Review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research

13. What is the name of your organisation?

Cancer Council Australia

14. Is your organisation located in an urban, regional, rural or remote area?

Note: if your organisation has multiple locations, you may select all options that apply.

- [✓ Urban]
- Regional
- Rural
- Remote

15. Which state or territory is your organisation located in?

Note: if your organisation has multiple locations, you may select all options that apply.

- [✓ Australian Capital Territory]
- [✓ New South Wales]
- [✓ Northern Territory]
- [✓ Queensland]
- [✓ South Australia]
- [✓ Tasmania]
- [✓ Victoria]
- [✓ Western Australia]
- Outside of Australia

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

You can view the current Consumer Statement here: Statement on consumer and community involvement in health and medical research

Please provide comments in the free text field below

Within our current ways of working, we do not use this Consumer Statement, and are not able to comment directly on which parts of this current Statement work well/or not. We have developed an internal organisational policy around the appropriate engagement of community members and those with lived experience into our policy and advocacy work.

As part of this review, we strongly recommend that consideration is given to refreshing the language that is employed within the Statement to fit with more current understandings of ‘consumers’. Significant research now supports that generally people no longer identify with the phrase ‘consumer’ to describe those within the community who have lived or living experience and who participate in health and medical research.[1-4]

The terms “consumers” and “community” do not reflect the role of all stakeholders with lived experience who are involved in research activities. The preference is for flexibility in the terms used to allow the person to choose how they identify in their role. There is momentum at a national level around incorporating more community friendly language, that it would be useful for the NHMRC to be part of to gain consistency in language for this Statement. This includes for example Cancer Australia and the Australian Cancer Plan, and the National Consumer Engagement Strategy for Health and Wellbeing released in 2023 by the Department of Health and Aged Care.

17. Why is consumer and community involvement in research valuable?

Please provide comments in the free text field below.

Community and lived experience involvement in research is important to ensure that research is sensitive, appropriate, and responsive. The value of community involvement cannot be overstated when aiming to develop research- whether basic or complex- that will improve outcomes and influence policy. On the individual level, supporting people to be involved in research can empower them and the community that they represent to be better able to advocate for their own health needs.

People with lived experience have a unique understanding of how systems and procedures work in practice, not just how they should work in theory. Incorporating this real-world experience into the design and development of trials and interventions can support the success of research.

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

Please provide comments in the free text field below.

Focused investment prioritising Australian research in Australian settings to improve cancer outcomes is essential, and where practical people with cancer, and their families and communities, should be supported with the opportunity to participate in research or clinical trials.

First Nations Australians, people from culturally and linguistically diverse communities, and people who live in regional, rural and remote areas, are currently significantly underrepresented in research and clinical trials in Australia. Supporting opportunities to improve equity of access to participation in research will ensure that the research outcomes are more likely to be reflective of the communities needs and wants, applicable to all members of our community, and policy-relevant. This revised Statement provides a critical opportunity in its implementation to be able to reach those community members who may not have participated before, due to a range of equity issues, and build their skills and confidence in being able to participate fully.

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

Please provide comments in the free text field below.

From our perspective, the values of inclusiveness and diversity are imperative when considering lived experience and community involvement. These should be accompanied by the existing value of respect.

20. 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?

You can view the current Consumer Statement here: Statement on consumer and community involvement in health and medical research

Please provide comments in the free text field below.

The value of shared understanding could be improved by promoting a stronger focus on inclusiveness, diversity and collaboration in research.

We would suggest the value of trust is better placed in this strategy. Developing trusting relationships between researchers, policy-makers and community members is an essential component of a Statement like this, to ensure best outcomes in participation can be achieved.

Respect remains an important value.

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

Please provide comments in the free text field below.

Yes, we support each of these values being included in the revised statement. We would also add trust as an important value that should be considered for inclusion in the Statement. It is essential to build relationships with communities in an ongoing capacity, that might not directly relate to immediate policy outcomes, but are critical to genuine collaboration with communities and people with lived experience.

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

Please provide comments in the free text field below.

The most important principles to include in the statement should be reflective of the proposed values. The principles that best reflect the proposed values we believe are the following:

- Respect for lived experience and community expertise (source: Principles of Community Engagement – CDC US Publication)
- Consumers and community members should be involved with broad diversity and equity (source: MRFF Principles)
- Consumers and community members should be involved at all stages of research (source: MRFF Principles).

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

Please provide comments in the free text field below.

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

Please provide comments in the free text field below.

In engaging community members in research, there are a number of responsibilities of the researchers to ensure safe, effective and equitable participation and engagement. These might include:

- Clear, plain-English summaries of the project and what will be required of community members in participating (time, engagement etc);
- Clear remuneration and/or reimbursement information (and developing a standard organisational process for remunerating community members);
- Pre-project meet and greet meetings between the individual and project team, to answer any questions, talk through process (how the project/meetings will work), provide information on other community members and content experts who are participating; and
- Discuss how the community member would like to best contribute/be engaged and involved.
- Encouraging communication methods with the project team and other community members involved.
- Provide de-brief and regular check-in opportunities.
- Provide any learning/education to support and supplement.

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

- [✓ Yes]
- No
- Not sure

Please provide reasons for your response below.

Involvement of community representatives should be an expectation of all research conducted by and funded through NHMRC, although it is up to individual organisations, funding bodies, publishers, and leaders to ensure that the voice of lived experience and community is prioritised in the development of research safely. As eventual beneficiaries of the research outcomes, the involvement of lived experience representatives and community members, can enhance research applications and viability as well as ensuring patient safety and improved outcomes.

26. Is there an ethical imperative to involve consumers and community representatives in research?

- [✓ Yes]
- No
- Not sure

Please provide reasons for your response below.

Appropriate involvement of lived experience in research design, management and conduct can ensure that research addresses the perceived needs, and the felt needs of people. Therefore, there is an ethical imperative to involve people with lived experience and community representatives in research to ensure that the research is meeting the needs of the community.

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

Please provide comments in the free text field below.

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

Please provide comments in the free text field below.

Research funding should require research projects to clearly involve community representatives.

29. 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.

This change should happen from the top down, with community and lived experience involvement being prioritised by systems owners such as funding bodies. This can be more easily implemented through a mandated process. People with lived experience should be acknowledged and remunerated appropriately for their time spent on research projects, where they are a part of the research team, and this needs to be factored in to grant funding applications and budgets.

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

Please provide comments in the free text field below.

Community representatives and people with lived experience should ideally be involved at every stage of research, from inception to reporting and dissemination. People may want to engage in different ways, and to different degrees and this should be decided in consultation with the research team and the community and lived experience members. It should be a priority to build the capacity of those involved through offering training, and support where needed.

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

Please provide comments in the free text field below.

There is the risk that by increasing the importance of community and lived experience in research, the level of tokenistic engagement will increase too. This must be monitored, ensuring that researchers are engaging in an appropriate, empowering and safe manner.

1. Hutchison B. Consuming healthcare: what's in a word? Healthc Policy. 2006;2(1):8-12.
2. Waterland JL, Beer C, Forbes Shepherd R, Forrest LE. Exploring Consumers' Motivations and Experiences of Engaging as Partners in Cancer Research. The Patient - Patient-Centered Outcomes Research. 2024.
3. Deber RB, Kraetschmer N, Urowitz S, Sharpe N. Patient, consumer, client, or customer: what do people want to be called? Health Expectations. 2005;8(4):345-51.
4. Costa DSJ, Mercieca-Bebber R, Tesson S, Seidler Z, Lopez AL. Patient, client, consumer, survivor or other alternatives? A scoping review of preferred terms for labelling individuals who access healthcare across settings. BMJ Open. 2019;9(3):e025166.