

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



The National Health and Medical Research Council (NHMRC) and the Consumers Health Forum of Australia Ltd (CHF) undertook a review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research. In March 2024, a public consultation was opened to inform the Statement review. Cancer Council are supportive of the review of the Statement and welcomed the opportunity to provide input to this consultation.

In our submission, we highlighted the biggest opportunities for improving the Statement on Consumer and Community Involvement in Health and Medical Research, including:

- Refreshing the language that is employed within the Statement to reflect current understandings of ‘consumers’, with significant evidence now supporting that most people who participate in health and medical research identify as ‘community’ or as those who have lived or living experience.
- Stronger emphasis on embedding practices and protocols that ensure that community representatives and people with lived experience are involved at every stage of research, from inception to reporting and dissemination.
- Accentuating the value of having community and lived experience involvement in research, to ensure that research is sensitive, appropriate, and responsive.
- Emphasising the ethical imperative to involve people with lived experience and community representatives in research to ensure that the research accurately reflects and meets the needs of the community.

We also provided examples from our own work for how to effectively engage people from the community or with lived experience, including:

- Clear, plain-English summaries of the project and what will be required of community members in participating
- Clear remuneration and/or reimbursement information
- Pre-project meetings between the individual and project team to talk through process and provide information on other community members and content experts who are participating
- Discuss how the community member would like to best contribute
- 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.

Further information can be found on the [National Health and Medical Research Council](#) website.