



Review of the *Statement on Consumer and Community Involvement in Health and Medical Research*

For those that could not attend the workshop on 15 November 2022, these questions were posed during the workshop and provide an opportunity to give feedback to guide the review of *the Statement*.

For those who did participate in the online workshop, this form gives opportunity to give more detailed input than was possible using Menti. There are also new questions at the end of this survey, asking for your feedback on the workshop itself, and how else to be involved in the process.

1. What is your role in consumer and community engagement?

- Consumer
- Consumer advocate
- Research
- Research administrator
- Policy maker
- Interested member of the public
- Other:

Responses collated from multiple stakeholder review (consumers, researchers, program managers).
Answers to questions 4-6 indicate a majority response.



2. What do you see are the major enablers or facilitators of consumer and community involvement in health and medical research?

Committed organisations: Executive leadership to build capacity and capability for effective practice. Embedded structures and processes to enable consumer and community involvement in planning, design and setting research priorities. Monitoring and assessing the level of consumer involvement as an organisational key performance indicator.

Capable researchers and consumers: Education, promotion and communication of the value and benefit of community and consumer involvement to researchers/research institutions. Well-informed researchers who are both aware of the opportunities and have access to tools and evidence-based approaches. Education and skills development for consumers in effective practice, along with regular feedback mechanisms for all stakeholders to enable continual improvement. Shared training approaches with both consumers and researchers facilitates better engagement practices.

Shared focus: Building working relationships where consumers are integral and viewed as valued contributors. Adopting a collaborative approach, clear expectations of the consumer roles by all, and agility in research design to incorporate the expertise of a lived experience at all stages of research; from inception to implementation. Enacting consumer involvement as an approach that involves the development of meaningful relationships that is underpinned by trust and mutual respect, and a commitment by all involved in active two-way dialogue. Involvement indicates action that is more than simply taking part.

Funding agencies: Provide clear criteria and guidance of consumer involvement across the research cycle and incorporate metrics for assessment of the level and quantity of consumer engagement throughout the research proposal. Connect funding to evidence of engagement with consumers.



3. What do you see are the major barriers or challenges for consumer and community involvement in health and medical research?

Organisations: Poor leadership and cultural acceptance of lived experience as a source of valuable expertise could be strengthened. Limited infrastructure to develop and support consumer involvement in research strategy across the organisation. Inadequate organisational attention to diversity and inclusion.

Researchers and consumers: Limited educational offerings to support the professional development of researchers, consumers, and institutional leaders. Inconsistent use of evidence-based resources to support working together respectfully and meaningfully with consumers and communities. Communication barriers that lead to mis-aligned expectations and comprehension. For the cancer sector, lack of appreciation for the time and energy commitment for long research projects when consumers are simultaneously dealing with a chronic illness.

Shared focus: Minimal involvement with consumers that results from a lack of understanding of the richness, benefits and meaning for what effective practice can achieve. The continual misperception that time and complexity is a barrier to meaningful engagement.

Funding agencies: Lack of clarity on definitions and expectations of co-design and consumer-led research, combined with limited empirical evidence around the impact of consumers in research. Not having defined assessment criteria and metrics for grant review panels. Limited funding opportunities specifically intended to support consumer-led research projects.

4. What is your level of familiarity with *the Statement on Consumer and Community Involvement in Health and Medical Research (2016)*?

- I am not familiar with *the Statement*
- I am familiar with *the Statement* but have not used or referenced it in my work/involvement in health and medical research
- I am familiar with *the Statement* and have not used it myself, but it has been used/referred to by colleagues in my research organisation
- I have used/referred to *the Statement* in my research activities but have not yet fully integrated it into practice
- I have fully integrated the principles of *the Statement* in my research activities

5. [For institutions and researchers] How would you rate the awareness of *the Statement* across your institution?

- No awareness
- Low
- Moderate
- High
- Very High



6. [For consumers] If you've been involved in research projects as a consumer participant/representative, how would you rate the following:

a) How well researchers and institutions are aware of the need to include consumer voice:

- No awareness
- Low
- Moderate
- High
- Very High

b) How well the researchers integrated consumer voice into the research activities:

- No awareness
- Low
- Moderate
- High
- Very High

7. What have you found useful about *the Statement*?

The Statement illustrates that NHMRC encourages researchers to consider consumer involvement in research. Importantly, the document provides definitions, is a useful reference resource, and presents a state, national and international perspective.

The Statement fulfils a purpose to provide information about the benefits and importance of consumer involvement at various stages of the research cycle. The Statement is a framework giving an overview of consumer and community involvement together with considerations on how to integrate best practice into research design. Useful as an educational resource for students.



8. If you have used/referred to The Statement in research activities, what do you perceive as a gap that needs to be addressed?

Strengthen intent and purpose: The Statement ‘encourages’ utilisation of consumers so researchers can maximise quality of research outcomes. The language is tentative and should be more definitive in expressing strategic intent, benefit, and value through involvement and inclusion of a lived experience. The tone could be more direct to ensure the lived experience is an element of all health and medical research. The Statement currently includes principles, values, and briefly refers to implementation strategies. Either enhance the implementation components to illustrate best practice or create accompanying resources for implementation. In addition, the language is high level that can be misinterpreted in practice. Ensure language is inclusive and accessible.

Account for changing practice: Consumer and community involvement practice has evolved since 2016, in conjunction with acknowledging diversity and inclusive practices. Communication with community groups and peak bodies can be added as appropriate. Emphasise that a consumer’s responsibility is to bring the expertise of a lived experience and to share their perspective with researchers to expand knowledge. Health and medical research is ultimately to benefit patients and improve patient outcomes, consumer involvement is one mechanism to assist this goal. The VCCC Alliance Model of Consumer Engagement would be a very worthy addition to the Appendix 2 list (<https://vccc.alliance.org.au/our-work/consumer-engagement/model/>).

Define consumer-led research: There is no clear consensus / definition from funding agencies for what is meant by consumer-led research. This leads to confusion across all stakeholders including consumers, community, researchers, and institutions. Describe consumer-led research in a practical and meaningful way that demonstrates that the power of decision making remains with the consumer. Responsibilities and accountabilities may differ throughout the project as researchers collaborate to ensure quality and robust research design and outputs. Differentiate between co-design, which is an iterative developmental approach with consumers to direct research questions, design, and implementation.

Relevance: The Statement needs to reflect the current environment and expectations of consumer and community involvement. For example, inclusive practice, support and learning opportunities, governance, and remuneration (examples include, UK Standards for Public Involvement, Victorian Cancer Agency Statement on Consumer Engagement).

9. What principles and values should be reflected in the updated *Statement*?

- Diversity and inclusion.
- Collaboration and partnership with diverse representation of the lived experience.
- An empathetic and compassionate approach with two-way communication.
- Relevant, meaningful, and confidential.
- Respect, commitment, and a shared focus.
- Strong emphasis on social determinants.



10. What roles, expectations and responsibilities for consumers should be reflected in the updated *Statement*?

Role: The consumer's role in a research team is to bring the expertise of a lived experience and to share their perspective with researchers to expand knowledge.

Expectations: Consumers require information about time commitment and level of involvement requested to make an informed decision before joining a research team. It should be clear that consumers can decline if there is no interest or can see no value resulting from their involvement. Experienced consumers expect involvement at the early stages of research development to aid prioritising research direction. There is an expectation to receive information in accessible language about the parameters of the project. If necessary, skill development or training that can assist their roles, and remuneration for their time and contribution with reimbursement for out-of-pocket expenses.

Responsibilities: Consumers often feel underutilised by research teams. Strengthen the opportunities to interact with other consumers and community groups, be part of advocacy for a research area, and provide relevance to the area of health and medical research. The responsibility for grant application review to have a comprehension of all levels of consumer engagement *Informing, Consulting, Involving, Partnership, Consumer-led* (<https://vccalliance.org.au/our-work/consumer-engagement/model/>).

11. What responsibilities for researchers should be reflected in the updated *Statement*?

- Providing clear expectations and parameters of the project to enable informed decision making for consumer involvement being requested.
- Demonstrating evidence of meaningful consideration of consumer and community involvement throughout the research cycle, and ensuring all consumers feel safe and comfortable to contribute.
- Allowing time with consumers for briefing of the research and advocating for multiple consumers on a project.
- Including budget for consumer remuneration, reimbursement, education and training, conference/workshop attendance.
- Committing to cultural inclusion training and writing in Plain English. To undertake research that actively seeks out experiences of underserved groups to improve equity of outcomes.
- Gathering evidence and reporting on the impact of consumer involvement research. Creating a learning and feedback mechanism that leads to improved engagement practices.
- Incorporating the expertise of a lived experience at all stages of research; from ideation to implementation.



12. What responsibilities for institutions should be reflected in the updated *Statement*?

- Create a research culture that ensures consumer and community involvement is a priority output supported by appropriate policies and procedures on the how, when, and why consumers can be involved in research.
- Support for researchers, staff and consumers integration throughout the Institution through provision of education and training to support the research, consumer, and executive workforce. In addition to systems, policies and guidelines need to be in place.
- Consider and provide appropriate remuneration.
- Utilise consumer and community voices to ensure research targets.

13. If you attended the online workshop on 15 November 2022, how would you rate your experience?

- ☆
- ☆ ☆
- ☆ ☆ ☆
- ☆ ☆ ☆ ☆
- ☆ ☆ ☆ ☆ ☆

14. If you attended the online workshop on 15 November 2022, do you have any feedback on the workshop that you would like to share?

The workshop was organised well; however, the purpose and intent were not clear and led to confusion amongst attendees. The didactic format did not allow opportunity for discussion, or to address some of the key issues raised. Additionally, it seemed to surprise the organisers of the level of enthusiasm, degree of feedback received through the 'chat' function, and the request for more consultative opportunities to update the 2016 Statement.

15. How else would you like to be involved in the review process? Please share your suggestions and ideas for consumer involvement, feedback and co-design.

VCCC Alliance works with consumers, researchers, clinicians, and program managers and can be a multistakeholder group for further consultation of a revised draft statement.

VCCC Alliance is willing to share learnings obtained through development of a consumer engagement strategy.



16. Would you like to provide any other feedback?