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BreastScreen Australia Evaluation

Participation Qualitative Study

July 2008



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Prepared by Blue Moon Research and Planning for the Australian Government Department of Health and Ageing

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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

Accessibility	Level of ease with which women can participate in Program.
Acceptability	Level of satisfaction with the Program among women and / or health professionals.
<i>Active Barriers</i>	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 with women with 'passive barriers' who simply have low awareness or low motivation to attend (see below).
Assessment centres / services	BreastScreen Australia services that assess women who have been recalled for further investigation following an initial mammogram.
Availability	Perceptions of whether or not women could theoretically use service.
<i>Diagnosed and treated</i>	Women who self report a history of diagnosis of breast cancer as a result of screening and have subsequently been treated.
EAC project sponsors	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.
Eligible audience / eligible women	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.
Interval cancers	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.
<i>Lapsed screeners</i>	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.
<i>Never screeners</i>	Women in the eligible age range who self-report never having had a mammogram.
Mobile services	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').

<i>Passive Barriers</i>	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)
<i>Proactive GPs</i>	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.
<i>Reactive GPs</i>	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.
<i>Recalled</i>	Women who following a screening mammogram self-report being recalled for further assessment, but subsequently found not to have breast cancer.
<i>Regular screeners</i>	Women who have had a mammogram for screening rather than diagnostic purposes in the last two years.
Static services	BreastScreen Australia services in fixed locations offering year-round screening.
Target audience / target women	Women aged 50 to 69 who are actively targeted by the BreastScreen Australia Program via its communications.

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 questions¹. 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 total². 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* screeners³; 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.

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 evidence⁴.

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.

4 For example, see:
Beran et al., (2005). Correlation of targeted ultrasound with magnetic resonance imaging abnormalities of the breast. *American Journal of Surgery*, 190, 592-4.
Knutson, D & Steiner, E (2007). Screening for breast cancer: current recommendations and future directions. *American Family Physician*, 75 (11).
Teh W, Wilson AR. (1998). The role of ultrasound in breast cancer screening. A consensus statement by the European Group for Breast Cancer Screening. *European Journal of Cancer*, 34(4), 449-450.

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.