



Review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research – Position Paper Questions

We are encouraging all interested stakeholders to provide a written submission to the questions in the NHMRC Consumer Statement Review Position Paper via NHMRC's Consultation Hub. These questions will also be discussed in an open forum at Australia-wide workshops in the first half of 2024.

You may enter your responses directly using the online survey. If you provide an email address, you can save your progress and return to the survey as many times as you wish while it is open.

This document has been developed for individuals and organisations who would prefer to prepare their responses offline, for entering on NHMRC's Consultation Hub once complete. It contains the discussion questions in the order that they appear in the online survey.

Please note that none of the questions below are mandatory, and that there is no word or character limit for each question in the online survey. You are welcome to provide a response to as many or as few questions as you wish. You will also be asked some questions about you or your organisation when you complete the online survey.

Please ensure that you have read the Position Paper (available for download on the Overview page of the survey) prior to answering the questions.

The current Statement and importance of consumer and community involvement in research

The current (2016) statement is available for download from NHMRC's website at:
<https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research>

- What parts of the current Statement have or have not worked well?

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

The Statement can be strengthened in the following ways:

Intent and purpose: *The Statement 'encourages' utilisation of consumers so researchers can maximise quality and relevance of research outcomes. The language is tentative and should be more definitive in expressing strategic intent, benefit, and value through involvement of the lived experience. The tone can be more direct to ensure the lived experience is an element of all health and medical research. The Statement currently includes principles, values, and ventures into implementation strategies. Mixing the intentions of the Statement dilutes the purpose. 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 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 balance of decision-making power 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).*

- Why is consumer and community involvement in research valuable?

Involving consumers and integrating the lived experience ensures that research funded with public money is being used to meet the needs and values of the population. Consumer and community involvement can help to enhance or improve the relevancy of research, consumers have an opportunity to use their lived experiences to inform and influence research direction.

- Why does consumer and community involvement in research matter to you?

The VCCC Alliance is a powerful partnership of leading research, academic and clinical institutions working together to accelerate and amplify leading-edge cancer research. Through innovation and collaboration, the alliance is leading the development of integrated, consumer-informed research, education, and patient care models. A dynamic, inclusive approach is utilised to ensure consumer involvement is embedded throughout the organisation to keep patient-centred as a core value.

Value Statement

A value statement is important as it is a brief, high-level statement that underpins and acknowledges the spirit and purpose of consumer and community involvement in the research cycle. The value statement will help to embed the aspirations of the principles into better practice.

- What overarching values are essential to include in the value statement of the revised Consumer Statement, and why?



- *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.*
 - *Respectful, commitment, and a shared focus.*
- The values that underpin the 2016 Statement are ‘shared understanding, respect and commitment.’ How might this be strengthened and improved in the revised Consumer Statement?

The three values used in the 2016 Statement still apply to consumer involvement in research. A shared understanding aids the bringing together of diverse perspectives, developing respectful working relationships is foundational for engagement practices between different stakeholders, and it does take commitment and resourcing to do effective involvement.

- Should values such as accountability, transparency, collaboration and partnership, equity, diversity and inclusiveness be included in the revised Consumer Statement?

No matter what values are used, provide clear expectations on how the values translate into practice for consumers, researchers, and involvement approaches. The values, once decided, should be adopted by the research community at large, and promoted by NHMRC that aims to be instil the highest ethical standards for health and medical research.

Better practice principles for consumer and community involvement in research

The Position Paper provides some examples of broad principles that could be included in the revised Statement. You are welcome to provide comments on these examples, or on any other principles you would like to see included.

- What do you regard as the most important principles that should be included in the revised Consumer Statement?

Refer to the UK standards for patient and public involvement (<https://sites.google.com/nih.ac.uk/pi-standards/standards>)

- ***Inclusive opportunities*** Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.
- ***Working together*** Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.
- ***Support and learning*** Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.



- **Communications** Use plain language for well-timed and relevant communications, as part of involvement plans and activities.
- **Impact** Seek improvement by identifying and sharing the difference that public involvement makes to research.
- **Governance** Involve the public in research management, regulation, leadership, and decision making.

Roles and responsibilities

The Consumer Statement Review Position Paper provides some examples of roles and responsibilities of **consumers and community members, researchers, research institutions and research funders** that could be included in the revised Statement. You are welcome to provide comments on these examples, or on any other roles and responsibilities you would like to see included.

- What roles and responsibilities for **consumers and community members** should be included in the revised Consumer Statement?

Roles and responsibilities

- *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.*
- *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/>).*

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.*

- What roles and responsibilities for **researchers** should be included in the revised Consumer Statement?

Roles and responsibilities

- *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 in 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.*
- Should involvement of consumers and community members be an expectation of research?
- Yes
- No
- Not sure

Provide reasons for your response below.

Involving consumers in health and medical research is an obligation of the research sector. It is now widely accepted in developed countries that people affected by research have a right to have a say in how it is conducted and translated into policy and practice. The World Health Organisation's Declaration of Alma-Ata 1978, VI 'people have a right and duty to participate individually and collectively in the planning and implementing their health care'. This statement has underpinned global movements for greater involvement of consumers in health services and research.

- Is there an ethical imperative to involve consumers and community representatives in research?
- Yes
- No
- Not sure

Provide reasons for your response below.

Underpinning consumer involvement is an 'ethic of responsibility'; a responsibility to attend to different perspectives in health and medical research. There are relationships of responsibility between patients as research participants, and with consumers as research partners for non-clinical and clinical researchers. There is an imperative to build trusting relationships and two-way learning as a means of authentic engagement practice. (Laidlow et al. 2022. Future Healthcare Journal 3: 238–42)



- What roles and responsibilities for **research institutions** should be included in the revised Consumer 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.*
- What roles and responsibilities for **research funders** should be included in the revised Consumer Statement?

Roles and responsibilities:

- *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. The 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 causes confusion.*
- *Connect funding to evidence of engagement with consumers. Having defined assessment criteria and metrics for grant review panels. Provide funding opportunities specifically intended to support consumer-led research projects.*
- Should funders of research mandate the involvement of consumer and community representatives in the research they fund?

- Yes
- No
- Not sure

Provide reasons for your response below.

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Important considerations and structures are required as funders mandate involvement of consumer community:



- *Provide clear definitions and expectations of consumer involvement, combined with defined assessment criteria and metrics for grant review panels.*
- *Education, promotion and communication of the value and benefit of community and consumer involvement to researchers/research institutions.*
- *Develop 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.*
- *Budget line for consumer remuneration, consumer skill development, education and training costs, and reimbursement.*

Implementing the revised Statement

The revised Statement is intended to be a high-level, overarching document that does not focus on issues related to implementation of consumer and community involvement in health and medical research. However, we acknowledge that you may like to share your views on how the revised Statement may be implemented. Responses to the questions on this page may be used to develop implementation guidance once the revised Statement is published.

- How should researchers involve consumers and community representatives in their 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.*

- What issues should be considered once the revised Consumer Statement has been finalised and published?

Develop and implement a communications strategy that has:



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- *Broad outreach to health and medical researchers with support from research associations and organisations.*
- *Clear intent and purpose for why the Statement has been revised and the vision to enhance future research practice.*
- *Provide an outline on how the NHMRC will use the Statement through the development of grant schemes and assessment.*
- *Ensure the 'Values' are more than just words and are a way of working for all associated with NHMRC funding.*