

Response to 'Review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research' online survey questions

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

There is one part of the Statement that is not working well, which is the lack of a clear distinction between *consumer participation* and *consumer involvement* in research. In consumer participation, an individual volunteers to participate in a research study after giving informed consent, and is the subject of the research. Consumer involvement refers to individuals working in partnership with researchers, to inform the design of a research study, how the research is undertaken, and how the study results are shared and applied. As an example, feedback from an NHMRC grant review panel member suggests that many researchers are still referring to qualitative studies, where research participants provide their views on a particular topic, as examples of consumer involvement. Therefore, these two roles need to be more clearly defined in the revised Statement.

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

The importance of meaningful consumer involvement in the research process is now well recognised, and incorporating the lived experience is key to impactful research. Health and medical research in Australia is largely funded from the public purse, therefore from an ethical standpoint, it is critical researchers ensure their studies reflect the priorities, needs and preferences of consumers, who are the end-users of this research.

Consumers are able to contribute to research in a variety of ways, including by guiding and providing input to researchers to influence decisions about research priorities and how research is conducted, as well as about policy and practice. Critically, the involvement of those with a lived experience ensures research outcomes are relevant to the needs of the community, which facilitates the translation of research into practice.

Survivors of stroke, families, carers and the community are central to stroke research. We know that when researchers and people with lived experience of stroke work together, the quality of research is better and it is more impactful. People living with stroke are uniquely placed to help guide researchers with many aspects of their work, including study design. For example, one in three survivors of stroke will experience difficulties with communication, including difficulties talking, reading, writing or understanding other people when they speak (aphasia). Having lived experience experts as part of a research team helps to ensure challenges faced by survivors of stroke, such as communication difficulties, are properly addressed during the design and development of resources and programs. Lived experience of stroke is the cornerstone of Stroke Foundation's work, especially its Research Program. At each stage of the Program we listen to, involve, engage, collaborate with, and empower members of our stroke community, to ensure our research priorities address the areas that matter most to them. Stroke Foundation has developed an e-learning module for researchers on 'Working effectively with people with lived experience to design, conduct and promote stroke research'. Importantly, all researchers who apply for Stroke Foundation research grants are required to complete this e-learning module, and must clearly explain how they will include consumer involvement in their research.

3. 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?

Stroke Foundation strongly supports the values of 'shared understanding, respect and commitment' that underpin the current Statement, but believes these values could be strengthened by linking them to specific principles (statements that describe these values in more detail, providing further information and context). One example is the Involve/NHS NIHR 'Public involvement in research: values and principles framework' (<https://www.invo.org.uk/wp-content/uploads/2017/08/Values-Principles-framework-Jan2016.pdf>). In this framework, the value 'respect' is underpinned by the following principle: Researchers, research organisations and the public respect one another's roles and perspectives. Further, this principle has a number of associated

‘principles in practice’, which put the principle into practice, and provide an example of good practice, such as ‘Public members are included as key partners of research’.

These values of ‘shared understanding, respect and commitment’ could also be strengthened by implementing specific structural changes to ensure accountability. For example, the NHMRC could create a separate category in grant applications for the quality of consumer involvement. In addition, the NHMRC could set a target for the inclusion of consumers with scoring power on grant review panels, who could assess the quality of consumer involvement (like the MRFF does). Other structural changes that are needed include removing the barriers to having consumers as Chief Investigators (CIs) on grants. The current Sapphire grant management system is not fit for purpose for this and creates barriers to access, for example by requiring an individual to be affiliated with a research institution. Further, capability statements and publication requirements should be amended to better reflect an understanding of a consumer CI’s skills and experience.

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

Role

Consumers play an important role advising researchers, drawing on their lived experience, and can be involved in a range of research activities, including planning, governance, research design, recruitment, funding applications, undertaking research, and communicating research findings. Consumers can also play a role in championing research, and supporting/mentoring other consumers to be involved in all aspects of research. Importantly, the form and degree of consumer involvement should be appropriate to the specific project and the cohort of consumers, and roles and responsibilities should be determined and mutually agreed to by all members of the research team, to ensure they are appropriately matched to team members.

Responsibilities

- Engage with tasks relevant to their knowledge and experience and seek additional support where there may be limitations in that experience or knowledge, in order to meet agreed expectations for their involvement.
- Offer their knowledge, skills, experiences and networks as appropriate to a given research task or activity, while recognising the limits of their own knowledge and experience.
- Respect the knowledge, roles and responsibilities of other team members, and work collaboratively and constructively, to add value to the research activities and teams they are involved in.
- Seek mentorship and guidance from researchers and their institutions as to the regulations, guidelines and processes/methods that must be complied with, and respect and comply with those requirements.

5. What roles and responsibilities for researchers should be included in the revised Consumer Statement?

Role

Researchers can play a number of roles, facilitating and championing consumer involvement in research, demonstrating leadership in this area, and in some cases, mentoring and/or supporting consumers who are interested in developing skills in this field.

Responsibilities

- Work with consumers to help them define their role, responsibilities and expectations of how they will be involved in the development, conduct and communication of research.
- Treat consumer partners as equal members of the research team, and provide them with the support they need to meet agreed expectations.
- Actively understand, and address the needs, barriers and burdens of consumers and create accessible ways of working with them.
- Recognise the contributions that consumer partners make to research studies, including when findings are formally presented and published, and report on the nature of consumer involvement in research.

- Undertake professional development with consumers and other researchers in order to learn from each other's knowledge, experience and best practices.

6. Should involvement of consumers and community representatives be an expectation of research?

- Yes
- No
- Not sure

Please provide reasons for your response below.

For the reasons outlined in our response to Question 2, Stroke Foundation agrees that the involvement of consumers and community representatives should be an expectation of research. We recognise however that there is no one size fits all approach to ensure optimal consumer involvement in research. For each research project, a variety of factors, including the stage and nature of the research (e.g. pre-clinical vs clinical), the research team, the availability of resources, and the level of interest and capacity of consumers to be involved, will inform what the most appropriate approach to consumer involvement will be.

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

Role

Research institutions should lead by example, and demonstrate their commitment to consumer involvement in research by embedding a consumer focus within their organisational culture, and involving consumers in key areas of their work, including the development of relevant policies and procedures, as well as in their own governance structures.

Responsibilities

Research institutions must ensure that the governance arrangements and processes associated with consumer involvement in research are not overly burdensome for researchers or their consumer partners. Research institutions are also responsible for making the necessary investments to facilitate consumer involvement in research, including:

- Efficient processes and guidelines for activities such as consumer recruitment, induction and remuneration.
- Access to training, mentorship, resources and other supports for consumers and researchers.

Research institutions are also responsible for holding their own researchers accountable for meaningful consumer involvement in their work.

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

Role

Research funders should lead by example, and demonstrate their commitment to consumer involvement in research by involving consumers in key areas of their work, including grant review and funding decisions and the development of policies and procedures, as well as in their own governance structures.

Responsibilities

- Develop scoring criteria and weighting for the assessment of consumer involvement in research.
- Provide grant review panels, including consumer reviewers, with guidance and training on how to review and score consumer involvement in grant applications.
- Require specific reporting by researchers on consumer involvement activities throughout the life-cycle of a grant.
- Deliver real consequences if promised consumer involvement activities are not met without a reasonable justification.

- Provide researchers with clear expectations of how consumers should be involved in research and best-practice guidance on the recruitment and remuneration of consumers.

9. Should funders of research mandate the involvement of consumer and community representatives in the research they fund?

- Yes
- No
- Not sure

Please provide reasons for your response below.

For the reasons outlined in our response to Question 2, Stroke Foundation agrees that funders of research should mandate that consumer and community representatives are involved in research that affects them; however, as outlined in our response to Question 6, we recognise that for each research project, a variety of factors will influence the type and extent of this involvement.

Currently, there are very few mechanisms for funding the involvement of consumer and community representatives in the early co-design/development of grant proposals, and this is a major barrier to meaningful consumer involvement in this part of research process. Should funders mandate consumer involvement in research, it is critical that seed funding is prioritised to facilitate their involvement in grant development.

It is important to note that there are some areas of research, such as the basic sciences, where researchers are still determining the best ways to involve consumers, as their research topics may not easily lend themselves to consumer involvement. For areas such as this, funders should continue to strongly encourage consumer involvement, while understanding that researchers may need more time and support in order to meet expectations.

10. How should researchers involve consumers and community representatives in their research?

Stroke Foundation believes that the way in which researchers should involve consumers and community representatives in their research needs to be underpinned by the values and principles detailed in the Statement; however, as outlined in our response to Question 6, the specific approach used will be influenced by a variety of factors. Researchers should consult regularly with consumers to understand their priorities and how they want to be involved in the research project, and ensure they are clear on their roles and responsibilities. It is important that researchers foster an environment where consumer involvement is safe and supported. For example, where possible, it is good practice to include more than one consumer on a research project for a number of reasons, including diversity of opinion and experience, and to protect people against power imbalances. For consumers that are new to the role, there need to be procedures in place to ensure appropriate peer support and mentoring, ideally via another more experienced consumer. Researchers should ensure consumers have access to the support, training, and information they need to contribute to their full potential, and are appropriately remunerated for their time and contribution.

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

Stroke Foundation believes that in and of itself the publication of the revised Statement is unlikely to result in any significant shift in the way consumers are involved in research. Rather, the publication of the revised Statement must be accompanied by investment by both funders and research institutions in the training, infrastructure, processes, and resource development needed to enable meaningful consumer involvement. For example, a central repository of best-practice guidance and templates could be developed for a wide variety of topics, such as the recruitment and remuneration of consumers, governance structures, and authoring publications, in order to assist researchers wanting to involve consumers in their research. As this field is evolving rapidly, Stroke Foundation would support a 'Living Guidelines' approach, where new resources and examples of best-practice undergo peer-review, and are collated and shared with researchers in a timely way.

Awareness of the current Statement among researchers and consumers is limited. There are opportunities to raise awareness of the revised Statement once it is published, for example by ensuring it is included as part of compulsory research training for undergraduate to postgraduate students. In order to raise awareness of the revised Statement among consumers, it is important they are engaged in co-designing implementation strategies for the Statement.

The intended audience of the Statement is important in determining the language that should be used, the way it is presented, and its accessibility; however, currently it remains unclear whether the audience is limited to stakeholders for whom roles and responsibilities have been defined in the Statement (consumers, researchers, research institutions and funders), or is more broad. Similarly, it is unclear whether the expectation is that the Statement will only be used for NHMRC-funded research or for all research undertaken in Australia.