

Research Participant Summary:

Feedback on the BreastScreen service from women aged 70-74 years

What we heard from women about BreastScreen's decision to send regular reminders/invitations to women aged 70-74 years

March 2021

nous

BreastScreen
AUSTRALIA

A joint Australian, State and Territory Government Program

Participant summary: Feedback on the BreastScreen service from women aged 70-74 years

SUMMARY OF RESULTS

Thank you for sharing your experiences with us in a research survey last year about the BreastScreen service, and BreastScreen's decision to expand the age range for invitations and reminders to include women aged 70-74 years. Your contribution is very much appreciated. You told us that you would like to receive a short summary of what we found. We are delighted to share that summary here.

BreastScreen is a nationwide service that offers routine breast screens (mammograms) to women free of charge. In 2013, the decision was made to actively invite or remind women aged 70-74 years to attend for routine screens, whereas before this decision women aged 50-69 years of age were actively invited to attend. This decision to expand the service was the focus of the evaluation research.

WHO PARTICIPATED IN THE RESEARCH?

The research team asked women aged 70-74 years from across Australia, including women who live in each state and territory, and in metropolitan, rural, and remote locations, to participate in the research. The team did a range of activities to understand women's views:

- A **telephone survey** of a random sample of 743 Australian women aged 70-74 years from the general population
- An **online survey** of 4,295 current BreastScreen clients aged 70-74 years from every state and territory
- **Individual telephone interviews** with 37 current BreastScreen clients aged 70-74 years from every state and territory.

Overall, **over 5,000** Australian women participated in this research.

What did women say?

WOMEN'S SATISFACTION WITH BREASTSCREEN

Overall, women's experience of BreastScreen is highly positive before and after the expansion

Women said they are highly satisfied with the service. This was true for women living in the country or the city, and for women from a range of cultural backgrounds. No women reported any impact or concerns in terms of their care or experience around the time of the expansion, Women said that they are highly satisfied with the service because it's prompt and punctual. Women report that their "...visits are fairly quick...", service staff are "...prompt and efficient..." and "...always on time...".

Many BreastScreen clients said that 'friendly staff' is the main reason for their positive rating

Women said that the BreastScreen receptionist is an important part of their experience. Overall, women are highly satisfied with the receptionists they had dealt with. Women said that they were welcoming and friendly, that they treated women "...with respect and kindness...", and "...made me feel comfortable...". This means that attending BreastScreen feels "...safe..." and "...welcoming...". Women said that because the BreastScreen clinics and vans are staffed by females this also makes them feel safe and comfortable.

Women said getting a screen is quicker and less painful now compared to when they first started getting breast screens

Women said that, compared to when they first started going to BreastScreen on average about 20 years ago, getting a screen is more efficient now, "...with far less waiting time for an appointment, more screening centres open and a different approach to the process". The "...customer service is much better..." and it's a "...quicker process now...I don't feel rushed to get out". The experience is also better "...now white gowns do not have to be worn" – women said that not having to change makes the service feel less clinical.

Women also said that the screening procedure and machine is less painful now compared to when they first started coming to BreastScreen. However, women agreed that on the whole getting a breast screen is uncomfortable.

WHAT WE HEARD

"I found that the [staff] were absolutely marvellous. Their manner cannot be faulted. They are friendly and...there was no embarrassment. They do a very good job of instilling confidence in the [client]."

"From the lady who answered the phone when I rang for an appointment, to the receptionist and the technician, they were all so happy to help me."

REASONS WHY WOMEN DO AND DO NOT PARTICIPATE IN BREAST SCREENING

Most of the women who the research team talked to are regular BreastScreen clients. However, there were some women who said that they did not go to BreastScreen, which helped the research team understand the reasons why women do and do not get breast screens.

WHAT WE HEARD

"Having breast screens is worthwhile and reassuring for me."

"[Routine screening is]...a necessary and worthwhile check, especially as my sister has had breast cancer."

Most women said that 'peace of mind' was the main reason they get a breast screen

BreastScreen clients said that they get breast screens because it gives them reassurance and peace of mind that everything's ok. Women who said that they get breast screens every year or two years did so because they were worried about their health, because a female family member has or had breast cancer, or because their doctor said they should. Women said that now women aged 70-74 years are also sent reminders for screening that this means they can feel safer for longer.

Having a family member or friends diagnosed with breast and other cancers is big reason why women get breast screens

Women with a female family member who has or had breast and/or other cancer are most likely to want to screen, because they are worried about getting cancer too. These women feel that getting a breast screen is a non-negotiable activity because the risk that they might get breast cancer feels much higher.

For women aged 70-74 years, many said that they get regular breast screens because they know women their age or older who have been diagnosed with breast cancer. Women said that knowing older women who get breast cancer makes them fear that they could also still be diagnosed with breast cancer, even past the age of 74, and it's this fear that means they still want to get regular breast screens.

REASONS WHY WOMEN DO AND DO NOT PARTICIPATE IN BREAST SCREENING

If women get a reminder from BreastScreen, they're more likely to attend for a screen – If they don't get a reminder, women are unlikely to attend

Overall, women said that being reminded/invited to screen by BreastScreen was the most important factor in remembering to get a breast screen. Most women who did attend their last breast screening appointment said it was because they received a reminder.

Of the women who said that they did not go to BreastScreen, the main reason they reported was not getting a reminder. Women said that the letter is important because it helps them remember when they are due for a screen, especially because having to remember every two years is hard. Women who did not get a reminder said that they thought this means they are no longer allowed, or they simply forget.

There are common things that make it easier or harder to have a breast screen

Most women said that having regular breast screens is important, even if it is inconvenient. When asked what makes it easier or harder to get a breast screen, things such as short travel time, good public transport, and good parking all make getting a screen easier, but that longer travel time or a lack of parking (for example) would not stop them attending.

Women living with disability said that they sometimes found getting to BreastScreen sites was something that made it harder for them to have a breast screen. Women from three states and territories around Australia said that the reason they did not attend their last screen was because they found access hard – for example their disability means that they can't get there by themselves, they find it hard to get up the steps of a mobile van, or they can't drive and they live in a regional area.

WHAT WE HEARD

"I am glad they sent reminders otherwise I would probably have forgotten to go".

"I very strongly want the routine reminders from BreastScreen to continue past 70 years old."

REASONS WHY WOMEN DO AND DO NOT PARTICIPATE IN BREAST SCREENING

COVID-19 meant that during 2020 some women couldn't get a breast screen

The research was done during 2020, when cases of COVID-19 in Australia meant that most states and territories were in lockdown. Some states and territories had stricter lockdowns than others, so depending on where they lived, women were affected very differently. Of those women who lived in the most affected states, some said that lockdown meant that their usual BreastScreen site was closed, so they were unable to attend. In some cases, women also postponed their appointment because they were worried about COVID-19 transmission.

WHAT WE HEARD

"I got a letter to get screening done this year, but because of COVID-19, I was not able to go."

"...my GP informed me that the over 70s can have a breast screen. I'm pleased to hear that this is now available."

"I was disappointed that [BreastScreen] stopped at 70 years old and I could never get another free screening. As you get to a certain age, they start saying you are too old for most medical things...which really cheeses me off."

WOMEN'S AWARENESS OF, AND FEELINGS ABOUT, BREASTSCREEN'S EXPANSION TO SEND REMINDERS AND INVITATIONS TO WOMEN AGED 70-74 YEARS

Some women have a good understanding of the expansion and some are less clear

Overall, the message about BreastScreen's expansion has been well understood by some women, but not by others. Only a small number of women were aware that BreastScreen had started inviting women aged 70-74 years to attend a free breast screen, but about half of the women who participated in the research said that they had had a breast screen after the age of 70. Of these women who knew about BreastScreen's expansion, most women said they found out by a letter from BreastScreen. Women who lived in metropolitan areas were most aware of the expansion.

What did women say?

WOMEN'S AWARENESS OF, AND FEELINGS ABOUT, BREASTSCREEN'S EXPANSION TO SEND REMINDERS AND INVITATIONS TO WOMEN AGED 70-74 YEARS EVERY TWO YEARS

Women feel that the 'cut-off' age of 75 undervalues older women

Even though women over the age of 75 can still get breast screens (but will not receive regular reminders to screen after this age), most women said that having a 'cut-off' age for invitations or reminders being sent made them feel dispensable and 'old'. Women talked at length about how younger people and society in general relate to people aged 70+ - that is, they are seen as 'old' and 'frail'; women said that this was even more the case during COVID-19 when most of the cases were in older adults.

One woman commented that *"...the message of stopping screening at a certain age seems to me to suggest that the lives of over 70s are not as valued as younger people in the community."* Another woman said, *"...just because we are older does not mean that we aren't as caring of our health or deserving of preventative health care."*

It is unclear to women when they should stop screening

Women who participated in the research had different views on the recommended age to stop screening (and the reasons why they should stop). Some women did not realise that there was a recommended age to stop. Of the women who understood there was a recommended age to stop, most said that this message was not clearly communicated. Women said that there is poor information on the purpose of, and reasons behind, the recommendation to stop screening at age 74. As well, women said that the message they heard from clinic staff, their doctor, and through word-of-mouth is not consistent.

Women said that they will continue screening after the age of 74 years, even without a reminder letter

Most women who participated in the research said that even though they knew they would not be invited to screen after the age of 74 years, that they wanted to keep screening for as long as they could. A lot of women said that they would continue screening even if they had to pay.

WHAT WE HEARD

"I was very surprised when they stopped inviting me to come – it was as if at that age it didn't matter anymore, but it does to me."

What did women say?

WHAT COULD BE IMPROVED

There are still things that make it hard to get a breast screen

Women said that there are a number of things that make it hard to attend BreastScreen. These include:

- worry about the pain or discomfort of the procedure
- not really understanding why screening is important
- other health concerns are more important (particularly for women who have lots of health problems)
- limited screening hours, which particularly impacts women who work during the day
- issues with transport and parking
- inconsistent messages or advertisements around when women are/are not recommended to screen
- lack of accessible facilities for women with disabilities.

More could be done to reach women in regional and remote parts of Australia

Women in regional and remote parts of Australia said that they still have trouble attending BreastScreen sites, with driving distance and a lack of transport being the main reasons why it is hard. Some women from regional areas said that having BreastScreen-provided transport was good, but this service is not available in every state and territory. Some women also asked whether the BreastScreen service is advertised in regional and remote areas. One woman in a very remote location said that she *"...has no experience of [BreastScreen]..."* because she *"...was out on a sheep station for years"*. Other women asked if there is *"...any form of assistance from the government for remote women to get screening..."*, because *"...there has to be considerable support..."* to make women in remote areas aware of BreastScreen and help them access the service.

More could be done to ensure BreastScreen is truly inclusive for all women

Some women said more could be done to make sure BreastScreen is friendly, welcoming and informative for all women, especially women from different cultures or those that speak languages other than English, and women who may be questioning their sexuality, or who identify as trans or gender diverse.