

Research Report

Campaign Developmental Research for Breast Screening

Prepared for: Australian Government Department of Health

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Executive Summary

Objectives

The key task for this project was to provide a platform of insight to contribute to the communication strategy for a campaign to encourage women aged 50-74 to have a screening mammogram every two years. Particular emphasis was placed on women aged 65-69, and those aged 70-74, an age group which has not been invited to free screenings in the past.

The strategy will in turn feed into development of potential campaign materials which will be tested and fine-tuned through research prior to launch.

This Developmental research explored underlying perceptions, motivation and barriers to breast screening and the essential needs of the communication campaign from the target audience perspective.

The primary target audience for the campaign is defined as women aged 70-74 years and women aged 65-69 years who will continue to receive the BreastScreen invitations. The secondary target are women aged 50-64 years and women aged 40-49 years and 75 plus years who are not invited to screen but are still eligible to use the program (inclusive of women from CALD and ATSI backgrounds). Health professions are also secondary target audiences.

Research Design

- This Developmental Research phase was conducted with the primary campaign audience (65-74) and secondary audience (45-64) as well as with health professionals. It was undertaken across metropolitan, regional, rural and remote locations across four states.

The design consisted of the following:

- A mix of n=11 mini-group discussions and n=28 in-depth interviews with regular screeners, under-screeners and non-screeners.
- Separate mini-groups (n=5), paired depth interviews (n=2) and in-depth interviews (n=6) amongst both ATSI and CALD communities.
- Inclusion of n=20 depth interviews with health professionals including BreastScreen Australia staff.

Research Findings

Health concerns

There were a wide range of health issues discussed by participants, however breast cancer did not emerge across the primary or secondary target age groups as a strong top of mind issue, unless there was a family history. More chronic health issues emerged among the older target groups while aspects such as maintaining a healthy, active lifestyle were common across all age groups. Some of the more common health issues cited in this research included: weight problems, menopause related issues, arthritis, diabetes and ageing generally.

Concern about Breast Cancer

Participants with a history of breast cancer in the family were more likely to mention it spontaneously as a concern. There was felt to be a lot of attention given in the media to breast cancer and a great deal of publicity surrounding celebrities with the disease. 'Pink days' at sporting events encouraging people to wear pink were seen to gain heavy media coverage but despite the perceived publicity and discussion in the public arena regarding breast cancer, there was felt to be a much lower emphasis on encouraging women to screen or to check for breast cancer.

The perceived causes of breast cancer or aspects that increased the risk of the disease mentioned most often by research participants included having breast cancer in the family, a stressful lifestyle, an unhealthy diet, artificial ingredients and preservatives in our food, and carrying the 'breast cancer gene'. While age was mentioned generally as a risk factor for cancer and other types of diseases, it was not mentioned specifically in relation to breast cancer.

Awareness of the BreastScreen Program

Awareness of BreastScreen Australia was high, as was awareness of the recommended frequency for having mammograms as being every two years. Many also knew that women over the age of 50 were recommended to have mammograms, unless there was a history of breast cancer in the family or a lump had been found, in which case it was thought they should see their GP and be screened at a younger age. A significant proportion of women were unsure of the recommended age to start screening, and often it was estimated or 'guessed' to be 'in their 40s'.

The upper age for screening was less clear. The majority generally did not perceive that there was an upper age, particularly those aged in their 40, 50's and early 60s. Awareness of the current 'cut off' age of 69 years was considerably higher amongst those regular screeners aged in their late sixties and early seventies.

The impact of General Practitioners on the screening frequency of patients

General practitioners (GPs) appeared to be an important influence on many women regarding their health issues, and their advice was listened to and usually followed. However many participants indicated that their GP was not discussing breast cancer with them at all. It seemed the GPs were rarely promoting breast screening, and did not often suggest mammograms to them. Participants reported the GPs were more likely to prompt women about their pap smears.

BreastScreen Experiences

Experience with the BreastScreen facilities

Participants' experiences with the BreastScreen Australia facilities themselves were mixed, with some positive and some negative. For example, BreastScreen facilities in hospitals were often described as like a typical hospital room, and the experience was somewhat impersonal, cold, clean, and clinical. Other facilities were very well regarded, such as those in Myer or David Jones, which were seen as feminine, and pleasant, and could be combined with lunch or shopping.

The BreastScreen vans were generally well received in rural/regional areas – they were viewed as a prompt to attend and the ‘event’ nature of the van coming to town was felt to be an important component in encouraging involvement.

Perceptions of BreastScreen staff

The vast majority of women thought that BreastScreen staff were extremely pleasant, helpful and friendly, and that they helped make an otherwise unpleasant experience more bearable. A few participants thought some staff acted like it was just “business as usual” and didn’t go the extra mile to make them feel comfortable. Some ATSI participants commented on the lack of Aboriginal staff assisting them and felt embarrassed by white women touching their breasts.

Perceptions of Mammograms and the BreastScreen Process (amongst regular screeners)

There was strong agreement that the process of having a mammogram was painful and uncomfortable, with some finding the pain more intense than others. Some reported very negative experiences which had made them very reluctant to return. There was a level of real annoyance or frustration about the pain level, and they questioned why it had to be so painful “in this day and age”. Some women felt like they were treated as if their breasts were unattached to their body, and they were treated without sensitivity.

Prior to attending, many spoke of being anxious and nervous, and waiting in the waiting room for an extended period of time only heightened these feelings. Participants also dreaded how long they would have to wait for results, although once cleared, there was a great feeling of relief and a sense of real satisfaction that the process had been worth going through.

Perceptions of Mammograms amongst Non and Under Screeners

Amongst those who had never been for a breast screen, most imagined and had heard from others, that it would be uncomfortable and painful. They imagined that they would feel very anxious and worried, both prior to attending and when waiting for the results. Again there was agreement that they would feel very relieved and happy once the process was over.

Ultrasounds and Private Screening

There were discussions and general confusion regarding the difference between mammograms and ultrasounds, and whether you needed to have both conducted. Some women felt that ultrasounds would be a very appealing alternative to having a mammogram and this led women to question why BreastScreen Australia did not offer this service.

Some GPs recommended private screening. A considerably high proportion of participants across the study had been screened through a private clinic, which had been suggested by their GP, or by friends, although this was more likely reported by women of mid-high socio-economic status. Women with breast cancer in the family, those who reported to have ‘lumpy breasts’ and those aged under 50 years, were more likely to be using private screening clinics.

Motivations and Barriers to Breast Screening

In an unprompted sense, the main motivations encouraging women to screen were concerning the early detection of cancer, and the provision of peace of mind and relief from the concern of potentially having breast cancer.

Important underlying motivations for many of the regular screeners were to feel in control of their own health and to simply be determined to live as long as possible, enjoy life and be around for their family. The more immediate triggers for breast screening included receiving the letter from BreastScreen Australia, the GP being proactive and friends or family encouraging them to attend.

There were many reasons cited by participants regarding why they had not been screened at all or why they (or other women) did not screen as regularly as they should. In summary, the main barriers to emerge in this research were as follows:

- Denial and the attitude that it's not going to happen to me
- Fear associated with dying, cancer and a long term illness
- The discomfort of the mammogram
- Self consciousness and embarrassment
- Accessibility (in some locations)
- Lack of time
- Radiation concerns from the x-ray
- Concerns about the accuracy of mammograms
- Language barriers and
- Procrastination

Reactions to the Program Expanding to include 70-74 year olds

Initially there were positive reactions to this information. It was seen as a positive step to ensure more women would be able to access the service, and it had the secondary benefit of implying that the Government and society cares about people as they age.

Amongst those who were aware of the previous 'cut-off' age of 69 years or 70 years, this expansion was well received, however in many instances participants became more focussed on the cut off age as opposed to the expansion. There were numerous questions asked about the reasons for the expansion, and the cut off age. Amongst those aware of the current 69 years limit for the program, there was a suggestion that the mere presence of a cut off age at all contradicted the message that the risk of getting breast cancer increases with age. Some other interpretations of the message were that the risk of developing breast cancer ends or decreases after the age of 74 years; that the BreastScreen program would not be available to women after this age, that is, that they would be turned away or it would not be free; and it tended to heighten the perception that after 74 years 'nobody' cares or society doesn't care. In addition, alerting women to this expansion of the program caused many participants to ask questions surrounding the reason for the change, assuming that perhaps there had been an increasing number of cases of breast cancer being picked up in women aged 70-74 years.

Alternatively it was thought that perhaps people are living longer, and that they are relatively healthy (compared to previous generations) so it is therefore becoming more worthwhile to be able to identify a lump and have treatment.

Reactions to Key Messages

A number of key messages addressing some of the motivations and barriers to breast screening were shown to participants and reactions elicited. The messages addressed incidence of breast cancer, early detection, mammograms and age being the greatest risk factor.

Strong motivators or positive reasons to breast screening tested well in this study, as opposed to negative, 'fear tactics'. Early detection, that is, identifying signs early so that you can live a longer life and that treatments are less severe, and to a lesser extent, effectiveness of mammograms in early identification of a lump, appeared to have the greatest potential to motivate both the primary and secondary target groups.

Communication Channels

In relation to information sources used by women regarding general health related issues and breast cancer specifically, there was mention of radio and specifically listening to guest speakers and GPs on the radio, brochures obtained from their GP, listening to the various television morning shows and 'Googling' the specific health issue and seeing what comes up.

In terms of how the Government could best communicate messages to encourage women to breast screen, whilst women initially suggested a television campaign, upon greater consideration there was also mention of radio stations, government websites, posters in GP surgeries, sending a brochure in the mail, text messages, emails and an App (smartphone application) to remind women when they were due for a mammogram.

Key Communication Development Implications

We would suggest the primary target for the communication campaign would best be defined as the under screeners. Non-screeners will be an extremely difficult group to convince and the regular screeners are converted and only require reminders and reinforcement.

Overall the indications from the research suggest there is a need to communicate the positive aspects of breast screening and present motivations to attend; and downplay the more negative, more confronting aspects, as these can act as implicit demotivators.

In terms of the expansion of the program to include 70-74 year olds, in any mass communication this message needs to be handled sensitively as it has the potential to raise questions and unnecessarily draw attention to the notion that there is a cut off age. The expansion message could therefore be addressed through a targeted campaign aimed at those regular screeners aged 64-74 years, informing them that they will still be invited to attend a BreastScreen service as the program has been expanded to 74 years. However if the expansion message is to be communicated to a wider audience we would suggest that the message be focussed, at headline level, on extending the program to 70 and over year old women. A secondary message would

also need to be included to inform them that after 74 years, they would not receive a reminder letter, but they are still welcome to attend and should consult their doctor. Further information could also to be included to explain the reasons for the change and dispel any potential concerns, for example, *with more women living longer lives, we've expanded the program.*

Background

BreastScreen Australia (the National Program for the Early Detection of Breast Cancer) actively invites women aged 50-69 to attend free breast cancer screening. Currently women aged 40-49 years and women aged over 70 years are able to participate in the program however they are not actively invited, and therefore do not receive the reminder letter.

As part of the 2013-14 Federal Budget the Australian Government committed \$55.7 million over four years to expand BreastScreen Australia's target age range by five years inviting women 50-74 years of age to participate in the program.

A new campaign is therefore required which will work to increase the number of women within the target age groups having a screening mammogram every two years, with emphasis on the older age brackets as they will now continue to receive invitations up until age 74 years.

While the Department has not had a breast cancer screening related campaign since the late 90s, there has been a mix of activity through state and not for profit organisations, as well as a range of celebrities having publicised their breast cancer, and some women may therefore have a number of preconceived ideas about screening mammograms and their importance. Others may however have not taken in this activity and be relatively unaware. It is important therefore that the campaign is relevant and cuts through to a broad target, in an effective and motivating manner.

The primary target audience for the campaign is defined as women aged 70-74 years (who have or have not previously screened) and women aged 65-69 years who will continue to receive the BreastScreen invitations. The secondary target are women aged 50-64 years and women aged 40-49 years and 75 years and over who are not invited to screen but are still eligible to use the program. These targets also include women from a Culturally and Linguistically Diverse background (CALD) and Aboriginal and Torres Strait Islander (ATSI) women. Health professions including GPs and BreastScreen staff are also secondary target audiences for the campaign.

Developmental research was therefore required amongst the primary and secondary target audiences to inform the proposed BreastScreening campaign and this document reports the main findings of this research project.

Objectives

The key objectives for the development research included the following:

- To gain a better understanding of awareness, knowledge, opinions, attitudes and current practices and intentions regarding breast cancer screening and breast screening programs, including exploration of the relationship among cancer screening behaviours,
- To identify key cancer screening motivators and barriers; including perceptions of risk and cultural perceptions regarding breast cancer,
- To determine which key messages and channels are appropriate for communicating with women about breast cancer screening.

This understanding will in turn feed into development of potential campaign materials which will be tested and fine-tuned through research prior to launch.

The exploration amongst women from the target audiences included the following more detailed areas of investigation:

- Identification of levels of general knowledge, awareness and beliefs regarding breast cancer, its prevalence and the sorts of people typically affected,
- Any gaps in knowledge or misperceptions;
- The reasons behind the perceived personal risk, or lack of it;
- The consideration and decision making process regarding screening and stages in that process.
- Screening activity in relation to other cancers;
- The key perceptual influencers (positive and negative, emotional and rational) on the decision to screen.
- Levels of understanding about the frequency of screening, what is perceived to be the correct frequency and why, and views regarding the efficacy and necessity of two year screening;
- In particular, what do older women feel about the frequency of screening, are they aware that invitations currently stop after 70, do they see screening as continuing to be relevant for them, how would those aged 70-74 react to receiving an invitation, does it create alarm or concern that they are now being targeted;
- Other influences encouraging or discouraging screening,

- The role of General Practitioners (GPs) and other health professionals in communication and in providing information and prompting screening, when and why this works, which sources are trusted, what sort of information do they expect from health professionals;
- Previous screening experience, feelings about that experience, what motivated the decision to go, what was good, what was bad and how that impacts on decision making;
- Feelings after screening and achieving a clear result (peace of mind, relief, satisfaction etc.)
- Perceived ease of accessing screening services;
- Recall of any campaigns or activity around breast cancer from other sources such as state bodies,
- Channels of communication used currently and suggested for the future for media campaigns and dissemination of messages surrounding screening.
- Websites or other sources used for information concerning screening and its efficacy and importance;
- Particular attitudes or beliefs that are evident amongst women from Culturally and Linguistically Diverse (CALD) backgrounds, or amongst Aboriginal and Torres Strait Islander (ATSI) women in the target audiences which may impact screening uptake, and how these aspects might be overcome, what sources of advice or information do these women look to; and,
- Evaluation of a range of potential messages to help give direction to campaign development.

The exploration amongst health professionals and BreastScreen staff included:

- Background to their role and involvement;
- Their observations/understanding of the beliefs and attitudes of the target audiences that they come in contact with;
- What they see as their role in the encouragement of screening, and providing of advice;
- What sources, tools and resources they use currently, and what (other) tools and resources they would find useful to assist them in their role in encouraging participation in the program in future,
- What aspects they feel are relevant to them to use to increase awareness and confidence in the BreastScreen Australia program;

- What they see as the key elements required in a campaign for women regarding screening, and what they feel should be avoided; reactions to potential messages and statistics from the health professionals perspective; and,
- Their attitudes toward the expansion of the invitation age group, how they perceive this will be received, and
- What impact this will have on their role and information needs.

Research Design

This developmental research was conducted qualitatively, via a combination of mini-group discussions and in-depth interviews, amongst the primary, secondary and ATSI and CALD target audiences.

Rationale for the Research Design

Mini group discussions (comprising 4-6 people) rather than full groups were chosen because they allow deeper probing on knowledge and attitudes regarding sensitive issues such as breast screening, while still offering the opportunity to view group dynamics and interaction and the support that the group environment provides. They also provided wider coverage across various locations. Individual in-depth interviews were also conducted amongst certain segments that required individual probing and understanding to allow an even greater depth of attitudes and barriers to breast screening in particular. Some of these in-depths with the older women were conducted in-home. In-depths are also the most effective means of researching the views and attitudes of health professionals (either by phone or face to face). Paired in-depths were selected amongst the ATSI participants to help overcome any reluctance amongst this target.

Greater emphasis was placed on the under and non screeners as opposed to the regular screeners in the design. While it was important to understand the prompts and triggers to screening amongst regular screeners it was particularly useful to ensure we grasped the barriers and aspects that discouraged screening.

The design structure reflected a slight bias towards those from mid to lower socio-economic groups, as screening is lower amongst these groups. However some group discussions in the metropolitan areas were specified to be either from the lower-to-mid or the higher socio-economic groups. Within the design there was a spread of employment and relationship status.

The Cultural and Indigenous Research Centre Australia (CIRCA) conducted a separate component of research amongst CALD and ATSI women. Some of the research was conducted utilising in-language moderators. The language groups of Chinese, Arabic and Italian were selected because they account for the largest population numbers in this older age group, and provide a broader coverage in relation to region and migration history. Both under screeners and non screeners were included across metropolitan and regional areas. Additionally, in order to include some remote ATSI views we sub-contracted a researcher who has been living and working amongst a number of Aboriginal communities in Kununurra in Western Australia.

Design structure

Woolcott Research (in partnership with CIRCA) conducted the following:

- n=11 mini-group discussions and n=28 in-depth interviews with regular screeners, under-screeners and non-screeners.

- Separate mini-groups (n=5), paired depth interviews (n=2) and in-depth interviews (n=6) were conducted amongst women from both ATSI and CALD communities.
- n=20 in-depth interviews amongst health professionals including BreastScreen Australia staff and GPs.

Groups with women were broken by key campaign primary and secondary target age groupings. Coverage was across metropolitan, regional, rural and remote locations across four States. The metropolitan locations chosen for the research included Sydney, Adelaide and Brisbane. The rural and regional locations selected were Traralgon (Victoria) and Gold Coast (Queensland) which have a high proportion of older residents. The remote phone in-depths were conducted amongst participants from NSW, Queensland and Northern Territory.

Below is a summary of the research structure.

Consumers – Primary and Secondary Target

Females	Regular Screeners <i>Metro</i>	Regular Screeners <i>Rural/ Regional/ Remote</i>	Under-Screeners <i>Metro</i>	Under-Screeners <i>Rural/ Regional/ Remote</i>	Non-Screeners <i>Metro</i>	Non-Screeners <i>Rural/ Regional/ Remote</i>	TOTAL
Primary: 70-74 years	1 group (Syd)	-	1 group (Adel) 2 depths (Syd m- l/Adel)	1 group (GCoast) 2 depths (T'gon/ GCoast) 1 remote ph depth)	2 depths (Syd u/ Logan m-l)	1 depth (T'gon) 1 remote ph depth	3 groups 9 depths
Primary: 65-69 years	-	1 group (G'Coast)	1 group (Syd) 2 depths (Syd u /Adel m-l)	1 group (T'gon) 1 depth (GCoast) 1 remote ph depth	1 group (Adel) 1 depth (Syd m-l)	2 depths (G'Coast/ T'gon)	4 groups 7 depths
Secondary: 50-64 years	1 group (Adel m-l)	-	1 group (Syd) 1 depth (Adel u)	1 depth (GCoast)	2 depths (Syd u /Logan m-l)	2 depths (GCoast/ T'gon)	2 groups 6 depths
Secondary: 40-49 years	1 depth (Syd u)	1 depth (T'gon)	1 group (Logan)	-	1 group (Syd)	-	2 groups 2 depths
Secondary: 75+ years	1 depth (Adel m-l)	1 depth (GCoast)	1 depth (Syd m-l)	-	1 depth (Logan m-l)	-	4 depths
TOTAL	2 groups 2 depths	1 group 2 depths	4 groups 6 depths	2 groups 6 depths	2 groups 6 depths	6 depths	11 groups 28 depths

As mentioned, in order to understand the differences by socio-economic group in some groups in metropolitan areas, the group/depth was specified as either mid-to-low socio-economic status (shown in the above table as 'm-l') or upper (u), with the remainder falling out as was relevant to each location.

ATSI and CALD representation

ATSI Females aged 50-74 years	Regular Screeners	Under-Screeners and non-Screeners	TOTAL
NSW: Sydney	1 paired depth	1 group	1 group 1 paired depth
Vic: Shepparton	1 paired depth	1 group	1 group 1 paired depth
WA: Kununurra	1 depth	2 depths	3 depths
TOTAL	1 depth 2 paired depths	2 groups 2 depths	2 groups 3 depths 2 paired depths

CALD Females aged 50-74 years	Regular Screeners	Under-Screeners and non-Screeners	TOTAL
Italian (65-74 years) - Metro (Melb)	1 depth	1 group	1 group 1 depth
Chinese • Metro (Sydney)	1 depth (65-74years)	1 group (50-64 years)	1 group 1 depth
Arabic • Regional (Shepparton Vic)	1 depth (65-74 years)	1 group (50-65 years)	1 group 1 depth
TOTAL	3 depths	3 groups	3 group 3 depths

Health Professionals

A total of n=20 in-depth interviews with Health Professionals were also conducted. This included n=9 face to face interviews with GPs, n=1 face to face interview with an ATSI community health professional and n=9 in-depths (2 face to face and 7 telephone in-depths) amongst BreastScreen staff across the majority of States, in metropolitan, regional and rural locations. Below is a summary of this component of the research:

Health Professionals	Metro	Regional/Rural/Remote	TOTAL
GPs	5 in-depths	4 in-depths	9 in-depths
BreastScreen staff (nurse counsellors, radiographers, radiologists etc)	6 in-depths (combination of face to face and phone in-depths)	3 in-depths	9 in-depths
ATSI Community health professionals	1 in-depth (La Perouse)	1 in-depth (Kununurra)	2 in-depths
TOTAL	12 in-depths	8 in-depths	20 in-depths

Conducting the Fieldwork

Recruitment of research participants was subcontracted to a specialist market research recruitment agency, Stable Research, who used a variety of methods for recruiting, such as random telephone interviews and emailing people off their own data base in the proposed locations. A recruitment screener was designed for this purpose, and a copy of the screener is appended to the back of this document.

During the group discussions and in-depth interviews it was ensured that women felt comfortable and relaxed enough to contribute to the discussion. They were assured of confidentiality and anonymity of their responses. Projective techniques were used where necessary to help uncover less rational barriers and responses. By projecting potential thoughts and feelings on 'other people' participants provided us with indications regarding their own underlying attitudes and emotions. Participants were provided with a small token of appreciation for their time and to cover the cost of any travel expenses incurred.

Fieldwork was conducted between 10th and 17th March 2014.

Informal Review of Past Research

Prior to commencement of this project Woolcott Research conducted an informal review of research conducted either by our own organisation or by the Department, to re-familiarise ourselves with the issues surrounding breast screening and to assist in the development of the topic guides. These research studies included the following:

- Cancer Screening Formative Research for the NSW Cervical Screening Program and BreastScreen NSW (conducted for The Cancer Institute, NSW in 2012). This research involved both qualitative and quantitative components.
- Concept Evaluation Research for Breast Cancer Screening (conducted for The Cancer Institute, NSW in 2006),
- Formative research for the BreastScreen Australia Program conducted by Bluemoon, for Department of Health and Ageing in 2006, and
- A summary of a qualitative research report conducted in 2009 for the Department of Health and Ageing.

The research found that awareness of breast cancer was high and women tended to overestimate the prevalence of the condition. It was therefore important to put breast cancer into perspective with other health issues, so we included an initial section in the topic guide whereby participants discussed general health issues so that we could put their degree of knowledge and concerns regarding breast cancer into perspective.

Previous research also suggested that the GP played an important role in reminding women to breast screen, so it was important to include questions about the way in which GPs discuss and prompt about breast screening. Many of the motivations and barriers that were used as prompts in the topic guide were gleaned from this previous research, for example ‘peace of mind that you don’t have breast cancer’ as a motivator.

Research amongst non screeners revealed that perceptions and misinformation about mammogram procedures was a deterrent for some, so questions regarding perceptions of the experience were included for those who had never screened.

1.0 Health Concerns

Initially participants were asked what sorts of health issues were confronting them at their age and stage of life. While there was a wide range of health issues discussed, breast cancer did not emerge across the primary or secondary target age groups as a strong top of mind issue, unless there was a family history.

The key health concerns for each age group were more immediate aspects, and included the following:

40-49 years

Within this age bracket participants claimed to be watching their weight, trying to eat healthy foods and trying to maintain exercise. Those with children spoke of ensuring they do not catch children's colds and viruses in the fear of not being able to look after their family and run the household. Blood pressure was also mentioned, as well as specific diseases that run in the family, such as asthma. Quitting smoking and cutting down on alcohol consumption were also mentioned in relation to trying to live a healthier lifestyle. Cancer of various types was only mentioned if there was a definite family history involved.

50-59 years

Amongst the 50-59 years group, menopause and menopause related issues, for example, weight gain sleep quality and mood swings were top of mind. Increasing aches and pains often associated with arthritis were also mentioned. Osteoporosis was beginning to be a worry for some, as well as many other issues emerging at a lower level, such as eyes starting to deteriorate, and problems with knees, hips and cholesterol levels.

60-69 years

Heart issues were starting to concern participants in this age bracket more, as well as arthritis, blood pressure, strokes and various cancers – although again cancer was more likely to be a concern if the participant had a family member or a close friend affected. Diabetes was also mentioned, particularly amongst ATSI participants. Weight gain, watching sugar intake and cholesterol were also concerns mentioned by ATSI participants in particular.

70 years and over

For this age group many of the health concerns mentioned by their younger counterparts were felt to be relevant for them, as well as the general impact of ageing on their ability to participate in all the activities they had been able to do in the past. Aspects such as ensuring they keep mobile and keeping their mind active to avoid dementia and depression were also often mentioned by women in this age group. While many types of cancers, including breast cancer, were mentioned quite frequently amongst this age group, there was little evidence to suggest that concern about breast cancer specifically increased with age. It was more the case that mention of all types of diseases increased.

2.0 Concern about Breast Cancer

2.1 Awareness and understanding of breast cancer

As mentioned those participants with a history of breast cancer in the family were more likely to mention it spontaneously as a concern. The majority of participants had however known someone who had experienced breast cancer and many commented that there appeared to be many more women being diagnosed with breast cancer nowadays than ten to twenty years ago, particularly younger women. This was consistent amongst ATSI and CALD participants as well.

“My daughter in law has just been diagnosed with breast cancer” (Regular screener, 65-69 years, regional Queensland)

“I reckon at my work there were about ten women (out of say 200), that were diagnosed with breast cancer over a 10 year period” (Regular screener, 70-74 years, Sydney)

There was felt to be a lot of attention given in the media to breast cancer and a great deal of publicity surrounding celebrities with the disease, for example, Angelina Jolie, Kylie Minogue and Jane McGrath.

In addition there was also seen to be heavy media coverage and support given to ‘pink days’ at various sporting events such as the cricket. The aim of these ‘pink events’ was felt to be to encourage people to wear pink to support breast cancer awareness and fundraising.

Despite all of the perceived publicity and information ‘out there’ about breast cancer, there was felt to be a much lower emphasis in the publicity on encouraging women to screen or to check for breast cancer. There was almost no awareness of campaigns or advertising that addressed breast screening specifically.

The main sources of encouragement regarding screening were the invitations or letters received in the mail and the breast screening vans which were particularly noticed by women from rural and regional areas.

Interestingly Arabic speaking participants noted that they do not refer to cancer or use the word ‘cancer’ instead referring to cancer as ‘the big sickness’.

2.2 Perceived causes of breast cancer

As mentioned there was a strong feeling that if you have breast cancer in the family then you are possibly at a greater risk of experiencing it, however many women in the research also accepted that cancer can strike anyone, at any time, with no particular explanation regarding the cause.

“Anyone can get it. People can be fitness fanatics and can get it” (ATSI, under screener, 50-66 years, Sydney)

Some linked the perceived increases in breast cancer to the more stressful lifestyle of today, as well as to an unhealthy diet, and the presence of more artificial ingredients and preservatives in our food these days.

“I think that sometimes if you have stress of a big shock in your life, you will get cancer” (Regular screener, 70-74 years, Adelaide)

There was also some mention of the presence of ‘the breast cancer gene’ which could be carried through generations, and it was felt there had been some publicity about this.

“There’s a gene, it’s there, you can be tested on it”(Under screener, 40-49 years, Brisbane)

It was thought breast cancer could occur at any age, and many agreed that they were hearing more and more instances of younger women, in their twenties and thirties getting breast cancer nowadays. Having said that, overall there was relatively high belief that the older you get, the greater the probability of getting breast cancer, or indeed any type of cancer.

“You’re more likely to get everything as you get older”(Under screener, 65-69 years, Adelaide)

“Women older than 40 have a higher chance of cancer(Regular screener, 50-64 years Adelaide)

Many other ‘myths’ and perceptions associated with breast cancer emerged, and these included the following:

- that women with larger breasts are more likely/smaller breasts are less likely,
- after menopause, your body changes and breast cancers can emerge,
- something to do with hormones and the age at which you first start ovulating,
- an unhealthy lifestyle, e.g. unhealthy food, alcohol, smoking,
- the increase in pollution/chemicals
- artificial preservatives and flavourings in food
- a potential link to breast feeding
- hormones in chickens

On a rational level participants agreed that they were all possibly at risk, but amongst the ‘under screeners’ and ‘non-screeners’ there was a sense that there were many other health aspects that pose a more urgent risk (heart disease, blood pressure, diabetes) than breast cancer, and that a screen every two years was probably excessive and unnecessary if there were no signs or symptoms.

“I think we are over screened and over diagnosed these days” (Non screener, 50-64 years, regional Victoria)

There was also a degree of cynicism overall surrounding cancer, the multitude of concerns in society and the many contributing and contradictory causes of cancer discussed in the media.

“Everything gives you cancer these days!” (Non screener, 65-69 years, Adelaide)

‘I am so sick of hearing about all these cancers... I am all cancer’d out’ (Non screener, 40-49 years, Sydney)

Interestingly even amongst some of those with a family history of breast cancer who theoretically felt they could be at higher risk, there was a reluctance to allow the fear of it take control of their lives, so they tended to deliberately put it to the back of their minds. In many cases, this lead to them not screening at all.

“I don’t want to think about my risk because the more I think about it the more anxious I will be, so I choose to turn a blind eye” (CALD (Chinese), under/non screener, 50-64 years Sydney)

One of the GPs who dealt with the Aboriginal community mentioned that cancers such as lung cancer and bowel cancer were more prevalent amongst Aboriginal communities perhaps due to smoking and poor diet, while breast cancer was not as common.

2.3 Key differences amongst the Primary Audience Regarding Breast Cancer Concern

The primary audiences of 65-69 and 70-74 year olds were very similar in their responses regarding breast cancer concern and perceived causes. As mentioned many in this age group had various health conditions to contend with and the threat of contracting breast cancer was no greater. There were no discernable differences in terms of perceptions of risk of breast cancer as they approached sixty or seventy years of age – they simply thought they were more ‘at risk’ of all types of diseases and health conditions.

3.0 Awareness of the BreastScreen Program

3.1 Awareness of the Program

Unprompted awareness of BreastScreen Australia was high, as was awareness of the recommended frequency for having mammograms as being every two years. This level was similar amongst ATSI and CALD participants and almost all of the primary target (65-69 and 70-74 year old women) were aware of BreastScreen Australia and the 2 year recommended frequency for breast screening). The non-screeners were less likely to cite the exact period of two years. The main source of this awareness appeared to be the letter they received from BreastScreen and their GP.

Awareness of the idea that women over the age of 50 are recommended to have mammograms was also quite high, unless there was a history of breast cancer in the family or a lump had been found, in which case it was thought they should see their GP and be screened at a younger age.

There were a significant proportion of women who were unsure of the recommended age to start screening, and often it was estimated or 'guessed' to be 'in their 40s'. Those participants aged in their 40's were particularly confused and wondered whether or not they should be getting screened. There was also confusion and uncertainty regarding whether or not women in their 40's could be screened for free at the BreastScreen clinics.

The upper age for screening was less clear. The majority generally did not perceive that there was an upper age, particularly those aged in their 40, 50's and early 60s. Many of the older (late 60 years and 70-74 years) participants who screened regularly, were aware that there was a 'cut off' at around 70 years but they wondered why this was the case. There was confusion amongst these participants regarding the extent to which they are 'allowed' to participate in the BreastScreen program after this 'cut off' age, and whether or not it would continue to be free.

"Don't I matter anymore?" (Regular screener, 70-74 years , Adelaide)

"I got told that it was for women up to 69 years, but it was up to me – what does that mean?" (Regular screener, 70-74 years, Sydney)

There was also high awareness that the BreastScreen process was free to women and that was well regarded.

3.2 Reactions to the BreastScreen Invitation Process

The vast majority claimed to receive reminder letters from BreastScreen Australia. They were felt to be an important reminder of the fact that they were due for a breast screen and they also appeared to be an effective trigger influencing women to make an

appointment. Some spoke of the letter being placed on the fridge or the kitchen bench 'under their nose' until the appointment was made.

Under and non screeners were aware of receiving 'numerous' letters but they were either thrown out immediately or simply forgotten. There were some however, who claimed that they do not recall ever receiving a letter from BreastScreen Australia.

Recollections of how they first became aware of BreastScreen Australia were mainly through receipt of the letter in the mail, their GP mentioning it or directly from a friend who had recently visited.

3.3 The impact of General Practitioners on the screening frequency of patients

General practitioners (GPs) appeared to be an important influence on many women regarding their health issues, and their advice was listened to and usually followed. This was particularly pertinent amongst those aged in the primary target (65-74 years).

However many participants indicated that their GP was not discussing breast cancer with them at all. It seemed the GPs were rarely promoting breast screening, and did not often suggest mammograms to them. Participants reported the GPs were more likely to prompt women about their pap smears.

Women GPs were reportedly more likely than male GPs to discuss breast cancer and screening, as were those at specific women's health centres. Many older women, particularly those with chronic health conditions were visiting the GP very regularly and were in frequent contact – often to simply get scripts renewed.

However while a few had been prompted to screen by their Doctor initially, this was not common (unless they had a long term relationship with their GP).

"My doctor never mentions it to me" (Regular screener, 65-69 years, regional Queensland)

"They don't have time, they just churn us through"(Under screener, 65-69 years, regional Victoria)

A number of the 40 to 49 year old participants went to a GP regularly for themselves or their children, but the doctor had either not mentioned mammograms to them, or if asked, had said that it was not necessary yet (unless there was a family history of breast cancer).

Some regular screeners participants aged over 50 years who had a regular GP did not see the prompt as necessary as long as they were receiving the reminder letters.

"I get the letter every two years and that often prompts me to go". (Regular screener, 50-64 years, Adelaide)

Older women with chronic health issues felt they had enough problems to worry about, and that their GP was more likely to be concerned with those issues rather than suggesting screening.

Aboriginal Medical Services (AMS) and other Indigenous Health Professionals were felt to be very good at proactively suggesting regular breast screening to the Indigenous women, alerting them to van visitation days in their areas and encouraging them to go along.

Some Indigenous women found exposing their bodies for a mammogram embarrassing, and they were often encouraged to visit with friends or family members.

"I would be tested if there were groups organised because we need support, we could support one another" (ATSI, under/non screener, 50-66 years, Sydney)

3.4 Relationship between Breast Screening and Other Screening Behaviour

The relationship between breast screening and other types of screening such as cervical and bowel screening appeared to be strong. Most appeared to be aware that the recommended frequency for obtaining a Pap smear was also two years, although the suggested frequency of bowel screening was less certain.

Many of the younger participants (in their 40s and 50s) spoke of times of the year when they made their screening appointments, including health checks at the GP.

Amongst older participants aged in their late 60's and 70's with more chronic health conditions this behaviour was less pronounced because they were simply visiting their GP relatively frequently anyway, so were more reliant on the GP to prompt screening. Some of these participants in this age group indicated that they were no longer obtaining regular Pap smears (even though they had been regular screeners previously) because they felt they had 'had enough' and that the risk was probably very low 'at their age'.

The majority did not know whether or not there was an upper age limit for cervical screening.

4.0 BreastScreen Experiences

4.1 Experience with the BreastScreen facilities

Experiences with the BreastScreen Australia facilities themselves were mixed, with some positive and some negative. For example, BreastScreen facilities in hospitals were often described as like a typical hospital room, and the experience was somewhat impersonal, cold, clean, and clinical. However other facilities were very well regarded, such as those in Myer or David Jones, which were seen as feminine, pleasant, and could be combined with lunch or shopping.

“What you would generally expect from the hospital” (Under screener, 70-74 years, regional Victoria)

Many of the 70-74 year old participants were screening with BreastScreen Australia, and there were no differences in their experiences with the procedure, compared to their younger counterparts. A minority of the 70-74 year olds were also continuing to screen privately.

The BreastScreen vans were generally well received in rural/regional areas – they were viewed as a prompt to attend and the ‘event’ nature of the van coming to town was felt to be an important component in encouraging involvement.

This aspect was supported by BreastScreen staff who mentioned that participation rates in regional areas were often higher than in urban areas – because of the ‘event nature’ of the van and people ‘making a day of it’. This was a particularly strong factor in encouraging the ATSI community to attend.

However, older women who had been initially prompted to screen by the presence of a van in their area, had missed their presence in the last few years, and were more likely to let their screening lapse as they were not getting that tangible reminder.

“Mine was easy; I went to the caravan near the swimming pool” (ATSI, regular screener, 60 years, regional WA)

“OVAHS (Ord Valley Aboriginal Health Service) take me to the BreastScreen clinic” (ATSI, regular screener, 52 years, regional WA)

On the negative side there was often felt to be a lot of women waiting to be screened when the vans visited which was off-putting for some.

“It felt like I was in a production line”. (Under screener, 65-69 years, regional Victoria)

Some were also concerned that the vans were not clinical enough to be able to do an accurate screen.

4.2 Perceptions of BreastScreen staff

The vast majority of women thought that BreastScreen staff were extremely pleasant, helpful and friendly, and that they helped make an otherwise unpleasant experience more bearable.

“Oh the people doing it are lovely” (Under screener, 70-74 years, Adelaide)

A few participants however thought some staff acted like it was just “business as usual” and didn’t go ‘the extra mile’ to make them feel comfortable. They felt they were treated as a number, and rushed through at busy times.

“Perhaps if it’s a free service that’s what you get” (Regular screener, 65-69 years, regional Queensland)

Some ATSI participants commented on the lack of Aboriginal staff assisting them and felt embarrassed by white women touching their breasts.

“A lot of black women don’t want to go to white organisations. People don’t like other people touching their body” (Under/non screener, ATSI, 50-66 years Sydney)

4.3 Perceptions of mammograms and the BreastScreen Process (amongst regular Screeners)

Almost all participants agreed that the process of having a mammogram was painful and uncomfortable, with some finding the pain more intense than others. Some reported very negative experiences which had made them very reluctant to return.

There was a level of real annoyance or frustration about the pain level, with many questioning why it had to be so painful “in this day and age”.

“A man obviously invented that machine” (Under screener, 56-69 years, regional Victoria)

“It’s torture – in the future we’ll look back at this time and be amazed that we put women through it!” (Under screener, 65-69 years, Sydney)

Some also felt like they were treated as if their breasts were unattached to their body, and they were treated without sensitivity.

“My breasts were treated like a piece of meat” (Under screener, 65-69 years, Adelaide)

“I don’t know I think it’s just the way they push them around” (Non screener, 50-64 years, regional Queensland)

“It’s degrading especially if you’ve got flabbier breasts” (Under screener, 70-74 years, Adelaide)

Prior to attending, many spoke of being a little anxious and nervous, and waiting in the waiting room for an extended period of time only heightened these feelings. Participants also dreaded how long they would have to wait for results. Some had heard stories about messages left on answering machines, and some had experienced time periods when they had been waiting and stressing – and then getting an all clear. Once cleared however, there was a great feeling of relief and a sense of real satisfaction that the process had been worth going through.

4.4 Perceptions of Mammograms amongst Non/Under Screeners

Amongst those who had never been for a breast screen, most imagined and had heard from others, that it would be uncomfortable and painful. They imagined that they would feel very anxious and worried.

“I’d feel sick about it” (Non screener, 40-49 years, Sydney)

“I’d take a friend” (Under screener, ATSI, 50-64 years, regional Victoria)

“I’m such a wimp” (Under screener, 65-69 years, Sydney)

Most presumed it would be staffed by females which was a positive aspect.

Some of the non screeners expected that they would find out results at the time – perhaps wait 10-15 minutes and then talk to a staff member/Doctor about the results before leaving. Others had heard that the waiting time was much longer, and that they would feel very anxious waiting for the results.

“It’d be hell waiting longer” (Non screener, 50-64 years, Brisbane)

It was frequently agreed that they would feel very relieved and happy once the process was over.

4.5 Ultrasounds

There were discussions and general confusion regarding the difference between mammograms and ultrasounds, and whether you needed to have both conducted. Some GPs recommended private screening because of the ability to have both performed, and they were promoting it as being a more thorough approach.

Ultrasounds were perceived to be a very appealing alternative to having a mammogram (if they were offered) amongst many research participants as they would be less painful and potentially more accurate. This led some to question why BreastScreen Australia did not offer this service.

4.6 Private screening

Overall, there was a considerably high proportion of participants across the study that had had private screening suggested by their GP, or by friends, although this was more likely reported by the white collar women.

It was also more likely to be suggested to those with breast cancer in the family, those who reported to have 'lumpy breasts' and those aged under 50 years of age.

Participants who had experienced privately run facilities were equally likely to report pain and discomfort as were those who had experienced BreastScreen, and there appeared to be little difference in the actual mammogram process.

Some were of the belief however that private screening, particularly if it involved an ultrasound, was likely to be more thorough in detecting any problems.

5.0 Motivations and Barriers regarding Breast Screening

5.1 Motivations

In an unprompted sense, the main motivations encouraging women to screen were concerning the early detection of cancer, and the provision of peace of mind and relief.

Under screeners acknowledged that screening was a generally positive thing to do in this regard, but for many it lacked urgency. They felt that multiple reminders and prompts were important to help increase the urgency and encourage them to make an appointment, particularly those who were already quite positively disposed to screening, and did intend to screen at some time.

Other key, more immediate, triggers for breast screening were the GP being proactive and pushing the need for screening, and friends or family nagging and/or encouraging them to attend. As mentioned previously, the reminder letter received from BreastScreen Australia was a very important trigger to make women actually telephone and make an appointment.

The notion of being in control was an important underlying motivator for many of the regular screeners. Screening (for cervical cancer, bowel cancer, skin cancer) and general health checks (blood tests, blood pressure, cholesterol) were felt to be important to carry out as recommended, to 'get the tick' that all is under control, and to allow people to move on with their lives.

"It is just the responsible thing to do" (Regular screener, 40-49 years, Sydney)

In this regard, some had a regular time of the year or every two years when they screened, for example, Valentine's Day, birthdays, spring.

Regular screeners also mentioned aspects centred around simply being determined to live as long as possible and enjoy life, now that they had some more freedom, and for some it was important to ensure they would be around for their family and grandchildren. This was supported by the general perception that people are living longer and still live very active, healthy and fulfilling lives into their mature years of life.

"I want to do more travelling and I love gardening and I feel like I can" (Under screener, 70-74 years, Adelaide)

Amongst some ATSI participants there was a feeling that in the greater scheme of things regular screening was a less important issue and a lower priority because of other health concerns and negative lifestyle factors (for example, smoking).

"If I'm putting this (cigarettes) in my body, it defeats the purpose of being screened" (Under/non screener, ATSI, regional Victoria)

5.2 Barriers

There was agreement that an attitude of denial and the general attitude that ‘it’s not going to happen to me’ was a strong barrier to breast screening for many. This was supported by the common perception amongst some of the non-screeners that they felt they were healthy and lived a healthy lifestyle, with no family history of breast cancer and so it was highly unlikely to be a disease that would impact them.

An innate or underlying fear associated with dying and cancer and of aspects such as disfigurement and chemotherapy also prevented some women from participating in mammograms and screening. They would rather not raise the issue into their consciousness, and choose to ignore it rather than face up to screening.

“It’s fear of what they’ll find” (Under/non screener, CALD, 65-74 years, Melbourne)

The discomfort and pain of the mammogram was also mentioned frequently as a barrier to screening or more frequent screening. This was both a perception based on what they had heard from others and a reality for some. In this respect there was discussion surrounding why it was more/less painful for certain people. Many with larger breasts felt it was more painful for them, while those with smaller breasts felt similarly. As mentioned, some had previous negative experiences such as pain, bruising, pulling and tugging.

There were, however, some regular screeners who while agreeing that a mammogram was uncomfortable, did not think it was as bad as they had heard and that it was considerably better than a pap smear.

“They should say ‘mammograms – better than a Pap smear’” (Regular screener, 50-64 years, Adelaide)

Many of the under screeners mentioned that self-checking was sufficient, and a mammogram would only be necessary if they found a lump.

*‘I haven’t had a mammogram before, but if I found a lump myself I’d go to the Doctor’
(Under screener, 50-64 years, Sydney)*

However, few reported that they really were self checking regularly, or that their GPs had conducted breast examinations.

For some, there was a general self-consciousness and embarrassment associated with having a mammogram. Some women (it seemed particularly those overweight or obese) felt self-conscious of their body and embarrassed about revealing it for a mammogram. This was also evident amongst both ATSI and CALD participants. As mentioned, ATSI women frequently talked about being shy and embarrassed by other women (particularly

non-Aboriginal women) viewing and touching their breasts. Arabic women also had concerns in this regard.

“Body image – from our 40s we get out of shape a bit and we don’t want anyone to see us more intimately!” (Under screener, 65-69 years, remote NSW)

Access to services in some locations was a barrier, although it did not emerge as a problem in larger regional centres as the hospitals were able to carry out the service. In smaller areas however, most were happy to wait for the van to come to their town, assuming it did come. In these instances breast screening was totally reliant on the presence of the vans.

Many women of Aboriginal background in the research felt that they would only feel comfortable going to the Aboriginal Medical Service or going through an Aboriginal Health Worker, that is, someone they trusted and ideally somebody who was also Aboriginal. BreastScreen staff mentioned that Indigenous women often visited BreastScreen with friends/family which helped them considerably.

Lack of time was also cited as a reason for not going, with many stating that you needed at least half a day set aside to get a mammogram. Many however also freely admitted that this was very much an excuse for not going as regularly as they perhaps should, particularly those who were retired from work.

Concerns regarding radiation from the mammogram were also raised amongst non and under screeners, and some questioned how many x-rays can be had before it starts impacting health.

There were also some low level concerns about the accuracy of mammograms, with some participants citing instances or stories where friends had been to BreastScreen and been given the all clear, only to find they had breast cancer a short time after. In Adelaide there was mention of a recent re-screening of people because of an error.

Language barriers for the CALD participants also were evident and this was felt to impact their regularity of attending breast screen appointments (and many other appointments).

“I waited for my daughter to arrange a day off so she can take me to the appointment” (Regular screener, CALD (Chinese), 65-74 years, Sydney)

“I need to use my children to get me there and find out the information” (Under/non screener, CALD (Arabic speaking), 50-64 years regional Victoria)

Amongst some CALD participants there was a suggestion that older women within their culture were less concerned about their own health, and focussed more on other family members. There was evidence of this attitude amongst both the Arabic-speaking and Italian participants.

“Arabic women generally care about their families and they don’t care about themselves. If their son or daughter was sick they would run with them to the doctor or hospital and they would never leave them and give them all their time and energy but for themselves they don’t do the same and that is the reality for us women” (Under/non screener, CALD (Arabic-speaking), 50-64 years, regional Victoria)

It must also be noted that for some of the under screeners it was difficult for them to state a reason why they delayed or procrastinated their breast screen visit or did not attend as often as they should. They cited many of the benefits of breast screening and were not opposed to screening, but they simply put it off for a while. In some instances they admitted that they were probably a bit lazy or complacent.

“I got three reminders – I felt awful to be wasting someone’s time and money” (Under screener, 65-69 years, Adelaide)

“Time just goes quicker when you get older, like a toilet paper roll – it goes quicker at the end” (Under screener, 70-74 years, Adelaide)

“I think ‘do I really have to go’ - it’s like a psychological thing- it’s weird” (Under screener, 50-64 years, regional Queensland)

5.3 Key Differences in Motivations and Barriers amongst the Primary Target Audience

Amongst those aged 65-74 years and breast screening regularly the key motivation to continue to screen was so that they can continue to enjoy a long and healthy life, and to remain disease free for as long as possible. These women often expressed the attitude that they were still healthy so why not continue to check for breast cancer and other conditions. Those with more serious health conditions were somewhat less likely to express this attitude towards continuing to screen into their 70s.

While many of the barriers to screening were consistent across this group, for non and under screeners, there were some (who had screened regularly in the past) who indicated that they would not continue to screen into their 70’s because they felt they were probably unlikely to contract the disease. Others also admitted that even if they did have the cancer, the pain and trauma they would have to go through if they sought treatment, would be unbearable, so they felt there was no point in screening. Some also commented that the cancer might be slow growing and that they might die of old age before they died of breast cancer.

6.0 Reactions to the Program Expanding to include 70-74 year olds

Participants were informed that the BreastScreen Australia program is expanding to invite women 70-74 years of age. The following statement was shown to participants, and reactions elicited:

The risk of breast cancer increases with age, that's why the Australian Government is expanding the BreastScreen Australia program to invite women 70-74 years of age.

Initially there were positive reactions to this information because essentially it was seen as a positive step to ensure more women would be able to access the service. It also had the secondary benefit of implying that the Government and society, cares about people as they age.

"It's nice to think that they care enough about people in their 70s...it's good to hear"(Under screener, 65-69 years, Adelaide)

Those aged in their 40s and 50s, reacted positively to the information although most had not realised that it was not offered to this age group previously.

Amongst those who were aware of the previous 'cut-off' age of 69 years or 70 years, this expansion was well received, however in many instances participants became more focussed on the cut off age as opposed to the expansion. Overall there were numerous questions asked about the reasons for the expansion, and the cut off age. As mentioned previously, those aware of the current age limit of 69 years suggested that having any cut off age contradicted the message that the risk of getting breast cancer increases with age. However, this message alerted the women who were previously not aware that there was a cut off, to the fact that there was an upper age limit.

"I didn't know it finished" (Regular screener, 50-64 years, Adelaide)

Some felt that the expansion indicated that the risk of getting the disease ends or decreases considerably after the age of 74 years. This interpretation was also commonly held by CALD participants.

There was also the interpretation of this message to mean that the BreastScreen program would not be available to women after the age of 74, that is, that they would be turned away after 74 years or that it was not free to women above this age. Once it was explained to women that BreastScreen Australia would not turn away anybody, the majority reacted very positively to this news. Indeed the idea the women aged over 74 years would no longer be 'actively invited' or 'receive a reminder letter' was considerably more acceptable than the notion of a 74 years 'cut off' or limit.

The mention of expansion to include the specific age group also appeared to heighten the perception that after 74 years 'nobody' cares or society doesn't care.

In addition, alerting women to this expansion of the program also caused many women to ask questions surrounding the reason for the change and they assumed that perhaps there had been an increasing number of cases of breast cancer being picked up in women aged 70-74 years.

“Oh they’re finding cancer in 70 year olds as well!” (Regular screener, 70-74 years, Adelaide)

For some the perceived suggestion that they were finding cancer amongst more women in their 70s prompted them to feel that they needed to continue breast screening, when they had been considering not doing so.

“It makes me think you’ve got to keep checking” (Under screener, 70-74 years, regional Queensland)

Alternatively it was thought that perhaps people are living longer, and that they are relatively healthy (compared to previous generations) so it is therefore becoming more worthwhile to be able to identify a lump and have treatment on it.

There were also some that questioned the exact age of 74 years as for them it seemed like a ‘strange’ number because it did not mean many more screens would be conducted.

“It only means another two screens’. (Regular screener, 50-64 years, Sydney)

Amongst those in the primary target (65-74 years), likelihood to continue screening after 70 years was mixed. Some regular screeners thought they would continue to screen, especially now that they would be reminded, and they felt healthy enough to cope with treatments available. While others felt that they probably wouldn’t bother to screen after 70 years anyway, because as mentioned, they thought they were unlikely to have breast cancer at this stage in life or they felt that even if they did have breast cancer it was unlikely they’d have treatment on it as they might die of old age before they died of breast cancer. Those with less chronic or serious health issues were more likely to suggest that they would continue to keep screening after 70 years of age, while others felt that screening for a cancer they might get was less of a priority.

“I’ve decided I’m not having anymore... when I’m 70 (later this year) I’m not worrying anymore... If they haven’t found it now they probably won’t” (Under screener, 65-69 years, Adelaide)

7.0 Reactions amongst GPs and BreastScreen Staff

7.1 GP reactions

Many GPs indicated that most women do not proactively ask about breast screening unless prompted by finding a lump, or unless they have lumpy breasts and have difficulty determining lumps, or unless they have a friend with cancer or breast cancer in the family.

GPs reported that they were unlikely to be asked questions about the process of breast screening such as the pain or discomfort of a mammogram, or radiation concerns.

Some GPs were however clearly proactive in this regard and claimed to refer all their women patients from the age of 50 years onwards to either BreastScreen Australia or private health clinics. A few also reported sending women from 40 years of age, although this was mainly to private screening clinics. BreastScreen Australia was suggested to these women only if they had asked about it.

Most of the GPs interviewed felt that they were relatively knowledgeable about the BreastScreen services, and the location of the services. Some had the BreastScreening notepads which they used occasionally.

The barriers to breast screening observed by the GPs amongst their women patients tended to match those mentioned by women themselves.

Most GP's were in favour of the expansion of the program to include 70-74 year olds, but were generally uncertain as to the exact reasons for the expansion. In that regard they felt it would be good to have access to a fact sheet or explanation of the reasons for the change, so that they could discuss the reasons with women if they were asked about it.

ATSI Community Health Professionals agreed that breast cancer was not as common as cancers such as lung cancer and bowel cancer in the ATSI community. They claimed to alert women to the dates when the van was in town and encourage patients to make an appointment. They stressed that it is very important to tell women about breast cancer and other types of cancers because older aboriginal women generally don't ask a lot of questions themselves. The physical presence of the van in town was thought to be an important prompt to screen, as was other women encouraging them to go and attending with their friends and/or relatives.

With low literacy rates in the ATSI community, health professionals also feared that many women did not read their reminder letters from BreastScreen Australia, especially the older women. In that respect, they doubted that the expansion of the program to invite 70-74 year old women would have any major impact on aboriginal women's attendance behaviour.

7.2 The views of BreastScreen staff

The BreastScreen staff consulted in the research included a mix of Nurse Counsellors, Promotions and Education Managers, radiographers and Program Managers.

They projected a very passionate approach to their work and appeared knowledgeable about the barriers and motivations to breast screening. They were generally in favour of the expansion, although some had similar questions to the women regarding aspects such as the reasons for the expansion. The list of concerns and questions amongst the BreastScreen staff were similar to those raised by consumers.

Staff also mentioned the need for access to information which they could use to answer questions from women regarding the differences between ultrasounds and mammograms, what 'thermography' is and how implants affect the screening process.

The staff were very aware of the discomfort of mammograms that women felt and many had strategies to address this, as much as possible. They emphasised however that screening staff were often very busy and needed to get through many clients in a day, so can't always give women the amount of attention they require.

Many of the BreastScreen staff anticipated that many women will be pleased by the expansion of the program but will question the cut off age and that it will draw people's attention to this aspect of the program.

Most felt it was a good idea because they had feedback previously from women aged over 70 years who had felt 'left out' by the program. Some States has a separate brochure addressing this message and which informed women that they would no longer receive a reminder letter after the age of 69 years.

Some also questioned whether or not they will they have certain goals or targets to meet in terms of achieving a certain number of women screening between 70-74 years, and that there will be a flow on effect to call centre staff, staffing etc, which will need to be managed carefully because they are already very stressed and busy.

There were also questions about finding a lump in an older woman and having to advise the woman of that and that they should participate in further testing. Some felt that this will unnecessarily impact on the quality of life of some women (when the cancer may be slow growing, and the women may die of another cause well prior to the breast cancer having an impact.

Some suggested that there may be the potential for Practice Nurses to take on more of a role in reminding women to screen regularly, rather than leaving it up to the GP.

While most of the BreastScreen jurisdictions appeared to have their own pamphlets with Q&As and websites with a great deal of detailed information, BreastScreen staff indicated

there was the need for information about the reasons for the expansion and how best to communicate why there was an upper limit of 74 years.

7.0 Reactions to Key Messages

A number of key messages addressing some of the motivations and barriers to breast screening were shown to participants and reactions elicited.

7.1 Reactions to a message addressing Incidence of breast cancer

1 in 8 women will develop breast cancer in their lifetime

Amongst those regularly screening this statement confirmed the prevalence of breast cancer and the need to screen regularly. It also caused an emotional reaction amongst these women.

Some were surprised that it was that low. Some had cited 1 in 4 earlier in the discussion so for them so this statistic created the opposite effect, that is, it caused surprise that the number was lower than they thought.

“Oh it’s not as bad as I thought” (Under screener, 70-74 years, Sydney)

There were many who agreed that this approach was trying to ‘shock’ or scare women, and there were mixed reactions to this ‘scare tactics’ strategy. Some thought it was a very negative message and not motivational to them personally, and that statistics were not personal and ‘not me’. Women in their 60s and 70s in particular, did not believe that ‘scary’ statistics motivated them to get a breast screen (or any type of health check), and that they were ‘growing tired’ of this approach. Others (mainly younger participants) rationalised that ‘we’ occasionally need to be shocked to ‘cut through all the ‘clutter of our busy lives’ to get us to get up and do something about it’.

“It makes me think that I’ll be one of the ones that will miss out...for some reason” (Under screener, 40-49 years, Sydney)

Overall this statement was not seen as a positive emotional message and the intended ‘fear’ seemed unlikely to motivate the non and under screeners to attend. It was however reinforcing the importance of checking for breast cancer amongst the regular screeners.

This message seemed unlikely to prompt any action amongst CALD and ATSI participants. Some ATSI participants were reminded of the anti-smoking campaigns and anti-drinking campaigns of the past, which they were generally cynical towards.

7.2 Reactions to messages addressing early detection:

With early detection, 9 out of 10 women will still be alive 5 years after a breast cancer diagnosis – getting a free mammogram every two years is the most effective way to detect breast cancer early.

The earlier breast cancer is detected, the more treatment options you may have.

The concept or sentiment of breast screening to gain early detection was well received – and a strong motivator amongst the regular screeners, and potentially the under screeners. It also gained positive reactions amongst ATSI and CALD participants, with many indicating that this was new information.

There were some language issues such as the notion of still *being alive 5 years after a breast cancer diagnosis* which was less appealing and motivational and considered quite *‘doom and gloom’*.

It made some participants think about quality of life and cancer treatments and whether they’d be alive in 6 years, and why they had chosen 5 years as the marker. So while the intent was a positive aspect – often this statement was taken quite negatively,

The statement mentioning the free aspect was well received and an important reminder of this benefit.

The notion of *‘more treatment options’* was not immediately understood – some women often had to have this one explained to them by other group members, and some dismissed it on the basis of *‘it depends on the type of cancer’*.

Overall however the early detection benefit is a very strong motivator to attend a BreastScreen service regularly.

7.3 Reactions to messages regarding mammograms

Mammograms can detect breast cancer before you can feel it

There were positive reactions to this statement, however it was interpreted in two ways: Firstly, that you will not know you have breast cancer (no pain, sickness, etc) and secondly, that you won’t feel a lump (self-check).

When interpreted the first way, most were aware that you cannot feel pain or any sickness associated with breast cancer – participants cited numerous stories of people they knew who did not know or feel they had breast cancer, so amongst these women the statement reinforced this. Although some non-screeners felt they would instinctively know if their body was sick so they rejected the statement. This attitude was mainly amongst those with a more natural or non invasive attitude to health and well being.

"I know my body and I know when something is wrong with it" (Under screener, 65-69 years, Sydney)

For those who interpreted 'feel it' as feel a lump, there were mixed reactions. Some agreed that it would be hard to feel a lump and others thought they would feel it, as they knew what their breasts felt like. Amongst this latter group this statement did work at challenging this perception.

So overall this statement put some doubt into the minds of the self-diagnosis segment.

Women who have breast cancer detected through mammograms are less likely to have a mastectomy

This message was confronting to those who were fearful of having a mastectomy as it presented a very negative outcome.

The message was clearly impactful – evident by many questioning whether this was in fact true.

Upon consideration, it was felt to be realistic because if the cancer or lump is detected earlier then you would be able to try alternatives before a mastectomy was necessary.

Clearly the fear of having a mastectomy was very strong amongst participants, however some of the older participants (in their 70s) in particular felt fear of cancer was a more powerful and effective message than fear of a mastectomy. Younger participants (aged under 60 years) perceived a mastectomy as a symbol of taking away their femininity, while older women had a somewhat more pragmatic attitude toward mastectomies. There was also some ATSI and CALD participants who appeared to be more motivated by fear of breast cancer than fear of a mastectomy.

Overall while emotionally powerful it was viewed as a negative message and did not encourage or motivate participants, but potentially deterred them from thinking about it.

Mammograms are safe, while they may be momentarily uncomfortable, attending regular mammograms could save your life

This message raised concern amongst many group members, with some wondering if mammograms were in fact, unsafe. This then prompted discussion of the effects of radiation from an x-ray, however it was more of a secondary concern as far as mammograms were concerned.

Addressing the discomfort of mammograms in communication was met with mixed reactions. Many felt it was best not to raise or bring up mammograms and admit they were uncomfortable, because it raised a negative and made them think about that aspect more. Non and under screeners within the ATSI and CALD communities also made negative comments regarding mammograms in response to this statement.

“If they’re saying it’s uncomfortable – imagine how painful it is” (Non screener, 40-49 years, Sydney)

Others thought it was good to address the fear and have a reality check that it’s a small negative for a potentially huge reward. For the non and under screeners this raised the negative and reinforced this barrier.

Overall this statement gives a reason for not going, it was not felt to be motivational and not recommended to address in communications terms.

7.4 Reactions to messages about risk increasing with age

It’s not just about family history, getting older is the biggest risk factor for breast cancer.

Getting older is the biggest risk factor in developing breast cancer.

The family history association with breast cancer was well known, however amongst those with no history it was also felt to be a common excuse or justification for not breast screening as often as they should. Therefore amongst this segment this statement challenged their perceptions to some extent. However again there were some who felt that raising the subject almost helped put the excuse forefront in their minds again.

The notion of getting older being the biggest risk factor was known by many, but it was also met with scepticism amongst this target group. Many women in their 60s and 70’s questioned just how old ‘older’ was, and if this was the case why was there a cut off age for breast screening at all.

‘Getting older’ being the biggest risk factor raised debate and discussion surrounding the notion that all diseases and cancers increase with age, and that it was because we are living longer.

“That’s the case for all cancers isn’t it?” (Under screener, 40-49 years, Brisbane)

“I thought once you reached a certain age the risk dropped off” (Regular screener, 40-49 years, Sydney)

Furthermore, many simply did not believe that getting older was the biggest risk factor because they had seen and heard about so many young women getting breast cancer, and the incidence of breast cancer appeared to have increased, while people always get older. This attitude was common across all age groups, with many of the older women agreeing that they never used to hear much about breast cancer when they were younger, in younger women or older women, so they felt that there must be more to it than simply getting older.

8.0 Communication Channels

8.1 Current Sources of Information for Health Issues

With regard to information sources used by women regarding general health related issues and breast cancer specifically, there was mention of radio and specifically listening to guest speakers and GPs on the radio, brochures obtained from their GP, listening to the various television morning shows and 'Googling' the specific health issue and seeing what comes up.

Active seeking of health information was most likely to be carried out by asking their GP, picking up a brochure at the surgery, 'Googling' a symptom or remedy, or asking a friend or relative who they knew had experienced the same health issue. Examples of situations when this would occur were when their GP mentioned a term or condition they had not heard of, and/or they wanted to learn more about it, and if a friend or relative had been diagnosed with some condition and they wanted to learn more about it. They also occasionally searched symptoms they or their family experienced, to gain an 'educated guess' of a diagnosis, prior to seeing their GP.

There were few who could cite specific websites that they used for health information, with the exception of "The Mayo Clinic" website and "any that end with '.gov.au'". This was consistent across age groups and screening behaviour. Some of the older (aged 60 years and over) women mentioned that the internet advice was dangerous and that it was not advisable to trust websites regarding their health.

"They don't say real stuff on the internet about health problems" (Non screener, 65-69 years regional Victoria)

8.2 Online Behaviour amongst the Primary Target Audience

Participants aged 65-74 years appeared to have quite simple online activity. While most claimed to use the internet, their main usage needs were sending and receiving simple emails (often with photographs attached), conducting simple "Google" searches or visiting well known sites for shopping, travel, maps/directions. Social activity and visiting social media sites such as 'facebook' were less common. The majority also claimed to have mobile phones and Smartphones. Texting was something they felt comfortable doing and some had 'Apps' (Smartphone applications).

Those aged 40-64 years appeared to be more regular users of the internet per se, with social media used much more frequently. The internet was their primary source of information, using it for online shopping, emails, sharing and communicating with friends and relatives. Almost all claimed to have a Smartphone and were frequently sending and receiving text messages, viewing apps, playing games on their phones and searching the internet on their phones.

8.3 Suggested Channels for Communicating the Expansion Message

Participants were asked their opinions regarding how they believe the Government could best communicate messages to encourage women to breast screen. While most women initially suggested a television campaign, upon greater consideration there was also mention of the following channels:

- placing advertising on radio stations that older people listen to;
- placing advertising and information on Government websites;
- posters in GP surgeries (rather than brochures);
- sending a brochure in the mail from BreastScreen Australia;
- advertisements on the backs of public toilet doors;
- advertising in mainstream magazines targeting older women,
- sending an SMS/text message to remind women that they were due for a breast screen;
- sending an email;
- booking on-line; and,
- having access to an App which could remind them about key breast screen appointments (and other screening dates).

There extent to which these suggestions for communication channels differed by age group and screener type was minimal. Women aged in their 40s and 50s were generally more likely to suggest text messages, apps, websites and on-line bookings, however channels such as radio, GP surgeries, brochures were mentioned across most of the group discussions, amongst regular screeners, non and under screeners.

9.0 Key Communication Development Implications

We would suggest the primary target for the communication would best be defined as the under screeners, because non screeners will be an extremely difficult group to convince and the regular screeners are converted and really require reminders and reinforcement only. While some regular screeners aged over 70 years will continue to screen, there are some who will not. These women may need to be reassured that it is worthwhile to detect a lump early because women at their age are living longer and women are able to cope with the relatively less invasive treatments available.

Those who wish to continue screening for breast cancer will need to be made aware that they are able to continue to screen over the age of 70, and the key reasons why it is advantageous for them. The reminder letters will continue to play an important role in prompting them to make an appointment, and may be an effective way of explaining some of the reasons why the program has been expanded. Other reminder methods such as emails, text messages and an 'App' may also be effective for regular screeners across all age groups.

Amongst under screeners across all ages, strong motivators or positive reasons to breast screen tested well in this study, as opposed to negative 'fear tactics'.

Overall the indications from the research suggest there is a need to:

1. Communicate the positive aspects of breast screening and present motivations to attend BreastScreen Australia, and
2. To downplay the more negative, more confronting aspects, as these can act as implicit demotivators.

Some of the potential strong positives or motivators that tested well in this research include the following:

- early detection – that is, identifying a lump early so that you can live a longer life and so that treatments are less severe and more options are available; and that mammograms can detect lumps that you cannot.
- reinforcing the access to free screening every 2 years,
- being 'in control' of your health and having responsibility for yourself, and
- recommended for women 50 years and over.

There is also however a need for a further layer of more rational information and detail to clarify misperceptions and provide detail about the program, incorporating FAQs that include the following information:

- that all women will receive a letter of invitation at 50 years,
- clarifying the different purposes of a mammogram versus an ultrasound, and
- stating that mammograms can detect a lump before you can.

In terms of communicating the message regarding the expansion of the program to include 70-74 year olds, drawing attention to the expansion will be sensitive and has the potential to raise questions and unnecessarily draw attention to the notion that there is a cut off age. Having said that, there is a need to communicate the change to women who are within or approaching this age bracket because it is a favourable change, while continuing to reinforce the benefits of breast screening at any age. We would suggest that a mass media campaign be adopted because the targets are not active seekers of health information so they may not learn of the expansion on their own. If television is not feasible for the campaign because of budget reasons, radio and print advertising would be appropriate for the following reasons:

- The target audience frequently listen to the radio during the day and at night. It is a trusted and familiar medium and content on 'talk back' style radio stations is paid attention to rather than simply being background music or noise.
- Print advertising in newspapers and magazines are also likely be seen and read by the target and print have the potential to include more detailed messages targeting those regular screeners aged 70-74 years, informing them that they will still be invited to BreastScreen as the program has been expanded to 74 years. Similarly for posters displayed in doctor's surgeries and community health centres.

While the primary targets are not avid internet users, online content would have a role in the campaign, through simple advertisements on websites and sharable content through emails. The secondary targets will be more likely to view online communications messages and younger family members of women in the primary target who could alert them to the expansion via emails or content shared with their mother, for example, to encourage them to continue screening. As mentioned, text messages and 'Apps' also appear to have potential to be effective ways of communicating with both the primary and secondary target audiences.

In communicating the expansion message to a wider audience (both primary and secondary target audiences) we would suggest that the main message or headline message be focussed more on extending the program to 'over 70 year old women' rather than 70-74 year old women. A secondary message, perhaps within the copy, would then need to be included to inform them that after 74 years, they would not receive a reminder letter, but they are still welcome to attend, or to consult their doctor after this age. Further information may also need to be included to explain the reasons for the change and dispel any potential concerns, for example, *with more women living longer lives, we've expanded the program*. This level of detailed information could be provided online or within the reminder letter.

There is also a potential need for factsheet for BreastScreening staff and GPs outlining the key reasons and benefits of the expansion and how to explain the changes to the program to their patients, for example, based on new research.

For the ATSI community – the AMS and Aboriginal Health Professionals will be key in communicating changes and prompting women to attend the clinic or BreastScreen van regularly. The suggestion of attending with friends or other family members would also be a strong message to communicate to this target group.

For the CALD community, brochures and materials in own language with visuals would need to be provided, and again the suggestion of attending with friends or other family members may help encourage more regular visitation and allay any fears they may have regarding the procedure of having a mammogram. This ‘peer group’ aspect may also help reduce the potential for procrastination.

Summary of Communication by target group

Target	Message	Communication channel
Primary: (65-69 years and 70-74 years)	<p>Same message for all targets:</p> <ul style="list-style-type: none"> - Early detection, and - BreastScreen Australia are expanding the program to include women aged over 70 years. <p>Secondary message - 70-74 years will now be invited. After 74 years you are still welcome but consult your doctor.</p> <p>Further detailed messaging to explain the reasons for the change and dispel any potential concerns, for example, <i>with more women living longer lives, we’ve expanded the program</i></p>	<p>Radio, print and simple on-line ads and sharable emails.</p> <p>Text messages and an app for reminders.</p>
Secondary: (40-49 and 50-64 years)	The message for this target group was the same as for the Primary target group (ages 65-74 years).	Radio, print and online advertising, but also more ‘sophisticated’ online content such as films, interactive content.
CALD audiences	The message for this target group was the same as for the Primary target group (ages 65-74 years).	Same as above except more materials in own language. Online amongst other younger female family members may have strong potential.
ATSI audiences	The message for this target group was the same as for the Primary	As above, as well as continued support to community health

Target	Message	Communication channel
	target group (ages 65-74 years).	professionals via factsheets, simple visual materials and hand outs.
Health Professionals	The message for this target group was the same as for the Primary target group (ages 65-74 years).	Factsheets. Online materials on website.

Appendix:
A: Topic Guides and B: Recruitment Screeners

APPENDIX A: TOPIC GUIDES

TOPIC GUIDE – BREAST SCREENING - CONSUMERS

INTRODUCTION

Put everyone at ease, explain that this is a study being done by the Australian government to ensure they understand women's health needs and the issues, and to ensure they can offer the right sort of support where needed.

Reassure everyone that it is an open discussion, all comments welcome, definitely no right or wrong answers, that we believe everyone has the right to decide what is best for themselves, and we don't have a view on that one way or another.

Also let them know that they have been grouped together with people who have relatively similar attitudes, so they can feel very open about saying how they feel at any time.

Tell the group members that they can feel free to let us know if they are uncomfortable in any way, and to get up and go to the loo etc.

Also inform them that people might be viewing, and that we will be recording for our purposes only.

GROUP INTRODUCTION

- o First of all we might just go round the room for each of you to briefly tell us a little bit about yourselves

GENERAL KNOWLEDGE AND ATTITUDES TOWARDS HEALTH ISSUES

- o Thinking now about health generally, what sort of health issues do you feel are confronting you these days? What are some health issues that are affecting other women you know/your age?
- o And where does cancer fit within this? Have you thought much about it in the past? What has prompted you to think about it in the past? Are there any sorts of cancer in particular that might be more or less likely to affect women you know/of your age?
- o Do you know what cancer screening programs are available in Australia?
- o (IF NOT MENTIONED PROMPT) What about breast cancer in particular, is that something you ever think about? When and why? What about cervical and bowel cancer?

TOP OF MIND ASSOCIATIONS

- o We are going to be mostly talking about breast screening and other related issues, so let's just have a quick five minute sharing of the first five words that come in to you head when you think of mammograms and breast screening. Regardless of whether you know much about it, or the amount of experience you've had with it... shout it out and we will scribble them on here (write on butcher's paper, don't allow time to think

or discuss at this stage).

That's great... we might come back to some of those later!

AWARENESS AND KNOWLEDGE

- Thinking about the number of women who get breast cancer, what do you know about this? Has anyone heard of any figures?
- Do you think there are certain people who are typically more prone to breast cancer? PROBE. Any certain ages or lifestyles? What about family history? People's size? Diet? Alcohol? Any other aspects?
- Do you know of others who have had breast cancer? Has this caused you to do anything as a result of this information?
- To what extent do you feel you are personally at risk of breast cancer? Why/why not? In reality, do you think it is likely? Why/why not? INSIGHT TEST SHOW CARD 'Although she knew there was a risk for all women, Jane felt she was unlikely to get breast cancer' Why do you think Jane felt this way, why did she feel unlikely....what is it about Jane that caused her to feel this?

ROLE OF HEALTH PROFESSIONALS

- Roughly how often do you see a GP or doctor for yourself? Would it just be if you had a specific issue, or do you have regular check-ups?
- Does your GP or health professional ever talk to you about cancer and recommend or remind you to get screened for breast, cervical or bowel cancer at all? Have they ever talked to you about breast cancer and mammograms? What have they told you? Where have they suggested you screen? What have they told you about BreastScreen vs others.
- **(IF YES)** Do you find this useful? Has this ever prompted you to get a breast screen?
- Do you want GPs or health professionals to tell you more about breast screening? What sort of questions would you ask?

OTHER CAMPAIGNS/ACTIVITY

- Have you heard much publicity or advertising about breast screening? What have you seen or heard?
- Does anything particularly stick in your head from what you have seen or heard?
- Has any of it prompted you to think about screening? For those lapsed or never attended – has it encouraged them to attend for breast screening?
- Any particular facts or figures stick in your mind? PROBE for any effective facts or figures?
- Where would you go to for information on breast screening?

FREQUENCY...

- So when it comes to breast screening, what have you heard about how often women should be doing this? Have you been told/ heard different things?

- Have you heard anything about the age at which women are recommended to start getting screened? Or the age that they can stop?
- If I told you the recommended frequency was every two years for women aged 50-74 years, what would you think?
- PROBE PARTICULARLY FOR AWARENESS/REACTIONS AMONGST THOSE AGED 70-74...Are they aware of any changes, how do they feel about it being recommended for them?
- Do you think this frequency is necessary? Do you think there is value in doing it this frequently?

ASK ALL: SCREENING MOTIVATORS

- Some women do have mammograms regularly and some don't, what sort of women do you think are more likely to have them?
- What do you think encourages them to go along? What do they feel or think about it? How do they feel after having one?
- (OVER 50s) Have you ever received a BreastScreen invitation letter or a reminder letter? How did you feel about that? How often do you think they should be sent? SHOW EXAMPLE
- What do you do when you receive a letter? Do you put it somewhere for later, make an appointment straight away, just throw it away....
- 70-74 YEAR OLDS...In the past, letters have not been sent to women aged 70-74, but now they are going to be sent these letters. How do you feel about that, do you think it will encourage you to go, how will you react to that, what questions would you ask about it?
- Would it make you concerned in any way, or would you see it as a good thing?
- SHOW CARDS: These are some things women who have mammograms feel have encouraged them...to what extent did/would these things encourage you?
 - It is better to get an early warning if you are at risk of cancer
 - They give you peace of mind that you don't have cancer
 - It is better to put up with a mammogram than get cancer
 - It is important to be in control about your health
 - They help me feel confident that I will be around for my family and to see them grow.
 - They are generally really accurate in detecting early cancer
 - If you pick it up early there is a higher chance of survival
 - PROBE Any other things?

BARRIERS (ASK ALL)

- Why do you think people put off ever having mammograms or going back when they are meant to?
- What about you, what puts you off/discourages you? PROBE (e.g. IF "NOT ENOUGH TIME" MENTIONED - Why? is it not a convenient location to go? Not that important?, other things more pressing? ...Use Laddering...e.g. What if you had a lot more time, do you think you would have them when you are meant to, or would there be other reasons why not, what would these be etc.

- SHOW CARDS and explore: These are some things other people like yourselves have told us put them off having a mammogramto what extent, if at all, do you feel they influence you and why?
 - Pain and unpleasantness
 - Embarrassment
 - My health is just not that important compared to the needs of my family
 - Screening doesn't always work
 - Too hard to get there ...
 - They can be wrong
 - I do not have a high risk of breast cancer
 - I can feel for lumps myself
 - It is not something women from my cultural or religious background do
 - PROBE Any others?
- In terms of getting to screening services, do you feel you know where you could go, and what your options are?
- Would you know where to go within your local area? Do you feel this is an issue at all? Would you be confident that your local area would have the appropriate facilities?
- Do you know if it is free, who it is free for?
- Any other barriers? Why (else) wouldn't people have one? What (else) would cause you to have one?

INSIGHT TESTS

- Show insight material relevant to age - explore any other potential motivators/barriers to screening
- 'Carol was 55 and had never had a mammogram. When she got a letter suggesting she have one she just threw it away' Why did she do this, what was her reaction to it, how did she feel about it?
- 'Jenna got a reminder letter about having another mammogram but she just didn't get round to making an appointment' Why was this, was she reluctant to do it, or were there other things that got in the way/discouraged her?
- 'Aisha is in her early sixties and has mammograms every couple of years' what prompts her to do this, how does she feel about having them?
- 'Bev was in her early seventies and had assumed she didn't need to screen any more, but she received an invitation to screen'how did she feel about that? What did she do?

ACTUAL (REGULAR AND INFREQUENT) AND (NEVERS) PERCEIVED EXPERIENCE

ACTUAL EXPERIENCE

- Have you ever had a mammogram? Did you have symptoms at the time? Do you know if was with BSA or with a private service?

- Thinking about the last time you got a breast screen, what prompted you to go along? What encouraged you to think about it initially, what was the final prompt or trigger that made you make an appointment? Probe for letters, reminders, advertising, friend or family diagnosis etc,
- Have you done screening for anything else? Cervical cancer? Bowel cancer? Etc. How often? Do you feel differently about any of these compared to breast screening? How/why?
- Screening behaviour: Do you book in for breast screening and pap smears around the same time? Why / why not?
- How did/do you feel before going in to get a breast screen? What are all the thoughts going through your mind, is it a stressful time or is it just another check-up , why,
- What about during? (Probe fully for all aspects of the experience...) tell me what it is like and how you are feeling from the time you think about making an appointment through to the time you turn up, the process, the service, the surroundings etc.
- And afterwards? Firstly before you know the results and then when you find out the results ... how are you feeling at that time?
- How do you feel about going back? Why is that?
- If appropriate, refer back to the 'top of mind' words- what made them say these words?
- Overall how effective do you think mammograms are? Do you think they're worth doing?
- Do you talk about breast screening much with friends or family? Or is it something that's private and not really talked about?

NEVER SCREENED: PERCEPTIONS OF THE EXPERIENCE

- What do you think having a mammogram would be like?
- what have you heard about it?
- What do you imagine will happen?
- What thoughts would be going through your head if you were going to have one? Would you be worried or nervous about anything? What? What sort of questions would you ask about it?
- What sort of reassurances would you need about the process?
- Why do you think you have never been for a mammogram?
- If appropriate, refer back to the 'top of mind' words- what made them say these words?
- Overall how effective do you think mammograms are? Do you think they're worth doing at all?
- Do you talk about breast screening much with friends or family? Or is it something that's private and not really talked about?
- Have you done screening for anything else? Cervical cancer? Bowel cancer? Etc. How often? How would breast screening compare to that?

BREASTSCREEN VS PRIVATE PROVIDER EXPERIENCE

- Thinking about your previous experience/s, did you get a breast screen through BreastScreen or was it with a private provider? Has anyone had a screen with both, or heard different things?
- What have you heard about the differences?
- What made you choose BreastScreen /the private provider?

COMMUNICATION CHANNELS

- If a campaign was developed to try and encourage breast screening, how do you think they could best communicate these messages to people like you? (. TV, radio, print, and social & electronic media)
- PROBE: If tv isn't an option, what would be the best way to do this?
- PROBE: If advertising isn't an option, how would you want the information to be promoted to you?
- PROBE: If they say "brochure from a GP waiting room", ask how many of you have picked up brochures in GP waiting rooms and read them?
- Are there any websites, programs, publications you think you would go to, or have gone to, for information concerning screening? Which ones, which ones do you trust?

If anyone would like any further information regarding Breast cancer or screening please visit or call.....

Breast Screening:

- National phone line: 13 20 50
- www.cancerscreening.gov.au
- 'BreastScreen and You' – consumer information resource available at cancerscreening.gov.au

Breast Cancer:

- *Cancer Australia: www.canceraustralia.gov.au*

TOPIC GUIDE – BREAST SCREENING – HEALTH PROFESSIONALS

INTRODUCTION

Explain that this is a study being done by the Australian Government to ensure they understand women's health needs and the issues, and to ensure they can offer the right sort of support where needed to women and to health professionals.

It is important to include the views of health professionals who have 'hands on' experience with women concerning their health.

Reassure that their comments will be confidential and will not be revealed to the Department.

BACKGROUND TO THEIR ROLE AND INVOLVEMENT;

- Clarify what their role is / where they work
- Understanding of how they discuss cancer and cancer screening with patients, when the subject arises;
- Is there any relationship between discussions about breast cervical and bowel screening. Is it reviewed at the same time or driven specifically?
- What about specifically for breast cancer, do they ever suggest screening/when and why?
- Do they see the suggestion for screening as a part of their role/ What they see as their role in the encouragement of screening, and providing of advice; where does it fit within the consultation process?
- What sort of patients do they suggest it to...only those with a family history, all women, women of a certain age, only those who ask etc?
- Are there instances when they might recommend private screening rather than BreastScreen, why, why not?

THEIR OBSERVATIONS/UNDERSTANDING OF THE BELIEFS AND ATTITUDES OF THE TARGET AUDIENCES THAT THEY COME IN CONTACT WITH;

- Do they have a feeling about how the women they see feel about screening and mammograms?
- Are they asked questions about it, what sort of questions are asked?
- What sort of knowledge levels do women have, do they know a lot, a little?
- Are there any misperceptions they come across/misunderstandings and beliefs/cultural sensitivities; how do they deal with these?
- What do they see as the main barriers their patients have toward screening?
- What about motivators, what encourages women to screen, do the health professionals try to 'push' screening at all, why/why not, what sort of role do they play?
- Do they ever get questioned about the accuracy of screening? What do they tell women about this?
- Do patients tend to ask about screening after receiving a reminder, do they ever comment on the reminders, are they seen as usual?

- Do patients talk about their experiences in screening, what do they say? Do they ask questions about it? What sort of things do they ask? Probe for whether this is private or BSA.

WHAT SOURCES, TOOLS AND RESOURCES HEALTH PROFESSIONALS USE CURRENTLY AND WHAT (OTHER) RESOURCES WOULD BE USEFUL

- What resources and tools do the health professionals use currently to provide advice to women about screening (generally & then specifically for breast screening), what works well, what is not of much use (brochures, information leaflets, websites?)
- Are there any websites they would go to, or have gone to, for information concerning screening? Which ones, which ones do they trust?
- What (other) resources and tools would the health professionals like to have to assist them in their role in encouraging participation in the program in future, for themselves, and to give to patients?
- What are the key pieces of information that should be in material the health professionals use themselves to advise their patients/ what other aspects about breast cancer, the process, the benefits of screening etc? What value do health professionals perceive there is in producing a resource that addresses all cancer screening programs for women?
- And what should be in information that could be provided to patients?
- Are there particular tools or resources they have used in other areas that have worked well, which could be adapted for breast screening?
- Are they aware of where the BreastScreen facilities are, do they get advice about when the van is coming; is location an issue in the area, are they accessible?

CAMPAIGN DEVELOPMENT

- Have they heard much publicity or advertising about breast screening? What have they seen or heard?
- Any pieces in campaigns or other publicity they think has worked well/not so well.
- What do they see as the key elements required in a campaign for women regarding screening, and what they feel should be avoided; reactions to potential messages and statistics from the health professionals perspective?

ATTITUDES TOWARD THE EXPANSION OF THE INVITATION AGE GROUP,

- Are they aware of this?
- How do they perceive this will be received, and what impact this will have on their role and information needs?
- What sort of reaction would they expect from their patients of this age?
- Do you think this frequency is necessary for those aged 70-74? Do you think there is value in doing it this frequently?
- Do they need specific information about the expansion, what form should it take, what would be most useful?
- What are their opinions of the BSA program?

Any other comments?

Thanks and Close

TOPIC GUIDE – BREAST SCREENING – BRESTSCREENING STAFF

INTRODUCTION

Explain that this is a study being done by the Department of Health regarding some potential changes to breast screening and that is important to include the views of BreastScreen health professionals who have ‘hands on’ experience with women with regard to breast screening.

Reassure that their comments will be confidential and will not be revealed to the Department.

BACKGROUND TO THEIR ROLE AND INVOLVEMENT;

- What is their role within the organisation?
- How long have they been working in the area?

THEIR OBSERVATIONS/UNDERSTANDING OF THE BELIEFS AND ATTITUDES OF THE TARGET AUDIENCES THAT THEY COME IN CONTACT WITH;

- Do they have a feeling about how the women they see feel about screening and mammograms?
- Are they asked questions about it, what sort of questions are asked?
- What sort of knowledge levels do women have, do they know a lot, a little,
- Are there any misperceptions they come across/misunderstandings and beliefs/cultural sensitivities; how do they deal with these
- What do they see as the main barriers their patients have toward screening;
- What about motivators, what encourages women to screen in the first place, did their GP ‘push’ screening at all, did they get a reminder, ask to be screened,
- Do they ever get questioned about the accuracy of screening? What do they tell women about this;
- Do patients worry about the experience, what do they say? Do they ask questions about it? What sort of things do they ask?
- What sort of information do women ask for? What would the need?

SOURCES, TOOLS AND RESOURCES USEED CURRENTLY AND WHAT (OTHER) RESOURCES WOULD BE USEFUL

- What resources and tools do they use currently to provide advice to women about screening, what works well, what is not of much use (brochures, information leaflets, websites)
- Are there any websites they suggest for information concerning screening? Which ones, which ones do they trust?
- What (other) resources and tools would they like to have to assist them in their role in encouraging participation in the program in future, to give to patients;

- What are the key pieces of information that should be in material the health professionals use themselves to advise their patients/ what other aspects about breast cancer, the process, the benefits of screening etc?
- Are they aware of where the BreastScreen facilities are, do they get advice about when the van is coming; is location an issue in the area, are they accessible;

CAMPAIGN DEVELOPMENT

- What publicity or advertising do you recall about breast screening?
- Any pieces in campaigns or other publicity they think worked well/not so well;
- What do they see as the key elements required in a campaign for women regarding screening, and what they feel should be avoided;
- Reactions to potential messages and statistics from a BreastScreen health professionals' perspective;

ATTITUDES TOWARD THE EXPANSION OF THE INVITATION AGE GROUP,

- Awareness of the expansion of the invitation age group to include 70-74 yr olds.
- Opinions/reactions to the change – what will be the positive and negative aspects
- How do they perceive this will be received by women/their patients
- What impact this will have on their role if any?
- What sort of reaction would they expect from their patients in this age group?
- Do they think this frequency is necessary for those aged 70-74? Is value in doing it this frequently?
- Do they need specific information about the expansion, what form should it take, what would be most useful?

Any other comments?

Thank and Close

APPENDIX B: Recruitment Screener

Recruitment Screener

(FEMALES ONLY)

S1. Do you work in the health industry or in advertising or market research?

Yes 1 **TERMIINATE**
No 2

S2. Which of the following age categories do you fit in to?

Under 18 years **TERMINATE**
18- 25 years
25-39 years
40-49 years
50-69 years
70+ years **TERMINATE**

S3. Could I just ask if you have had a breast cancer diagnosis in the last 5 years?

Yes – **TERMINATE**
No – **CONTINUE**

ASK ALL

S4. Which best describes the last time you had any of the following.....”?

	Within the past 12 months	1 to 2 years ago	More than 2 year ago	Never
Pap smear for Cervical cancer screening	1	2	3	4
Blood pressure check for high blood pressure	1	2	3	4
Bone density screening for Osteoporosis	1	2	3	4
Mammogram for Breast cancer	1	2	3	4
Blood test for diabetes	1	2	3	4

Statement to base recruitment – Breast screen via mammogram

No, never had one (code 4)

In the last two years (code 1 and 2)

1- Eligible as a ‘**Non-Screeners**’

2- Eligible as a ‘**Regular Screener**’

Not in the last two years/a while ago (code 3) 3- Eligible as an **'Under Screener'**
 Don't know/refused 5- **TERMINATE**

S5. FOR METRO GROUPS ONLY: CHECK SOCIO ECONOMIC STATUS: CHECK UPPER, MID AND LOW QUOTAS.

a) What is the highest level of education you have completed?

- Primary school 1
- Year 10 or below 2
- Year 11 or below 3
- Year 12 or below 4
- Trade/apprenticeship 5
- Other TAFE/Technical Certificate 6
- Diploma 7
- Bachelor Degree 8
- Post-Graduate Degree 9
- Other (Specify) _____ 10
- Refused 11

b) What is your current employment status? Are you ...

- Employed full-time 1
- Employed part-time 2
- Unemployed 3
- Retired or on a pension 4
- A full-time student 5
- Engaged in home duties 6
- Other (Specify) _____ 7
- Refused (DO NOT OFFER) 8

c) What is the occupation of the main income earner in the household? **PROBE FOR TITLE AND MAIN DUTIES. CHECK CODING – SEE CLASSIFICATION BELOW**

Title _____

Duties _____

Recruit for 'Low' socio-economic group if the participant is in upper or lower blue-collar occupations, without tertiary qualifications, and as 'Mid' socio-economic group if in lower white-collar occupations, or in blue collar occupations with Tertiary qualifications. 'Upper' SES are those in upper white collar or professional occupations.

S6. Which of the following best describes your current marital status?

- Never married 1
- Defacto or living together 2
- Married 3 **Ensure good cross section**
- Separated/divorced/widowed 4
- Refused (DO NOT READ OUT) 5