



Consumer and Community
Involvement Program



WAHTN

Western Australian Health Translation Network

BREAST CANCER SCREENING: INCREASING PARTICIPATION AND UNDERSTANDING RISK

COMMUNITY CONVERSATION REPORT



Prepared By

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Briony Abraham
Jennifer Stone**

June 2024



THE UNIVERSITY OF
WESTERN
AUSTRALIA

 **Australian
Breast Density**
Consumer Advisory Council

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ACKNOWLEDGEMENTS

Acknowledgement of Country

The WAHTN CCIP Program acknowledges the Aboriginal people of the many traditional lands and language groups of Western Australia. We acknowledge the wisdom of Aboriginal Elders both past and present and pay respect to Aboriginal communities of today.

Thank you to the consumers and community members who attended the online Community Conversation. We couldn't have done this without any of you.

We'd also like to acknowledge the team from the University of Western Australia and the Consumer and Community Involvement Program (CCIP Program) support team for their hard work in successfully delivering the Community Conversation. Our heartfelt thanks.

Acknowledgement of Lived Experience

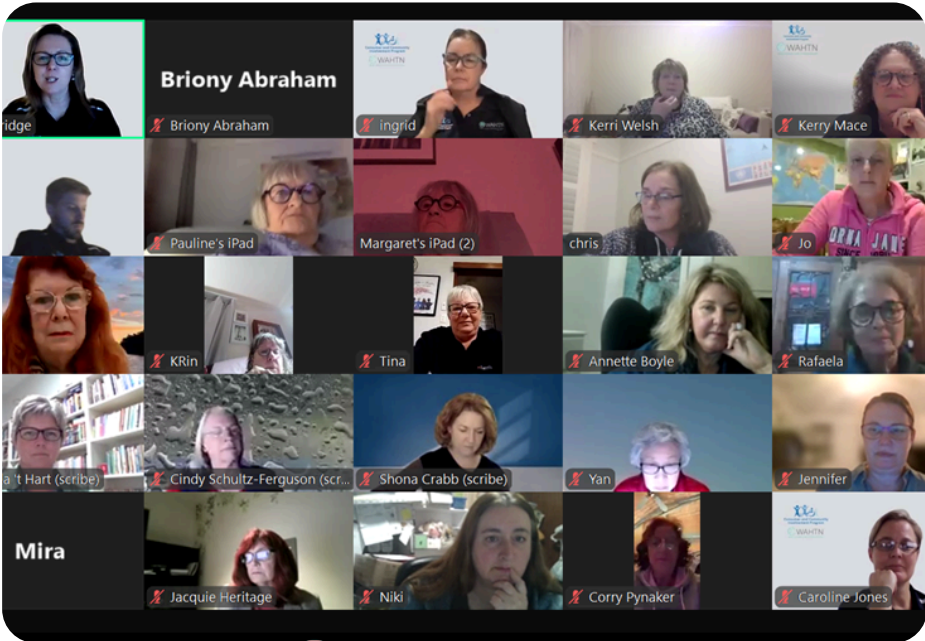
We acknowledge the importance and expertise of the lived experience voice of health consumers and carers. We recognise their involvement in making a difference in supporting health research and impacting the health and wellbeing of our communities.



BACKGROUND

The CLEAR BC research team actively partnered with the Consumer and Community Involvement Program to facilitate a Community Conversation event to bring together women aged 40+ with an interest in breast cancer screening to discuss and capture feedback around possible interventions to increase breast screening participation. The information obtained during the event will be used to inform the acceptability and feasibility of implementing and evaluating these interventions in the future.

Consumer Led research into EARly detection of Breast Cancer (CLEAR BC) aims to significantly reduce breast cancer mortality in Australia by improving screening. Due to low participation rates in breast cancer screening in Australia, CLEAR BC is investigating novel approaches to co-design three consumer-driven research projects that deliver ways to sustainably increase breast screening participation in Australia.



WHAT IS THE CONSUMER AND COMMUNITY INVOLVEMENT PROGRAM?



The Consumer and Community Involvement Program (CCIProgram) supports consumer and community involvement across the Western Australian Health Translation Network (WAHTN) partner organisations.

CCIProgram's **Vision** is to improve lives by ensuring the community's voice is heard and understood in health research

CCIProgram's **Mission** is enabling consumer and community involvement in health research by supporting and connecting community with researchers, partners and policy makers.

In order to achieve CCIProgram's Vision we:

- Are inclusive
- Trust, respect, support and value each other and those we work with
- Work as a team
- Are relevant and sustainable so as to make a difference.

WHAT IS A COMMUNITY CONVERSATION?

A Community Conversation is an event using an abridged version of the Word Café Method [1] and allows for the facilitation of informal, open conversations around a specific topic of importance. This method allows researchers to informally obtain a range of communal ideas from a group of people with lived experience around a particular topic specified prior to the event [2],[3]. Additionally, a Community Conversation provides an opportunity for attendees to reflect upon their own relevant experiences and contribute in meaningful discussions within a safe and comfortable space.



[1] Brown, J., & Isaacs, D. (2005). *The World Cafe : Shaping our futures through conversations that matter*. Barrett-Koehler

[2] Chieh-Ling Yang, Delphine Labbé, Brodie M. Sakakibara, Janneke Vissers & Marie-Louise Bird (2022) World Café- a community conversation: a Canadian perspective on stroke survivors needs for community integration, *Topics in Stroke Rehabilitation*, 29:5, 392-400.

[3] Carter, E. W., Schutz, M. A., Gajjar, S. A., Maves, E. A., Bumble, J. L., & McMillan, E. D. (2021). Using Community Conversations to Inform Transition Education in Rural Communities. *The Journal of Special Education*, 55(3), 131-142.

ABOUT THE COMMUNITY CONVERSATION

The Community Conversation was held on Wednesday 12th June 2024, and included 31 women aged 40+ from across Australia and six members of the Consumer and Community Involvement Program. Five members of the Research Team from the University of Western Australia, the University of Adelaide, the University of Melbourne and the Australian Breast Density Consumer Advisory Council (ABDCAC) who participated as scribes. The Research Team aims to foster collaboration with consumers in the co-design of relevant and highly translatable research projects aimed at enhancing breast cancer screening outcomes in Australia.

To hear real people's concerns, to help address the reason lay people might not screen

Wonderful to have non screeners. Non screeners [are] the most valuable to talk to

Knowing that research is listening to these conversations and hopefully guiding the pathway



PROMOTION

The Research Team worked closely with the CCI Program to recruit women aged 40+ to hear their thoughts on possible intervention strategies to increase screening participation. We shared promotional communications across multiple channels.

Flyers and social media posts (Twitter, Facebook, Instagram and LinkedIn) were posted and circulated around relevant networks, including consumer and/or related health service provider networks and community groups.



COMMUNITY CONVERSATION



ARE YOU A WOMEN AGED 40+?

The focus of the discussion for this Community Conversation will centre around strategies to encourage more women to attend routine breast screening. Additionally, the dialogue will explore participants' understanding of risk factors and how risk-based screening could be utilized to improve screening outcomes.

A national web-based network named CLEAR BC (Consumer Lead research into Early detection And Reducing risk of Breast Cancer) is currently being established. The information gathered through this community conversation will play a vital role in informing CLEAR BC and prioritizing research initiatives within the network.

A \$70 honorarium is offered to attendees.

Register your interest



WHEN: Wednesday 12th June 2024
TIME: 6-8pm (AWST)
WHERE: Online via Zoom

<https://bit.ly/3TaHYvG>



THE COMMUNITY CONVERSATION TEAM

Deb Langridge - Head, CCIProgram

Lead Facilitator



Deb has worked in the public health and prevention space at all levels of government – Federal, State and Local – and not for profit sectors to contribute to the health and well-being of communities. She has worked to capture the voices of all parts of community including access and inclusion, Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities, children and young people, mental health, health and community services. Deb has been the Chair of Advisory Groups in both NSW and WA. She has always worked connecting community, government, and community with a well-being focus, and was a representative on WA Sustainable Health Review with this in mind.

Deb's role leading the Consumer and Community Involvement Program as a platform of the Western Australia Health Translation Network is to connect researchers in WA Universities, Medical Research Institutes, Government, and Health Service Providers with people with lived experience to support and encourage best practice research. Deb is passionate about ensuring research can impact policy, practice and wellbeing of communities and enjoys bringing people together to make a difference.

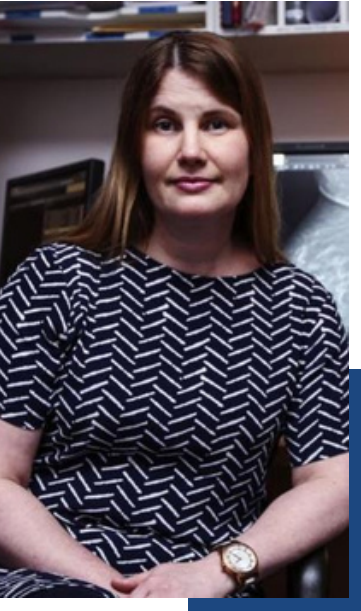
Kerry Mace, Ingrid Laing, Caroline Jones and Matt Hands - CCIProgram

Breakout room Facilitators



Thankyou to the CCIProgram facilitators for their assistance in facilitating the conversation with the attending community members.

THE COMMUNITY CONVERSATION TEAM



A/Prof. Jennifer Stone
School of Population and Global Health - University
of Western Australia

A/Prof Jennifer Stone is a cancer epidemiologist/biostatistician and a prominent international and national expert in breast cancer screening research, particularly relating to breast density. As a Cancer Council WA-funded Principal Research Fellow and Head of the Genetic Epidemiology Group at the University of Western Australia, her research aims to improve breast cancer screening and breast cancer outcomes through early diagnosis and primary prevention strategies. A/Prof Stone is currently leading an NHMRC Targeted Call for Research project, BreastScreen Plus, investigating a novel intervention targeting obesity-related barriers to mammographic screening. She is also a chief investigator on a recently funded NHMRC Centre for Research Excellence investigating Precision Public Health Approaches to Breast Cancer Screening, Early Detection and Mortality Reduction. A/Prof Stone recently established the Australian Breast Density Consumer Advisory Council (ABDCAC) to provide a community perspective on the research activities across Australian institutions interested in breast density research and breast cancer screening.

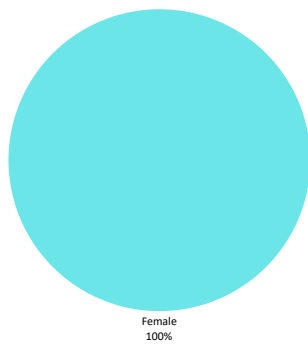
Thankyou to the Research Team members:
Shona Crabb, Cindy Schultz Ferguson, Jocelyn Lippey and
Dorinda 't Hart for their assistance in scribing the conversation
with the attending community members.

ATTENDEES

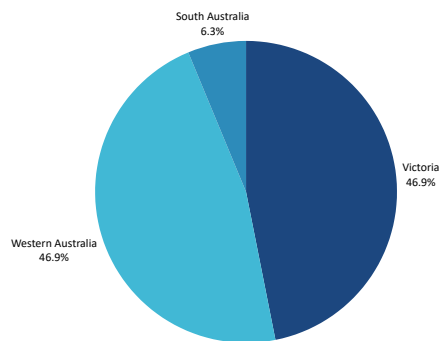
- 31 Community participants
- 6 CCIP facilitators
- 5 Researcher team members

DEMOGRAPHICS

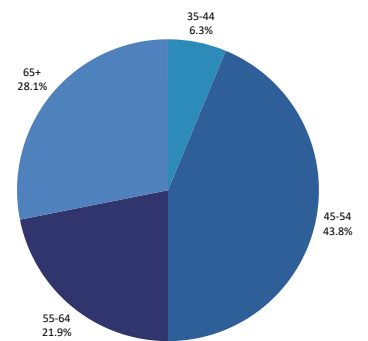
AGE RANGE GENDER



ETHNICITY STATE



LOCATION AGE RANGE



Breast cancer screening – increasing participation and understanding risk:
 Community Conversation
 Wednesday 12th June 2024 – 6pm to 8pm (AWST)
 Online via Zoom

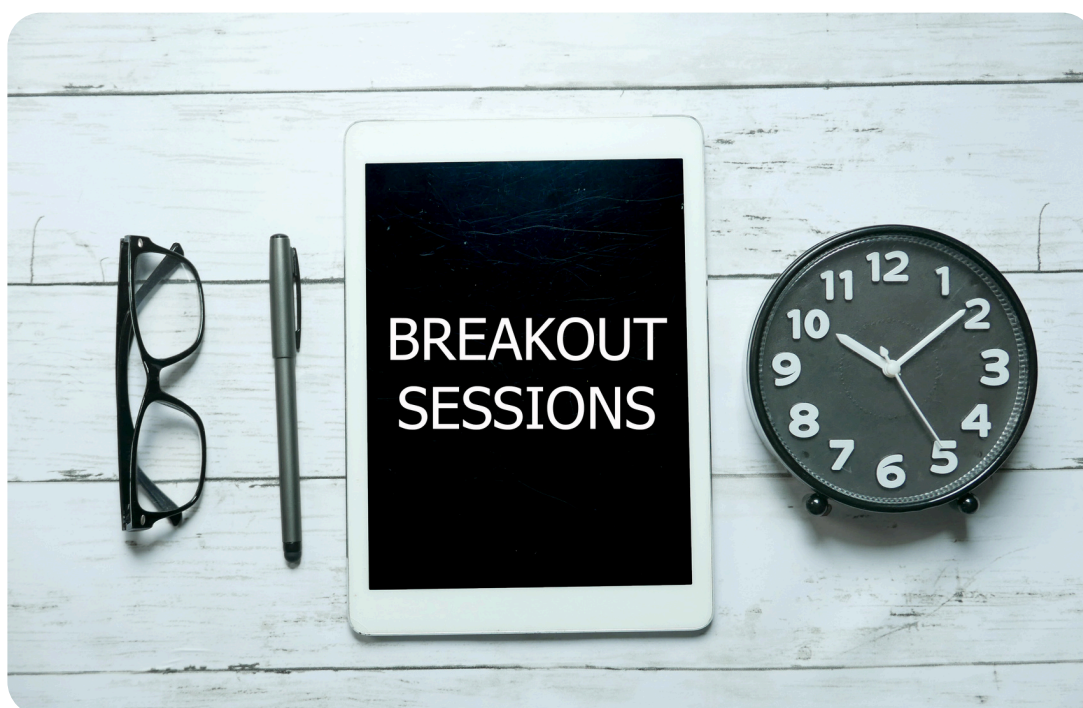
Agenda

5.45pm	Join via the Zoom link	All
6.00pm	Welcome <ul style="list-style-type: none"> • Acknowledgement of Country and Acknowledgement of Lived Experience • Welcome to the Community Conversation • Introductions using chat function 	Deb Langridge
6.10pm	Presentation	A/Prof Jennifer Stone
6.20pm	<ul style="list-style-type: none"> • Process of the evening • Send to breakout rooms 	Deb
6.25pm	Approach 1 – Fixed Appointment Times: How do you feel about approach one to improve screening attendance? (20 mins)	All
6.45pm	Approach 2 – Education/Decision Aid How do you feel about approach two to improve screening attendance? (20 mins)	All
7.05pm	Approach 3 – GP Referral How do you feel about approach three to improve screening attendance? (20 mins)	All
7.25pm	Room facilitator feedback	Deb and CCI Coordinators
7.45pm	Next steps and questions	Deb and Jennifer
7.55pm	Evaluation and honorarium information	Deb
8.00pm	Thanks and close	Deb

STRUCTURE AND PROCESS

The Community Conversation was held online, to enable participation from other Australian states as well as rural and regional localities.

To ensure attendees fully understood the purpose of the Community Conversation, Associate Professor Jennifer Stone introduced the Research Team and the three different potential interventions that were to be discussed.



Attendees were then split between 4 breakout rooms. Each room had a facilitator from the CCI Program to help guide the discussion and a scribe from the CLEAR BC Research Team to collect all attendee feedback.

Facilitators posed 3 approaches in total to the group:

- Fixed vs Flexible appointments
- Education and Decision Aids
- Opportunistic Referrals

Each individual approach was allotted 20 minutes for discussion. The comments, feedback and suggestions were all captured by each scribe and are presented in the following pages of this report.

KEY TAKEAWAYS OF THE COMMUNITY CONVERSATION



Most women were open to fixed appointments with these caveats:

- Flexibility/option to change the allocated appointment time
- Changing the appointment time has to be easy eg. Link/QR code
- Most women require a lot of notice for the allocated appointment time eg. 4 wks.
- Confirmation of appointment time would be required eg. text y/n and reminder closer to the date to reduce the number of ‘no shows’.



Most women agreed that education to improve screening participation is needed:

- Women need to know the risks for breast cancer and that early detection is best
- General Practitioners (GPs) need to know that breast screening is free for women aged 40+ via the BreastScreen Programs



Most women expressed that:

- Many people trust what their GP has to say
- Many women would benefit from a ‘Turning 50’ medical plan

COMMUNITY CONVERSATION APPROACHES AND RESPONSES

The following pages contain the responses and thoughts shared by attendees at the Community Conversation. They are categorised according to the three potential approaches to increase screening participation.

APPROACH 1

FIXED OR FLEXIBLE APPOINTMENTS

PROMPT: Invitations to participate in Breastscreen programs in Australia currently offers flexible (open) appointments where women are invited to make an appointment either by telephone or online. An alternative is to provide fixed (allocated) appointments (common in the UK) where a screening invitation includes a screening appointment with a given date, time and place, with the option to change to a more suitable time.

Theme	Consumer Thoughts and Considerations
How do you feel about this approach?	<ul style="list-style-type: none"> • Good prompt, makes ‘half the work done’ • Takes away the issue of reluctance – always putting off making the appointment • Precedent with other allied health professionals eg. dentists
Are you confident you could do what is asked?	<ul style="list-style-type: none"> • Many women are time poor with competing demands. Their own health is not a priority (especially because they are healthy). • Literacy and language issues need to be addressed so invitation letter is accessible • I have not been to Breastscreen because ‘I’ve got dense breasts.’ and family history. My GP sends me to a “proper radiologist.”
Do you think this will improve screening participation?	<ul style="list-style-type: none"> • Good way to get first time screeners into the system • Need to address motivation. On the one hand, women are not motivated, so a fixed appointment will not make a difference. On the other hand, women are highly motivated, so this might make a difference • For regional areas: arrival of invitation letters needs to be linked to the arrival of the Breastscreen bus

APPROACH 2

EDUCATION AND/OR DECISION AIDS

PROMPT: Education to improve screening participation could include printed materials, videos, community engagement. Decision aids could also be used. Decision aids are interventions or tools designed to facilitate shared decision making and patient participation in health care decisions, such as breast screening.

Theme	Consumer Thoughts and Considerations
What information is needed?	<ul style="list-style-type: none"> • Breast screening is available from 40+ • Breast cancer risk factors • Risks of NOT screening • Benefits of early detection • Statistics eg. how many people saved through early detection • Where the local clinic is • Description of what to expect at your appointment
How should information be shared?	<ul style="list-style-type: none"> • Schools – part of sex/health education • Outreach clinics and GPs • TV advertising • Community ambassadors • Stories/word of mouth • iPrevent (a breast cancer risk assessment tool) • Work with bra companies, combine with bra shopping/fittings, put pamphlet in bag when shopping • My Health Record • Ladies’ toilet doors - bright posters with QR code to make a booking • GP waiting room • Facebook/social media
Barriers	<ul style="list-style-type: none"> • Fear/anxiety <ul style="list-style-type: none"> ◦ Countered by: <ul style="list-style-type: none"> ▪ group bookings, target community groups eg dance groups, senior citizen centres, churches. ▪ ‘grab a friend’ ▪ get a coffee afterwards

APPROACH 3

OPPORTUNISTIC RECOMMENDATIONS

PROMPT: Opportunistic recommendations from GPs or allied health professionals occur when a person presents for an unrelated condition and the GP or health professional asks if the patient's screening is up to date. This could significantly improve screening participation, not just breast but also cervical and bowel screening.

Theme	Consumer Thoughts and Considerations
Who could be involved?	<ul style="list-style-type: none"> • GPs (acknowledging that some GPs already do this) • Pharmacists • Community health nurses • Hairdressers • Allied health professionals
Barriers	<ul style="list-style-type: none"> • Accessibility: cost and time to see GP • Costs to GP • GPs are time poor • Lack of bulkbilling; costs to patients • Not everyone has or goes to a GP • No family history, why check? • Negative word of mouth eg. pain • Access for Aboriginal and Torres Strait Islanders • Literacy/trust in the medical system
Would this approach improve screening participation?	<ul style="list-style-type: none"> • Many people trust their GP: <ul style="list-style-type: none"> ◦ “So many people listen to their doctor.” ◦ “My GP always checks if I’m doing the right thing.”

EVENT SUMMARY



Evaluation and feedback from attendees were collected through the CCIProgram following the closing of the Community Conversation. The consensus from all who attended was that the Community Conversation was extremely informative, interactive, and engaging. Attendees were enthusiastic around their involvement with this particular event and commented that they felt their contributions were valued and appreciated. Overall, the event was extremely successful and will allow the Research Team to provide informed consumer and community member feedback for further grant opportunities and research priorities.

WHAT'S NEXT FOR BREAST SCREENING RESEARCH?

Consumer-driven research is needed to provide more relevant, high-quality outcomes that are directly translatable into clinical practice and more likely to succeed.

We will use the information from the Community Conversation to co-develop future screening interventions. We will seek further funding to trial these interventions to increase participation in breast cancer screening and to increase the evidence base to promote future screening interventions.

Breast cancer screening – increasing participation and understanding risk: Community Conversation

12 June 2024 (online via Zoom)

Evaluation Summary

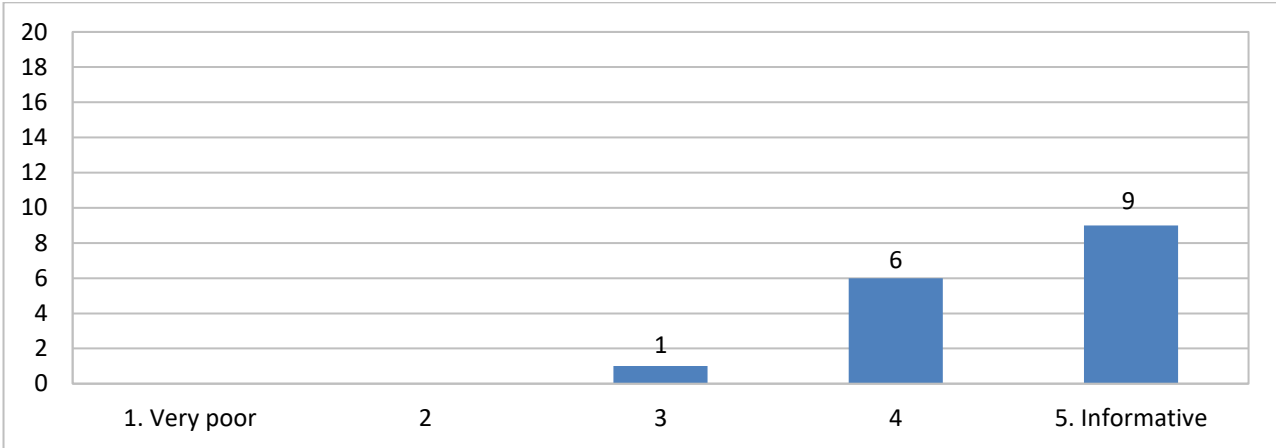
16 Forms completed / 31 attendees

Please tick the responses which best match your view:

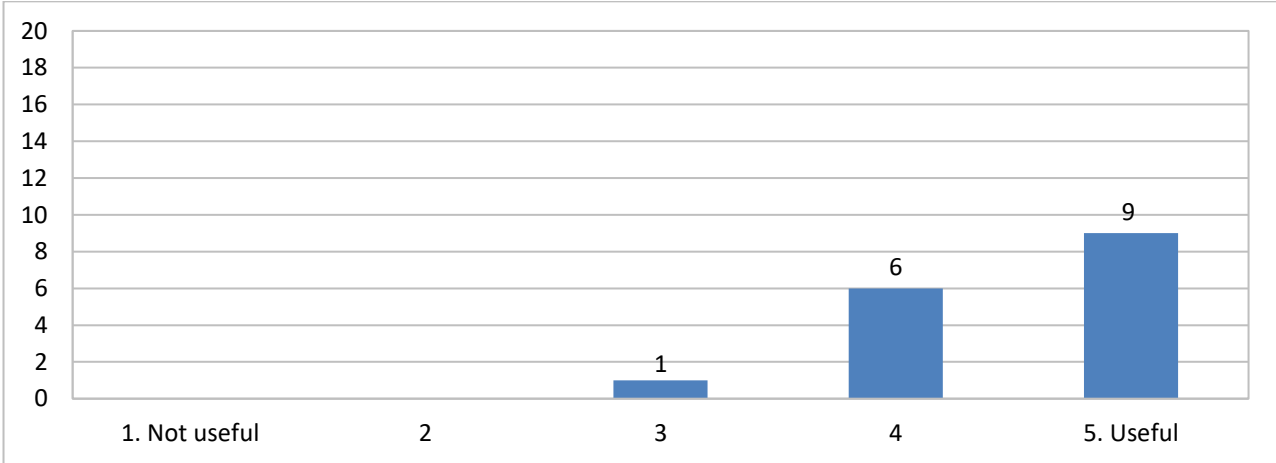
1. **The Community Conversation was:**

NEGATIVE → OR → POSITIVE

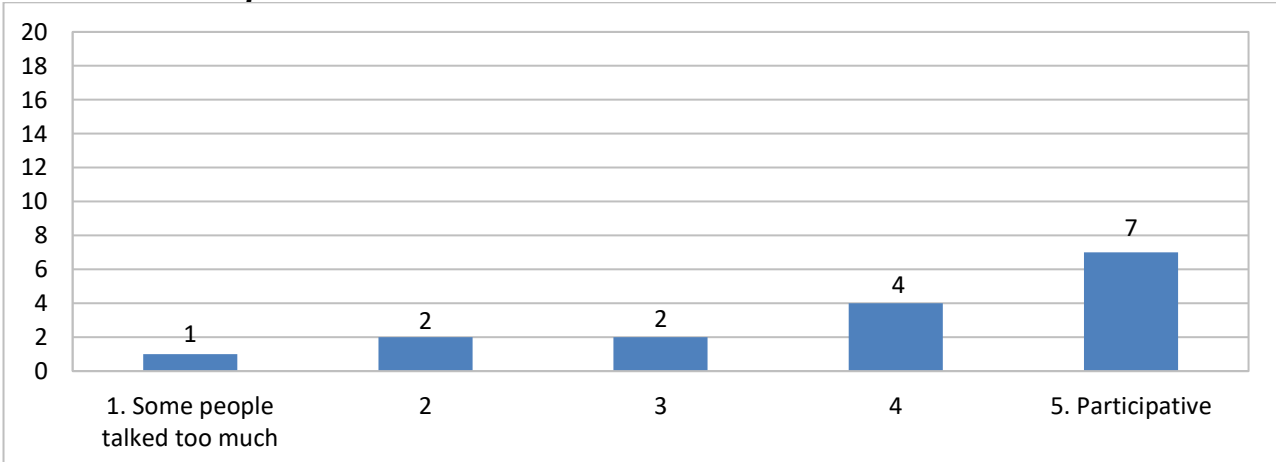
1.1 Informative



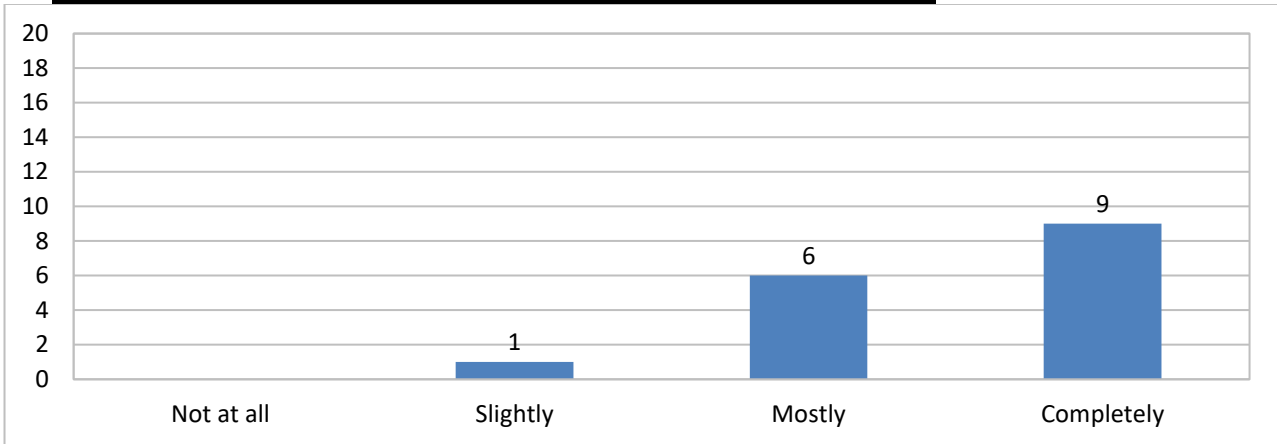
1.2 Useful



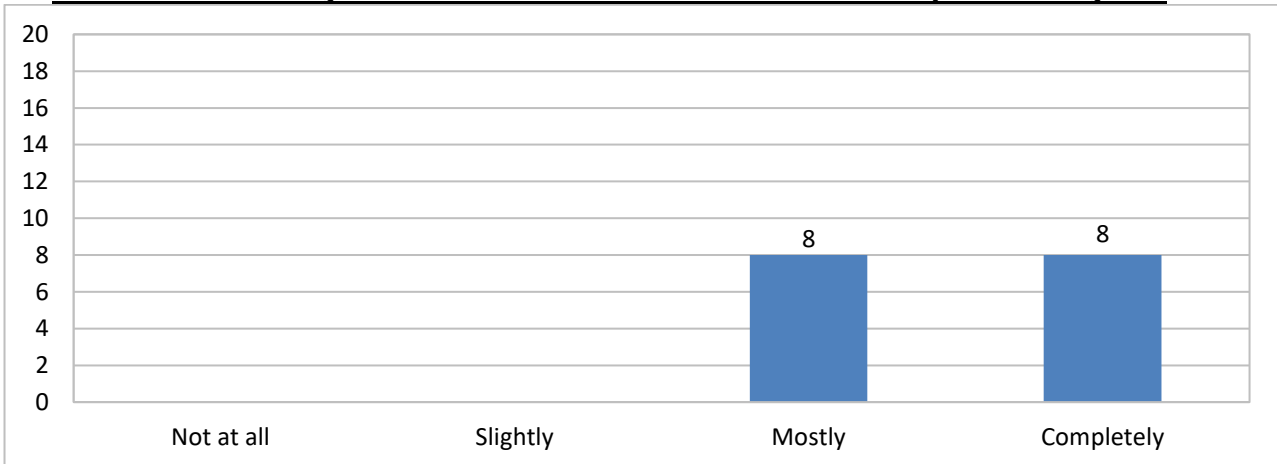
1.3 Participative



2. **Did the community conversation meet your expectations?**



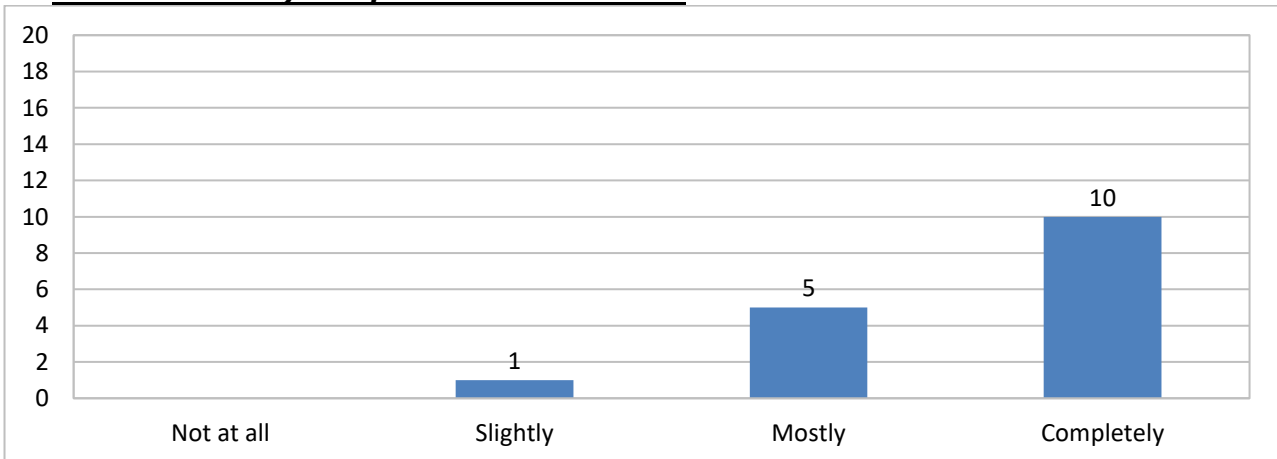
3. **Did the community conversation cover areas that were important to you?**



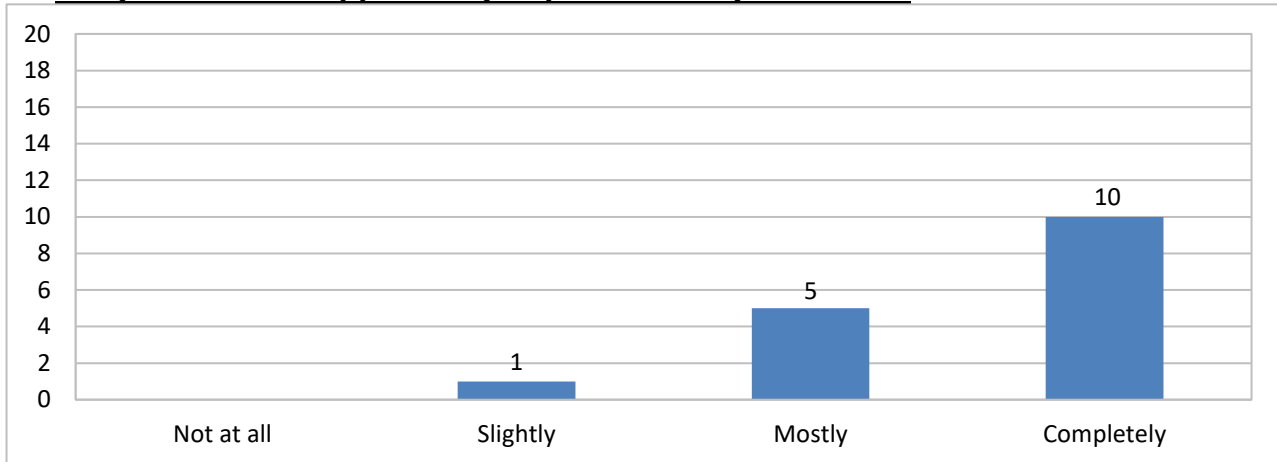
If "not at all" please specify what additional information could have been included:

- I attended this Conversation not fully aware of what was going to be discussed so not sure if I can answer this Feedback Form truthfully. I did enjoy participating though and found it interesting

4. **How well were your questions answered?**



5. **Did you have the opportunity to put forward your ideas?**



6. **Is there anything else you would like to add?**

- It astounds me that some women have to wait up to 4yrs for a mobile breast unit.
- It's all about education and spreading of the information. We must assure people of benefits and assurances.
- One person in our group did not comment, it could be useful to make contact with her (or others in other groups) to check if all was OK.
- Love the way the topics were kept to a time frame. Too many times these things go way over the expected timelines
- I wonder why all screening (Cervical/Bowel/breast) do not gather funds and facilities and develop a general promotional activity. For example just a flyer? advertising TV Radio Mags? Health check in GP. Discussion with GP's should be opportunistic but being time poor or directing attention to a made issue it may not be given by GP/Nurse or even absorbed by the client. Screening should be promoted as normal, just a check aimed at prevention.
- I understand people like to speak but sometimes we seemed to get off track. Lucky our Facilitator was able to pull it back to answering the questions.
- I didn't think the facilitator had the best skills to be honest. She shut some people down and I didn't think she valued what was said.
- No, it was facilitated well and fairly.
- I think if the moderators had a little more control over some people who took over the conversation, possibly guiding the conversation when it went badly off topic which left others unable to discuss the topics. Some people had hands raised to speak for long periods and were not asked to speak. There is being polite to hear people's views but also making sure we stay on topic.
- Moderator Deb was excellent. Jennifer Stone was concise and informative.
- The technology was excellent-transition to and from break-out groups worked very well.

7. ***The best thing about the community conversation was:***

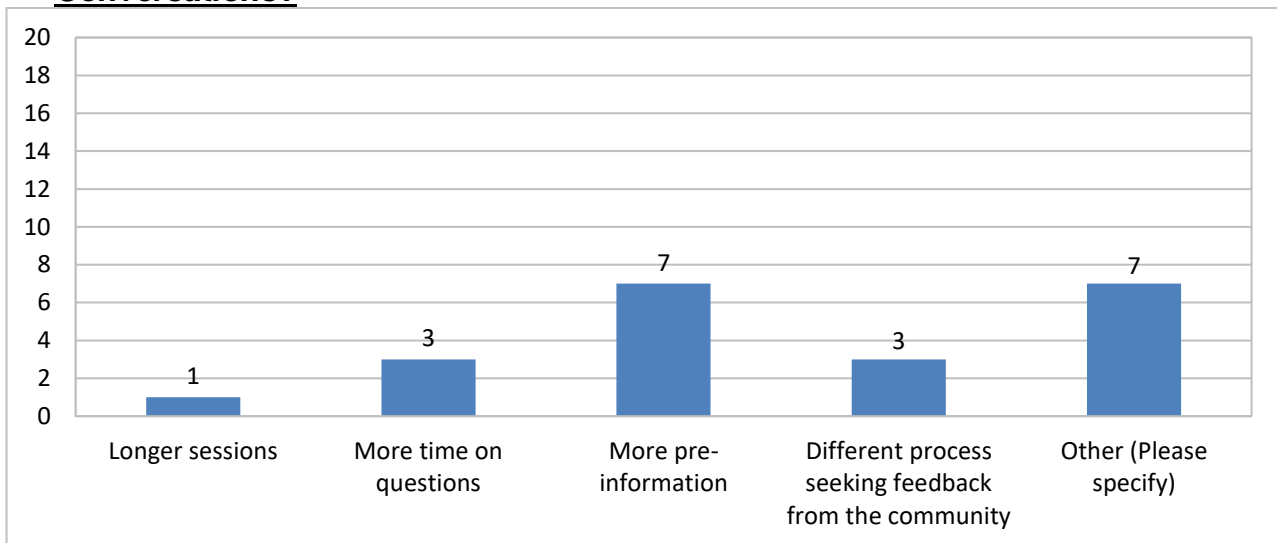
- Being honest about our lived experiences
- Being involved
- To hear the expert and the ordinary people talk about it.
- The geographic spread, the age spread, some good diversity, amongst the participants.
- The background information from Jennifer Stone.
- Great MC by Deb L - keeping us all on time.
- Well run, excellent facilitator, just enough time to cover the topics, clear instructions
- It is always interesting to hear others opinions. Not everyone will agree but that is what makes it interesting
- An interesting conversation to find out other people's views.
- To hear real people's concerns, to help address the reason lay people might not screen. Wonderful to have non screeners. Non screeners the most valuable to talk to.
- Listening to other people's ideas and thoughts. Understanding the many differences between each State & Territory. Why something so important cannot be uniform on a national level. Not realising how many amazing people there are who are concerned and willing to assist.
- Hearing the views of others and noting the breadth of misconceptions out there about screening mammography, even within this selected interested group.
- Discussion in the group
- Everyone was included and felt heard.
- Knowing that research is listening to these conversations and hopefully guiding the pathway.
- Knowing our feedback will assist in getting the info out to community
- The passion of the participants.
- Opportunity to hear different views from a range of people.
- I was impressed with the smooth running of the event, keeping to time and staying focused. Well done team!

8. ***The worst thing about the community conversation was:***

- Access
- Realising that participation rate is so low
- Had to feed myself!
- More time could have been spent, however I believe the essence was captured
- I think with all conversations like these, you have some people who seem to do the most talking and some who just seem to stay in the background. Maybe try to control those who tend to do all the talking and try to encourage the ones who don't to come forward a bit more
- To take off my nurses hat to explain and talk about answering their concerns (this was not what it was about). I have taken this conversation and will implement them into my daily job, again not what this event was about but productive for me as a nurse.
- I did not have anything prepared so felt there was not a lot I could offer. Was there information sent leading up to the Conversation on what was to be discussed, did I overlook this. If so then I apologise.
- A few people going off track from the topic, too often, for too long.
- The facilitator

- people talking off topic and taking over the conversations, people not muting microphones and listening to their chit chat.
- The time (I was eating dinner while on call so just felt a little rude when I turned camera off to eat
- Nothing 'bad'. Perhaps a little more information about ideas already discussed in other forums about ways to improve participation in screening. And, a couple of people did speak too much, and a couple were reluctant to contribute.

9. **Do you have any suggestions about how we might improve future Community Conversations?**



Other (Please specify):

- Different times for the conversation e.g. daytime
- Might have been useful to get a bit of background in our groups of the other people involved.
- Just a little information on what the topics are actually geared more towards
- Not to improve community conversation but an idea to promote screening. I wonder by asking more people why they haven't done screening will in itself promote uptake. Encouraging mindfulness, just putting the question front of mind, maybe will promote action.
- Find a way to keep people on track. Perhaps people could be pre-informed that the facilitator will hold you to the topic and to expect action from the facilitator in the form of a re-direction if this occurs.
- Go around the group for feedback to avoid people speaking over each other or put hands up.
- Definitely some moderator education how to politely guide clients back on topic
- Maybe different time of day
- Maybe one session per question. So many great ideas were suggested
- Perhaps canvas a number of questions prior to the 'conversation' so that participants can then comment.

WANT TO KNOW MORE?

PHONE: (08) 6151 1071

E-MAIL: ADMIN@CCIPROGRAM.ORG

WEBSITE: WWW.CCIPROGRAM.ORG

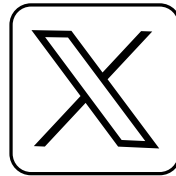
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