

# "A Natural Progression": Australian Women's Attitudes About an Individualized Breast Screening Model



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## Abstract

Individualized screening is our logical next step to improve population breast cancer screening in Australia. To explore breast screening participants' views of the current program in Victoria, Australia, examine their openness to change, and attitudes toward an individualized screening model, this qualitative work was performed from a population-based breast screening cohort. This work was designed to inform the development of a decision aid to facilitate women's decisions about participating in individualized screening, and to elicit Australian consumer perspectives on the international movement toward individualized breast screening. A total of 52 women participated in one of four focus groups, and were experienced with screening with 90% of participants having had more than three mammograms. Focus group discussion was facilitated following three main themes: (i) experience of breast screening; (ii) breast

cancer risk perception, and (iii) views on individualized screening. Participants had strong, positive, emotional ties to breast screening in its current structure but were supportive, with some reservations, of the idea of individualized screening. There was good understanding about the factors contributing to personalized risk and a wide range of opinions about the inclusion of genetic testing with genetic testing being considered a foreign and evolving domain. Individualized breast screening that takes account of risk factors such as mammographic density, lifestyle, and genetic factors would be acceptable to a population of women who are invested in the current system. The communication and implementation of a new program would be critical to its acceptance and potential success. Reservations may be had in regards to uptake of genetic testing, motivations behind the change, and management of the women allocated to a lower risk category.

## Introduction

Population breast screening commenced in Australia in the 1990's and since then, women ages 50–74 years have been actively invited to undertake biennial bilateral mammography. The Australian model of population-based mammography screening is similar to that adopted in many countries and most, but not all, studies have credited it to the significant reduction in breast cancer mortality

over this time (1–3). It has not been without controversy. In particular, concerns regarding overdiagnosis and subsequent overtreatment, and the harms associated with false positive recalls for assessment lead some to call for an overhaul of the system or abandoning population mammographic screening programs (4–9). In addition, the reduced sensitivity of mammography in those with high-mammographic density has led to question the role of supplementary screening in this group (10, 11).

There is a growing interest in risk-stratified population breast screening (9, 12–17), due to the robust evidence of the skewed distribution of breast cancer risk in the population (18). For example, based on polygenic risk estimates, women in the highest centile have an estimated absolute lifetime risk of developing breast cancer by the age of 80 of 33% compared with only 3% for women in the lowest risk centile (19). Personal breast cancer risk can be quantified according to endogenous, lifestyle, and environmental risk factors (12). Endogenous factors, such as genetic information, mammographic density, and proliferative breast disease are strong predictors of breast cancer risk and can be incorporated into prediction models (18).

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Although the high- and moderate-risk genes, such as *BRCA1*, *BRCA2*, *TP53*, *STK11*, *PTEN*, *CDH1*, *ATM*, *PALB2*, and *CHEK2* are clinically important, they affect only a small proportion of the population. More recent research has demonstrated the potential of using common SNPs in predicting breast cancer risk at the population level (20). This information regarding personal risk has not as yet been incorporated in to population screening programs (21).

Risk stratification involves combining the various elements of risk and allocating each individual into a discrete category of risk with each group offered a different screening modality and frequency. For example, an individual calculated to be lower than average risk could be allocated to reduced intensity of screening. Tailoring risk information to an individual can increase the likelihood of a preventative intervention being adopted (22). In a computational model, a risk-stratified screening program was more effective in terms of reducing interval cancers and false positive screens than the existing system based only on age and gender (23). International studies undertaken in United States (13), United Kingdom (24), and the Netherlands (25) have demonstrated acceptability of risk-stratified screening programs, however Australian women's attitudes are unknown.

Prior to modifying the current population-based breast screening program to a personalized risk-stratified approach, it is important to determine whether this would be acceptable to the target population, and whether they would have any concerns or unmet needs when considering the adoption of such a program. This study aims to examine the acceptability of an individualized mammographic screening model and attitudes toward adopting such a program with women who are engaged with the current population-based breast screening program in Australia.

## Materials and Methods

### Setting for study: LifePool

LifePool is a cohort of women attending population-based mammographic screening in the State of Victoria, Australia, with over 54,000 participants currently enrolled. Over 50% of participants have consented to the donation of germline DNA for the purposes of genetic testing. LifePool participants who expressed interest in future studies were invited to participate in this qualitative study. This study was conducted in accordance with the Declaration of Helsinki and approval was granted by the Peter MacCallum Cancer Centre Human Research Ethics Committee (protocol number 17\_194L). All participants provided written consent prior to taking part in a focus group.

### Recruitment

Invitations were emailed in batches of initially 20 and then 60 to partake in a focus group located within a 20-km radius of their home address. LifePool participants were

randomly selected on the basis of their postcode and stratified by age. Women were not eligible if they had a previous breast cancer diagnosis, significant comorbidities, or non-English speaking (due to lack of interpreting services). There were 12,500 participants within the LifePool cohort who fit these criteria. Batches of emails were sent until the maximum number of 12 participants per group was reached.

### Focus groups

Four focus groups were conducted in local community centers at different suburban locations in and around Melbourne, Victoria. A focus group discussion guide (Appendix A – focus group discussion guide) was developed by the authors and used to facilitate each group. The discussion guide consisted of three topics, examining: personal experiences of breast screening, breast cancer risk perception, and individualized breast screening. Before individualized screening was discussed, a brief presentation was given. This covered the rationale behind the proposed change, an explanation of the known risk, and protective factors, as well as, the skewed distribution of risk.

A potential program of individual screening was then introduced with possible screening frequency and modality variations for different risk groups. This potential program comprised of higher risk women having more frequent mammography with the potential for additional imaging modalities (e.g., ultrasound or MRI) and lower risk women undertaking mammography less frequently. We assumed women in the moderate-risk group would remain with the current regime of bilateral mammography biennially.

### Data collection and analysis

Qualitative data were collected using focus groups, which were audio recorded and transcribed verbatim. The transcripts were checked for accuracy and participants deidentified with numbers within their respective focus groups as unique identifiers. Coding was initially performed by J. Lippey, however then each transcript was read and reread by three authors (J. Lippey, L.A. Keogh, and L.E. Forrest) who independently coded the data to enable the identification of ideas, concepts, categories, and themes. An inductive approach to thematic analysis (26) was performed to ensure the codes were data driven. Saturation was defined as per grounded theory as the point in which no new codes were arising from the data (27), and was deemed to have been reached as this occurred after analysis of the first two focus groups. During analysis of the third and fourth focus group transcripts, repetition was noted of previously stated views without emergence of new data. The coding was used to develop a coding framework (Table 1) that included three main themes and a number of subthemes. NVivo12 was used to manage the transcript data.

**Table 1.** Coding framework

Theme	Subtheme
Values around breast screening	Beliefs about breast screening Practical/experiential issues Understanding of issues Conflicting advice False positives Missed cancers Overdiagnosis
Risk perception	Individual risk Risk factors Causation Myths
Individualized screening	Fears and reservations Genetic testing Impression of concept

## Results

### Participant characteristics

A total of 52 women participated in four focus groups, which took between 80 and 90 minutes each. Although we aimed for 12 women in each group, as invitations were sent in batches of 20 and then 60, the groups varied in number of participants from 11 to 15. Table 2 summarizes the participant demographics.

### Attitudes and values toward the current breast screening model

**Strong emotional connection with a sense of being "cared for" by breast screening.** Throughout all four focus groups, women repeatedly expressed strong feelings that by undergoing breast screening they were being looked after. It appeared this impression of being cared for came from the programs' reputation, staff, and organizational strength coupled with the emotional relief when the "all clear" letter arrived. They expressed feelings of being valued and respected during most components of the screening

**Table 2.** Participant demographics

	n	%
Age	61 (range 48–72)	SD 5.18
Education		
Did not complete high school	3	5.8
High school	7	13.5
Trade/apprentice/certificate/diploma	22	42.3
University education	20	38.5
Postcode IRSAD <sup>a</sup> quintiles (1, least advantaged; 5, most advantaged)		
1	0	0
2	2	3.8
3	9	17.3
4	28	52.8
5	10	19.2
Missing	3	5.8
Mammography experience		
Never had a mammogram	0	0
1–3 mammograms	5	9.6
>3 mammograms	47	90.4
Undergone genetic testing?		
Yes	5	9.6
No	45	86.5
Missing	2	3.8

<sup>a</sup>IRSAD, Index of relative socio-economic advantage and disadvantage.

process. There was acknowledgement of the physical discomfort of the test, however this was strongly overshadowed by the reassurance and attention they felt from the process:

"... because there's such a high percentage of women who develop breast cancer... it's nice to know that someone's looking after us" (Participant 3, Focus group 2)

**Appreciation of the current breast screening program.** Participants were overwhelmingly appreciative of the current breast screening program, especially regarding the practical and financial aspects. Every group discussion mentioned their gratitude of the lack of out of pocket costs for breast screening. Furthermore, the logistical processes employed by the program, reminder letters, booking appointments online, timeliness and efficiency of appointments, and staff professionalism and kindness, were noted and valued by every group.

"We're very lucky in Australia... the fact that it exists and, um, it's free and they send you a reminder letter every two years... you don't have to make much effort really on your part" (Participant 10, Focus group 2)

### Experiences of false positives detected by breast screening

**False positives did not deter women from future screening.** The participants who reported being recalled after their initial mammogram for further investigations but had been ultimately cleared for breast cancer. This experience of being recalled for further investigations was described as a stressful event, although ultimately the event reaffirmed their faith in the program. This presumably is due to the relief of being cancer free, affirming their trust in the program to detect breast cancer before symptoms are apparent. None of these women reported this as causing reluctance to attend for further screens.

"I had a recall saying... they did a number of other investigations and then... the specialist came out at the end and said it's fine, you're okay. So that was concerning in that period. But no, it didn't stop me from wanting to continue to get checked. I'm just grateful that there's this system in place..." (Participant 6, Focus group 3)

**Unaware and unalarmed of overdiagnosis.** None of the participants instigated discussion of the issue of overdiagnosis of breast cancer of their own accord. Instead, overdiagnosis was raised by the facilitators in the last two focus groups in a specific attempt to ascertain participants' awareness. The participants were not aware of

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overdiagnosis being an issue for breast screening. However, participants were aware of this as an issue with prostate cancer. There was very little diversity on opinion regarding overdiagnosis.

"I guess I assumed that if there was a lump in my breast, it's actually going to be aggressive, and it's diagnosed so therefore needs treatment. I hadn't really thought about degrees of aggressiveness . . . Whereas I know with . . . prostate . . . there's been a huge debate about over treatment and so on. But I've just been delightfully ignorant of degrees with breast cancer." (Participant 1, Focus group 4)

Following an explanation about overdiagnosis for breast cancer, participants did not express any alarm or concern about having surgery and/or medical treatment for a breast malignancy that would not impact on their life expectancy. Instead, many participants were adamant that if there was any kind of breast cancer detected on screening they would want it removed or treated.

"I'd prefer to be over diagnosed than under diagnosed" (Participant 8, Focus group 4)

"If I was told I had a cancer. . . I imagine I'd think, I don't care what sort of cancer it is, I want it out" (Participant 13, Focus group 4)

### Individualized screening presentation

A 10 minute presentation was given at this juncture in the focus groups covering the rationale behind an individualized approach, an explanation of risk and protective factors, and a potential program protocol with variation of frequency and modality of screening for different risk groups explained. Genetic testing was mentioned during the presentation with a brief explanation of the different genetic alterations relating to breast cancer risk including both mutation and SNP testing.

### Attitudes toward individualized breast screening

*Acceptance of concept and place in BreastScreen.* Women, even although they may have been previously unaware of the notion of individualized screening, when explained to them, understood the concept of multiple risk factors contributing to individualized risk and that this could be used to individualize breast screening. There was an appreciation, this could have advantages over the current system by detecting some cancers earlier.

"I'd be happy with a personalized plan. I probably feel more confident with it" (Participant 8, Focus group 4)

"(in regards to numerous risk factors)...but I've never heard that before. I thought family history was a huge component. But you're saying it's one of many" (Participant 2, Focus group 4)

Most participants agreed BreastScreen would be an appropriate place for individualized breast screening to take place.

"We already have the confidence in BreastScreen. Then it just seems like a natural progression that they're then saying to us, OK, this has worked so far, this is our next step." (Participant 1, Focus group 3)

*Reassessment of risk.* After discussion of several factors which contribute to breast cancer risk, many women expressed concern about change in some risk factors and highlighted the nonstatic nature of some of the variables. For example, women identified that their lifestyle factors, such as body mass index, alcohol, or exercise, may change significantly over a 5-year period. Many women expressed a preference for their risk to be reassessed at regular time points in the program, rather than just a one-off assessment on entry to the program.

"..your family history would change quite possibly as your parents get older and brothers and sisters. . . a lot of things that would be changing like exposure to hormones where you might end up going on HRT but ten years ago you weren't. . .there's a lot of stuff that would need to be readdressed. . .on a regular type basis" (Participant 12, Focus group 2)

### Reservations about individualized screening

*Importance of comprehensive communication and education.* Women were cognizant about how important it would be to communicate any change to the current model of breast screening clearly and concisely to the target population and that education would be a vital component to the process.

"So does that mean maybe an education process? Not just a testing process, and filling in a form and having a little chat, but an education process, so you understand all of those factors better. . .because you've had it all explained to you" (Participant 4, Focus group 3)

*Suspicion about motivation for change to the current model of screening.* In each group there was at least 1 participant who expressed concern about the motivation for this potential change with suspicion that the change was being driven to save money at the cost of individual health.

"We're so used to...hearing the politicians going on about the money and we're going to do this because it's better for you...It's got nothing to do with the money. Which we all know is not true" (Participant 6, Focus group 2)

**Concern about losing the low-risk participants.** There was some reservation around classifying some women as low risk. This may be an issue with nomenclature; however, it bore out in each discussion the same concern about women losing vigilance around screening if labeled as low risk.

"I just think that when you put somebody into a low risk, um, there's not as much attention on those people and people can slip through the system" (Participant 6, Focus group 2)

#### Attitudes toward genetic testing

**Diverse range of attitudes about incorporating genetic testing into screening.** The opinions about genetic testing varied from excitement and optimism to uncertainty and distrust. Despite this diversity of opinion, a common thread was that genetic testing was considered an incomplete, unknown, or future science rather than technology and information that are understood with present day utility.

In regards to genetic testing: "It's quite a foreign thing, I think for most" (Participant 15, Focus group 2)

"I think genetic testing's the way of the future for medicine" (Participant 8, Focus group 1)

**Genetics not being a panacea.** There was concern about the overemphasis on genetics within the risk algorithm and apprehension that the more commonly accepted risk factors, such as family history, would be overlooked.

"Too much emphasis on genetics. Really it's only called for if there's an obvious family lineage in my opinion. And even then, you'd probably just confirm what you already know" (Participant 9, Focus group 2)

"Genetics isn't predestination" (Participant 1, Focus group 1)

**Reservations about discrimination due to genetic testing.** At least 1 participant in each focus group spontaneously raised the issue of genetic testing impacting on life and income protection insurance, in regards to increased premiums or obtaining coverage. The participants knowledgeable about this issue explained to the group and generated a diverse range of opinions from shock to nonchalance.

"Feel the insurance system needs a bit of a shake up...I don't think they should have access to it [genetic information]" (Participant 5, Focus group 1)

"If the implication was you can still get insurance it would just cost you more, I'm all for it, I'm not bothered" (Participant 7, Focus group 2)

**Distrust about data security of genetic information.** There was concern from a few women that genetic information could be used inappropriately and this could be an issue with population level testing. This echoed the distrust about genetic testing as an unknown or foreign concept.

"Don't you also have to be careful where that information of your genetic test could be used or sent elsewhere? Because haven't there been cases in America where people were convicted on their DNA when actually they weren't actually there at the robbery and things like that?" (Participant 10, Focus group 2)

#### Perceptions about changing the screening frequency

**Concerns about having screening at 5-year intervals.** Very few participants were accepting of a 5-year mammographic screening interval for women stratified into a low breast cancer risk group. This may relate to women having faith in the current screening interval, the worry of "missing out," and the concern of an interval cancer. These findings were in keeping with the initial sentiment of being looked after by the program and it is understandable women would be reluctant about losing that sense of care.

"I'd be put on a low risk I'm sure of it and if I was asked to...do five years I'd be really uncomfortable and I'd probably...after two to three I would...have it privately which is really unfair". (Participant 2, Focus group 1)

Those women who were accepting of a 5-year interval still wanted some form of reassurance during that 5-year gap.

"Well because my doctor also does the checking of the breasts when I go in for certain activities...I...would be fine with the five years". (Participant 6, Focus group 3)

**Three-year interval.** More women would accept a 3-year interval for the low-risk group however this was not universal.

"Three <years>...I've done..three years in the past...three years would be fine". (Participant 2, Focus group 1)

**Maintaining the status quo of current screening frequency.**

There was discussion around keeping the low-risk group screening at the current program of every 2 years and women appeared more accepting of this idea. This may represent a sense of rejection from a program which has worked at delivering inclusiveness and a sense of being valued as a client or may be related to it being the norm. Alternatively, it may suggest that women have come to expect the sense of reassurance provided by a normal mammogram every 2 years, and to remove this reassurance could increase anxiety.

"Say you were put in the low risk category and you weren't screened every two years. I would probably feel, oh, I would actually like to continue to be screened every two years even though I'm low risk" (Participant 6, Focus group 2)

Participants appreciated they were coming to this opinion from their past experiences and that women who were yet to enter the breast screening program may feel differently about being allocated a less frequent program.

"We're all been the same era. Where as we've done it every two years for the last fifteen, twenty years. Today's society probably accept the five year gap" (Participant 9, Focus group 1)

**Contrast with recent change to cervical screening.** Each group raised the point that cervical screening in Australia has recently changed, so women who are human papilloma-virus negative now only require a pap smear every 5 years. This was acknowledged by each group about how contradictory their response was to a potential change in mammographic screening.

"I don't know what I'd do. Like, I was recently told I didn't need a pap smear for five years, and I just skipped out of the clinic" (Participant 5, Focus group 4)

**Discussion**

This study provides unique evidence to the acceptability of a risk-stratified approach to population breast screening in Australia. It demonstrates women are interested in understanding the numerous risk factors contributing to individual breast cancer risk and has provided novel insight to women's attitudes about genetic testing in an asymptomatic population-based cohort.

Within this cohort of women there was great appreciation of the publicly funded breast screening service. They agreed in principle that individualized screening on the basis of personal risk made sense, however they did not identify with concerns about false positive or overdiagnosis, and there were concerns and reservations about chang-

ing the status quo. These findings of false negatives are in contrast to the literature, which often reports persisting levels of anxiety up to 6 months after being recalled but cleared of breast cancer (28).

There was reluctance for decreasing the frequency of screening within our cohort. This is understandable within this cohort of women who have come to rely on the screening program to reassure them they do not have breast cancer at regular intervals. There was concern that women allocated to a lower risk group may cease screening altogether and this risk would need to be managed in a new system. Women had a strong trust in the current system, and they saw it as a signal of the government's investment in their health. A willingness to change is critical for the success of a new program (29). Women who have not had experiences of the current system may view risk-stratified screening differently and assessing this would be important. If women started screening with a different program they may be more likely to accept it.

Women noted that their response to the increase in cervical screening intervals ("skipped out of the clinic") was in stark contrast with their anxiety about such a long interval between mammograms. This could be explained by either the social and physical discomfort associated with pap smears or the invasive nature of the procedure (although the discomfort of a mammogram was discussed as well) or more likely is related to the relative salience of cervical and breast cancer. Most of the participants know somebody who has had breast cancer whereas they do not perceive their risk of cervical cancer to be as high.

The views on genetic testing as part of population screening were a novel component of our work. We noted a spectrum of responses from excitement to reluctance and a consistent mention of the possible negative financial implications of such testing. The discourse in this topic ranged from too much emphasis being placed on genetics, which was also highlighted in a study from the Netherlands addressing a similar topic (25) to optimistic excitement of the possibilities. It appeared that genetic testing would be acceptable to some but not all women in our cohort. Work done in the United Kingdom around risk-stratified breast screening through the Predicting Risk at Breast Cancer Screening (PROCAS) program, which lay the foundation for risk stratified screening in the United Kingdom, also found overall but not universal acceptability to genetic testing (30). Another interesting finding from PROCAS around genetic testing was for women who's risk was calculated purely on genetic inputs alone were more likely to choose the statement "this result does not tell me anything about my future likelihood of breast cancer" (30) possibly indicating their cohort may also hold similar opinions about genetics not being a well-established science.

In terms of overdiagnosis, the findings of this study concur with previous qualitative research in this field demonstrating limited understanding of and difficulty

understanding overdiagnosis in the realm of breast cancer (31). The confusion about the concept of overdiagnosis suggests the women in this study may be disregarding information which does not fit with their current attitudes. This has been described in previous qualitative work on overdiagnosis (32).

Women were concerned that if someone were placed in a low-risk cohort they may no longer attend for screening. This was not the experience of women in the United Kingdom who partook in the PROCAS study, whereby women allocated to their less than average risk still presented for subsequent screens at the same participation rates as the higher risk groups (30). Women within PROCAS allocated to a higher risk group did have higher participation rates with 94.4% attending for a rescreen compared with 84.2% for the lower risk group, however, the rate the comparison group attended for rescreening was 84.3%.

Women were concerned about the reasons driving the change and were suspicious that it was merely a cost cutting exercise, which reflects the views raised in a previous study assessing how women in the United States viewed the change in mammography guidelines (33). The dissemination and explanation around change is critical to alleviate fears of malintent.

Considering the emotional ties women have to the current program, a major change in that program will need to be undertaken with consideration of this emotional investment, which has been fostered and encouraged over many years by the public health system in Australia.

### Limitations

Despite actively attempting to recruit a diverse range of women, the participants in our focus groups were not widely racially or linguistically diverse. Their views were representative of a cohort of women who were well-educated and experienced with screening, and we appreciated this as a limitation of our data, limiting the generalizability to a wider population of women. Future work could be undertaken to assess the same views in younger women who have yet to start screening as they are likely to have a different perspective on an individualized model.

### Conclusion

Moving toward a risk-stratified or individualized breast screening program in Australia will require a large shift from our current model. This work suggests that although this is a feasible concept to women who are currently engaged in biennial breast screening, the participants were particularly concerned about a lower risk cohort being lost

to the system, the importance of communication and the motivator of the change.

The information gathered around risk perception will be used to build the educational component of an online decision aid to facilitate decision making for a new screening protocol. This will be reported in a separate publication detailing the decision aid development.

The security women feel in the current system is a testament to the strength of our breast screening program and it would be important to carry this forward when planning any change. The importance of how individualized risk and screening is communicated is critical as well to the success of a change in the program and this work marks the initial progress in that direction for Australia. Although this work has been conducted in Australia, it would be internationally transferable to many other countries, which also have long standing, well-established population screening programs.

### Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

### Authors' Contributions

**Conception and design:** J. Lippey, L.A. Keogh, G.B. Mann, I.G. Campbell, L.E. Forrest

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**Administrative, technical, or material support (i.e., reporting or organizing data, constructing databases):** J. Lippey, I.G. Campbell

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