</td>
<td></td>
</tr>
<tr>
<td>24</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>26</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Table 3: Telephone in-depth interviews with women in the target age range in remote areas

<table>
<thead>
<tr>
<th>DTH</th>
<th>Segment</th>
<th>Screening history</th>
<th>Age</th>
<th>SES</th>
<th>State</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>General population</td>
<td>Lapsed / never</td>
<td>50-59</td>
<td>Lower</td>
<td>WA</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td>60-69</td>
<td>Higher</td>
<td>QLD</td>
</tr>
</tbody>
</table>

### Table 4: Mini-Group discussions with General Practitioners

<table>
<thead>
<tr>
<th>GP</th>
<th>Profession</th>
<th>Location</th>
<th>State</th>
</tr>
</thead>
<tbody>
<tr>
<td>M1</td>
<td>General practitioners</td>
<td>St. Leonards</td>
<td>NSW</td>
</tr>
<tr>
<td>M2</td>
<td></td>
<td>Hobart</td>
<td>TAS</td>
</tr>
<tr>
<td>M3</td>
<td></td>
<td>Canberra</td>
<td>ACT</td>
</tr>
<tr>
<td>M4</td>
<td></td>
<td>Perth</td>
<td>WA</td>
</tr>
<tr>
<td>M5</td>
<td></td>
<td>Darwin</td>
<td>NT</td>
</tr>
<tr>
<td>M6</td>
<td></td>
<td>Maroochydore</td>
<td>QLD</td>
</tr>
</tbody>
</table>

### Table 5: Telephone in-depth interviews with other health professionals

<table>
<thead>
<tr>
<th>DTH</th>
<th>PROFESSION</th>
<th>LOCATION</th>
<th>STATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>D1</td>
<td>Breast physicians</td>
<td>Regional</td>
<td>NSW</td>
</tr>
<tr>
<td>D2</td>
<td></td>
<td>Metro</td>
<td>QLD</td>
</tr>
<tr>
<td>D3</td>
<td>Aboriginal health workers</td>
<td>Remote</td>
<td>NT</td>
</tr>
<tr>
<td>D4</td>
<td></td>
<td>Metro</td>
<td>QLD</td>
</tr>
<tr>
<td>D5</td>
<td>Nurse counsellors</td>
<td>Metro</td>
<td>QLD</td>
</tr>
<tr>
<td>D6</td>
<td></td>
<td>Metro (with regional coverage)</td>
<td>WA</td>
</tr>
</tbody>
</table>
Table 6: Interviews with women who have experienced interval cancers

<table>
<thead>
<tr>
<th>DTH</th>
<th>Last screening service used</th>
<th>Interview type</th>
<th>Location</th>
<th>State</th>
</tr>
</thead>
<tbody>
<tr>
<td>D1</td>
<td>BreastScreen Australia</td>
<td>Individual face to face</td>
<td>Metro</td>
<td>NSW</td>
</tr>
<tr>
<td>D2</td>
<td>Metro</td>
<td>Metro</td>
<td>Metro</td>
<td>NSW</td>
</tr>
<tr>
<td>D3</td>
<td>Individual telephone</td>
<td>Metro</td>
<td>Metro</td>
<td>WA</td>
</tr>
<tr>
<td>D4</td>
<td>Private radiology service</td>
<td>Regional</td>
<td>Regional</td>
<td>WA</td>
</tr>
<tr>
<td>D5</td>
<td>Paired depth interview</td>
<td>Metro</td>
<td>Metro</td>
<td>VIC</td>
</tr>
<tr>
<td>D6</td>
<td>Private radiology service</td>
<td>Regional</td>
<td>Regional</td>
<td>VIC</td>
</tr>
<tr>
<td>D7</td>
<td>Private radiology service</td>
<td>Paired depth interview</td>
<td>Metro</td>
<td>NSW</td>
</tr>
</tbody>
</table>

5.4 SAMPLE DETAIL

Target and eligible women

All groups included the following (as far as possible):

- a spread of ages within the defined age bands indicated in the sample grids above;
- a mix of married, co-habiting, single, divorced and widowed women; and
- women from a representative mix of Culturally and Linguistically Diverse (CALD) backgrounds for the area in which each group was being conducted, except in specific language groups which focused on one language only.

Regular screeners’ groups were recruited as follows:

- none had ever been diagnosed with breast cancer;
- all had a mammogram for screening rather than diagnostic purposes in the last two years;
- a mix of women who had screened through BreastScreen Australia and private services were recruited in each group (section 5.8); and
- at least one woman who had a self-reported family history of breast cancer was included in each group.

Lapsed and never screeners’ groups and in-depth interviews were recruited as follows:

- none had ever been diagnosed with breast cancer;
- roughly half were lapsed screeners, that is they had had a mammogram for screening rather than diagnostic purposes in the past, but not in the last two and a half years;
- roughly half had never had a mammogram;
- those under the age of 53 were not intending to have a mammogram in the next two years;

15 as reported by women
• a mix of BreastScreen Australia and private service users were included among lapsed respondents, with a skew towards BreastScreen Australia users; and

• as far as possible, at least one of the lapsed screeners in each group had used private services.

The recalled groups were recruited as follows (section 5.7):

• all had had a mammogram for screening rather than diagnostic purposes through BreastScreen Australia;

• all had been asked to come back for further tests on another day because of suspected breast abnormalities (not because of problems with the x-ray, as far as they were aware);

• all had been assessed by BreastScreen Australia when they were recalled for further tests; and

• none had been diagnosed with breast cancer.

Diagnosed and treated groups were recruited as follows:

• all had had a mammogram for screening rather than diagnostic purposes through BreastScreen Australia and had been diagnosed with breast cancer in the course of the process;

• all had been treated for breast cancer; and

• none were still in treatment for breast cancer.

Interval cancer groups were recruited as follows:

• all had been screened through BreastScreen Australia at least once in the past and all were over 40 years old;

• all had been diagnosed with breast cancer within two years of their last screening mammogram, at which they had been given an ‘all clear’ result; and

• women came from a mix of socio-economic backgrounds.

Groups with women from non-English speaking backgrounds were recruited as follows:

• ethnic / language groups were selected based on Australian Bureau of Statistics data from 2006, as well as literature review findings (section 6.2);

• criteria were the same as for the main sample; and

• groups with women from non-English speaking backgrounds were conducted in their language spoken at home, by bi-lingual moderators.

Groups with Indigenous communities were recruited as follows:

• criteria were the same as for the main sample; and

• groups with Indigenous women were conducted in English with the assistance of local Indigenous women who were able to translate any terms that respondents were not familiar with.
Women with disabilities were recruited as follows:

- all had one or more impairment(s) that could make going for a mammogram difficult, based on Australian Bureau of Statistics disability variables\(^1\) and women’s own judgements about this;
- the following disabilities were represented among the five women in the sample:
  - severe multiple sclerosis and quadriplegia;
  - blindness (10% vision) and depression;
  - chronic fatigue syndrome / fibromyalgia;
  - spinal damage following an accident and chronic fatigue syndrome; and
  - mobility problems due to post polio syndrome.
- all had had an impairment since before the age of 50 to avoid including women who were experiencing typical symptoms of ageing as these women were represented in the sample more broadly;
- one had never screened, two were *lapsed* screeners and two were *regular* screeners;
- all were aged 50-69; and
- all *regular* screeners had used BreastScreen Australia services in the past.

**Health professionals**

General practitioner groups included a mix in terms of:

- the age of the GPs;
- males and females;
- practice size;
- locations served and the socio-economic and ethnic, cultural and linguistic backgrounds of their patients; and
- ethnic, cultural and linguistic backgrounds of the GPs.

Breast physicians were recruited from those listed on the Australian Society of Breast Physicians website and included:

- one who worked within a BreastScreen Australia service; and
- one who worked in a private clinic.

Nurse counsellors were recruited through BreastScreen Australia services.

Aboriginal health workers were recruited via CIRCA’s network of contacts. Both managed women’s health programs in Indigenous health centres.

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\(^1\) ABS 1200.0.55.001 - Disability Variables, 2006 Retrieved from http://www.abs.gov.au
5.5 TIMING OF FIELDWORK

Fieldwork was conducted between 14 November 2007 and 31 March 2008. Four group discussions were conducted at the beginning of this period with the remaining fieldwork being conducted from 27 November onwards. This provided an opportunity to monitor the effectiveness of the research instruments prior to the majority of the fieldwork being conducted – a qualitative ‘pilot test’. Recruitment screeners and discussion guides were then revised, following discussions between the research team and the Department. The bulk of the fieldwork was conducted in late November and early December with the remainder in January. The interval cancer research was conducted in February and March.

5.6 LOCATIONS

Fieldwork was conducted in all jurisdictions to ensure representation across Australia (Tables 1 to 6 in section 5.3). Locations were chosen taking into account the rural, remote and metropolitan areas (RRMA) classifications but also qualitative research practicalities such as availability of suitable respondents, as well as the scope of recruiters’ databases and existing networks.

As this research is qualitative, findings can not be reported by location because the sample is not representative at this level. Moreover, findings have not been attributed to specific locations to avoid singling out the services that happened to be covered.

5.7 RECRUITMENT OF RESPONDENTS

The full recruitment screeners for each audience, based on the characteristics described above, can be found in Appendix B.

Recruitment for women in the regular, lapsed / never, Recalled and Disabled groups was conducted by specialist Interviewer Quality Control Australia (IQCA) accredited recruitment companies. Recruiters used a combination of commercial respondent lists and the ‘snowballing’ technique, whereby respondents on the lists were asked if they knew anyone who might be eligible for the difficult-to-recruit groups.

Respondents for the diagnosed and treated and interval cancer groups were recruited via a combination of the processes described above and a letter that was sent out to women who fitted the criteria. The Breast Cancer Network of Australia (BCNA) assisted the researchers in the recruitment of the diagnosed and treated group in Melbourne and the interval cancer research in all locations. BCNA sent an email to members of their Review and Survey Group, as well as the liaison officer of BCNA Member Groups in relevant locations, explaining the nature of the research and inviting participation.

All jurisdictions were approached to facilitate the recruitment of women who had been recalled for assessment. BreastScreen Tasmania assisted the researchers in recruiting women who had been diagnosed and treated. A letter was sent to women living in Hobart who had had a screening mammogram and were subsequently diagnosed with breast cancer. The letter detailed the broader evaluation, explaining the qualitative research and extended an invitation to participate.
5.8 NOTE ON RECALLED GROUPS

The sample proposed by Blue Moon originally included three group discussions with women who had been recalled for assessment but had not been diagnosed with breast cancer. After the ‘pilot’ recalled group in St. Leonards, it became clear that recall could be interpreted in more than one way, that is either in terms of a technical or diagnostic recall. For example, some of the women recruited had been asked to have further tests on the same day. This consisted of a second or even third mammogram because the x-ray was not readable, or in the case of private services, an ultrasound. Others had been asked back on a subsequent day for further tests. All except one of the respondents in the pilot group fell into the first category.

The sample was adjusted to include three group discussions with recalled women using a revised specification. This was that all had been recalled on a subsequent day because of suspected abnormalities in the breast as opposed to problems with the x-ray. In addition, the researchers and Department agreed that focusing on the experience of women who had been recalled through BreastScreen Australia, rather than private services, would be appropriate. This was to ensure that findings would be in line with the evaluation objectives.

5.9 NOTE ON IDENTIFYING BREASTSCREEN AUSTRALIA AND PRIVATE SCREENERS

Researchers made every effort to identify whether or not respondents had previously used BreastScreen Australia services. At recruitment and during discussions respondents were asked:

- about the circumstances of the mammograms they had had, to establish that they had used screening rather than diagnostic mammography;
- whether they believed they had used BreastScreen Australia services or private screening;
- where they had been for screening (moderators checked this against the clinic names and addresses of local BreastScreen Australia services); and
- whether or not they paid for the procedure and / or collected a Medicare rebate.

In most cases, researchers were confident that they were able to establish whether respondents were users of BreastScreen Australia or private services as a result of asking these questions. However, it is possible that some comments have been misattributed. This is a limitation that would affect any research on this topic.

5.10 GROUP SIZE AND DURATION

Each of the discussion groups included between four to nine respondents, except where problems with recruitment were encountered (section 5.3). Groups with more difficult to recruit audiences were conducted with fewer participants, and generally included three to four respondents. Larger groups lasted two hours while smaller groups lasted for 1.5 hours. Individual in-depth telephone interviews lasted from approximately 30 minutes to one hour.
5.11 DISCUSSION COVERAGE

Semi-structured discussion guides were developed for use in all groups and in-depth interviews to ensure that all the issues were covered in every session. The use of semi-structured guides allowed the respondents themselves to dictate the flow of discussions with guidance from the moderator, rather than the questions being administered in the question / response format common in quantitative research.

Separate guides were prepared for sessions with: regular screeners; lapsed / never screeners; recalled women; diagnosed and treated women; women who had experienced interval cancers; women with disabilities; GPs; nurse counsellors; Aboriginal health workers; and breast physicians. The discussion guides are appended (Appendix C). Each guide was approved by the Department prior to use.

5.12 STIMULUS

Women in the target and eligible population were shown a selection of materials. These were not evaluated and responses to questionnaires were not analysed statistically. Rather these were used to stimulate discussion. Materials shown were as follows:

- randomly selected images from magazines for a ‘picture sort’ projective activity, to help elicit emotional responses to breast screening (where the moderator felt this was required);
- a series of statements in the format of ‘other women’s comments’ about breast screening and the Program, to stimulate discussion on particular topics (Appendix D); and
- communication materials from the jurisdictions in which the session took place, where these were provided by the jurisdiction.

GPs were shown communication materials from relevant jurisdictions, where time permitted.

5.13 PROJECT AND ANALYSIS APPROACH

A highly collaborative and iterative process was adopted to maximise the usefulness of the findings and value of the interpretation and insights generated. As described in section 3.4, communication between Blue Moon, CIRCA, the Department and the EAC sponsors was on-going throughout the project.

The researchers’ aim was not to evaluate the Program per se but rather to highlight findings and to analyse and interpret responses, to assist the EAC in addressing the evaluation questions. This report therefore focuses on:

- overall themes emerging from across jurisdictions;
- examples of perceived ‘best practice’; and
- examples of opportunities for enhancing the Program identified by participants.

Qualitative research was conducted to allow for the in-depth exploration of motivations, attitudes, feelings and behaviour. The findings were interpretive in nature, and analysis was based on the researchers’ experience and expertise in this type of research. As with all qualitative research,
the findings are likely to be broadly representative of the range of motivations, attitudes, feelings and behaviour held by the population at large. However, it should be noted that the questioning style and sample size for each sub-population were not appropriate for statistical analysis. Ideally, many of the findings in this report would be quantified to confirm the extent to which they are applicable to proportions of the population at large.

Blue Moon and CIRCA’s approach to qualitative analysis is in keeping with international market research industry and social research standards\(^\text{17}\). All depth interviews and group discussions were conducted by experienced qualitative research moderators and were audio recorded. Groups conducted by CIRCA in respondents’ home language were translated by the bi-lingual moderators who conducted the groups to ensure that meaning was not lost. Quotations from these groups are provided in English throughout this report.

Interviewers reviewed tapes or transcripts of the sessions they conducted and analysed the data for key themes and patterns. Ideas and hypotheses were then tabled and debated by the qualitative project team from Blue Moon and CIRCA, as well as members of the Department, at the internal analysis workshop. The analysis was written up in draft form and agreed on by the researchers before being presented in PowerPoint format. The presentation formed the basis of this report.

6. FACTORS THAT FACILITATE AND DISCOURAGE PARTICIPATION

6.1 INTRODUCTION

The evaluation question for this section is: ‘What are the factors that discourage participation? What are the implications of this for the Program?’ Barriers to participation are discussed, predominantly focusing on those that do not relate to the BreastScreen Australia Program. Those relating to the Program are addressed in depth in the subsequent sections of the report, in particular in section 7 on the availability and accessibility of the Program and in section 8 on its acceptability.

Facilitators of participation in mammographic screening are also discussed in this section. This provides useful context for analysis of the barriers, since differences between perceptions of regular and lapsed / never screeners are highlighted. The implications for the Program are addressed in the conclusions (Section 6.6).

6.2 LITERATURE REVIEW FINDINGS AMONG TARGET AND ELIGIBLE WOMEN

‘Active’ versus ‘passive’ motivations and barriers to breast screening

A qualitative study in 2006 [18] identified a spectrum of attitudes towards screening and suggested that barriers and motivations may be ‘active’ or ‘passive’ (figure 1). Women with strongly held ‘active barriers’ were at the rejection or denial end of the spectrum. Women with more ‘passive barriers’ tended to have low awareness of BreastScreen Australia or low motivation to attend, rather than having very strident reasons for their behaviour.

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18 As discussed in section 7.2, all abstracts from documents reviewed in the literature can be found in Appendix A, numbered and in alphabetical order.
Women with ‘passive motivations’ to participate tended to have responded to some form of stimuli to take part, such as a letter from BreastScreen Australia. However these women were not committed to screening and seemed to be easily persuaded not to take part. Some regular screeners were highly committed and had ‘active motivations’ to screen, such as a strong belief in the benefits of the activity.

**Facilitators of participation**

Four key types of facilitator of breast screening are covered in the literature review:

- personal beliefs about breast cancer screening;
- a doctor’s referral;
- communications encouraging participation; and
- encouragement from within the community and family.

**Personal beliefs**

Several studies indicate that some women are motivated to participate in mammographic screening by already existing beliefs and knowledge. One study found that an understanding of the benefits of screening encourages take-up (1). Two articles indicate that women who take responsibility for their health in general, including participating in other preventative activities, are more likely to have regular screening mammograms than those who do not (53, 75). Two articles in the review also referred to screening becoming a ‘habit’ among regular screeners (74, 75) and women who believe themselves to be at risk have been found to be likely to attend (69).
**Doctors’ recommendations**

Numerous studies point to the positive influence of a doctor’s recommendation or endorsement on breast cancer screening behaviour (1, 23, 28, 29, 49, 53, 54, 56, 58, 70, 76). In particular, one article highlighted that studies have shown that between 68% and 91% of women will attend for screening after a recommendation from their GP (76). Another study indicated that there is a link between doctors’ involvement and re-screening activity (28). While a doctor’s recommendation or referral seems to be influential across audiences, one study suggests that this can be particularly beneficial among women from non-English speaking backgrounds (23).

**Communications**

Several studies point to the influence of communications, such as advertising campaigns and invitation letters, on take-up of mammographic screening services (19, 42, 49, 48, 50, 53, 56, 58). The impact of BreastScreen Australia communications and motivating messages are discussed in section 10.

**Community and family encouragement**

Few of the articles discuss the impact of family and friends on participation. However, one study among Chinese-Australian women indicates that daughters and husbands can be influential, especially where women speak limited English (42). Seniors club activities to encourage women to participate were also found to be effective (42).

**Barriers to participation across audiences**

Findings from the literature review indicated that barriers to participation in the Program are difficult to disentangle from women’s often uncomfortable experience of mammograms or attitudes to screening more broadly. Both the literature review and qualitative findings on barriers to participation in the BreastScreen Australia Program have therefore been explored in terms of:

- those that relate to having a mammogram;
- those that relate to taking part in mammographic screening; and
- those that relate to the Program.

Further detail is provided on barriers to the BreastScreen Australia Program in subsequent sections, including those relating to perceptions of the availability and accessibility of the Program (section 7), the acceptability of the Program (section 8) and reasons for choosing private mammography (section 9).

**Barriers to having a mammogram**

There are some barriers to participation that relate to the process of having a mammogram under any circumstances. Embarrassment (1, 18, 53), fear of the results (18, 40, 47 and 53) and concerns about radiation from the x-ray (18, 40, 42) are three key barriers to having a mammogram that are raised in the literature.
Pain, discomfort and breast compression are mentioned in numerous studies as a reason for non-participation (4, 18, 32, 40, 42, 47, 53, 61). The studies are contradictory in terms of the extent to which this is a genuine and significant barrier. A review of the literature on pain (4) indicates that one study found 73% of women reported pain while another found only 2% did so. The language used to describe ‘pain’ or ‘discomfort’ is also discussed. For example, one study (61) found that ‘discomfort’ is a more accurate descriptor than ‘pain’ since the negative sensations were not long-lasting. Given the lack of clarity on this subject, the experience of ‘discomfort’ was identified as a topic for further exploration in the qualitative research.

It was not clear from the literature how far these barriers would be applicable to diagnostic mammography as opposed to screening mammography. The hypothesis drawn was that women may accept these disadvantages more readily if asked to have a diagnostic mammogram. This was discussed with women in the qualitative research.

**Barriers to taking part in mammographic screening**

Some women do not participate in screening because they do not understand why it might be beneficial for them. Studies indicate that not all women believe they are at risk, or feel that they do not need to have a mammogram unless they experience symptoms of breast cancer (18, 24, 28, 40, 47, 53, 69). Some also have doubts about the efficacy of mammography or believe self-examination makes mammograms unnecessary (40, 42, 69, 75).

Another key barrier to taking part in screening mammography is that other priorities in peoples’ live take precedence. Women for whom this applies may agree that screening is a good idea but are prevented from attending due to family responsibilities, poor health or complicated circumstances in their lives (18, 53). At a less extreme level, some women simply do not ‘get around to it’ (18, 40). One study indicates that women who have never screened are more likely to be under 60 years old and to be employed (2). This suggests that women who are working may have more difficulty attending screening due to competing priorities.

Some of the studies among women from non-English speaking backgrounds highlight that modesty and fear of stigmatisation may be barriers to taking part in screening mammography (42). For Chinese-Australian women, being concerned with or expressing curiosity about breasts was reportedly considered inappropriate, which may be a deterrent to screening in the absence of symptoms (24). Women from this background were also reported to believe they are not at risk because breast cancer is a “white ladies’” disease (24). Moreover, in some cultures, screening is not compatible with beliefs about health promotion, which focus on achieving balance in their lives rather than seeking out disease when they are asymptomatic (43).
Barriers to participating in the BreastScreen Australia Program

Barriers to screening through BreastScreen Australia identified in the literature review are discussed in subsequent sections. These include:

- low awareness of, and knowledge about, the Program, such as a belief that a doctor’s referral is required (70) (section 7.2);
- perceived issues relating to the accessibility and availability of the Program (section 7.2);
- perceived issues relating to the acceptability of the service provided (section 8.2); and
- a preference for screening through private services (section 9.2).

Barriers to participation among sub-populations

Four audiences were identified in the Participation Qualitative Research brief as of particular interest due to lower participation rates:

- women from lower socio-economic groups;
- women from non-English speaking backgrounds;
- women from Indigenous communities; and
- women in rural and remote communities.

Two additional audiences for whom participate may be an issue also emerged within the literature review:

- women with disabilities (56, 62); and
- single women (67).

Women from lower socio-economic backgrounds

The brief identified that participation rates were slightly lower for women from lower socio-economic backgrounds than for the population as a whole (53.6% of women participated in the most disadvantaged areas versus 56.3% in the least disadvantaged areas). However, it could be assumed that women from higher socio-economic backgrounds are more likely to screen privately. If this is the case, it may be possible that the differences in breast screening rates between women from higher and lower socio-economic backgrounds are considerably greater. This was explored further in the qualitative research.

Three studies suggest that accessibility is an issue for women from lower socio-economic backgrounds (17, 34, 35) (section 7.2). No other barriers for this audience were identified within the literature review. Perceptions of mammographic screening and the Program among this audience were therefore explored in the qualitative research.
Women from non-English speaking backgrounds

Australian Bureau of Statistics data from 2006\(^9\) provides information on the numbers of women in the age range 50-69 with poor proficiency in spoken English living in Australia. The top six language groups are Greek (15,273 women), Cantonese (12,102 women), Vietnamese (9,537 women), Mandarin (7,978 women) Italian (7,912 women) and Arabic (5,542 women). This data was used to inform the sample. In addition, other considerations were taken into account, such as which of these audiences were included in the literature review and a desire to explore the views of women who have recently arrived in Australia.

Barriers to participation for women from non-English speaking backgrounds are various and complex. Studies included in this review highlight the specific issues for Chinese-Australian women (24, 42, 43), Italian-speaking women (58), Thai immigrant women (29, 36) and Macedonian women (3). Other studies explore issues across non-English speaking backgrounds (22, 23, 36, 55, 67). The key issues for non-English speaking women in general seem primarily to relate to perceptions of mammography (see above) as well as the perceived accessibility and (section 7.2) acceptability (section 8.3) of the BreastScreen Australia Program.

Indigenous women

As with women from non-English speaking backgrounds, cultural barriers to having mammograms (46, 73), acceptability of the service (section 8) and accessibility (section 9) seem to be key reasons for non-participation among this audience.

Women in rural and remote communities

The research brief identified that participation rates are higher among women in regional and remote communities than in major cities. The literature indicates that support for BreastScreen Australia mobile units is often high because they provide a visual reminder of rural health service provision (74). Re-screening rates in Victoria have also been recorded as higher among women in rural and regional areas (55). This has been attributed to the commitment to the service among women in these areas because they want to ensure that it remains viable.

Participation in very remote areas is lower than elsewhere at 44.3%. There is likely to be a high correlation within this audience with lower participation among Indigenous women. In 2001, around one in four Indigenous people (26%) were living in remote areas compared with only one in fifty non-Indigenous people (2%)\(^{20}\), although the review did not provide any illumination on this issue. Issues relating to access for these audiences are discussed in section 7.

\(^{19}\) Australian Bureau of Statistics, Census of Population and Housing, 2006
\(^{20}\) Australian Bureau of Statistics ‘National Aboriginal and Torres Strait Islander Health Survey, 2004-05’
Women with disabilities

In 2003, severe disabilities, defined as ‘the need for assistance with self-care, mobility or communication’, were experienced by 5.5% of women aged 45-54, 8.9% of women aged 55-64 and 10.3% of women aged 65-69. This represents a sizeable minority of the target and eligible population for BreastScreen Australia. The literature identified issues relating to the availability and accessibility of services of this audience (section 7.4). Perceptions of screening mammography more broadly and the acceptability of the service were explored in the qualitative research.

Single women

Several studies indicate that women who are single, divorced or widowed are less likely to screen than women who are in long term relationships. This may be attributable to encouragement from husbands to screen, as is suggested by one study among Chinese-Australian women. The literature did not throw any light on the key barriers for these women, so this was explored further in the Participation Qualitative Research.

6.3 LITERATURE REVIEW FINDINGS AMONG HEALTH PROFESSIONALS

Only one study focused on GPs’ perceptions of breast screening. This survey found that 97% of GPs in WA self reported referring their patients to screening mammography or reminded them to take-up the BreastScreen WA service. The study identified barriers to discussing breast screening with patients in order of importance as: ‘the competing demands of the consultation’; ‘patients being over 70 years old’; or ‘too many patients per session’.

Another study indicates that physicians’ perceptions of the barriers to women participating in mammographic screening do not always coincide with the barriers cited by women. The authors conclude that it would be helpful for doctors to be better informed about women’s reasons for not participating, to help them address women’s concerns more effectively.

6.4 QUALITATIVE RESEARCH FINDINGS AMONG TARGET AND ELIGIBLE WOMEN

Facilitators of screening

Main sample

The key facilitator for participation among regular screeners was the belief that the benefits of screening outweigh the downsides. The principal benefit was believed to be that early detection offers the best chance of successful treatment. Some regular screeners also talked about the importance of knowing about cancer as early as possible so that the treatment would be less invasive. This point was often made by women who had friends and family members who had suffered from being treated at later stages. Some of the women who had been diagnosed through the BreastScreen Australia Program also felt that early detection had been highly beneficial for them.
“[It provides] early warning if there is a problem.”

“My friend was diagnosed very late. But if it was just… the very early stages, which it would be if you’re having regular mammograms, it wouldn’t be so bad. If it was one of those too late things where they’ve got to remove all the glands and everything…I wouldn’t want to know about that.”

“They found mine when it was tiny so I only had to have a lumpectomy.” (Diagnosed and treated woman)

A ‘negative’ or ‘all clear’ result was felt to provide reassurance, especially for those who saw themselves as at high risk. Those who believed themselves to be at high risk had often been told this was the case by their doctor, usually because they had a family history of breast cancer. In a smaller number of cases women had been told they were at high risk because they had been through the menopause, they had had an early menopause or were using hormone replacement therapy.

“My Aunty on my mum’s side had been diagnosed with breast cancer and the doctor said because it’s sort of next of kin it’s a good idea [to start screening].”

“I do not like boob sandwiches! But it’s security I suppose.”

For committed regular screeners, the downsides were perceived as inconveniences rather than barriers. They tended to argue that the pain or discomfort and embarrassment, while not negligible, were worth enduring to gain the reassurance of an ‘all clear’ result. They also often commented that the discomfort only lasts a short time and was not as bad as some other unpleasant experiences in life, such as giving birth. Moreover, these women felt that the inconvenience of participating was minimal.

“It’s nothing if you’ve given birth!”

“Out of two years it’s only ten minutes. When you put it like that it’s not very much is it? It’s less time than if you went for a cup of coffee… and it’s a huge relief at the end of it.”

Another reason a few women gave for screening was to ‘keep the doctor happy’ in cases where s / he was insistent that the woman should attend. While this was only a motivator for a small number of women, many agreed that their doctor had encouraged them to have regular screening mammograms. A doctor’s recommendation or referral seemed to be particularly influential for ‘wavering’ women, that is among those who did not immediately make an appointment for screening on receiving a letter from BreastScreen Australia.

“Originally my doctor had said ‘you should do this’ and so I got onto the books… I hate it but I have done it fairly diligently each time they tell me.”

Friends and family members had also encouraged some women to screen regularly, either directly or indirectly. Many said that their mother, sisters or friends had mentioned the importance of breast screening. In some cases women had been influenced by their daughters to take part, though this was more common among women from non-English speaking backgrounds than in the main sample.
Few said they had been actively encouraged by their partner to screen. However a few married women commented that their main concern if they were diagnosed would be how their husbands and families would cope, which suggests that having a partner may be a motivation to screen for some.

Many regular screeners commented that the quality of the service provided by BreastScreen Australia provided motivation for them to participate. Several spontaneously mentioned that the service is free and relatively accessible for those living in metropolitan areas (section 7.4). A sizeable majority of women in the sample overall found the service either acceptable or highly satisfactory (section 8.3). Many had also been motivated to attend by BreastScreen Australia communications (section 10.3).

Having friends or family members who had experienced breast cancer, as well as media reports about breast cancer were also cited as reasons to screen. However, lapsed/never screeners frequently mentioned that they knew women who had been diagnosed with breast cancer or had seen media reports on the subject but were not motivated by this. Awareness of breast cancer alone does not therefore seem to be a motivator to screen.

**Facilitators among women from non-English speaking backgrounds**

Motivators for women from non-English speaking backgrounds were similar to those for the main sample. In particular, the provision of information and referrals from bilingual GPs were seen as effective motivators, especially given the respect and trust that many women in these groups felt for their doctors.

However, GPs did not appear to be particularly proactive in informing or referring women from some backgrounds to attend breast screening. This was reportedly a particular issue in the Greek community, where participants said that their bilingual doctors, who were generally male, had never spoken about breast screening. Chinese women who had screened, in contrast, reported that the main reason they initially participated was due to a recommendation by their doctor.

“My doctor said women over 45 should have a mammogram and it is a free service.” (Chinese woman)

“My doctor said I should have a mammogram because of my age and many women at my age are at risk.” (Chinese woman)

Other motivators were similar to those in the main sample. These were:

- reassurance from an ‘all clear’ result;
  “I felt relief that it was an all clear result. I felt so happy!” (Chinese woman)
  “When I got the result saying everything was OK, I was happy. It’s more important to spend half a day getting checked than a whole day walking around the shops or cleaning at home.” (Lebanese woman)
knowledge that the service is free, which appeared to be particularly relevant among Chinese women, who hinted at feeling obliged to use free health care services;

“My doctor said that I could go because of my age, and it’s a free service!” (Chinese woman)

encouragement or pressure from a female family member, especially for Chinese and Greek women;

“My mother encouraged me to perform the mammogram. She said that it is better to check your health at around fifty years old. She said early detection is better.” (Chinese woman)

the diagnosis or death of a woman in the community, particularly among Iraqi participants, perhaps because this is a relatively small, new community in Australia; and

receiving a reminder letter from BreastScreen Australia among Chinese participants.

“If they did not mail me a letter, I would not know I am due for a check up.” (Chinese woman)

“I did not act when I received my first letter and they sent me another one so I thought I better undergo the screen.” (Chinese woman)

Facilitators of screening for Indigenous women

Encouragement from a health professional, especially an Aboriginal health worker, was a key motivator for Indigenous women. In the remote area covered in this sample, an Indigenous health worker was reported to have motivated many women, including those who had very negative perceptions of the screening process, to attend. They said they did so because they ‘knew her and trusted her’ and she ‘roused’ on them if they did not turn up. This seemed to generate an increased sense of accountability, with some participants suggesting that if they did not screen they would have to explain themselves to the health worker.

The health worker also facilitated participation by organising transport and appointment times on women’s behalf. This particular health worker had been working in the community covered in the research for sixteen years and may be unique in her approach. However, this example suggests that a trusted local Indigenous woman can be very successful in encouraging regular screening.

“I found out through [the Aboriginal health worker]. She gets all the ladies [to attend].”

 “[The Aboriginal health worker] loves her clients. She follows them through and through.”

Some Indigenous women in a metropolitan area had been encouraged by their GP to attend. In one location, in contrast, women said no health professionals had ever discussed breast screening with them and this may have contributed to a lower understanding and awareness of breast screening processes in this area.
As in the main sample, *regular* screeners in the Indigenous focus groups were more likely than *lapsed/never* screeners to take personal responsibility for their health. Some *regular* screeners had made an appointment, or repeat appointment, after receiving a letter from BreastScreen Australia.

”I know I’m doing the right thing.”

”[When I receive the letter I think] I’m due again…better make an appointment.”

”I make sure I’m looking after myself.”

”I got to have this because I don’t want to get [cancer].”

However, few Indigenous women had received letters and there was suspicion among some about how BreastScreen Australia had accessed their contact details. Literacy was also an issue for many older Indigenous women, who rely on their children to read the letters they receive.

*Facilitators of screening for women with disabilities*

All the women with disabilities in this sample felt that screening was a good idea because of the opportunity to detect breast cancer early, which enhances the likely success of treatment. Most of the facilitators for screening for these women were not connected to their disabilities. Two had been encouraged to participate by their GP and one had been ‘told to go’ by a specialist because she was receiving treatment for a hormonal problem. Three out of five had received invitation and/or reminder letters from BreastScreen Australia. All had discussed breast screening with a friend or family member, who had encouraged them to attend.

However, one issue was mentioned that was specific to women with disabilities. None of these women were able to work and one commented that people with disabilities often have time on their hands, which they may spend worrying about their health. Having a breast screen was a positive step they could take to reassure themselves about one aspect of their health.

”People with a disability often have a lot of time to think and worry about all sorts of things and it’s one of the things that you can basically set your mind at rest about. That’s one worry you’re not worrying about”.

*Barriers to screening across audiences*

*Barriers identified in the literature review*

All of the barriers to screening identified in the literature review were raised in this research. The key barriers, by category, are summarised in figure 2. Further findings on the pain or discomfort involved in screening are discussed here. Additional barriers not identified in the review, the relationship between barriers and the relative importance of barriers are discussed below.
Figure 2: Summary of barriers to breast screening raised in the literature review

<table>
<thead>
<tr>
<th>Barriers to having a mammogram (for screening purposes)</th>
<th>Barriers to participating in screening mammography</th>
<th>Barriers to taking up BSA services</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Pain / discomfort</td>
<td>• Low perceived risk</td>
<td>• Low awareness of service</td>
</tr>
<tr>
<td>• Embarrassment</td>
<td>• (no family history)</td>
<td>• Lack of GP referral / recommendation</td>
</tr>
<tr>
<td>• Radiation Concerns</td>
<td>• Asymptomatic</td>
<td>• Availability / accessibility issues</td>
</tr>
<tr>
<td>• Fear of results / treatment</td>
<td>• Viewed as superfluous due to self / clinical examination</td>
<td>• Acceptability issues</td>
</tr>
<tr>
<td></td>
<td>• Other priorities</td>
<td>• Preference for using private services</td>
</tr>
<tr>
<td></td>
<td>• take precedence</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Not getting around to it</td>
<td></td>
</tr>
</tbody>
</table>

Perceptions of pain / discomfort

In common with the literature review, findings indicated that women’s descriptions and experiences of the level of discomfort involved in breast screening, vary enormously. Some women said they had found mammograms to be mildly uncomfortable while others insisted that they had been in a great deal of pain. In a small number of cases women described having been left badly bruised or with split skin, following the procedure.

“It’s not the best fun thing to do but I felt no pain.”

“One time I had this learner guy and they actually tore the tissue underneath and I bled!”

There was debate in several groups about whether women with larger or smaller breasts are likely to feel more pain and no consensus was reached, since there did not seem to be a pattern to this. Some women thought that the different perceptions of pain could be due to different pain thresholds. However, others vehemently disagreed, arguing that they normally had a high pain threshold yet were adamant that having a mammogram was one of the most painful procedures they had ever experienced.

“I’ve got a hugely high pain tolerance. I don’t have any injections for dental work at all, root canals the full bit, no injections I can handle pain and [the mammogram operator] had me with tears running down my face.”

There was some agreement among women from all audiences that the approach of the member of staff operating the mammography machine has an impact on the level of pain or discomfort experienced. The attitude of the staff member, in terms of their level of concern about the degree to which a woman was in pain, also affected perceptions of the experience overall (section 8.3).

“It was something wrong with her, not me and I’ve had it done probably ten times at [BreastScreen service X], no trouble at all.”

Interestingly, there seemed to be little discernable difference between descriptions of the pain or discomfort experienced by regular screeners and lapsed screeners in the qualitative research. This suggests that for these women pain may be a contributory, rather than a primary factor in discouraging women to participate. Moreover, as mentioned above, it was clear that women
across audiences who had a good understanding of the benefits of screening and a strong preventative approach to their health were more prepared to accept pain or discomfort than those who did not.

“It’s not anything that you look forward to. It’s like going to the dentist, it’s got to be done.”

The expectation of pain or discomfort was also a barrier for many women who had never had a mammogram. Most had been exposed to negative word-of-mouth about this (see below). However, in this sample, very few women cited concern about the pain or discomfort as the only reason not to participate. Indeed those with active barriers to screening tended to claim that the expectation of discomfort was not a key reason to avoid screening (see below).

**Additional barriers**

Three additional barriers were identified that were not highlighted in the literature review:
- disengagement from primary health services;
- the separation of BreastScreen Australia from familiar services; and
- negative word of mouth.

**Disengagement from health services**

Women who are disengaged from primary health services were less likely to be aware of the BreastScreen Australia Program and its benefits (section 7.4). This included women who do not like visiting their GP and claimed only to do so when they were extremely sick, as these women had had less opportunity to be encouraged to screen by their doctor. Women from non-English speaking backgrounds and Indigenous women who had limited access to services or awareness of what is available to them were also less likely to be aware of the Program (see below for more information on barriers for these audiences). This was a particular problem if women no longer received reminder letters from BreastScreen Australia because they had moved house or changed names.

**The separation of BreastScreen Australia from familiar services**

The separation of the process from familiar health services can be a deterrent to participation for some women. Several lapsed / never screeners claimed they would have a mammogram if it were offered at their GP surgery, as is the case for pap smears. However, these women said they dislike visiting a different place because this involves negotiating a new environment and may be less convenient. The lack of familiarity with BreastScreen Australia services and facilities was also a barrier for some women with disabilities.

“If the doctor just said go next door now and do it, I probably would.”
Negative word-of-mouth

Negative word-of-mouth can trigger or reinforce resistance to mammography across audiences. Most women who had never screened had heard graphic descriptions of the process. For example, the degree of ‘squashing’ of the breasts was often demonstrated to women by friends and family members who had experienced mammography, using hand gestures. In addition, poems and jokes about mammography are reportedly widely shared.

“Some women take great delight in telling you what they do and that has put me off.” [Never screener]

Negative word-of-mouth (as well as experience) of pain seems to act either to lead women to think about all the reasons why they should not screen or this reinforces the other barriers. This seemed to be a particular problem among women from some non-English speaking background communities, especially for Lebanese and Iraqi women.

“We have heard from other women that it is a very uncomfortable test especially for younger women with firm breasts. The older women said it was a bit easier because their breasts were not so firm but they still didn’t like doing the test. And they told us it hurts!” [Iraqi woman]

While some women encouraged others to screen (see above), word-of-mouth communication often seemed to focus on the downsides, rather than the benefits, of screening. There may therefore be an opportunity for BreastScreen Australia to encourage regular screeners to highlight the positives when talking to other women about their experiences.

The relationship between barriers

Barriers to having a mammogram did not appear to be applicable to diagnostic mammography. Almost all women said the barriers would be surmountable if they found an obvious symptom, such as a lump, or if their doctor said they were concerned about something in their breast during a clinical examination. Only a very small minority would not follow up symptoms. This indicates that barriers to having a mammogram and barriers to participating in screening mammography are closely linked.

“I suppose if there was a lump or my doctor told me to go then I’d have to do it wouldn’t I?” [Never screener]

Indeed findings highlighted that many of the barriers are inter-related and often difficult to disentangle. Many women cited more than one reason not to screen or not to re-screen and these barriers were often from across the categories identified in the literature review. Moreover, many women admitted that while individual barriers were not genuinely compelling in isolation the cumulative effect of the combination is off-putting. This is an important finding because it suggests that focusing on individual barriers may not be productive. Instead, it may be more useful to identify and attempt to address a series of barriers and to highlight that the benefits outweigh all of these combined. Moreover, this finding illustrates the importance of identifying the suite of primary barriers among different target audiences.
Primary barriers to screening by attitude type

Women struggled to identify which were primary and which secondary barriers or post-rationalisations. However, the spectrum of attitudes towards breast screening described above proved to be a helpful starting point in the analysis of this, since primary barriers appeared to be different at different points on the spectrum (figure 3).

Figure 3: Primary barriers at key points in the spectrum of attitudes towards breast screening

**Rejection (‘active barriers’)**

The primary barriers for women at the rejection end of the spectrum related to the fact that they did not want to have ‘unnecessary’ mammograms, as they saw it. They often raised concerns about the potential for the mammogram procedure to be damaging to women’s health, either due to the radiation from the x-rays or because of the trauma to the breast. They were also more likely than women with attitudes at other points on the spectrum to question the efficacy of mammographic screening. For example, some drew attention to the potential for anxiety caused by ‘unnecessary’ recalls for further tests. Others seemed to feel that the occurrence of breast cancers that develop between screening events negated the validity of the exercise.

“I have heard that they’ve had negatives that should have been positives and positives that should have been negatives. So it’s not always accurate anyway.”

They also tended to believe that it is not ‘healthy’ to look for breast cancer in the absence of symptoms and when they felt well. This was coupled with a preference for ‘natural’ health remedies and ‘positive thinking’, rather than more established medical approaches. The availability, accessibility and acceptability of the BreastScreen Australia Program were largely irrelevant to
these women as they were unlikely to participate under any circumstances. Pain and discomfort were also less of an issue for these women, though embarrassment seemed to be a factor, perhaps due to their relatively limited exposure to medical procedures.

These women tended to be from higher socio-economic backgrounds and / or were relatively highly educated. They were disproportionately single, though no clear reason for this emerged. They were most likely to be Anglo-Australians, although the literature review showed some Chinese women had similar views on preventative health. They also tended to have strong opinions, which were not influenced by the views of other participants in the groups or by information in the communications materials.

Denial and reluctance (‘active / passive barriers’)

Women at the denial and reluctance points on the spectrum tended not to have fully internalised the benefits of screening mammography. The key barriers were that they saw themselves at low risk because of a lack of family history of breast cancer, despite being in the target age range, or had a low appreciation of why screening is necessary for asymptomatic women. They were also likely to believe that self-examination is sufficient.

Resistance for this audience was often exacerbated by concerns about pain, embarrassment and fear of the results or any treatment that might be required. Unlike regular screeners, these women had not considered that the benefits outweighed the downsides. As a result, their first experience of BreastScreen Australia had sometimes had an impact on whether or not they re-screened. For example, their perceptions of the behaviour of staff towards them and the extent to which staff seemed to make an effort to minimise pain could determine whether or not they re-screened. Moreover, they seemed more likely to consider re-screening if the benefits of screening had been conveyed to them.

Those at the denial and reluctance points on the spectrum could be found across all socio-economic and cultural backgrounds. This is an interesting finding since some of the articles in the literature review among particular non-English speaking background communities suggested that these views were specific to certain cultures (section 6.2). The findings here indicate that this is not the case. There seemed to be more single women among this audience than some others. However, no clear reason for this emerged.

Low Awareness / Motivation (‘passive barriers’)

For those at the Low awareness or Low motivation points on the spectrum, the primary barrier appears to be other priorities taking precedence in their lives. This means that these women may have some appreciation of the benefits of screening but do not manage to find the time for the activity. In some cases this is because they work in jobs with inflexible hours, such as teaching or on night-shifts.

“\textit{I’ve had the letter in my bag for about two years. I will do it at some point.”}
Women who had complicated family circumstances or family health problems also often fell into this category. Such women tended to display a lack of concern for their health over the long-term because they had more immediate concerns or problems to deal with. Women from lower socio-economic backgrounds, women from non-English speaking backgrounds, Indigenous women and women with disabilities were over-represented among this attitudinal group, though some were from higher socio-economic backgrounds and/or were Anglo-Australians.

As with those at the denial and reluctance points on the spectrum, pain and embarrassment contributed to the lack of motivation to attend but these concerns did not appear to be primary reasons for their lack of interest in participating. Awareness of the BreastScreen Australia service was often low among this audience because it was of relatively low interest to them. Targeted communications could therefore have an impact, as indicated in the literature review (17).

Access was an important additional barrier for working women. Several called for extended opening hours at BreastScreen Australia services and improved public transport accessibility.

Regular screeners (‘active motivations’)

Regular screeners who were not participating in the BreastScreen Australia Program were, by definition, using private mammography services. Women variously preferred private screening services because of the shorter time taken to receive results and greater convenience of making appointments.

Familiarity with private services due to previous experience of a particular provider was another key reason to screen outside BreastScreen Australia. These regular screeners often had a family history of breast cancer or a personal history of breast problems. As a result they had often either undergone diagnostic mammography in the past or had begun screening at a young age. In some cases, they had begun screening between the ages of 40 and 49 but were not aware that they were eligible for free screening through BreastScreen Australia. Reasons to screen outside the Program are discussed in more detail in section 9.

These women had similar attitudes towards screening to regular screeners within the BreastScreen Australia Program. Most had a strong sense of the importance of preventative health and saw themselves as being at relatively high risk, especially those who had undergone diagnostic mammography in the past. Like regular screeners, they recognised but accepted that the procedure involved pain or discomfort and embarrassment, as well as anxiety while waiting for results.

Attitudes among lapsed and never screeners

Both lapsed and never screeners were found at all points on the spectrum from Low motivation to rejection (figure 4).
Barriers among lapsed women

Some lapsed women had moved from the Initial acquiescence point on the spectrum or from having ‘passive barriers’ through to having ‘active barriers’. These women seemed to have entered a negative spiral and may never be convinced to participate again. For example some had had an unpleasant experience, such as a high level of perceived discomfort, whereas others had experienced exceptionally high levels of anxiety as a result of several recalls that did not lead to a diagnosis. This had led such women to question the value or relevance of screening, as well as the acceptability, and in some cases, the accessibility of services. Ultimately they had decided that the pain, embarrassment or anxiety were not worthwhile. It should be noted that women who had only experienced one recall did not express these views and tended to accept the experience as a necessary part of the process.

However, the majority of lapsed women had ‘passive barriers’ and were relatively open to re-screening. Their reasons for not screening tended not to be very considered. Indeed several expressed embarrassment at admitting to their behaviour in the groups, describing the barriers as ‘excuses’.

“Well I’m just a big coward when it comes down to it. I know I should do it.”
Moreover some said that they would be making an appointment for mammographic screening as soon as possible following the group discussion. The heightened motivation to re-screen appeared to be in response to hearing other respondents talking about the reasons to participate and reading about them in the communication materials. Messages that were particularly motivating included the following:

- there is a high incidence of breast cancer among women their age (1 in 8 women will be diagnosed);
- early detection and treatment success stories; and
- the pain and embarrassment do not last long and are outweighed by the benefits. This message may be particularly compelling for lapsed women, compared with never screeners because lapsed women were able to base their assessment of the relationship between benefits and downsides on personal experience, rather than on any unknown factors.

**Barriers among never screeners**

Never screeners were also found to have either ‘passive’ or ‘active barriers’. Those with ‘passive barriers’ tended to be at the younger end of the target age range, that is in their early to mid fifties. They were more likely than those with ‘active barriers’ to have low awareness of screening services and reasons to screen. They were also more likely to be working or caring for elderly parents or teenage children. This meant other priorities had taken precedence in their lives and access was often perceived to be a barrier.

Several opportunities to encourage never screeners with passive barriers to participate are evident from these findings. These include: encouraging GPs to raise the subject with them and discuss their concerns; highlighting that the benefits outweigh the barriers; extending opening hours; and providing, or helping to facilitate transport solutions.

‘Active barriers’ appeared much more difficult to tackle among never screeners. These women had strong opinions and in some cases had rejected their GP’s suggestion that they should screen. They were often sceptical about information provided by health professionals, BreastScreen Australia and the Department of Health and Ageing in general and rejected information in the local materials shown which aimed to address their concerns.

**Barriers to screening for women from lower socio-economic groups**

As found in the literature review, findings indicate that access may be more of an issue for women from lower socio-economic backgrounds than for more affluent women. While women from lower socio-economic backgrounds rarely cited costs related to using BreastScreen Australia services as a barrier, they were more likely to have ‘complex lives’ and access was therefore often difficult (section 7.4). However they also expressed all the other barriers and could be found at all points on the spectrum of attitudes towards screening, though they were less likely to be active rejecters.
Barriers to screening among women from non-English speaking backgrounds

As with the main sample, the primary factors that discouraged women from non-English speaking backgrounds from participating in initial or regular screening were mostly related to having a mammogram as opposed to participating in the BreastScreen Australia Program. The issues raised were similar, but tended to be compounded by language problems and culturally-specific misconceptions.

Limited understanding of relevance and purpose of screening

In common with some women with ‘passive barriers’ across the sample, many women from non-English speaking backgrounds did not understand the purpose of regular screening mammography and did not appreciate that it is relevant to them. Women in these groups commonly expressed two misconceptions. Firstly, those who had never been screened often did not feel there was a need to have mammograms in the absence of symptoms. Secondly, some lapsed women did not appreciate the need to continue with screening after the first ‘all clear’ result. The first issue was raised across all the audiences in this research but the second seemed to be specific to women from non-English speaking backgrounds and Indigenous women (see below).

“I feel healthy and I have no problem with my breasts so I don’t need a mammogram.” [Chinese woman]

“The truth is unless we feel something in our breast we won’t do it.” [Iraqi woman]

Other factors were raised by women from particular non-English speaking backgrounds. However, it should be noted that only one group discussion was conducted with women from each cultural background and some issues were also raised by women in the main sample. It is therefore possible that these barriers are applicable more widely among non-English speaking women. For example, Lebanese women expressed the belief that if there was no history of breast cancer in the family, regular screening was not relevant and Chinese and Iraqi women felt that self examination was sufficient.

“If you have it in your family, if your mother or sister has it, yes, OK, maybe you will get it, but for me, no one in my family has it. Why should I waste my time?”[Lebanese woman]

“Many of us know how to examine our own breasts with our hands because this is all we used to do in Iraq so we are familiar with this and we think this is enough… if we find a lump then we know to go to the Doctor for more tests.” [Iraqi woman]

However, some views did seem to be culturally driven. Among Greek participants, there was a sense that regular breast screening was not relevant because individuals’ destinies are predetermined. This seemed largely to be influenced by a religious belief that God has a chosen path for individuals. In contrast to this, Chinese women spoke about an ‘individual’s responsibility’ to keep healthy and tended to frame breast screening as an act they had control over, a way they could intervene in their own health.
“If you’re meant to go, you’re meant to go.” [Greek woman]

“Even if you treat cancer it still comes back anyway.” [Greek woman]

“I attended voluntarily with no resistance because I am responsible for my health.” [Chinese woman]

In addition to a limited appreciation of the relevance of screening mammography, women from non-English speaking backgrounds often had a limited understanding of mammography processes and what to expect. As in the main sample, women’s understanding was largely informed by stories from friends and/or family members, many of which had concentrated on negative factors such as pain and embarrassment. As a result, the perceptions of women who had never screened were dominated by physical discomfort rather than the benefits. Awareness of the process was particularly limited among women from recently arrived communities. For example, Iraqi women said breast screening was not available or common in their home country.

“ ‘I knew I should get checked out but I didn’t know where to start. I relied on my friends to tell me this the first time.’ ” (Lebanese woman)

Women who had participated in one or more breast screens had a better understanding of the process than those who had never screened. However, feedback suggested that their understanding had been gained through participating in the process, rather than in advance of doing so. The exception was within the Chinese community, where participants said the procedure had been outlined by their GP. Women from other communities said their GPs had not discussed the subject with them.

“If [my GP] had encouraged me… I would have thought about getting checked….. All he had to do was mention it.” (Lebanese women)

As in the main sample, expectations of pain, discomfort and embarrassment were significant contributing factors in discouraging women from non-English speaking backgrounds from having screening mammograms. However, also as in the main sample, women indicated that they would be prepared to have diagnostic mammograms if they discovered symptoms of breast cancer. This suggests that lack of understanding of the purpose and relevance of screening is a key barrier.

Cultural and religious concerns

Despite the willingness of most to have diagnostic mammograms, findings suggest that embarrassment may be a more difficult barrier to overcome in relation to screening mammography for some women from non-English speaking backgrounds. In particular, Iraqi and Lebanese women associated mammograms with discomfort, humiliation and invasive handling of their breasts. This was most acute for one Lebanese participant, who felt that mammograms were against her Muslim religion as they required a woman to reveal her breasts to a stranger. While this was not an issue raised by all Lebanese Muslim participants or Muslim Iraqi women, the feedback suggests that there is the potential for mammography to be framed in opposition to Muslim religion.
However, findings suggest that culturally sensitive staff and staff from particular ethnic or religious backgrounds can positively influence perceptions about the religious appropriateness of screening mammograms. For example, another Lebanese Muslim respondent who felt mammograms were against her religion had been reassured by the knowledge that there was a Muslim staff member working at the BreastScreen Australia clinic she visited.

“I wanted to go… but I had to re-think it because I’m a Muslim. When my cousin told me there is a Muslim woman working where I could get checked, I decided to go.”

(Lebanese woman)

An additional barrier was raised by some women who were refugees in Australia. They believed they had experienced their initial mammogram as an entrance requirement, either to Australia or an intermediary country during their journey to Australia. For example, one Iraqi woman said she had been screened in Greece. Another said she had been screened nine or ten years ago as a requirement for Australian residency. Both women had very negative perceptions about mammograms and had never re-screened. It is possible that these women have confused a chest x-ray with mammography. However, it is important to note that their perception was that they had experienced a mammogram and they did not want to have another in the future.

“I had to have it because of health tests for permanent residency in Australia but I hated it and felt so uncomfortable and embarrassed so I haven’t had one since.”

(Iraqi woman)

Another issue for women from across non-English speaking backgrounds was that they often said they regularly travel overseas, particularly to their country of birth, and can be away for long periods. Some women indicated that this was a potential barrier to regular screening because if they received notification to screen while they were overseas, they often missed their screening dates and did not know how to reschedule.

**Issues relating to the BreastScreen Australia Program**

Key barriers to participating in the BreastScreen Australia Program among women from non-English speaking backgrounds related to:

- low awareness of the Program and problems with access (section 7.2);
- expectations that the Program would not be appropriate for women from their background (section 8.2); and
- very low recall of communications among this audience (section 10.3).

**Barriers to screening among Indigenous women**

Some of the barriers for Indigenous women were similar to those for women from non-English speaking backgrounds and the rest of the sample. Many of the key barriers for this audience related to having a mammogram rather than the BreastScreen Australia Program. However, some significant cultural barriers emerged and access was seen as a particular problem for Indigenous women.
Lack of perceived relevance

A key issue among Indigenous women was a low appreciation of the purpose or relevance of mammograms in the absence of symptoms or family history. As in the main sample, some women believed that self-examination is sufficient and, in common with some women from non-English speaking backgrounds, some Indigenous women did not see regular screening as necessary after an initial ‘all clear’ result.

“I always test myself so why would I go there?”

The lack of perceived relevance for women in Indigenous communities was compounded by a belief that this is not a disease that is particularly relevant to them. Respondents did not necessarily believe that Indigenous women get breast cancer at the same rate as in the wider community. This was partly because they accepted that life expectancies are shorter for Indigenous women and therefore did not see themselves as at particularly high risk of a cancer that appeared predominantly to affect women aged over 50. Women’s perceptions may also have been influenced by a cultural tendency to live day-by-day rather than to plan ahead. Moreover, Indigenous women saw breast cancer as less of a priority than type 2 diabetes and heart disease, which are promoted more actively in their communities.

“It needs to be elevated because all you hear is about diabetes and heart disease.”

In common with women from non-English speaking backgrounds, Indigenous women who had never screened were deterred by a lack of understanding of the processes involved.

“I didn’t know what was going to happen.”

“There was no information about what they were going to do.”

Cultural attitudes towards breasts

Concerns about pain and embarrassment were a key contributing factor among Indigenous women, as with all women. However, Indigenous women were more likely to talk about perceived lasting effects of having mammograms. For example, one woman said the experience had changed the way she viewed her breasts.

“You got to go there, take off your top, stand there in the nude and put your breasts on the plate!”

“It made me feel different about my breasts afterwards because they’d always been something special and female, and after the mammogram they felt like a piece of meat.”

In common with some rejecters in the main sample, some Indigenous women were concerned about damage to their breast caused by the procedure. Some were also concerned about losing their breasts if they were diagnosed with cancer. This indicates that there may be less of a distinction between perceptions of screening mammography and diagnostic mammography for Indigenous women than for the majority of Australian women. This feedback also suggests that Indigenous women may over-estimate the likelihood of being diagnosed as a result of screening.
“I just worry about what I’ll look like with one titty!”

“It’s scary to think I might have to get my breasts cut off.”

“If I go to check up, they’ll find something.”

Another important issue raised by Indigenous women was that men in the community are not necessarily supportive of the practice of breast screening. In one community women said they had been actively discouraged from screening by their partners, who saw it as an inappropriate activity. Breast screening was certainly not something that Indigenous women said they would discuss with men.

“They [men, particularly younger men] don’t like them to get their breasts checked.”

“You don’t talk about women’s issues with men…You keep women’s issues to yourself.”

**Issues relating to the BreastScreen Australia Program**

In common with women from non-English speaking backgrounds, barriers to participating in the BreastScreen Australia Program among Indigenous women were related to:

- low awareness of the Program and problems with access (section 7.2);
- expectations that the Program would not be appropriate for women from their background (section 8.2); and
- very low recall of communications among this audience (section 10.3).

**Barriers to screening among women with disabilities**

**Overview**

All but one of the women with disabilities in this sample were keen to have regular screening mammograms in theory but were faced with a series of practical and psychological barriers to achieving this.

“It’s a routine thing that everyone has a right to have. Just because you have a disability you shouldn’t be precluded.”

Most had been concerned that the facilities would not be appropriate for them or staff would not be able to cope with their condition. An additional barrier that all these women agreed on was that they are extremely tired of having to explain their particular circumstances and needs to staff whenever they use a new service. The separation of BreastScreen Australia from familiar services was therefore a barrier.

“The psychological and emotional aspect can be very daunting because of having to instruct them…Also explaining lengthy things over and over again. I get sick of it!”
Barriers for women with specific conditions

Note: Findings in this section include detailed descriptions of the experiences of the women interviewed to provide context for their responses. The issues raised provide insight into how disabilities may affect access to BreastScreen Australia. However, some barriers may be a function of the particular circumstances of the women who were included in the study, given the limited number of respondents included. Findings should therefore be regarded as indicative only.

The woman with severe Multiple Sclerosis and quadriplegia was in a motorised wheelchair and had very limited mobility. She had once made an appointment to have a screening mammogram at BreastScreen Australia but had decided not to attend. She had no complaints about the way in which she had been dealt with when she called to make her appointment. However, she had found in the past that people often under-estimate her needs before they see her in person. She had therefore not been convinced that she would be able to be accommodated. This woman was also under the impression that screening takes place in mobile units only, as a friend of hers had used one of these. She therefore anticipated problems with getting into the unit and expected there to be a lack of space to manoeuvre her wheelchair.

“I didn’t end up going because I’ve had experience of having x-rays and it’s just a nightmare. I really need a ceiling hoist. And a lot of people aren’t trained in how to do it…it can be very awkward and uncomfortable with the equipment and they struggle. And to me it’s very stressful.”

In addition, this woman had not received a letter from BreastScreen Australia inviting her to attend and wondered whether this was because she lived in an aged care facility. She was also surprised to hear that others in the group had been encouraged to attend screening by their GP as her doctor had never mentioned mammograms to her. This is not surprising given GPs said they sometimes do not recommend screening mammography to patients who are struggling with other conditions (see below).

Both of the women with Chronic Fatigue Syndrome were regular screeners. However, one had only had her first mammogram eight years after her GP had first suggested she should attend. This was because she expected the process to be too difficult and that staff would not understand if she was unable to make it to her appointment on a given day because of a ‘flare up’. Eventually she had decided to go for screening and had been very pleasantly surprised by the experience (section 8.3).

The other woman with this condition had missed appointments on a number of occasions as a result of ‘flare ups’. However, she had always managed to reschedule within a few weeks and had been attending every two years for many years.

The woman who had mobility problems as a result of having had polio as a child had decided to stop having mammograms. She had always experienced pain for some time after the procedure because it involved lifting her arm above shoulder height, which she cannot do unaided. However, the last time she had a mammogram she said she had remained in pain for ten months subsequently. She had phoned BreastScreen Australia to discuss the problem and the person she had spoken to had suggested that she have an ultrasound next time instead. However,
she had been told she would have to go to a private service and would need a GP’s referral as BreastScreen Australia does not provide ultrasounds to women who have not had mammograms\(^{22}\). At the time of the research she was considering this course of action, although she also expected an ultrasound to be painful, so was not intending to arrange this in the near future.

Only one of the women in the group did not want to screen regularly. The woman with blindness and depression said she was ‘more scared of old age than breast cancer’. This was because she had a fear of being in aged care facility and not being given her anti-depressant medication and not being able to dispense it herself because of her visual impairment. She said BreastScreen Australia would not be able to do anything to persuade her to participate and she had no complaints about the service, which she had used once as a condition of undergoing hormone treatment.

**Barriers to screening among single women**

Single women are less likely to screen than women in relationships and they were disproportionately represented in *lapsed / never* groups compared with *regular* groups in this sample. However, no clear reason for this emerged. Women who were in relationships did not necessarily discuss breast screening with their partners and single women did not suggest any reasons why their relationship status might affect their behaviour.

Two hypotheses were developed by the researchers, though it should be noted that these interpretations are based on insights gained during the qualitative research and are not based on further evidence. Firstly, it is possible that women who are in relationships may be more favourably disposed towards preventative health because they want to be able to be healthy so that they are able to look after their partners. Secondly, there were differences between married and single women’s responses in accepting recommendations from health professionals. The following quotations illustrate this:

“I got the letter and I went. I do what I’m told!” (Married woman)

“I don’t accept what people in authority tell me. I think about it or I do my own research.” (Single woman)

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\(^{22}\) BreastScreen does not offer ultrasounds for screening as the evidence does not support the efficacy of this approach. For example:

Impact of interval cancer experience on perceptions of screening

All of the women in this sample who had experienced an interval cancer had been regular screeners prior to their breast cancer being detected and none had ‘wavered’ when they received a letter or a recommendation from their doctor to attend screening. They were all surprised and shocked when they were diagnosed with breast cancer as most had felt they did not need to worry about breast cancer since they felt they had done all they could to ensure they did not have it, by having screening mammograms. Some felt they had been overly reassured by the screening process and might have been more aware of their breasts or vigilant in self-examining, or would have asked their doctor for an examination, if they had not had the ‘all clear’ result.

“There’s a sense of security about it.”

“You come away thinking ‘I’m clear, it’s fine’ and you’re not aware that there could still be an issue.”

“I thought doing that [having screening mammograms] once every two years, I’m well covered…I was doing what they suggested, that’s all I needed to do.”

“I’m sure I would have been talking to the doctor more if breast screening wasn’t around…I was self-examining but probably too casually.”

However others said they checked their breasts carefully, even though they were regular screeners. None in this sample had delayed reporting symptoms to the doctor once they became aware of symptoms.

“I knew you had to check and I knew that they [mammograms] weren’t definitive”.

All the respondents in the interval cancer sample felt breast screening is a worthwhile activity, even though it had not been successful for them. Moreover, all said they would recommend that their friends and family members undergo screening.

“I think for most women, they’d be mad not to have regular mammograms because a lot of women do get their cancers picked up through mammograms.”

“I’m a great believer in screening…I’m still a believer, but I now know I can’t rely on it.”

However, some had lost confidence in mammography as a standalone screening procedure. These participants had heard from other women, and in some cases health professionals, that a mammogram plus an ultrasound is more effective way to identify breast cancer reliably. They were also influenced by their own experiences since several had undergone additional diagnostic test, such as an ultrasound or MRI, which had successfully detected their own cancer.

“Next time I see my surgeon I’m going to ask for an ultrasound, and I will pay for that, as well as a mammogram. I will trust an ultrasound more than a mammogram – it seems that it is more definitive and gives you more information than a mammogram.”
6.5 QUALITATIVE RESEARCH FINDINGS AMONG HEALTH PROFESSIONALS

GPs’ perceived role in promoting participation

The literature review and qualitative research among target and eligible women identified that one of the key facilitators of participation in breast screening is GPs encouraging women to participate. Most GPs acknowledged they have a role in this. However, two very different perceptions of this role emerged: proactive and reactive approaches.

Proactive GPs

Proactive GPs saw their role in encouraging screening as multi-faceted. They felt that it was their responsibility to:

- raise awareness of the Program among eligible women, although some were unclear about the eligible age range (section 7.5);
- attempt to motivate and encourage those who are reluctant to screen, by clearly describing the benefits;
  
  “I often bring it up at times of check-ups… I ask them questions about general health issues. It’s a good time to say ‘when did you last have a breast screen?’”
  “Even just to mention it is quite powerful. They often just do it.”
- respond to questions or concerns about mammograms or screening in general. For most this was about acknowledging the patient’s fear of discomfort or embarrassment and / or radiation concerns while reassuring them about the benefits; and
  
  “I say ‘[breast cancer is] commonly occurring and is curable if picked up early. Australia has a good cure rate because we have the screening program’. That kind of thing. Getting over the concept that a cancer diagnosis isn’t the end of the world.”
- provide reassurance to women who had been recalled if required, though most were not contacted by recalled women until after the further tests (section 12.4).

Proactive GPs were more likely to be female or younger males. All female GPs claimed to actively mention breast screening to their patients. This appears to be driven by a greater interest in women’s health than their male counterparts and having more female patients. Older female GPs also had personal experience of the BreastScreen Australia Program, which meant the subject was particularly top-of-mind for them.

Younger male GPs claimed to raise the subject with female patients when appropriate but often admitted that they did not have the same numbers of female patients as their female colleagues. They were also conscious that their regular female patients often go to a Women’s Health Clinic or female GP for women’s health issues.
Reactive GPs

Reactive GPs were highly unlikely to raise the topic with patients unless asked. They accepted and endorsed screening mammography but often did not feel it was their role to raise the subject or remind their patient about it. Instead they said they tend only to treat the patient for the problem they present with. If preventative health is addressed at all in the consultation it is usually focused on more ‘noticeable’ problems, such as weight, smoking and alcohol consumption. Indeed they said even these issues only tend to be addressed if linked to symptoms that the patient has presented with.

Reactive GPs were often older males. They claimed to have fewer regular female patients and were therefore less likely to be involved in preventative women’s health issues, including breast screening, pap tests, contraception for younger women and hormone replacement therapy.

Some of these GPs were from larger practices, where patients may see a number of different doctors in the practice over time. As a result they were often unsure whether mammography has been discussed with one of their colleagues. GPs said this issue is exacerbated by the fact that a discussion about breast screening is not often recorded on a patient’s history.

Reactive GPs were also from bulk billing practices, where there tends to be: a pressure of shorter consultation times; a more transient patient population with patients seeing other GPs both within and outside of the practice; and patients from lower socio-economic backgrounds for whom preventative health may not be a priority given the other competing priorities in their lives. The ‘competing demands of the consultation’ issue, identified in the literature review (section 6.3), therefore appeared to be a particular problem for doctors in larger and bulk billing practices.
Prompts to discussing screening

Female patients’ age was cited as the most common prompt to discussing screening mammograms with patients. GPs with proactive attitudes to screening claimed they usually raise the subject with their female patients in their early fifties. However, some reported that screening may be discussed with younger female patients. This was likely to occur: if a woman has a family history of breast cancer; if the patient had other breast problems in younger years such as cysts or inflamed nodes; or in response to specific anxiety about breast cancer from the patient.

Proactive GPs sometimes referred women under fifty to private services because they were uncertain about BreastScreen Australia eligibility criteria (sections 7.5 and 9.4) In a minority of cases, GPs were keen to discuss screening mammography with all women between 40 and 50. A reason given by one GP for this was that she had experience of female patients in this age range having been diagnosed with breast cancer through screening.

“I’ve picked up two women [with cancer] aged between 40 and 50 through BreastScreen in the last few months.”

GPs with proactive attitudes identified a number of other circumstances which might prompt them to raise the topic. These included: taking the history of a new patient; routine health checks, including blood pressure, cholesterol, pap tests and osteoporosis; discussion of menopause or hormone replacement therapy; and any discussion of cancer in the family.

Some GPs felt there is an opportunity to make the discussion of mammograms more of a standard routine when recording a patient’s history. This was particularly called for in large practices where a woman may see multiple doctors. Another suggestion was to incorporate alerts and reminders in GP desktop software. For example reminders could be activated: when a woman turns fifty; when the patient’s history is first recorded; or on a bi-annual basis. Some of the reactive GPs felt that practice managers would be responsible for this, rather than themselves.

Proactive GPs recognised that the practice is responsible for introducing alerts and reminders such as this. However, in most cases, this had not been done as it was not seen as a high enough priority. Practices run by proactive GPs may therefore be open to assistance in enhancing their systems.
Barriers to discussing mammography with patients

This research supported the finding that the ‘competing demands of the consultation’ was the primary barrier to discussing breast screening for all GPs, whether they had proactive or reactive attitudes. GPs agreed that they had difficulty finding the time to discuss the issue, especially if the patient presents with a number of other complaints or a very complicated problem. In addition, this may not be a priority if other ‘lifestyle’ risks to health need to be addressed, such as smoking, alcohol and weight.

“There is a time factor involved.”

“If someone comes to you in an emergency you’re not going to raise it.”

“You try and cover things off, but there is only so much time that you have…you just can’t address everything.”

“By the time you’ve had the pap smear, [they’ve asked] ‘what’s this Gardasil stuff? What’s my blood pressure? How are my blood sugars?’ Where do you finish? And then ‘by the way me and my husband aren’t talking’. You can’t spend four hours with each patient and do a comprehensive check.”

“If they come in for their ‘gynae’ check then it gets raised then but if they come in for something else I don’t discuss it.”

Women’s attitudes and ethical considerations were also identified as barriers to discussing screening. GPs argued that some women are simply not receptive to being questioned or reminded about mammograms. Some expressed concern that extra pressure from a GP could result in the patient discontinuing the relationship. This was supported by findings among women themselves.

“You discuss it, and sometimes they just keep refusing, so you leave it.”

“I changed GPs because mine kept nagging me about going for a mammogram.”

[Lapsed screener]

Some GPs did not see it as ethical to highlight the need for a mammogram among certain types of women, such as those with: mental health problems such as depression and anxiety; competing health problems; or other social difficulties, such as family or financial strain.

“Some women have other things to worry about … you don’t want to add to their problems … especially those from low SES.”

“There are those who have so many other things to look out for … you can’t add to the strain.”
GPs’ perceptions of barriers

GPs’ perceptions of the key barriers to participation supported the findings among the women in the research. They said patients had mentioned barriers such as: fear of the pain among never screeners; unpleasant experiences of the pain among lapsed women; a lack of appreciation of the benefits; concerns about radiation and a lack of familiarity with the services.

“There are some people who feel anxious about going to a big government bureaucracy. They’re happy to go to the practice they know.”

“The people who are resistant are anti-medicine and only came [to see the GP] because their leg was falling off and they’re usually highly educated Anglo-Saxons who’ve never had anything go wrong. They’re negative about drugs and radiation.”

Most were not aware of any particular barriers to participation for women from non-English speaking backgrounds. They tended to be unsure whether non-Anglo Australian women who were reluctant to screen were influenced by cultural factors or whether their attitudes were simply a function of their personality.

“Some of the older ethnic women are resistant. There’s a lady from Croatia who says ‘I don’t get cancer.’ She’s not going to go. I don’t know if it’s her ethnic background.”

Few were aware of any particular barriers for women from any other sub-groups. Though one GP had received negative feedback from a patient with a disability about the service. This is described in section 8.4.

Findings among breast physicians and nurse counsellors

The breast physicians and nurse counsellors were not particularly aware of facilitators and barriers to screening as they tend to come into contact with women who are already screening regularly.

Findings among Aboriginal health workers

Involvement in encouraging participation

The two Indigenous health workers in this sample indicated that they are very influential in whether or not Indigenous women choose to screen. They encouraged women to participate by explaining why it is important and organising transport. Explaining the purpose and process of breast screening before the procedure was felt to encourage regular re-screening. They mostly provide this information in English. However in remote communities, some older women prefer to have someone with them who can help explain screening in their own language.

“If you just bring them in, do it and then go home, they’re not likely to come back because they don’t understand.”

“Most women wouldn’t understand what it is.”

These health workers said they promote services among women who are over 40 and those who have a family history. They also visit communities, particularly in remote areas, to tell women that the mobile service will be visiting.
“We go out and explain that they need an appointment.”

Interestingly, Aboriginal health workers said they would not discuss breast screening with one of their own close relatives. They said they do not see this as culturally appropriate as the relative might be embarrassed by the discussion. If the health workers wanted a relative to be told about screening, they said they would ask another Indigenous health worker to do so.

“It’s probably a bit different to explain to them because they get embarrassed…It would be better for someone who is not related.”

Facilitators of screening

Other than their own involvement in encouraging screening, the Aboriginal health workers said that hosting mammography services in or near to Indigenous health centres helps to encourage participation. This is because Indigenous women are more comfortable having mammograms at a clinic that they are already familiar with.

The collaboration between BreastScreen Australia and Aboriginal health workers was also seen as helpful. Respondents said information is shared between the two and in one area they worked together to promote breast screening.

“She [BreastScreen Australia staff member] keeps in touch with us about women who have had diagnostic procedures.”

“We keep in touch about how to promote BreastScreen together.”

Barriers to screening

In common with Indigenous women in the sample, Aboriginal health workers identified transport as a key barrier to participation for this audience. They felt BreastScreen Australia should work with Indigenous health services to organise travel for women, both in metropolitan and remote areas. They felt travel is particularly challenging for older women who might have mobility issues.

“They only have travel when we organise it….We usually go and pick up a whole heap of them.”

Another issue from the point of view of Aboriginal health workers was that the centralised system used for reminders does not seem to be very effective in reaching Indigenous women. Moreover, the system does not inform health workers that a woman is due for re-screening. The respondents therefore felt there was a reliance on Indigenous health services to monitor women and ensure they attend regularly.

“They (BSA) rely on us to fill the gap. We have to remind ourselves…we need a registry.”

Lack of promotion aimed at Indigenous women was another barrier to participation identified. The health workers felt reminder letters are only appropriate and effective for a small proportion of Indigenous women because populations are transient and Indigenous women often have low literacy levels.
6.6 CONCLUSIONS

Facilitators of mammographic screening include: a belief that the benefits of screening outweigh the barriers; a referral or recommendation from a doctor; communications from BreastScreen Australia encouraging participation; encouragement from friends and family and the quality of the service provided by BreastScreen Australia. Facilitators were similar among women in all sub-populations. However, encouragement from a health professional within their community appears to be particularly motivating for women from non-English speaking backgrounds and Indigenous women, where this occurred.

A wide range of factors discourage participation in the BreastScreen Australia Program. Women with active barriers to mammographic screening have entrenched views and may require more in-depth information and arguments than other women to persuade them to participate. Those with passive barriers often seem to be put off by the cumulative effect of a series of barriers, including some or all of the following: a lack of appreciation of the relevance and benefits of screening; concerns about the process such as the lack of familiarity of the service; the pain and embarrassment experienced during the procedure; low awareness of the BreastScreen Australia Program; and a perceived lack of accessibility and/or acceptability of the BreastScreen Australia Program.

Issues relating to awareness of the Program and perceptions of its accessibility and acceptability are discussed in the following sections. This section has predominantly focused on barriers among lapsed and never screeners relating to mammographic screening. Within this, three key issues need to be addressed in order to enhance participation rates. Firstly there is a need to ensure that all women appreciate the purpose of regular screening mammography in the absence of symptoms. Secondly, women in the target age range from all cultural backgrounds need to understand why screening is particularly relevant to them. Thirdly, the benefits of screening need to be reinforced and women reminded that these outweigh the barriers, even though the downsides may seem more numerous and immediate.

Findings indicate that these messages could be delivered via three key channels: mass-marketing communications; direct marketing including materials sent with invitation letters; and via GPs and community health workers. The latter audiences may require some assistance to help make discussions about BreastScreen Australia a more routine part of their work and to ensure they are appropriately prepared to discuss the topic with women who are resistant to participating.
7. THE PERCEIVED AVAILABILITY AND ACCESSIBILITY OF THE PROGRAM

7.1 INTRODUCTION

The evaluation question covered in this section is: ‘To what extent is the Program available and accessible to all eligible women, in particular to sub-populations of women where participation is lower than the national average?’ Awareness of the Program is discussed in this section, since women and health professionals’ perceptions of its availability and accessibility are only relevant if they are aware that it exists.

‘Availability’ and ‘accessibility’ are similar terms and are sometimes used interchangeably by respondents. In this report, ‘availability’ is used to relate to perceptions of whether or not women could theoretically use the service. For example, the service is not available to women who are under 40 or to women who are not physically capable of making use of mammography services due to a disability that means an x-ray cannot be taken. The service could also be considered to be unavailable to women who live in remote areas that are not visited by the mobile unit.

‘Accessibility’ is used to relate to the level of ease with which women can participate in the Program. This covers issues such as perceptions of: how long it would take a woman to get to the clinic; costs associated with travelling to the service or opportunity costs of taking time off work; their ability to visit the service during its opening hours; the flexibility of the appointment system; and the ease of getting into the building or using facilities when there.

7.2 LITERATURE REVIEW FINDINGS AMONG TARGET AND ELIGIBLE WOMEN

Awareness

The studies that mention awareness in the literature review tend not to distinguish very clearly between awareness of the Program and familiarity with the BreastScreen (Australia) brand name. A qualitative study in NSW, Queensland and Victoria found that most women seem to be aware of the existence of free mammography (18). However, findings in the literature review were contradictory over whether women are able to identify whether or not they have used BreastScreen Australia services. A national study found that women in the eligible age range were able to recall the brand name (9) and another found that two in three had heard of BreastScreen Australia (41). A qualitative study in contrast (18) found most could not recall the name of the service they had used. It should be noted that the latter study was only conducted in three states. A hypothesis drawn was that awareness of the brand varies across Australia. This was explored further in the qualitative research.

The literature review indicated that some women may not be aware that BreastScreen Australia is a self-referral service and believe that a doctor’s referral is required (50, 70). This may be a barrier to using the service for some.
Perceived availability

The review found limited information on perceptions of the availability of BreastScreen Australia services. Two articles contained relevant information on this issue and indicated that availability is a problem in remote areas, especially in the Northern Territory (NT) and for women with certain physical impairments.

A report on 10 years of service by BreastScreen NT (56) highlights that the Northern Territory was the last jurisdiction in which the Program was introduced, following pressure from local women for BreastScreen Australia services to be available to them. The study concluded that women seldom view population level screening services from a ‘rational’ cost-benefit perspective. This study also noted the availability of services in the NT is relatively limited with breast screening only taking place in four regional centres.

Research in the UK highlights that mobile screening mammography units make breast screening available (as well as accessible) to more women (15). Within Australia, a report on Rural Mobile Screening Services in Victoria indicated that the availability of the service would be enhanced if women were made aware of when the units would be visiting all the towns in the area, not just their nearest town (48).

One article on screening mammography for women with cerebral palsy (62) highlights that some women with more severe disabilities are not able to make use of mammographic breast screening because of the need to remain motionless as the x-ray is taken. The Program is therefore not available to this audience, since no alternative means of screening are offered. The article suggested that ultrasound screening could be made available to these women instead. However it should be noted that there is little clinical evidence that supports the use of ultrasound in screening asymptomatic women23.

Several studies highlight that many women feel that the service should be more widely available to include women aged under 40, often describing the current age eligibility criteria as unfair or discriminatory (18, 48, 50, 56, 75). Some women have been reported to believe that the target age range has been set for economic reasons (75)24. In many cases women express bewilderment at why younger and older women should be ‘excluded’ (18). This is exacerbated by inaccurate perceptions of risk fuelled by media-reporting of breast cancer, which focus on young celebrities such as Belinda Emmett and Kylie Minogue (20, 27) (section 11.3).

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23 Beran et al., 2005; Knutson & Steiner, 2007; Teh & Wilson, 1998 (see section 6.4 above)
24 The BreastScreen Australia program targets women 50-69 years of age as an assessment of evidence by the Department of Health and Ageing indicates these are the years of higher risk and optimum benefit from screening.
Perceived accessibility

There was limited information in the literature on perceptions of accessibility of the Program among women in general. However, findings confirmed that accessibility is a particular issue for the key sub-populations discussed in section 6.2, except for single women:

- women from lower socio-economic groups (17, 34);
- women from non-English speaking backgrounds (22, 23, 34, 43, 53, 55);
- women from Indigenous communities (18, 46, 73); and
- women in rural and remote communities (74) and
- women with disabilities (56, 62).

Women from lower socio-economic backgrounds

Three studies referred to accessibility for women from lower socio-economic backgrounds (17, 34, 35). Two indicated that participation could increase for women from the most disadvantaged groups if they have less distance to travel (34, 35). The other study identified that participation among women from this audience increased when they were actively targeted and followed-up by BreastScreen NSW (17). The latter finding suggests that accessibility issues for this audience may be perceptual in some cases, since they can be reduced by reinforcing beliefs about the benefits of screening.

Women from non-English speaking backgrounds

The review suggests that accessibility may be an issue for some women, in particular for recent arrivals to Australia who speak South-West Asian, South-East Asian and African languages (55). This may be due to lack of access to, and knowledge of, health services, especially where screening is not a practice in their country of origin, as a result of language barriers and possibly perceived discrimination.

Indigenous women

The literature indicates that travel is a key barrier to access for Indigenous women living in remote communities (46), though Well Women’s clinics help to improve accessibility and some women from remote areas in the NT make group bookings and travel to screening centres together (56).

Women in remote communities

As discussed in section 6.2, there may be a correlation between access issues for Indigenous women and women living in very remote communities. However, the literature did not provide any illumination on this, nor on any other access issues for women in these areas. Indigenous and non-Indigenous women in remote areas were included in the qualitative research sample to explore this further.
Women with disabilities

The literature search only found two studies that focused on issues of accessibility for women with a disability. The first reviewed barriers to taking part in breast screening among women with cerebral palsy (62) and highlighted that lack of assistance with transport was a barrier for these women. The other study referred to accessibility as an issue for women with physical impairments (56).

Single women

The literature did not provide any information on whether accessibility is a key barrier for these women, so this was explored further in the Participation Qualitative Research.

7.3 LITERATURE REVIEW FINDINGS AMONG HEALTH PROFESSIONALS

There were no studies in the review that mentioned awareness of either screening mammography or the BreastScreen Australia Program. However, one study in WA (64), found that 97% of GPs surveyed reported referring patients to screening mammography, which suggests awareness of the existence of screening mammography is almost universal.

The same study found that 32.6% of GPs spontaneously indicated that the 'close proximity' of the BreastScreen Australia service for patients was one of the reasons given for recommending it. However, proximity was less top-of-mind for respondents than the fact that the service is free (97%) and of high quality (65.9%). This finding gives some indication that access is perceived to be acceptable among GPs.

7.4 QUALITATIVE RESEARCH FINDINGS AMONG TARGET AND ELIGIBLE WOMEN

Awareness of the Program and BreastScreen Australia brand

Awareness of the existence of a free, national mammographic screening Program was high across the sample. However, certain groups seemed to have lower awareness (section 6.4), including: women who are disengaged from primary health services; women at the younger end of the age spectrum; and women with complex lives for whom breast screening is a low priority. Awareness of the national Program also seemed to be lower among women from Arabic and Vietnamese communities. Iraqi women were particularly unfamiliar with the Australian health system and appeared to find the idea of accessing services overwhelming.

“The fact is we really know that it is good to get early information about our health so we can get treatment but here we feel like strangers and don’t really know how to do things.” (Iraqi woman)

Awareness was higher for Chinese and Greek participants. Indeed recruiters for this study reported that Greek women in the target age range who were lapsed and never screeners were difficult to find. Some women in the Chinese group also mentioned that their GPs had discussed screening
mammography with them. Awareness was relatively high among Indigenous women, especially those in rural and regional areas who had seen the ‘bus’ or ‘van’ and among women with disabilities.

Despite high awareness of the Program overall, awareness of the BreastScreen Australia brand varied considerably across locations. In some areas women spontaneously used the terms ‘BreastScreen’, ‘BreastScreen Australia’ or ‘BreastScreen [their state]’. These women tended to be completely sure that they had used BreastScreen Australia rather than private services. This seemed to apply in areas where there is less choice of services, such as in large regional centres, or where women were aware of marketing activities. For example one woman had brought a BreastScreen Australia mirror with her to the group discussion.

“They give you mirrors and shopping bags. There’s lots of advertising paraphernalia. It’s all about awareness. I got [the mirror] at a seminar. I might have been to their breakfast.”

In other areas, especially some large metropolitan areas, women were not sure whether the service they had used was BreastScreen Australia or not. They did not use the brand name. Instead they described the location of the place they been to for screening, or used the clinic name.

Awareness of the BreastScreen Australia brand was particularly low among women from non-English speaking backgrounds and Indigenous women. It should be noted that the research among women from non-English speaking backgrounds took place in large metropolitan centres where awareness of the brand was also lower among the main sample. Indigenous women tended to use other terms for the brand such as ‘the van’, ‘the bus’ or ‘the Government one’.

**Perceived availability**

Overall, the Program was perceived to be highly available and accessible. Many felt that Australian women are lucky to have access to such a service. They appreciated that a free breast screening service is not available in all countries and that men do not have similar screening services available for diseases such as prostate or testicular cancer.

“They’re available to everybody and it costs nothing, so really you have no excuse whatsoever for not going.”

However the restricted availability by age was questioned by women in this research, as in many studies cited in the literature review. The overwhelming majority believed free breast screening should be available to women of all ages. This was either because they did not appreciate that age is a key risk factor or, even if they did know this, could not understand why younger women cannot also be screened. In particular, many questioned why women over 70 were no longer targeted, given longer life expectancies in today’s society. Very few had heard that the efficacy of the procedure is lower for women outside the target age range.

“They say 70 is the new 50!”
In addition, the woman with Post Polio Syndrome did not consider that BreastScreen Australia was available to her. She did not want to have another mammogram because of the long-term pain she experienced afterwards as a result of her condition. However she reported she had been told that her only alternative was to have an ultrasound at a private service, since she could not have an ultrasound within BreastScreen Australia without having a mammogram.

**Perceived accessibility**

Many of the women in the main sample felt that the service is highly accessible. For those living in metropolitan or regional centres, few would have to travel for more than 30 minutes to reach a screening centre and metropolitan mobile services can make it even easier to get to. In some cases, women reported that staff had gone out of their way to enhance accessibility. For example, one woman was very complimentary about a receptionist who always coordinates her appointment with the bus timetable.

However, as was identified in the literature review, accessibility was an issue for some women. The particular issues for each sub-population raised in this research are discussed below.

**Women with ‘complex lives’**

As discussed in section 6.4, getting to a BreastScreen Australia centre during its opening hours can be difficult for women who work or those who have caring responsibilities such as a sick husband or parent. However, access often seems to be a reinforcing factor rather than a primary barrier for these women, since some admitted they can find time to make use of other health services. This supports the hypothesis that women are deterred by the cumulative impact of barriers, such as a lack of perceived relevance and the expectation of pain, as well as access issues.

**Women from lower socio-economic backgrounds**

Costs associated with travelling to BreastScreen Australia were not cited in general by women from lower socio-economic backgrounds as a barrier, though a few complained that parking can be very expensive at some services. However, women from this audience seemed to be more likely to be working or caring for relatives than women from higher socio-economic backgrounds. The issues relating to having ‘complex lives’ (see above) were therefore more likely to be relevant to this audience.
Women from non-English speaking backgrounds

Lack of transport and interpreting services were perceived to restrict access among women from non-English speaking backgrounds. Transport was reportedly a problem for Iraqi, Greek, Chinese and Vietnamese women, who tended to be dependent on family members as they did not have driving licences or their own vehicle. In some cases, they expected BreastScreen Australia not to be accessible by public transport and suggested that mini-bus services could be provided.

“I heard that the locations are hard to find. I had a friend who had an appointment and couldn’t find it on public transport so she didn’t go.” (Iraqi woman)

“Really the problem is that we don’t know where to go…unless someone organises an appointment for us and actually takes us to the clinic it is very difficult for us to go on our own. We don’t speak English. It’s hard to get around on public transport in areas we don’t know.” (Iraqi woman)

However, some Chinese and Lebanese women did not find access a problem. For example, they were aware of services near shopping centres and said the visual presence of mobile units had provided a trigger to action.

“It is a very good idea to have these places where the main shopping centre is so we know where it is and when we see it, we can remember to go as well.” (Lebanese woman)

“I go shopping after my screen. It’s very close to home.” (Chinese woman)

Across non-English speaking audiences, there was an expectation that access to interpreters would be limited. Lapsed users in these groups confirmed this was their experience of using BreastScreen Australia services. Both lapsed and never participants felt that having access to either an interpreter or bilingual health worker would increase comfort levels and encourage them to screen regularly. Assistance of this kind was seen as particularly important during a first visit to help explain unknown factors and procedures. This issue was most crucial for recent arrivals to Australia.
Indigenous women

Some Indigenous women in metropolitan areas who were regular screeners saw BreastScreen Australia services as convenient and accessible. Regular screeners in the remote area were served by a two-yearly visit from the bus and said they would be unlikely to screen if this was not available to them.

“If we didn’t have them [the mobile service] I wouldn’t be going.”

“We’d get lazy wouldn’t we?”

However, accessibility can also be a serious barrier for Indigenous women. Women in one remote area said that the mobile service is easy to miss because they reported it is only in town for two days every two years. Reasons for missing the visit included being away from the community or being busy caring for grandchildren. This was considered a common problem in Indigenous communities because of the transient nature of the populations. For example, one woman who was committed to regular screening had lapsed because she had been visiting relatives in another community when the ‘bus’ was in her town.

“It’s not there when we need to go.”

“I just wait for the next one...you got to wait two more years to have one.”

Some Indigenous women also said they had missed out if they were menstruating when the mobile service was visiting. It was not clear whether they had been told they could not visit at this time or had assumed it would be a problem. There was no indication that this was a culturally-based belief. However, it is possible that some Indigenous women may have mistakenly assumed instructions for other women’s health tests, such as pap smears, also apply to mammography. Some women also suggested that women in their forties might not be able to attend because they were breastfeeding.

Accessing services beyond the mobile service required travelling to regional centres, which was seen as inconvenient, expensive and difficult. Another issue for this audience was that there was a tendency to prefer to use mammography services with a family member for support. The lack of a fixed location service was therefore an important barrier, since both the woman and her companion would need to be available when the mobile service is in town. Women therefore requested that the mobile unit was in the community for longer periods to give them more flexibility about when they attended.

In addition, getting to the mobile unit was problematic for some Indigenous women, particularly those who did not have their own transport, as they had to travel up to 50km to reach it. In addition, in one area, Indigenous women reported not being able to access the BreastScreen Australia mobile unit was ‘full up’.

Findings indicate that the location of the mobile service can affect its perceived accessibility, and hence take-up. For example, in one area, women liked the fact that the mobile screening unit is parked near the Indigenous health centre. This was considered a familiar location and women felt

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25 Note: The length of time that a mobile unit stays in each location varies according to the size of the population. The unit may only be available in the remote area referred to by this respondent for two days but in other areas mobile units stay in a single location for weeks or months.
other people would not know whether they were attending the breast screening ‘bus’ or the clinic. In another area, women complained that the ‘bus’ was parked in the town square because they felt this was too public.

“They should put it in a place where people don’t see you going it. Not at the town square!”

Indigenous women across locations felt access could be enhanced. Those in metropolitan areas who had to travel to another suburb to access a BreastScreen Australia service felt this was a barrier, as they did not own cars. However, regular screeners who lived in the same suburb as a BreastScreen Australia service did not feel access was an issue. Nevertheless, many felt that if mobile services visited Indigenous areas, including in metropolitan areas, accessibility would be significantly enhanced.

**Women in rural and remote communities**

Access was primarily considered to be a barrier for Indigenous women who did not have their own transport in rural and regional areas, as well as those who were dependent on the mobile unit. In contrast, the two women in the sample living in remote areas who were not Indigenous did not cite distance as a barrier to using BreastScreen Australia. Both women had their own cars and believed there was a static BreastScreen Australia service at their nearest regional centre, which they regularly travelled to for other purposes. They said they were used to travelling large distances and their reasons for screening were not related to access issues. However, it is likely that non-Indigenous women who are dependent on mobile units or who do not have their own transport would face some of the same barriers as Indigenous women.

**Women with disabilities**

The women with disabilities who had used BreastScreen Australia services in this sample had not found that physical access was a problem. All could reach their nearest service on public transport and had not had any difficulties getting into the building. They had also found that staff were willing to accommodate their needs to enable them to access the procedure, for example by lifting their arm for them if they were not able to do this for themselves.

“They treated me very well. They knew I couldn’t lift my arm so they held it.”
However, the woman who had never screened had heard that screening took place in mobile units and had therefore assumed she would not be able to access the unit in her wheelchair. She also said she would need a hoist and at least two staff members to help get her into position to use the mammogram machine and was not sure if this would be possible.

All of the women with disabilities felt there was scope to enhance accessibility for women with conditions like theirs. They suggested that BreastScreen Australia clinics that have facilities for women a disability, such as extra wide doorways or hoists, could be advertised more widely. They also suggested that assistance with transport to and from the clinic would greatly enhance accessibility for disabled women. Encouragement to attend from a disability coordinator was also suggested as a way to motivate women with disabilities to participate.

Single women

As discussed in section 6.4, (page 71) no obvious barriers in terms of awareness or access were raised that were specific to single women.

7.5 QUALITATIVE RESEARCH FINDINGS AMONG HEALTH PROFESSIONALS

Awareness of, and knowledge about, the Program

The majority of GPs were aware of the Program. They commonly described it as a free mammography service for asymptomatic women over 50 years of age for the purpose of early detection of breast cancer. Features that were spontaneously described included the following:

- women are encouraged to attend every two years;
- once started in the Program women are sent reminder letters;
- BreastScreen Australia clinics specialise in screening mammography to the exclusion of other radiology services;
- a certain proportion of women are recalled and sent to an assessment clinic, however most of these cases do not result in a diagnosis of breast cancer;
- as GPs, they are sent a copy of the results at the same time as their patient and are often phoned if a diagnosis is made; and
- women should still have clinical examinations between screenings.

Only two GPs displayed little or no knowledge of the BreastScreen Australia Program. In the sample they represented an anomaly within this sample but it should be noted that GPs with low levels of awareness of the service may have been disinclined to take part in the research, resulting in a skew towards more knowledgeable GPs. The views of the two less knowledgeable GPs may therefore reflect a larger proportion of the audience in reality.

Despite the high levels of knowledge about the Program overall among GPs in the sample, gaps were evident. These spanned both knowledge about operational and policy aspects of the BreastScreen Australia Program and breast cancer detection more generally. One of the key gaps in knowledge about the BreastScreen Australia Program was age eligibility. GPs in some
jurisdictions were uncertain about whether women aged 40-49 and over 70 could participate. They were also unclear about the age at which women with a family history could, and should, be encouraged to take part.

GPs said they would appreciate more information on best practice principles in terms of motivating women to attend. In addition, several expressed a desire to know how women are first invited into the Program. Some thought this was through the electoral roll, while others did not have any idea how this was managed. There was also interest in the process itself, which some had been asked about by patients. Given women are uncomfortable about their first visit (section 6.4), participation may be enhanced if GPs are able to talk them through the process.

“I don’t know how it works…If someone says ‘can you do it in your lunch break?’ I have to say ‘I don’t know’…I want to know do they need to take the day off work, the morning?”

In terms of screening and breast cancer prevention more broadly, some GPs wanted to know more about best practice clinical guidelines, particularly the efficacy of clinical examination and breast self examination. There was also interest in finding out more about the suitability of screening for women from older age groups and for those with breast implants.

“I think it’s just changed. Are we supposed to do a clinical exam each year?”

“I’ve got some really healthy female patients in their seventies and eighties…I want to know if they can go.”

The nurse counsellors and one of the breast physicians worked within BreastScreen Australia and thus were highly knowledgeable about the Program. The other breast physician worked in a private clinic but had some knowledge about the way the Program worked. This came from hearing about BreastScreen Australia experiences from her patients, as well as from colleagues who had worked at BreastScreen Australia in the past.

Both Aboriginal health workers worked to help encourage participation in the Program so were aware of its existence. However, one was more knowledgeable about the Program than the other. The more knowledgeable respondent worked at a health centre that is visited by a mobile BreastScreen Australia unit and was therefore aware of how the Program works, including recall and diagnosis procedures. The other respondent had not visited the local BreastScreen Australia clinic and did not know much about the procedures, how the results are communicated or follow-up services. Both expressed interest in being provided with more information about the Program, in particular in relation to best practice in encouraging participation.

**Perceived availability and accessibility**

GPs, both in metropolitan and regional areas, tended to feel that the availability and accessibility of BreastScreen Australia is one of the Program’s strengths. They made similar points to women in the sample about this, commenting that it is free to women in the target age range and there are enough clinics to enable most women to get to one with relative ease.
In common with the women in the research, some GPs felt that the age eligibility criteria is questionable, arguing that women should be encouraged to talk to their doctor about whether it is still appropriate for an individual woman to participate beyond the age of 70. For example, one GP said she felt it appropriate to refer a woman of any age if she still has a life expectancy of more than 10 years.

“When women turn 70 they get the impression that they can’t get cancer now they’ve reached the magic age of 70. I think that’s the wrong message. They should be reading that the government is not prepared to pay any more because they think [women over 70] are going to die with breast cancer not from it.”

“For the patient [aged 70] who feels they’ve been lopped off the list and finds a lump they would be incredibly confused. Literature should be given to them about it. That is a definite failing.”

Some GPs were also unclear about the eligibility of women aged 40 to 49 and the rationale for targeting women aged 50 to 69. Not all were aware that there is less evidence to support the efficacy of screening from 40 to 49 (section 13.4).

The breast physicians and nurse counsellors working within BreastScreen Australia felt that the Program does a good job of providing access to women, given the resources available. However, they did acknowledge that accessibility was greatly reduced for women who do not live in a town or city which has a static BreastScreen Australia service. Even in areas that are served by mobile units, accessibility is compromised by the fact that women may have to travel long distances if recalled for assessment.

Indeed one breast physician working in a regional area said she had noticed a fall in participation when petrol prices had risen in 2007. She attributed this to women from outlying areas reducing their travel into the regional centre. However, she said her regional service aimed to reduce financial inaccessibility for women in rural areas by providing forms for the Isolated Patients’ Transport and Accommodation Service (IPTAS). In another state, a nurse counsellor said her service encouraged take-up of a similar travel allowance. Moreover, health professionals working in regional areas tended to say that women who live in rural and remote areas are often used to travelling long distances for all their needs, so did not attribute distance as a key barrier to participation.

However, all health professionals acknowledged that access is more of a problem for women from Indigenous communities. One breast physician reported that her service had recently taken a mobile unit to a remote Indigenous community but had not had great success in encouraging the women they encountered to participate. She felt that more work needs to be done to prepare for this type of activity in future. The Aboriginal health workers cited access as a key barrier for their clients, although both said their services provide transport to help women attend screening.
7.6 CONCLUSIONS

Awareness of the existence of a free national Breast Screening program was high across the sample. However, some groups were less aware, especially among women from non-English speaking backgrounds. Awareness of the Program and the BreastScreen Australia brand could therefore be enhanced, in order to increase participation. This is discussed further in the section on the impact of BreastScreen Australia communications (section 10). There is also scope to increase GPs’ awareness of the BreastScreen Australia operational and policy process. This would enable them to talk women through what happens, if they are concerned about using the service because it is unfamiliar. Possible ways of conveying this information to GPs were not covered in the discussions.

Overall the program was perceived to be accessible and available by women and health professionals. Some groups however feel the program is less available and accessible. Improving availability of services in rural and remote areas would be welcomed by many. However, consideration could be given to enhancing the availability of breast screening for women with disabilities.

Findings indicate that access is an important contributory factor in lower participation rates among women from non-English speaking backgrounds, Indigenous women, women with disabilities and women with ‘complex lives’. Other factors also need to be addressed among these audiences, such as communication of the relevance of screening (section 6.4) and the acceptability of the service for women from different cultural backgrounds. However, assistance with transport and accessibility could help to reduce the cumulative effect of the barriers facing these women.
8. THE PERCEIVED ACCEPTABILITY OF THE PROGRAM

8.1 INTRODUCTION

The question addressed in this section is: “To what extent is the Program acceptable to women and other stakeholders, such as health professionals?” ‘Acceptability of the Program’ is used in this report to refer to the level of satisfaction women and health professionals have with the elements of the Program that BreastScreen Australia has control over. This includes the attitudes and approach of staff, the facilities provided and the information imparted (although communication issues are also covered in sections 10 and 11).

Issues that are not covered here are those which BreastScreen Australia has limited ability to affect such as perceptions of mammography. Issues relating to ‘availability’ and ‘accessibility’ are also not covered here as they have already been addressed in section 7.

8.2 LITERATURE REVIEW FINDINGS

Perceived acceptability of the Program to women

Perceived acceptability overall

Two satisfaction surveys were included in the literature review. One (22) indicated that 80% of users of the BreastScreen NSW service rated it as ‘excellent’. In a survey of women who had attended assessment clinics in NT (57), 94% rated the service as ‘excellent’ or ‘good’. However, these findings should be treated with caution since the surveys were conducted with users of the service, and are therefore likely to be skewed towards the views of those who have positive attitudes towards screening. Moreover, those who were less satisfied may not have taken part in the survey. The NT survey for example was a self-completion postal survey and the response rate was 38% (57).

One study in Victoria found that women had a high regard for the expertise of BreastScreen Australia staff (50). There was a common assumption that BreastScreen Australia staff would be more capable than their peers in private services because breast screening is ‘all they do’ (50).

As discussed in section 6.2, perceptions of the acceptability of the Program are closely linked to the experiences of the mammogram itself and to views on screening. It was not clear from the literature review whether issues relating to physical discomfort are predominantly a function of having a mammogram or relate to the acceptability of the service. One study identified that women may be dissatisfied if the ‘pain’ or ‘discomfort’ experienced was worse than last time, worse than expected or if women experience problems with their breasts following the mammogram (22). This suggests that the mammography experience affects perceptions of breast screening to a greater degree than the acceptability of the service.
However, a different study indicated that the acceptability of the service can be enhanced by setting expectations about the discomfort involved in advance, especially for first-time screeners (66). In another report, findings indicate that women may view staff more positively if they offer prior warning about the discomfort involved (48). This was therefore explored at a national level in the Participation Qualitative Research.

The acceptability of the service appears to be affected by the extent to which women feel emotionally comfortable throughout the process. Embarrassment seems to be a key barrier to participation (2, 18, 57) (section 6.2). Satisfaction with the service provided is therefore influenced by the extent to which privacy is offered to allow women to maintain their dignity (50, 57). The ‘courteousness’ and ‘sensitivity’ of staff are also highly valued (57). The satisfaction surveys indicate that BreastScreen Australia staff are highly rated on these criteria among users of the service (22, 57). However, qualitative research indicates that there is room for improvement in some services (18).

Studies among women from non-English speaking backgrounds (see below) suggest that acceptability of the Program may have an impact on re-screening rates (53, 55). The issue of the acceptability of the Program on re-screening for women in the general population was not covered by the articles reviewed and was therefore explored in the qualitative research.

**Perceived acceptability for women from sub-populations**

Issues with the acceptability of the service among women from a wide range of non-English speaking backgrounds, Indigenous women, lesbian and bi-sexual women and women with disabilities, were also raised in the review (22, 53, 55, 56, 62, 73). The lower re-screening rates among women from non-English speaking backgrounds, such as speakers of Asian and African languages identified in two studies (53, 55), may be due to a lack of cultural sensitivity on the part of staff (22). One study suggests that this issue may be most acute for the most recent arrivals to Australia due to greater cultural differences between these women and BreastScreen Australia staff (55).

This is also an issue for Indigenous women. A report evaluating the Well Women Program (73) indicates that take-up among this audience could be enhanced by involving more Aboriginal health workers in the Program. Studies indicate that lower screening rates among women with disabilities (56, 62) and lesbian women (56) may also be due to experiencing, or expecting to experience, ‘negative attitudes’ from BreastScreen Australia staff.

**Acceptability of the Program to health providers**

The review revealed limited information about GPs’ perceptions of the acceptability of the BreastScreen Australia Program. The WA study mentioned previously (64) reported that 44% of GPs preferred BreastScreen WA services, 7% preferred private services and the remainder had no preference. However, it was not clear from this study to what extent preferences were based on perceived acceptability versus other factors. This was therefore investigated in the qualitative research.
8.3 QUALITATIVE RESEARCH FINDINGS AMONG WOMEN

Overview

Findings from across the sample revealed a great deal of variability in the service exists, both between and within jurisdictions. For example, differences were apparent in terms of: the perceived attitudes of staff; whether invitation or reminder letters are followed up with phone calls or not; whether recalled women are phoned or receive a letter to ask them to attend an assessment clinic; and if males are allowed to accompany women to the centre. There was also a great deal of difference between services in different areas in terms of time taken to receive initial results and book in for an assessment appointment.

Levels of satisfaction among women in this sample were high overall. Many were extremely complimentary in general and few were critical, albeit most offered suggestions for improvement (see below).

“It’s an excellent program… they choose their staff really well.”

“They’ve got a really good set up.”

“They are to be commended on how they run it and who they have running it.”

As was noted in the literature review, many felt the BreastScreen Australia staff must be experts because breast screening is ‘all they do’. Moreover, women who had participated for many years tended to feel BreastScreen Australia is improving.

“It’s changed a lot over time. It’s much better than it used to be. Where we go is nicer, the women are nicer.”

“When I first went it tended to be older women doing it. Some of them were a bit brusque because they were old school. And the machines were terrible! They’re a doddle now. They just finally redesigned them. One of the operators said ‘we’ve got new machines and we’ve finally had a say in the design’.”

The acceptability of the Program has been analysed in terms of the four key stages that emerged as potentially being involved in the process. This is represented in figure 5.

Figure 5: Key stages in the BreastScreen Australia Program process discussed by women
Getting booked in

Most women in this research reported positive experiences of being invited to participate and when making appointments. *Regular screeners welcomed the letters they received encouraging or reminding them to screen.* Several spontaneously commented that the tone of these was appropriate because they appear to be ‘inviting’, rather than issuing a command.

In some cases, staff members had called women to follow-up the letter. This was perceived as an effective and acceptable approach, particularly for women screening for the first time, who said they had required more encouragement to take the step to confirm the appointment.

“*The letter is good because it’s] sort of almost saying ‘we’d like you to come in on this day because it is for your benefit’.*”

In most cases, women reported that the staff members they spoke to when making appointments or asking questions were polite, friendly and helpful. There was particular praise for some receptionists who seemed to have gone out of their way to accommodate patients, for example by fitting the appointment in with the bus timetable, as described previously.

Only a minority had criticisms of this stage in the process. A small number felt that not enough had been done by the service to accommodate their needs. In particular, some of those who were working full time in occupations with inflexible hours felt that appointment times were too rigid. In addition, one of the women with a disability reported poor experiences of rescheduling appointments (see below).

On the day

While none of the respondents said they *enjoyed* their experience of mammography through BreastScreen Australia, since discomfort and embarrassment were unavoidable, many reported an *optimal* experience on the day. Women felt the experience was to their satisfaction when they found themselves in a welcoming, women-friendly and reassuring environment. This occurred when staff, including receptionists, were talkative and warm at the same time as projecting professionalism by not being over-familiar.

“I thought the staff were absolutely brilliant. They were very caring.”

“The girls that do the mammogram I believe are very aware of your discomfort and possibly your embarrassment and whatever and they speak relaxingly.”

“People spoke calmly and dealt with me in a gentle way, probably guessing that I was feeling a bit vulnerable, I just thought they were just the right people for that job, they had been clearly well chosen.”

“They talk to you about other things as well, they really try and take your mind off it.”

Women also liked the environment to be homely rather than clinical in terms of the décor and commented positively on details such as access to tea, coffee and magazines in the waiting room. In one clinic, a joint knitting project was available for all women to take-up in the waiting room, which was a highly praised initiative.
There was also appreciation of attempts to create a sense of individualisation in the process, as opposed to leaving women feeling like they were being ‘herded through a cattle station’. Examples of this were the provision of baskets for women to put their belongings in during the mammogram and providing brightly coloured, rather than clinical-looking, gowns. Both of these embellishments were spontaneously mentioned in extremely enthusiastic terms by numerous respondents across groups, where they were available. In some areas, women were complimentary about the fact that they had not had to wait in the waiting room for very long.

“They don’t over book, they’re very good…I’m in and out probably within 15 minutes.”

The extent to which women felt the mammogram operator had made an effort to minimise their discomfort and embarrassment emerged as a key factor that affected perceptions of the acceptability of the service. The most important manifestation of this was that there should be a perceived attempt not to squash women’s breasts any harder than necessary. Those who had screened more than once commented that the level of compression had varied on different occasions and they attributed this to the level of concern the operator had for their feelings and comfort.

“One of them said to me ‘there is no need to pressurise that much to get the photo, if it doesn’t come out properly they will do it again from another angle but there’s no need to squash it until tears run out your eyes’. [Whereas] the first time was so painful I’ve never had anything like it in my life.”

As identified in the literature review, prior warning about the discomfort was considered helpful, especially for first-time screeners. However, women felt it was important that this information was imparted appropriately, that is the operator should not also comment on the woman’s breasts and not underplay the level of discomfort that would be experienced. In addition, women in one area spontaneously mentioned that they had been told why the compression is necessary and had found this helpful.

“She said this might be a bit uncomfortable. That was the understatement of the decade!”

“Once I read something, sitting in a cubicle. It said they’ve got to squash it because they’ve got to get it as thin as possible so if there’s a problem in the middle of the fat they can see it. That was good to know. I wish I’d known that before. There’s a reason for it.”

Not all women reported positive experiences on the day. In some cases, staff members were perceived to be unfriendly. For example, in one case, a woman was irritated that the staff members did not provide their names, either spontaneously or on request. In other cases, staff members were seen as unnecessarily brusque or rude. In a couple of instances women reported that staff had made inappropriate comments about the size of their breasts. This was particularly unwelcome for those who were already feeling humiliated by the experience.
Women across audiences commented that receptionists were sometimes less friendly and helpful than other staff members at BreastScreen Australia. In another case, a woman reported being irritated by the mammography machine operator making numerous erroneous assumptions about her, such as that she had had mammograms before and that she had children.

Some staff members reportedly seemed to lack empathy with patients and appeared not to care about the discomfort caused, for example, seeming to squash harder than necessary. Several first-timers felt they had not been adequately prepared for the process. This finding was common across audiences but was particularly acute among Indigenous women (see below).

“I think she used to work in a hamburger shop or something… it was unbelievable, she was cruel to the stage where I had tears running down my eyes, she didn’t say ‘sorry dear’ or anything.”

Those who had used both mobile units and static services commented that the former can feel less welcoming, more rushed and less private than the latter. For example, a few women said that they had felt uncomfortable and exposed because they could hear the conversation of the woman and mammographer in the next cubicle. One woman was unhappy with the service she had received because she had been handled by a male technician. Many women said that they would only feel comfortable with a female operating the mammography machine.

“I had an experience of a male having to do it and I didn’t like it … You’ve got this man pulling you around and squashing you.”

It should be noted that negative experiences were more commonly related by lapsed than regular screeners and this may have had an impact on their willingness to re-screen. This means that many of the less than ideal scenarios described above may have occurred several years ago. These findings should also be read in the context of comments from regular screeners that they had noticed improvements to the service over time (see above).

Receiving results

Most were comfortable with the mode and timing of the delivery of results. Most were happy to receive a letter, especially when the result was ‘all clear’. Some regular screeners said they had been given some indication on the day whether or not something might be wrong and therefore knew not to worry too much about the letter. Moreover, many felt the time taken to receive results was acceptable, especially those who had to wait less than two weeks for a letter to arrive.

However, time taken to get results was a concern for some women. Where results took more than two weeks to arrive, women tended to feel this was too long and could not understand what caused the delay. In particular, recalled women in one location felt the initial wait for results of four to six weeks was a concern, though the 10 days to two weeks for assessment was considered acceptable.

“I thought, how long have I been walking around possibly with cancer?”
Recall and assessment

The women who had been recalled reported a variety of different experiences during the assessment process. Some said they had only had to have another mammogram, some had needed a mammogram and ultrasound, some had a fine needle aspiration and some had a core biopsy (section 5.7).

“There was just something wrong with one of the photos or x-rays whatever they’re called, I had to have another mammogram and that was all clear, no trouble.”

“I had another mammogram and I had a doctor examine me and then they thought it was just a little bubble and so they then inserted a needle into the bubble and I watched the screen and just saw the bubble burst and that was it.”

Women’s reactions while waiting for assessment varied hugely. Some experienced a great deal of anxiety, while others took it in their stride. This finding was corroborated by one of Nurse Counsellors working with those who had been recalled (see below).

“It was very frightening. You think, this is it!”

“I didn’t tell anyone, I had nothing to tell.”

Several felt that every effort had been made to make the appointment for assessment as soon as possible. However, those who were most anxious wanted their assessment as quickly as possibly to minimise the time spent worrying about the outcome. Some felt that almost any wait was too long.

“[The assessment appointment is] within days of getting your letter so you don’t have more stewing time.”

“I went through hell because my sister had lost both breasts to cancer, two aunties have died of it and so yeah it was a pretty horrifying time just to sit there and wait. I cried a lot…I would have loved to have been able to get in a few days earlier.”

However, whatever their level of anxiety at the time of waiting for assessment, most were strong advocates for the service provided by BreastScreen Australia. They tended to feel that recall was a ‘necessary evil’ and said they had not stopped, or would not stop, screening as a result of this experience. Indeed many felt that the process of being recalled demonstrates the service is thorough and had enhanced their perception of staff expertise.

“It was worrying for those few days but I’d rather them be thorough and do that [recall women for assessment] than let it go.”

‘I was actually amazed when I saw the mammogram. I thought how on earth did they pick that up, it was so tiny.”
Moreover, many seemed to feel that staff had made an effort to minimise their anxiety. Examples of this included:

- mentioning when first screened that they may be asked back but not to worry as this happens to a lot of women who are not later diagnosed;
- asking how they would like to be contacted if they are recalled during the initial screening appointment, including whether they can leave a message on an answer machine or with the woman’s husband;
- communicating in a reassuring tone, for example clearly explaining in the recall letter that most women who are recalled do not have breast cancer, though providing statistics was not necessarily helpful (section 10.3);
  
  “I got this letter but they didn’t try to scare you they sort of said could you please come in and get it checked.”

- the receptionist appeared to make an effort to make an appointment as quickly as possible and sounded reassuring;
  
  “When I rang up the girl she was just so nice to me about making the appointment.”

- offering flexibility over further tests such as having half on one day and half on another for those working full-time or with caring responsibilities;
- being encouraged to bring someone with them to assessment for emotional support; and
- being telephoned with the ‘all clear’ result even though the letter was in the post, to minimise the time spent waiting.

One woman who was subsequently diagnosed with breast cancer felt the assessment process was not optimal. She found the time spent waiting for tests and results extremely stressful and suggested that appointments should be staggered to minimise this.

  “I waited and waited and waited and waited. Everyone else was leaving and I started to realise something wasn’t right. I was in a terrible state in the waiting room.”

As mentioned above, a small minority of women had decided to discontinue screening following repeated recalls with no diagnosis of breast cancer\(^ {26} \). Two such women had also experienced a series of biopsies. This had led them to become exasperated with the process and to question its efficacy. They had ‘given up’ on screening because it involved too much anxiety and inconvenience.

However, these women were not particularly critical of BreastScreen Australia, indeed some had experienced repeated recall without diagnosis outside the BreastScreen Australia system. They seemed to see this as a failure of the screening process, rather than of any particular service provider.

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\(^ {26} \) These women may have had another abnormality of the breast detected, such as calcification, cysts or fibroadenoma. Indeed some women mentioned the first two of these diagnoses. However, in general women were unable to be specific about their diagnosis, except that they did not have breast cancer.
Diagnosis

Women who had been diagnosed with breast cancer through BreastScreen Australia, and had been successfully treated, tended to have confused memories of the Program. This was because all respondents in this audience had been diagnosed some time ago, given they had to be out of treatment to qualify to take part in the research. Moreover they often had difficulty separating their experiences of BreastScreen Australia from those of the other medical services they had come into contact with in the course of their treatment. However, all were strong supporters of the BreastScreen Australia Program as they believed it had saved their lives or minimised the invasiveness of the treatment they had undergone. In addition most felt the service provided was highly satisfactory, as far as they could recall.

All felt the delivery of the diagnosis had been well handled. For example some reported that a nurse counsellor had sat in with the doctor delivering the news and had provided help with the next steps. In one case a nurse counsellor had made herself available to talk for over an hour on the phone, even though the diagnosed woman was in treatment and was therefore no longer within the jurisdiction of the BreastScreen Australia Program.

Indeed, some diagnosed and treated women were disappointed to have to leave the care of BreastScreen Australia. They said they did not receive the same level of support throughout the treatment process as they had done at the initial diagnosis. Moreover, these women were extremely disappointed they could not return to BreastScreen Australia for screening for five years after treatment, as they found the service to be preferable to private alternatives. One described feeling ‘discriminated against’ as a woman diagnosed with breast cancer, because she was no longer able to use BreastScreen Australia services.

The key criticism of BreastScreen Australia offered by women who had been diagnosed and treated was that they felt the service was not advertised widely enough (section 10.3). They were concerned that not all women knew about the service, which meant that some women do not have the opportunity to be treated at any early stage of the disease, as they had been.

The impact of perceived acceptability on re-screening

Findings indicate that levels of satisfaction with the service provided by BreastScreen Australia can have an impact on willingness to re-screen. Some women had not returned because they had had an unpleasant experience, which they attributed to the perceived attitude of staff members. This finding was reinforced by the fact that recruiters had difficulty finding genuinely lapsed screeners in areas where regular screeners were particularly positive about the quality of the service.

However, some regular screeners had also had unpleasant experiences and had nevertheless either returned to the same service, hoping to be treated by a different staff member, or had used a different BreastScreen Australia service, if one was accessible to them. This suggests that the acceptability of the service is not necessarily a barrier to participation in itself and other issues also come into play. This illustrates the effect of cumulative barriers on participation (section 6.4).
Perceived acceptability among women from non-English speaking backgrounds

It should be noted that all women in the non-English speaking background sample were either lapsed or never screeners. None therefore had any recent experience of the BreastScreen Australia Program.

The perceived acceptability of the service varied among women from different non-English speaking backgrounds. Chinese and Vietnamese women were more likely to find the service satisfactory. They felt sufficient privacy was provided and they had not had to wait or queue on the day. They tended to describe staff as ‘friendly’ and ‘respectful’, and they did not mind that staff could not speak to them in their own language.

“The staff were warm and served you with a smile.” (Chinese woman)

“Having a bi-lingual worker is not necessary because someone always accompanies me.” (Chinese woman)

“The staff explained by demonstration so it’s not essential to have a Chinese worker.” (Chinese woman)

Vietnamese and Chinese participants indicated that their perceptions of the acceptability of the service were influenced by their understanding that the Program is an Australian Government initiative. They felt that government endorsement gave the Program more legitimacy and encouraged women to trust that the service and staff would be professional. Feedback from Chinese participants suggested that birth country experiences were used to frame perceptions of Australian health services. Chinese participants tended to feel that BreastScreen Australia services, as well as health services more widely, are ‘much better’ than services in China.

“(The brochure) is produced by the Government so it must be accurate and reliable.” (Chinese woman)

“The Government wouldn’t recommend it if it wasn’t good for you.” (Vietnamese woman)

In other communities, women tended to be more critical of services. Lebanese women had poor expectations of the service, based on negative stories from other women in their community. The views of some Muslim Lebanese women may also have been clouded by the perception that screening may conflict with their religious practices (section 6.4). In addition, Iraqi women were unsure whether health workers would be female, contributing to a heightened sense of unease and embarrassment about the procedure.

Prior to the initial screening, they expected the environment to be sterile, uninviting and impersonal. They thought that the process would be rushed, rough and embarrassing and that staff would not be sensitive to their cultural needs. In particular, there was an expectation that staff would not be sensitive to the heightened embarrassment among women from very modest cultures and would be impatient in explaining processes to women with limited English skills.

“All nurses and doctors and those people just want you in and out so they can get to the next person in the waiting room.” (Lebanese woman)
Encouragingly, however, the research found that among lapsed women from Lebanese and Greek communities, the initial visit to BreastScreen Australia had resulted in a more positive outlook about the acceptability of the service. Those who had used the service had found the environment to be comfortable and staff attitudes were better than expected.

“Like a small medical centre”.

“Uncomfortable but bearable”.

There were only rare exceptions, where staff had indeed been impatient with women with low English language proficiency. In addition, some women from non-English speaking backgrounds had experienced difficulties with communicating with staff at BreastScreen Australia due to a lack of interpreting services.

“When I went I didn’t speak the language very well so whatever she said to me I couldn’t understand. If there is no one to interpret for me then I don’t understand the whole process and what to expect. If she is asking me “Does it hurt?” and I don’t understand, then it is very hard.” (Iraqi woman)

As in the main sample, some lapsed women from across non-English speaking backgrounds expressed concern about the time taken to receive results. This was usually described as between two to three weeks, and was felt to be “too long”. Women said they could not understand why their results were not given to them on the spot.

“It would be nice if they could tell you they see nothing when they see nothing. Why can’t they do that? Why do I have to stress and think a million things?” (Lebanese woman)

“It’s agonising waiting for the results.” (Greek woman)

Amongst Lebanese women, there was feedback that suggested women would be more likely to screen regularly if they could access a ‘walk in’ service where they did not need to make an appointment. However, Chinese women indicated a preference for appointments in advance and were generally satisfied with the current appointments process.

“It would be good if we could just walk in and didn’t have to make an appointment. I would probably go more often.” (Lebanese woman)

“I don’t have to wait long because it’s a pre-arranged appointment, and not many women are lining up.” (Chinese woman)

Perceived acceptability among Indigenous women

Unlike in the sample among women from non-English speaking backgrounds, the Indigenous groups included regular screeners, as well as lapsed and never screeners. Indigenous women who had used the BreastScreen Australia service, especially those who used the mobile unit in regional and remote communities, tended not to be very satisfied with their experiences. They said the environment was sterile, staff members were not very friendly and were ‘rough’. This seemed to have exacerbated negative perceptions of the procedure, which was seen as painful and invasive.
“[The staff] could be more polite. At least ask, ‘how’s your day been?’ and tell you what to expect, especially if it’s the first time!”

“I feel like a number. They don’t chat to you or anything.”

“They just said come in, strip off.”

Some Indigenous women did not feel that they had been fully prepared for the experience. In one group, women suggested that an Indigenous specific DVD that outlined the procedure could be played in the waiting room. Women felt that this would have an impact on them because they would be a ‘captive audience’. A DVD was also felt to have the added advantage of overcoming literacy issues and providing a visual reference for women who had low English proficiency.

Indigenous women in this sample had not come across any Indigenous health workers at BreastScreen Australia. Several said they would feel more comfortable if an Indigenous staff member was present. Indeed, negative perceptions of breast screening through BreastScreen Australia were overcome where the Program had been recommended by a trusted Indigenous health worker. Regular screeners in one area said they had participated largely out of respect for the Aboriginal health worker who had encouraged them to attend (section 6.4).

The women using the mobile service in one area were told to come either in the morning or afternoon on a given day. As a result they spent some time waiting around for the procedure. While women were not particularly critical of this, they said their perceptions were influenced by women who had undergone the process ‘warning’ them about the pain involved. In addition, some Indigenous women, in common with other audiences, were concerned about the time taken to receive results.

“I don’t like not knowing whether I have the all clear or not”

“They make you wait for ages, meanwhile you worry ‘bout if your tit is well or not. It’s not right!”

Perceived acceptability among women with disabilities

All of the women who had used BreastScreen Australia services were very complimentary about the Program and staff. One noted that the invitation letter she had received had indicated that women with disabilities should mention this when they made an appointment. She had noticed that BreastScreen Australia had a record of her condition when she came for the appointment and staff were able to accommodate her needs.

The two women who were lapsed users of the service said that their decision to discontinue with screening was not a fault of the Program or the staff. The woman with Post Polio Syndrome had experienced too much pain following the procedure and the woman with depression did not want to ‘live to an old age’.

“They’ve always been very helpful and attentive. It’s my body that’s the problem”.

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The two women who were regular screeners felt that the mammography staff were very accommodating. One had attended for the first time only after eight years of her doctor encouraging her to go. Her expectations of the service were not high but she was very pleasantly surprised by how helpful and sensitive the staff were.

“The women there were just gorgeous and so kind and accommodating and they would have done anything. They said if you don’t feel well we’ll stop’. It just wasn’t a big deal. …And I now know if they send me an appointment and I’m not well enough to go, they will be fine about it.”

However, one of the women with Chronic Fatigue Syndrome reported negative experiences of dealing with receptionists when she was unable to make her appointment due to a ‘flare up’. She said the receptionist was often unsympathetic and brusque, telling her she had to ‘go to the bottom of the queue’. This had not deterred this particular woman from returning for screening. However, the other woman with Chronic Fatigue Syndrome, who used a different service, said she would not return if she had been spoken to in this way.

Perceived acceptability among women with interval cancers

Two different types of reactions to the experience of interval cancer were described by women in this sample. Some women felt angry with BreastScreen Australia, which they felt had failed to pick up their cancer. These women tended to have been diagnosed with breast cancer less than a year after their last screening mammogram or had been told by a specialist that their cancer had probably been present at their last screen. They were upset because they felt the invasiveness of their treatment could have been minimised if they had been diagnosed earlier.

“I think BreastScreen missed something. I’ve been told I’ve had it for longer than twelve months by the surgeon…she seems to think it was there…”

“If they’d picked it up earlier it would have been smaller…it could have been done as a lumpectomy…if they’d gotten it before it was in the lymph then it would be different…that then brings a whole lot of other things: chemo, radiation therapy, Herceptin for twelve months.”

“It would have meant I would have had less treatment…it would have been bloody good.”

Other women, in contrast, were more philosophical, especially those who had been diagnosed under the age of fifty and had been told that the density of breast tissue in women their age makes cancer more difficult to detect or that breast cancers tend to be more aggressive in younger women. For example one woman, who had been given an ‘all clear’ by BreastScreen Australia and then also by a private diagnostic service within a few months, blamed the technology rather than the providers of the services.

“It made me realise the technology has come so far but there are some that are just going to slip through the cracks…I don’t have any bad feelings towards BreastScreen. They were doing the best of their ability.”
“There’s never going to be anything that picks up 100% of everything. It’s not that different from any screening or when you take your kids to get their needles at the health clinic. There’s always going to be a small percentage that it doesn’t work. That’s life.”

“It’s possible that there was nothing there at the time [of the BreastScreen mammogram] as it was a particularly aggressive cancer I had.”

Whether they were angry or more philosophical, all women who had experienced interval cancers in this sample welcomed the government funding of BreastScreen Australia and most felt the staff at the service they had used were very pleasant.

“It’s a plus they’re putting money into it, that it’s available for women to go and have screening.”

“I was very grateful to have the free screening.”

“It’s a nice homey kind of place, not like your typical waiting room…I think they do as well as they possibly can.”

“I was very happy with the staff at BreastScreen and rang them up and complemented them. They were really caring and honest and you could tell it was run by women…there was a female consideration that pervaded and I really liked that.”

However, most of those who had been screened through BreastScreen Australia had lost confidence in the quality of the screening mammography provided by BreastScreen Australia. This applied both to women who were angry and those who were philosophical about their experience. In some cases, this lose of confidence was due to derogatory comments about the Program made by health professionals who subsequently treated them or from other women who had been diagnosed with breast cancer. Some also based their views on their own retrospective perceptions of the experience.

“I’m not very confident [about BreastScreen Australia]. The doctors all say BreastScreen is just a screening thing. You can’t rely on it”

“They had a terrible time getting me lined up. So I always wondered if something could have been missed…maybe a more skilled operator might have been able to do a better job and maybe something would have been picked up, if there had been anything there. But who would know?”

“I don’t trust them.”

“Someone told me that the BreastScreen mammograms aren’t as good as the private mammograms.”

One woman had asked to see her BreastScreen Australia x-rays after her surgeon had told her that the breast cancer had probably been present when she was last screened. When she compared these with subsequent diagnostic mammograms from a private provider she felt the quality of the former was inferior.
“I got my BreastScreen results because I asked for those after I’d been diagnosed. I wasn’t happy when I saw the actual x-rays. [At the private service] there’s nice big x-rays and you can see what’s on there. The thing from BreastScreen is this little piece of x-ray...and I think how can they see anything from that anyway? I don’t believe it was the same quality as the other x-ray from the private place.”

8.4 QUALITATIVE RESEARCH FINDINGS AMONG HEALTH PROVIDERS

GPs’ perceptions of the acceptability of the Program

Overall, GPs in this sample valued and endorsed the BreastScreen Australia Program. They saw it as an important service that is delivered well. They felt its most notable characteristics were that it is free for all asymptomatic women over 50, deals with women sensitively and has high standards of professionalism. In common with target and eligible women, GPs tended to feel that BreastScreen Australia staff are experts in breast screening because they specialise in the area. Most felt communications with both the GP and patient are effective (section 10.4).

“They’re getting a free service with a reminder. It’s hard to be too critical.”

“I’ve had really good feedback.”

“I think it may be more accurate than private because there are two radiologists and it’s all they do.”

In common with the target and eligible women, some GPs also felt the service had improved over the last decade and had responded well to feedback. In one case, a GP had phoned a service to complain because a patient had had a poor experience and had been reassured that this would not happen again.

“I’ve had people who were reluctant to go because they had bad experiences. Once I spoke to the Director at [local service X]. She said put in the request that this person has had a bad experience and they’ll get the senior radiographer next time. I thought that was very personalised that they were able to help.”

“They’re gentler than they were 10 years ago. They’re trained to be nice to people, that’s improved. I get less complaints. I might be wrong but that’s what I put it down to.”

Some GPs were a little concerned about delays within the process. This was predominantly because they had found that women could lose their motivation to attend if they could not be seen for an initial screen within a month or so.

“There’s quite a wait for it. Occasionally there’s been a delay.”

“There’s often a delay until the date that’s available. So people may lose their incentive to go. It can be six weeks.”
Very few had received negative reports of the service from patients. However, one GP had experienced problems with a disabled patient whose partner had not been allowed to attend the session to assist with interpreting her needs.

“I’ve got a patient who is disabled by a stroke, she can’t make herself understood. Her partner went with her. He said he wasn’t allowed in because he was a male... Maybe because women are in gowns etc. but there are some people who need a male carer to come with them. In that sense she’s vulnerable. She can’t let [the operator] know how she’s feeling.”

Breast physicians’ and nurse counsellors’ perceptions of the acceptability of the Program

Perceived acceptability

The nurse counsellors and breast physicians, including the breast physician who worked for a private breast clinic, were very complimentary about BreastScreen Australia services. The positive aspects of the service mentioned were similar to those cited by GPs. They welcomed the fact that it is a free service with high standards and professional staff. The breast physician working within BreastScreen Australia felt that the way in which professionals from different disciplines work together, including breast physicians, nurse counsellors, radiologists and sonographers, contributes to the professionalism of the output.

Counselling, from nurse counsellors and breast physicians, was regarded by some health professionals as one of the key strengths of BreastScreen Australia. Some of those working within BreastScreen Australia thought that counselling on diagnosis would not be available to women who screened privately. One nurse counsellor based this belief on her experience of having to explain issues to women who had used private services and had not fully understood what had happened to them. However, the breast physician who worked at a private clinic said counselling is provided by her staff.\footnote{NB: It was not clear whether this counselling was provided by specifically trained counsellors or by other health professionals.}

Breast physicians and nurse counsellors also mentioned the coverage of the service in regional, rural and remote areas as a key strength, as well as strong contacts with local GPs, especially in regional areas. Those working within BreastScreen Australia in regional areas felt that the service they offered was well-adapted to the specific needs of local sub-populations. For example, in one area, BreastScreen Australia was reportedly working with the Asian community to organise group bookings. Similarly, attempts were being made to work with disability organisations to arrange group bookings for women with disabilities, and to develop a protocol for staff working with this audience.

Those who worked within BreastScreen Australia felt a key strength of the Program is the effort that is made to ensure the environment is comfortable for women, for example by providing lounge chairs, baskets for women’s belongings, fresh flowers in the waiting room and using brightly coloured gowns.

“It looks more like a home than a hospital.”
One nurse counsellor mentioned that the friendly atmosphere is enhanced on assessment days at her clinic by volunteers who are trained to talk to patients in the waiting room. These women have usually been diagnosed with, and treated for breast cancer themselves and are there to minimise anxiety by answering questions and steering the conversation away from ‘negative’ topics.

One of the nurse counsellors said that her BreastScreen Australia service placed a great deal of emphasis on ensuring the process is optimal, especially for first-time screeners. A detailed protocol for the information that should be conveyed to women the first time they screen had been developed. This includes staff being encouraged to work on establishing rapport with women and seeking to reassure and minimise anxiety, such as by mentioning that a high proportion of women who are recalled are not diagnosed with breast cancer.

The respondent believed that this protocol had a positive impact on re-screening rates. However, she also commented that this had not been supported by monitoring data relating to this service. The respondent attributed this to the rigidity of re-screening measurement which focuses on women returning within 27 months. She believed that women are more likely to screen again as a result of this protocol but may do so within three years, rather than two and a half.

The Aboriginal health workers felt that the BreastScreen Australia services provided within Indigenous medical centres were acceptable to Indigenous women as this enabled the service to meet with their cultural needs and expectations. However, they felt screening delivered to Aboriginal women through mainstream services was unlikely to be appropriate.

**Opportunities for improvement**

Despite their positive views on the Program, the health professionals were able to identify areas in which the Program could be enhanced. The breast physician in the private clinic believed that BreastScreen Australia offered comparatively poor diagnostic and ultrasound capabilities in comparison with some private clinics. For example, she cited examples of finding additional lesions in the breasts of women who had been screened and assessed through BreastScreen Australia. She also advocated offering ultrasound more widely because she believes women in the community are now becoming more aware of the limitations of mammograms and are therefore demanding access to this technology. This view was supported by the finding in this research that some women prefer private services because ultrasounds are provided routinely (section 9.3). However, this conflicts with published literature suggesting that there is little evidence to support the use of ultrasound in population screening of asymptomatic women28.

The breast physician working privately also felt that BreastScreen Australia’s policy not to target women aged 40-49 should be reconsidered. The policy at her private clinic was for women to have yearly screening mammograms between the ages of 40 and 49 and then bi-yearly screening from over 50. The exception to this is where a woman has a first-degree family history, in which case she is encouraged to continue with yearly mammograms. The respondent argued that studies she had read about show that, although the incidence of breast cancer is lower among women aged 40 to 49, cancer tends to be more aggressive among this age group so yearly screening is more effective than having bi-annual mammograms.

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28 For example, see Teh & Wilson, 1998, section 6.4
All the breast physicians and nurse counsellors agreed that the turnaround of results is a comparative weakness within BreastScreen Australia. However, one of the nurse counsellors argued that women accepted the time taken for results when they were told that two radiologists needed to read the x-ray, as this gave them confidence in the expertise of the staff and quality of the Program.

There was agreement that delays in some areas are caused by the lack of qualified radiologists available to read the mammograms. Those working within the BreastScreen Australia Program reported that mammograms were sent to larger cities from regional and rural areas. Moreover, assessment centres can only be held at certain intervals in certain areas as radiologists sometimes need to be flown in. This can result in increased anxiety for recalled women as they have to wait for further testing.

The shortage of qualified radiologists was identified as an issue both for private and public services. However, some private services have alleviated the pressure by training other staff, such as breast physicians, to read the x-rays. Both breast physicians in this sample felt this policy could also be adopted by BreastScreen Australia, in order to speed up the process. The breast physician working within the Program also felt that the national Standards for BreastScreen Australia do not acknowledge the difficulties experienced in regional areas in terms of reporting timeframes.

The nurse counsellors and breast physician working within BreastScreen Australia commented that there are noticeable variations in the protocols adopted by different BreastScreen Australia services. While this has the advantage of allowing services to be adapted to their local communities (see above), there was some concern that best practice is not being put into action at a national level.

Moreover, one breast physician felt that the accreditation system lacks professionalism. She described how staff from another service come to ‘assess’ activities in a particular BreastScreen Australia service. Rather than analysing the service in question objectively, she said they tend simply to compare the service with their own. The respondent did not feel this was particularly productive.

“They just say ‘well we do it this way’. Which doesn’t help us much.”

A key example of a difference in approaches between services appears to be the way in which they deal with recalling women. Of the small number of representatives of the services included in the sample, each had a different protocol and described other services which followed a different protocol to their own. Findings among women who have been recalled confirm that approaches vary (section 8.3).

In some cases a service provides pre-screening communication about the possibility of recall, the low likelihood that a recall will lead to diagnosis and an explanation in layman’s terms of why this occurs. For example, women may be told that there is sometimes a problem with the x-ray or that something may be unclear and will need to be looked at from a different angle. However, health professionals said that not all services provide this information at the initial screening.
The nurse counsellors and breast physicians described how women can react very differently to a recall, and this was attributed to their ‘personality’. Some do not seem to be worried until there is something for them to be worried about, while others are extremely anxious until they receive an ‘all clear’ result regardless of the reassurances they are given. The health professionals working within BreastScreen Australia in this sample felt that providing information before a recall is helpful because this minimises anxiety among women who are recalled.

Differences were also reported in how BreastScreen Australia services prefer to notify women of a recall. In some cases, letters are sent to women asking them to make an appointment. Relevant literature is sometimes included with the letter, and questions are welcomed when women call to make an appointment. In other cases, women are phoned with the news, which was considered preferable by some as this provides women with a faster result and the opportunity to ask questions immediately. However advocates of the letter approach argued that a phone call can come at an inappropriate time, such as when the woman is at work when they may have little time to listen to, and absorb, the information.

**Aboriginal health workers’ perceptions of the acceptability of the Program**

Aboriginal health workers felt services delivered at Indigenous medical services are appropriate and acceptable to Indigenous women, whereas those that are provided at mainstream facilities struggle to cater for the cultural needs of women from these communities.

One of the Aboriginal health workers requested more notice of visits from mobile units. She said she currently knows around one month in advance but would like to know earlier to enable her to plan other women’s health activities around this. More notice would also help them to promote the visit more effectively.

Neither of these health workers had any contact with women who were recalled or had been diagnosed with breast cancer. They felt GPs were better equipped to discuss this with patients. They were therefore not able to comment on the extent to which the assessment service meet the needs of Indigenous women.
8.5 CONCLUSIONS

Findings indicate that the BreastScreen Australia service is considered highly acceptable by many women and health professionals and that the quality of the service can encourage women who are not committed to screening to return. However, there appears to be a great deal of variability in the way in which the service is delivered across Australia. There are therefore a number of opportunities for improving services in some areas by ensuring best practice principles are adopted more universally.

Some modifications to the service that appear relatively easy to instigate could have a significant impact on the willingness of ‘wavering’ women to screen and re-screen. For example, the women’s experiences of the service provided can leave extremely long-lasting and deep impressions on some women, particularly in relation to the extent to which their dignity and comfort seem to have been considered. The environment also appears to be highly influential on perceptions, with details such as baskets for women’s belongings having an exponential effect on levels of satisfaction. These impressions can be particularly important at the first screen. Protocols on ensuring screening is optimal for first-time screeners may therefore be appropriate.

In addition, findings suggest that the needs of women with disabilities, women from non-English speaking backgrounds and Indigenous women are not currently met as effectively as those of the rest of the population. The development of best practice protocols for dealing effectively with these audiences could go some way towards addressing this.

The anxiety caused by a recall for women who are not subsequently diagnosed can be a significant downside to participating in screening. However, it appears that this can be substantially reduced by clear communication about the likelihood of recall at this stage. Findings indicate that protocols around the recall process as reported by participants are variable and some services have developed explicit written protocols whereas others have not. While women do not see recall as limiting the ‘acceptability’ of the Program, ensuring that all women are fully aware of the implications of a recall result could greatly improve women’s experiences of the Program.

Women who had experienced interval cancers tended to have retained their belief in the importance of regular screening but some had lost confidence in the quality of the service provided by BreastScreen Australia. These women felt that private services would be more accurate. Communication about the Program’s quality standards could help to minimise the negative impact of these perceptions.

While most women and health professionals were comfortable with the mode and timing of receiving results the time taken for results to be received was expressed as a concern by some women across all groups. The Program needs to consider how this could be addressed.
9. FACTORS THAT LEAD TO WOMEN CHOOSING MAMMOGRAPHY OUTSIDE THE PROGRAM

9.1 INTRODUCTION

The evaluation question addressed in this section is: “What are the factors contributing to women choosing mammography outside the Program?” Perceptions of eligible women and health professionals about private services in comparison with BreastScreen Australia services are covered, in order to help identify why women choose screening outside the Program. The extent to which women make this choice for themselves, or are influenced by GPs, is also discussed.

9.2 LITERATURE REVIEW FINDINGS

Women’s perceptions of private services

The literature review did not provide much insight into women’s perceptions of private services or reasons for choosing them. One report, a market research study conducted in Victoria, mentioned private services (50). This study found that 98.7% of respondents believe that the BreastScreen Victoria service would be at least as good as that of private providers. A key reason for women to use private screening was cited as the expectation that they would receive results on the same day. This was of particular importance to those who considered themselves to be at high risk. However, those who attended private services were less satisfied with the time it took to receive results than those who attended BreastScreen Victoria. This probably reflects higher expectations of private services. Attitudes towards private screening at a national level were explored in the qualitative research.

Two issues that were relevant to the sample and recruitment processes for the Participation Qualitative Research were raised in the literature. Firstly, as anticipated, three studies show that some women defined as lapsed by BreastScreen Australia may actually be screening elsewhere (2, 40, 47). Another study found that women were able to recall whether or not they had used BreastScreen Australia or private services (9). However a market research study (18) found that there was confusion about this and extended discussions were required to identify whether or not women had used BreastScreen Australia services.

As a result, recruitment processes in the Qualitative Participation research were developed to assess which category women fell into, using a series of questions. Moderators also asked a number of questions to clarify this during the discussions (section 5.9 for a more detailed discussion of recruitment processes. The recruitment screener can be found in Appendix B).
Health professionals’ perceptions of private services

Two studies referred to GPs’ perceptions of private services. One study among GPs in WA found that 7% have a preference for private services over BreastScreen Australia services (64). This was due to a belief that the quality of services is higher, though the cost to patients was also a consideration. The other study, in NSW, suggested that GPs may refer patients to private services if they have established links with private providers (70). Health professionals’ perceptions of private services were explored in depth in the qualitative research in order to build on these findings.

9.3 QUALITATIVE RESEARCH FINDINGS AMONG WOMEN

Perceptions of private services

Findings in this study confirmed, at a national level, those from the Victorian market research study mentioned in the literature review (50). Women did not necessarily expect private screening services to be superior to those provided by BreastScreen Australia. Indeed many users of BreastScreen Australia could not imagine why someone would want to pay since they felt that the environment and attitudes of staff could not be bettered. These women expected BreastScreen Australia to be as accurate as private services, if not more so since breast screening is all they do (as discussed in sections 8.2 and 8.3). They also thought private services would be more typically ‘clinical’ and less woman-friendly than BreastScreen Australia. When pushed by moderators to describe how they expected the services to be different, some felt they should be treated better if they paid for screening. However they struggled to articulate in what way this would be the case.

Experiences of private services tended to match these expectations. Those who had used both services found the environment tended to be less women-friendly at private services. While most users of private services felt the experience had been adequate, fewer specific positive experiences were mentioned than in relation to BreastScreen Australia. For example, none mentioned examples of unexpected and exceptional service similar to those that were reported about BreastScreen Australia, such as the provision of baskets or receptionists coordinating appointments with the bus timetable.

Moreover some women reported negative experiences with private services. For example, one woman had been ‘forgotten about’ in a cubicle while the staff member went for lunch. Another had been sent to a specialist, had lived through an anxious two week wait, only to be told by the radiologist that there was nothing wrong on the mammogram and he did not know why she had been sent to him.

Motivations for using private screening services

Those who used private services had specific reasons to do so. Most had originally undergone diagnostic mammograms with a private provider and continued to screen with them due to familiarity with this experience. In some cases they were not aware that they were eligible for BreastScreen Australia, especially those aged 40 to 49. In other cases, women who had used private services believed these were superior to BreastScreen Australia because they routinely received an ultrasound as well as a mammogram. Some women believed that ultrasound
technology is superior to mammography and is not used routinely for screening purposes due to cost. Many women also said they would prefer to have ultrasounds rather than mammograms because the former is much less uncomfortable than the latter.

Another reason cited for using private services was to receive results on the same day. This was of most interest to women who saw themselves as at high risk due to having a strong family history or previous breast problems.

In a few cases, women said they had been told at the radiology service or by their GP that they should screen annually, which they had been informed was not possible through BreastScreen Australia. Some of these women always screened at private clinics. Others screened at BreastScreen Australia every two years and used private services in-between.

A small minority chose to use private services because they found them more convenient and accessible. In two cases, women preferred to use a private clinic because they knew one of the mammogram operators at BreastScreen Australia personally and did not want to expose their bodies to them.

“The mum of one of the kids I teach does them. I don’t want her doing it to me!”

“I was at school with one of the women who does it…She’s looked after herself better than me. I don’t want her thinking I’ve let myself go!”

**Perceptions of private services among sub-populations**

Take-up of private services appeared to be very low among Indigenous women and women from non-English speaking backgrounds. Indeed, private services were not available for the Indigenous women in the remote area. There was some confusion about which services had been used in these groups due to lower familiarity with the BreastScreen Australia brand. It is also possible that some had been referred for diagnostic mammography and had been bulk billed but were not sure about what the circumstances of their mammogram were, due to language problems. Certainly, few felt they could justify the costs of private screening.

“You got to pay heaps [for private screening].” (Indigenous woman)

As in the main sample, time taken for results was cited as the key reason why someone might want to use private services among these audiences. However, this was not a particularly compelling factor for women from non-English speaking backgrounds, especially given many were not clear about the purpose of screening.

All of the women with disabilities who had been screened had used BreastScreen Australia services. One commented that people with disabilities rarely use private medical services of any kind because they already spend a great deal of money on medical expenses and cannot afford to do so unless absolutely necessary. However, the woman who no longer wanted to have mammograms because of the pain she experienced following the procedure due to Post Polio Syndrome said she was considering obtaining a doctor’s referral for an ultrasound at a private screening service. She hoped that an ultrasound would be less painful than a mammogram and had been told by a member of staff at BreastScreen Australia that she could not have an ultrasound through the Program.
Women who had experienced *interval cancers* tended to believe the quality of private radiology services is better than that of BreastScreen Australia. This was variously due to BreastScreen Australia being a ‘free service’ and therefore perceived to be inferior, BreastScreen Australias’ inability to detect their cancer and the lack of a routine ultrasound as part of the procedure. As a result, most said they had, or would, encourage friends and family members to screen privately if possible.

“Someone told me they had bigger machines at private radiology services.”

“You can’t rely on the mammogram…you should have an ultrasound as well.”

“With BreastScreen it’s precisely that, it’s screening so they’re looking at mammograms all day long and they’re just looking to see things quickly I’d imagine. Whereas if you go to a private clinic you’d hope they’re taking a bit more time to really check your mammogram.”

### 9.4 QUALITATIVE FINDINGS AMONG HEALTH PROFESSIONALS

#### GPs’ perceptions of private services

Most GPs in the sample claimed that they did not have a practice policy on whether they referred to BreastScreen Australia or private clinics. Instead they said they made recommendations based on their perceptions of the local services and the needs of the individual patient.

Many GPs in this sample claimed to prefer BreastScreen Australia to private services. They said this was because the Program is free and offers a specialised service, with staff who are particularly experienced in mammography. Many GPs also felt it provides a more appropriate environment than radiology services typically do, with more friendly staff and less clinical waiting rooms.

“It’s all they do, they are specialists in mammograms.”

“A lot of mine have been going privately. When I refer them to BreastScreen Australia, which I think is a better service, they’re pleasantly surprised.”

“Often the people [at private clinics] are people with breast cancer. The patient’s sitting there with the negative ions in the air.”

A minority of GPs indicated a preference for screening carried out by private services. This was because, variously:

- the practice was affiliated with a radiology service;
- the GP said they did not like the local BreastScreen Australia service, citing the building or staff as inferior to local private services, though in some cases these respondents also admitted their practice was affiliated with a private radiology service, which may have influenced their views;
- they were not aware of the BreastScreen Australia service, as was the case for two of the older, reactive GPs; and
the GP believed that a mammogram and ultrasound conducted routinely is more thorough than a mammogram alone, and they believed this was the case at private services. Moreover, there was a belief that additional tests could be conducted on the same day, which would be quicker and more convenient for the patient.

“They do ultrasounds and aspirations on the same day.”

Despite tending to prefer BreastScreen Australia, most GPs said they refer to private services in certain circumstances. In some cases, they said patients request a referral to somewhere where they have previously had a mammogram or other ‘sensitive’ radiology and are therefore comfortable and familiar with that clinic. In other cases, GPs referred to private services if a woman had had an unpleasant experience at the local BreastScreen Australia service, commonly in relation to the level of pain they had experienced.

“I would send those sort of patients who’ve had breast problems in the past but are now doing screening [to private services]. They want to be referred back to where they’ve been before because they’re familiar with it.”

GPs said it was also appropriate to refer patients to private services where these are more convenient, assuming the patient is prepared to pay. This was considered particularly relevant for working women or if they are anxious about getting the results quickly, as they are likely to be able to make an appointment at an early date. Indeed most GPs identified faster results as the key benefit of screening at private services.

“I refer them to a private service if they work in the city and that’s where they want to go. And if they have lots of money because it’s expensive.”

“Some people just want a mammogram on a Saturday. You won’t say ‘no you can’t’. If patients request it I don’t have a problem.”

Some GPs also referred women under forty with family history to private services. As discussed (section 7.5), not all GPs were aware that women aged 40 to 49 were eligible for BreastScreen Australia and therefore referred them to private services at this age.

In one case, a GP said she would refer a patient to a private screening service if the patient was going overseas for an extended period. This was to enable the woman to take the x-rays with her, which she erroneously believed is not possible under BreastScreen Australia.

“If a woman is going overseas I recommend private so she can take the x-rays with her.”

In some GP groups, there was debate about whether it is preferable for patients to keep their x-rays, as they do in the private sector, or for the service to hold on to them, as in the case of BreastScreen Australia.

29 NB: X-rays are not provided to women routinely within BreastScreen but women are entitled to be given them on request.
“The only thing wrong with it is you don’t own your x-rays. So then if you go overseas you can’t bring them with you...

…But on balance that’s better because people lose them. Comparisons years later can be helpful.”

Some of the GPs who were most favourably disposed to BreastScreen Australia said they would send women to private services where they knew that the staff also worked within BreastScreen Australia, if the patient wanted to screen privately. They said this would give them confidence in the quality of the work carried out.

“There’s a number of validated radiology practices so you know the technicians there are doing BreastScreen some days and private practice another. So if they don’t want to wait, you know they’re having the same quality of service without those minor problems like the delay in getting an appointment. That’s the type of practice I might refer to.”

Some GPs admitted to referring women to private services for ‘diagnostic’ purposes when in fact the woman required a screening mammogram. This is because referral in this manner enables women to claim a Medicare rebate, with only minimal out of pocket expense. GPs who admitted to this practice claimed that the benefit of ensuring women were screened outweighed any ‘wrong-doing’ on their part.

Some GPs argued that it would be better if women could be referred to private services for screening, rather than diagnostic purposes, and still receive a rebate. They argued this would facilitate the accurate collection of data on participation in screening overall. Moreover, this could help to dispel the belief, held by some women, that private services are superior to BreastScreen Australia.

Other health professionals’ perceptions of private services

The health professionals working within BreastScreen Australia, not surprisingly, felt the Program offered a better service than private providers. This was for similar reasons to those given by GPs for preferring the BreastScreen Australia service. They argued that it is free, woman-friendly and highly professional.

However, they did acknowledge that delays in the process can be an issue. The BreastScreen Australia breast physician and nurse counsellors felt that private screening was likely to be preferred by some women in certain areas where travel to BreastScreen Australia services may be time-consuming and expensive. In particular, they said women who had used a mobile BreastScreen Australia unit for an initial mammogram sometimes choose to use a private radiology service if they require further assessment, if assessment services are not available in their area.

“Women in [regional centre X] often prefer to go to the private service there than travel the 50km to [regional centre Y].”

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30 A Medicare rebate, including bulk billing, is only available for a diagnostic mammogram where a doctor’s referral is required. Doctors can refer for a diagnostic mammogram on the basis of family history or suspicion of breast cancer. However, it is possible for women to choose to pay and be screened outside the BreastScreen Australia Program in private radiology services,
The breast physician working in the private clinic identified a series of advantages of private services. She saw the most important of these as the quick turnaround of results, with follow-up services including ultrasounds and biopsies available on the same day. If required, follow-up assessment was also very quick. For example, if there was disagreement between the two radiologists reading an x-ray, a third reading would be conducted within four days.

As a result, she said the clinic is frequently contacted by women who have been recalled for assessment within BreastScreen Australia who are not happy with how long they would have to wait to be seen if they stayed within the Program. However, the breast physician acknowledged that her service cannot always accommodate women at very short notice as they are also busy.

Other benefits offered at this clinic were that: all woman see a specialist breast physician or breast nurse; interpreters are available for non-English speaking women at no extra cost; and double bookings can be made for women with disabilities, with extra staff available to assist. This breast physician believed that the training is similar for BreastScreen Australia and private staff. All study for a Mammography Certificate and some of the staff at her private clinic had been attached to BreastScreen Australia as part of their training. However, she was not sure whether the training of BreastScreen Australia staff is as thorough as theirs. For example staff at her private clinic are given in-service training if they have received complaints about the level of compression they employ. She did not know whether this was common practice within BreastScreen Australia.

As discussed in section 8.4, the breast physician working outside the Program said that one of the benefits of screening privately is that yearly screens are provided for women aged 40 to 49, whereas BreastScreen Australia only offers bi-annual screening. Some GPs and eligible women in the sample were also under the impression that BreastScreen Australia only offers bi-annual screening. However, one of the breast counsellors said that her service allows women with a family history to screen annually from 40.  

The Aboriginal health workers said they would not refer Indigenous women to private services because of the cost. They were not familiar with how private services differ from BreastScreen Australia services as they had had very little contact with them. As far as they were aware, very few Indigenous women used private services for screening purposes, though some may be referred to these for diagnostic purposes.

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31 State and Territory BreastScreen services may offer more frequent screening to particular women based on their family history or other breast cancer risks.
9.5 CONCLUSIONS

Findings indicate that some women are choosing to screen privately because the BreastScreen Australia Program does not currently meet their needs, either because they want to continue to screen at a familiar service or find a private service to be more convenient. The key issues that BreastScreen Australia would need to address in order to attract these women would be the opening hours of services and the time taken to receive results.

However the findings in this report indicate that a significant proportion of those who screen privately may be doing so because either they or their GP are not aware that they are eligible for BreastScreen Australia. This seems to be due both to communication issues and the variability between protocols in different services. Many of these women may be happy to use BreastScreen Australia if they are made aware that the free service is available to them.

In addition, while many women in this sample were happy with the quality of BreastScreen Australia services, there was an assumption among women who had experienced interval cancers, and some health professionals who they reported having discussed the issue with, that the quality of the BreastScreen Australia service is lower than that of private services. Communication about the quality standards adopted by BreastScreen Australia, such as the requirement for every x-ray to be checked by two radiologists, could help to address this.

Findings indicate that some GPs refer women for screening mammograms to private diagnostic services. These referral patterns have the potential to reduce participation rates in the BreastScreen Australia Program.
10. THE IMPACT OF BREASTSCREEN AUSTRALIA COMMUNICATION ACTIVITIES

10.1 INTRODUCTION

The evaluation question addressed in this section is: ‘What impact have BreastScreen Australia communication activities had on participation rates?’ Women’s awareness of BreastScreen Australia communications and the perceived impact of materials or messages respondents recalled were explored in this phase of the research. Reactions to formal communication materials directed at the target audience of women developed by BreastScreen Australia jurisdictions are discussed, as well as communication protocols and information and materials accessed by health professionals.

10.2 LITERATURE REVIEW FINDINGS

Awareness and impact of communications

The review included several studies that explored communications activities at certain stages of the screening pathway. Many of these indicated that participation in population level breast screening programs is increased by sending an invitation letter followed by a phone call or a second letter (15, 19, 56, 59). One study indicates that the invitation letter and reminders used in Victoria are effective (49). Two studies indicated that set appointment dates and times encouraged some women to attend as this made them feel obliged or committed (48, 53).

Two studies found that awareness of the national Sara Henderson campaign in Australia was high (51), even after the campaign ended following her death (18). Sara Henderson was considered to be a compelling and motivating spokesperson for the campaign (51).

Impact of key messages

Five studies in the literature review evaluated BreastScreen Australia communications. These suggest that some of the messages used in communications are broadly accepted and appear to encourage participation. These messages include:

- breast cancer has a high incidence (48);
- that the service is free (48, 50);
- that no doctor’s referral is required (50);
- that early detection enhances women’s chances of survival (18, 50); and
- mammograms can detect cancers the size of a grain of rice (18, 51).
Various studies show that other messages either cause confusion or are not fully understood by many women (18, 43, 48, 50, 51, 56, 68, 75). This is not surprising given issues relating to population level screening are complex. However, it is important to be as clear as possible, since one study indicates that conflicting information about breast screening can deter women from participating (33).

As discussed in section 7.2, many women do not understand the rationale for the target age range for the Program (18, 48, 50, 56, 75). Improved communication on this issue could therefore be helpful. There also seems to be confusion about the difference between screening and diagnostic services. Most women reportedly believe it is appropriate to use screening mammographic services if they notice symptoms of breast cancer (48, 68). Another study indicated that mammography is predominantly seen as a tool for investigating symptoms among Chinese-Australian women, rather than being appropriate for screening purposes (43).

The review highlights that findings on communicating statistics or ‘facts’ about breast cancer can be contradictory. The review of the Sara Henderson campaign (51) indicated that statements such as ‘1 in 11 women will get breast cancer’ and ‘in 9 out of 10 cases, breast cancer is not caused by hereditary factors’ are likely to be motivating. However, another study (18) found that this type of message can be confusing or can be interpreted in different ways, with some women using these ‘facts’ to support their decision not to participate in screening mammography (18). Although not used in BreastScreen Australia communication materials, another study (38) experimentally investigated threat and fear and found that ‘threat arousal’ can reinforce fearful attitudes towards screening, which may not enhance participation.

**Additional communication needs**

The review highlighted three areas requiring further investigation in the qualitative research. The first related to setting women’s expectations of mammography, especially on their first visit. As was discussed in section 8.2, two reports suggest that prior warning about the discomfort involved in screening mammography may improve perceptions of the experience (48, 66). Although it should be noted that some women felt information that is too explicit could be off-putting (48).

The second issue was the role of language-specific communications. One study indicated that a campaign in Italian did not directly increase participation (58), though the campaign did act as a prompt for 20% of women interviewed. However, the importance of language and culturally specific communications could vary by different groups and there was little information on this in the literature reviewed. The only other guidance on this issue was that women have reported that they feel more comfortable communicating in their own language about sensitive issues (56).

The third communication issue relates to the extent to which women are informed about risk factors and the risks associated with screening mammography. This is covered in sections 11 and 12.
Communications with health professionals

In the study among GPs in WA, 75.8% of GPs who preferred BreastScreen Australia to private radiology services spontaneously cited ‘good feedback to the GP’ as a reason for their preference. No other information was found in the literature on health professionals’ views of BreastScreen Australia communications. This was explored further in the qualitative research.

10.3 QUALITATIVE FINDINGS AMONG TARGET AND ELIGIBLE WOMEN

Findings among the main sample

Impact of communications on participation

Findings in this research support those in the literature review, in that BreastScreen Australia communications seemed to have encouraged many women to screen. For example, many women said they had responded to an invitation letter when it was first sent. Many others had responded to reminder or follow-up letters, or had agreed to make an appointment during a follow-up phone call from BreastScreen Australia.

Despite the fact that there has not been a national television campaign in recent years, some said they had made their original appointment in response to a Sara Henderson television commercial, rather than in response to an invitation letter. Not surprisingly, recall of mass media campaigns was lower than in previous market research studies (for example, see abstract 18), especially among women at the younger end of the target and eligible age range. Nevertheless, the Sara Henderson campaign was still mentioned, including specific recall of her message ‘you bloody well should!’

Some of the diagnosed and treated women felt that the Program is not advertised widely enough. Indeed this was the principal criticism of BreastScreen Australia for respondents in this sub-population. These women felt that promotion of the availability and importance of free screening mammography is vital to ensure that all women have the opportunity to detect breast cancer early, as had been their experience. However, it should be noted that some of the women who made this comment were at the younger end of the target age range and lived in a large metropolitan area. Awareness of communications was generally lower among these audiences so this view may not be reflected among women who have been diagnosed with breast cancer through BreastScreen Australia at a national level.
Text message appointment confirmations have been introduced by BreastScreen WA and response to the idea of this was explored across jurisdictions. Attitudes were split, with some women feeling this could be an effective memory aid, and is a familiar technique that is already being used by many other services such as hairdressers. Others were not interested in the idea because they did not use text messaging or did not feel an additional reminder was necessary. This suggests that the use of this technology may enhance attendance at appointments but seems unlikely to encourage those who do not intend to screen to do so.

“I wouldn’t mind it. It would be alright, anything that reminds me to do whatever I’ve got to do helps.”

“I’d think it was an extra thing that wasn’t necessary.”

Motivating messages

Some messages from the communications materials shown to respondents were spontaneously picked up on as being particularly motivating or useful. Those that were commonly mentioned and considered to be effective included:

- that a woman is still at risk even if she does not have a family history;
- 1 in 8 women will get breast cancer;
- women over 40 are entitled to free screening mammograms;
- why compression is necessary; and
- you can be recalled but there is a good chance that you will not be diagnosed with breast cancer.

While the message that ‘1 in 8 women will get breast cancer’ was motivating, other statistics tended to cause confusion. For example, as in the study mentioned in the literature review, findings from this research indicated that the statement ‘9 out of 10 women who are diagnosed with breast cancer do not have a family history’ caused confusion. Some interpreted this as meaning that those with a family history are not at elevated risk at all. This message was often therefore met with disbelief as women often believed this contradicted information in the media and even from BreastScreen Australia itself. Indeed, some women said they were aware that family history was a risk factor because they had been asked about this the first time they came for screening.

While many women were reassured to hear that a high proportion of those who are recalled for further tests will not be diagnosed with breast cancer, statistics on this subject were often problematic. The statement ‘90% of women recalled for further tests have a normal outcome’ was misread more than once as 90% of women will have to come back for further tests. Those who read the statement in this way felt it did not reflect well on BreastScreen Australia because it seemed to suggest the service has an extremely high rate of inaccurate readings.
In one case, a respondent reported that a nurse counsellor had tried to explain to her that one in ten women are recalled and one in ten of those are diagnosed. The woman in question, and the other women in the group, found this difficult to understand and could not interpret the personal implications for them.

“You don’t know where you are in that 1 to 10 or 1 to 20.”

In the focus groups participants were shown communications materials from the relevant jurisdiction. Few had previously seen this material, especially lapsed and never respondents. Those who had seen them tended to have read them when they first screened or if they had received one with an information letter.

Some women were interested in reading the leaflets, particularly women from higher socio-economic backgrounds and more educated women. However, the majority said they did not want to read leaflets about screening, especially in the waiting room. Two very different reasons for this were given. Regular screeners who had been for mammograms on several occasions felt they already knew what they needed to know. More anxious screeners, especially those who were new to the experience, said they preferred to read magazines to relax in the waiting room rather than reading about what was about to happen.

Many women said they did not want to read text-dense materials. Rather, they tended only to be interested in a few key points. Posters in waiting rooms, which had one clear message, were therefore seen as effective. The bookmark was another example of a simple piece of communication and was popular among the target audience (figure 6).

*Figure 6:* BreastScreen Australia bookmark used across jurisdictions
Verbal information seemed to be particularly effective. Women tended to recall being told about various issues during or immediately after the procedure. For example, several remembered being told verbally that screening does not pick up all cancers so they should be aware of any changes in their breasts and go to the doctor if they notice anything different.

Some of the women who had experienced interval cancer could not recall being provided with information on this risk, even though they thought it was likely that this information had been available to them in written form. In one case, a respondent discovered a paragraph on this issue in a letter she had received from BreastScreen Australia some time before her cancer had been diagnosed, while taking part in the interview. She admitted that she had not read this at the time because it did not seem relevant to her. She felt she would have been more likely to take this message on board if it had been communicated verbally. Others also made this point.

“You might pick it up [a brochure] but it’s unlikely you’ll read it all… and even if you did, at the time you’re not really thinking about those things, you’re thinking about getting through the mammogram. Someone should really just tell you also.”

On their first visit, some women had been told that they would experience some discomfort, thought not all women had been warned. Indeed, most of those who had not been told about the potential for discomfort in advance felt they would have liked to have been told this immediately prior to the procedure.

Impact of communications among women from non-English speaking backgrounds

Impact of communications on participation

Few women from non-English speaking backgrounds thought they had received invitation or reminder letters from BreastScreen Australia. However, some women said that they might have received them but had thrown them away because they could not read them as they were in English.

Awareness of BreastScreen Australia communication materials among women from non-English speaking backgrounds was low, though there were some differences between audiences. It should be noted, however, that awareness of materials was also low among the main sample, especially among lapsed and never respondents. Given all women from non-English speaking backgrounds were lapsed or never screeners, it is not surprising that few had come across them.

While some individuals recognised key images such as the “the cherry and the pea”, on leaflets, others had never seen BreastScreen Australia materials, either in translated form or in English. Women who had never had a screening mammogram were least likely to have seen BreastScreen Australia resources. In particular, none of the Iraqi women had seen any BreastScreen Australia materials.

Awareness of resources among lapsed women was mixed. Chinese, and to a lesser extent Vietnamese, participants were more likely to have seen resources, while Greek and Lebanese participants had low awareness. Higher exposure among Chinese women was linked to GPs in their community playing a more active role in distributing information and referring women for breast screening. In the Greek community, in contrast, respondents reported that GPs, particularly
male GPs, rarely raised breast screening and never distributed information. This feedback suggests that the commitment of GPs to distributing information influences women’s awareness of materials.

*Lapsed* women were also more likely than never screeners to have seen materials as they had come across them during the process of screening within the Program. This indicates that resources are not currently effective in helping women to understand breast screen procedures in advance of screening.

**Motivating messages**

Participants were asked to identify messages, from the materials shown and from their own knowledge, which would motivate them to screen regularly. Findings were consistent across non-English speaking backgrounds. Key messages mentioned included:

- breast cancer is common;
- breast screening saves lives / early detection gives you a better chance of surviving;
- breast screening is free if you’re over the eligible age;
- breast screening can find lumps that you can’t;
- your breasts change over time so you need to keep screening;
- regular screening gives you and your family peace of mind;
- staff are professional, friendly and culturally sensitive. They are understanding and patient with people who have low English language proficiency, and accommodating for women who may have a heightened sense of embarrassment or concern about the process for cultural reasons; and
- for Iraqi women in particular, staff are female.

Across audiences, feedback suggested that information and key messages that are tailored to particular language groups will appear most relevant and have the greatest impact on target populations. For example, the use of culturally specific images on the front cover of a leaflet was felt to be more eye-catching than generic images.

Across non-English speaking background audiences, researchers noted that first language literacy, as well as English literacy, tends to be low among women of this age group. Respondents therefore felt it would be helpful if all written materials used large fonts to make reading as easy as possible. They also recommended that information should be presented in a format that is brief and clear, and uses images to emphasise key messages where possible.

Another issue to tackle among women from across non-English speaking backgrounds was the problem that they often miss appointments due to travelling overseas and do not know how to reschedule. Women from this sub-population may therefore benefit from additional information about how to organise or reschedule breast screening appointments under these circumstances.
For the Iraqi community, it was felt that a reference to women’s birth country experiences might increase the impact of the message. For example, ‘You may not have heard about breast screening in Iraq, but that doesn’t mean it’s not relevant to you.’

The research suggested that there was particular confusion among women from non-English speaking backgrounds about the difference between screening and diagnostic mammography. This was especially apparent among those who had never been screened and those who were newly arrived in Australia. Participation could potentially therefore be enhanced if BreastScreen Australia communications clarify the need for screening among asymptomatic women.

**Impact of communications among Indigenous women**

**Impact of communications**

Some Indigenous women who were *regular* screeners were aware of having seen communications on breast cancer screening but recall of specific materials and messages was low. None of the *lapsed* and *never* screeners recalled having seen any materials. However, the presence of the mobile unit was considered to be an effective advertisement for BreastScreen Australia in the communities it visited, as women said they had seen it on a number of occasions.

Women in the remote community covered in this sample received verbal information from the Aboriginal health worker who encouraged them to attend. However, the information she provided was mostly about appointment times and travel arrangements rather than screening procedures, risks or benefits.

**Motivating messages and styles**

All the Indigenous women in this sample were shown a leaflet and poster aimed at Indigenous women that had been developed in Queensland, as this was the only jurisdiction that provided Indigenous specific materials (figure 7). Feedback on this was mixed. Some felt these were effective because they were bright, eye-catching and used stylized images. However, some of the more highly educated Indigenous women in the sample felt the tone and style trivialised an important issue. This indicates that different approaches may be required for different Indigenous communities.
There were also differences in interpretation of materials by region due to cultural differences between Indigenous communities. For example, the Queensland poster was confusing to women in one area because it used images depicting outlines of the figures of women (see poster above), which symbolised death to them. This suggested breast screening could be dangerous. However, these symbols were not interpreted in this way by Indigenous women in other areas.

Indigenous women were asked to identify key messages that might motivate them to screen regularly, from the materials they had seen and their own knowledge. Women were particularly receptive to messages about the benefits that screening would bring to their children and grandchildren. Key messages mentioned covered the following issues:

- breast screening helps you to keep your family together;
- get screened. You owe it to your family and yourself;
- getting a breast screen every two years will help you see your grandchildren grow up;
- getting a breast screen helps you avoid ‘a bad, slow death’;
- regular screening gives you and your family peace of mind;
- early detection gives you a better chance of surviving;
- act now, live longer;
- breast cancer affects Indigenous women too (to counter the sentiment that statistics and prevalence only relate to the wider population); and
- it hurts a bit, but it’s worth it.
Given the findings on understanding of the Program and barriers to participation, the following messages may also be motivating for Indigenous women:

- breast screening is free if you are over 40 (to clarify the target age for Indigenous women);
- breast screening can detect lumps that you cannot (to counter the belief that self-examination is sufficient); and
- your breasts change over time so you need to keep screening (to counter the perception that one screening is enough).

Indigenous women also said they would respond to stories about other Indigenous women, their experiences and their journeys through the breast screening process. For example, one woman felt she would be motivated by photographs or images of Indigenous women talking about the peace of mind they gained from screening or how their lives were saved by participating in the Program.

**Perceptions of communications among women with a disability**

As in the rest of the sample, there was low awareness of the leaflets shown among women in the disabled group. Those who had received an invitation letter from BreastScreen Australia felt that these were accessible and one woman remembered the letters having indicated that women with disabilities should mention their condition when making an appointment. Respondents also welcomed this message in the leaflets.

All of the women with a disability agreed that there could be advertising or resources that indicated which services are most appropriate for women with disabilities, in particular for those who would only be able to attend facilities with good disabled access. More specific messages to indicate that screening is accessible for women with disabilities would also be welcomed. The woman with Multiple Sclerosis felt this might have encouraged her to attend for screening.

Two disabled respondents expressed concerns about the availability and accessibility of communications. The woman who had Multiple Sclerosis and lived in an aged care facility felt she would only come into contact with materials such as this if her GP had given them to her. This was because she does not visit a surgery as her GP comes to the aged care facility to see her. In addition, she had never been sent any materials by BreastScreen Australia.

The woman who was visually impaired had received letters from BreastScreen Australia in the past and had been able to read them with the assistance of a magnifier. She found black print on a light background easiest to read so the letter and some of the leaflets she was shown were readable, though she felt the print could have been larger. She had difficulty reading the bookmark, however, as this features light coloured writing on a dark background.
10.4 QUALITATIVE FINDINGS AMONG HEALTH PROFESSIONALS

GPs’ perceptions of communications

Overall GPs were satisfied with the communications they received from BreastScreen Australia, though some opportunities for improvement were identified (see below). In particular, GPs appreciated the fact that they receive a copy of their patients’ results, despite the fact that this is a self-referral service.

“It’s good that they send results to the GP and the patient. If the patient has breast symptoms they inform the GP and they keep sending reminders.”

“Keeping the GP in the loop is incredibly helpful.”

A minority of GPs were not completely comfortable with women receiving a letter informing them about a recall, as this is not common practice for patients receiving ‘bad news’ more generally. However others felt that this was unavoidable, since the service does not require referral. Most supported the self-referral process as they felt that this enhances participation rates.

“I don’t like that they get a letter in their letterbox because patients can be quite distraught. That doesn’t happen with any other investigations. The doctor gives the news and picks up the pieces…

…A lot self refer or don’t have GPs. That would be the reason for that decision.”

GPs reported that most regular communications from BreastScreen Australia came through their routine interactions with the Program. The most common points of contact were: their own experience of screening (among female GPs in the eligible population); receiving copies of their patients’ results and, in some cases, information in results letters. Other more general communication varied across jurisdictions. For example, GPs in one state recalled recently receiving notification of a change to the age eligibility criteria.

“We had a letter saying they will no longer accept women between 40 and 50. They said they won’t say no to a women who had been coming along every two years, but if it’s a first referral they will discourage us from making that referral.”

GPs talked about having the ‘pink slip’ in some states, while others did not. The ‘pink slip’ was described as a referral pad for BreastScreen Australia services. This provides an easy method of referral when the topic is discussed with women during a consultation and contains a phone number and the address of local services. This was welcomed as it can easily be handed over to the patient and can be kept in their pile of referrals pads until it is required.

“A lot of my patients don’t know where [BreastScreen Australia] is so I give them [a page from] the pad.”

Very few GPs were familiar with the literature shown in the groups from their state. Though it should be noted that it is possible that this is sent to the practice and displayed in waiting rooms, where it is not noticed by the GP.

“They go from the practice manager to the wall. They by-pass me.”
GPs’ communication needs

GPs identified opportunities for BreastScreen Australia to improve regular communications with them. As discussed in section 7.5, there are some knowledge gaps that GPs would like filled. Some of these are relatively straightforward such as clarifying the age eligibility parameters, both at the younger and older ends of the range, and reminding them of the latest NHMRC best practice clinical guidelines on breast examination. They also wanted to know about the latest information on risk factors.

“They could put in a slip that says ‘for women who smoke risk increases by...’, in big writing.”

Many GPs were uncertain as to who has the responsibility to ensure women start screening and how women are contacted by BreastScreen Australia. Most felt this is likely to be a joint responsibility between GPs and the Program, but would welcome clarification on this. Some felt that a greater understanding of how women are first invited to participate would encourage them to raise the subject of screening.

“Are they sent a letter? Isn’t it based on the electoral roll?”

As discussed in section 6.5, some GPs felt they should be enlisted by BreastScreen Australia to have a more active role in encouraging women to begin participating in the Program. In order to do this they requested more communication tools to help them deal with patients’ queries and more information to help them make referrals. This would also help to reinforce knowledge about the Program and ensure this is consistently updated.

GPs called for best practice responses to commonly asked questions from patients, which they felt would assist them in reassuring women on the ‘unknowns’ about the Program. GPs said that women often ask them about issues such as: the purpose of screening; why a mammogram but not an ultrasound is conducted; what effect the radiation might have; whether there is any danger from the trauma to the breasts experienced during a mammogram; and what the chances are of recall.

Women who have never been for a mammogram were reported to ask about the level of pain or discomfort and what can be done to minimise this. They also ask about the process because of their lack of familiarity with the service and a desire to know what to expect on their first visit. Typical questions include: ‘Will others be there?’; ‘How much will I need to undress?’; and ‘Can I wear jewellery?’. GPs who did not have personal experience of the service said they feel poorly equipped to answer this type of question.

While most appreciated receiving letters on patients’ outcomes from BreastScreen Australia, some improvements to the format of these were suggested. Many did not feel the style of the communication was optimal, as it is currently too lengthy. A clearer summary report, more like one received from private diagnostic imaging services, was requested. Moreover, some felt the results provided were too generic and they wanted more detail on positive results, such as what type of abnormality had been detected. They argued that this would arm them more effectively to discuss
the result with the patient, if the patient came to talk to them about it. For some, the report on a patient would ideally come in electronic format as they no longer use paper filing systems so do not find a letter particularly useful.

“I’d like the radiologists report. That’s a bit annoying. We just get the standard letter saying there’s no physical evidence of breast cancer… The letter to the GP could be more clinically based and less verbose.”

“It would be nice if results could be downloaded.”

Many were knowledgeable about the need for a certain participation rate for screening programs to be effective. However, there were differences of opinion and confusion about the effectiveness of the BreastScreen Australia Program. GPs in some groups therefore said they would welcome reporting on its effectiveness as a population based screening initiative. In particular, there was interest in data on the 40-49 age group, since some GPs had come across different evidence on this topic. Some mentioned the possibility of a National Register, such as is used for immunisation and cervical screening to help provide information on the efficacy of population level mammographic screening.

“They could send us a letter once a year telling us that X number of women were screened in the past 12 months and X number of cases of breast cancer were detected. Thanks for all your help.”

“It’s quite controversial in that age group [40-49]. Population based screening may not yield the same results.”

“I still send women at that age [40-49] because there’s evidence that it’s beneficial.”

“Economically it’s not worthwhile [at age 40-49] but for the individual women it might be.”

**Other health professionals**

Breast physicians and nurse counsellors working within BreastScreen Australia noted that written literature is often not well absorbed by patients. This is evident when women do not follow the instructions in a letter of recall, such as to allow two hours for assessment. Respondents who commented on this attributed the phenomenon to anxiety while reading the material.

Verbal communication, either before or after screening, along with written literature was therefore considered to be more effective. In addition, one of the nurse counsellors said her service provides tailored information for women by helping them to search the internet for relevant material, if the BreastScreen Australia communications do not cover something a woman is particularly interested in.

The Aboriginal health workers said they rely heavily on verbal communication with Indigenous women. The less knowledgeable health worker said she would welcome the opportunity to attend a training workshop on breast cancer and breast screening to bring her up to speed in this area.
Both Aboriginal health workers said they would appreciate resources they could use during consultations with clients to help them explain the breast screening process. They felt this should present the information in a sequential way via maps or flow charts. They requested that this type of material should use images and minimal words to illustrate key processes. They also wanted the resource to be large enough to allow them to take it to local communities to explain the importance of breast screening, particularly in the lead up to a visit from the mobile service.

10.5 CONCLUSIONS

Invitation and reminder letters and phone calls appear to be an effective means of encouraging participation in the Program among the mainstream population. National advertising and GP recommendation were also important in driving take-up of the service. However, there is scope to improve the effectiveness of all of these channels. Not all women had received direct communications from BreastScreen Australia, many women at the younger end of the eligible age range did not recall seeing the national advertising and not all had been encouraged to attend by their GP.

Consideration could be given to more actively involving GPs, both in the process of monitoring whether or not women are participating, and in encouraging them to do so. GPs’ referrals may also increase if they receive more active communications encouraging them, and arming them, to discuss the issue with patients.

Findings indicate that a new communication strategy would be helpful to boost awareness of the Program particularly among women in their forties and fifties. This could seek to address some of the barriers to participation. For example, communication strategies could address ‘passive barriers’ as well as clarifying the purpose of screening mammography. In addition, communications could inform women about the rationale for the target screening age to ensure that women aged 40 to 49 and over 70 are aware that they are still at risk and report symptoms to their GP.

Targeted communications aimed at Indigenous women and women from specific non-English background communities could also help to enhance participation. These would need to address specific issues such as the importance of continuing screening after the first ‘all clear’ result and could reassure women that staff will be sensitive to their cultural and linguistic needs. Communications aimed at women with disabilities may also reassure those who want to attend that it is possible for them to do so.

Leaflets and posters developed in individual jurisdictions are important because some women want to read them and their existence provides reassurance that information is available to women if they need it. However, these do not appear to be a very effective means of encouraging women to participate or in preparing women for the process. Invitation letters, GPs referrals and national communication campaigns are likely to be the most effective means of driving take-up of services, while verbal information and materials that make one simple point may be more useful to convey key messages about the procedure.
11. WOMEN’S UNDERSTANDING OF THE POTENTIAL HARMS AND BENEFITS OF SCREENING

11.1 INTRODUCTION

The evaluation question which the findings reported in this section are intended to answer is: ‘What impact has the Program had on breast cancer morbidity?’ The Qualitative Participation research focuses on women’s and health professionals’ perceptions of the Program. Findings below therefore relate to women’s understanding of the potential harms and benefits of screening.

Women’s awareness of the risk factors for breast cancer and its prevalence are also covered in this section, as these help explain their understanding of the harms and benefits of screening. Findings among health professionals that shed light on all of these issues are also included. In addition, findings from this section help to set the context for discussion around the question in the next section, which is: ‘Do the current BreastScreen Australia communication mechanisms help women to make an informed choice about screening and re-screening?’ (section 12).

11.2 LITERATURE REVIEW FINDINGS

Potential harms identified by researchers

The literature review indicates that commentators on population level screening have identified three key potential harms associated with breast cancer screening. These are:

- a high risk of recall for further investigation that will not necessarily lead to diagnosis, potentially leading to unnecessary anxiety (11);
- unnecessary distress, anxiety and treatment as a result of ‘uncovering clinically irrelevant disease’, such as low grade ductal carcinoma in situ (DCIS) that would not have progressed (10, 11, 14); and
- a lack of understanding among participants that screening does not detect all cancers, which means that it is still possible for women who screen regularly to be diagnosed with cancers between screens, as well as the potential for ‘false negative’ results (11, 14).
Women’s knowledge about the benefits and potential harms of screening

Little of the literature in this review focused on women’s perceptions of the benefits of breast cancer screening. The articles that discuss the issue of ‘informed choice’ tend to emphasise women’s lack of understanding of the potential harms (10, 11, 14), as well as highlighting that women’s ‘knowledge’ may be dependent on subjectively presented information.

Three studies indicate that the way in which information about breast screening is framed has an impact on perceptions of screening (31, 31, 53). These show that information about the ‘Relative Risk Reduction’ (RRR) is more compelling and also more familiar than information about ‘Absolute Risk Reduction’ (ARR). Examples of RRR statements include ‘having this test every two years will reduce your chance of dying from breast cancer by about 34% over a 10 year period’ (31) and ‘Program A will reduce the risk of dying from breast cancer by 34% among those who are offered screening compared with those who are not’ (30). Examples of ARR statements are ‘instead of 6 out of 1000 women dying from breast cancer, 4 will die’ (30) and ‘Program B will reduce the risk of dying from breast cancer from 1 in 45 to 1 in 46’ (31).

Several other studies suggest that many women are currently not well informed about the risk factors for breast cancer. Two studies highlight that women tend to over-estimate their personal risk. The first reports that only a third of women made a near accurate estimate of the incidence of breast cancer in Australia (60). In the second, 91% of women aged 50-70 over-estimated their risk of breast cancer (68). In addition, many women over-emphasise family history rather than age as a key risk factor (18, 60).

However there is evidence that women appreciate the benefits of screening. The BreastScreen Australia Evaluation report 2000/2001 indicates that most women (98%) believe screening for breast cancer through BreastScreen Australia is a ‘very good’ or ‘fairly good’ idea (41). In addition, a qualitative study found that many women support the provision of free breast screening services and regular screeners report enjoying positive feelings after having a mammogram due to a sense that they are maintaining their health (18).

Impact of media coverage on knowledge

Findings on media coverage in the articles and reports reviewed are very consistent. Five of the studies mention media coverage of breast cancer (16, 18, 20, 27, 37) and all confirm that this does not necessarily enhance target and eligible women’s understanding of the issue. There is agreement that the media focuses on cases of young celebrity women who have breast cancer, which reinforces erroneous perceptions about the level of risk for younger women (18, 20, 27, 37). In addition, age as a risk factor is rarely mentioned. One article in the literature review indicates that the key objective of this type of story is usually to help women cope with illness through stories from ‘women like them’, rather than to educate them about breast cancer (20).

Nevertheless, appropriate messages are sometimes conveyed in the media. The importance of early detection is often stressed (20, 27). Moreover, while mammographic screening is rarely mentioned specifically (37), when it has been featured this has been found to be effective in driving interest in screening services (16).
11.3 QUALITATIVE FINDINGS AMONG TARGET AND ELIGIBLE WOMEN

Awareness of risk factors

As found in studies in the literature review, perceptions of the key risk factors tended to be inaccurate. Most believed family history is the most important risk factor, especially those in the *lapsed*/*never* groups. Indeed this was often used as a justification for not screening. That is, many women felt that breast cancer screening was unnecessary for them because they had no family members who had been diagnosed with the disease.

“Well no one in my family’s had it so I don’t think I need to go really.”

“A lot of people think if it’s in the family then I’ve got it but it may not be. So I think a lot of women need to be possibly educated a little bit more about the whole stuff about mammograms and screening.”

The perception that family history is particularly important had also been reinforced for some *regular* screeners because they had been asked to answer questions about their family history when attending for screening. Interestingly, some *regular* screeners had no family history and did not see themselves as at particularly high risk but chose to participate nevertheless. Overall attitudes to preventative health appeared to determine whether or not women who perceived themselves to be at low risk elected to screen. *Regular* screeners tended to be relatively conscientious about all aspects of their health, whereas *lapsed*/*never* screeners tended to have a more *laissez faire* attitude.

“It says on the form, ‘do you have a family history?’ I tick ‘no’ and think, that’s good.”

“I do look after myself, have pap smears and my cholesterol checked…mammograms are another thing you’ve got to do.”

Other risk factors were also mentioned, most commonly by *regular* screeners. Some had been told by their GP that they were at risk because they had used hormone replacement therapy and/or they had been through the menopause, especially those who had experienced an early menopause. A small number had read or heard that their history of breast feeding and the age at which their first child was born were factors. A few were aware that lifestyle factors could come into play, especially diet.

A small minority of *regular* screeners had picked up from BreastScreen Australia communications that age is a key risk factor. However, not all who had heard this were prepared to believe the fact because they were aware of younger women being diagnosed with the disease.

“They said that it’s most common between 50 and 70. But I don’t really think that’s true because my friend was in her forties when she got it.”

In addition to risk factors that women had been told about by health professionals or BreastScreen Australia, women across audiences cited other factors that they believed could lead to the development of breast cancer. Many women blamed contemporary lifestyles and environments for the increase in cancer in general. For example, toxins from pollution and food production processes, as well as electromagnetic radiation from electronic devices such as computers and
mobile phones were thought by some to cause cancer. Many also said they thought stress was a contributory factor. This was a particular concern for the women with disabilities who said that their lives can be extremely stressful and frustrating, which may put them at increased risk.

As discussed in section 6.4, many women were concerned about radiation from mammograms and the compression of their breasts during the procedure, as they felt this could cause breast cancer. Women across audiences also mentioned that other causes of trauma to breasts could increase women’s chances of developing breast cancer. One woman was concerned that her husband’s ‘fondling’ of her breasts over the years might lead to long term damage. Some Indigenous woman thought that domestic violence could lead to breast cancer and one had been told by her mother to avoid being hit on the breasts for this reason.

“[My mother told me] don’t get hit on the boob ‘cause you’ll get a lump.”

Awareness of prevalence

Awareness of the prevalence of breast cancer was high. Almost all were aware that the disease is one of the most common cancers among women. Many based this on personal experiences of friends and family being diagnosed, while some had read that this is the case at a population level.

A few regular screeners spontaneously mentioned lifetime risk figures, with a fair degree of accuracy. For example, the numbers ‘1 in 10’ and ‘1 in 9’ were used. Though women were not always able to specify exactly what the ‘10’ or ‘9’ referred to.

Those in the lapsed / never groups were less likely to appreciate the high relative prevalence of breast cancer, compared with other conditions. In some cases this was used as a justification not to participate in the Program.

“You could be screening for breast cancer and then die of a brain tumour. We don’t have screening for brain tumours so I don’t see why we have to have it for breast cancer.”

Indigenous women expressed interest in the prevalence of breast cancer in their communities. Some indicated that they would be more likely to listen to messages that contained information about the rate of breast cancer among Indigenous women, as opposed to among women generally.

The women with disabilities did not know whether the incidence of breast cancer is higher among women with disabilities compared with the population as a whole. However, they did not perceive themselves to be at lower risk than anyone else. As mentioned above, some felt that stress might be a contributory factor in the development of breast cancer and, given women with disabilities often experience a great deal of stress, they felt this could put them at slightly higher risk than the general population.
Perceived harms and benefits of screening

Participants had difficulty separating the potential harms and benefits of screening from their personal barriers and motivations. Not surprisingly, the benefits tended to be seen in personal, rather than population, terms. For example, many said they felt that they were increasing their own chances of surviving breast cancer by taking part in screening.

“You’ve got a better chance of living longer.”

“If something was wrong they’ve found it early so it’s an upside, not a downside, if you didn’t go in the first place that’s a downside because it could be years before you find it and then it would be too late.”

Many regular screeners could not identify any potential harms or downsides other than the pain or discomfort. They were often confused by questions about potential harms and downsides of breast screening.

“What do you mean? There aren’t any downsides are there?”

Those in the lapsed / never groups were more likely to cite potential harms than regular screeners. The most commonly mentioned potential harm was that the radiation from the x-ray could cause breast cancer. Trauma to the breast as a result of the breast screen procedure, potentially leading to breast cancer, was also mentioned across audiences. In addition, one Iraqi women was afraid to have a mammogram because she was concerned that the procedure would interfere with her pacemaker. None of the women in the disabled group were aware of any potential harms associated with screening for women with conditions such as theirs, though some had experienced, or anticipated, disadvantages such as additional pain.

Several women, from across audiences, mentioned that screening does not pick up 100% of breast cancers and participating can therefore give women a false belief that they are healthy. In a small number of cases, this issue was mentioned by women who knew someone who had been diagnosed with breast cancer shortly after receiving an ‘all clear’ result through screening. Women who were aware of this issue tended to assume that interval cancers were a result of the inaccuracy of the mammography procedure, rather than as a result of cancers developing between screens.

“It could lull you into a false sense of security.”

“I heard about a woman who had a mammogram and they said she was clear but later her doctor found that she had cancer in her breast. So even with the mammogram they did not find her cancer.” (Iraqi woman)

Women who had experienced interval cancers did not identify the phenomenon they had experienced as a ‘risk’ or potential harm related to screening, in that all still supported the idea of screening despite their experiences (see section 8.3). However, some of these women were concerned about the impact of radiation and trauma to the breasts as a result of mammography, and wondered if this might have contributed to their own condition developing. Some therefore said they would prefer to have an ultrasound or MRI in future instead. However others were dismissive of this idea and felt the benefits of early detection clearly outweigh the possible risks or harms associated with having mammograms.
“I want to tell [people who are worried about radiation] that a little bit of radiation now could save them from a lot of radiology [treatment] later.”

“I think the risk of breast cancer is higher than any of the risks posed by radiation.”

Very occasionally women mentioned that screening could lead to unnecessary anxiety as a result of a recall that did not lead to a diagnosis. A very small number of women also felt that the treatment for breast cancer is worse than the disease, so discovering its existence was not beneficial, especially if the cancer had progressed to a later stage.

“It will get you in the end anyway.”

“I would not have chemotherapy. I saw what [a friend] went through and at my age and stage I don’t want it. I’d rather enjoy myself and then die if necessary rather than have chemo.”

Other potential harms were not mentioned or not seen as a concern by the majority. The issue of unnecessary treatment of disease that would not have progressed was not mentioned by any respondent. This was not prompted to avoid causing unnecessary concern or confusion among women who are currently happy to participate in screening.

As discussed in section 8.3 the majority saw the anxiety caused by being recalled as a ‘necessary evil’, rather than as a risk or potential harm associated with screening. Indeed most saw this as a reassuring sign that the system is ‘thorough’. This view was held both by those who had and those who had not been recalled.

“You just have that anxiety for a short time...whereas the anxiety would be a hell of a lot more if you never went, then...it could be a lot worse than having a mammogram and finding something smaller than a grain of rice.”

“You got no choice. You’ve got to go back if you want to live.” (Indigenous woman)

**Sources of existing knowledge**

Regular screeners cited numerous sources of information and often did not know where they had picked up specific facts from. These included: word-of-mouth among friends and family members and the media, though they acknowledged this offered more information on breast cancer than screening and BreastScreen Australia.

Sources of information from BreastScreen Australia were: television and print advertising; the presence of a mobile unit in their area; invitation and reminder letters; verbal information provided by staff during the screening process; posters on the wall in the changing rooms; and leaflets. These are discussed in section 10.

Very few had accessed any information about breast cancer or mammography on the internet. Those who had tended to have been recalled, diagnosed or had experienced symptoms of breast cancer in the past.
Findings were similar among women from non-English speaking backgrounds. However, there were two notable differences. Firstly, word-of-mouth among friends and family members was not a common source of information among Chinese women, who said they would not discuss this topic openly; although word-of-mouth was an important source of information for women from other backgrounds.

“It is part of Chinese culture not to talk about personal matters to others. We are unlike the Western community who are open.” (Chinese woman)

Secondly, women from non-English speaking backgrounds were less likely to have come across media coverage of breast screening than those in the main sample as they predominantly used ethnic media.

Indigenous women tended to have been exposed to similar media coverage to the main sample. In some areas, they had also been informed by Aboriginal health workers. Word-of-mouth was a key form of communication about the Program among Indigenous women in remote and regional communities. As with other audiences, word-of-mouth was often negative, focusing on the physical pain and embarrassment or ‘shame’ involved, rather than the benefits.

“We talk to other women…we ask ‘what did they do to you?’”

Women with disabilities used support organisations, such as the Multiple Sclerosis Society, as sources of information about most health issues. However none had previously thought to contact them to find out about breast screening.

### 11.4 Qualitative Findings Among Health Professionals

**Discussions with patients around potential harms and benefits**

Findings among health professionals supported those from the literature review and qualitative research among women. GPs said there are widespread misconceptions about the importance of family history as a risk factor. As discussed in section 13.4, some said patients over 70 believe they are no longer at risk because they are not invited for breast screening. Moreover, GP reported that women in the target age range who do not have a family history tend to underestimate their risk and women who do have a family history often overestimate their risk at all ages.

“There’s a huge misconception about the importance of family history. They say but ‘I don’t have a family history’. I point out to them that it’s a small proportion and there are these other factors that influence it and they are in no way protected.”

“I find the other problem is that women in their late twenties, their mum has had breast cancer and they’re super paranoid. They want a mammogram and ultrasound. You think this is totally unnecessary.”

GPs tended to say that they do not usually have much time to discuss the potential harms and benefits of breast screening with patients unless the patient has particular questions. As discussed in section 6.5, where possible they highlight the benefits, such as that early detection of breast cancer provides excellent opportunities for successful treatment.
Other than concerns about the discomfort, GPs reported that the most common potential harm that they are asked about is the possibility of damage being caused by radiation or trauma to the breast as a result of the procedure. Most said that they would tell the patient that the risk is minimal and is outweighed by the potential for saving lives through early detection of breast cancer. However, some also said that women who bring up this issue can be difficult to convince. A small number of GPs were themselves somewhat concerned about the affect of radiation when women have a large number of mammograms from a young age.

“\textit{I've got patients who think the radiation will give you cancer...}”

“\textit{...That's possible if you have enough in your 40s.}”

The breast physicians and nurse counsellors said they tend not to have direct contact with women at the initial screening service so did not personally talk to women about the potential harms and benefits. However, some worked at clinics which had a protocol on what to inform women about. The key messages these included were that women could be asked back for assessment when they do not in fact have breast cancer and that there is potential for interval cancers to occur. As discussed in section 8.4, all said they aim to minimise the potential for these to cause harm through their communications with women. This is achieved by reassuring women that the chances that they will be diagnosed with breast cancer at assessment are low and making sure they are aware of the potential for interval cancers so that they report any changes in their breasts to their GP.

One nurse counsellor worked at a call centre that fields queries from women about breast cancer as part of her role. She said she is sometimes asked about potential harms, in particular about the effects of radiation from the x-rays on the breasts. She said she had heard a doctor telling a patient that the risk is equivalent to smoking one cigarette a year. She had found this to be an effective way to reassure women.

Aboriginal health workers felt that it is GPs’ and radiographers’ role to explain the potential harms to their clients. They themselves were not aware of any so did not discuss this with patients.

“I don’t explain the risks because I don’t have the training.”

11.5 CONCLUSIONS

Regular screeners appear to be well aware of the benefits of breast screening, which they see as early detection improving their chances of tackling breast cancer and the reassurance of an ‘all clear’ result. Their understanding of the high incidence of breast cancer reinforces this. However, the benefits are not always well understood among lapsed / never women, especially those from non-English speaking backgrounds and Indigenous women. This tends to be compounded by a poor appreciation among these women of the extent to which they are at risk of breast cancer. Moreover, the benefits often seem to be less top-of-mind than personal barriers such as the discomfort and embarrassment involved in the procedure. A sustained effort is likely to be needed to address these issues through communications and verbal information provided by BreastScreen Australia services.
The main harm that is of concern to women appears to be the impact of radiation from the x-rays and trauma to the breast caused during the mammography process. However, women who raise this concern often have active barriers to participation that are very difficult to shift. Detailed information and arguments on the benefits of screening in comparison with the potential harms may be required for such women.

There seems to be low awareness of, or levels of concern about, the potential harms of screening as reported in the literature review (section 13.2). Anxiety caused by recall was not considered to be a ‘harm’ but was rather viewed as a necessary part of the process, though there is scope to minimise this by ensuring all women are aware that a recall often does not lead to diagnosis. There appears to be no awareness of the potential for unnecessary treatment of breast cancer that would not have progressed. However, attempting to discuss this with women was not recommended by health professionals (section 12.4).

The potential for interval cancers to occur between screens was raised by some women and health professionals. Those who were aware of this issue felt it is extremely important that women know of the potential for interval cancers to occur. There seems to be scope to ensure this information is taken on board by all women who participate in the Program.
12. THE EXTENT TO WHICH WOMEN MAKE AN ‘INFORMED CHOICE’ TO PARTICIPATE

12.1 INTRODUCTION

Findings from this section are intended to address the evaluation question: ‘Do the current BreastScreen Australia communication mechanisms help women to make an informed choice about screening and re-screening?’ Section 10 on the impact of communication activities and section 11 on women’s understanding of the risks and benefits of screening are also relevant to this question. This section focuses on women’s perceptions of the extent to which they feel informed, and health professionals’ views on the ‘informed consent’ debate.

12.2 LITERATURE REVIEW FINDINGS

Commentators on the issue of ‘informed choice’ have called for greater disclosure of information (10, 11, 12, 31) and for decision making aids to be made available to help women make informed choices in participating in screening (71).

The literature did not reveal any findings about perceptions on this issue among women or health professionals. Findings from the literature review on perceptions of the prevalence of breast cancer, risk factors and women’s understanding of the risks and benefits can be found in section 11.2.

12.3 QUALITATIVE FINDINGS AMONG TARGET AND ELIGIBLE WOMEN

Findings among the main sample

None of the target and eligible women were familiar with the term ‘informed consent’ in the context of breast screening, and very few regular screeners recalled the content of the consent form. Most could vaguely remember signing something but could not describe what it said.

“I don’t know what [informed consent] means…It just sounds like you agree to something happening.”

“I probably did [sign the consent form], I can’t remember though.”

A minority spontaneously mentioned they had read and signed their agreement to, a statement which outlined that the results will go to their doctor and that screening does not pick up all cancers. However, given women had difficulty remembering how they knew what they knew about various issues (section 11.3), it is possible this information came through sources other than the consent form (such as verbally).

Nevertheless, a sizeable majority, including the women with disabilities, felt they had enough information available to them to make an informed decision about participating. Almost all agreed with the statement: ‘I think they give us enough information to be able to make an informed decision about whether to take part or not.’
Regular and lapsed screeners said that they felt it was their decision whether or not to read the literature provided and expected honest answers would be provided to any questions they had. The consensus view was that they were provided with enough information at relevant stages in the process. For example, few who had not been recalled for further tests wanted to know more about recall and diagnosis until it happened to them.

“We want to know what relates to us.”

“If you tell people too much a lot of people would be scared off going.”

Some women felt they needed more information on certain topics. When prompted, many said they felt women who are recalled should be told that there is a high chance that they will not be diagnosed with breast cancer, to minimise anxiety while waiting for assessment. In addition, some of those with ‘active’ barriers to breast screening were not satisfied with the information on radiation provided in the leaflets shown.

“It says ‘the risk of the small amount of radiation’. They always say it’s a small amount. But if you have a lot of them it adds up. I want to know more about that.”

Some were also alerted by the questions being asked by the moderators that there may be some risks that they were not aware of. These respondents wanted to know what the risks were.

“Now you’ve got us worried!”

Informed consent among women from non-English speaking and Indigenous Backgrounds

Recall of receiving information about potential harms and benefits was low among women from Indigenous and non-English speaking backgrounds and most said they would have liked to have been told in advance of the screening about the potential harms and benefits. Women who had participated in multiple breast screens reported that they were still unfamiliar with the potential harms of screening. In particular, women from these backgrounds felt it was important to be told in advance about what would be involved in the procedure, to prepare them for the discomfort involved.

“Also we don’t know exactly what happens. If we knew more information and we knew that it is painful, at least we could be prepared.” (Iraqi woman)

“Knowing about the pain is better. I prefer to find out beforehand.” (Indigenous woman)

A lack of information did not come as a surprise to some women from non-English speaking backgrounds, as they were accustomed to not being able to understand information provided by health professionals and government organisations, such as Centrelink. This was particularly the case among Iraqi women who had very low English language proficiency.

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32 In these instances moderators mentioned the potential for anxiety due to recall and for breast cancers to be detected in between screens. They did not mention the potential for unnecessary treatment of breast cancer that would not have progressed, as this was considered too complex and contentious an issue for moderators to be able explain adequately.
“I assumed that they would also speak Arabic but of course they didn’t. So when they gave me the form to sign I didn’t understand anything, but I just signed it.” (Iraqi woman)

A limited number of participants felt that ‘informed consent’ was not a priority as they had come from countries where it was not common practice. One Lebanese woman felt that informed consent was a formality designed to protect Australian health workers from legal damage, rather than for the benefit of the participant. She hinted that informed consent might lead to information overload. A Chinese participant felt similarly.

“Here in Australia they tell you everything because they are afraid of getting into trouble with lawyers and everything. In other parts of the world they will not tell you.” (Lebanese woman)

“In China, there is no such concept [as informed consent]. In hospital situations, say if you receive a blood donation, no one tells you anything about your rights. There are no responsibilities on hospitals or staff...[In Australia] if you had breast cancer and they did not detect it initially, the service would be sued.” (Chinese woman)

Generally women indicated that understanding the risks would not further deter them from participating in breast screening, particularly if it was clear that the benefits outweighed the risks. There was also no indication that better understanding of the risks would actively motivate people to participate.

“We know we have to do it, regardless of information or not.” (Greek woman)

**Informed consent among women who have experienced interval cancer**

There were different levels of awareness of the possibility of interval cancers occurring among women who had experienced this, prior to it happening to them. All said they had not paid much attention to the information they were given at the time of screening because the risk of interval cancer was not a concern at that point. Some thought they might have been provided with information about the possibility of interval cancers, either on the consent form or in leaflets.

“If I remember rightly they do explain that mammograms only pick up a certain percentage of lumps...I can’t remember if they told me or whether I read it on the thing you sign when you go in there.”

Others said they did not know about the risk and had no memory of this being conveyed to them. Although they tended to acknowledge that they were not particularly interested in this information at the time because they were more focused on the procedure itself (see section 10.3).

All of the respondents felt the possibility of interval cancer and the importance of being ‘breast aware’ should be clearly conveyed when women screen. Some also felt their GP should have made this clear when recommending screening.
None of the women who had experienced interval cancers had any sympathy for the argument that recall without diagnosis may cause unnecessary anxiety. All felt BreastScreen Australia should be as thorough and rigorous as possible and that recalling women for further tests when they do not have breast cancer is preferable to failing to pick up breast cancer due to not wanting to be overly cautious.

“I think they’re doing the right thing. If they see something and they can’t determine what it is then obviously they need the person to go back and have another look at it.”

As discussed in section 10.3 there was a strong feeling this information should be imparted verbally by BreastScreen Australia staff and GPs, since they had absorbed little information from written materials on these topics when screening.

“I think definitely they need to tell women [about interval cancers] and they need to tell doctors to tell women.”

“I think it’s a good idea to say in the year off it’s your responsibility to have your doctor examine you…I guess it’s linking between the breast screeners, me and the doctors.”

“BreastScreen should offer information to people in different ways: through leaflets, through videos by including people you can relate to, put information on websites or offer a helpline where they can talk to someone”.

12.4 QUALITATIVE FINDINGS AMONG HEALTH PROFESSIONALS

GPs’ views on the ‘informed consent’ debate

Overall GPs tended to dismiss the ‘informed consent’ debate. In particular, all questioned the need to inform women about the potential for uncovering illness that would not have progressed. This was considered to be a highly complex issue that could de-motivate women to participate in screening unless explained well. They felt that discussing the topic appropriately would take considerable time and would require some ‘tried and tested’ ways of explaining these issues so as not to dissuade women. Some totally dismissed the idea of a ‘wait and see’ approach, arguing that no woman who had been told she had cancer, even low grade DCIS, would be prepared to wait.

“Would you wait and see?! I don’t think any of my patients would.”

Indeed some GPs said that they avoided talking about anything in relation to breast screening that is not immediately relevant to the woman. However most GPs recognised that women may suffer undue anxiety if recalled and made to undergo further tests and they identified methods to minimise this anxiety. These included explaining the chances of being recalled and the low incidence of diagnosis in full to recalled women and ensuring results are made available quickly. However, few claimed to have any contact with their patients between screening and the subsequent visit to the assessment clinic. They therefore did not feel they were in a position to provide this reassurance.
“I sometimes get into that discussion about what happens if the result is positive. It raises anxiety levels. So I steer away from that. You don’t want to speculate too much. It’s on a need to know basis.”

“Often they over-react. They think it’s cancer. You have to reassure them. I always minimise the chances of it being cancer. And also reassure them that if it is something they’re in good hands and they’ll get good treatment. That’s the whole point.”

“They’ve usually been and had the tests and everything is fine before I see them again.”

GPs felt the argument raised in the literature that women should be aware that interval cancers can occur between screening events was valid. Some said they mention this to their patients themselves. Some also felt it was the responsibility of BreastScreen Australia to ensure all women are aware of this. They tended not to know whether BreastScreen Australia currently provides this information or not.

“BreastScreen can give them a false sense of security.”

“Some don’t let you examine them because they’ve got their mammogram. They think the mammogram is it.”

“You do get patients who get a negative result and then a few months later they’re diagnosed with breast cancer. But BreastScreen asks you to report those people.”

Other health professionals’ views on the ‘informed consent’ debate

The breast physicians and nurse counsellors tended to be more aware than GPs about the ‘informed consent’ debate and were also less dismissive of it. All claimed to provide information at the time of screening on the risk of interval cancers. In one service this is included in the consent form and requires the client to tick a box to say they have read the information before signing. The breast physician working at the private clinic said they send their patients home with a card with the result, which also mentions that screening only detects 90% of breast cancers and indicates that they should contact their GP if they notice any symptoms33. In addition, representatives of some services said they tell patients about the possibility of recall, in order to minimise anxiety (section 8.4).

Nurse counsellors and breast physicians noted that the amount of information women seemed to want varies enormously. They said some women want to know everything when they first participate in screening, while others only want to know about anything that is relevant to them at the point they are at in the process.

One of the nurse counsellors working within BreastScreen Australia was particularly aware of the ‘informed choice’ debate. While the respondent felt that some of the literature she is aware of makes a strong case, she disagrees with the argument. The nurse counsellor felt it is important for all of those involved in breast screening to be up-to-date on the debate.

33 The respondent did not mention whether or not the possibility of aggressive cancers developing quickly following screening is mentioned to women.
All of the other breast physicians and nurse counsellors agreed that it is preferable to treat disease at an early stage, even if it might not have progressed, rather than run the risk of not treating disease that would have progressed. The breast physicians and nurse counsellors noted that patients appear to be more concerned about the prospect of not picking up breast cancer than the prospect of treating disease unnecessarily. Indeed none of these professionals had ever been asked about the possibility of unnecessary treatment of cancers that would not have progressed.

Moreover, both breast physicians argued that it would be a ‘brave person’ who left even a low-grade DCIS case untreated, given no-one can know in advance which cases will progress and which will not. In addition, the breast physician working in the private clinic mentioned that no health professional would want to risk being sued if they recommended a ‘wait-and-see’ approach and the cancer did progress. She said clinical trials would be required to provide better evidence on this subject. However, it would also be a ‘brave person’ who volunteered to participate in trials by foregoing treatment at an early stage.

“Patients just want to get it out! We don’t want to be sued.”

The Aboriginal health workers were not familiar with the ‘informed consent’ debate. However, both felt it was more important for Indigenous women to understand the benefits, rather than the risks, associated with regular screening. This was because they felt that focusing on the risks could discourage more Indigenous women from participating.

12.5 CONCLUSIONS

Findings indicate that many women feel well informed in making their decision to participate. The exception being women from Indigenous communities and non-English speaking backgrounds who tend to feel poorly informed about most medical procedures they undergo.

This research suggests that many women have been informed about the potential for recall that will not lead to diagnosis and the risk of interval cancers. However there is scope to ensure that all women who participate are well informed on these issues. This is important because there is potential to reduce levels of anxiety by informing women who receive a recall that many women in this situation are not diagnosed with breast cancer. Moreover, health professionals expressed concerns that women who are not aware that breast screening is not 100% accurate or that aggressive cancers can develop between screens may not report symptoms to their doctor.

There was little support for the argument that women should be informed about the risk of unnecessary treatment of disease that would not have progressed. No women spontaneously mentioned this as a concern and health professionals believed that raising the issue with women would be counter-productive.
13. OVERALL CONCLUSIONS

13.1 OVERVIEW

This report has sought to highlight key factors that affect participation in the free national breast screening Program in Australia as well as how far BreastScreen Australia is perceived to be available, accessible and acceptable to target and eligible women and health professionals. The extent to which women are adequately informed in making their decisions to use the service has also been explored.

13.2 STRENGTHS OF THE PROGRAM

Findings overall indicate that the Program has many strengths. In broad terms these are that:

- most women and health professionals strongly support the existence of the Program;
- the Program is perceived by many women and health professionals to be widely available and accessible;
- the experience of the Program is highly acceptable to many who use it as well as to most health professionals;
- many women are satisfied with the BreastScreen Australia communications they have been exposed to and report that they were prompted to participate in the Program as a result of these; and
- most women feel they are well informed about the Program when the participate.

13.3 KEY ISSUES

Several opportunities to improve the Program and enhance participation have been identified. The conclusions have been structured around five key issues, which are illustrated in figure 8. Figure 8 also highlights that these issues form a hierarchy. This is based on Maslow’s Hierarchy of Needs34, which indicates that the issues at the top of the hierarchy are dependent on those further down having been satisfied before they can be addressed. Importantly, the model does not indicate that any of the issues are more or less important than the others.

In this case, the hierarchy indicates that women firstly need to understand the relevance and benefits of mammographic screening if they are to be open to participating in the Program. Once they are open to participating, they must be made aware of the Program and most must be reminded to utilise it at appropriate intervals. In order to actually take up the offer women must perceive services to be available and accessible to them. Their experience of the service then has an influence on whether or not they will re-screen. Finally, all women who are willing to use the Program and feel comfortable with screening regularly should ideally understand the potential harms involved and be armed with appropriate information to help them make informed decisions.

13.4 KEY ISSUES

Issue 1: Appreciation of the relevance and benefits of screening mammography

Many lapsed and never screeners do not have a good appreciation of why they should participate in screening mammography. Attitudes among women in this category fall into two types: those with active barriers and those with passive barriers. Women participating in this research with active barriers had strongly entrenched reasons not to participate, often based on concerns about the effects of radiation from mammograms and a preference for ‘natural’ medical approaches. While we do not know the proportion of these women in the total population a discreet approach may be required to attempt to change their views. Women with ‘active’ barriers were highly educated and informed and require more detailed information than most other women to help them weigh up the benefits and risks of screening.

The majority of women who do not have a good appreciation of the reasons to screen have passive barriers to participation. Passive barriers include low awareness of the Program and for lapsed users poor experiences of the service (which are discussed under issues 2 and 3 below). In addition, some of these women have misconceptions and negative perceptions about screening mammography that could be addressed to encourage greater levels of openness to participating.

Some women, from across cultural backgrounds, do not understand why mammography is necessary or relevant to them in the absence of symptoms. In addition, some Indigenous women and women from non-English speaking backgrounds are under the impression that screening only
once is sufficient. This indicates that there is a need to convey the difference between screening and diagnostic mammography and the benefits of the ongoing participation in screening in the absence of symptoms.

Few *lapsed* and *never* screeners in the qualitative research had a good appreciation of the relevance of screening mammography to someone like them. In particular there was low awareness of the importance of age as a risk factor, irrespective of family history and a lack of understanding of the rationale for the target age range for the Program of 50 to 69 years of age. This has three key implications. Firstly, some women in the target age range who have no family history believe screening is unnecessary for them. Secondly, some women who are outside the target age range, including those aged over 70 assume they are no longer at risk of breast cancer and may not report symptoms to their GP as a result. Thirdly, there is a widespread sense that the Program is ‘unfair’ in that it does not cater for women of all ages. Clarifying to women via communications that the target and eligible age criteria are determined as a result of the efficacy of screening mammography in reducing mortality amongst those groups could help to enhance participation and also improve perceptions of the Program.

These problems are compounded by confusion among GPs about the age eligibility criteria and its rationale. This can lead to GPs being unsure whether or not they should refer certain types of women for screening mammography, such as fit and healthy women in their early seventies. In addition some GPs refer women aged 40 to 49 to private screening services because they do not realise that BreastScreen Australia would accept them. Informing GPs about age eligibility criteria and when to encourage women in the eligible age range to attend screening could resolve confusion.

The literature review and qualitative research indicated that some Indigenous women and women from non-English speaking backgrounds do not see breast cancer as a disease that is particularly relevant to women from their communities. This suggests that communications that focus on the relevance of breast cancer for specific communities would be useful for these audiences.

Many women are able to articulate the benefits of screening mammography in the research context, that is screening offers the opportunity to detect breast cancer early to enhance the chances of successful treatment. However, the disadvantages they articulate are numerous and more immediate than the benefits, and are therefore more top-of-mind in women’s daily lives. In particular, an expectation of pain or discomfort can be generated by negative word-of-mouth among women who have *never* screened. Among women who have experienced mammograms in the past, perceptions of pain or discomfort vary greatly. However, *lapsed* women who are not clear about the benefits of screening seem more likely to use unpleasant experiences as a justification not to participate.

Other perceived downsides include fear of the results, embarrassment / indignity, the unfamiliarity of the service and the inconvenience of attending. The cumulative effect of these barriers can be overwhelming. As a result, women either refuse to participate or delay making an appointment. There is therefore an opportunity to enhance participation rates and encourage re-screening at appropriate intervals by highlighting the benefits and reminding women that these outweigh the downsides.
Issue 2: Awareness of the Program and BreastScreen Australia brand

Levels of awareness of the availability of mammographic screening are high overall among target and eligible women. Nevertheless, awareness that free screening mammography is available for women aged over 50 in Australia is relatively low among women from Indigenous communities and recent arrivals to Australia. There was confusion about whether or not women have used BreastScreen Australia or private services in some parts of the country, indicating awareness of the BreastScreen Australia brand is low in these areas.

In addition, many are routinely reminded to participate through three key channels: direct marketing such as invitation letters, mass-marketing communications or a recommendation from their GP. However, some lapsed and never screeners claim they have not been communicated with via any of these channels. These tend to be women at the younger end of the eligible and target age range, women who do not access medical services very frequently, women from Indigenous communities and women from non-English speaking backgrounds. There is therefore scope to ensure that all women who are open to screening are prompted to attend in some way and none ‘fall through the net’.

Findings from the qualitative research indicate that women’s recall of marketing activity is very variable across Australia, suggesting that some jurisdictions may be more active than others. In addition, although awareness of the last national campaign is relatively high, not all women can recall mass-marketing communications about the Program. BreastScreen Australia may therefore wish to consider developing further mass-marketing communications to ensure all women are aware of the Program, with a particular focus on materials aimed at audiences for whom awareness of the Program is lower, such as Indigenous women and recent arrivals to Australia.

Findings among respondents working within BreastScreen Australia indicate that there is variability between jurisdictions in how they remind women to participate. This may explain why some women in the qualitative sample said they had received invitation letters or phone calls from BreastScreen Australia and others had not. BreastScreen Australia may therefore need to consider how to ensure the coverage of direct marketing is more widespread, given its usefulness as a prompt to screen and re-screen.

Women in this research report that GPs and Aboriginal health workers are particularly effective channels for communicating with them because they are widely trusted, they can provide information about the relevance of screening mammography and direct women to local services. However GPs admit that they do not discuss the topic with female patients as often as they could. Reactive GPs, who may work in bulk billing or larger practices with a high turn-around of patients, admit that they rarely discuss breast screening with patients. Moreover, while many proactive GPs feel it is their responsibility to encourage women in the target age range to participate, they are not always able to do so due to the ‘competing demands of the consultation’.

The lack of a system for reminding and educating doctors and Aboriginal health workers to discuss the issue with patients or clients is felt to exacerbate this, as well as their limited knowledge about the Program, such as age eligibility criteria, the processes involved and how best to overcome women’s resistance to participating. Assisting health professionals in routinely discussing the topic with target women would therefore be a step towards raising awareness of the Program.
and ensuring screening is top-of-mind for more women. However, it should be noted that reactive GPs may not be very interested in such assistance because they are less conscious than proactive GPs and Aboriginal health workers of their role in encouraging participation. This highlights the importance of utilising multiple channels to communicate with women about the Program.

**Issue 3: Perceived availability and accessibility**

The availability of the Program is widely seen as one of its strengths. However, a key exception to this is the availability of static services and assessment centres in some regional and rural areas, and the limited number of radiologists in some parts of the country. This creates access problems and can also have a negative impact on the time taken for patients to receive results and to make appointments for further testing.

These issues deter some women from taking up screening mammography altogether and encourage others to choose to use private services instead of BreastScreen Australia. In addition, some GPs refer women who have access issues or are uncomfortable with the time taken to receive results to private radiology services for diagnostic mammograms when screening mammography is actually required. These issues may be difficult for BreastScreen Australia to address directly but consideration could be given to exploring how the implications of workforce shortages could be tackled and how to help women access mobile and assessment services, including transport. In addition, perceptions of the Program could be enhanced by communicating clearly to women the time taken for results to be provided as a result of the programs quality standards which require two radiologists to read the mammograms to maximise accuracy.

The Program is not available to some women with disabilities because they are physically unable to undergo mammograms. For example, women with disabilities may not be able to remain motionless and / or assume positions (such as raising their arm) required by the procedure. One means of addressing this suggested in the literature review was to allow such women to access free ultrasounds through BreastScreen Australia without first having to undergo a mammogram. Findings from the qualitative research indicated that this would be welcomed by some women who are affected as they felt it would provide them with reassurance that they have access to at least some means of screening for breast cancer. However, BreastScreen Australia needs to consider how to address this issue given the efficacy of using ultrasound in asymptomatic women is not supported at the population level by appropriate evidence. Highlighting the lack of evidence to support the efficacy of ultrasound as a screening tool could be part of a communication strategy.

Issues with access to BreastScreen Australia services appear to be an important contributory factor in lower screening rates among women from non-English speaking backgrounds and Indigenous women. These women do not always have their own vehicle and may face difficulties with negotiating public transport. Findings indicate that participation can be enhanced where transport is organised and provided on behalf of these women. Access to services can also be a problem for some women who work if they have difficulty attending during business hours. Extending opening hours at selected services may encourage these women to attend.
The women with disabilities in the qualitative sample who were able to use mammography had not experienced access problems. However, interestingly, they reported expecting to experience difficulties. Communicating more widely that BreastScreen Australia services are accessible to women with disabilities may therefore increase the likelihood of disabled women using the Program.

**Issue 4: Experience of the service**

Overall there is a great deal of satisfaction with BreastScreen Australia services among regular screeners and health professionals. Moreover, there is a perception that the Program has improved over time. However this national study has highlighted that there is a high degree of variability in perceptions of the acceptability of services, which may in part be due to different approaches being adopted by services within and between jurisdictions. Attitudes towards the service provided, in particular, perceptions of the level of discomfort and indignity experienced during the procedure and the cultural appropriateness of services, can have an important impact on the perceived acceptability of the Program and on re-screening behaviour. The manner in which recall and diagnosis are handled can also affect perceptions of acceptability.

This suggests that adopting ‘best practice’ service approaches nationally could have a beneficial impact on participation rates and on perceptions of the acceptability of the Program. For example, this could include: ensuring mammography staff are aware of the importance of appearing to minimise discomfort and embarrassment; creating a personal and comfortable environment; developing service protocols for women from non-English speaking backgrounds, Indigenous women and women with disabilities; and determining the most effective means of informing women about recall.

These measures are likely to have most impact if there is a particular focus on audiences at greatest risk of failing to re-screen or of having negative experiences, such as first time attendees, women from non-English speaking backgrounds, Indigenous women, women with disabilities and women who have been recalled.

**Issue 5: Information needs and informed consent**

The overwhelming majority of women who would consider using the service feel they are satisfactorily informed about their decision to participate in the Program. Regular screeners are well aware of the benefits of screening and tend to feel that they are provided with adequate information about the process.

There is scope to more effectively prepare first-time screeners for the process by outlining what will happen and warning them about the potential for discomfort. This is particularly important for Indigenous women and for women from non-English speaking backgrounds. In addition, as discussed under issue 1, women with active barriers could be provided with more detailed information on the relative importance of the potential harms and benefits associated with screening.
Many women in this research who had been recalled for assessment and have not been diagnosed with breast cancer accepted this as a necessary part of the process and evidence of the Program’s thoroughness. However, there is evidence to support the proposition of some researchers that all women should be adequately informed about all issues and two issues in particular prior to screening. Firstly, there is potential for women to be very anxious when they receive a recall for further tests. However, this can often be substantially reduced by informing them that a high proportion of women who are recalled for assessment are not diagnosed with breast cancer. This message can be effective if conveyed either at the first screening and / or when the recall result is provided.

Secondly, findings from women and health professionals indicate that some women are not aware that screening mammography is not fully effective in detecting breast cancer and also that breast cancer can develop in between screens. Health professionals and some women, in particular those who have experienced interval cancers feel it is extremely important to ensure all users of the service are aware of this and are encouraged to report any symptoms to their GP.

Findings suggest that these two key pieces of information are sometimes, but not always, conveyed effectively. Feedback from women indicates that they may not read the consent form carefully before signing and few seem to have read the general literature provided to them at BreastScreen Australia services, which includes this information. Imparting these messages verbally and via dedicated communications materials, such as posters in changing cubicles, may therefore be a more effective means of ensuring the information is absorbed.

The literature review identified that some researchers believe women should be informed about the risk of the unnecessary treatment of cancers that would not have progressed. There was little support for this perspective in the current qualitative research. No women expressed any concern about this issue, including those with active barriers who raised numerous other objections to screening mammography. Moreover the health professionals in the sample felt this was a complex message to convey and attempting to do so is likely to be counterproductive.
APPENDICES

A  ABSTRACTS FROM THE LITERATURE REVIEW

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Question A: The availability and accessibility of the Program to all sub-populations, including those with low participation rates
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<td>1</td>
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<td>To identify associations between beliefs and knowledge about breast cancer and mammography, socioeconomic (SES) indicators, and health related factors, and having a mammogram.</td>
<td>Telephone survey</td>
<td>n=2974 women aged 50-69 years selected from the BreastScreen NSW (BSNSW) database and the NSW Electoral Roll.</td>
<td>Strong positive associations were found between age, marital status, knowledge about and belief in the benefits of screening, indicators of health status and service utilisation, and whether women had ever had a mammogram or had one within the recommended period. SES was weakly associated with regularity of mammography, which is not felt to be surprising given the program is free for women over 40. Most respondents reported having had at least one mammogram. Specific aspects of knowledge and beliefs about mammograms and individual health-related factors would be important components of initiatives to encourage initial and repeat screening in the targeted age group.</td>
<td>Specific aspects of knowledge and beliefs about mammograms and individual health-related factors would be important components of initiatives to encourage initial and repeat screening in the targeted age group.</td>
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<td>2</td>
<td>B, E, F</td>
<td>To undertake a comparative cross-sectional study among women 50 to 69 years of age in NSW and identify attitudes and beliefs about mammograms plus compare characteristics of current attendees, late/lapsed attendees and never attendees to BSNSW.</td>
<td>Telephone Survey</td>
<td>3,104 women were selected from the BSNSW database (those who had at least one mammogram at BSNSW) and from the NSW Electoral Roll (those who had never attended BSNSW for a mammogram).</td>
<td>The ‘never’ attendees were more likely to be less than 60 years old compared with attendees and were more likely to be employed. ‘Never’ attendees were significantly more likely to describe their mammography experience in negative terms (e.g. painful, embarrassing or uncomfortable). 78% of women who BSNSW identified as never having received a mammogram from BSNSW (‘never’ attendees) reported that they had in fact had a mammogram (from another provider). Other main providers were ‘private practice’ or ‘hospitals’. Among women who attended BSNSW, ‘never’ attendees were significantly more likely to be younger, engaged in full time work and have a yearly incomes of $80K plus. The most common reason for women of both groups for not having a mammogram is ‘fear of the results’. It is likely that many women who do not receive their mammograms from BSNSW are being screened through Medicare.</td>
<td>Women who have not attended BSNSW often have a negative attitude toward mammography or are being screened elsewhere.</td>
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<td>3</td>
<td>A</td>
<td>Aleksoska, K. Macedonian women and breast cancer: A model of Psychosocial support for early detection and treatment Australian Journal of Primary Health, 11(3), 63-71.</td>
<td>To explore key controversies surrounding the early detection, management and prevention of breast cancer as a backdrop to considering the psychological support needs of women living with breast cancer, particularly those in already marginalised positions.</td>
<td>Qualitative interviews and development of a psychosocial support model.</td>
<td>18 Macedonian women aged 45 to 60 years living in Melbourne’s Western Suburbs.</td>
<td>There are a number of key controversies around the efficacy of mammography as a tool for early detection i.e. lead-time bias, length-time bias and detecting increasing abnormalities that are not terminal. From initial screening through to treatment women are not always given the relevant information and hence are unable to make an informed decision. Macedonian women respond to diagnosis with ‘k’met’: shock, denial, anxiety, fatalism and becomes an existential crisis. Women often have difficulty understanding the diagnosis and there is an absence of adequate psychosocial support.</td>
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<td>4</td>
<td>E</td>
<td>Andrews, F.J. (2001) Pain during mammography: Implications for breast screening programmes Australian Radiology, 45, 113-117.</td>
<td>To review the current literature on pain experienced during mammography focusing on 3 main areas of interest: (1) reports of the frequency of pain (2) Identification of predictors of pain (3) Strategies for responding to pain.</td>
<td>Literature review</td>
<td>n/a</td>
<td>Pain experienced during mammography can deter women from attending for breast cancer screening. Two recent studies suggest that pain is the main reason why women fail to re-attend for screening mammography. Results of the frequency of reported pain vary considerably. In one study 73% of women reported pain, whilst in another only 2% reported pain. Risk factors identified that might predispose women to pain have been categorized as physiological, demographic and psychological. Prior expectation of pain is a significant factor in likelihood of experiencing pain. Little research is available into how screening programs respond to pain. Some suggest programs could provide extra support to women at high risk of experiencing pain or intervene with analgesics.</td>
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<td>5</td>
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<td>Australian Institute of Health and Welfare (2005). <em>BreastScreen Australia Monitoring Report 2001-2002</em>. AIHW cat. No. CAN 25. Canberra: AIHW (Cancer Series no. 29).</td>
<td>To monitor the success of the BreastScreen Australia (BSA) Program in reducing mortality and morbidity from breast cancer.</td>
<td>Multiple data analysis of BreastScreen Australia screening activity, National Cancer Statistics Clearing House and the National Mortality Database.</td>
<td>n/a</td>
<td>In 2001-2002, of the 1,611,262 Australian women screened by BSA, 68% were in the target age group of 50-69 years. Participation among the target population has been steadily increasing from 52.3% in 1996-1997 to 57.1% in 2001-2002. Participation by Indigenous Australian women (34.8%) was significantly lower than for non-Indigenous, as is participation of non-English speaking women (47.4%) compared to women whose main language is English. In 2002, 63% of all invasive breast cancers detected by BSA were small-diameter cancers. The early detection of which helps to reduce morbidity and mortality resulting from breast cancer.</td>
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<td>6</td>
<td>H</td>
<td>Australian Institute of Health and Welfare and the National Breast Cancer Centre (2006). <em>Breast Cancer in Australia: an overview 2006</em>, Cancer Series, Number 34.</td>
<td>To provide a comprehensive statistical overview of breast cancer in males and females.</td>
<td>Compilation and analysis of national data from 1983 with projections to 2011.</td>
<td>n/a</td>
<td>Breast cancer is the most common invasive cancer diagnosed in females in Australia but rare in males. It is also the leading cause of cancer death in females. In 2002 the age-standardised incidence of breast cancer in females is 1.17% and projected to remain at this level. Since the inception of the BreastScreen Australia public mammography screening program, the number of cases reported within the screening target age group of 50–69 years has increased. Over half (56.1%) of the target age group had been screened in 2002-2003 but has yet to reach the target of 70%. Women living in the areas of highest urbanisation had significantly higher rates of breast cancer in 1998–2002, as did those living in high socioeconomic status areas. Breast cancer is the most common cancer experienced among Aboriginal and Torres Strait Island (INDIGENOUS) women, but the incidence rate is lower than for the non-Indigenous women. Despite this, INDIGENOUS women had 9% higher rates of breast cancer mortality. Total expenditure on breast cancer was $241 million in 2000–01. $96 million was spent on population screening mammography.</td>
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<td>7</td>
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<td>Australian Institute of Health and Welfare. (2007). <em>BreastScreen Australia Monitoring Report 2003-2004</em>. AIHW cat. No. CAN 31. Canberra: AIHW (Cancer Series no. 36).</td>
<td>To determine whether the BreastScreen Australia (BSA) Program has been successful in reducing mortality and morbidity from breast cancer.</td>
<td>Multiple data analysis of BreastScreen Australia screening activity, National Cancer Statistics Clearing House and the National Mortality Database.</td>
<td>n/a</td>
<td>In 2003-2004, of the 1.6 million Australian women screened by BSA, just over 70% were in the target age group of 50-69 years. Participation by Indigenous Australian women (35.3%) was significantly lower than for non-Indigenous, as is participation of non-English speaking women (42.8%) compared to women whose main language is English. Although breast cancer was the most common cause of cancer-related deaths in women in Australia in 2004 with 2,641 deaths, among women aged 50-69 years there was a mortality reduction from 69 deaths per 100,000 women in 1990 to 51 deaths in 2004. In 2004, women attending the program for the first time have a significantly higher recall rate (9.9%) due to the higher all-size cancer detection rate, than those who had previously been screened (4%).</td>
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<td>8</td>
<td>C, D</td>
<td>Ballard-Barbash, R., Bullard, J., Fraichet, J., Geler, B.M., Sancho-Garnier, H., Zapka, J.K. Print information to inform decisions about mammography screening participation in 16 countries with population-based programs. <em>Patient Education and Counselling, 62</em>, 126-137.</td>
<td>To profile and compare the content and presentation of written communications related to informed decision-making about mammography.</td>
<td>Material and content from 16 screening programs organised at the national or regional level were analysed according to five major information domains suggested by the international literature.</td>
<td>n/a</td>
<td>The majority of communications include information on breast cancer, although the trend was to include less information if the program started after 1992. There was considerable variance in the comprehensiveness of elements in the domains e.g.: test characteristics (false positive/negative) and pros and cons of screening. Majority noted the likelihood of recall for further tests. Few commented on the risks of additional tests or finding unimportant tumours.</td>
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<td>9</td>
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<td>To assess the reliability and validity of self-reported attendance for mammographic screening.</td>
<td>Structured telephone interviews. Reliability element: Initial call followed by a second one week later. The percentage agreement between 1st and 2nd interviews and Kappas were calculated. Validity element: letters sent to respondents from the National Breast Health Survey and matched against BSA records.</td>
<td>Reliability element: 130 women, randomly selected from the Electronic White Pages. 100 took part in both stages. Validity element: 127 women who had taken part in the National Breast Health Survey and who consented to participate.</td>
<td>Women are reliable in recalling and reporting whether they have ever had a mammogram. Only 5.5% of women who reported being screened by the national program could not be matched, suggesting that most women can distinguish between the national program and private mammographic screening practices. 91.3% reported the mammogram date accurately to within 12 months of the recorded date.</td>
<td>The data suggest that Australian women provide reliable and valid information in relation to mammographic screening attendance. Women do not over-report having had a screening mammogram and are able to reasonably accurately report the time and location of their last mammogram.</td>
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<td>10</td>
<td>D</td>
<td>To explore both the benefits and harms of cancer screening to determine whether early detection is always best.</td>
<td>Radio interview: Dr Alex Barratt, Associate Professor of Epidemiology at the University of Sydney; Dr Gilbert Welsh, physician with the US Department of Veteran Affairs and Professor of Medicine at Dartmouth Medical School; Paul Glasziou, Director of the Centre for Evidence Based Medicine at the University of Oxford; Professor John Forbes, Head of the Australian New Zealand Breast Cancer Trials Group; Associate Professor Karla Kerlikowske, University of California; Sue Lockwood, consumer representative with the National Breast Cancer Centre, Australia.</td>
<td>n/a</td>
<td>Some people are diagnosed with cancer unnecessarily causing distress and anxiety. Benefits of screening are perceived to be over-stated, whilst playing down the negatives. There are two definitions of cancer - one is a progressive disease, the other is its pathologic appearance. 40% of women will have microscopic evidence of breast cancer, ductal carcinoma in situ (DCIS).</td>
<td>Although screening has benefits for those where invasive cancer is detected early, it can often over-state the problem by testing healthy people and diagnosing low-grade, non-aggressive cancers, which then causes distress to the patient and potentially unnecessary treatment.</td>
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<td>11</td>
<td>D</td>
<td>To further explore both the benefits and harms of cancer screening to make a more informed decision about whether to screen or not.</td>
<td>Radio interview: Dr Alex Barratt, Associate Professor of Epidemiology at the University of Sydney; Dr Gilbert Welch, physician with the US Department of Veteran Affairs and Professor of Medicine at Dartmouth Medical School; Paul Glasziou, Director of the Centre for Evidence Based Medicine at the University of Oxford; Professor John Forbes, Head of the Australian New Zealand Breast Cancer Trials Group; Professor Ian Hammond, Chair of the committee overseeing policy change on cervical cancer screening; Professor Pam Russell, Cancer biologist; Professor Mark Elwood, Director of Australia’s National Cancer Control Initiative; David Sandoe, co-chair of the Support and Advocacy Committee of the Prostate Cancer Foundation of Australia.</td>
<td>n/a</td>
<td>‘Watchful waiting’ where low-grade changes are monitored over time is a technique being used with prostate cancer and trialed in cervical cancer to avoid invasive treatments. The immune system can often rid the body of these abnormalities independent of treatment. The Public needs to be educated about why treatment of low-grade abnormalities is not always the best option. 5-10% of all people screened for cancer will experience a false positive. Over 10 years of annual mammograms, half of women screened will have at least one abnormal test. 20-30% of breast cancer diagnoses are not found via screening, but rather are interval cancers. Screening does not pick up all cancers.</td>
<td>Cancer screening is a process that helps a small minority, but in a life changing way. The majority have nothing to gain and some of them are in fact harmed as a result of screening via physical or psychological harm.</td>
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<td>12</td>
<td>D</td>
<td>Barratt, A. (2005). <em>Cancer Screening: Benefits and Harms, Part 3</em>. Transcripts of the Health Report ABC Radio National are available from <a href="http://www.abc.net.au/rn/healthreport/stories/2005/">http://www.abc.net.au/rn/healthreport/stories/2005/</a></td>
<td>To understand the forces driving cancer screening and explore the decision making process as to whether to screen or not.</td>
<td>Dr Alex Barratt, Associate Professor of Epidemiology at the University of Sydney; Dr Gilbert Welch, physician with the US Department of Veteran Affairs and Professor of Medicine at Dartmouth Medical School; Paul Glasziou, Director of the Centre for Evidence Based Medicine at the University of Oxford; Dr Angela Raffle, world leader in research on cervical cancer screening; Associate Professor of Health Economics Glenn Salkeld, University of Sydney; Dr Muir Gray; Dr Annette O'Connor, Professor of Nursing and Clinical Epidemiology at University of Ottawa.</td>
<td>n/a</td>
<td>There are many economic drivers at play to encourage screening programs and to raise fear around cancer.</td>
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<td>13</td>
<td>D</td>
<td>Barratt, A. (2005). <em>Models of outcomes of screening mammography: information to support informed choices</em>. <em>British Medical Journal</em>, 330; 936.</td>
<td>To provide easy to use estimates of the benefits and harms of biennial screening mammography for women aged 40–70 years.</td>
<td>Markov process model based on two hypothetical cohorts. In one cohort women undergo biennial screening over 10 years and in the other they do not. The model was populated with data collected from BreastScreen Australia (BSA), the Australian Institute of Health and Welfare, and the Australian Bureau of Statistics.</td>
<td>For every 1000 women screened over 10 years, 167-251 (depending on age) receive an abnormal result and are recalled; about 56-64 of these have at least one biopsy. Nine to 26 women (depending on age) have an invasive cancer detected by screening and three to six ductal carcinoma in situ (DCIS) detected by screening. About 0.5, 2, 3, and 2 fewer deaths from breast cancer occur over 10 years among 1000 women aged 40, 50, 60, and 70 years respectively, who choose to be screened compared with women who decline screening.</td>
<td>Benefits and harms of screening mammography are relatively finely balanced and these quantitative estimates can be used to support individual informed choices about screening.</td>
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<td>14</td>
<td>D</td>
<td>Barratt, A. (2006)</td>
<td>To explore and understand the potential harms of cancer screening and evidence for the benefits.</td>
<td>Literature review</td>
<td>n/a</td>
<td>Well recognised harms include the psychological and physical harms of false positive and false negative tests. More recent research is uncovering what may turn out to be the downside of cancer screening; the potential to uncover clinically irrelevant disease (pseudo-disease) and therefore harm from unnecessary treatment. Screening is complex and involves trading off benefits and harms.</td>
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<td>Baskaran, V., Bali, R. K., Arochena, H., Naguib, R. N., Wheaton, M., &amp; Wallis, M.</td>
<td>To describe a study currently underway to identify how GPs could be involved in a Knowledge Management (KM) system to enhance uptake of breast screening in the UK.</td>
<td>Self-completion questionnaires</td>
<td>GPs in Coventry UK, (number not provided)</td>
<td>Previous research indicates 75% of the intended population take up free mammograms through the National Screening Programme in the UK. Access to screening has been improved through free rides to and from units and the introduction of mobile units, publicity campaigns and education. Previous research in the UK has identified that an additional letter from a GP would appreciably increase uptake. But the resources involved are costly. A new software solution is under development to predict which women are less likely to attend, so that letters can be sent in a more targeted fashion. Knowledge management may be used to feed into GP based interventions to enhance screening rates. No results are yet available.</td>
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*The Radiographer*, 48, 65-71. | Self complete questionnaire | 595 women in attendance for mammographic screening between June 1997 and September 1997. | 98% of respondents had access to women's magazines.  
62.7% had been influenced to undergo mammography after reading related articles in women's magazines.  
95.2% agreed with the concept of women's magazines having a role to play in the education of women about mammography.  
The preferred method of delivery for specific information was a mixed publication of medical facts and anecdotes (42.2%).  
An increase in the current number of articles published was desired by 73.7%.  
After reading an article on mammography 17.6% had actively sought further information on mammography. | Australian women's magazines are a significant influence in women's presentation for mammographic screening.  
There is potential for women's magazines to be further utilised to generate a higher profile for breast screening, increase recruitment into mammographic screening programs and to further educate women as to the benefits of mammographic screening. |
*Australia and New Zealand Health Policy* 2007, 412dx10.1186/1743-8462-4-12. | Compiling data from 1997 and 1998 NSW Health Surveys conducted by telephone among a random sample of NSW residents aged 16 and over. Based on this data, probit models were estimated on the probability of having had a screening mammogram in the last two years for all women aged 40–79. | n/a | Women in higher socio-economic groups are more likely to have been screened than those in lower SEGs, among all age groups.  
However, the socio-economic effect is significantly less among women who were in the actively targeted age group.  
No evidence that the association between income and use of the service among target-age women varied across areas. | Recruitment and follow up is associated with a modest reduction in social inequalities in utilisation although significant income differences remain. |
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<td>18</td>
<td>A, B, C, E</td>
<td>To explore current knowledge, attitudes and behaviour of women regarding breast cancer and the BreastScreen Australia Program, and to understand women’s communication needs regarding breast cancer to help inform new concepts and communication material.</td>
<td>Twenty qualitative focus groups</td>
<td>Women aged 50-69 years, including a mix of regular screeners, lapsed and never screened. Key indigenous stakeholders were also included in a separate group.</td>
<td>Independent of their screening history, all women were positive about the need for early detection of breast cancer. Majority aware of and endorse free mammograms, with the only criticism being that screening should be free for all women. Widely held view that breast cancer is becoming more common overall. However, the media spotlight on younger celebrities i.e. Kylie has contributed to the perception that breast cancer is becoming more common among younger women as well. This diluted the belief that age is a risk factor. Women are driven to screen or not by either active motivations/barriers i.e. family history or negative past experiences or passive motivations/barriers i.e. Reminder letter or low awareness. Never screened had some fears of the process or gave excuses. Lower level of awareness and concern in Indigenous communities around breast cancer due to a lack of information and perceived relevance of the disease. Key barriers identified were family responsibilities, transport, fear of pain, lack of interest, embarrassment, sickness and lack of resources i.e. Indigenous health workers.</td>
<td>Among the target population communications should aim to challenge the ‘Kylie’ age perception to not only educate women on the age risk factor but also to dispel the misconception that ‘family history’ is the greatest risk factor. Mammography also needs to be promoted as the most effective screening tool.</td>
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<td>19</td>
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<td>To assess the effectiveness of different strategies for increasing the participation rate of women invited to community (population based) mammography programs.</td>
<td>Meta-analysis of 16 randomised controlled trials or clinical controlled trials where the control group had not been exposed to any active intervention.</td>
<td>n/a</td>
<td>A letter of invitation, mailed educational material, a phone call and some combined actions (such as a letter of invitation plus a phone call and training activities plus reminders) all seem to increase numbers of women participating. However the analysis did not determine which of these work better. Other interventions, such as a home visit, have not been proven to work.</td>
<td>Further studies should explore the effect of more specific actions addressed to subgroups that are less likely to attend.</td>
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<td>20 G</td>
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<td>Bonner, F., McKay, S. (2004)</td>
<td><em>Educating readers: breast cancer in Australian women's magazines</em> (International Journal of Qualitative Studies in Education, 17:4). To examine how the role of women's magazines operates in public health awareness.</td>
<td>Examining coverage of breast cancer awareness in 3 Australian women's magazines: <em>New Idea</em>, <em>Women's Day</em>, <em>Australian Women's Weekly</em>.</td>
<td>n/a</td>
<td>Magazines continue to advocate early detection through self examination and mammography. Magazines repeatedly publicize contact details for relevant foundations, charitable organisations and support groups. The increase in the number of celebrity breast cancer stories over those of ordinary women, which also then tends to overstate the extent to which younger women are at risk. It appears that the idea of relating experience of illness can be of help to others in a similar situation, and this is the principal justification for the printing of illness narratives.</td>
<td>Overall, in spite of the changed context, magazine information on breast cancer has changed little in that personal narratives still dominate. While general health and diet information is still provided, it has diminished significantly.</td>
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<td>21 H</td>
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<td>Brennan, E. &amp; Spilane, J., (2007)</td>
<td><em>The breast physician: an example of specialisation in general practice.</em> (Medical Journal of Australia, 187(2) 111–114). To describe the emergence of breast physicians and discuss advantages and disadvantages.</td>
<td>Viewpoint</td>
<td>n/a</td>
<td>Breast physicians care for women with breast disease and work in multi-disciplinary teams in hospitals, clinics, private practice and the breast screening program – i.e. not only in the screening and diagnostic setting. Their GP background is central to their valuable skills and perceptions of patient needs. However some observes are concerned that the development of special interest areas for GPs such as this may lead to the fragmentation of patient care. Patients and referring GPs may also be confused about their role.</td>
<td>GPs face the challenge of developing a career path and professional pathway for specialist GPs such as breast physicians.</td>
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22 B | Brotherton, J., Taylor, R., Ivanov, O., Tewson, R., & Page, A. (2007). *It’s much easier than going to the dentist*: high levels of satisfaction in a mammography screening program, Australian and New Zealand Journal of Public Health, 31: 353-359. | To develop a suitable instrument for measuring client satisfaction in a standardised and co-ordinated manner within the BreastScreen NSW (BSNSW) program and to use the instrument to measure client satisfaction. | Self-complete questionnaire | 2,091 women aged 40+ years who participated in the BreastScreen program. | Majority (80%) rated the overall service of BSNSW in the highest category of ‘excellent’. Staff were rated as ‘excellent’. Highest levels of dissatisfaction reported were in terms of the experience during the appointment. Negative ratings were largely due to discomfort of the mammogram being greater than expected or more painful than previous visits and breast problems following the mammogram (both at 9%). Other areas of dissatisfaction were parking and public transport access as well as the time taken to receive results. Non-English speaking women were more likely to be dissatisfied, as they may have difficulty communicating with staff, as well as potential cultural differences influencing their perceptions. | Although overall satisfaction was high, the survey indicated service functions where improvements could be made i.e. transport and language. |
23 A | Brushin, B., Gonzalez, M., Payne, R. (1997) Exploring cultural attitudes to breast cancer NHMRC National Breast Cancer Centre. | To understand attitudes towards breast cancer held by women from Arabic, Greek, Italian and Polish speaking backgrounds. | Focus groups and individual interviews | 151 women from Greek, Italian, Arabic and Polish speaking backgrounds within metropolitan Melbourne. | Fear, religion and community attitudes all play a role in how breast cancer is perceived. Doctor plays a key role in influencing whether these women go for a mammogram. Culture has an influence on the perception of illness, with things such as religion, family structure function and sex roles all having an effect on how when a women seeks medical advice, discloses information about her illness and interacts with health professionals. | Given that culture shapes behaviour, there should be different courses of action and recommendations for dealing with women from differing cultural backgrounds when it comes to breast cancer. |
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<td>24 A</td>
<td>Cant, R., Kwok, C., Sullivan, G. (2006).</td>
<td>To explore how cultural meanings of the breast impact on perceived images of breast cancer and breast health practices.</td>
<td>In depth interviews in their native language (Cantonese)</td>
<td>n=20 Chinese-Australian women.</td>
<td>The meaning of the breast is constructed within the women’s social and cultural context where breasts are associated with sex; and talking about, being concerned with or expressing curiosity about breasts is considered inappropriate. Most had heard of breast cancer but given the close link between breasts and sex – many felt that breast cancer was a shameful disease and that one of the perceived causes was ‘promiscuity’. Very few had conducted breast self examination and found the clinical examination highly embarrassing. Many believe that breast cancer will not happen to them as it’s perceived as a ‘White ladies’ disease’.</td>
<td>These views have a significant impact on 1) the way the informants viewed breast cancer; 2) perceptions of breast health practices and 3) the explanations of breast cancer and associated risk perception. Understanding the nature of culturally-based barriers to utilisation of breast cancer screening is the first step to discovering solutions for making screening tests more acceptable to women from other cultures.</td>
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<td>25 D</td>
<td>Castells, X., Molins, E., &amp; Macia, F. (2006).</td>
<td>To investigate the cumulative false positive recall rate throughout the period of participation in a population based breast cancer screening programme and to examine its association with future participation.</td>
<td>Analysis of a database of participants in the breast cancer screening programme to estimate the cumulative false positive recall rate after 10 biennial mammograms in a cohort of women.</td>
<td>8502 women aged 50-69 years who participated in four consecutive screening rounds in Barcelona, Spain.</td>
<td>The false positive recall rate at the first screening for women who entered the screening programme at the age of 50-51 years is 10.6%. At the second screening it decreased to 3.8% and remained almost constant for the remaining rounds. After 10 mammograms, the cumulative false positive recall rate was estimated at 32.4%. Factors associated with a higher cumulative risk of false positive recall were: previous benign breast disease, perimenopausal status, body mass index above 27.3, and age 50-54 years.</td>
<td>One-third of women could have at least one false positive recall over 10 biennial screens. Women participating in screening programs should be informed about this risk.</td>
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<td>26 D</td>
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<td>Cawson, J.</td>
<td>Screening for breast cancer: false positive expensive. BreastScreen Melbourne.</td>
<td>Literature review of a US study</td>
<td>n/a</td>
<td>False positives occurred with 6.5% mammograms and 3.7% clinical examinations. 24% of women had at least one false positive mammogram, and 13% had at least one false positive clinical examination. The cumulative risk of having at least one false positive after 10 screenings was 49% for mammography and 25% for clinical examination. False positive testing required 870 consultations, 539 mammograms, 186 ultrasounds and 188 biopsies at the cost of around US$1 million on screening and US$320,000 on work-up tests.</td>
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<td>27 G</td>
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<td>Chapman, S., McLeod, K., Wakefield, M., &amp; Holding, S. (2005)</td>
<td>Impact of news of celebrity illness on breast cancer screening: Kylie Minogue’s breast cancer diagnosis. Medical Journal of Australia (MJA), 183 (5): 247-250.</td>
<td>Collation of all news media that referred to Kylie Minogue, or which used her diagnosis as a news hood to cover various aspects of breast cancer. This was augmented by mammogram booking data from four state BreastScreen units.</td>
<td>n/a</td>
<td>There was a 20-fold increase in new coverage of breast cancer, which emphasised that young women get breast cancer and that early detection was critical. Overall screening bookings rose 40% in the 2 weeks of the publicity, with a 101% increase in non-screened women in the eligible age group 40-69 years. Six weeks after the publicity, bookings remained more than a third higher in non-screened women.</td>
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<td>28 E</td>
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<td>Clutton, C., Pakenham, K.J., Pass, M. (2000)</td>
<td>The utility of sociodemographics, knowledge and health belief model variables in predicting re-attendance for mammography screening: A brief report Psychology and Health, 15: S85-S91.</td>
<td>Questionnaire</td>
<td>88 re-attendees and 44 non-re-attendees of an Australian breast screening service.</td>
<td>Re-attendees were more likely to be older, married and report physician involvement than non-re-attendees. Family history and knowledge did not significantly predict re-attendance. Of the HBM variables, perceived benefits were related to re-attendance above and beyond socio-demographics.</td>
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<td>29</td>
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<td>Crombie, K. et al. (2005) <em>Breast screening education at Australian and Thai worksites: A comparison of program effectiveness</em> Contemporary Nurse, 19(1-2), 181-196.</td>
<td>To determine whether a nurse-led breast screening educational program in the workplace improved the breast screening practices and attitudes of women.</td>
<td>Work site survey</td>
<td>Women in 3 participating blue-collar industries (factories) in Australia and Thailand.</td>
<td>Findings indicate that doctors continue to exert a major role in breast health. There is no correlation between education and breast screening practices for the Australian group, but higher levels of education were related to having had physical breast examination (PBE) in Thailand. The education program had positive influences on the practices and attitudes. There was evidence that the group education program resulted in an increase in the number of women likely to perform BSE.</td>
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<td>30</td>
<td>D</td>
<td>Davey, C., Ward, J., Young, J. (2003) <em>Influence of ‘framing effect’ on women’s support for government funding of breast cancer screening</em> Australian and New Zealand Journal of Public Health, 27(3), 287-290.</td>
<td>To explore whether Australian women’s support for government funding of mammographic screening is influenced by ‘framing effect’.</td>
<td>Self-administered survey</td>
<td>701 women in general practice.</td>
<td>The proportion of respondents indicating they ‘definitely would support’ funding was significantly greater when benefits were expressed as relative risk reduction (RRR) (i.e. “Program A will reduce the risk of dying from breast cancer by 34% among those who are offered screening compared with those who are not”) than absolute risk reduction (ARR) (i.e. ”Program B will reduce the risk of dying from breast cancer from 1 in 45 to 1 in 46”) or number of cases detected for additional deaths avoided. 55.8% of women were not influenced by ‘framing effect’. Younger women and those with higher educational levels were more likely to be susceptible to ‘framing effect’.</td>
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<td>31</td>
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<td>Davey, C., White, V., Gattellari, M., &amp; Ward, J. (2004).</td>
<td>To explore women’s reactions to ‘informed choice’ in mammographic screening.</td>
<td>Telephone survey</td>
<td>n=106 women aged 45-70 years recruited from general practices in Sydney.</td>
<td>Many women (42%) preferred an active role in decision-making. The women in the sample understood and recommended for others full disclosure of the complexities of mammographic screening. Respondents indicated significantly greater willingness to have a test when the benefit of a ‘new’ screening test for breast cancer was expressed as relative risk reduction (RRR) than either absolute risk reduction or all-cause mortality e.g. ‘having this test every two years will reduce your chance of dying from breast cancer by about 34% over a 10 year period’. Significantly more respondents considered information about Absolute Risk Reduction (ARR) ‘new’ to them compared with RRR information e.g. ‘Instead of 6 out of 1000 women dying from breast cancer, 4 will die.’</td>
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<td>32</td>
<td>E</td>
<td>Galletta, S., Joel, N., Maguire, R., Weaver, K., &amp; Poulos, A. (2003).</td>
<td>To identify the causes of anxiety experienced by mammographers and clients during mammography and strategies to decrease the anxiety generated by the mammographic procedure.</td>
<td>2 self-complete questionnaires</td>
<td>Mammographers (n=80) in public and private centres and women (n=72) who have experienced mammography.</td>
<td>Mammographers’ and clients’ rankings of causes of clients’ anxiety demonstrated many similarities indicating that mammographers’ acknowledgement of factors contribute to client anxiety. Breast compression, potential results and pain were all nominated by both groups as the three most important causes for client anxiety. Thematic analysis indicated that mammographers’ anxiety was a result of feeling rushed, clients being late or complaining. Mammographers provided a comprehensive range of behaviours which they considered decreased clients’ anxiety. This list was very similar to the behaviours indicated by the clients that decrease anxiety.</td>
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<td>Han, P., Kobrin, S., Klein, W., Davis, W., Stefanek, M., &amp; Taplin, S. (2007).</td>
<td>Perceived ambiguity about screening mammography recommendations: association with future mammography uptake and perceptions. Cancer Epidemiology Biomarkers &amp; Prevention, 16(3), 458-466.</td>
<td>Secondary analysis of longitudinal data collected from the 1995 Maximizing Mammography Participation trial which examines the effectiveness of patient reminders in increasing mammography utilization among women ages 50 to 79.</td>
<td>n/a</td>
<td>Higher levels of perceived ambiguity were associated with both diminished subsequent uptake of mammography, lower mammography intentions and higher levels of subsequent mammography-related worry.</td>
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<td>34</td>
<td>A</td>
<td>Hyndman, J. C., &amp; Holman, C. D. (2000).</td>
<td>Differential effects on socioeconomic groups of modelling the location of mammography screening clinics using Geographic Information Systems (GIS). Australian &amp; New Zealand Journal of Public Health, 24 (2), 281-286.</td>
<td>To evaluate special access to mammography clinics and to investigate whether relocating clinics can improve global access. To also determine whether any change in access is distributed equitably between different social groups.</td>
<td>Analysis of travel distances to mammography clinics, comparing distances to the pattern of existing clinics and modelled relocation clinics.</td>
<td>n/a</td>
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<td>35</td>
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<td>Hyndman, J. C., Holman, C. D., &amp; Dawes, V. P. (2000).</td>
<td>Effect of distance and social disadvantage on the response to invitations to attend mammography screening. Journal of Medical Screening, 7 (3): 141-145.</td>
<td>To investigate whether public response to an invitation to attend mammography screening can be increased by strategic relocation of the clinics.</td>
<td>Data classification of women participants invited to attend any of the six mammography screening clinics run by BreastScreen WA in the Perth metropolitan area.</td>
<td>n/a</td>
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<td>Jirojwong, S., Manderson, L. (2001). Beliefs and behaviours about pap and breast self-examination among Thai immigrant women in Brisbane, Australia Women &amp; Health, 33 (3/4), 47-66.</td>
<td>To describe women’s beliefs and perceptions about the body, breast and cervical cancer, and their perceptions of the causes of the diseases.</td>
<td>Structured questionnaire</td>
<td>n=145 Thai immigrant women in Brisbane.</td>
<td>Some believed that they would have breast cancer because they had a history of benign tumour or cyst of the breast. Others felt if you injured your breast or wore a bra too tightly you could develop it. First generation Thai immigrant women use both medical knowledge and traditional beliefs to describe the causes of cancer and link to their personal risk. 44% of the women had biennial pap smears in the past 5 years. Only 25% conducted breast self-examination in the past 2 years.</td>
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<td>37</td>
<td>G</td>
<td>Jones, S.C. (2004). Coverage of breast cancer in the Australian print media - does advertising and editorial coverage reflect correct social marketing messages? Journal of Health Communication, 9 (4): 309-325.</td>
<td>To investigate the accuracy of breast cancer detection messages in the media against the major ongoing national social marketing advertising campaign conducted by BreastScreen Australia (BSA).</td>
<td>Analysis of messages from ten top-selling Australian women’s magazines and three weekend newspapers in the six-month period from December 2000 to May 2001 that included any reference to breast cancer.</td>
<td>n/a</td>
<td>Current coverage of breast cancer in the Australian print media convey messages that are unlikely to encourage appropriate screening. None of the advertisements mentioned the age-related nature of breast cancer. Also, since a similar 1995 study, related articles clearly portraying women under 40 years has increased from 33% to 44%. At least 50% of illustrations were of women aged under 40 years, and 10% or less were aged over 50 years. Mammographic screening of women over 50 was rarely mentioned in print media stories or advertisements. There was also an absence of adequate information on lifetime risk.</td>
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Objectives / Aims

To examine the impact of an experimental threat manipulation for mammography screening on a group of women in regional Australia, to ultimately understand whether the use of fear motivates health behaviour.

Methods

Four experimental advertisements were created using low and high threat images/words. Pre-exposure and post-exposure self-complete questionnaires were completed.

Participants

n=149 women from regional NSW aged 18 years and over.

Results

Varying the level of threat in persuasive communications appears to have had no impact on stated intentions to undergo mammographic screening among older women (50+).

Among younger women with low levels of perceived efficacy, high threat messages appeared to reduce intentions to undergo mammograms upon reaching the target age for screening.

High threat messages appeared to result in stronger (negative) emotional reactions, more sympathy for breast cancer victims and higher perceived susceptibility among younger women.

Conclusion

This research suggests that high fear may result in reduced detection behaviours and recommends that high levels of threat should be limited in social marketing campaigns. Campaigns need to be appropriately designed to specifically impact upon and motivate the target group rather than scare them.

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<td>41 C</td>
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<td>King, E., Ball, J. &amp; Carroll, T. (2003). <em>Evaluation report for the 2000/2001 phase of the BreastScreen Australia Campaign</em>. Department of Health and Ageing, Canberra.</td>
<td>To provide a post-campaign measure of recall of advertising and campaign messages, awareness of the program, impact on knowledge of breast cancer and breast cancer screening, as well as attitudes, behaviour and intention with regards to screening for breast cancer.</td>
<td>Two national telephone surveys conducted pre and post the 2000/2001 wave of BreastScreen Australia (BSA) media activity. n=1210 women aged 40-69 years surveyed pre campaign, n=1234 women aged 40-69 years surveyed post campaign.</td>
<td>More than half of 50-69 year old women reported having seen, read or heard a advertising relating to screening mammograms in the recent past. TV advertising was the most frequently cited source of information, followed by brochures/leaflets from doctors' surgeries. Nearly eight in ten (76%) could report accurate descriptions of the advertising, particularly in relation to Sara Henderson. Over two in three respondents had heard of 'BreastScreen Australia' the majority were able to provide accurate descriptions of what the organisation did. Almost all (98%) believed that screening for breast cancer through BreastScreen Australia was either a 'very good' or 'fairly good' idea. There is a high acceptance of the benefits of the mammogram with over nine in ten reporting that it was 'very' or 'quite' effective. In fact, one-third (34%) believe that screening should commence younger, between 40-49 years, whilst one-quarter (26%) nominated 30-39 years.</td>
<td>Given the positive support for BreastScreen Australia and the high rate of campaign awareness, it is clear that the Sara Henderson campaign is having cut through. The campaign also successfully promotes mammograms as the most effective way to detect breast cancer.</td>
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<td>42 A</td>
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<td>Kwok, C., Cant, R., &amp; Sullivan, G. (2005). <em>Factors associated with mammographic decisions of Chinese-Australian women</em>. Health Education Research, 20(6): 739-747.</td>
<td>To explore and investigate the factors associated with mammographic decisions of Chinese-Australian women.</td>
<td>In-depth qualitative interviews augmented by ethnographic observations.</td>
<td>20 Chinese-Australian women aged 50-69 years old.</td>
<td>There are two mammographic screening facilitators identified: organisational factors (invitation letter from BreastScreen and seniors' clubs activities) and the influence of 'significant others', particularly daughters and husbands. Family members allows for the provision of transport, facilitating communication with the staff and providing psychological support in a strange environment. The free service is also a key facilitator of participation. Barriers identified were fear of physical damage of mammography, concerns about radiation, and doubts about the efficacy of mammography. Breast cancer is often perceived as a 'Western disease' and more prevalent among large-breasted women, therefore not relevant to Chinese women. Modesty is another major barrier and fear of stigmatisation, if they discuss what they regard as a private health issue.</td>
<td>There is a need for revised and innovative promotional material for the Chinese-Australian community that addresses many of the barriers including modesty, language barriers, and the cultural beliefs about cancer.</td>
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<td>43 A</td>
<td>Kwok, C. &amp; Sullivan, G. (2007)</td>
<td>To explore concepts of health and health promotion and how they influence Chinese Australian women’s decisions to participate in cancer screening.</td>
<td>Qualitative, in-depth interviews conducted in Cantonese (which was found to be the language in which respondents felt best able to express themselves).</td>
<td>20 Chinese Australian women aged 50 to 69 who had never been diagnosed with breast cancer and had arrived in Australia between 3 and 14 years ago.</td>
<td>4 of the participants had never heard of screening mammography. Health is assumed; most trusted their feeling of being healthy and happy and expected this happy state to continue at least until old age. Concepts of health promotion focus on striving to maintain harmony and balance in their lives. This covers physical factors (healthy diet, regular sleep and exercise) and psychological factors (maintenance of emotional harmony, constantly being seen to be optimistic). Many did not perceive medical ‘check-ups’ as a useful method of preventing illness. They tended to see a mammogram as only having a place as a diagnostic tool, rather than being useful for asymptomatic women.</td>
<td>Definitions of health are context dependent and vary according to cultural and environmental factors. It is important for traditional health beliefs and concepts of health promotion be taken into account in promoting and providing services. Chinese Australian women are unlikely to be influenced by appeals to look for diseases when they are asymptomatic. However, it may be worth exploring whether participation rates for this audience could be enhanced by explaining that the risk of breast cancer increases following migration.</td>
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<td>Llewellyn, G., Poulos A. (2004)</td>
<td>To consider discomfort from a holistic perspective of the mammography experience derived from women’s experiences</td>
<td>Qualitative interviews, theoretical sampling.</td>
<td>12 women who had recently experienced mammography.</td>
<td>The process effecting a woman’s perception about mammography discomfort is sequential: 1) beliefs about mammography 2) the experience on the day 3) the perception of the procedure. Change in any one of these will alter the perception of mammography discomfort. This perception is then communicated and sustained by “women talk” which feeds back into the process.</td>
<td>This framework creates an understanding of the experience grounded in the experiences of women themselves and is better able to describe the richness and complexity of a woman’s perceptions.</td>
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**Objectives / Aims**
To investigate trends towards early detection of infiltrating ductal carcinomas (DCIS), possible effects on patients’ prognosis, and characteristics of women still at high risk of late detection.

**Methods**
Data analysis of the South Australian Cancer Registry to compare breast tumour diameters by age across a period of 20 years.

**Participants**
n/a

**Results**
The proportion of tumours with diameters smaller than 15mm increased from 13% in 1980-86 to 36.7% in 1997-2002, whereas the proportion with large diameters reduced from 43% to 18.6%.

This is supported by reductions in case fatality also reported during this time and is indicative of the improvements in prognosis as a result of early detection.

Women with large diameter tumours were more likely to be in age ranges outside the 50-69 year target for mammography screening; low socio economic areas; non-Caucasians; patients born in Northern/Eastern Europe and potentially Asia-Middle East; and in some country locations.

**Conclusion**
Increased emphasis on early detection should be directed at sectors of the population where delays in diagnosis and poorer prognosis are evident. Projected reductions in breast cancer mortality among patients are indicative of effects of earlier detection on patients’ prognosis, but require confirmation with follow-up data.


**Objectives / Aims**
To identify cultural, gender and logistic/distance issues among Indigenous women in Queensland that impacted the detection of breast cancer, and the treatment and post-treatment care and support of cancer.

**Methods**
Qualitative focus groups, case histories and interviews. Research conducted over a nine month period.

**Participants**
Aboriginal women (n=101) of child bearing age and older. Service providers in urban, rural and remote areas of Queensland.

**Results**
Limited access to primary health services and lack of trust towards services means these women often present to screening late or less often. If treatment is required this raises even more concerns as can be intimidating and require travelling some distance. Although BSE is widely known and raises awareness, it is not something many indigenous women feel comfortable with. Aboriginal women feel more comfortable presenting to a female worker, particularly an Aboriginal one. Medical terms upon diagnosis are often misunderstood and can cause anxiety and confusion.

**Conclusion**
Barriers to diagnosis, treatment and care can be addressed by increasing women’s awareness of breast cancer and the benefits of preventative health behaviour, and improving the quality and appropriateness of health care and counselling services for Indigenous women and their families.


**Objectives / Aims**
Looking at why 12,000 women do not return for a mammogram at BreastScreen within 30-50 months of their being contacted for rescreening.

**Methods**
Review of recent surveys n/a

**Results**
The main reasons women do not return for re-screening include:
- Inconvenient/too busy/forgot
- Attended elsewhere
- Painful
- No symptoms.

**Conclusion**
The study suggests that the single most effective way of increasing attendance is to improve the referral rate by GPs to the services, to avoid women going elsewhere or using pre-conceived beliefs to avoid it.
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<td>48</td>
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<td>To evaluate a range of communications concepts for the Rural Mobile Screening Service (MRSS). Qualitative: 5 focus groups.</td>
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<td>Women aged 50 to 60 in rural Victorian communities, including those who have previously screened and those who have never screened.</td>
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<td>‘It’s important. It’s free. It’s here’ was seen as a simple, relevant and positive statement that would get their attention. Respondents questioned why MRSS only targeted women over 50, and often felt this was discriminatory. Women did not always understand the difference between screening and diagnostic mammography. Some thought it would be appropriate to use MRSS services if they noticed symptoms. The information on this subject that was tested did not help to clarify the issue and it seems a long explanation would be required. Women from outlying areas of the towns visited by the RMSS wanted information on when the service would be available in a number of towns, as more than one could be accessible for them. This would enhance accessibility for this audience. Women wanted promotional materials to include opening times for RMSS as they wanted to know if it was possible to visit outside business hours. Information about the incidence of breast cancer helped motivate women to make an appointment. Some women wanted reassurance that the service is run by women. Providing information about the discomfort involved is welcomed as this demonstrates that the staff are empathetic. However, giving detailed information about ‘compression’ could put some women off attending. Many felt set appointment dates and times encouraged women to attend as they felt obliged or committed. However under-screened women could find this ‘pushy’. Women who are concerned about having a mammogram may be reassured by visiting the RMSS before making an appointment if they perceive it to be professional, comfortable and private.</td>
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<td>Information on how to access the RMSS, why they should do so and how to make an appointment are all likely to enhance take-up. Further research among under-screened women is needed to provide a more comprehensive understanding of the communication needs of these women.</td>
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<td>49</td>
<td>C, E, F</td>
<td>To explore decision making in relation to taking up (BreastScreen Victoria) BSV services perceptions of the initial invitation letter, reminder letter and confirmation letters sent by BSV, with a view to providing developmental recommendations that could enhance take-up of breast screening amongst the target audience.</td>
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<td>50</td>
<td>C, F</td>
<td>Qualitative: 5 focus groups and quantitative: CATI.</td>
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<td>51</td>
<td>C</td>
<td>Market &amp; Communications Research (2000). Evaluation of BreastScreen Australia “Sara Henderson” Campaign Materials, Research and Marketing Group – Population Health Division, Commonwealth Department of Health &amp; Aged Care.</td>
</tr>
<tr>
<td>52</td>
<td>B, E</td>
<td>Market &amp; Communication Research (2005). BreastScreen Queensland Research Findings, Prepared for Queensland Health.</td>
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<td>53</td>
<td>A, E, D</td>
<td>To compare organised and opportunistic screening programs in five countries: Australian, Sweden, France and Switzerland.</td>
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<td>54</td>
<td>B, D, E</td>
<td>To review the accumulated literature on screening intervention research.</td>
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<td>55</td>
<td>A, E</td>
<td>To determine the socioeconomic, cultural, and clinical predictors of non-attendance for second round mammography.</td>
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<td>56</td>
<td>A, B, C</td>
<td></td>
<td>Northern Territory Department of Health and Community Services (2004). BreastScreenNT 10 Years: a decade of achievement 1994–2004.</td>
<td>Analysis of relevant data, literature and positive comments from women, health workers and BSNT staff.</td>
<td>n/a</td>
<td>The recruitment and retention of health service staff is a concern in the NT, especially in radiography and radiology. The NT was the last state or territory to implement BSA as cost-benefit analysis by the government indicated it should not be a priority. However NT women successfully lobbied the government for access. BSNT does not travel to very remote areas but visits four of the of the largest regional towns. Confusion about the 50-69 year target group has caused emotional responses from community members. Misunderstanding and community debate have also surrounded access for women with breast symptoms. Participation in NT was 44.18% in 2003-4. Sending personalised letters of invitation when they turn 50 has been a very effective recruitment strategy, with response rates between 35 and 40%. Direct recommendation from a GP has been found to increase response. A Queensland study found factors such as language, communication difficulties, rigid appointment times, distance and discrimination all impact on access for Indigenous women. Nevertheless, some indigenous women in remote areas make group bookings to visit BSNT and travel together. Research indicates women with disabilities are under-screened due to reduced access caused by economic, physical and cultural barriers. Women whose first language is not English have been found to prefer to discuss issues in their own language: “When you have fear you go back to your own language” (Bilingual Educator). Gay, lesbian and bisexual women are also under-screened, possibly due to homophobic discrimination.</td>
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<td>57</td>
<td>B, C</td>
<td>Northern Territory Department of Health and Community Services (2004). BreastScreen Assessment Clinic Client Satisfaction Survey 2005. Evaluation Report.</td>
<td>To identify strengths of the BreastScreen Northern Territory (BSNT) Assessment Clinics and opportunities for improvement.</td>
<td>Self-completion postal survey</td>
<td>111 women who had attended the Assessment Clinic either in Darwin or Alice Springs (38% response rate).</td>
<td>94% rated BSNT’s assessment service as excellent or good (73% rated it as excellent).</td>
<td>Satisfaction levels are high overall, with some room for improvement to enhance the acceptability of the service.</td>
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<td>58</td>
<td>A, C</td>
<td>Page, A., Morrell, S., Tewson, R., Taylor, R., &amp; Brassil, A. (2005). Mammography screening participation: effects of a media campaign targeting Italian-speaking women, Australian and New Zealand Journal of Public Health, 29 (4): 365-371.</td>
<td>To evaluate the effect of a radio and newspaper campaign encouraging Italian-speaking women aged 50-69 years to attend a population-based mammography screening program.</td>
<td>A series of radio and newspaper advertisements ran weekly in the Italian-language media over an 8 week period. Mammography data was analysed. Followed up by a self-complete survey.</td>
<td>n=240 Italian-speaking women attending BreastScreen NSW (BSNSW).</td>
<td>Radio and newspaper Italian-specific advertisements did not significantly increase attendance to BSNSW and would need to be combined with an intervention campaign to have an impact. One in five (20%) cited the Italian media campaign as a prompt to attend but this was not evidenced in the recorded numbers of mammography screens during that period. The most common prompt was the BSNSW invitation letter, followed by information or recommendation from a GP. Radio and newspaper advertisements developed for the Italian community did not significantly increase attendance to BSNSW.</td>
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<tr>
<td>59</td>
<td>C</td>
<td>Page, A., Morrell, S., Chiu, C., Taylor, R., &amp; Tewson, R. (2005). Recruitment to mammography screening: a randomised trial and meta-analysis of invitation letters and telephone calls, Australian and New Zealand Journal of Public Health, 30 (2): 111-118.</td>
<td>To determine the effectiveness of three recruitment strategies to encourage women to attend for an initial mammography screen, and to compare results with similar service studies.</td>
<td>Three interventions (personalised invitation letter, two personalised invitation letters – initial and follow up, and a personalised invitation followed up by a telephone reminder) were trialed and compared with a no intervention group.</td>
<td>n=3,175 women on the electoral roll aged 50-54 years who had never attended BreastScreen NSW for a mammogram in two catchment areas.</td>
<td>Screening rates in all three interventions were significantly higher than the non-intervention group after 12 weeks. The response rate was highest (13.3%) among women who received the letter plus a phone call (where a phone number was available). Screening rates were also significantly higher (8.5%) among the women who received a second invitation letter, compared with the standard practice of one letter. The study suggests that using a combined strategy of telephone contactable numbers and two letters sent to non-contactable numbers would maximise mammography screening recruitment. However a follow-up invitation letter is the most cost-effective.</td>
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<td>60 D</td>
<td>Paul, C., Barratt, A., Redman, S., Cockburn, J., &amp; Lowe, J. (1999). Knowledge and perceptions about breast cancer incidence, fatality and risk among Australian women. Australian and New Zealand Journal of Public Health, 23(4), 396-400.</td>
<td>Telephone survey</td>
<td>2,935 Australian women</td>
<td>Australian women were well aware of breast cancer in general terms, however there were major aspects of incidence and risk which were poorly understood. Only 5% of women nominated age as a risk factor. Women still do not understand that increasing age is the major risk factor for breast cancer placing a much greater emphasis on family history than age. Only one-third were able to make an approximately correct estimate of the incidence of breast cancer in Australia. This study suggests that future information campaigns need to target understanding of lifetime risk of developing breast cancer, age as a risk factor, survival from breast cancer and the need to separately address the perceptions of older versus younger women.</td>
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<td>61 E</td>
<td>Poulos, A. (2004). Having a mammogram: How does it feel? The Radiographer 51(3), 129–131.</td>
<td>Self-complete questionnaire</td>
<td>30 women who attended routine breast screening by mammography at BreastScreen NSW Central &amp; Eastern Sydney.</td>
<td>90% of participants did not feel pain, however one-third experienced discomfort indicating that “discomfort” is a more accurate descriptor than “pain”. The transitory nature of the experience and the short amount of time involved contributed to the perception of discomfort rather than pain. The results support the use of the term ‘discomfort’ in rating scales to assess the reported response to mammography. Some of the more positive aspects of the experience could be used in promotional material and in describing the procedure to clients.</td>
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<td>62 A</td>
<td>Poulos, A. E., Balandin, S., Llewellyn, G., &amp; Dew, A. H.</td>
<td>Review of mortality data and existing literature.</td>
<td>n/a</td>
<td>Women with CP have a 3 times higher mortality rate from breast cancer than the general population and are significantly less likely to use screening mammography services. A series of barriers to access are identified including: accessing information in appropriate formats; not being told by their doctor to have a screening mammogram; and difficulties obtaining assistance to get to the screening facility. Acceptability may also be a serious concern for this audience as staff have been reported to show negative attitudes to women with CP. This magnifies the pain and indignity of the procedure. Some women with CP may have difficulty in complying with the need to remain motionless during the mammogram, resulting in the outputs being unreadable. Mammograms are not an appropriate form of screening in some cases, whereas adapting positioning techniques could enhance outcomes for others.</td>
<td>Further in-depth appraisal of entry and outcome barriers should be undertaken, including developing guidelines for staff on how to interact with women with CP. Exploration of alternative forms of screening for women with CP for whom mammography is not appropriate is required.</td>
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<td>63 C</td>
<td>Right Marketing (2001). Post-campaign evaluation: BreastScreen WA’s 2000/01 recruitment campaign. Presented to BreastScreen WA Department of Health Western Australia.</td>
<td>Campaign evaluation</td>
<td>n/a</td>
<td>Those recalling the campaign were significantly more likely to agree that BSNA offers free screening mammograms for women over 50, than those who could not. Respondents recalling the campaign were significantly more likely to know that women aged over 50 were the age group most at risk of getting breast cancer, than those who could not recall the campaign. 4 respondents indicated the campaign motivated them to make an appointment for a screening mammogram.</td>
<td>The campaign was conceived, developed and implemented in a highly efficient manner, generating excellent levels of recall, message take-out and “cut-through” amongst the target audience.</td>
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<td>64</td>
<td>B, F</td>
<td>To investigate reasons why GPs do not universally refer patients to BreastScreen WA for mammography screening, given that it is a free service for women over 40 years.</td>
<td>A self-administered questionnaire</td>
<td>Completed by GPs (n=318) practising in the Perth metropolitan area.</td>
<td>97% claimed to refer patients for screening mammography. Main barriers making GPs less likely to refer a patient for screening mammography were identified as the competing demands of the consultation (67%), patient being over 70 years (57%) and being too busy with too many patients in a session (34%). 44% preferred to use BSWA, 7% preferred to use private radiology and half (50%) claimed to have no preference. Among those that preferred to use BSWA, the most important reason (43%) is that the service is free. However the main concern among women was the automatic referral without GP input (17%). Among the minority that preferred private, the most important reason is the quality of service (47%). However the main concern is the cost to the patient (15%).</td>
<td>Although GPs are supportive of screening mammography, this does not always translate into referrals to BSWA. Perceived quality of service and proximity of private clinics outweighed the free cost of the BSWA for some GPs.</td>
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<td>65</td>
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<td>To examine the impact of risk counselling on mammography use one year after intervention.</td>
<td>Participants were randomised to either the breast cancer risk counselling or the general health education groups, one year after the intervention participants were contacted for a blinded follow-up interview.</td>
<td>First degree relatives of women who were under treatment for breast cancer.</td>
<td>Among less-educated participants, those receiving risk counselling showed reduced mammography use relative to the general health education group. The treatment groups did not differ in mammography use at baseline or follow up. This study found that as treatment groups did not differ in mammography use at baseline or follow up, risk counselling does not appear to lead to increased mammography use. However standard breast cancer risk counselling could have an adverse impact on the health behaviours of less educated women.</td>
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Royal Australian College of General Practitioners WA Research Unit (2003). *Screening Mammography in General Practice.* Prepared for BreastScreen WA.

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<td>66 C</td>
<td></td>
<td>Shrestha, S., Poulos, A. (2001) <em>The effect of verbal information on the experience of discomfort in mammography.</em> Radiography, 7, 271-277</td>
<td>To evaluate the effect of verbal information given prior to the examination on women's expectations of discomfort and on actual discomfort experienced.</td>
<td>Expectations of discomfort were recorded. Half the respondents were verbally given information prior to the procedure ('experimental group'). The other half completed the procedure routinely ('control group'). All participants were asked to report levels of discomfort following the procedure.</td>
<td>236 women attending routine screening by mammography at Central and Eastern Sydney BreastScreen Service. Aged from 40 to 86.</td>
<td>62% of first time attendees reported their friends and relatives as being the source of their expectations of discomfort. 90% of those in the experimental group reported actual discomfort being less than expected. 87.5% of the control group reported actual discomfort to be more than expected. The effect of information on reducing actual discomfort was more pronounced for first time attendees than those who had been screened before.</td>
<td>Prior information given to women routinely during screening mammography will develop positive attitudes towards the mammography procedure. This may potentially increase regular attendance of these women. Focusing on first time attendees is likely to be particularly effective.</td>
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<td>67 A</td>
<td></td>
<td>Siahpush, M., &amp; Sing, G. K. <em>Sociodemographic variations in breast cancer screening behaviour among Australian women: Results from the 1995 National Health Survey.</em> Preventative Medicine, 35, 2, 174-180.</td>
<td>To understand the impact of sociodemographic variations on breast cancer screening behaviour among Australian women.</td>
<td>Data collected from the 1995 National Health Survey.</td>
<td>A sub sample of n=10,179 women aged 18 years and over was used for analysis.</td>
<td>Being in the oldest age group (70+), never being or previously being married and living in rural regions were all associated with a smaller likelihood of screening. Clinical self examination (CSE) is under-utilised by women in non-metropolitan regions, due more to regional variations in access to professional screening as opposed to lack of knowledge/awareness. Residing in more disadvantaged areas and having lower levels of education were also associated with a smaller likelihood of screening. Ethnicity was also significantly associated with screening. Women born in Southern Europe, the Middle East and Asia were more likely to never have had a mammogram and also to not examine their own breasts regularly.</td>
<td>Strategies to promote breast cancer screening practices should pay particular attention to the disadvantaged and cultural sub-groups and should be part of a more comprehensive policy that ensures the accessibility to regular health care of these population groups.</td>
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<td>To ascertain if there are misunderstandings with regards to mammographic screening and what the difference is if women are given not only accurate information about the risks but also information about the benefits, harms and costs of screening.</td>
<td>Self-administered questionnaires were completed before and after exposure to a 16 page evidence based consumer booklet comprising four parts: I. Mammograms and mammographic screening; II. Survival from breast cancer; III. Risks of developing breast cancer; and IV. Risks of dying from breast cancer.</td>
<td>Women aged 50-70 years were recruited from three Australian general practices.</td>
<td>Before reading the booklet 91% overestimated the risks of developing &amp; dying from breast cancers. At post test, significantly fewer did so.</td>
<td>Women participating in the study exhibited the same misunderstandings about breast cancer risk and mammographic screening as other community samples of women, reinforcing a view that current resources have failed to meet women’s rights to accurate information. This uncontrolled evaluation suggests that evidence based information can improve women’s knowledge in an acceptable manner.</td>
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<td>To investigate the role of five health beliefs: response efficacy, seriousness, concern, susceptibility and barriers to the likelihood of attending a breast screening programme.</td>
<td>Self-complete questionnaire</td>
<td>n=127 of women who presented themselves at the North Coast Breast Screening Unit and a second sample of n=185 women over 40 years who had not attended the Unit but knew about the service.</td>
<td>Of those that attended the mammography screening, the majority (77%) regularly performed breast self examinations (BSE). However of those that did not attend, only 10% regularly performed BSE. Among those that do not conduct BSE’s, reasons were a fear of finding a lump, lack of confidence in performing a BSE and lack of concern as they felt it was the responsibility of the GP. Of those that did not attend mammography screenings, reasons included that regular BSE made it unnecessary, or that it was inconvenient or was not a priority for them. Women who did not attend claimed to feel well, which suggests that rural women only use health services if they are ill. In terms of health beliefs, women who believed themselves to be at risk of developing breast cancer and those who were less concerned about undergoing mammography were more likely to be screened.</td>
<td>This study suggests that it is important to ensure that women understand the risks of developing breast cancer and that mammography is presented as a low risk and not too unpleasant an experience to encourage them to attend.</td>
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<td>70</td>
<td>E, F</td>
<td>Taylor, R., Ivanov, O., Page, A., Brotherton, J., Achat, H., &amp; Close, G. (2003). <em>Predictors of non-attendance from BreastScreen NSW in women who report current mammography screening</em>, <em>Australian and New Zealand Journal of Public Health</em>, 27(6): 581-587.</td>
<td>To identify among self-reported current screeners: (1) predictors of never attendance at BreastScreen NSW (BSNSW); (2) predictors of late or lapsed attendance to BSNSW (attendance to alternative providers).</td>
<td>Telephone survey of women selected from the BSNSW database and the NSW electoral roll.</td>
<td>n=3,104 women aged 50-69 years among current attendees, late and lapsed attendees and never attendees.</td>
<td>Late or lapsed attendance and attendance to alternative providers is associated with higher education, higher SES, private health insurance coverage, recent clinical breast examination and a family history of breast cancer. Doctor may refer women for private mammography if the practitioner has established links with providers. Some never attendees of BSNSW appear to hold the belief that a doctor's referral is required. Women who stayed in the BSNSW program were more likely to have received advice from a health professional to get a mammogram or be prompted by publicity about breast cancer and screening.</td>
<td>Currently screened women who do not attend BSNSW, or who are late or lapsed for a mammogram, appear to be influenced by referral patterns of their health care providers and their higher socio-economic status.</td>
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<td>71</td>
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<td>Trevena, L. (2006). <em>Informing patients about screening</em>, <em>Australian Doctor</em>.</td>
<td>To review and discuss the presence of screening in Australia and the role of the GP.</td>
<td>Review of program guidelines.</td>
<td>n/a</td>
<td>Australia has three main population screening programs, with a fourth being introduced in 2006; newborn screening, mammography, pap smears and colorectal cancer screening to be introduced. There is a growing call for patients to provide 'informed consent' and be informed of both the benefits and risks of the procedure. To aid this information gathering stage, effective communication tools for informing patients about screening are required i.e. decision aids which include booklets, web sites and videos.</td>
<td>It is important for GPs to play a role in discussing the pros and cons of screening and more balanced decision aids and communication would help this process.</td>
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<td>72</td>
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<td>Thornton, H., Edwards, A., Baum, M. (2003). <em>Women need better information about routine mammography</em>, <em>British Medical Journal</em>, 327; 101-103.</td>
<td>To explore the information and language used in breast screening literature to determine whether it is allowing women to make truly informed choices.</td>
<td>Literature review of relevant breast screening information and data.</td>
<td>n/a</td>
<td>Estimates of the effect of mammographic screening on mortality from breast cancer vary widely. Women offered screening are given limited information on the potential harms. Data is presented in terms that are hard to understand i.e. DCIS (ductal carcinoma in situ). Women shown more detailed information about their personal risks are less likely to opt for tests.</td>
<td>There is a need for more consistent and balanced information that encompasses the range of outcomes of mammography so that women can make truly informed choices.</td>
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<td>73</td>
<td>A, B</td>
<td>Volkmar Campbell, J., Kurnoth, P. (2000)</td>
<td>Impact evaluation to examine how the Well Women’s Program is working, how it is meeting its objectives and whether the objectives match needs.</td>
<td>Qualitative, evaluation and Data mining of NT Pap Smear Register and NT Cancer Register.</td>
<td>Qualitative: 300 women, 59 health centre staff and 40 other key individuals in 15 remote communities and all regional centres.</td>
<td>(NB: primary focus of the evaluation was cervical screening.) Aboriginal women stressed that women’s health should be grounded in Aboriginal culture and tradition, and they want to be more involved in the program at all levels, especially Aboriginal Health Workers (AHWs) and senior women. Non-Aboriginal women in remote areas report that they have little access to women’s health information and programs, and are not sure where to find the help they need. Four out of five AHWs and three in five nurses consulted wanted more training and support to do well women’s screening.</td>
<td>Aboriginal women across the Territory should be supported to take an increased role in women’s health.</td>
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<td>74</td>
<td>A</td>
<td>Willis, K. (2001)</td>
<td>Identifying individual, social, moral and relational factors that go into explaining a woman’s choice to participate in mammography screening.</td>
<td>Qualitative Interviews</td>
<td>22 women ranging in age from 43 to 52.</td>
<td>Screening among these participants had become a habit that is now entrenched in their way of life. Screening provides reassurance for these women. The mobile BreastScreen service provides a powerful visual symbol of health service provision for rural communities. Many participants indicated they would not attend for screening before the age of 50 if they had to travel to the nearest centre, but they would travel once they were over this age.</td>
<td>In rural communities health practices are relational practices, where responsibilities at an individual level are interwoven with social networks and the possibilities and challenges of living in rural communities.</td>
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<td>A, D</td>
<td>Willis, K. ‘Trusting technology: Women aged 40-49 years participating in screening for breast cancer - An exploratory study’, Australian and New Zealand Journal of Public Health 27(3), 2003. pp. 282-286.</td>
<td>To explore factors associated with the decision of women outside the target age range to participate in mass mammography screening in Tasmania.</td>
<td>Semi-structured interviews</td>
<td>14 women in rural Tasmania who had had their first screening mammogram under the age of 50.</td>
<td>Previous research indicates screening in the 40-49 age group is much higher in rural Tasmanian communities than, for example rural Victoria. This is possibly related to the fact that women who present for screening under the age of 40 in Tasmania are sent reminder letters after two years, whereas this does not happen in some other states. Three key reasons for screening in this age group were identified: • fear of breast cancer due the perception that incidence is rising among younger women, coupled with the belief that the program focus on over 50s is arbitrary or due to economic reasons. The belief that younger women are at risk was generated by knowing a young woman who had breast cancer and local media coverage which focused on personalised stories about women in their 40s; • trust in the technology, which is seen as more effective than BSE – though one woman became sceptical when a repeat screening revealed a lump had ‘disappeared’; and • taking responsibility for their health. Screening was seen as a ‘good health habit’ as part of a healthy lifestyle. Issues relating to informed choice also emerged. One woman reported having been given an information sheet saying that ‘mammogram was harmless – that the rays won’t create any abnormalities’.</td>
<td>The study highlights the importance of dominant ideas and values when providing information to women about screening. There is a need to further explore the impact of reminder letters on women under 40 in terms of their beliefs about screening.</td>
</tr>
<tr>
<td>Ref No.</td>
<td>Cross Ref</td>
<td>Ref</td>
<td>Objectives / Aims</td>
<td>Methods</td>
<td>Participants</td>
<td>Results</td>
<td>Conclusion</td>
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</tr>
<tr>
<td>76</td>
<td>B, D</td>
<td>Zorbas, H. M. (2003). <em>Breast cancer screening</em>, Medical Journal of Australia, 178(12), 651-652.</td>
<td>Discussion of women and health professionals’ beliefs about mammographic screening versus breast self-examination.</td>
<td>Commentary based on relevant data and literature.</td>
<td>n/a</td>
<td>GPs are highly effective at encouraging women to participate in screening. Australian studies show between 68% and 91% of women will attend for screening after a recommendation from their GP. Accurate information about the benefits, limitations and tests used to investigate abnormalities are vital to enable women to make an informed decision. Women and health professionals often fondly believe in the benefits of breast self-examination but randomised trials do not show that a systematic approach to BSE impacts on survival. In fact, ‘breast awareness’, that is noticing changes and presenting to doctors early, is equally effective.</td>
<td>It is important to ensure that clear, evidence-based messages are propagated and that women are not given confusing health advice.</td>
</tr>
</tbody>
</table>
APPENDICES

B RECRUITMENT SCREENING QUESTIONNAIRES

BSA EVALUATION. MAIN GROUPS RECRUITMENT SCREENER

Hello. My name is _____________________. I work ____________________, a market research company. I am looking for people to take part in a market research study for the Government about breast cancer screening. We are interested in talking to women who do and do not have regular screening mammograms. We will talk about your views on the process of having a mammogram and how you find the written information (e.g. invitation letters etc.). You will not have to talk about your personal experiences if you do not want to, just about screening in general. There are no right or wrong answers, and all points of view are welcome.

We need people to take part in a group discussion / in-depth interview on ____________ at ________________________. 

We will be talking to women across Australia and will focus on women with particular characteristics in each area. We therefore need to ask some questions to ascertain whether you are eligible to take part in a discussion in this area.

1. Do you or any of your close relations, work in any of the following industries?

<table>
<thead>
<tr>
<th>Industry</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Market research</td>
<td>1</td>
</tr>
<tr>
<td>Advertising, marketing, public relations</td>
<td>2</td>
</tr>
<tr>
<td>Media and journalism</td>
<td>3</td>
</tr>
<tr>
<td>Water industry</td>
<td>4</td>
</tr>
<tr>
<td>Energy industry</td>
<td>5</td>
</tr>
<tr>
<td>Automotive manufacture or retail</td>
<td>6</td>
</tr>
<tr>
<td>Teaching</td>
<td>7</td>
</tr>
<tr>
<td>Medicine or healthcare</td>
<td>8</td>
</tr>
<tr>
<td>Department of Health &amp; Ageing</td>
<td>9</td>
</tr>
<tr>
<td>An organisation dealing with health issues</td>
<td>11</td>
</tr>
</tbody>
</table>

TERMINATE

CONTINUE

TERMINATE

2. When was the last time you took part in a group discussion or depth interview? (Write in) 

TERMINATE IF LESS THAN 6 MONTHS AGO
3. Which of the following age ranges do you fall into:

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>39 or under</td>
<td>1</td>
</tr>
<tr>
<td>40–44</td>
<td>2</td>
</tr>
<tr>
<td>45–49</td>
<td>3</td>
</tr>
<tr>
<td>50–53</td>
<td>4</td>
</tr>
<tr>
<td>54–59</td>
<td>5</td>
</tr>
<tr>
<td>60–64</td>
<td>6</td>
</tr>
<tr>
<td>65–69</td>
<td>7</td>
</tr>
<tr>
<td>70–75</td>
<td>8</td>
</tr>
<tr>
<td>76+</td>
<td>9</td>
</tr>
</tbody>
</table>

4. When did you last have a mammogram?

<table>
<thead>
<tr>
<th>Time Frame</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Within the past 12 months</td>
<td>1</td>
</tr>
<tr>
<td>1 to 2.5 years ago</td>
<td>2</td>
</tr>
<tr>
<td>More than 2.5 years ago</td>
<td>3</td>
</tr>
<tr>
<td>Never</td>
<td>4</td>
</tr>
</tbody>
</table>

5. (Ask those who have had a mammogram, including ‘lapsed’) Which of the following best describes the reason you had your most recent mammogram?

<table>
<thead>
<tr>
<th>Reason</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>For routine screening purposes, that is you had no symptoms of breast cancer.</td>
<td>1</td>
</tr>
<tr>
<td>Because you have a family history of breast cancer but did not have any symptoms.</td>
<td>2</td>
</tr>
<tr>
<td>Because you or your doctor noticed symptoms that needed to be checked out, so your doctor referred you for a diagnostic mammogram.</td>
<td>3</td>
</tr>
</tbody>
</table>

6. (Ask all those who have had a mammogram) Which of these best describes the type of service you used last time?

<table>
<thead>
<tr>
<th>Service</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>You used the free service offered by BreastScreen (insert appropriate state).</td>
<td>1</td>
</tr>
<tr>
<td>You doctor referred you for the mammogram and the mammogram was bulk billed</td>
<td>2</td>
</tr>
<tr>
<td>You doctor referred you for the mammogram and you paid for the mammogram, and then claimed for it on Medicare</td>
<td>3</td>
</tr>
<tr>
<td>You paid for a private screening mammogram and were unable to claim for it on Medicare</td>
<td>4</td>
</tr>
<tr>
<td>I don’t know</td>
<td>5</td>
</tr>
</tbody>
</table>
7. **(Ask those who have had a mammogram)** Where did you go for your most recent mammogram?

<table>
<thead>
<tr>
<th></th>
<th>BSA</th>
<th>SEE QUOTAS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

<table>
<thead>
<tr>
<th></th>
<th>Private</th>
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</tr>
</tbody>
</table>

| Somewhere else (write in) | 9 | Check |

8a. **(Ask those who have ever had a mammogram with BreastScreen Australia)**

After a mammogram through BreastScreen Australia, have you ever been asked to return on a different day for more tests or investigations? (i.e. something on the mammogram needed further investigation)

- Yes, recalled for assessment of a screen-detected abnormality. **GO TO Q8b**
- Yes, the original film(s) were technically unsatisfactory (e.g. blurred x-ray, equipment fault/failure or operator error). **GO TO Q10**
- No

8b. **(Ask those who needed further investigation)**

Firstly, check if respondent is comfortable talking about this? (If not, thank respondent for their time and explain they probably won’t feel comfortable taking part in the research). If they are comfortable ask: which of the following statements best applies to you? Before you were asked to return, you…

- …had not had any symptoms of breast cancer. **Consider for recalled but no treatment required group**
- …had had symptoms of breast cancer. **Thank and close. Explain the research is about routine screening mammography only**

9. **(Ask those who needed further investigation)**

What was the outcome?

<table>
<thead>
<tr>
<th></th>
<th>Thank and Close: explain that it is probably too soon to be talking about their feelings about screening so we do not recommend they take part</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Thank and Close: explain that it is probably too soon to be talking about their feelings about screening so we do not recommend they take part</td>
</tr>
<tr>
<td>2</td>
<td>Consider for ‘recalled but no treatment required’ groups</td>
</tr>
<tr>
<td>3</td>
<td>Consider for ‘diagnosed and treated’ groups</td>
</tr>
<tr>
<td>4</td>
<td>Thank and Close: explain that it is probably too soon to be talking about their feelings about screening so we do not recommend they take part</td>
</tr>
</tbody>
</table>
10. **(Ask all)** Which of the following statements best reflects how you feel about having a mammogram in the future? (Record all answers and provide to moderators prior to discussions)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>I definitely intend to have a mammogram within the next two years</td>
<td>1</td>
</tr>
<tr>
<td>I will probably have a mammogram within the next two years</td>
<td>2</td>
</tr>
<tr>
<td>I’m not sure whether or not I will have a mammogram within the next two years</td>
<td>3</td>
</tr>
<tr>
<td>I probably won’t have a mammogram in the next two years</td>
<td>4</td>
</tr>
<tr>
<td>I definitely won’t have a mammogram in the next two years</td>
<td>5</td>
</tr>
</tbody>
</table>

11. **(Ask all)** What is your employment status?

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working full or part time</td>
<td>1</td>
</tr>
<tr>
<td>Unemployed</td>
<td>2</td>
</tr>
<tr>
<td>Full time student</td>
<td>3</td>
</tr>
<tr>
<td>Retired</td>
<td>4</td>
</tr>
</tbody>
</table>

12. What is (or was prior to retirement) the occupation of the chief wage earner in your household? (Record job and SES)

<table>
<thead>
<tr>
<th>Occupation</th>
<th>SES</th>
</tr>
</thead>
<tbody>
<tr>
<td>White collar</td>
<td>Higher SES 1</td>
</tr>
<tr>
<td>Upper white collar</td>
<td>2</td>
</tr>
<tr>
<td>Blue collar</td>
<td>Lower SES 3</td>
</tr>
<tr>
<td>Unemployed</td>
<td>4</td>
</tr>
</tbody>
</table>

13. We need to ensure we include a representative sample of the population in our study. How would you describe your family’s ethnic background? **READ LIST AND CODE ANY THAT APPLY**

<table>
<thead>
<tr>
<th>Ethnic Background</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aboriginal or Torres Straight Islander</td>
<td>1</td>
</tr>
<tr>
<td>African</td>
<td>2</td>
</tr>
<tr>
<td>Asian</td>
<td>3</td>
</tr>
<tr>
<td>Australian</td>
<td>4</td>
</tr>
<tr>
<td>Eastern European</td>
<td>5</td>
</tr>
<tr>
<td>Latin American</td>
<td>6</td>
</tr>
<tr>
<td>Middle Eastern</td>
<td>7</td>
</tr>
<tr>
<td>North American</td>
<td>8</td>
</tr>
<tr>
<td>Northern European</td>
<td>9</td>
</tr>
<tr>
<td>Southern European</td>
<td>10</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>11</td>
</tr>
</tbody>
</table>

**SEE QUOTAS**
14. Do you ever speak a language other than English at home?

<table>
<thead>
<tr>
<th>Yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>2</td>
</tr>
</tbody>
</table>

**SEE QUOTAS**

15. What is your marital status?

<table>
<thead>
<tr>
<th>Single</th>
<th>Married / co-habiting</th>
<th>Divorced</th>
<th>Widowed</th>
<th>SEE QUOTAS</th>
</tr>
</thead>
</table>

**Quotas**

All respondents must be women (!).

Exclude:

- those who work in the usual excluded industries as well as government departments or in medicine or health care
- anyone who has taken part in a group discussion in the last 6 months
- Please also ensure they did not take part in the previous breast screening research conducted by Blue Moon in Feb 06
- Women currently undergoing diagnostic investigations or treatment for breast cancer.

Within each group include:

- a spread of ages within the defined age bands
- a mix of married / co-habiting women and women who are not in relationships (single, divorced, widowed)

Across the sample include:

- a representative mix of ethnic backgrounds and those who speak a language other than English at home for the area that each group is being conducted in (except in specific language groups)

Within ‘regular’ screening groups (8 respondents for 2 hours):

- include at least 3 women who used private screening services and at least three who used BreastScreen Australia (BSA) for their most recent mammogram – use a combination of questions 8 and 9 to ascertain this and check with us if you’re still not sure.
- aim to include 1-2 women who screen regularly because they have a family history of breast cancer – these respondents must use BreastScreen Australia, not private services
- none should have had a ‘positive result’
Within ‘lapsed / never’ groups (8 respondents for 2 hours)

• aim for an equal mix of ‘lapsed’ (have not screened in the last 2 years) and ‘never’ (have never had a mammogram)

• none should have been asked back for further tests on another day after having a screening mammogram

• if under 53 they must not be definitely / probably intending to have a mammogram in the next 2 years

• aim for at least 1 of the ‘lapsed’ who has used BreastScreen Australia and 1 who has used private screening (if possible)

Within ‘recalled but no treatment required’ groups (4-5 respondents for 1.5 hours):

• all must have had a screening mammogram i.e. for routine purposes, NOT because they had symptoms

• all must have been asked to come back for further tests on another day

• all to have been asked to have further tests because of suspected abnormalities NOT because of problems with the x-ray film.

• NONE to have been diagnosed with breast cancer

• all to have screened through BSA when they were called back

NB: Please keep hold of contact details of any women who have been diagnosed and treated and are not OK – we may hold a group with them at a later stage.
BSA EVALUATION. DIAGNOSED AND TREATED RECRUITMENT SCREENER

Hello. My name is _____________________. I work _____________________, a market research company. I am looking for people to take part in a market research study for the Government about breast cancer screening. We are interested in talking to women who have been diagnosed with breast cancer as a result of having a screening mammogram through BreastScreen [insert relevant state]. We will talk about your views on the Program and how you felt about the process. There are no right or wrong answers, and all points of view are welcome.

We need people to take part in a group discussion / in-depth interview on ______________ at ______________________. All the other women taking part will have had similar experiences to you.

We will be talking to women across Australia and will focus on women with particular characteristics in each area. We therefore need to ask some questions to ascertain whether you are eligible to take part in a discussion in this area.

1. Do you or any of your close relations, work in any of the following industries?

<table>
<thead>
<tr>
<th>Industry</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Market research</td>
<td>1</td>
</tr>
<tr>
<td>Advertising, marketing, public relations</td>
<td>2</td>
</tr>
<tr>
<td>Media and journalism</td>
<td>3</td>
</tr>
<tr>
<td>Water industry</td>
<td>4</td>
</tr>
<tr>
<td>Energy industry</td>
<td>5</td>
</tr>
<tr>
<td>Automotive manufacture or retail</td>
<td>6</td>
</tr>
<tr>
<td>Teaching</td>
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<td>Medicine or healthcare</td>
<td>8</td>
</tr>
<tr>
<td>Department of Health &amp; Ageing</td>
<td>9</td>
</tr>
<tr>
<td>An organisation dealing with health issues</td>
<td>11</td>
</tr>
</tbody>
</table>

2. Which of the following age ranges do you fall into:

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>49 or under</td>
<td>1</td>
</tr>
<tr>
<td>50–59</td>
<td>2</td>
</tr>
<tr>
<td>60–69</td>
<td>3</td>
</tr>
<tr>
<td>70+</td>
<td>4</td>
</tr>
</tbody>
</table>

3. Which of the following apply to you? (Circle all that apply)

<table>
<thead>
<tr>
<th>Description</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>You have used the free service offered by BreastScreen (insert appropriate state).</td>
<td>1</td>
</tr>
<tr>
<td>Your doctor has referred you for the mammogram and the mammogram was bulk billed</td>
<td>2</td>
</tr>
<tr>
<td>Your doctor has referred you for the mammogram and you paid for the mammogram, and then claimed for it on Medicare</td>
<td>3</td>
</tr>
<tr>
<td>You have paid for a private screening mammogram and were unable to claim for it on Medicare</td>
<td>4</td>
</tr>
<tr>
<td>I don’t know</td>
<td>5</td>
</tr>
</tbody>
</table>
4. Where have you been to have a mammogram? (Circle all that apply)

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>BSA</th>
<th>SEE QUOTAS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
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<td>3</td>
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<td>7</td>
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<td>8</td>
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<td></td>
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<tr>
<td>9</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5. (Ask those who have ever had a mammogram with BreastScreen Australia) Which of the following best describes the reasons you had a mammogram with BreastScreen Australia?

<table>
<thead>
<tr>
<th>Reason</th>
<th>1</th>
<th>Continue (See Quotas)</th>
</tr>
</thead>
<tbody>
<tr>
<td>For routine screening purposes, that is you had no symptoms of breast cancer.</td>
<td>1</td>
<td>Continue (See Quotas)</td>
</tr>
<tr>
<td>Because you have a family history of breast cancer but did not have any symptoms.</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Because you or your doctor noticed symptoms that needed to be checked out, so your doctor referred you for a diagnostic mammogram.</td>
<td>3</td>
<td>Thank and close. Explain the research is about routine screening mammography only</td>
</tr>
</tbody>
</table>

6a. (Ask those who have ever had a mammogram with BreastScreen Australia) After a mammogram through BreastScreen Australia, have you ever been asked to return on a different day for more tests or investigations? (i.e. something on the mammogram needed further investigation)

- Yes, recalled for assessment of a screen-detected abnormality. (GO TO Q9b)
- Yes, the original film(s) were technically unsatisfactory (e.g. blurred x-ray, equipment fault/failure or operator error). (GO TO Q10)
- No

6b. (Ask those who needed further investigation) Firstly, check if respondent is comfortable talking about this? (If not, thank respondent for their time and explain they probably won’t feel comfortable taking part in the research). If they are comfortable ask: which of the following statements best applies to you? Before you were asked to return, you…

<table>
<thead>
<tr>
<th>Statement</th>
<th>1</th>
<th>Consider for recalled but no treatment required group</th>
</tr>
</thead>
<tbody>
<tr>
<td>…had not had any symptoms of breast cancer.</td>
<td>1</td>
<td>Consider for recalled but no treatment required group</td>
</tr>
<tr>
<td>…had had symptoms of breast cancer.</td>
<td>2</td>
<td>Consider for recalled and diagnosed group</td>
</tr>
</tbody>
</table>
7. Which of the following applies to you?

<table>
<thead>
<tr>
<th>Option</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>You will need to have more tests but have not had them yet.</td>
<td>Thank and Close: explain that it is probably too soon to be talking about their feelings about screening so we do not recommend they take part</td>
</tr>
<tr>
<td>You had more tests but it turned out you did not have breast cancer</td>
<td>Consider for ‘recalled but no treatment required’ groups</td>
</tr>
<tr>
<td>You were diagnosed with breast cancer and had treatment and are currently OK</td>
<td>Consider for ‘diagnosed and treated’ groups</td>
</tr>
<tr>
<td>You were diagnosed with breast cancer and are currently having treatment</td>
<td>Thank and Close: explain that it is probably too soon to be talking about their feelings about screening so we do not recommend they take part</td>
</tr>
</tbody>
</table>

8. (Ask all) What is your employment status?

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working full or part time</td>
<td>1</td>
</tr>
<tr>
<td>Unemployed</td>
<td>2</td>
</tr>
<tr>
<td>Full time student</td>
<td>3</td>
</tr>
<tr>
<td>Retired</td>
<td>4</td>
</tr>
</tbody>
</table>

SEE QUOTAS

9. What is (or was prior to retirement) the occupation of the chief wage earner in your household? (Record job and SES)

<table>
<thead>
<tr>
<th>Occupation</th>
<th>SES</th>
</tr>
</thead>
<tbody>
<tr>
<td>White collar</td>
<td>Higher SES</td>
</tr>
<tr>
<td>Upper white collar</td>
<td>1</td>
</tr>
<tr>
<td>Blue collar</td>
<td>Lower SES</td>
</tr>
<tr>
<td>Unemployed</td>
<td>2</td>
</tr>
</tbody>
</table>

SEE QUOTAS

10. We need to ensure we include a representative sample of the population in our study. How would you describe your family’s ethnic background? READ LIST AND CODE ANY THAT APPLY

<table>
<thead>
<tr>
<th>Ethnic Background</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aboriginal or Torres Straight Islander</td>
<td>1</td>
</tr>
<tr>
<td>African</td>
<td>2</td>
</tr>
<tr>
<td>Asian</td>
<td>3</td>
</tr>
<tr>
<td>Australian</td>
<td>4</td>
</tr>
<tr>
<td>Eastern European</td>
<td>5</td>
</tr>
<tr>
<td>Latin American</td>
<td>6</td>
</tr>
<tr>
<td>Middle Eastern</td>
<td>7</td>
</tr>
<tr>
<td>North American</td>
<td>8</td>
</tr>
<tr>
<td>Northern European</td>
<td>9</td>
</tr>
<tr>
<td>Southern European</td>
<td>10</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>11</td>
</tr>
</tbody>
</table>
11. Do you ever speak a language other than English at home?

<table>
<thead>
<tr>
<th>Yes</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>2</td>
</tr>
</tbody>
</table>

12. What is your marital status?

<table>
<thead>
<tr>
<th>Marital Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
</tr>
<tr>
<td>Married / co-habiting</td>
</tr>
<tr>
<td>Divorced</td>
</tr>
<tr>
<td>Widowed</td>
</tr>
</tbody>
</table>

**Quotas**

All respondents must be women.

Exclude those who work in the usual excluded industries as well as government departments or in medicine or health care.

‘Diagnosed and treated groups’ (4-5 respondents for 1.5 hours):

- all must have had a screening mammogram i.e. for routine purposes, NOT because they had symptoms
- all must have been asked to come back for further tests and have been diagnosed with breast cancer following a screening mammogram with BSA
- all must have been successfully treated for breast cancer
- none to still be in treatment (as the discussion is likely to be too raw for them)

Within each group, if possible, include:

- a spread of ages within the defined age band
- a mix of married / co-habiting women and women who are not in relationships (single, divorced, widowed)
- a mix of SES
- a representative mix of ethnic backgrounds and those who speak a language other than English at home for the area that each group is being conducted
BSA EVALUATION. INTERVAL CANCERS SCREENER

Hello. My name is ________________, I work ________________, a market research company. I am looking for people to take part in a market research study for the Government about breast cancer screening. We are interested in talking to women who have had regular, routine screening mammograms through BreastScreen [insert relevant state] but were in fact diagnosed with breast cancer as a result of noticing symptoms in between screens.

I will need to ask a few questions to check that your circumstances fit in with the criteria for this research. If you are not eligible we would like to keep hold of your details so that we can invite you to take part in subsequent research projects on this topic. Either way, the Department of Health and Ageing team would like to thank you very much indeed for expressing interest in assisting with this project.

If you are eligible, we will talk about your views on the BreastScreen Program given your circumstances. You will not be asked to talk about your experiences of breast cancer or provide any personal information that you may be uncomfortable about discussing. There are no right or wrong answers, and all points of view are welcome. If you take part in a group discussion, all the other women taking part will have had similar experiences to you.

We will be conducting the research in early March. Please let me know your availability in this period:

Daytime:  Y  /  N
Evenings: Y / N
Days / dates to avoid: ________________________________

1. Do you or any of your close relations, work in any of the following industries?

<table>
<thead>
<tr>
<th>Industry</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Market research</td>
<td>1</td>
</tr>
<tr>
<td>Advertising, marketing, public relations</td>
<td>2</td>
</tr>
<tr>
<td>Media and journalism</td>
<td>3</td>
</tr>
<tr>
<td>Water industry</td>
<td>4</td>
</tr>
<tr>
<td>Energy industry</td>
<td>5</td>
</tr>
<tr>
<td>Automotive manufacture or retail</td>
<td>6</td>
</tr>
<tr>
<td>Teaching</td>
<td>7</td>
</tr>
<tr>
<td>Medicine or healthcare</td>
<td>8</td>
</tr>
<tr>
<td>Department of Health &amp; Ageing</td>
<td>9</td>
</tr>
<tr>
<td>An organisation dealing with health issues</td>
<td>11</td>
</tr>
</tbody>
</table>

Thank and close (see script above)
2. Which of the following applies to you?

<table>
<thead>
<tr>
<th>Option</th>
<th>1 Thank and Close: explain that it is probably too soon to be talking about their feelings about the Program so we do not recommend they take part</th>
</tr>
</thead>
<tbody>
<tr>
<td>There is a possibility you may have breast cancer and will need to have more tests but have not had them yet.</td>
<td>1 Thank and Close: explain that it is probably too soon to be talking about their feelings about the Program so we do not recommend they take part</td>
</tr>
<tr>
<td>You have been diagnosed with breast cancer and are currently having / waiting to have treatment</td>
<td>2 Continue</td>
</tr>
<tr>
<td>You were diagnosed with breast cancer and had treatment and are currently OK</td>
<td>3 Thank and close (see script above)</td>
</tr>
<tr>
<td>None of the above</td>
<td>4 Thank and close (see script above)</td>
</tr>
</tbody>
</table>

3. Which of the following applies to you?

<table>
<thead>
<tr>
<th>Option</th>
<th>1 Continue</th>
</tr>
</thead>
<tbody>
<tr>
<td>You were diagnosed with breast cancer after you or your GP noticed symptoms, such as a lump or other abnormality in your breast</td>
<td>1 Continue</td>
</tr>
<tr>
<td>You were diagnosed with breast cancer following a routine screening mammogram, when you did not have any symptoms that you were aware of.</td>
<td>2 Thank and close (see script above)</td>
</tr>
<tr>
<td>I don’t know</td>
<td>3 Thank and close (see script above)</td>
</tr>
</tbody>
</table>

4. BEFORE you were diagnosed with breast cancer, had you ever had a routine screening mammogram? That is you did NOT have any symptoms of breast cancer?

<table>
<thead>
<tr>
<th>Option</th>
<th>1 Continue</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1 Continue</td>
</tr>
<tr>
<td>No</td>
<td>2 Thank and close (see script above)</td>
</tr>
<tr>
<td>I don’t know</td>
<td>3 Thank and close (see script above)</td>
</tr>
</tbody>
</table>

5a. Which of these best describes the type of service you used for any ROUTINE screening mammograms you had? (Please circle all that apply) **NB: do not include any mammograms you had after symptoms were detected.**

<table>
<thead>
<tr>
<th>Option</th>
<th>1 Continue</th>
</tr>
</thead>
<tbody>
<tr>
<td>You used the free service offered by BreastScreen [insert appropriate state].</td>
<td>1 Continue</td>
</tr>
<tr>
<td>Your doctor referred you for the mammogram and the mammogram was bulk billed</td>
<td>2 Thank and close (see script above)</td>
</tr>
<tr>
<td>Your doctor referred you for the mammogram and you paid for the mammogram, and then claimed for it on Medicare</td>
<td>3 Thank and close (see script above)</td>
</tr>
<tr>
<td>You paid for a private screening mammogram and were unable to claim for it on Medicare</td>
<td>4 Thank and close (see script above)</td>
</tr>
<tr>
<td>I don’t know</td>
<td>5 Thank and close (see script above)</td>
</tr>
</tbody>
</table>

5b. Where did you go for any ROUTINE screening mammograms you had? (Please circle all that apply) **NB: do not include any mammograms you had after symptoms were detected.**

<table>
<thead>
<tr>
<th>Option</th>
<th>1 BSA Continue if a BSA venue is mentioned, otherwise thank and close (see script above)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2 Private</td>
</tr>
<tr>
<td></td>
<td>3 Private</td>
</tr>
<tr>
<td></td>
<td>4 Private</td>
</tr>
<tr>
<td></td>
<td>5 Private</td>
</tr>
<tr>
<td></td>
<td>6 Private</td>
</tr>
<tr>
<td></td>
<td>7 Private</td>
</tr>
<tr>
<td></td>
<td>8 Private</td>
</tr>
<tr>
<td></td>
<td>Somewhere else (write in) 9 CHECK</td>
</tr>
</tbody>
</table>
5c. How long before you or your doctor noticed symptoms had you had your last SCREENING mammogram through BreastScreen (i.e. a mammogram when you did NOT have any symptoms)?

<table>
<thead>
<tr>
<th>Less than a year</th>
<th>1</th>
<th>Record and Continue</th>
</tr>
</thead>
<tbody>
<tr>
<td>One to two years</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Two to three years</td>
<td>3</td>
<td>Thank and close (see script above)</td>
</tr>
<tr>
<td>More than three years</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

6. Which of the following age ranges do you fall into:

<table>
<thead>
<tr>
<th>39 or under</th>
<th>1</th>
<th>Thank and close – see script above and explain that women under 40 are not eligible for BreastScreen</th>
</tr>
</thead>
<tbody>
<tr>
<td>40-49</td>
<td>2</td>
<td>See quotas and continue</td>
</tr>
<tr>
<td>50-59</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>60-69</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>70+</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

7. **(Ask all)** What is your employment status?

| Working full or part time | 1 | |
| Unemployed                | 2 | |
| Full time student         | 3 | |
| Retired                   | 4 | |

**SEE QUOTAS**

8. What is (or was prior to retirement) the occupation of the chief wage earner in your household? (Record job and SES)

<table>
<thead>
<tr>
<th>White collar</th>
<th>Higher SES</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Upper white collar</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Blue collar</td>
<td>Lower SES</td>
<td>3</td>
</tr>
<tr>
<td>Unemployed</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

**SEE QUOTAS**
9. We need to ensure we include a representative sample of the population in our study. How would you describe your family’s ethnic background? **READ LIST AND CODE ANY THAT APPLY**

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aboriginal or Torres Straight Islander</td>
<td>1</td>
</tr>
<tr>
<td>African</td>
<td>2</td>
</tr>
<tr>
<td>Asian</td>
<td>3</td>
</tr>
<tr>
<td>Asian</td>
<td>4</td>
</tr>
<tr>
<td>Eastern European</td>
<td>5</td>
</tr>
<tr>
<td>Latin American</td>
<td>6</td>
</tr>
<tr>
<td>Middle Eastern</td>
<td>7</td>
</tr>
<tr>
<td>North American</td>
<td>8</td>
</tr>
<tr>
<td>Northern European</td>
<td>9</td>
</tr>
<tr>
<td>Southern European</td>
<td>10</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>11</td>
</tr>
</tbody>
</table>

**SEE QUOTAS**

10. Do you ever speak a language other than English at home?

<table>
<thead>
<tr>
<th>Language</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
</tr>
</tbody>
</table>

**SEE QUOTAS**

11. What is your marital status?

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td>1</td>
</tr>
<tr>
<td>Married / co-habiting</td>
<td>SEE QUOTAS</td>
</tr>
<tr>
<td>Divorced</td>
<td>2</td>
</tr>
<tr>
<td>Widowed</td>
<td>3</td>
</tr>
</tbody>
</table>

**Quotas**

Exclude those who work in the usual excluded industries as well as government departments or in medicine or health care.

The ‘Interval cancer’ group will take place in Sydney at a time and date when respondents are able to attend. The group will ideally consist of 4-5 respondents and will last for 1.5 hours.

In-depth interviews will be conducted with women in regional areas by telephone and will last 45 mins to an hour.

Criteria for all respondents:

- all must have been diagnosed with breast cancer and have been successfully treated
- none to still be in treatment (as the discussion is likely to be too raw for them)
- all must have had at least one screening mammogram i.e for routine purposes, NOT because they had symptoms before they noticed symptoms / were diagnosed with cancer
• they must have had at least one screening mammogram at a BreastScreen service
• their last screening mammogram i.e for routine purposes, NOT because they had symptoms must have been LESS THAN 2 years before being diagnosed with breast cancer
• all must be aged 40 or over (women under 40 are not eligible for BreastScreen)

If possible, include:
• a spread of ages over 40
• a mix of SES
• a representative mix of ethnic backgrounds and those who speak a language other than English at home for the area that each group is being conducted
• a mix of married / co-habiting women and women who are not in relationships (single, divorced, widowed)

However we are likely to want to interview anyone who fits this specification so please keep everyone’s details.
BSA EVALUATION. DISABLED WOMEN RECRUITMENT SCREENER

Hello. My name is _________________. I work ____________________, a market research company. I am looking for people to take part in a market research study for the Government about breast cancer screening. We are interested in talking to women with disabilities who do and do not have regular screening mammograms. We will talk about your views on the process of having a mammogram and how you find the written information (e.g. invitation letters etc.). You will not have to talk about your personal experiences if you do not want to, just about screening in general. There are no right or wrong answers, and all points of view are welcome.

We need people to take part in a group discussion / in-depth interview on __________ at _________________.

We will be talking to women across Australia and will focus on women with particular characteristics in each area. We therefore need to ask some questions to ascertain whether you are eligible to take part in a discussion in this area.

1. Do you or any of your close relations, work in any of the following industries?

<table>
<thead>
<tr>
<th>Industry</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Market research</td>
<td>1</td>
</tr>
<tr>
<td>Advertising, marketing, public relations</td>
<td>2</td>
</tr>
<tr>
<td>Media and journalism</td>
<td>3</td>
</tr>
<tr>
<td>Water industry</td>
<td>4</td>
</tr>
<tr>
<td>Energy industry</td>
<td>5</td>
</tr>
<tr>
<td>Automotive manufacture or retail</td>
<td>6</td>
</tr>
<tr>
<td>Teaching</td>
<td>7</td>
</tr>
<tr>
<td>Medicine or healthcare</td>
<td>8</td>
</tr>
<tr>
<td>Department of Health &amp; Ageing</td>
<td>9</td>
</tr>
<tr>
<td>An organisation dealing with health issues</td>
<td>11</td>
</tr>
</tbody>
</table>

TERMINATE

2. Which of the following age ranges do you fall into:

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>39 or under</td>
<td>1</td>
</tr>
<tr>
<td>40–44</td>
<td>2</td>
</tr>
<tr>
<td>45–49</td>
<td>3</td>
</tr>
<tr>
<td>50–59</td>
<td>4</td>
</tr>
<tr>
<td>60–69</td>
<td>5</td>
</tr>
<tr>
<td>70+</td>
<td>6</td>
</tr>
</tbody>
</table>

THANK & CLOSE

CONSIDER IF YOU HAVE HAD A SCREENING MAMMOGRAM

SEE QUOTAS

CONSIDER IF YOU HAVE HAD A SCREENING MAMMOGRAM
3a. Do any of the following apply to you?

<table>
<thead>
<tr>
<th>Condition</th>
<th>Code</th>
<th>Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>You have sight problems not corrected by glasses or contact lenses</td>
<td>1</td>
<td>GO TO Q3C</td>
</tr>
<tr>
<td>You have hearing problems</td>
<td>2</td>
<td>THANK &amp; CLOSE</td>
</tr>
<tr>
<td>You have speech problems</td>
<td>3</td>
<td>THANK &amp; CLOSE</td>
</tr>
<tr>
<td>You have limited use of arms or fingers and/ or legs or feet</td>
<td>4</td>
<td>ASK Q3B</td>
</tr>
<tr>
<td>You have blackouts, fits or loss of consciousness</td>
<td>5</td>
<td>ASK Q3C</td>
</tr>
<tr>
<td>You have difficulty learning or understanding things (e.g. intellectual disability)</td>
<td>6</td>
<td>THANK &amp; CLOSE</td>
</tr>
<tr>
<td>You have any condition that restricts physical activity or work (e.g. back problems, migraines)</td>
<td>7</td>
<td>ASK Q3B</td>
</tr>
<tr>
<td>You have any mental illness for which help or supervision is required</td>
<td>9</td>
<td>THANK &amp; CLOSE</td>
</tr>
<tr>
<td>You experience long term effects as a result of a head injury, stroke or other brain damage</td>
<td>10</td>
<td>ASK Q3B</td>
</tr>
<tr>
<td>None of the above</td>
<td>11</td>
<td>THANK &amp; CLOSE</td>
</tr>
</tbody>
</table>

3b. (ASK THOSE WHO ANSWERED 4 OR 7 AT Q3A) Do any of the following apply to you:

<table>
<thead>
<tr>
<th>Condition</th>
<th>Code</th>
<th>Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>You have Cerebral Palsy</td>
<td>1</td>
<td>CONTINUE</td>
</tr>
<tr>
<td>You have Multiple sclerosis</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>You have a Musculoskeletal condition</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>You use a wheelchair on a daily basis</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>None of the above (Check with Blue Moon)</td>
<td>7</td>
<td>ASK Q3C</td>
</tr>
</tbody>
</table>

3c. (ASK ALL) Has your condition negatively impacted on your experience of having a mammogram or would you expect it to do so?

<table>
<thead>
<tr>
<th>Response</th>
<th>Code</th>
<th>Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1</td>
<td>CONTINUE</td>
</tr>
<tr>
<td>No</td>
<td>7</td>
<td>THANK &amp; CLOSE</td>
</tr>
</tbody>
</table>

3d. (ASK ALL) How long have you had this condition for?

<table>
<thead>
<tr>
<th>Duration</th>
<th>Code</th>
<th>Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Since birth</td>
<td>1</td>
<td>CONTINUE</td>
</tr>
<tr>
<td>Since under the age of 50</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Since over the age of 50</td>
<td>3</td>
<td>THANK &amp; CLOSE</td>
</tr>
</tbody>
</table>

3e. Would you be able to take part in a group discussion without any assistance from anyone e.g. a family member or carer? (NB: a carer or family member can assist you in getting to the venue and can wait outside the group room but you must be able to speak for yourself in the group)

<table>
<thead>
<tr>
<th>Response</th>
<th>Code</th>
<th>Instructions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1</td>
<td>CONTINUE</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
<td>THANK &amp; CLOSE</td>
</tr>
</tbody>
</table>
4. When did you last have a mammogram?

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Consider as ‘regular’</th>
<th>GO TO Q5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Within the past 12 months</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 to 2.5 years ago</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than 2.5 years ago</td>
<td>3</td>
<td>Consider as ‘lapsed’</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>4</td>
<td>Consider as ‘never’</td>
<td>GO TO Q8</td>
</tr>
</tbody>
</table>

5. (Ask those who have had a mammogram, including ‘lapsed’) Which of the following best describes the reason you had your most recent mammogram?

<table>
<thead>
<tr>
<th>Reason</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>For routine screening purposes, that is you had no symptoms of breast cancer.</td>
<td>Continue (See Quotas)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Because you have a family history of breast cancer but did not have any symptoms.</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Because you or your doctor noticed symptoms that needed to be checked out, so your doctor referred you for a diagnostic mammogram.</td>
<td>3</td>
<td>THANK AND CLOSE, EXPLAIN THE RESEARCH RELATES TO SCREENING MAMMOGRAPHY ONLY</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6. (Ask all those who have had a mammogram) Which of these best describes the type of service you used last time?

<table>
<thead>
<tr>
<th>Service Description</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>You used the free service offered by BreastScreen (insert appropriate state)</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You doctor referred you for the mammogram and the mammogram was bulk billed</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You doctor referred you for the mammogram and you paid for the mammogram, and then claimed for it on Medicare</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>You paid for a private screening mammogram and were unable to claim for it on Medicare</td>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I don’t know</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

CONTINUE

7. (Ask those who have had a mammogram) Where did you go for your most recent mammogram?

<table>
<thead>
<tr>
<th>Location</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td>BSA</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SEE QUOTAS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhere else (write in)</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
8. *(Ask all)* Which of the following statements best reflects how you feel about having a mammogram in the future? (Record all answers and provide to moderators prior to discussions)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>I definitely intend to have a mammogram within the next two years</td>
<td>1</td>
</tr>
<tr>
<td>I will probably have a mammogram within the next two years</td>
<td>2</td>
</tr>
<tr>
<td>I’m not sure whether or not I will have a mammogram within the next two years</td>
<td>3</td>
</tr>
<tr>
<td>I probably won’t have a mammogram in the next two years</td>
<td>4</td>
</tr>
<tr>
<td>I definitely won’t have a mammogram in the next two years</td>
<td>5</td>
</tr>
</tbody>
</table>

9. *(Ask all)* What is your employment status?

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working full or part time</td>
<td>1</td>
</tr>
<tr>
<td>Unemployed</td>
<td>2</td>
</tr>
<tr>
<td>Full time student</td>
<td>3</td>
</tr>
<tr>
<td>Retired</td>
<td>4</td>
</tr>
</tbody>
</table>

10. What is (or was prior to retirement) the occupation of the chief wage earner in your household? (Record job and SES)

<table>
<thead>
<tr>
<th>Occupation</th>
<th>SES</th>
</tr>
</thead>
<tbody>
<tr>
<td>White collar</td>
<td>Higher SES</td>
</tr>
<tr>
<td>Upper white collar</td>
<td>Higher SES</td>
</tr>
<tr>
<td>Blue collar</td>
<td>Lower SES</td>
</tr>
<tr>
<td>Unemployed</td>
<td>Lower SES</td>
</tr>
</tbody>
</table>

11. We need to ensure we include a representative sample of the population in our study. How would you describe your family’s ethnic background? *READ LIST AND CODE ANY THAT APPLY*

<table>
<thead>
<tr>
<th>Ethnic Background</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aboriginal or Torres Straight Islander</td>
<td>1</td>
</tr>
<tr>
<td>African</td>
<td>2</td>
</tr>
<tr>
<td>Asian</td>
<td>3</td>
</tr>
<tr>
<td>Australian</td>
<td>4</td>
</tr>
<tr>
<td>Eastern European</td>
<td>5</td>
</tr>
<tr>
<td>Latin American</td>
<td>6</td>
</tr>
<tr>
<td>Middle Eastern</td>
<td>7</td>
</tr>
<tr>
<td>North American</td>
<td>8</td>
</tr>
<tr>
<td>Northern European</td>
<td>9</td>
</tr>
<tr>
<td>Southern European</td>
<td>10</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>11</td>
</tr>
</tbody>
</table>
14. Do you ever speak a language other than English at home?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
</tr>
</tbody>
</table>

RECORD

15. What is your marital status?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td></td>
</tr>
<tr>
<td>Married / co-habiting</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td></td>
</tr>
</tbody>
</table>

Quotas

Group with disabled women should include 4-5 respondents and will last 1.5 hours.

Exclude those who work in the usual excluded industries as well as government departments or in medicine or health care.

All must:

- have a physical impairment that could make going for a mammogram difficult (check with Blue Moon if you think someone might qualify but does not have one of the conditions listed)
- each respondent should have a different impairment
- have had the impairment since before the age of 50
- NB: please make sure potential respondents can make themselves understood (e.g. women with Cerebral Palsy may have impaired speech, this is fine but do not recruit anyone who cannot be understood at all)
- respondents must also be able to take part in the group without a carer (i.e. they must be able to speak for themselves and make themselves understood in the group setting) The group will be held at a venue with accessibility for disabled people. If they need assistance from the carer to get to the group this is fine, however, the carer will not be able to take part in the discussion with them.

Age:

- respondents should be aged 50-69 if they have never had a screening mammogram.
- respondents aged 40-49 and 70+ can be included if they have had a screening mammogram (i.e. they did not have symptoms of breast cancer when they had the mammogram)
Aim to include:

- a mix of physical impairments
- if possible a mix of regular, lapsed and never respondents
- ideally at least one should have used BSA services in the past (we’re also interested in anyone who has used private screening – as opposed to diagnostic – services)
APPENDICES

C DISCUSSION GUIDES

BSA EVALUATION MAIN GROUPS DISCUSSION GUIDE – REGULAR SCREENERS

Notes to moderator:

• there is a lot to get through in these groups. Questions in bold are most important and should be probed in as much depth as possible, though ideally all issues should be covered

• make a note of women from non-English speaking backgrounds and aim to understand any differences in attitudes, behaviour or experiences for these respondents

• where the guide refers to BSA, it may be necessary to describe this as BreastScreen Victoria (or whichever State you are in, depending on which respondents are more familiar with)

1) Background (10 mins)

Moderator will explain we will be talking about breast cancer screening. We are interested in their views on the services they have used and reactions to communications. They do not have to talk about their personal experiences in depth if they do not want to. There will also be opportunities to write down anything they would prefer not to discuss in front of the group.

• What is your first name?

• (If appear to be from a non-English speaking background) Where are you from originally? How long have you been in Australia?

• Who do you live with? Do you have children / grandchildren, how old are they?

• When was the last time you had a mammogram?

• Was it a routine screening mammogram or did you have symptoms?

• Do you know whether it was a BreastScreen Australia or private service? If not, where did it take place? (Moderator to check with recruitment screener to help confirm whether private or BSA service used)

• How many times have you been screened in total (approximately)?

• Roughly how often have you been screened?

2) Overall feelings about screening (10 mins)

(Moderator to use if group is reticent in talking - give respondents a range of images, randomly cut from magazines. They will be asked to select an image that sums up their emotions around having a screening mammogram.)

• (ASK ONLY IF IMAGE EXERCISE REQUIRED) What image have you selected and why?

• How do you feel about going for a mammogram?

• What are the advantages and disadvantages?
3) Decision making (15 mins)

- **How did you first come to have a mammogram?**
  - If from GP:
    - did you bring the topic up or did s/he?
    - **what did s/he say to you?**
    - Did they tell you where to go? What type of clinic was it? Is it where you go now?
    - (Probe: Did you discuss both private mammography & BreastScreen Australia as options)
  - **what about an invitation letter? What was your reaction?**
    - what thoughts went through your mind when you received the letter?
    - was the invitation letter followed up in any way? (Probe: another letter / phone call) If so, what was your reaction to the follow-up?
    - do you get reminder letters for your regular two yearly screening? How do you feel about these?
    - When you first had to go for a mammogram – what were all the reasons that made you not want to go? (moderator to generate list on flipchart)
    - what were all the reasons that encouraged you to go? (moderator to generate list on flipchart)
    - **to what extent did other people influence your decision e.g.:**
      - family members (partner, daughter)?
      - GP / other health professionals?
      - friends?
    - what did they say to you? (Moderator to probe for as much detail as possible, especially on what GPs say about private versus BreastScreen Australia services)
    - how did you weigh up the pros and cons in coming to your decision?:
      - which issues from those on the flipchart list were more / less important? (moderator to generate prioritised list on flipchart)

4) Perceived risks and benefits of screening (10 mins)

- How common do you think breast cancer among women in Australia compared with other diseases?
- What causes breast cancer? Which are more / less important? (Probe: age, family history, weight, diet, alcohol intake, HRT etc.)
- **What are the benefits to women of breast cancer screening?** (Probe if not raised spontaneously: what feelings are associated with an ‘all clear’ result?)
- **What are the disadvantages of screening (if any)?** How do you feel about these risks?
- How do you weigh up the benefits of and risks of screening when deciding whether or not to screen
• To what extent did these issues come into your decision making? (Refer back to decision making on flip charts earlier)
• How do you know about these issues?

Moderator will ask respondents to complete self-completion sheet 2 then discuss as a group:
• Which of these statements do you / don’t you agree with? Why?

5) Services provision (comparison between BSA and private services) (20 mins)
• (Recap) Who thinks they have used BSA and who has used a private screening service?
  – those who have not used private services:
    • what do you know about alternatives to BSA?
    • would you ever consider using them? Why / why not?
  – how would you expect the two types of services to be different?:
    • (once spontaneous comments are exhausted): what would be your expectations in terms of the time taken to get results?
• Those who have used BSA, (if not already raised spontaneously) describe the process of having a screening mammogram with BSA:
  – did you make an appointment or confirm one indicated on the invitation letter? How did you feel about this?
  – how did you feel about the location of the service? How easy was it for you to get to?
  – how does it feel (Probe on meaning of words used e.g. ‘pain’, ‘discomfort’ and listen for comments about short term pain versus concern about long term damage to breasts):
    • at the time?
    • afterwards?
  – has this varied on different screening occasions?
  – how did you feel about the staff? (Probe: what they said, their manner, how they behaved)
  – what information was provided to you beforehand, if any?
  – (Those who received information): how did this make you feel?
  – describe the environment. (Probe: to what extent did it promote privacy / minimise embarrassment?)
  – how did you feel afterwards? (Probe: did the discomfort / pain continue?)
  – how were the results received? How long did it take to receive results?
  – how did you feel about practicalities such as transport / parking?
• Which of these factors are part of having a mammogram and which are related to the service provided by BSA?
  – How could the BSA service be improved?
• Those who have used private screening services: how was this different? (Probe all issues as for BSA users above)
Moderator will ask respondents to complete self-completion sheets 3 then discuss as a group:

- Which of these statements do you / don’t you agree with? Why?

6) Potential / actual reactions to recall (15 mins)

- Have you thought about the fact that there is a chance that you might be asked back for more tests / treatment? How likely do you feel this is to happen?
- Roughly what proportion of women would you say are asked back for further tests / treatment? What makes you say that? Have you heard this anywhere or are you guessing?
- Have you thought about how you would feel if you were asked back for further tests / treatment (assuming this was because the was a suspicion that there may have been something abnormal on the results as opposed to the mammogram being unreadable)?
- How would you expect to feel while you are waiting for the results?
- Imagine you have further tests but it turned out that you did not have breast cancer? How would this leave you feeling? How would you feel about BSA?
- **What would you expect further tests/treatment to involve? What would be the implications of this? (Probe: costs, emotional impact, effect on lifestyle)**
- **How do you feel about the amount of information BSA provides you with on these issues?**
- Has anyone here been recalled for further tests or investigations? If so:
  - did these take place on the same day or subsequently?
  - were you told whether this was because of suspected abnormalities or problems with reading the mammogram?
  - how did you feel while you were waiting for the additional tests?
  - how did you feel when you received the result?
  - how did you feel about the way the staff you come into contact with handled the situation (moderator to take note of whether respondents had used private or BSA services)?
  - How did this leave you feeling?
  - How did it leave you feeling about breast screening / BSA?

7) Sources of Information (10 mins)

- **Where do you hear about breast cancer? Where do you hear about breast screening from?** Once spontaneous comments are exhausted, probe:
  - newspapers, magazines (if so, which?)
  - current affairs TV shows
  - friends and family
  - GP / other health workers
  - internet sites (is so, which?)
• For each source:
  – what sort of information do you get from here?
  – how useful / credible is information from this source?
• Do you ever hear anything in the media that might make you change your mind about having a mammogram?

8) Response to BSA Communications Materials (10 mins)

Moderator will show respondents a selection of materials from their jurisdictions and will encourage them to flick through all of them, without reading them in detail.

• Have you seen any materials like this? If so, where / when?
• Where would you expect to see materials such as this?
• Which messages / types of materials do you feel are particularly effective / motivating?
• Are there any messages that are confusing / that are not believable? If so, which?
• Which styles of material would be more / less likely to catch your attention?
• Have you seen / heard any TV / print / radio / poster advertising for BreastScreenAustralia / BreastScreenNSW? If so, what was your reaction to it? How effective do you think it is?
• How would you feel about receiving a text message to remind you to go for screening in the future?

9) Informed Consent (10 mins)

Moderator will ask respondents to complete self-completion sheet 4 then discuss as a group:

• Which of these statements do you / don’t you agree with? Why?
• How do you feel about the amount / content of information provided to you for breast screening?
• Were you asked to sign a consent form before being screened originally? If so, can you remember what the form said? How did you feel about this?
• Do you think knowing about the possible discomfort/ pain beforehand is better or worse? Do staff tell you about this? How does that make you feel towards them?
• Is it enough? Is there any information you would like but you do not get?
• Are there any circumstances where you might want more / different information?
• Have you heard of the idea of ‘informed consent’? If so, what does this mean to you? If not, what do you think it means in relation to breast cancer screening?
Informed consent is where a person can be said to have given consent based upon an appreciation and understanding of the facts and implications of an action.

• What are your views on this?

10) Summing up (5 mins)

• How do you feel about the BSA Program overall?
• What are its strengths and weaknesses?
• How could it be improved?
• Hypothetically, what would your reaction be if it was no longer available?
BSA EVALUATION MAIN GROUPS DISCUSSION GUIDE – LAPPED / NEVER

Notes to moderator:

- make a note of women from non-English speaking backgrounds and aim to understand any differences in attitudes, behaviour or experiences for these respondents
- where the guide refers to BSA, it may be necessary to describe this as BreastScreen Victoria (or whichever State you are in, depending on which respondents are more familiar with)

1) Background (10 mins)

Moderator will explain we will be talking about breast cancer screening. We are interested in their views on screening mammograms, the services they have used, if any, and reactions to communications. They do not have to talk about their personal experiences in depth if they do not want to. There will also be opportunities to write down anything they would prefer not to discuss in front of the group.

- What is your first name?
- (If appear to be from a non-English speaking background) Where are you from originally? How long have you been in Australia?
- Who do you live with? Do you have children / grandchildren, how old are they?
- Have you ever had a mammogram? If so:
  - when was the last time you had one?
  - was it a routine screening mammogram or did you have symptoms?
  - do you know whether it was a BreastScreen Australia or private service? If not, where did it take place? (Moderator to check with recruitment screener to help confirm whether private or BSA service used)
  - how many times have you been screened in total (approximately)?
  - roughly how often have you been screened?

2) Expectations of ‘Never’ respondents (10 mins)

Moderator will give ‘lapsed’ respondents sheet 1a on their experiences of BSA and ‘never’ respondents sheet 1b on their expectations of the experience.

- (Those who have never had a mammogram): what are your expectations of what it would be like if you used the BSA service? Probe:
  - the mammogram itself
  - environment
  - staff attitudes and behaviour
  - practicalities (e.g. transport/parking)
3) Overall feelings about screening (10 mins)

(Moderator to use if group is reticent in talking - give respondents a range of images, randomly cut from magazines. They will be asked to select an image that sums up their emotions around having a screening mammogram).

- (ASK ONLY IF IMAGE EXERCISE REQUIRED) What image have you selected and why?
- How do you / would you feel about going for a mammogram?
- What are the advantages and disadvantages of screening?
- Why have / haven’t you had a mammogram?

5) Decision making (15 mins)

- How did you decide not to have a mammogram or not to re-screen regularly?
  - have you discussed this with your GP:
    - did you bring the topic up or did s/he?
    - what did s/he say to you?
    - Did they tell you where to go? What type of clinic was it? Is it where you go now?
    - (Probe: Did you discuss both private mammography & BreastScreenNSW as options)
  - did you get an invitation letter? What was your reaction? (Probe: Thoughts and emotions)
    - was the invitation letter followed up in any way? (Probe: another letter / phone call) If so, what was your reaction to the follow-up?
  - do you get reminder letters for your regular two yearly screening? How do you feel about these?
  - What are all the reasons that made you not want to have a mammogram or re-screen? What actually stopped you from going? (moderator to generate list on flipchart)
  - what were all the reasons that encouraged you to go? (moderator to generate list on flipchart)
  - to what extent did other people influence your decision? What did they say to you? (Moderator to probe for as much detail as possible, especially on what GPs say about private versus BreastScreenNSW services)
    - family members (partner, daughter)?
    - GP / other health professionals?
    - friends?
  - how did you weigh up the pros and cons in coming to your decision?:
    - which issues from those on the flipchart list were more / less important? (moderator to generate prioritised list on flipchart)
5) Perceived risks and benefits of screening (10 mins)

- How common is breast cancer among women in Australia compared with other diseases?
- What causes breast cancer? Which are more / less important? (Probe: age, family history, weight, diet, alcohol intake, HRT etc.)
- What are the benefits to women of breast cancer screening? (Probe if not raised spontaneously: what feelings are associated with an ‘all clear’ result? Or do you expect to be associated if never screened?)
- What are the disadvantages of screening (if any)?
- To what extent did these issues come into your decision making? (Refer back to decision making on flip charts earlier)
- How do you know about these issues? (Refer back to discussion about sources of information)

Moderator will ask respondents to complete self-completion sheets 2 then discuss as a group:
- Which of these statements do you / don’t you agree with? Why?

6) Services provision (Lapsed) (10 mins)

- Those who have used BSA, (if not already raised spontaneously) describe the process of having a screening mammogram with BSA:
  - did you make an appointment or confirm one indicated on the invitation letter? How did you feel about this?
  - how did you feel about the location of the service? How easy was it for you to get to?
  - how does it feel (Probe on meaning of words used e.g. ‘pain’, ‘discomfort’ and listen for comments about short term pain versus concern about long term damage to breasts):
    - at the time?
    - afterwards?
  - has this varied on different screening occasions?
  - how did you feel about the staff? (Probe: what they said, their manner, how they behaved)
  - what information was provided to you beforehand, if any?
  - (Those who received information): how did this make you feel?
  - describe the environment. (Probe: to what extent did it promote privacy / minimise embarrassment?)
  - how did you feel afterwards? (Probe: did the discomfort / pain continue?)
  - how were the results received? How long did it take to receive results?
  - how did you feel about practicalities such as transport / parking?
- Was there anything about the experience (not already mentioned) that discouraged you from having another mammogram?
• Which of these factors are part of having a mammogram and which are related to the service provided by BSA?
  – How could the BSA service be improved?
• Any who have used private screening services: how was this different? (Probe all issues as for BSA users above)

6) Potential / actual reactions to recall (15 mins)
• When thinking about breast cancer screening have you thought about the chance that you might be asked back for more tests / treatment?
• Roughly what proportion of women would you say are asked back for further tests / treatment? What makes you say that? Have you heard this anywhere or are you guessing?
• Have you thought about how you would feel if you were asked back for further tests / treatment (assuming this was because there may have been something abnormal on the results as opposed to the mammogram being unreadable)?
• How would you expect to feel while you are waiting for the results?
• Imagine you have further tests but it turned out that you did not have breast cancer? How would this leave you feeling? How would you feel about BSA?
• What would you expect further tests/ treatment to involve? What would be the implications of this? (Probe: costs, emotional impact, effect on lifestyle)
• How do you feel about the amount of information BSA provides you with on these issues?
• Has anyone here been recalled for further tests or investigations? If so:
  – did these take place on the same day or subsequently?
  – were you told whether this was because of suspected abnormalities or problems with reading the mammogram?
  – how did you feel while you were waiting for the additional tests?
  – how did you feel when you received the result?
  – how did you feel about the way the staff you come into contact with handled the situation (moderator to take note of whether respondents had used private or BSA services)?
  – How did this leave you feeling?
  – How did it leave you feeling about breast screening / BSA?

7) Sources of Information (10 mins)
• Where do you hear about breast cancer? Where do you hear about breast screening from? Once spontaneous comments are exhausted, probe:
  – newspapers, magazines (if so, which?)
  – current affairs TV shows
  – friends and family
  – GP / other health workers
  – internet sites (is so, which?)
• For each source:
  – what sort of information do you get from here?
  – how useful / credible is information from this source?
• What effect have these had on your decision to have a mammogram?
• Do you ever hear anything in the media that might make you change your mind about having a mammogram?

8) Response to BSA Communications Materials (10 mins)

Moderator will show respondents a selection of materials from their jurisdictions and will encourage them to flick through all of them, without reading them in detail (Please do not give these women brochures on assessment)

• Have you seen any materials like this? If so, where / when?
• Where would you expect to see materials such as this?
• Which messages / types of materials do you feel would motivate you to attend or re-screen?
• Are there any messages that are confusing / that are not believable? If so, which?
• Which styles of material would be more / less likely to catch your attention?
• Have you seen / heard any TV / print / radio / poster advertising for BreastScreenAustralia / BreastScreenNSW? If so, what was your reaction to it? How effective do you think it is?
• What effects could these have on your decision to have a mammogram?
• How would you feel about receiving a text message to remind you to go for screening in the future?

9) Informed Consent (10 mins)

Moderator will ask respondents to complete self-completion sheet 4 then discuss as a group:

• Which of these statements do you / don’t you agree with? Why?
• How do you feel about the amount / content of information provided to you for breast screening?
• Were you asked to sign a consent form before being screened originally? If so, can you remember what the form said? How did you feel about this?
• Do you think knowing about the possible discomfort/ pain beforehand is better or worse? Do staff tell you about this? How does that make you feel towards them?
• Is it enough? Is there any information you would like but you do not get?
• Do you feel you have enough information to decide whether or not to re-screen?
• Are there any circumstances where you might want more / different information?
• Have you heard of the idea of ‘informed consent’? If so, what does this mean to you? If not, what do you think it means in relation to breast cancer screening?
Informed consent is where a person can be said to have given consent based upon an appreciation and understanding of the facts and implications of an action.

- What are your views on this?

10) Summing up (5 mins)

- How do you feel about the BSA Program overall?
- What are its strengths and weaknesses?
- How could it be improved?
- Hypothetically, what would your reaction be if it was no longer available?
BSA EVALUATION MAIN GROUPS DISCUSSION GUIDE – RECALLED FOR FURTHER TESTS

Notes to moderator:

- make a note of women from non-English speaking backgrounds and aim to understand any differences in attitudes, behaviour or experiences for these respondents.
- where the guide refers to ‘BSA’, it may be necessary to describe this as BreastScreen Victoria (or whichever State you are in) depending on which respondents are more familiar with.

1) Background (10 mins)
Moderator will explain we will be talking about breast cancer screening. We are interested in their experiences of BSA and reactions to communications they may have received.

- What is you first name?
- (If appear to be from a non-English speaking background) Where are you from originally? How long have you been in Australia?
- Who do you live with? Do you have children / grandchildren, how old are they?
- When was the first time you had a mammogram?
- Was it a routine screening mammogram or did you have symptoms?
- Do you know whether it was a BreastScreenAustralia or private service? If not, where did it take place? (Moderator to check with recruitment screener to help confirm whether private or BSA service used)
- How many times have you been screened in total (approximately)?
- Roughly how often have you been screened?

2) Experience of recall (35 mins)

- When were you recalled for further tests?
- Describe the experience of being recalled for further tests.
- How did you feel when you received the result that told you that you needed further tests?
- Did you consult anyone when you received your results? (Probe: Your GP?) What did you discuss? What did s/he say to you?
- What happened next? Where did you go?
- Did you go to a private assessment centre or was it through BSA? (If not known) Where was the assessment centre?
- What did the additional tests involve? How long did this take?
- How long did it take to get the results of the additional tests? How did you feel while waiting for these results?
- Have you been back for screening mammograms since? Where did you go for this? How do you feel about screening now?
- To what extent did these tests have an impact on you? (Probe: emotionally, costs, lifestyle)
• How did you feel when you discovered you did not have breast cancer?
• How did the experience as a whole leave you feeling?
• How did it leave you feeling about breast screening / BSA?
• How did you feel about the way the staff you come into contact with handled the situation (Probe: what they said, their manner, how they behaved)?
• How could BSA improve the experience of being recalled?
• Had you thought about how you would feel if you were asked back for further tests / treatment before it happened?
• Had you thought about what further tests/ treatment would involve and the implications of this before it happened? (Probe: costs, emotional impact, effect on lifestyle)
• Roughly what proportion of women would you say are asked back for further tests / treatment? What makes you say that? Have you heard this anywhere or are you guessing?

3) Perceived risks and benefits of screening (15 mins)
• What do you see as the benefits to women of breast cancer screening? (Probe fully) Any others?
  – have your views changed since being recalled? If so, what were they before?
• What are the disadvantages of screening (if any)? (Probe fully) Any others?
  – have your views changed since being recalled? If so, what were they before?
• How do you know about these issues?
• In your personal experience, do the benefits outweigh the risks or vice versa? Why do you say that?

4) Informed Consent (15 mins)
Moderator will ask respondents to complete self-completion sheet 4 then discuss as a group:
• Which of these statements do you / don’t you agree with? Why?
• How do you feel about the information you were provided with on the risks and benefits before you were recalled?:
  – were you given the right amount of information?
  – was the content appropriate?
• Were you asked to sign a consent form before being screened originally? If so, can you remember what the form said? How did you feel about this?
• Do you feel women should be given more / less / different information in advance?
• Do you think knowing about the likelihood of recall and / or treatment in advance is a good thing?
• Have you heard of the idea of ‘informed consent’? If so, what does this mean to you? If not, what do you think it means in relation to breast cancer screening?

Informed consent is where a person can be said to have given consent based upon an appreciation and understanding of the facts and implications of an action. What are your views on this?
5) Response to BSA Communications Materials (10 mins)

Moderator will show respondents a selection of materials from their jurisdiction, including any that are related to assessment services, and will encourage them to flick through all of them, without reading them in detail.

- Have you seen any materials like this? If so, where / when?
- Where would you expect to see materials such as this?
- Which messages / types of materials do you feel are particularly effective in communicating with women who have been recalled?
- How would you feel about any of these materials on assessment services being provided to women before they screen?
- Are there any messages that are confusing / that are not believable? If so, which?
- Which styles of material would be more / less likely to catch your attention?
- How would you feel about receiving a text message to remind you to go for screening in the future?

6) Summing up (5 mins)

- How do you feel about the BSA Program overall?
- What are its strengths and weaknesses?
- How could it be improved?
- Hypothetically, what would your reaction be if it was no longer available?
BSA EVALUATION MAIN GROUPS DISCUSSION GUIDE – DIAGNOSED AND TREATED

Notes to moderator:

• make a note of women from non-English speaking backgrounds and aim to understand any
differences in attitudes, behaviour or experiences for these respondents.

• where the guide refers to ‘BSA’, it may be necessary to describe this as BreastScreen Victoria
(or whichever State you are in) depending on which respondents are more familiar with.

1) Background (10 mins)

Moderator will explain we will be talking about breast cancer screening. We are interested in their
experiences of BSA and reactions to communications they may have received.

• What is your first name?

• (If appear to be from a non-English speaking background) Where are you from originally?
How long have you been in Australia?

• Who do you live with? Do you have children / grandchildren, how old are they?

• When was the first time you had a mammogram?

• Was it a routine screening mammogram or did you have symptoms?

• Do you know whether it was a BreastScreenAustralia or private service? If not, where did it
take place? (Moderator to check with recruitment screener to help confirm whether private
or BSA service used)

• How many times have you been screened in total (approximately)?

• Roughly how often have you been screened?

2) Experience of recall (35 mins)

Thinking about when you were first recalled for further tests after a mammogram (before you
were diagnosed)

• When were you recalled for further tests?

• Describe the experience of being recalled for further tests.

• How did you feel when you were told you needed further tests?

• Did you consult anyone when you received this result? (Probe: Your GP?) What did you
discuss? What did s/he say to you?

• What happened next? Where did you go? Did you go to a private assessment centre or was
it through BSA? (If not known) Where was the assessment centre?

• What did the additional tests involve? How long did this take?

• How long did it take to get the results of the additional tests? How did you feel while
waiting for these results?

Then when you had further tests and you were told you had breast cancer?

• How were you advised of your results? What happened next?

• Describe the experience of being diagnosed (Probe: feelings).
• Did you consult anyone when you received this result? (Probe: Your GP?) What did you discuss? What did s/he say to you?
• What treatment did you have? How long did the treatment process take?
• How are you now? How long have you been ‘all clear’ for?
• Have you been back for screening mammograms since? Where did you go for this? How do you feel about screening now?
• To what extent did the diagnosis have an impact on you? (Probe: emotionally, costs, lifestyle)

Both Recall & Diagnosis
• How did the experience as a whole leave you feeling?
• How did it leave you feeling about breast screening / BSA?
• How did you feel about the way the staff you come into contact with handled the situation (Probe: what they said, their manner, how they behaved)?
• How could BSA improve the experience of being recalled and diagnosed?
• Had you thought about how you would feel if you were asked back for further tests / treatment before it happened?
• Had you thought about what further tests/treatment would involve and the implications of this before it happened? (Probe: costs, emotional impact, effect on lifestyle)
• Roughly what proportion of women would you say are asked back for further tests / treatment? What makes you say that? Have you heard this anywhere or are you guessing?
• Have you been back for screening mammograms since? Where did you go for this? How do you feel about screening now?

3) Perceived risks and benefits of screening (15 mins)
• What do you see as the benefits to women of breast cancer screening? (Probe fully) Any others?
  – have your views changed since being recalled and treated? If so, what were they before?
• What are the disadvantages of screening (if any)? (Probe fully) Any others?
  – have your views changed since being recalled / treated? If so, what were they before?
• How do you know about these issues?
• In your personal experience, do the benefits outweigh the risks or vice versa? Why do you say that?
4) Informed Consent (15 mins)

*Moderator will ask respondents to complete self-completion sheet 4 then discuss as a group:*

- Which of these statements do you / don’t you agree with? Why?
- How do you feel about the information you were provided with on the risks and benefits before you were recalled?:
  - were you given the right amount of information?
  - was the content appropriate?
- Were you asked to sign a consent form before being screened originally? If so, can you remember what the form said? How did you feel about this?
- Do you feel women should be given more / less / different information in advance?
- Do you think knowing about the likelihood of recall and / or treatment in advance is a good thing?
- Have you heard of the idea of ‘informed consent’? If so, what does this mean to you? If not, what do you think it means in relation to breast cancer screening?

Informed consent is where a person can be said to have given consent based upon an appreciation and understanding of the facts and implications of an action. What are your views on this?

5) Response to BSA Communications Materials (10 mins)

*Moderator will show respondents a selection of materials from their jurisdiction, including any that are related to assessment services, and will encourage them to flick through all of them, without reading them in detail.*

- Have you seen any materials like this? If so, where / when?
- Where would you expect to see materials such as this?
- Which messages / types of materials do you feel are particularly effective in communicating with women who have been recalled?
- How would you feel about any of these materials on assessment services being provided to women before they screen?
- Are there any messages that are confusing / that are not believable? If so, which?
- Which styles of material would be more / less likely to catch your attention?
- How would you feel about receiving a text message to remind you to go for screening in the future?

6) Summing up (5 mins)

- How do you feel about the BSA Program overall?
- What are its strengths and weaknesses?
- How could it be improved?
- Hypothetically, what would your reaction be if it was no longer available?
BSA EVALUATION DISCUSSION GUIDE – INTERVAL CANCERS

Notes to moderator:

- make a note of women from non-English speaking backgrounds and aim to understand any differences in attitudes, behaviour or experiences for these respondents.
- where the guide refers to 'BSA', it may be necessary to describe this as BreastScreen NSW (or whichever State the respondent is in) depending on which respondents are more familiar with.

1) Background (5 mins)

Moderator will explain we understand all respondents have been diagnosed with breast cancer and will not ask them to talk in any detail about their experiences of the cancer itself and treatment. Instead, we would like to understand more about their experiences of breast cancer screening and the BreastScreen Australia service, given their experiences.

(If and when appropriate) moderator will reassure them that they do not have to answer any of the questions if they find them difficult and are welcome to take a break or stop the interview at any time.

- What is your first name?
- (If appear to be from a non-English speaking background) Where are you from originally? How long have you been in Australia?
- Who do you live with? Do you have children / grandchildren, how old are they?

2) Screening History (15 mins)

- When was the first time you had a routine screening mammogram i.e. when you did not have symptoms?
- Where did you go for this? Do you know whether it was a BreastScreen Australia or private service? (Moderator to check with recruitment screener to help confirm whether private or BSA service used)
- Have you been to more than one place for screening mammograms? Where else have you been?
- How many times were you screened in total (approximately) prior to the breast cancer diagnosis?
- Roughly how often were you screened?
- What were your reasons for having breast cancer screening?
- What / who influenced your decision to have regular screens (Probe: GP, friends / family, letters from BSA, advertising)
- Were you ever recalled for further tests when you had screening mammograms (not including when you were diagnosed with breast cancer)? If so:
  - what tests did you have?
  - what information were you given / what were you told about this process?
  - what was the outcome?
How long after your last ‘all clear’ result from a screening mammogram were you diagnosed with breast cancer?

What information, if any, were you given / what were you told about the possibility of cancer being diagnosed in between screens by BreastScreen?
- Did you feel this was enough?

Were you aware of this from any other source? Probe: GP, friends / family, media.

3) Experience of diagnosis (20 mins)

Can you describe how you were diagnosed?:
- what were the symptoms? How were the symptoms detected? Did you notice symptoms yourself or did a doctor find them?
- (those who noticed the symptoms themselves) how long was it from when you noticed the symptoms to getting them checked?
- what happened next? How was the diagnosis made?
- where did you go for any further tests?

What went through your mind when you first noticed the symptoms? And when you were diagnosed?

Did you consult anyone when you received this result? (Probe: Your GP?) What did you discuss? What did s/he say to you?

How are you now? How long have you been ‘all clear’ for?

4) Response to Experience (15 mins)

How did the experience of being diagnosed after an ‘all clear’ result from screening leave you feeling?

How did it leave you feeling about breast screening / BSA?

Have you been back for screening mammograms since? Where did you go for this? How do you feel about screening now?

How did you feel about the information you were given by BreastScreen?

How could BSA improve this?

5) Perceived risks and benefits of screening (10 mins)

What do you see as the benefits to women of routine breast cancer screening when they do not have any symptoms? (Probe fully) Any others?
- have your views changed since you were diagnosed with breast cancer? If so, what were they before? What are they now?

What are the disadvantages of screening (if any)? (Probe fully) Any others?
- have your views changed since being treated? If so, what were they before?

In your personal experience, do the benefits of breast screening outweigh the risks or vice versa? Why do you say that?
6) Informed Consent (10 mins)

- Can you tell me a little more about the information you were provided with on the risks and benefits when you were screened through BreastScreen:
  - do you feel you were given the right amount of information?
  - was the content appropriate?

- Were you asked to sign a consent form before being screened originally? If so, can you remember what the form said? (Once spontaneous responses exhausted): Was the risk of breast cancer being diagnosed in between routine screens mentioned? How did you feel about this?

- Do you feel women should be given more / less / different information when they screen?

- Have you heard of the idea of ‘informed consent’? If so, what does this mean to you? If not, what do you think it means in relation to breast cancer screening?

  Informed consent is where a person can be said to have given consent based upon an appreciation and understanding of the facts and implications of an action. What are your views on this?

7) Response to BSA Communications Materials (10 mins)

Moderator will show respondents a selection of materials from their jurisdiction, including any that are related to the possibility of breast cancer being diagnosed in between routine screens, and will encourage them to flick through all of them, without reading them in detail.

- Have you seen any materials like this? If so, where / when?

- Which messages / types of materials, if any, do you feel are particularly effective in communicating with women, especially about the potential for women to be diagnosed with breast cancer in between routine screens?

8) Summing up (5 mins)

- How do you feel about the BSA Program overall?

- How could it be improved?

- Hypothetically, what would your reaction be if it was no longer available?
BSA EVALUATION DISCUSSION GUIDE – DISABLED WOMEN GROUP

Notes to moderator:

• questions relating specifically to disabled women are in bold – this is the focus for the discussion. However, reactions to the other issues are also of interest, if time permits
• make a note of women from non-English speaking backgrounds and aim to understand any differences in attitudes, behaviour or experiences for these respondents
• where the guide refers to BSA, it may be necessary to describe this as BreastScreen Victoria

1) Background (10 mins)

Moderator will explain we will be talking about breast cancer screening. We are interested in their views on screening mammograms, the services they have used, if any, and reactions to communications. We are particularly interested in the extent to which they feel the service is adequately accessible to all women. They do not have to talk about their personal experiences in depth if they do not want to.

• What is your first name?

• Everyone here has a condition that might mean you could experience difficulties accessing breast cancer screening. Can you tell us a bit about your condition? (NB: moderator will not press the respondent if they feel uncomfortable discussing this at this point)
  – what is the condition?
  – how long have you had this condition?
  – what impact does it have on your life? What sorts of places and services are difficult for you to access?

• (If appear to be from a non-English speaking background) Where are you from originally? How long have you been in Australia?

• Who do you live with? Do you have a carer / someone to help you with day-to-day activities?

• Do you work? If so, what do you do? How accessible is your workplace? What adjustments have been made at your workplace / home to accommodate your needs?

• Do you have children / grandchildren, how old are they?

• Have you ever had a mammogram? If so:
  – when was the last time you had one?
  – was it a routine screening mammogram or did you have symptoms?
  – do you know whether it was a BreastScreen Australia or private service? If not, where did it take place? (Moderator to check with recruitment screener to help confirm whether private or BSA service used)
  – how many times have you been screened in total (approximately)?
  – roughly how often have you been screened?
2) Expectations of ‘Never’ respondents (10 mins)

- (Those who have never had a mammogram): what are your expectations of what it would be like if you used the BSA service? Probe:
  - the mammogram itself
  - accessibility for someone with your condition (parking, ramps, lifts, doorways etc):
    - what would make BS difficult for you to access? Can you give us any examples of other (medical) services that have been inaccessible to you? In what way(s)?
    - what would make BS accessible for you? Can you give us any examples of other (medical) services that have been accessible to you? In what way(s)?
  - environment
    - to what extent would you expect it to cater for your needs?
  - staff attitudes and behaviour:
    - to what extent would you expect them to deal appropriately and sensitively with someone with your condition?
    - what would constitute appropriate and sensitive behaviour?

3) Decision making – Ask Lapsed / Never Screeners (10 mins)

- How did you decide not to have a mammogram or not to re-screen regularly?
  - have you discussed this with your GP:
    - did you bring the topic up or did s/he?
    - what did s/he say to you?
    - did they tell you where to go? What type of clinic was it? Is it where you go now?
    - did you discuss the impact of your condition on screening? If so, what was said?
    - (Probe: Did you discuss both private mammography & BreastScreenNSW as options)
  - did you get an invitation letter? What was your reaction? (Probe: Thoughts and emotions)
    - [visually impaired respondents] was the letter in a format that you were able to use?
    - was the invitation letter followed up in any way? (Probe: another letter / phone call) if so, what was your reaction to the follow-up?
  - do you get reminder letters for your regular two yearly screening? How do you feel about these?
  - what are all the reasons that made you not want to have a mammogram or re-screen? What actually stopped you from going? (moderator to generate list on flipchart)
  - what were all the reasons that encouraged you to go? (moderator to generate list on flipchart)
to what extent did other people influence your decision? What did they say to you?
(Moderator to probe for as much detail as possible, especially on what GPs say about
private versus BreastScreenNSW services)
• family members (partner, daughter)?
• GP / other health professionals?
• friends?
• carers?

how did you weigh up the pros and cons in coming to your decision?:
• which issues from those on the flipchart list were more / less important?
  (moderator to generate prioritised list on flipchart)

4) Decision making – Ask Regular Screeners (if not already covered above) (10 mins)
• How did you first come to have a mammogram?
  – If from GP:
    • did you bring the topic up or did s/he?
    • what did s/he say to you?
    • Did they tell you where to go? What type of clinic was it? Is it where you go now?
    • did you discuss the impact of your condition on screening? If so, what
      was said?
    • (Probe: Did you discuss both private mammography & BreastScreen Australia as
      options)
  – what about an invitation letter? What was your reaction?
    • [visually impaired respondents] was the letter in a format that you
      were able to use?
    • what thoughts went through your mind when you received the letter?
  – was the invitation letter followed up in any way? (Probe: another letter / phone call) If
    so, what was your reaction to the follow-up?
  – do you get reminder letters for your regular two yearly screening? How do you feel about
    these?
  – When you first had to go for a mammogram – what were all the reasons that made you
    not want to go? (moderator to generate list on flipchart)
  – what were all the reasons that encouraged you to go? (moderator to generate list on
    flipchart)
  – to what extent did other people influence your decision e.g.:
    • family members (partner, daughter)?
    • GP / other health professionals?
    • friends?
    • carers?
what did they say to you? (Moderator to probe for as much detail as possible, especially on what GPs say about private versus BreastScreen Australia services)

how did you weigh up the pros and cons in coming to your decision?:

- which issues from those on the flipchart list were more / less important?
  (moderator to generate prioritised list on flipchart)

5) Perceived risks and benefits of screening (5 mins)

- How common is breast cancer among women in Australia compared with other diseases?
- What causes breast cancer? Which are more / less important? (Probe: age, family history, weight, diet, alcohol intake, HRT etc.)
- What are the benefits to women of breast cancer screening? (Probe if not raised spontaneously: what feelings are associated with an ‘all clear’ result? Or do you expect to be associated if never screened?)
- Are there any particular benefits of breast cancer screening to women like you? (Probe if relevant: did you know incidence of breast cancer is a little higher among women with cerebral palsy? Would this affect your intention to screen?)
- Are there any particular disadvantages to women with a condition like yours of breast cancer screening?
- To what extent did these issues come into your decision making? (Refer back to decision making on flip charts earlier)
- How do you know about these issues? (Refer back to discussion about sources of information)

6) Services provision (Lapsed and Regular) (20 mins)

- Those who have used BSA, (if not already raised spontaneously) describe the process of having a screening mammogram with BSA:
  - did you make an appointment or confirm one indicated on the invitation letter? How did you feel about this?
  - how easy for you was it to make an appointment?
  - how did you feel about the location of the service? How easy was it for you to get to?:
  - how accessible was it for you?
  - how does it feel (Probe on meaning of words used e.g. ‘pain’, ‘discomfort’ and listen for comments about short term pain versus concern about long term damage to breasts):
    - at the time?
    - afterwards?
    - do you feel your condition had any impact on how it felt? If so, in what way?
  - has this varied on different screening occasions?
– how did you feel about the staff? (Probe: what they said, their manner, how they behaved)
  • how did you feel they handled your condition?
– what information was provided to you beforehand, if any?
  • was this provided in an appropriate format for you?
– (Those who received information): how did this make you feel?
– describe the environment. (Probe: to what extent did it promote privacy / minimise embarrassment?):
  • how well did it cater for your needs?
– how did you feel afterwards? (Probe: did the discomfort / pain continue?)
– how were the results received? How long did it take to receive results?
– how did you feel about practicalities such as transport / parking / lifts / ramps etc?

• Was there anything about the experience (not already mentioned) that discouraged you from having another mammogram?
• Which of these factors are part of having a mammogram and which are related to the service provided by BSA?
  – How could the BSA service be improved for women with disabilities?
• Any who have used private screening services:
  – how was this different? (Probe all issues as for BSA users above)
  – how do you think your experience might have varied from other women

7) Potential / actual reactions to recall (5 mins)

• When thinking about breast cancer screening have you thought about the chance that you might be asked back for more tests / treatment?
• Have you thought about how you would feel if you were asked back for further tests / treatment (assuming this was because the was a suspicion that there may have been something abnormal on the results as opposed to the mammogram being unreadable)?
• How would you expect to feel while you are waiting for the results?
• Imagine you have further tests but it turned out that you did not have breast cancer? How would this leave you feeling? How would you feel about BSA?
• What would you expect further tests/ treatment to involve? What would be the implications of this? (Probe: costs, emotional impact, effect on lifestyle)
• How do you feel about the amount of information BSA provides you with on these issues?
• Has anyone here been recalled for further tests or investigations? If so:
  – did these take place on the same day or subsequently?
  – where did the assessment take place?
  • if at a different location, to what extent was this location and environment accessible for you?
– were you told whether this was because of suspected abnormalities or problems with reading the mammogram?
– how did you feel while you were waiting for the additional tests?
– how did you feel when you received the result?
– how did you feel about the way the staff you come into contact with handled the situation (moderator to take note of whether respondents had used private or BSA services)?
– How did this leave you feeling?
– How did it leave you feeling about breast screening / BSA?

8) Response to BSA Communications Materials (10 mins)
Moderator will show respondents a selection of materials from their jurisdiction and will encourage them to flick through all of them, without reading them in detail (Please do not give these women brochures on assessment)

• Have you seen any materials like this? If so, where / when?
• Where would you expect to see materials such as this?
  – [visually impaired respondents] are these in a format you are able to use?
• Which messages / types of materials do you feel would motivate you to attend or re-screen?
• Are there any messages that are confusing / that are not believable? If so, which?
• Which styles of material would be more / less likely to catch your attention?
• Have you seen / heard any TV / print / radio / poster advertising for BreastScreenAustralia / BreastScreenNSW? If so, what was your reaction to it? How effective do you think it is?
• What effects could these have on your decision to have a mammogram?
• How would you feel about receiving a text message to remind you to go for screening in the future?

9) Informed Consent (5 mins)

• How do you feel about the amount / content of information provided to you for breast screening?
• Were you asked to sign a consent form before being screened originally? If so, can you remember what the form said? How did you feel about this?
• Do you think knowing about the possible discomfort/ pain beforehand is better or worse? Do staff tell you about this? How does that make you feel towards them?
• Is it enough? Is there any information you would like but you do not get?
  – is there any information specifically for women with disabilities that you would like to have?
• Do you feel you have enough information to decide whether or not to re-screen?
• Are there any circumstances where you might want more / different information?
• Have you heard of the idea of “informed consent”? If so, what does this mean to you? If not, what do you think it means in relation to breast cancer screening?
Informed consent is where a person can be said to have given consent based upon an appreciation and understanding of the facts and implications of an action.

• What are your views on this?

10) Summing up (5 mins)

• How do you feel about the BSA Program overall?
• **How well does it / would you expect it to cater for women with your condition?**
• What are its strengths and weaknesses?
• How could it be improved?
• Hypothetically, what would your reaction be if it was no longer available?
BSA EVALUATION MAIN GROUPS DISCUSSION GUIDE – GPS

1) Background (10 mins)

Moderator will explain we will be talking about breast cancer screening. We are interested in their views on BreastScreenAustralia / BSNSW and private screening services.

- Names.
- Where is your practice?
- How many GPs are there in your practice?
- Is your practice owned by the practitioners or by a corporation?
- What is the demographic profile of your patients?

2) Perceptions of BSNSW (25 mins)

- What do you know about BSNSW? How do you feel about the Program overall? (Let respondents exhaust spontaneous thoughts before prompting)
- What do you see as the strengths and weaknesses of BSNSW? (Probe for as many spontaneous thoughts as possible)
- What factors do you take into consideration when discussing breast screening with patients / making referrals? Which are more / less important?
- (Once spontaneous comments are exhausted): What do you know / how do you feel about:
  - practicalities e.g. transport, parking
  - communication before the mammogram about the experience
  - the environment and the extent to which it promotes privacy
  - attitude of staff
  - time taken to get results
  - the accuracy of results
  - the way in which results are communicated
  - follow-up services, if required
  - costs involved
- Does this vary according to the patient e.g. age, demographic background, risk factors?
- How well do you feel BSNSW caters for different sectors of the community? (Probe: people from non-English speaking backgrounds, disabled women, women from lower SES groups)
- Do your patients tell you about their experiences at BSNSW / private services? If so, under what circumstances does this happen?
- How else do you know about the Program / service provided?

3) Screening referral practices (20 mins)

- To what extent are you actively involved with your patients’ decisions about breast screening?
• Do you discuss the subject with them? If so:
  – under what circumstances?
  – with what type of women? (Probe: of what age, demographic background, with any particular risk factors e.g. obesity, family history, no children before 30)
  – do you tend to bring up the subject or do you respond if they bring it up?
• Why wouldn’t you bring up the subject?
  – under what circumstances?
  – with what type of women? (Probe: of what age, demographic background)
• What barriers are there to discussing breast screening with your patients, even if you would like to do so ideally? (Probe: ‘competing demands of the consultation’? If so, what does this mean?):
  – does this vary according to the characteristics of the patient? If so, how?
• What impact do you feel your discussions with patients about breast screening have on their behaviour?

4) Information on risks and benefits of screening (5 mins)
• Do you discuss the benefits of breast screening with your patients? Why/why not?
  – If so, what do you say to them?
• Do you discuss the risks/disadvantages associated with breast screening with your patients? Why/why not?
  – If so, what do you say to them?
• What do you say to them about these issues?
• At what stage/under what circumstances do you feel it is most appropriate to discuss these issues (Probe: before screening, on receiving a recall?)

7) Handling of recall/further treatment and ‘informed choice’ (10 mins)
• Do you ever discuss potential outcomes of positive test results with your patients? If so, at what stage?
• At what point in the process/under what circumstances do you see patients who have been recalled for further tests/treatment?
• What information do you receive if a patient is recalled? Does this meet your needs?
• What questions do patients ask you?
• What is your next step if a patient who is recalled comes to you? Why?
• Have you come across the ‘informed choice’ debate in relation to breast screening? If so, what do you know about it? What are your views on it?
• (If none aware) some academics argue that women are not fully informed about the potential for: uncovering illness that would not have progressed; creating unnecessary anxiety over recalls for further tests when cancer is not diagnosed; and the potential for interval cancers to occur between screening. What is your view on this? To what extent are/should women be ‘informed’?
• Whose role is it to inform women of the risks and benefits of Breast cancer screening?

8) Comparisons with Private Screening Services (5 mins)
• What do you know about private services?
• Where do you hear about them from?
• (Those who have not heard much about the services) how would you expect BSNSW and private services to be different?
• (Those who do know more) what have you heard about how the two types of services are different and who have you heard this from?
• Under what circumstances would you:
  – refer a patient to a private service for screening (so that they can claim a Medicare rebate)
  – suggest a patient use a private service, which they need to pay for themselves
• Does your practice have a policy on breast screening referral? If so, how has this been arrived at?
• Do you / does your practice have any established links with private providers? If so.
  – how has this come about?
  – what impact does this have on your referral approach?

9) Response to BSA Communications Materials (10 mins)
• How do you feel about the communications provided by BSNSW?
• Have you received any communications from BSNSW that are aimed at health professionals? If so:
  – what was the content?
  – how useful / informative did you find this?
• Have you received any information from private screening services? If so:
  – what was the content?
  – how useful / informative did you find this?
• What other communication materials would you like to receive? What would be the purpose / content of these? (Probe in as much detail as possible)
• (If time permits, show materials aimed at target women for relevant State) What are your feelings about the communications materials aimed at target women?

10) Summing up (5 mins)
• How do you feel about the BSNSW Program overall?
• What are its strengths and weaknesses?
• How could it be improved?
BSA EVALUATION DISCUSSION GUIDE – BREAST PHYSICIANS

1) Background (10 mins)

* Moderator will explain we will be talking about breast cancer screening. We are interested in their views on BreastScreenAustralia / BSA and private screening services.*

- How would you describe the role of a breast physician?
- Are you involved with BSA? If so, in what way?
- How would expect your approach to women in the eligible population (over 40) to differ from that of GPs?
- Where are you based?
- What is the demographic profile of your patients?

2) Perceptions of BSA (10 mins)

- What do you know about BSA? How do you feel about the Program overall? (Let respondents exhaust spontaneous thoughts before prompting)
- What do you see as the strengths and weaknesses of BSA? (Probe for as many spontaneous thoughts as possible)
- What factors do you take into consideration when discussing breast screening with patients / making referrals? Which are more / less important?
- (Once spontaneous comments are exhausted): What do you know / how do you feel about:
  - practicalities e.g. transport, parking
  - communication before the mammogram about the experience
  - the environment and the extent to which it promotes privacy
  - attitude of staff
  - time taken to get results
  - the accuracy of results
  - the way in which results are communicated
  - follow-up services, if required
  - costs involved
- Does this vary according to the patient e.g. age, demographic background, risk factors?
- How well do you feel BSA caters for different sectors of the community? (Probe: people from non-English speaking backgrounds, disabled women, women from lower SES groups)
- Do your patients tell you about their experiences at BSA / private services? If so, under what circumstances does this happen?
- How else do you know about the Program / service provided?

3) Screening referral practices (5 mins)

- To what extent are you actively involved with your patients’ decisions about breast screening?
• Do you discuss the subject with them? If so:
  – under what circumstances?
  – with what type of women? (Probe: of what age, demographic background, with any particular risk factors e.g. obesity, family history, no children before 30)
  – do you tend to bring up the subject or do you respond if they bring it up?
• Why wouldn’t you bring up the subject?
  – under what circumstances?
  – with what type of women? (Probe: of what age, demographic background)
• What barriers are there to discussing breast screening with your patients, even if you would like to do so ideally? (Probe: ‘competing demands of the consultation’? If so, what does this mean?):
  – does this vary according to the characteristics of the patient? If so, how?
• What impact do you feel your discussions with patients about breast screening have on their behaviour?

4) Information on risks and benefits of screening (5 mins)
• Do you discuss the benefits of breast screening with your patients? Why/ why not?
  – if so, what do you say to them?
• Do you discuss the risks / disadvantages associated with breast screening with your patients? Why / why not?
  – if so, what do you say to them?
• What do you say to them about these issues?
• At what stage / under what circumstances do you feel it is most appropriate to discuss these issues (Probe: before screening, on receiving a recall?)

5) Handling of recall / further treatment and ‘informed choice’ (5 mins)
• Do you ever discuss potential outcomes of positive test results with your patients? If so, at what stage?
• At what point in the process / under what circumstances do you see patients who have been recalled for further tests / treatment?
• What information do you receive if a patient is recalled? Does this meet your needs?
• What questions do patients ask you?
• What is your next step if a patient who is recalled comes to you? Why?
• Have you come across the ‘informed choice’ debate in relation to breast screening? If so, what do you know about it? What are your views on it?
• (If none aware) some academics argue that women are not fully informed about the potential for: uncovering illness that would not have progressed; creating unnecessary anxiety over recalls for further tests when cancer is not diagnosed; and the potential for interval cancers to occur between screening. What is your view on this? To what extent are / should women be ‘informed’?
6) Comparisons with Private Screening Services (5 mins)

- What do you know about private services?
- Where do you hear about them from?
- (Those who have not heard much about the services) how would you expect BSA and private services to be different?
- (Those who do know more) what have you heard about how the two types of services are different and who have you heard this from?
- Under what circumstances would you:
  - refer a patient to a private service for screening (so that they can claim a Medicare rebate)
  - suggest a patient use a private service, which they need to pay for themselves
- Does your practice have a policy on breast screening referral? If so, how has this been arrived at?
- Do you / does your practice have any established links with private providers? If so.  
  - how has this come about?
  - what impact does this have on your referral approach?

7) Response to BSA Communications Materials (5 mins)

- How do you feel about the communications provided by BSA?
- Have you received any communications from BSA that are aimed at health professionals? If so:
  - what was the content?
  - how useful / informative did you find this?
- Have you received any information from private screening services? If so:
  - what was the content?
  - how useful / informative did you find this?
- What other communication materials would you like to receive? What would be the purpose / content of these? (Probe in as much detail as possible)
- (If time permits) What are your feelings about the communications materials aimed at target women?

8) Summing up (5 mins)

- How do you feel about the BSA Program overall?
- What are its strengths and weaknesses?
- How could it be improved?
BSA EVALUATION DISCUSSION GUIDE – NURSE COUNSELLORS

1) Background (10 mins)

Moderator will explain we will be talking about breast cancer screening. We are interested in their views on BreastScreenAustralia and what the women they deal with say to them about the service.

• Where do you work? What area do you cover?
• Please tell me about your role and responsibilities:
  – at what stage in the process do you speak to women?
  – what are you aiming to achieve in dealing with the women you speak to?
  – what do you typically discuss?
  – do you speak to women face to face or by phone?

2) Perceptions of BSA (10 mins)

• What do you see as the strengths and weaknesses of BSA? (Probe for as many spontaneous thoughts as possible)
• How do you feel about the availability, accessibility and acceptability of the Program?
• How do you think women feel about it? Probe:
  – practicalities e.g. transport, parking
  – communication before the mammogram about the experience
  – the environment and the extent to which it promotes privacy
  – attitude of staff
  – time taken to get results
  – the accuracy of results
  – the way in which results are communicated
  – follow-up services, if required
  – costs involved
• Does this vary according to the patient e.g. age, demographic background, risk factors?
• How well do you feel BSA caters for different sectors of the community? (Probe: people from non-English speaking backgrounds, disabled women, women from lower SES groups)
• Do the women you work with tell you about their experiences at BSA / private services? If so, under what circumstances does this happen? What do they say?
3) Experience of women’s reactions to recall and diagnosis (10 mins)

- How do women tend to react (as far as you are aware) at different stages in the process:
  - if they are recalled?
    - how do responses differ if abnormalities are suspected versus a problem with the x-ray?
  - when they come in for further tests?
  - when they receive the results following a recall:
    - how do they respond to an all-clear result?
    - how do they respond if further tests are required?
  - if they are diagnosed with breast cancer?
- What do they say to you at each point? What kinds of questions do they ask?
- How do you deal with the situation at each point?

4) Information on risks and benefits of screening (5 mins)

- What do you think women know about the benefits of breast screening before you speak to them?
- Do you discuss this with them? If so, what do you say to them?
- What do you think women know about the risks / disadvantages associated with breast screening before you speak to them?
- Do you discuss this with them? If so, what do you say to them?
- At what stage / under what circumstances do you feel it is most appropriate to discuss these issues? (Probe: before screening, on receiving a recall?)

5) ‘Informed choice’ (5 mins)

- Have you come across the ‘informed choice’ debate in relation to breast screening? If so, what do you know about it? What are your views on it?
- (If not aware) some academics argue that women are not fully informed about the potential for: uncovering illness that would not have progressed; creating unnecessary anxiety over recalls for further tests when cancer is not diagnosed; and the potential for interval cancers to occur between screening. What is your view on this? To what extent are / should women be ‘informed’?
- Whose role is it to inform women of the risks and benefits of breast cancer screening?

6) BSA Communications Materials (5 mins)

- How do you feel about the communications provided by BSA?
- Are there any materials that you provide? If so, which do you use? What do they say?
- Do women ever mention how they feel about the communication materials they receive? If so, what do they say?
7) **Comparisons with Private Screening Services (5 mins)**

- What do you know about private services?
- Where do you hear about them from?
- (If has not heard much about the services) how would you expect BSA and private services to be different:
  - specifically would you expect counseling to be available to women you screen privately? How would you expect this to differ from the service you provide?
- (If knows more) what have you heard about how the two types of services are different and who have you heard this from?

8) **Summing up (5 mins)**

- How do you feel about the BSA Program overall?
- What are its strengths and weaknesses?
- How could it be improved?
BSA EVALUATION DISCUSSION GUIDE – AHW DEPTHS

1) Background (5 mins)

Moderator will explain we will be talking about breast cancer screening. We are particularly interested in their views on BreastScreenAustralia / BSQLD/NT.

- What is your role?
- Where do you work?
- What are the circumstances of the Indigenous women you work with? (Probe: demographics, where they live, socio-economic background)
- What role, if any, do you have in relation to BreastScreen and encouraging Indigenous women to attend?

2) Perceptions of BSA/QLD/NT (20 mins)

- What do you know about BSA/QLD/NT?
- Thinking about the needs of Indigenous women how do you feel about the Program overall? (Let respondent exhaust spontaneous thoughts before prompting)
- What do you see as the strengths and weaknesses of BSA/QLD/NT? (Probe for as many spontaneous thoughts as possible)
- Are you aware of participation rates among Indigenous women?
  - (provide statistics if necessary) what do you attribute lower participation rates to?
- Research has shown that often, Indigenous women are not aware they’re visiting a BSA/QLD/NT service. Why do you think this is?
- What factors do you take into consideration when discussing breast screening with your clients making referrals? Which are more / less important?
- Does this vary according to the woman e.g. age, demographic background, risk factors?
- (Once spontaneous comments are exhausted): What do you know / think about:
  - accessibility e.g. transport, parking:
    - what particular issues are there with accessibility for Indigenous women?
    - are these issues different at different stages in the process (e.g. initial screening, assessment, treatment if required)?
  - communication before the mammogram about the experience:
    - to what extent do you feel this communication is culturally appropriate?
  - the environment and the extent to which it promotes privacy
  - attitude of staff:
    - to what extent do you feel staff are sensitive to the cultural needs of Indigenous women?
  - time taken to get results
• the accuracy of results
• the way in which results are communicated
• follow-up services, if required
• costs involved

• Do your clients tell you about their experiences at BSA / private services? If so, When and why do they tell you?

• How else do you know about the Program / service provided?

• How well do you feel BSA/QLD/NT caters for the Indigenous community overall?

• How could the service be improved / participation rates raised?

3) Screening recommendation / referral practices (10 mins)

• How important do you think BreastScreen / screening mammography is for Indigenous women?

• To what extent are you actively involved with your clients’ decisions about breast screening and/or encouraging women to attend BreastScreen?

• Do you discuss the subject with them? If so:
  – under what circumstances?
  – with what type of women? (Probe: of what age, demographic background, with any particular risk factors e.g. obesity, family history, no children before 30)
  – do you tend to bring up the subject or do you respond if they bring it up?

• What would stop you from bringing up the subject?
  – under what circumstances?
  – with what type of women? (Probe: of what age, demographic background)
  – are there any cultural reasons you wouldn’t bring it up?
  – does this vary according to the characteristics of the patient? If so, how?

• What impact do you feel your discussions with clients about breast screening have on their behaviour?

• Do you do anything else to encourage women to screen (e.g. help them make appointments / arrange transport)?

4) Information on risks and benefits of screening (5 mins)

• What do you see as the risks and benefits of breast screening for Indigenous women?

• Do you discuss the benefits of breast screening with your clients? Why/ why not?
  – if so, what do you say to them?

• Do you discuss the risks / disadvantages associated with breast screening with your clients? Why / why not?
  – if so, what do you say to them?
• What do you say to them about these issues?
• At what stage / under what circumstances do you feel it is most appropriate to discuss these issues (Probe: before screening, on receiving a recall?)

7) Handling of recall / further treatment and ‘informed choice’ (5 mins)
• Do you ever discuss potential outcomes of positive test results with women? If so, at what stage?
• Are there circumstances in which you see women who have been recalled for further tests / treatment?
• Do the women ask you any questions about this? If so, what do they ask?
• What is your next step if a woman who is recalled comes to you? Why?
• Have you heard about ‘informed choice’ in relation to breast screening? If so, what do you know about it? What are your views on it?
• (If not aware) some academics argue that women are not fully informed about the potential for:
  – uncovering illness that would not have progressed
  – creating unnecessary anxiety over recalls for further tests when cancer is not diagnosed
  – the potential for interval cancers to occur between screening.
• What is your view on this? To what extent are / should women be ‘informed’?
• Whose role is it to inform women of the risks and benefits of breast cancer screening?

8) Comparisons with Private Screening Services (2 mins)
• What do you know about private services?
• To what extent do you think Indigenous women use private services? Why do / don’t they?

9) Response to BSA Communications Materials (5 mins)
• Have you received any information or resources from BSA/QLD/NT?
• How do you feel about the communications provided by BSA/QLD/NT?
• Have you seen any materials aimed at Indigenous women? Which ones? What did you think of them?
• Have you received any communications from BSA/QLD/NT that are aimed at Aboriginal Health Workers? If so:
  – what was the content?
  – how useful / informative did you find this?
• What other communication materials would you like to receive? What would be the purpose / content of these? (Probe in as much detail as possible)
• If you were designing some communications materials for Indigenous women in your area, what would they look like? What would the main message be?
10) Summing up (5 mins)

- How do you feel about the BSA/QLD/NT Program overall from the point of view of the Indigenous community?
- What are its strengths and weaknesses?
- How could it be improved?
Please fill in the blank spaces with the thoughts and feelings you have had about having a mammogram.

<table>
<thead>
<tr>
<th>Timeline</th>
<th>What did you think / feel?</th>
</tr>
</thead>
<tbody>
<tr>
<td>You decided to make an appointment</td>
<td></td>
</tr>
<tr>
<td>Getting there / on the way there</td>
<td></td>
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<tr>
<td>In the waiting room</td>
<td></td>
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<tr>
<td>During the mammogram</td>
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<tr>
<td>Immediately afterwards</td>
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<tr>
<td>When the test results arrived</td>
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</tr>
</tbody>
</table>
Group: N

Please answer the following questions as fully as possible:

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) What are the main reasons that you haven’t had a mammogram?</td>
<td></td>
</tr>
<tr>
<td>b) How easy would you expect it to be to make an appointment and get to the clinic?</td>
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<tr>
<td>c) What would you expect the experience to be like e.g. the mammogram itself, how the staff would behave, how long it would take?</td>
<td></td>
</tr>
<tr>
<td>d) Have you discussed mammograms with anyone? If so, who?</td>
<td></td>
</tr>
</tbody>
</table>
Group:____________________

Have you ever had a mammogram? Circle your answer: YES / NO

Instructions: These are comments that have been made by other women about having breast screening mammograms. Please tick a box for each to indicate how far these apply to you.

<table>
<thead>
<tr>
<th></th>
<th>Strongly applies</th>
<th>Applies somewhat</th>
<th>Neutral</th>
<th>Does not apply completely</th>
<th>Does not apply at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>2a</td>
<td>“If I had to travel for more than half an hour to get to the service I probably wouldn’t do it.”</td>
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<tr>
<td>2b</td>
<td>“The experience of mammography is too horrible. I’d rather take my chances and not have it done”</td>
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</tr>
<tr>
<td>2c</td>
<td>“A diagnosis for breast cancer could be difficult but I’d rather be treated and live longer”</td>
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<tr>
<td>2d</td>
<td>“I feel nervous waiting for the results but always feel reassured when I get them”</td>
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<td></td>
</tr>
<tr>
<td>2e</td>
<td>“Free screening mammograms should be available to all women, however old they are”</td>
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<tr>
<td>2f</td>
<td>“Breast cancer is more common among women over 40 than under 40.”</td>
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</tr>
</tbody>
</table>
Group:__________________________

Have you ever had a mammogram? Circle your answer: YES / NO

Instructions: These are all comments that have been made by other women about having breast screening mammograms. Please tick a box for each to indicate how far these apply to you.

<table>
<thead>
<tr>
<th></th>
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<th>Neutral</th>
<th>Does not apply completely</th>
<th>Does not apply at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>3a</td>
<td>“The way the staff treat me will affect whether or not I go again.”</td>
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<tr>
<td>3b</td>
<td>“I’d expect to get a better service overall if I have to pay for it.”</td>
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<tr>
<td>3c</td>
<td>“The staff warned me about the discomfort beforehand the first time I had a mammogram.”</td>
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</tr>
</tbody>
</table>
Group:__________________________  Have you ever had a mammogram? Circle your answer: YES / NO

Instructions: These are all comments that have been made by other women about having breast screening mammograms. Please tick a box for each to indicate how far these apply to you.

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Agree somewhat</th>
<th>Neutral</th>
<th>Do not agree completely</th>
<th>Do not agree at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>4a</td>
<td>“I think they should tell us more about the downsides of having mammograms, as well as the advantages”</td>
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<td></td>
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</tr>
<tr>
<td>4b</td>
<td>“I think they give us enough information to be able to make an informed decision about whether to take part or not.”</td>
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</tr>
<tr>
<td>4c</td>
<td>“Finding cancer early is always best.”</td>
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</tbody>
</table>