



Government of **Western Australia**
South Metropolitan Health Service

SMHS Consumer Involvement in Research Workshop Outcomes Report (2024)



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Introduction

In 2023, in consultation with consumers and researchers, SMHS set out to develop a framework to serve as a guide and an information source on how to achieve meaningful consumer involvement in research. Following multiple workshops and a community engagement activity, researchers advised that they genuinely wanted to involve consumers in their research projects but did not know how or who to consult with.

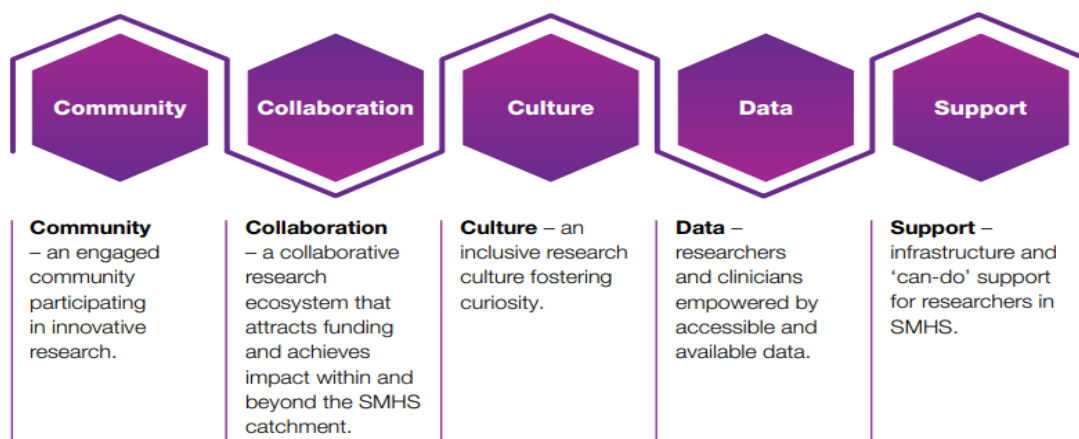
Using a co-design approach, a consultation process was developed which included a series of workshops led by a consumer with staff from the research team providing support. We held three workshops with consumers and researchers and engaged the community by asking for their input on the SMHS “Put it to the People” platform, as well as planning a community event to launch the Framework in late 2024.

The wealth of information that we gleaned from these interactions enabled us to develop the SMHS Consumer Involvement in Research Framework 2024 (The Framework) and the solutions to assist our researchers and our consumers become true partners in research projects.

This report details the planning, execution, and outcomes of the consultation process, as well as lessons learned along the way.

The consultation process was informed by the inaugural [SMHS Research Strategy 2023-2033 \(health.wa.gov.au\)](https://health.wa.gov.au), where engaging consumers and the community is key in two of the five pillars of change : **Community** and **Support**. The SMHS research vision is “*Research with purpose-working in partnership with SMHS communities and beyond to deliver excellence in health and wellbeing*”.

Our pillars of change



Objectives

There is growing awareness of the importance of involving consumers in all stages of health research. Benefits identified in the available literature include enhanced ethical standards, improved outcomes and translation, fresh perspectives, better communication with the community, and increased researcher satisfaction. Consumers gain the opportunity to shape research, acquire new skills, enjoy the satisfaction of making worthwhile contributions, and improve their own health and research literacy¹.

Although the benefits of consumer involvement in research are widely recognised, there was a need within SMHS for a document to provide practical guidance for consumers and researchers at the organisational level.

The main objective of this project was to co-design a framework that enables effective collaboration between consumers and researchers, maximising the benefits of consumer involvement in health research.

The second objective was to develop a plan to implement the framework, and third was the subsequent implementation.

¹ [A Consumer and Community Engagement Framework for the South Australian Health and Medical Research Institute \(sahmri.org.au\)](https://www.sahmri.org.au)

Methods

To demonstrate commitment to genuine consumer involvement, this project followed a consumer-led, co-design approach, with the Fiona Stanley Fremantle Hospital Group (FSFHG) Consumer Advisory Council (CAC) Chair leading the working group, supported by staff from the research team.

A literature review was conducted which supported the prevailing view of the importance and benefits of consumer involvement. Although there is a plethora of literature on the subject, practical frameworks on consumer involvement within the health research setting were less widely available.

Following on from this literature review, a series of three, 2-hour workshops were conducted, engaging with SMHS consumers and researchers. Both groups were consulted separately at first to gain independent responses from each cohort, and there was a conscious choice to consult the consumer group first, to reinforce the importance of the consumer voice in the project.

In the first two workshops, each group was asked to generate a list of contents for the framework, and to respond to the following three questions:

- What are the **benefits to researchers** of consumer involvement in research?
- What are the **benefits to consumers** of consumer involvement in research?
- What are the **barriers to consumer involvement** in research?

Finally, both groups were brought together in a collaborative third workshop to review the responses from the first two workshops and generate ideas on how they could be demonstrated and addressed in the framework.

All workshops followed a relatively informal format, where open and honest discussions were encouraged. Morning tea was provided to promote relationship building and networking opportunities and to encourage attendance. Workshops facilitators acted as scribes to capture important details and ideas.

To support the work being done in the workshops, and to gather responses from the wider community, an engagement activity was conducted on the SMHS 'Put it to the People' platform. The activity was anonymous and ran from December 6, 2023, until February 2, 2024. During that time, it was promoted on social media, on the SMHS, FSFHG, and Rockingham Peel Group (RkPG) internet sites, and to various consumer networks including the Office of Multicultural Interests, the Health Consumers' Council, and the Mental Health Commission.

Alongside the workshops and community engagement activity, key staff within SMHS were consulted, including the Aboriginal Health Strategy team, the Equity and Diversity lead, and the Patient Experience and Consumer Engagement lead.

Results

Workshops 1, 2, and community engagement activity

The consumer, researcher, and community responses to the three questions stated above, are detailed in Table 1.

Table 1: Workshop 1 and 2 responses

	Consumer Responses	Researcher Responses	Community Responses
Benefits to researchers	<ul style="list-style-type: none"> • Research is aligned with consumer needs, enhancing cost effectiveness • Relationship building • Benefit of lived experience • Benefit of diverse perspectives • Improved cultural sensitivity • Improved perception of consumer involvement • Encourages future consumer involvement 	<ul style="list-style-type: none"> • Research is aligned with consumer needs, leading to more meaningful outcomes • Relationship building • Improved research methods/quality • Improved research translation • Overcoming participation barriers • Help with lay-person friendly documents • Funding requirements 	<ul style="list-style-type: none"> • Research is aligned with consumer needs, leading to better translation • Consumer has a voice • Benefit of lived experience. • Benefit of diverse perspectives • Relationship building. • Innovative and practical ideas
Benefits to consumers	<ul style="list-style-type: none"> • Chance to Improve future health care • Having a voice • Improved self-esteem. • Improved health literacy. • Improved health • Relationship building and social connections • Greater understanding of health system • Income • Breaking down barriers 	<ul style="list-style-type: none"> • Chance to improve future health care • Having a voice • Empowerment • Improved health literacy • Improved health • Learning opportunities • Relationship building and social connections • Income • Catharsis 	<ul style="list-style-type: none"> • Chance to improve future health care • Having a voice • Empowerment. • Improved self-esteem • Improved health and research literacy • Learning and development opportunities • Relationship building • Greater understanding of health system • Income • Catharsis • Sense of 'belonging' • Satisfaction
Barriers to involvement	<ul style="list-style-type: none"> • Power imbalance • Unclear consumer role 	<ul style="list-style-type: none"> • Power imbalance • Unclear consumer role 	<ul style="list-style-type: none"> • Power imbalance • Tokenism

	<ul style="list-style-type: none"> • Tokenism • Finding involvement opportunities • Understanding of research and health terminology • Availability • Lack of remuneration • Lack of consumer interest in involvement • Cultural barriers • Lack of transparency 	<ul style="list-style-type: none"> • Consumers not valued • Finding consumers • Research and health literacy. • Availability • Lack of funding • Finding suitable, and diverse consumers • Cultural barriers 	<ul style="list-style-type: none"> • Finding involvement opportunities • Understanding of research terminology • Lack of funding/remuneration • Lack of organisational support • Inflexible/inaccessible ways to get involved • Research and health literacy • Health limitations • Lack of/limited information sharing
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The responses to the request for ideas for the framework list of contents are detailed in Table 2.

Table 2: Workshop 1 and 2 suggested list of contents

	Consumer Responses	Researcher Responses
List of contents	<ul style="list-style-type: none"> • Must be relevant to all SMHS sites • Outline the different levels of consumer involvement throughout all phases of research, including: <ul style="list-style-type: none"> ○ Generating research questions ○ Leading research ○ Collecting and analysing data ○ Disseminating research to community • Glossary of research terms including co-design • Specific focus on ways to involve people from culturally and linguistically diverse (CALD) and Aboriginal communities • Lots of supporting resources • Written in plain language • Stories and testimonials of successful consumer involvement 	<ul style="list-style-type: none"> • Forward from the Chief Executive • Outline of the vision and purpose of document, linking back to SMHS values • Explain ‘What is Research?’ • Glossary of research terms • Clearly defined roles and responsibilities • Consumer safety • Conflict management strategies • Tips for novice researchers • Roles for consumers in all phases of research • Types of consumer involvement, such as: <ul style="list-style-type: none"> ○ research buddy ○ consumer advisory group • Recruitment strategies • Supporting resources, such as: <ul style="list-style-type: none"> ○ SMHS policy for consumer reimbursement ○ List of contacts ○ Accessible version of framework for consumers ○ Websites with more information ○ Cartoons ○ First nations friendly version of the framework ○ Podcasts • A one-page, summarised version of framework • Success stories and examples as inspiration • Acknowledgements of those who attended the workshops and contributed to framework

Workshop 3

The responses from the final, combined workshop, where consumers and researchers worked together to identify ways in which the benefits and barriers to consumer involvement could be addressed or demonstrated in the framework, are detailed in Table 3.

Table 3: Workshop 3 outcomes

Benefits for researchers	
<p>Helps identify/confirm research goals that are most urgent, meaningful, and relevant to the community</p>	<ul style="list-style-type: none"> • Clearly explain the benefits, such as: <ul style="list-style-type: none"> ○ Cost savings ○ Improved patient care ○ Targeted research • Use dot points for clarity • Use examples of successful research projects that used consumer involvement • Section on what is a consumer group, including diversity, CALD and Aboriginal consumers • Section on involving the right consumers for your project, e.g. <ul style="list-style-type: none"> ○ Research on breast cancer should involve consumers with lived experience of that condition • Education on co-design (for researchers) • Include visuals, such as: <ul style="list-style-type: none"> ○ The research process from the beginning with opportunities to involve community clearly defined
<p>Processes made easier when informed by consumer perspectives (e.g., how to explain research, how to engage participants, how to disseminate research)</p>	<ul style="list-style-type: none"> • Include a quote from a researcher on how their research process was made easier by consumer involvement • Include strategies and resources to save time in connecting with, and orientating consumers, such as: <ul style="list-style-type: none"> ○ Consumer registry and links to community groups for finding consumers ○ Education ○ Ensuring documentation is accessible to consumers
<p>Capacity to conduct research that is meaningful and relevant enhanced by better understanding of consumer perspectives</p>	<ul style="list-style-type: none"> • Questionnaire or survey results from researchers on how consumer involvement has improved their research. Questions could include: <ul style="list-style-type: none"> ○ How consumers have helped with lay-language and important abbreviations ○ How consumers have helped them to understand the needs of end users • Include examples and stories, such as: <ul style="list-style-type: none"> ○ ‘Thud vs Tap’ example (Dr Oyekoya Ayonrinde)

	<ul style="list-style-type: none"> ○ Video testimonials
Builds sensitivity - cultural awareness, the need for empathy and compassion	<ul style="list-style-type: none"> ● Consumer/researcher champions to spread awareness ● Encourage consideration of consumer needs, such as: <ul style="list-style-type: none"> ○ Access points (e.g., for wheelchair accessibility) ○ Mental health considerations ○ Neurodiversity ○ Interpreters ○ Transport ○ Child-care considerations ○ Full-time workload
Builds research capacity as connections with community grow and become more productive	<ul style="list-style-type: none"> ● Encourage researchers to meet with consumers before/outside of research project
Informs future possibilities for building community-focused research	No responses
Benefits for Consumers	
Builds health literacy and supports lifelong and life-wide learning	<ul style="list-style-type: none"> ● Encourage consumers to ask questions ● Remind researchers to be aware of their audience when communicating ● Surveys or questionnaires for consumers before and after involvement in a project ● Testimonials and stories, such as: <ul style="list-style-type: none"> ○ Consumer with lived and learned experience ○ Different types of consumers ○ End users ○ Family, support workers and friends
Consumers build relationships and social connections with peers and the wider community	<ul style="list-style-type: none"> ● Encourage passing on of experience, providing support and confidence building (champions) ● Provide stories and examples <ul style="list-style-type: none"> ○ Story from Dr Olivia Gallagher of consumer who has found her team ○ Comparison of the experience of a consumer team vs a single/lone consumer on a research project ○ There may be stories on social media (e.g., Facebook – breast cancer community) ● Highlight that we are building a different culture
Potential research participants have consumer advocates	<ul style="list-style-type: none"> ● Be clear that participants also need researchers to be their advocates ● Clearly define consumer roles at different levels/stages of research

	<ul style="list-style-type: none"> • Stories of consumer acting as advocate for research participant
Empowerment and catharsis for individuals	<ul style="list-style-type: none"> • Include testimonials • Reminder for researchers to always acknowledge contributions • Reinforce the need for clear boundaries
Deep satisfaction from making a positive contribution – altruism	No responses
Provides a forum for consumers to have a voice in research	<ul style="list-style-type: none"> • Include stories • Highlight that consumer involvement opens up options in community
Improved healthcare for the community	<ul style="list-style-type: none"> • Examples - Review of projects with and without consumer involvement, to show consumer involvement has helped changed/improved health care • Reminder that consumer involvement adds credibility to a research project
Barriers to Consumer Involvement	
Power imbalance	<ul style="list-style-type: none"> • Consumer co-chair on research projects (top level feeding down) • Pre/post session debriefing (time constraints are a consideration) • Identify ways that power imbalance can occur • Have a group of consumers on a project, instead of just one • More consumers than researchers – tipping the scale • Add 'consumer update' to top of every meeting agenda • Clarify consumer role • Two-way non-disclosure agreement • Video/website available as education for potential consumer advisors • Consumer testimonials • Meetings dedicated to listening to consumers
Uncertainty/lack of confidence (on both sides)	<ul style="list-style-type: none"> • Training for consumers and researcher (professional development) • Mentors for researchers and consumers - someone to call to ask questions and provide debriefing • Consumers and researchers networking with each other outside of project (quarterly morning tea/catch-up) • A designated contact person for consumer within the project
Practicalities – time, identifying and contacting consumers	<ul style="list-style-type: none"> • Advise to contact existing foundations, organisations and community groups, such as: <ul style="list-style-type: none"> ○ Consumer Community Involvement Program ○ Health Consumers Council

	<ul style="list-style-type: none"> ○ List other consumer organisations ● Recommended going into the community (especially when looking to involve Aboriginal and CALD communities) <ul style="list-style-type: none"> ○ Target community events ● Consideration for people’s context outside of their role as a consumer – checking in ● Advice for managing expectations ● Recommend flexibility about ways of involving consumers, such as: <ul style="list-style-type: none"> ○ Online meetings ○ Mobile phone and iPad loans ● Establish a consumer bank ● Explain that past clinical trials participants can be contacted for consumer involvement, but ONLY if they have given prior consent to this
Need for education - consumers and researchers	<ul style="list-style-type: none"> ● Professional development ● Consumer and research ‘mentors’ who can provide advice and de-briefing ● Combined consumer and researcher education sessions
Communication	<ul style="list-style-type: none"> ● Advice on how to have difficult conversations, such as: <ul style="list-style-type: none"> ○ ‘Straight Shooting Brené Brown: 4 Steps for Tough Conversations’ ● In person courses/sessions ● Reminder to check-in with consumers
Lack of understanding of the value of consumer involvement	<ul style="list-style-type: none"> ● Testimonials ● Education

In the final workshop, consumers and researchers were asked to further develop the framework's content list. Working in mixed groups, they focused on how key elements could be demonstrated, addressed, or depicted. The results of this activity are detailed in Table 4.

Table 4: Workshop 3. List of contents

List of Contents	
What is research?	<ul style="list-style-type: none"> • Include definitions of what research is, such as: <ul style="list-style-type: none"> ○ General/layperson definition: Creating new knowledge or using existing knowledge creatively ○ Scientific definition: Systematic investigation to discover, interpret, and revise facts and theories • Explain that research is about the consumer and define the difference between participant and consumer • Explain different types of research and give examples, such as: <ul style="list-style-type: none"> ○ Ignaz Semmelweis' work on handwashing and childbed fever • Explain the principles of co-design • Highlight the benefits of research but be transparent about outcomes and limitations • Should be simple and engaging – don't overload • Include visuals to keep it engaging and accessible • Include supporting resources with further information, including: <ul style="list-style-type: none"> ○ Policies and guidelines ○ Testimonial videos or Vox Pop (SMHS specific) • Digital and non-digital versions to maximise accessibility
Why is consumer involvement worthwhile?	<ul style="list-style-type: none"> • Clarify why it is important, e.g. <ul style="list-style-type: none"> ○ Streamlining ○ Prioritising ○ Often a requirement (grant applications) ○ More impactful research ○ New research ideas ○ Feedback throughout project ○ Creates a mind-shift 'we're all in this together' ○ Consumers feel good about contributing • Incorporate inclusive visual representations • Include testimonials, such as: <ul style="list-style-type: none"> ○ Researcher perspective (with and without a consumer on their project) ○ Consumer perspective ○ Participant perspective
Involving and supporting consumers and researchers; mechanisms for support	<ul style="list-style-type: none"> • Have consumer and researcher mentors/champions to offer advice and support (and explain mentoring process) • Establish a consumer advisory body for research • Get community input on research priorities

- Resources and advice on recruiting consumers, such as consulting:
 - Community groups
 - CALD groups
 - Consumer Community Involvement Program
 - Health Consumers Council
 - Carers WA
 - SMHS Consumer Registry (if one established)
 - SMHS Aboriginal Health Strategy team
 - Aboriginal Health Council WA
 - CAHS Aboriginal Reference Group
- Run education and networking events
- Consider consumer needs (e.g., accessibility)
- Guidance on having difficult conversations
- Clarify that consumer perspective should be considered equal to that of the researcher
- Advice for getting the best out of people
- Establish a SMHS consumer bank – ensuring payment for consumers
- Establish a SMHS consumer registry
 - CAC could promote on CAC walk.
 - Ask clinical trials participants if they want to join
- Include link to CAC page – ‘Teach Back’ (3-4 min video)
- Include link to WAHTN resources such as Consumer Community Involvement training
- Involve clinicians (non-researchers)
- Establish clear roles and respect consumer boundaries
- Include guides and definitions:
 - Define co-design and the engagement process
 - Guide on how to plan involvement
 - Guide on how to run a group
- Highlight importance of choosing consumers wisely
- Include FAQs about what consumers want
- Recommended minimum number of consumers (e.g., 2)

Conclusions

Through consultation with SMHS consumers, researchers, and the wider community, it became clear that while the majority agreed that consumer involvement in research was highly beneficial to consumers, researchers, and research outcomes, it was difficult to know how to achieve it. These striking similarities between consumer, researcher, and community responses to the benefits and barriers to consumer involvement were in alignment with the prevailing views in the available literature.

Benefits of consumer involvement

Our consultation revealed numerous benefits to consumer involvement in research, including many common themes, such as:

Benefits to research and researchers

- Incorporating consumer perspectives ensures research goals and outcomes are relevant and meaningful to the community, enhancing cost effectiveness and efficiency.
- Consumers from diverse backgrounds or with specific lived experience provide unique insights and knowledge that researchers might otherwise miss.
- Processes are made easier when informed by consumer perspectives (e.g., how to explain research to non-researchers, how to recruit and retain participants, how to disseminate research).
- Builds sensitivity, cultural awareness, the need for empathy, and compassion.
- Builds research capacity and opportunities for collaboration as connections with community grow and become more productive.
- Fulfils grant requirements for consumer involvement.

Benefits to consumers

- Builds health literacy and supports lifelong and life-wide learning.
- Consumers build relationships and social connections with peers and the wider community.
- Potential research participants have consumer advocates.
- Empowerment and catharsis for individuals.
- Deep satisfaction from making a positive contribution (altruism).
- Provides a forum for consumers to have a voice in research.
- Improved healthcare for the community.

Barriers to consumer involvement

Likewise, many common barriers to consumer involvement emerged through the consultation process. These included:

- Power imbalance.
- Uncertainty/lack of confidence (on both sides).
- Practicalities – time, identifying and contacting consumers.
- The complex and specialized nature of health research.
- Communication barriers.
- Lack of clarity on consumer role in research.
- Limited or no funding for consumer involvement.
- Lack of understanding of the value of consumer involvement.

Solutions to barriers

When asked to propose solutions to the barriers they had identified, our group put forward many possible suggestions. These included several recurring ideas, such as:

- **A consumer bank** - to fund consumer involvement in research.
- **A consumer registry** - to make it easier for researchers and consumers to connect.
- **Education sessions** - for consumers and researchers, to address knowledge gaps and shift perceptions around consumer involvement.
- **Consumer and researcher champions/mentors** – to offer support, advice, and spread awareness of the value of consumer involvement.
- **Consumer advisory body for research** – to spearhead consumer involvement initiatives.
- **Networking events** – to break down barriers and build relationships between consumers and researchers.
- **Additional supporting resources** - such as relevant policies and guidelines, a research terms glossary, testimonial videos, and checklists, to help consumers and researchers navigate the consumer involvement process.

The consumer involvement framework

Our consultation group proposed numerous ideas for inclusion in the framework and offered various suggestions for its design. Together, these elements formed a clear vision of the final framework.

Overall, the framework should be:

- Relevant to all SMHS sites
- Simple and easy to read (written in plain language)
- Incorporate (inclusive) visuals to keep it engaging and accessible.

Specifically, the framework should contain:

- Forward from the Chief Executive
- Introduction: vision and purpose of document - linking back to SMHS values
- One-page summary
- Explain 'What is research?'
- Explain importance of involving consumers (particularly with lived experience and from diverse groups)
- Different levels of consumer involvement (throughout all phases of research)
- Clearly defined roles and responsibilities for consumers
- Glossary of research terms
- Consumer Bank
- Education and tips
- Consumer Registry and other recruitment options and strategies
- Supporting resources
- Stories and testimonials
- Acknowledgements

Further conclusions

In response to the outcomes of the workshops and community consultation, our working group concluded that to keep the framework as simple and straightforward as possible, whilst still providing everything that was needed, a new approach was required. Instead of a standalone framework document, we pivoted towards a threefold approach, the three main deliverables being:

1. A framework document, which contains the core principles of research and consumer involvements, as well as key solutions.
2. A workshop outcomes report (this document) to fully detail the outcomes and valuable insights gleaned from the consultation process.
3. A website to host the suite of resources needed to effectively support consumer involvement at SMHS, such as:
 - A SMHS Consumer Bank Fund (CBF)
 - A SMHS Research Consumer Registry
 - A glossary of research terms
 - Education sessions and links
 - Networking events
 - Consumer-researcher champions
 - Testimonial videos and success stories

Outcomes

At the time of writing (August 2024), one of the above deliverables/solutions has been established and launched (CBF) with others currently in development (framework developed and approved, website, registry, glossary, testimonial videos in progress) and more planned for 2025 (education, networking, champions). A community event is planned for Wednesday 27 November 2024 to launch the framework and supporting resources.

With these supports and resources in place it is hoped that consumer involvement in research at SMHS will become increasingly prevalent, accessible, and impactful.

Other outcomes

In addition to the above deliverables, other outcomes of this project to date include submission of a report to the WA Department of Health Sustainable Health Review Partnership Group, a WA Health Award nomination, and a SMHS Excellence Award nomination.

Purpose of this report

This report adds to the existing literature about consumer involvement in research, more specifically within the health service setting. It also provides a template or guide to other health service providers, on how we went about the consultation process, and which solutions may be beneficial to supporting consumer involvement at their own site. Lastly, it captures all the valuable insights gathered during the consultation process, which formed the basis for our framework and supporting resources.

Lessons learned

Prioritising the consumer voice

One of the first and most crucial lessons was the impact of prioritising the consumer voice. By deciding to meet with our consumer and researcher groups separately and consulting with consumers first, we signalled the value of consumers as leaders in the project. This reinforced the importance of the consumer voice and was supported by our consumer lead's active role in planning and facilitating all three sessions and subsequent work, demonstrating the principles of co-design.

Terminology matters

Our literature review highlighted the importance of terminology. We discovered that while 'consumer involvement' and 'consumer engagement' are used interchangeably, 'involvement' more accurately reflected our aim of having consumers meaningfully involved in all stages of research. This insight led us to rename our project to emphasise 'involvement' over 'engagement'.

Synergies in perspectives

Through our workshops, we learned that consumers and researchers share strong synergies in their views on the benefits and barriers to consumer involvement in research. These findings align with prevailing views in existing literature. These synergies reinforced the idea that we were on the right track when it came to developing the framework and resources.

Addressing barriers

The outcomes of our workshops made it clear that developing an effective framework required addressing the identified barriers. Our consultation process helped us identify several potential enablers that could overcome these obstacles.

Adopting a consumer-led approach and closely consulting with both consumers and researchers were integral to our learnings. We could not have arrived at our solutions without carefully listening to and considering both perspectives. Meeting the needs of the end-users (the consumers and researchers) is essential for the project's success. This is a vital lesson that should be applied to consumer involvement in research as well.

Acknowledgements

SMHS would like to acknowledge the many valuable contributions that enabled the development of the framework and the associated solutions (Table 5).

In addition to the below named individuals, SMHS also thanks those who contributed anonymously through the community consultation activity on the SMHS Put it to the People platform.

Table 5: Acknowledgements

Project Team	SMHS Consumer Group	SMHS Researcher Group	SMHS staff
McGavock, Isabella	Brennan, Pip	Ayonrinde, Oyekoya	Atkinson, Tara
Pearce, Jane - Project Lead	Elder, Kerry	Bayes, Sara	Di Lello, Michelle
Wright, Melanie	Purdy, Deborah	Brogan, Emily	Ford, Josie
	Robinson, Pamela	Cavalheri De Oliveira, Vin	Glover, Sarah
	Toffoli, Amelia	Dejong, Helen	Gregory, Lionel
		Fear, Mark	Hodgekiss, Bec
		Gallagher, Olivia	McDonald, Jeff
		Janerka, Carrie	Pudney, Jodie
		Palermo, Anna	
		Rooney, Sarah	
		Truter, Piers	
		Yeap, Bu	

The project has been fully supported by our Executive Director Transformation Tim Leen and the SMHS Research Steering Committee.

References

SMHS/FSFHG documents

[FSFHG Consumer Advisory Council \(CAC\) Annual Report 2022](#)

[SMHS Aboriginal Community and Consumer Engagement Framework](#)

[SMHS Equity, Diversity and Inclusion Plan 2021 – 2025](#)

[SMHS Research Strategy 2023-2033](#)

[SMHS Consumer and Carer Engagement Strategy](#)

[SMHS Consumer and carer participation policy 2019](#)

Research specific consumer involvement/engagement frameworks

[Cancer Australia National Consumer Framework](#)

[NSW Health Mid North Coast Consumer and Community Engagement Framework for Research 2019 – 2023](#)

[SAHMRI Consumer and Community Engagement Framework for the South Australian Health and Medical research Institute 2020](#)

[University of Queensland RECOVER Consumer Involvement Framework 2022](#)

Literature reviews

[Engaging Consumers in Health Research: A Narrative Review 2019-2020](#)

[HCASA Literature Review 2013](#)

Other key documents

[ACSQHC Partnering with Consumers: A Guide for Consumers 2023](#)

[AHRA CCI Measuring Impact](#)

[Department of Health Stakeholder Engagement Framework](#)

[Department of Health Working with Consumers and Carers Toolkit](#) and [WWCC Toolkit Overview](#)

[EY Health Care Consumer Health Survey 2023](#)

[NHMRC Australian Code for the Responsible Conduct of Research 2018](#)

[NHMRC National Statement on Ethical Conduct in Human Research 2018](#)

[NHMRC Statement on Consumer and Community Involvement in Health and Medical Research 2016](#)

[NSW Council of Social Services Principles of Co-Design](#)

[Road map II: A strategic framework for improving the health of Aboriginal and Torres Strait Islander people through research](#)

[UWA/Telethon Consumer and Community Participation in Health and Medical Research](#)

[WA Gov Mental Health Commission Lived Experience \(Peer\) Workforces Framework](#)

[WAHTN Involving Consumers in Health and Medical Research Handbook](#)

This document can be made available in alternative formats on request.

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