Consumer Organisations in Research

Submission on the DRAFT
Statement on Consumer and Community Involvement (CCI) in Health and Medical Research

21 September 2025

Submission 2 of 2

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1. About Health Consumers NSW

Health Consumers NSW (HCNSW) is a membership-based, independent, charity with over 1,000 individual consumer and 60 Consumer Organisational members. We provide a voice for patients, carers, patient leaders, and health consumer representatives in NSW. We represent health consumer organisations who, in turn, represent specific disease and population groups [1]. Our purpose is to inspire and lead health consumers to drive genuine, positive change across health systems, policies, services and research.

2. Why this submission

Since 2016, HCNSW has been actively working with health consumers and consumer organisations to support their **capacity** and **capability** to be actively involved in health and medical research. HCNSW has contributed to building the evidence base of Consumer and Community Involvement (CCI) through:

- partnering in research projects,
- partnering with research institutions, including universities and Research Translation Centres, to build their capacity to involve consumers and the community in research, and
- co-authoring publications (See Appendix 1 and Appendix 2).

Consumer Organisations are leaders in building the **capacity** and **capability** of people with living experience and health consumers to shape and influence health research across NSW and Australia. For over 20 years many HCNSW Consumer Organisation members (such as Cancer Voices NSW, Genetic Alliance, Stroke Recovery, Positive Life NSW, ACON, the Association for the Wellbeing of Children in Health Care, the NSW Users and Aids Association (NUAA), Mental Health Carers NSW, and Being) have supported and advocated for consumers and people with living experience to be actively involved in health and medical research.

On 8 September 2025, HCNSW facilitated an online consultation with Consumer Organisation members involved in health research (see Appendix 3). This workshop built on the consultation with Consumer Organisations, co-hosted by HCNSW and NUAA in May 2024, that formed the basis of one of HCSNW's submissions on the previous Statement. The most recent workshop explored four key questions:

- What is good about the draft statement?
- What is missing from the draft statement?
- What do participants think of the values and principles outlined in the draft statement?
- What do consumer organisations need from the National Health and Medical Research Council (NHMRC) to support the implementation of the statement?

This submission is based on the feedback from this workshop.

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[1] A full list of HCSW [Organisational Members](https://hcnsw.org.au/about-us/our-members/voting-members/) is available on our website: https://hcnsw.org.au/about-us/our-members/voting-members/

3. Key Feedback

Introduction

HCNSW and other consumer organisations welcome the explicit inclusion of Consumer Organisations in the Draft Statement. This inclusion recognises the vital role consumer organisations play in the nation's health and medical research ecosystem.

Consumer organisations are disappointed that the draft Statement does not reflect adequately reflect the current state of CCI in research. Consumer organisations are currently effective research collaborations with significant leadership roles. Consumer organisations would like to see the Statement include case studies and examples of some of the roles they play, such as:

- setting research agendas,
- developing engagement plans and budgets for research projects,
- training consumers and researchers
- ensuring researchers can provide a safe environment for consumer participation, and
- Assisting in recruiting both consumer representatives and research participants.

Consumer Organisations wish to see the final Statement that is more **future focused**. The final Statement should be a call to action for the next decade across health and medical research in Australia. They expressed the importance of CCI being **mandated** in all NHMRC funded research. One representative from a Consumer Organisation described the draft statement as "paternalistic" with the NHMRC research funder positioned being like a parent, the researchers being the favoured older sibling and the Consumer Organisations being the younger siblings.

Language and Definitions

Our members report that the definition of Consumer Organisations in the draft Statement is inadequate. The point of difference of Consumer Organisations, in the research ecosystem, is that they are made up of and governed by people with lived experience. Collaborations with Consumer Organisations are therefore fundamentally different from partnerships with service providers, research institutions, research foundations, and industry and industry funded groups.

Most consumer organisations are membership organisations that act to advance the interests of their members. HCNSW would suggest the following definition for consumer organisations. We recommend the following definition be used in the final Statement (noting that this definition was co-created with health consumers and consumer organisations):

> **Consumer Organisation**[2] – a group or organisation made up of health consumers or people with lived and living experience that exists to support and advance the interests of its members. Consumer organisations are peer led with people with lived and living experience in its governance structures; they may provide some services (such as mutual support and information), advocate for health consumers and people with lived and living experience but are not primarily providers of clinical care

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[2] See the Language guide for Consumer and Community Involvement in Health Research at Sydney Health Partners, co-created by consumers, researchers and researcher/clinicians in partnership with Health Consumers NSW, available at https://sydneyhealthpartners.org.au/guiding-principles-framework-and-language-guide/

Consumer Organisations reported that the language used in the document to describe consumers was outdated and did not reflect current practice. Some of our members posited that this suggests limited engagement of consumers and community organisations in the development and writing of the draft Statement. For example, many consumer organisations use the term “person with lived or living experience” as well as the term “consumer” and “community”. HCNSW acknowledges that the terminology and language in CCI is evolving, with this in mind we suggest using the following definition of people with lived and living experience.

> **People with lived and living experience[3] -** A person who uses their lived or living experience of disability, mental health or any other health condition to inform the planning, conduct and interpretation of research and health services.

Consumer Organisations said that the language used throughout the document about CCI was not strong enough. CCI in research should be **mandated** in all health and medical research. Furthermore, there are many times that the document uses the term ‘may’ or ‘could’. The language should be updated to include the words **‘must’** and **‘should’** to reflect that CCI **must be mandatory** in all NHMRC funded research.

Consumer Organisations reported that the Statement felt like consumers and people with living experience were not at the centre of the research process, but rather “invited in” by researchers to play specific roles largely determined by the researchers. Because of this, the document does not acknowledge the current reality that consumers, people with living experience, and consumer organisations *are* leading research projects.

The word ‘partnership’ is used throughout the Statement. Consumer Organisations felt that a stronger word is needed. People reported that ‘partnership’ does not imply an equal relationship between consumers and researchers. The word “collaboration” was preferred because it implies researchers, consumer organisations and people with living experience are working together to shape, design, conduct the research, and translate the findings into practice.

Consumer organisations also questioned who the audience for the draft Statement was and that it felt like it was written for a research audience and not for consumer organisations and people with living experience. Additionally, the final Statement would need to be in a more ‘consumer – friendly’ format. It is recommended that consumers, consumer organisations and people with living experience co-author a consumer-friendly version of the final Statement.

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[3] See the Language guide for Consumer and Community Involvement in Health Research at Sydney Health Partners, co-created by consumers, researchers and researcher/clinicians in partnership with Health Consumers NSW, available at https://sydneyhealthpartners.org.au/guiding-principles-framework-and-language-guide/

3B. Specific feedback questions

1. **Does the Statement set clear and suitable expectations that consumers and community will be involved in all stages of research?**

Consumer and community involvement should be **mandatory,** and the draft Statement does **not** describe how consumers and community organisations can be involved in the evaluation of CCI throughout the research process.

The current Statement limits the role of consumers and community organisations. It does not acknowledge the current leadership roles consumer organisations have in initiating and running research projects funded by the NHMRC.

2. **Does the Statement clearly explain the key values and principles that ensure effective consumer and community involvement?**

Values

Consumer organisations are pleased that there are identified key values that underpin the Statement.

Consumer Organisations described how the values seem to be disconnected from the principles in the draft Statement. The values need to be more clearly stated and integrated throughout the document. For example, mutual benefit is not a value and could be reflected more in principles.

The values could be streamlined and paired together. For example, diversity and inclusion could be paired, as could transparency, accountability and integrity. To make the values more impactful, Consumer Organisations suggest streamlining the key values to no more than 5, including a clear definition of each value, and referring to the values throughout the Statement.

Principles

Consumer organisations said that the principles provided a high-level overview of consumer and community involvement in health and medical research. However, they could be strengthened by providing practical examples of **what** the specific principle means in practice. There could be specific examples of health and medical research that demonstrate good practice in consumer and community involvement in research.

In regard to **principle 1: consumers and the community** should be involved **before** the research commences, to guide and advise on what health and medical research is undertaken and how to involve people with living experience in the research process. Additionally, they should also be involved **after** the research is completed to support the implementation of research findings.

Principle 3: working in partnership for mutual benefit, this principle should include partnering with communities to undertake research. There are significant benefits of involving communities in research.

In **principle 4: equitable inclusion of diverse consumers and communities,** this principle should explicitly include marginalised communities. Consumer Organisations described how they worked with many marginalised and underrepresented consumers and people with living experience and communities to support their involvement in research. It would be useful to define what is meant by the term 'diversity'. Health Consumers NSW suggest the following definition of diversity

> Diversity in health research often refers to culture, language and religious diversity. However, diversity can also include race, sexuality, gender identity, age, disability, ethnicity, socio-economic status and education. [4]

In **principle 5: Transparency, accountability and integrity in the conduct of research involving consumers and communities**, consumer organisations asked how integrity is defined and for whom? What does integrity mean and look like in practice for researchers, consumers and communities. Additionally, there is no mention of the concept of data sovereignty for researchers, consumers and communities.

In **principle 6: safety of consumers and communities** there was significant support for the principle of Safety, however, Consumer Organisations described this principle needing more detail. For example, describing what safety for consumers and communities looks like in practice. Additionally, there needs to be a recognition of **consumer organisations** in providing mentoring and guidance to research to ensure a safe environment for consumers and community members involved in research.

3. Roles and Responsibilities for CCI

Does the Statement clearly explain the shared roles and responsibilities of all involved to ensure effective consumer and community involvement?

Table 1 in the draft Statement has started to describe the different roles and the level of involvement of researchers, consumers, consumer organisations, however, needs additional information. Table A provides key comments against each shared role.

Table A - Feedback on shared roles and responsibilities

Shared role	Feedback from consumer organisations
Compliance	
Monitoring and evaluation	Consumers, consumer organisations and the community should be actively involved in monitoring and evaluating consumer and community involvement and provide feedback throughout the research process
Planning the research	Involvement of consumer organisations in research planning is crucial. Many organisations report that do not have any regular sources of income that allows them to resource their contribution to research planning, especially in grant preparation.
Conducting the research	Consumer organisations don't just partner with researchers they can also lead the research. The Statement needs to acknowledge the range of consumer organisations can, and are playing, in research.

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[4] See the Language guide for Consumer and Community Involvement in Health Research at Sydney Health Partners, co-created by consumers, researchers and researcher/clinicians in partnership with Health Consumers NSW, available at https://sydneyhealthpartners.org.au/guiding-principles-framework-and-language-guide/

Shared role	Feedback from consumer organisations
Research Governance	Consumer organisations should be peer reviewers on grant applications with equal scoring to researchers. This currently occurs in grant review processes for cancer funding by the Cancer Institute of NSW. See also the guidelines developed by Sydney Health Partners: Describing and Assessing Consumer Involvement in Health Research funding applications[5]
Resourcing, networking and recruitment	Consumer organisations can provide consumers with the opportunity to network with other consumers involved in research. Consumer peaks, such as HCNSW, are also in the position to bring consumers together from different disciplines and research areas. HCNSW's online community of consumer researchers is an example of this. This community consists of consumers with lived experience involved in research across different conditions such as mental health, cancer, HIV, and stroke, as well as consumers involved in health system research. This community not only shares information it is also a resource to recruit experienced consumers to contribute to new research projects.
Capacity building, training and championing	Consumer organisations said that capacity building, training and championing should be a higher priority in this table as it is the key element to foster and support the involvement of consumers and the community in health and medical research. Consumer organisations provide training, mentoring and capacity building to consumers and people with living experience if **funding** is available. Consumer organisations can also lead and initiate partnerships with researchers and research institutes to initiate research to benefit consumers and communities. Current funding structures do not allow for the sustained provision of training and other capacity building of consumers, communities and researchers. Specific **funding** and **infrastructure** needs to be developed for this.

4. Does the Statement clearly explain the roles and responsibilities of Consumers, Communities and Consumer Organisations that ensure effective consumer and community involvement?

Consumer organisations said that the language used throughout the Statement was outdated and they can play much wider roles than currently described. Consumer organisations lead and initiate health and medical research and also support researchers with living experience to be actively involved in research that uses their living experience to shape and influence research projects.

Consumer organisations reported that with appropriate funding and resourcing they can mentor, support and guide research institutes and universities to develop ongoing and sustainable consumer involvement infrastructure. For example, HCNSW has had a formal partnership with Sydney Health Partners for five years and has undertaken a range of capacity building work and initiatives to

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[5] Sydney Health Partners – Guide: Describing and Assessment Consumer Involvement in Health Research Funding Applications
https://sydneyhealthpartners.org.au/guiding-principles-framework-and-language-guide/

support consumers and researchers to collaborate on a range of research projects. HNSW also has a Memorandum of Understanding with The University of Sydney to collaborate on a range of initiatives in CCI in research.

5. **Does the Statement clearly explain the roles and responsibilities of Researchers that ensure effective consumer and community involvement?**

Consumer Organisations said that the statement does not acknowledge that consumers can be researchers who can lead research in health and medical research.

6. **Does the Statement clearly explain the roles and responsibilities of Research Institutions that ensure effective consumer and community involvement?**

Consumer Organisations said that more information was needed on creating a safe environment for consumer and consumer organisations in research. Consumer Organisations can play a key role in supporting and empowering consumers to be safely involved in the research process, and in training researchers in trauma-informed practices and processes.

7. **Does the Statement clearly explain the roles and responsibilities of research funders?**

The Statement needs to include Consumer Organisations being involved in the setting of health and medical research priorities in collaboration with research funders. Additionally, funders **should** appoint consumers and community members to participate in peer review, priority setting and designing funding schemes.

Consumer organisations should be peer reviewers on grant applications with equal scoring to researchers, currently consumer peer reviewers provide feedback on MRFF grants but there is no scoring which is outdated practice. The cancer research grant review for the Cancer Institute of NSW, has equal scoring for consumers and research peer reviewers reflecting collaboration in practice.

Capacity and Capability Limitations of Consumer Organisations

The statement does not acknowledge that most consumers organisations face significant capacity and capability restraints. Many consumer organisations are small NGOs with very limited financial resources.

The current in-kind requirements of NHMRC partnership grants limit the ability of consumer groups to get involved. As stated throughout this submission, most Consumer Organisations require additional support and resources to effectively engage with research. The requirement for research partners to provide **financial** or **in-kind** contributions stops many from being able to participate. Partnership grants were developed with industry partners in mind and applying this model to small NGOs is restricting. Industry partners have the financial resources to be able to make financial contributions to research, and they are motivated by the opportunity to commercialise research findings and get a return on their investment. Research outcomes are rarely ones consumer organisations can commercialise and not to the scale that would exceed their initial investment.

The current model of partnership grants negatively impacts on Consumer Organisations. Who are often out of pocket because of their involvement in research projects (projects that often have budgets many times more than the annual income of the consumer organisations).

Partnership grants should therefore exempt Consumer Organisations from having to make financial or in-kind contributions to research.

Implementing the Statement

Consumer Organisations were concerned about how to operationalise the values, principles and practices in the Statement. Without adequate funding to support and sustain infrastructure for Consumer Organisations to actively support consumers to be involved in research, the Statement will not be effectively implemented. This is a lost opportunity for the involvement of consumers and the community and consumer organisations and potential health outcomes in health and medical research in Australia.

Consumer Organisations said that the NHMRC should support the development of strategic infrastructure for CCI in research. This infrastructure must include direct funding of Consumer Organisations across Australia to support the implementation of the Statement working directly with consumers to build their **capability** and **capacity** to be research ready. A possible model could be a national collaboration of consumer organisations across Australia that share resources and networks funded by the NHMRC. Potential activities of the collaboration could include:

- Working with consumers and consumer organisations to develop a capability and capacity framework for consumers and consumer organisations in research that operationalises the principles and roles reflected in the final Statement;
- Access to free training, mentoring and support of consumers including a peer support program for consumers in research which would build the pool of consumers who are research ready across Australia;
- providing guidance to researchers on how to involve consumers in research including connecting and navigating their connections and relationships with relevant Consumer Organisations;
- Supporting consumer researchers who want to have a career as lived experience researchers to build their expertise and connect with researchers and clinician researchers across Australia;
- Monitoring and measuring the impact of the NHMRC grant process and key funding in health and medical research on consumer and community involvement and the translation of this into health outcomes and practice.

Appendix 1 HCNSW involvement in research

Includes capacity and capability building activities for consumers and people with lived experience, partnering with researchers and research projects, and awards.

2016

- co-hosted a Consumers in Research roundtable with AccessCR and co-authored a report entitled *Involving health consumers in health and medical research : enablers and challenges from a consumer perspective* Involving_health_consumers_in_health_and_medical_research_online_print.pdf (hcnsw.org.au)
- Partners on research projects with universities in NSW on a range of research projects in health and medical research
- Undertook one-off research and project work with researchers and research institutions and research on consumer engagement projects across Local Health Districts.

2017

- Co-presented findings on consumer representatives' experiences of partnering with researchers at *NSW Patient Experience Symposium.*

2019

- Initial partnership agreement with Sydney Health Partners to undertake a needs analysis of Consumer and Community Involvement and develop joint training for researchers and consumers.
- Initial partnership with the Australian Centre for Health Engagement, Evidence and Values (ACHEEV) at University of Wollongong. HCNSW partners with research investigating community attitudes to sharing health data using participatory methodologies (citizens' juries). Dr. Brown, HCNSW CEO, invited to become a Visiting Fellow at ACHEEV.

2020

- Needs analysis report for Sydney Health Partners published and joint training for researchers and consumers for Sydney Health Partners developed.

2021

- HCNSW Consumer Engagement Manager appointed, dedicated to support and build relationships with universities and research institutes and to work with HCNSW consumer members and organisations to support and foster consumer and community involvement in research

2022

- Publication of research and report on people with intersectional need's experienced of healthcare. https://www.hcnsw.org.au/intersections/resources/
- Creation of statewide network of Consumer Voices in Clinical Trials (ConViCTioN) funded through a small grant from the NSW Office of Health and Medical Research. ConViCTioN is a partnership between HCNSW, Sydney Health Partners, AccessCR and Northen NSW LHD, which co-created and developed information for consumers about clinical trials including a Checklist, Infographic and Video. https://clinicaltrials-consumervoices.com.au/home/
- HCNSW receives Consumer Award by NSW Research Centre for Primary Health Care and Equity at University of NSW, for contributions to consumer and community involvement.

2023

- SHP and HCNSW Consumer and Community Involvement Framework, Principles and Language Guide released – co-created by consumers, researchers and clinicians. https://sydneyhealthpartners.org.au/guiding-principles-framework-and-language-guide/
- Developed remuneration and reimbursement guidelines for consumers in research that was adopted by all Health Translation Centres across NSW https://hcnsw.org.au/training-resources/resources/remuneration-and-reimbursement-of-health-consumers/
- Free online training for researchers and consumers – Consumer and Community Involvement in Health Research co-created by Health Consumers NSW and Sydney Health Partners.
- Development of Intermediate training on how to involve consumers in research with Sydney Health Partners bringing researchers and communities together. https://hcnsw.org.au/training-resources/training-courses/training-researchers-and-consumers-in-research/
- Memorandum of Understanding signed between HCNSW and The University of Sydney to work collaboratively to support Consumer and Community Involvement in research and education.

2024

- Updated website and information on consumers in clinical trials through collaboration with ConViCTioN from a small grant from the NSW Ministry of Health. https://clinicaltrials-consumervoices.com.au/home/
- Facilitated workshops with UNSW, Charles Sturt University and the University of Wollongong to involve consumers in research

2025

- HCNSW are consumer partners in two successful grants with The University of Sydney and The University of NSW (funded by NHMRC and MRFF respectively).
- Designed and delivered a train the trainer program with Sydney Health Partners to deliver consumer and researcher training for consumer and researcher facilitators across Sydney Health Partners. SHP is providing training across their network for researchers and consumers, led by consumer and researcher facilitators.

Appendix 2 Key peer reviewed publications co-authored by HCNSW (names bolded) in CCI in health and medical research

Miller, E., **Hayter, C.**, & Manchester, H. (2025). Facilitating co-design in healthcare: a collaborative autoethnography of personalities, power, and competing priorities. *CoDesign*, 1–15. https://doi.org/10.1080/15710882.2025.2460037

Cheek, C., N. Hayba, L. Richardson, E. E. Austin, E. Francis Auton, M. Safi, N. Ransolin, M. Vukasovic, A. De Los Santos, M. Murphy, R. Harrison, K. Churruca, J. C. Long, P. D. Hibbert, A. Carrigan, B. Newman, K. Hutchinson, R. Mitchell, H. Cutler, L. Holt, J. Braithwaite, D. Gillies, P. M. Salmon, R. L. Walpola, Y. Zurynski, L. A. Ellis, K. Smith**, A. Brown**, R. Ali, K. Gwynne and R. Clay-Williams (2023). "Experience-based codesign approach to improve care in Australian emergency departments for complex consumer cohorts: the MyED project protocol, Stages 1.1-1.3." BMJ Open **13**(7): e072908.

Dahm, M. R., **A. Brown**, D. Martin, M. Williams, B. Osborne, J. Basseal, M. Potter, R.-A. Hardie, J. Li, J. Thomas and A. Georgiou (2019). "Interaction and innovation: practical strategies for inclusive consumer-driven research in health services." BMJ Open **9**(12): e031555.

Dahm, M. R., A. Georgiou, J. I. Westbrook, D. Greenfield, A. R. Horvath, D. Wakefield, L. Li, K. Hillman, P. Bolton**, A. Brown**, G. Jones, R. Herkes, R. Lindeman, M. Legg, M. Makeham, D. Moses, D. Badmus, C. Campbell, R.-A. Hardie, J. Li, E. McCaughey, G. Sezgin, J. Thomas and N. Wabe (2018). "Delivering safe and effective test-result communication, management and follow-up: a mixed-methods study protocol." BMJ Open **8**(2).

HCNSW Staff and members are also co-authors of other peer reviewed papers, and co-presenters at conferences, that present the findings of various research collaborations.

Appendix 3 Consumer Organisations who participated in consultations

ACON (AIDS Council of NSW)
Cancer Voices NSW
Genetic Alliance Australia
Health Care Consumers Association (ACT)
Hepatitis NSW
Mental Health Carers NSW
Positive Life NSW
Stroke Recovery NSW
The Association for the Wellbeing of Children in Healthcare
Weight Issues Network