



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

1. Demographic of respondents

Category	Workshop	Survey
Consumer	3	13
Consumer advocate	18	8
Research	25	6
Research administrator	22	7
Policy maker	4	1
Interested member of the public	1	2
Other	8	5

2. Feedback on the enablers/facilitators and barriers/challenges for consumer and community involvement in health and medical research

Enablers and facilitators

- Organisational/program/project level leadership. Having the appropriate policies and requirements in place to provide a framework is critical for successful consumer and community involvement.
- Training and support – where available.
 - for consumers interested in getting involved in health and medical research -as well as pathways for people to do so.
 - for researchers looking to involve people about whom research is being conducted
- Having a budget for consumer involvement, including grant funding and payment or reimbursement for consumers.
- Social media and internet are crucial for funding and facilitating consumer and community involvement.

Barriers and challenges

- Lack of funding for grants and non-standardised payment/reimbursement for consumers. Often consumers are asked to donate their time.



- Culture. Consumer and community involvement is often seen as burdensome and unnecessary, meaning it can be reduced to a performative or 'tick box' activity lacking any meaningful engagement.
- The lack of training and support to engage with consumers. Meaningful consumer involvement requires a different set of skills to those frequently used in some research environments, so support to build these skills early is important.
- Researchers find it difficult to find the right consumers, particularly if they do not have access to administrators who can support consumer involvement at their institutions.
- Meaningful consumer and community involvement activities is a significant time commitment. Many researchers do not have the time nor resources in their grants to manage this effectively.

3. Perceived gaps that should be addressed as part of the Statement review.

- There is no emphasis on consumer involvement being relevant to research across the translation pipeline. It would be useful to provide evidence supporting the impact of consumer engagement in research.
- Information on how to connect consumers and researchers that are well-matched.
- Additional supporting documents and training modules.

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

- Early involvement of consumers in research
- Respect and recognition of the value each party brings to the project
- Commitment to integrity, and to forming partnerships that are diverse, effective and equitable
- Accessibility of research information in plain language, and information made available in other languages where necessary