2. BACKGROUND TO THE RESEARCH

2.1 OVERVIEW

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

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

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

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

5 Wills (2003), cited in Lin et. al (2007) 'Public Health Practice in Australia' p. 369
6 Blue Moon (2006), 'BreastScreen Australia Communication Needs'
7 NSW Health (2000) 'Report on the 1997 and 1998 NSW Health Surveys'

for diagnostic mammograms with a doctor's referral on the basis of family history or suspicion of breast cancer. Research and anecdotal evidence suggest that women may not always know which type of service they have used.

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

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

2.2 THE NEED FOR RESEARCH

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

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

3. OBJECTIVES

3.1 EVALUATION QUESTIONS

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

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

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

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

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

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

8 Evaluation questions may be addressed in full or in part by an individual project.
9 The focus for this research is on women's understanding of the risks and benefits of screening.

3.2 OVERALL QUALITATIVE RESEARCH OBJECTIVES

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

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

The overall objectives among health professionals were to explore:

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

3.3 LITERATURE REVIEW OBJECTIVES

A limited literature review was conducted to explore existing knowledge and data that was expected to be of assistance in answering the evaluation questions. The review was limited in focus, as there were constraints due to available time and budget. Rather than attempting a full academic exploration of all issues, the review sought to identify key themes, insights, information gaps and hypotheses that could be tested in the subsequent Participation Qualitative Research. To ensure continuity with the qualitative research, the focus of the review was further limited to studies where the perspectives of women in the target audience on the identified research objectives were discussed.

Specific objectives were to identify from the literature reviewed:

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

3.4 DETAILED RESEARCH OBJECTIVES

The process of developing objectives

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

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

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

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

Factors that facilitate and discourage participation

To explore among women:

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

10 Each evaluation project is 'sponsored' by up to four members of the EAC. The sponsor role included active involvement in the development of the project and input at key decision points.

- which barriers *lapsed* and *never* screeners relate to:
  - having a mammogram;
  - participating in screening mammography;
  - the service provided by BreastScreen Australia;
- how far 'pain' or 'discomfort' is a primary barrier for *lapsed* and *never* screener and what is being done to mitigate this;
- how women who have been diagnosed with interval cancers feel about screening and BreastScreen Australia as a result of their experiences; and
- how all of these issues differ by sub-populations.

To explore among health professionals:

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

The perceived availability and accessibility of the Program

To explore among women and health professionals:

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

The perceived acceptability of the Program

To explore among women:

- broad levels of satisfaction with the Program across Australia and among different sub-populations;
- the impact of perceptions of the service on re-screening;
- the extent to which physical and emotional discomfort are perceived to be minimised within the Program;
- how women who have been recalled for further tests and / or treatment feel about how this was handled;

- how women who have been diagnosed with interval cancers feel about the Program;
- the extent to which the service is, or is expected to be, acceptable to women with disabilities; and
- who influences expectations and perceptions of the acceptability of the service.

To explore among health professionals:

- perceptions of the Program from their perspective; and
- what patients / clients say to them about the Program.

Factors that lead to women choosing screening mammography outside the Program

To explore among women:

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

To explore among health professionals:

- referral practices of GPs, including exploring referral to private providers; and
- health professionals' perceptions of private services compared with BreastScreen Australia services.

The impact of BreastScreen Australia communication activities

To explore among women:

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

To explore among health professionals:

- how they feel about the way in which BreastScreen Australia communicates with them;
- whether they have any other communication needs; and
- how they feel about the information they are provided with from BreastScreen Australia on recalled patients.

Women's understanding of the risks and benefits of screening

To explore among women:

- perceived risk factors for breast cancer;
- perceptions of the prevalence of breast cancer in Australia; and
- perceived benefits and risks of breast cancer screening;

To explore health professionals' experiences of women's perception of:

- the risk factors for breast cancer; and
- the benefits and risks of breast cancer screening.

The extent to which women make an 'informed choice'

To explore among women:

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

To explore among health professionals:

- knowledge of the 'informed choice' debate and how they feel about this in relation to breast screening; and
- views on the specific issues in the informed choice debate:
  - potential for uncovering illness that would not have progressed;
  - potential for creating unnecessary anxiety over recalls for further tests when cancer is not diagnosed; and
  - potential for interval cancers to occur between screening and the implications of this.

4. LITERATURE REVIEW METHODOLOGY

4.1 APPROACH TO SOURCING DATA

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

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

4.2 APPROACH TO DATA MINING

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

4.3 ANALYSIS

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

5. QUALITATIVE RESEARCH METHODOLOGY

5.1 OVERVIEW

The methodology, including the sample and discussion content, evolved following the literature review and discussions with members of the Department and BreastScreen Australia Program Managers. A program of 19 'standard size' groups, 13 'mini groups'[11] and 16 in-depth telephone interviews were conducted in total. These represented the target audiences identified in the brief:

1. Target and eligible women, aged 40 and over:

- from all jurisdictions, including metropolitan, regional, rural and remote areas;
- from Indigenous communities and non-English speaking backgrounds;
- who are regular screeners (*regular*[12]), lapsed screeners (*lapsed*) and women who had never screened (*never*);
- who have been recalled for further assessment of a screen detected abnormality on a subsequent day to the original screen and were not subsequently diagnosed with breast cancer (*recalled*);
- who have been recalled for further assessment, were diagnosed with breast cancer as a result of screening and have been treated (*diagnosed and treated*);
- who have been diagnosed with breast cancer in-between two-yearly screening events (*interval cancers*); and
- who had disabilities that might present access barriers to screening.

2. Health Professionals:

- general practitioners (GPs);
- Aboriginal health workers;
- breast physicians[13]; and
- nurse counsellors.

5.2 RATIONALE FOR THE METHODOLOGY

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

11 Standard groups comprised approximately eight participants and mini-groups approximately four.
12 Refer to glossary for the project definition of these groups of women.
13 Breast physicians are registered medical practitioners with training in the diagnosis and management of benign and malignant breast disease.

Group discussions with general practitioners were conducted as this is a highly cost and time efficient, approach. Individual in-depth interviews were conducted in situations where these were more efficient for the following reasons: because of the location of respondents; in situations where it would have been difficult to gather respondents together; and where there was a need to explore views of people with specific roles in the breast screening process individually, such as with breast physicians and nurse counsellors.

5.3 THE SAMPLE

The sample was as follows:

Table 1: Group discussions among target and eligible women

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

14 Only two respondents attended this group so it was supplemented with telephone in-depth interviews with women living in Melbourne.

Table 2: Groups discussions among women from non-English speaking backgrounds and Indigenous communities

GP	Segment	Screening history	Group size	Age	SES	Location	State
18	Chinese (in Mandarin)	Lapsed / never	Standard-group	50-69	Mix	Sydney	NSW
19	Lebanese (in Arabic)					Sydney	NSW
20	Iraqi (in Arabic)					Melbourne	VIC
21	Vietnamese (in Vietnamese)					Brisbane	QLD
22	Greek (in Greek)					Melbourne	VIC
23	Indigenous women (in English with assistance from local bi-lingual moderators)	Regular / lapsed		50-69	Mix	Ceduna	SA
24		Lapsed / never		50-69		Port Augusta	SA
25		Regular		50-69		Sydney	NSW
26		Lapsed / never		50-69		Perth	WA

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

DTH	Segment	Screening history	Age	SES	State
1	General population	Lapsed / never	50-59	Lower	WA
2			60-69	Higher	QLD

Table 4: Mini-Group discussions with General Practitioners

GP	Profession	Location	State
M1	General practitioners	St. Leonards	NSW
M2		Hobart	TAS
M3		Canberra	ACT
M4		Perth	WA
M5		Darwin	NT
M6		Maroochydore	QLD

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

DTH	PROFESSION	LOCATION	STATE
D1	Breast physicians	Regional	NSW
D2		Metro	QLD
D3	Aboriginal health workers	Remote	NT
D4		Metro	QLD
D5	Nurse counsellors	Metro	QLD
D6		Metro (with regional coverage)	WA

Table 6: Interviews with women who have experienced interval cancers

DTH	Last screening service used	Interview type	Location	State
D1	BreastScreen Australia	Individual face to face	Metro	NSW
D2			Metro	NSW
D3		Individual telephone	Metro	WA
D4			Regional	WA
D5			Metro	VIC
D6			Regional	VIC
D7	Private radiology service	Paired depth interview	Metro	NSW
D8				

5.4 SAMPLE DETAIL

Target and eligible women

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

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

Regular screeners' groups were recruited as follows:

- none had ever been diagnosed with breast cancer;
- all had had a mammogram for screening rather than diagnostic[15] purposes in the last two years;
- a mix of women who had screened through BreastScreen Australia and private services were recruited in each group (section 5.8); and
- at least one woman who had a self-reported family history of breast cancer was included in each group.

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

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

15 as reported by women

- a mix of BreastScreen Australia and private service users were included among *lapsed* respondents, with a skew towards BreastScreen Australia users; and
- as far as possible, at least one of the *lapsed* screeners in each group had used private services.

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

- all had had a mammogram for screening rather than diagnostic purposes through BreastScreen Australia;
- all had been asked to come back for further tests on another day because of suspected breast abnormalities (not because of problems with the x-ray, as far as they were aware);
- all had been assessed by BreastScreen Australia when they were recalled for further tests; and
- none had been diagnosed with breast cancer.

Diagnosed and treated groups were recruited as follows:

- all had had a mammogram for screening rather than diagnostic purposes through BreastScreen Australia and had been diagnosed with breast cancer in the course of the process;
- all had been treated for breast cancer; and
- none were still in treatment for breast cancer.

Interval cancer groups were recruited as follows:

- all had been screened through BreastScreen Australia at least once in the past and all were over 40 years old;
- all had been diagnosed with breast cancer within two years of their last screening mammogram, at which they had been given an 'all clear' result; and
- women came from a mix of socio-economic backgrounds.

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

- ethnic / language groups were selected based on Australian Bureau of Statistics data from 2006, as well as literature review findings (section 6.2);
- criteria were the same as for the main sample; and
- groups with women from non-English speaking backgrounds were conducted in their language spoken at home, by bi-lingual moderators.

Groups with Indigenous communities were recruited as follows:

- criteria were the same as for the main sample; and
- groups with Indigenous women were conducted in English with the assistance of local Indigenous women who were able to translate any terms that respondents were not familiar with.

Women with disabilities were recruited as follows:

- all had one or more impairment(s) that could make going for a mammogram difficult, based on Australian Bureau of Statistics disability variables[16] and women's own judgements about this;
- the following disabilities were represented among the five women in the sample:
  - severe multiple sclerosis and quadriplegia;
  - blindness (10% vision) and depression;
  - chronic fatigue syndrome / fibromyalgia;
  - spinal damage following an accident and chronic fatigue syndrome; and
  - mobility problems due to post polio syndrome.
- all had had an impairment since before the age of 50 to avoid including women who were experiencing typical symptoms of ageing as these women were represented in the sample more broadly;
- one had never screened, two were *lapsed* screeners and two were *regular* screeners;
- all were aged 50-69; and
- all *regular* screeners had used BreastScreen Australia services in the past.

Health professionals

General practitioner groups included a mix in terms of:

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

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

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

Nurse counsellors were recruited through BreastScreen Australia services.

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

16 ABS 1200.0.55.001 - Disability Variables, 2006 Retrieved from http://www.abs.gov.au

5.5 TIMING OF FIELDWORK

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

5.6 LOCATIONS

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

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

5.7 RECRUITMENT OF RESPONDENTS

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

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

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

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

5.8 NOTE ON RECALLED GROUPS

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

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

5.9 NOTE ON IDENTIFYING BREASTSCREEN AUSTRALIA AND PRIVATE SCREENERS

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

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

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

5.10 GROUP SIZE AND DURATION

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

5.11 DISCUSSION COVERAGE

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

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

5.12 STIMULUS

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

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

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

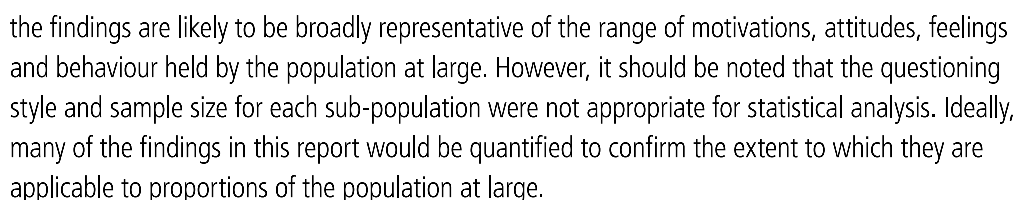
5.13 PROJECT AND ANALYSIS APPROACH

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

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

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

Qualitative research was conducted to allow for the in-depth exploration of motivations, attitudes, feelings and behaviour. The findings were interpretive in nature, and analysis was based on the researchers' experience and expertise in this type of research. As with all qualitative research,



the findings are likely to be broadly representative of the range of motivations, attitudes, feelings and behaviour held by the population at large. However, it should be noted that the questioning style and sample size for each sub-population were not appropriate for statistical analysis. Ideally, many of the findings in this report would be quantified to confirm the extent to which they are applicable to proportions of the population at large.

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

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

17 Gordon, W (1999) *Goodthinking: A Guide to Qualitative Research*, Admap, UK
Mariampolski, H (2001) Qualitative Market Research. A Comprehensive Guide, Sage, London pp. 255-6.
Donovan, R & Henley, N (2003) *Social Marketing Principles & Practice*, IP Communications Melbourne p. 122.
Hawe, P, Degelig D & Hall, J (2004) *Evaluating Health Promotion*, Maclennan+Petty, Sydney pp. 148-150