

Methods of engaging with consumers in the 21st century and beyond

BreastScreen Australia Conference

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Context

“Engagement is a mechanism that can enable health service organisations to better plan, design and deliver services that meet the needs of the people who use them, to gather feedback about initiatives and reforms that will impact upon service delivery and to monitor the quality and safety of providers to deliver improved services for consumers, their families and carers.”

Health Consumers Queensland, Consumer and Community Engagement Framework.

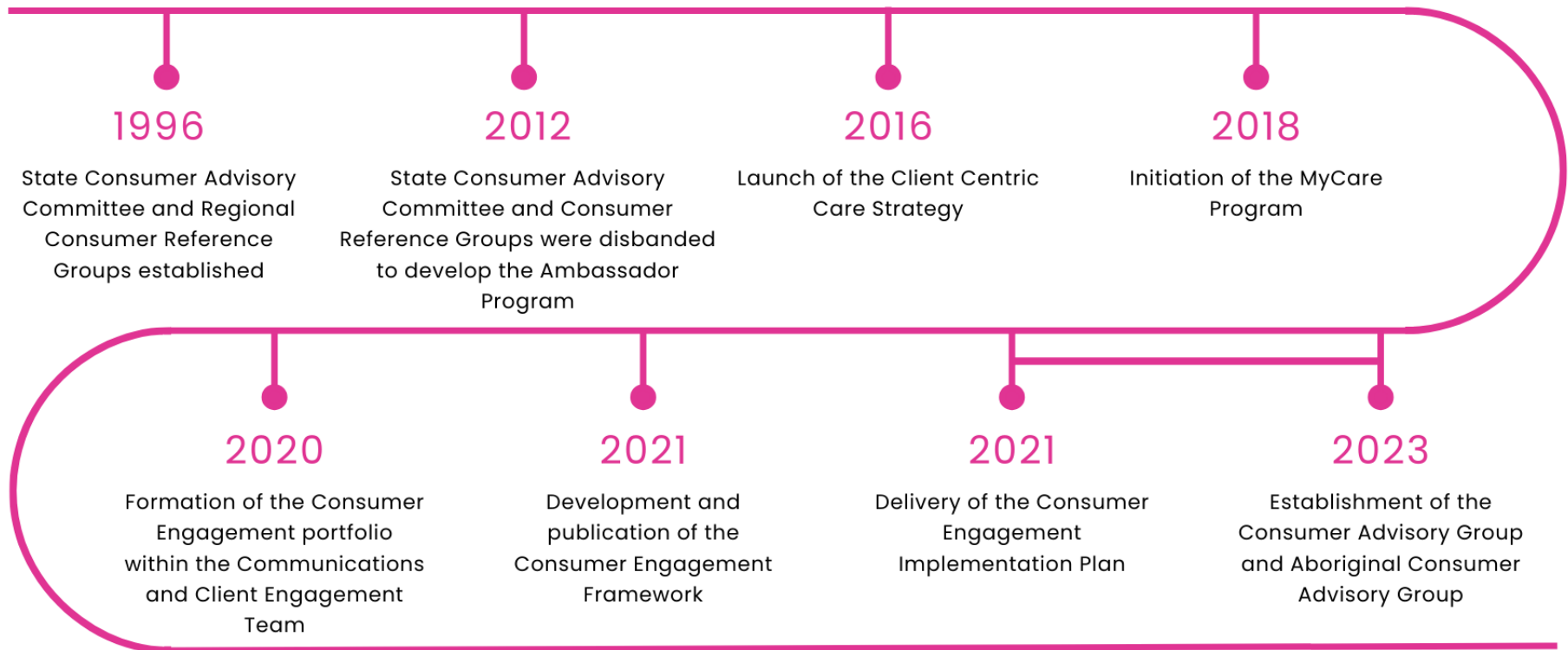


Why we do Consumer Engagement

Evidence has shown that advice / partnering / engaging / co-design with consumers in healthcare yields many benefits for the service and consumer.

- More accessible, responsive to current and future needs,
- Diversity and inclusion embedded
- Improved health and wellbeing outcomes
- Increased health literacy and understanding of the service
- Improved quality, responsiveness and sustainability

History of Consumer Engagement at BSV



BSV Consumer Engagement Framework

Purpose

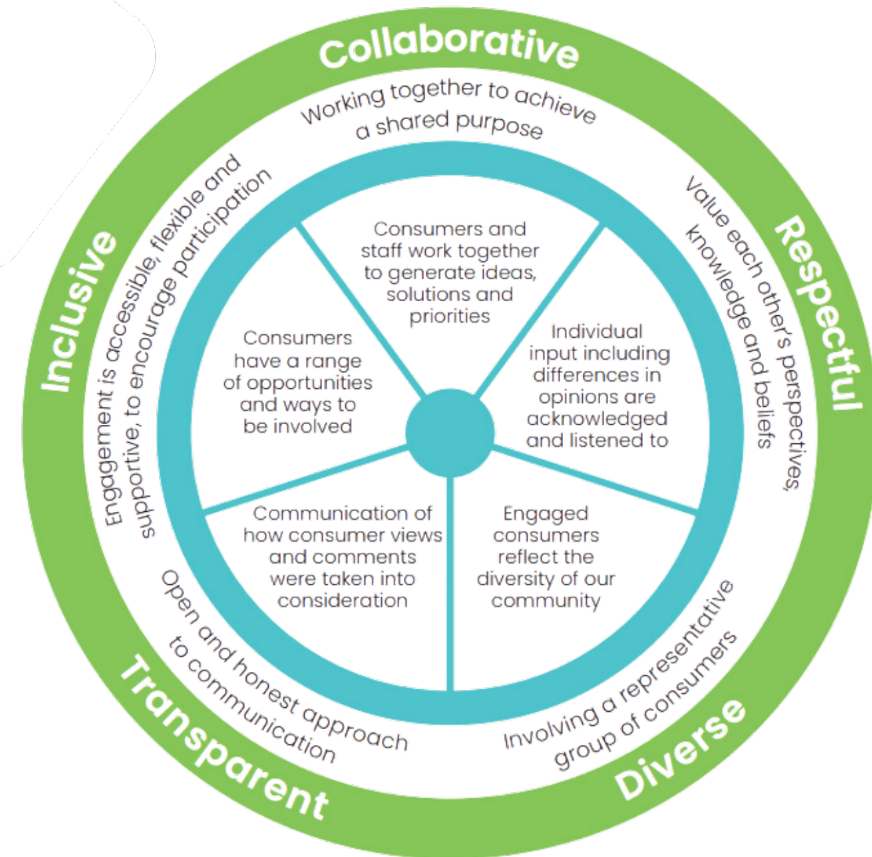
To improve the quality, accessibility and uptake of breast screening services for current and future clients, as informed by the consumer voice.

Aims






- Consumers are engaged early in projects and activities
- Consumers and staff work in partnership to achieve the best outcomes
- Consumer engagement is embedded in the culture of BSV

Principles

Five principles guide our approach. These principles reflect the values and priorities of the Consumer Network members involved in the development of the Framework. The model outlines the definition and practice for each principle.

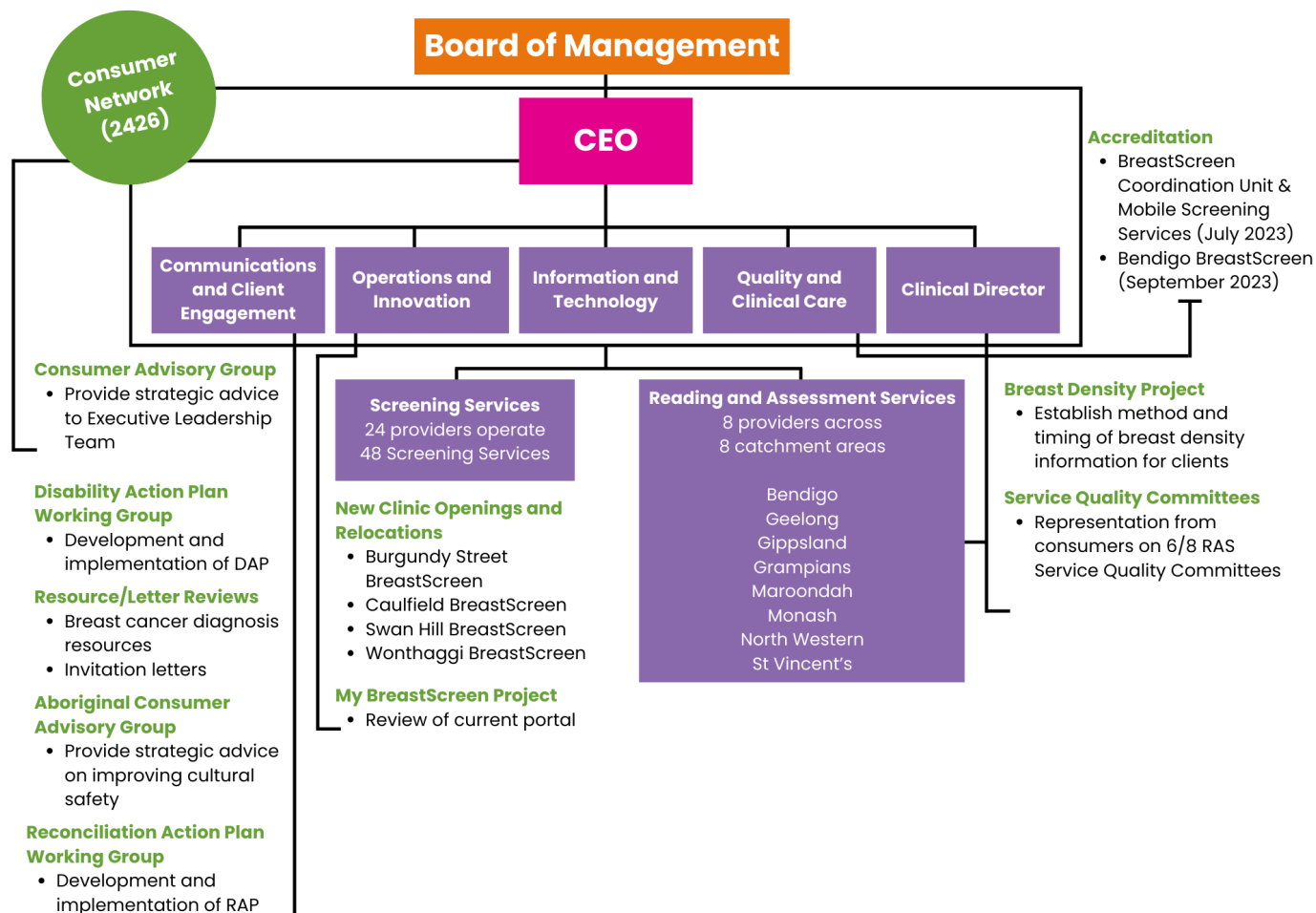


Spectrum of engagement

IAP2 Spectrum of Public Participation	 Inform	 Consult	 Involve	 Collaborate	 Empower
Level of engagement and influence	The consumer is provided with information. There is no two-way communication or opportunity to provide input.	The consumer is asked to provide their feedback and input on something previously prepared. This feedback may or may not be implemented.	The consumer works directly with the service in the development process. Their input is likely to influence the outcome.	The consumer is involved as a partner in the development process, including the initial idea generation, priority setting and outcome.	The final decision sits with the consumer. The service implements what the consumer decides.
Promise to consumers	We will keep you informed.	We will keep you informed, listen to and acknowledge any concerns, and provide feedback on how/if consumer input influenced the decision.	We will work with you to ensure that your concerns and issues are reflected in the work developed and provide feedback on how consumer engagement input influenced the eventual decision.	We will look to you for advice in identifying solutions and incorporate your recommendations into the decisions to the fullest extent possible.	We will implement what you decide.
Example tools	<ul style="list-style-type: none"> • Website • Letters • Leaflets/ Resources • Newsletters <p>e.g. Clients receiving a reminder letter when they are due for a breast screen.</p>	<ul style="list-style-type: none"> • Focus groups • Surveys • Interviews <p>e.g. Preparing a new screening results letter and asking a group of consumers to review the draft letter content.</p>	<ul style="list-style-type: none"> • Workshops • Lunch and Learn • Project Boards <p>e.g. Consumers are invited to a workshop to discuss potential changes to the service waiting area.</p>	<ul style="list-style-type: none"> • Committees • Working groups • Co-design <p>e.g. A dedicated consumer seat on a Service Quality Committee.</p>	<ul style="list-style-type: none"> • Voting • Delegated decision making <p>e.g. Artwork design for the Beautiful Shawl Project is chosen by local ACCO clients.</p>

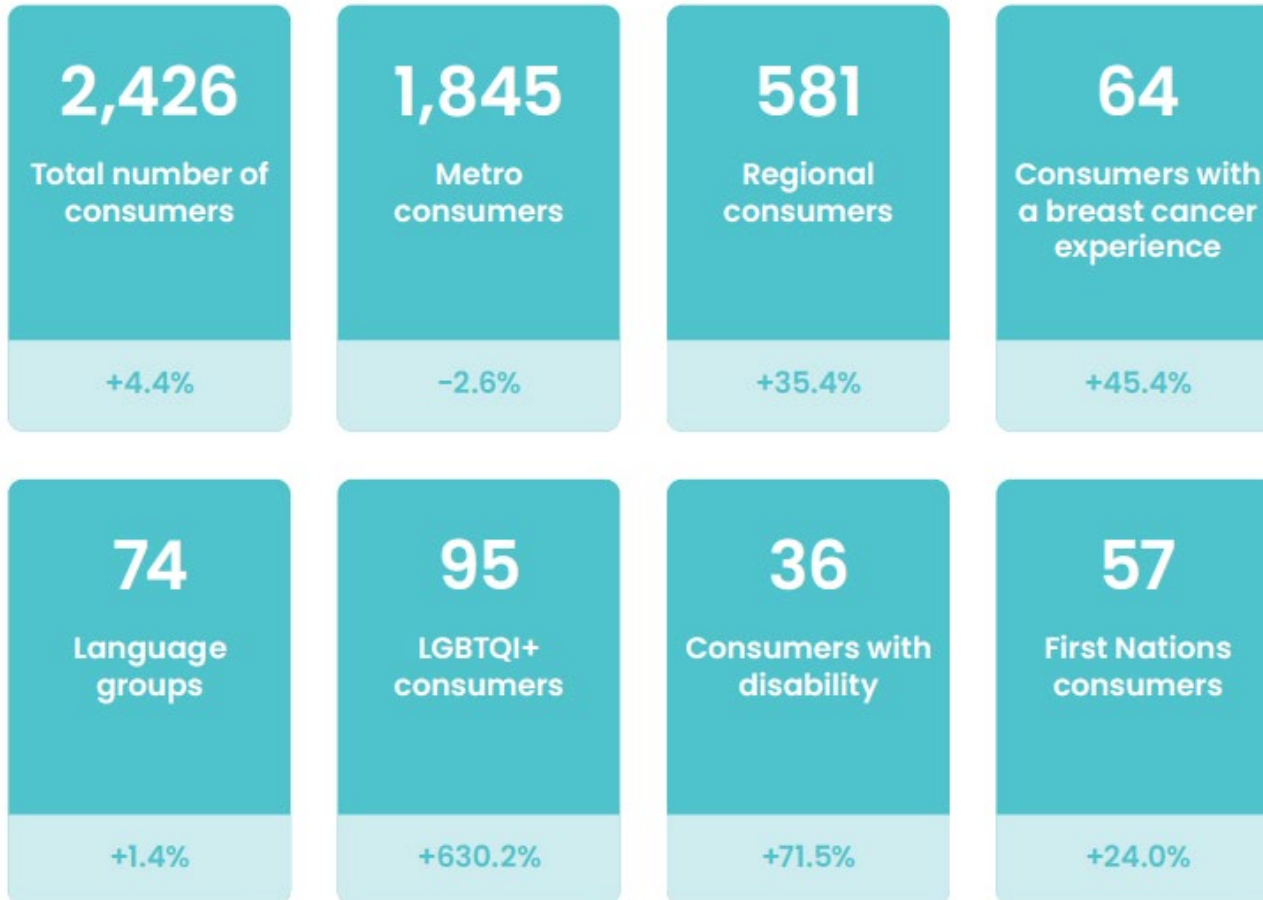
Embedding Consumer Engagement at all levels

Consumer Engagement 23/24



Our consumers – Snapshot

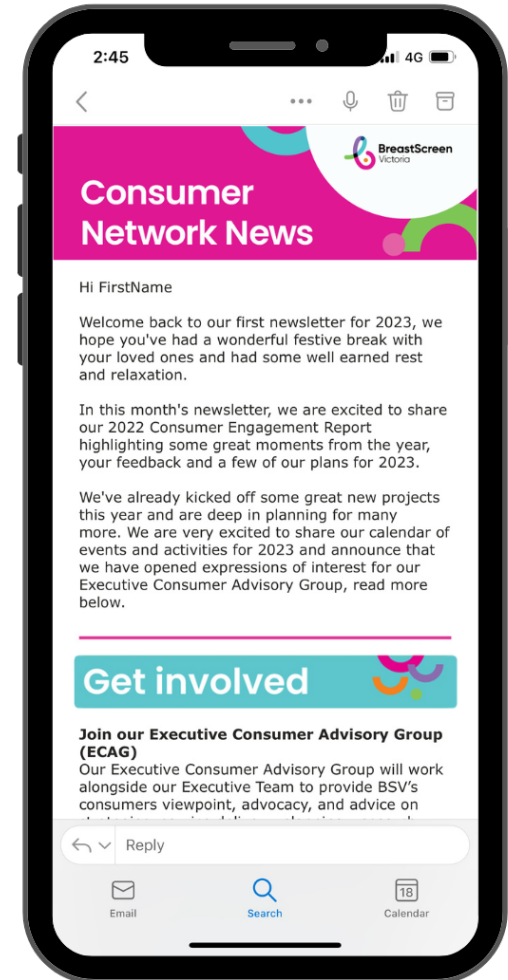
Our Consumer Network at a glance (2022 to 2023 variance)



Inform

Consumer Network newsletter


- Monthly
- Key service updates
- Expressions of interest for engagement opportunities
- Staff profiles
- Keeping connected



Consult

Resource review process

- Gain insight about how resources resonate with the target audiences
- Are they easy and accessible to read for a wide range of people
- Does it achieve its intended purpose (e.g., inform, understanding the call to action)



Lobular carcinoma in situ and atypical hyperplasia of the breast

This sheet provides information for clients who have been diagnosed with:


- Lobular carcinoma in situ (LCIS)
- Atypical lobular hyperplasia (ALH)
- Atypical ductal hyperplasia (ADH)

What are LCIS, ALH and ADH?
In unexplained LCIS, ALH and ADH, it helps to know what your breast looks like on the inside.
The breast normally contains the ducts which produce milk when a person is breastfeeding their baby. The milk travels from the ducts to the nipple through milk ducts. These ducts are surrounded by fatty tissue.

Sometimes cells on the inside of the lobules or ducts become abnormal in shape and size and begin to multiply. If the abnormal cells stay **inside the lobules** in the breast, this is called **LCIS** or **ALH**. In LCIS, there are more abnormal cells in the lobules than in ALH. Often LCIS and ALH are referred to as lobular neoplasia together.
If the abnormal cells **leave the ducts** in the breast, this is called **ADH**.

LCIS and lobules
Ducts and lobules
Normal duct
Normal lobule
Atypical lobular hyperplasia (ALH)
Lobular carcinoma in situ (LCIS)
Atypical ductal hyperplasia (ADH)
Normal duct
Normal lobule
Atypical ductal hyperplasia (ADH)
Lobular carcinoma in situ (LCIS)
Lobular carcinoma in situ (LCIS)
Lobular carcinoma in situ (LCIS)

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Breast screening and a previous diagnosis of breast cancer

This sheet provides information about having a breast scan (mammogram) with BreastScreen Victoria if you have been previously diagnosed with breast cancer.

What is BreastScreen Victoria?
BreastScreen Victoria is an accredited part of BreastScreen Australia - the national screening program for breast cancer. The program invites eligible women aged 50 to 74 to have a free breast scan every 2 years.
We extend our public and private health service providers to deliver breast screening in Victoria.

What sort of breast screening does BreastScreen Victoria offer?
BreastScreen Victoria provides standard breast scans. This includes two x-ray images of each breast - one from the top and one from the side.
If you have previously had breast cancer and have had a lump removed, we will take x-ray images of both of your breasts. If you have had a breast removed, we will take x-ray images of your other breast.
We will only ask you to come back for more tests if there is an issue on your breast screen that we believe needs further investigation. We do not routinely provide other tests if your breast screen appears normal.
You should discuss with your doctor to see if they recommend other tests.

Can I have free breast scans if I have had breast cancer?
This will need to be decided by a doctor for the best of your other breast cancer diagnosis.
After 5 years, you can have free breast scans through the BreastScreen Victoria program with the approval of your treating doctor.
We recommend you discuss with your doctor whether BreastScreen Victoria is suitable for you before booking an appointment. This includes if you have had a mastectomy and still have your other breast or breast if you have had a double mastectomy (both breasts removed) you will not need a breast screen as you will not have any remaining breast tissue.

What if I have been previously diagnosed with breast cancer?
If you have been diagnosed with breast cancer in the past and have had surgery to remove a lump or your breast, it is very important that you have regular check-ups. This is because people who have been diagnosed with breast cancer in the past have an increased risk of developing breast cancer again.
If you have had breast cancer, your regular check-ups should include:
• Annual physical examination of your breasts by a doctor
• Annual breast scans
• Other tests that may be required

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Involve

New clinic openings and relocations

- Get better understanding of local community / specific needs
- Better understand accessibility requirements
- Ensure the clinic is reflective of the diversity of the local community



Burgundy Street BreastScreen
Artist pictured: Anjee-
lee Bamblett, Ngarigo and Gurang Gurang
woman.

Collaborate

Reconciliation Action Plan

Development of a comprehensive Innovate RAP that will support the improvement of our organisation over the next 24 months. The RAP working group is co-chaired by Aunty Esmai Managan.

Disability Action Plan

The purpose of a Disability Action Plan (DAP) is to encourage, recognise and promote an active commitment to eliminating disability discrimination and to provide a roadmap to improve accessibility and inclusion for people with disability ([Australian Human Rights Commission](#)). The DAP working group is comprised of 50% consumers

Breast Density Reporting

The Breast Density Project has been established to implement reporting breast density to BreastScreen Victoria clients. To date, 15 consumers have participated in an initial survey with 2 consumers joining the project's advisory group.



Collaborate

Consumer Advisory Group

- To provide BSV's consumers viewpoint, advocacy, and advice on strategies, service delivery, planning, research, and policy development to improve the service.
- Provide opportunity for the diverse views, cultures and experiences of Victorian women, including trans and gender diverse people who are eligible to screen, to be considered in BSV's decision-making processes.





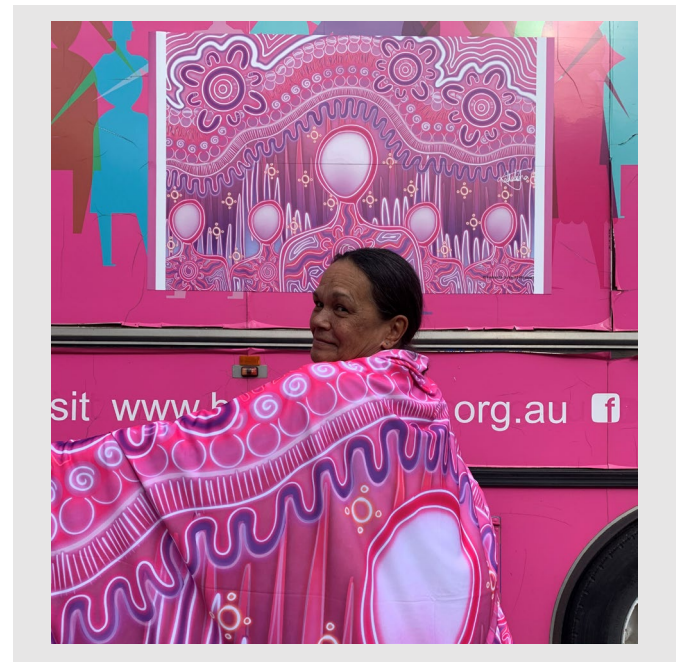
Collaborate

Aboriginal Consumer Advisory Group

Key activities:

- Review Aboriginal and Torres Strait Islander re-screen invitations
- Clinic walkthrough – visit a fixed clinic to make recommendations for improvement
- Participation in key RAP activities where relevant

Thanks to Aunty Esmai for her membership and contributions to the Aboriginal Consumer Advisory Group and as Co-Chair of the Reconciliation Action Plan Working Group.



Our program

- ✓ Is free
- ✓ Is with a woman radiographer
- ✓ Takes about 10 minutes
- ✓ Does not require a Medicare card or doctor's referral
- ✓ Group bookings available

Test client
1/31 Pelham Road
Carlton VIC 3000

Dear <insert first name and last name>

It's time to have your free breast screen again. The risk of breast cancer increases with age that's why it's

Empower

The Beautiful Shawl Project

To deliver the Beautiful Shawl Project (BSP), BSV and VACCHO partner with Aboriginal Community Controlled Organisations (ACCOs) and Aboriginal-led services across Victoria to provide culturally safe and empowering breast screening.

Each ACCO or Aboriginal led-service governs how the Project engages with their Community. The artwork displayed on the shawls is selected by the community and used for a two-year period. (supporting self determination)



Aunty Tracey Onus Bamblett, Gunditjmara, Yorta Yorta, Dja Dja Wurrung, Gunaikurnai – VAHS BSP visit. Artist: Aunty Lynette Briggs, Wiradjuri, Yorta Yorta.



Natasha Harney, Ngarigo, Gureng Gureng – Mullum Mullum BSP visit. Artist: Mullum Mullum Women's Healing Group.

Client Feedback and Consumer Engagement

- All clients with a valid mobile number/email address that consent to contact from BSV are invited to the survey
- Over 90% of clients respond and are invited to the satisfaction survey
- Average of 48% response rate (FY 22.23)
- Complaints management and quality improvement

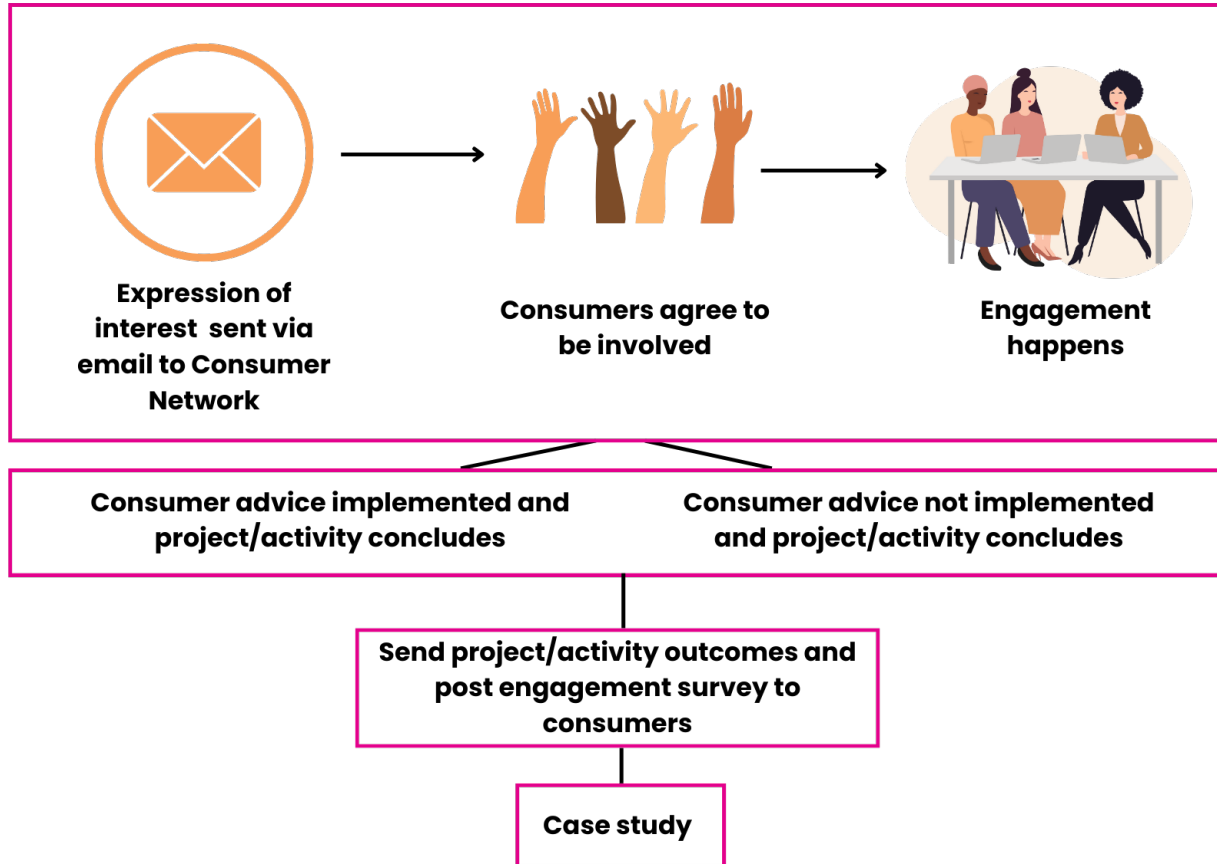
Response rates 22.23 FY

	Appointments	% clients survey invites sent to	% survey response rate of those invited	% survey response rate of clients overall
Screening	265,794	95.1%	48.1%	45.7%
Assessment	16,008	64.9%	48.2%	31.3%

Please note that clients that receive a positive diagnosis at assessment are not invited to the survey

Key learnings

The importance of closing the loop



Key learnings

Consumer engagement must look different for different groups:

- Meeting people where they are
- Using different communication styles, according to consumer needs
- Understanding different levels of health literacy



Key learnings

Comprehensive support for consumers including:

- Consumer allowance
- Reimbursement
- Position descriptions
- Relevant workplace policies (D&I, grievance etc)
- EAP



Key takeaways

Essential to success:

- Organisational structure and culture which embeds engagement
 - Strong **leadership** from the top "the way we do business"
 - **Diversity** at the core
- Using **evidence-based** consumer engagement frameworks
- Conversations, data and research to know your consumers and their barriers
- Effective two-way communication
- Empathetic, human centred approach
- Creativity and innovation
- Partnerships
- Continual improvement