

Supplementary Material

Consumer involvement in health service research: a cross-sectional survey of staff in an Australian public hospital and health service

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Supplementary material file S1

Section and topic	Item	Reported on page No
1: Aim	Report the aim of PPI in the study	5
2: Methods	Provide a clear description of the methods used for PPI in the study	Supplementary
3: Study results	Outcomes—Report the results of PPI in the study, including both positive and negative outcomes	Supplementary
4: Discussion and conclusions	Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	Supplementary
5: Reflections/critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience	Supplementary

Supplementary reporting on consumer involvement

Consumers were recruited from the health service's Consumer Advisory Group, which comprises of former patients or health service users and current family or caregivers. They were invited to participate if they met specific criteria: understanding the concept of *consumer involvement* and context, willingness to share their lived experience, and ability to provide feedback.

An inaugural stakeholder meeting was held in November 2022, attended by members of the Consumer Advisory Group, health service researchers and university academics. During this meeting, stakeholders contributed insights into project priorities and assisted in conceptualising and designing the methodology. A research team and an advisory group were formed from this group.

The research team, comprising three health service researchers with varying levels of experience, one academic, and three consumer research partners, actively participated in all stages of the research process. Consumers played a significant role in designing the project. One of the consumers was a principle investigator. They provided specific feedback on survey design, promotion, and interpretation of findings, drawing on their previous involvement in health research and knowledge of

the involvement of consumers in research. While managing expectations within project constraints posed challenges, decisions were made through consensus, with consumer partners in agreement.

Co-designing a consumer involvement in research framework

Survey tool

Consent question:

By selecting yes below and completing this survey, you are consenting to participate in this study.

- Yes
- No

Thank you for agreeing to participate, we appreciate your time.

There are six sections to this survey:

SECTION 1: ABOUT YOU AND YOUR BACKGROUND

SECTION 2: INFORMATION ABOUT YOUR EXPERIENCE WITH CONSUMER INVOLVEMENT

SECTION 3: EXPLORING STRENGTHS IN CONSUMER INVOLVEMENT

SECTION 4: YOUR VIEWS ON THE VALUE AND BENEFITS OF CONSUMER INVOLVEMENT

SECTION 5: YOUR VIEWS ON THE BARRIERS TO CONSUMER INVOLVEMENT

SECTION 6: YOUR VIEWS ON THE SOLUTIONS TO INCREASE OR ENHANCE CONSUMER INVOLVEMENT AT THE HEALTH SERVICE

Q1 Please choose your professional role from the list of options below.

- Medical
- Nursing and Midwifery
- Allied health
- Research
- Dual position (research and clinician)
- Other _____

Q2 Please provide your gender _____

SECTION 1: INFORMATION ABOUT YOU AND YOUR BACKGROUND

Q3 How long have you been working in the healthcare sector (in any capacity)?

- Less than 2 years
- 2 - 10 years
- 10 - 20 years
- more than 20 years

Q4 How long have you been working at this health service?

- Less than 2 years
- 2 - 10 years
- 10 - 20 years
- more than 20 years

Q5 What is your educational background (mark all that apply)?

- Certificate/diploma
- Bachelor's degree
- Honours degree
- Master's degree
- Higher research degree
- Experience working in academia
- Other _____

Q6 How often do you do research in your current role?

- Full time (Over 38 hours per week)
- Part-time (Less than 38 hours per week)
- Occasionally
- Never
- Other (please specify) _____

Q7 During the research you have been involved in, what roles have you played

[mark all that apply]

- Principal/Chief Investigator
- Co-investigator
- Associate investigator
- Trial manager
- Trial coordinator
- Research Nurse
- Research Fellow
- Research Officer/Assistant
- Other _____

SECTION 2: INFORMATION ABOUT YOUR EXPERIENCE WITH CONSUMER INVOLVEMENT

You will now be asked some questions about consumer involvement.

By 'consumer involvement', we mean when researchers work WITH health consumers (e.g., patients, friends, family, carers, paid service workers or consumer groups) on research projects. Consumers might participate in discussions about research priorities or lead or be involved in one or all of the phases of a research project (e.g. conceptualisation, design, data collection, analysis, reporting, implementation, evaluation). Having consumers take part as participants in your project is NOT consumer involvement.

Q8 How much do you agree with this statement?

I know how to involve consumers in research (according to the above definition).

- Strongly Agree
- Somewhat agree
- Neutral
- Somewhat disagree
- Strongly Disagree

Q9 Have you previously undertaken a **research project** which has involved consumers (according to the above definition)?

- Yes
- No
- Unsure

Q10 Have you previously undertaken a research project whilst at **this health service** which has involved consumers (according to the above definition)?

- Yes
- No
- Unsure

Q11 What types of consumer involvement best reflects the approach used in your research whilst at this health service? (mark all that apply)

- Consultation (consumers providing feedback and advice on specific research activities)
- Involvement (consumers working directly with a research team throughout the project)

- Collaboration (consumers partnering on equal footing with researchers in all aspects of research)
- Consumer leadership (consumers leading research decisions and activities)
- Other _____

Q12 Please select which phases of your research you have involved consumers in whilst at this health service? (mark all that apply)

- Identifying and prioritising research topics
- Conceptualisation and design
- Funding application
- Undertaking and managing research (e.g., data collection)
- Participant recruitment
- Data analysis and interpretation
- Dissemination (Including manuscript preparation).
- Implementation
- Monitoring and evaluation
- Other _____

SECTION 3: EXPLORING STRENGTHS IN CONSUMER INVOLVEMENT

Q13 How much do you agree with these statements? (*Likert*)

	Strongly Agree	Somewhat agree	Neutral	Somewhat Disagree	Strongly Disagree
<i>I am confident in networking and consulting with consumers about research.</i>					
<i>I am confident in recruiting consumers (not participants).</i>					
<i>I am confident in identifying research issues and prioritising research goals with consumers.</i>					
<i>I am confident in conceptualising and designing research with consumers.</i>					
<i>I am confident in undertaking a research funding application with consumers.</i>					

<i>I am confident in undertaking and managing research (e.g., data collection) with consumers.</i>					
<i>I am confident in doing data analysis and interpretation with consumers.</i>					
<i>I am confident in disseminating research findings (including manuscript preparation) with consumers.</i>					
<i>I am confident in implementing research recommendations/outcomes with consumers.</i>					
<i>I am confident in monitoring and evaluating research impact with consumers.</i>					

SECTION 4: YOUR VIEWS ON THE VALUE AND BENEFITS OF CONSUMER INVOLVEMENT

Q14 How much do you agree with the following statements: (*Likert*)

	Strongly agree	Somewhat agree	Neutral	Somewhat Disagree	Strongly disagree
<i>Involving consumers in research brings a 'lived experience' and other expertise to the research team.</i>					
<i>Involving consumers in research enhances the relevance of research to the target population.</i>					

<i>Involving consumers in research is often tokenistic.</i>					
<i>Involving consumers in research leads to research that is more culturally responsive.</i>					
<i>Involving consumers in research improves recruitment, participation, and retention.</i>					
<i>Involving consumers in research increases reach and dissemination through consumer/public networks.</i>					
<i>Involving consumers in research reduces research waste.</i>					
<i>Involving consumers in research increases the credibility of research within consumer groups.</i>					
<i>Involving consumers in research gives opportunities for all team members to learn new ways of collaborating.</i>					
<i>Involving consumers in research enables access to funding.</i>					
<i>Involving consumers in some research projects is not necessary.</i>					
<i>Involving consumers in research is important for ethical reasons.</i>					

Q15 What were the key learnings from involving consumers in your research?

SECTION 5: YOUR VIEWS ON THE BARRIERS TO CONSUMER INVOLVEMENT

Q16 How much do you agree with the following statement? (*Likert*)

It is difficult to involve consumers in research at this health service.

- Strongly agree
- Somewhat agree
- Neutral
- Somewhat disagree
- Strongly disagree

Q17 How much do you agree with the following statements: (*Likert*)

	Strongly agree	Somewhat agree	Neutral	Somewhat disagree	Strongly disagree
<i>A barrier to involving consumers in my research at this health service is my own beliefs and motivation.</i>					
<i>A barrier to involving consumers in my research at this health service is forgetting to involve consumers.</i>					
<i>A barrier to involving consumers in my research at this health service is difficulty in finding a suitable consumer(s).</i>					
<i>A barrier to involving consumers in my research at this health service is concerns about breaching research confidentiality.</i>					
<i>A barrier to involving consumers in my research at this health service is challenges in managing consumer expectations and maintaining motivation.</i>					

A barrier to involving consumers in my research at this health service is my lack of skills and knowledge in consumer involvement.					
A barrier to involving consumers in my research at this health service is a lack of time to involve consumers.					
A barrier to involving consumers in my research at this health service is the lack of funding needed to involve consumers.					
A barrier to involving consumers in my research at this health service is the difficulty in managing conflicting views, interests and power dynamics.					
A barrier to involving consumers in my research at this health service is the risks for researchers.					
A barrier to involving consumers in my research at this health service is.... _____.					

Q18 How much do you agree with the following statement? (*Likert*)

I plan to involve consumers in my next research project.

- Strongly agree
- Somewhat agree
- Neutral
- Somewhat disagree
- Strongly disagree

SECTION 6: YOUR VIEWS ON THE SOLUTIONS TO INCREASE OR ENHANCE CONSUMER INVOLVEMENT AT THIS HEALTH SERVICE

Q19 How much do you agree with the following statements? (*Likert*)

	Strongly agree	Somewhat agree	Neutral	Somewhat disagree	Strongly disagree
<i>This health service adequately supports researchers to involve consumers in research (consider finances, resources, training and other requirements).</i>					
<i>This health service should do more to support researchers to involve consumers.</i>					
<i>Most people whose opinion I value would approve of me Involving consumers in research at This health service.</i>					
<i>Academic literature has helped me to involve consumers in my research.</i>					
<i>Education or training has helped me to involve consumers in my research.</i>					
<i>General research frameworks (e.g., NHMRC) has helped me to involve consumers in my research.</i>					
<i>Health, cohort or service specific frameworks (e.g., Cancer Council) has helped me to involve consumers in my research.</i>					
<i>University contacts or resources have helped me to involve consumers in my research.</i>					
<i>Community/consumer contacts or resources have helped me to involve consumers in my research.</i>					
<i>A more experienced researcher (s) on my team has helped me to involve consumers in my research.</i>					
<i>The Consumer Advisory Group at this health service has helped me to involve consumers in my</i>					

research.					
<i>The Community and Consumer Involvement Team at this health service has helped me to involve consumers in my research.</i>					
<i>Something else has helped me to involve consumers in my research. (please indicate)</i>					
<i>Information about available external training on consumer involvement in research would help me to involve consumers in my research.</i>					
<i>This health service's consumer involvement (in research) training for researchers would help me to involve consumers in my research.</i>					
<i>This health service consumer involvement (in research) training for consumers would help me to involve consumers in my research.</i>					
<i>Prompts in the this health service's protocol template and ethics application would help me to involve consumers in my research.</i>					
<i>A step-by-step framework for consumer involvement in research at This health service would help me to involve consumers in my research.</i>					
<i>A designated consumer involvement officer for research at this health service would help me to involve consumers in my research.</i>					
<i>Regular research consultations with this health service consumers to understand research issues and priorities would help me to involve consumers in my research.</i>					

<i>Something else would help me to involve consumers in my research (please indicate).</i>					
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Q20 Do you have any final thoughts about consumer involvement in research at This health service?

Prompt: Could be any experiences of consumer involvement, challenges to Involving consumers or ideas to improve consumer involvement or something else?

Hyperlink to survey titled: Part 2 - register interest in future research

Thank you for taking part in our survey, your responses have now been submitted.

Q1 Can you think of any This health service consumers (who you have undertaken research with), who may be interested in being contacted by the research team about participation in future research linked to this project?

Please note, your response to this question cannot be linked in any way to your responses to the survey.

- Yes Please give them our contact details so they can email us for further information please contact XXXXX.
- No

Thank you for nominating a consumer to be contacted about future research in respect to this project.

Q2 Are you interested in being contacted by the research team about participation in future research linked to this project?

Please note, your response to this question cannot be linked in any way to your responses to the survey.

- Yes
- No

Thank you for indicating you would like to be contacted about future research in respect to this project.

Q4 Please provide your email address for us to contact you.

Your email address will be kept strictly confidential and cannot be linked in any way to your responses to the survey. If you have any questions or if you would like to remove these contact details from our database you can contact us using the information on the next page.

Click **continue** to end the survey.