HEALTH CONSUMERS NSW

NUAA

Being
Mental Health Consumers

Positive Life NSW
The voice of all people living with HIV

AWCH
Association for the Wellbeing
of Children in Healthcare
www.awch.org.au

NeuroEndocrine Cancer Australia
Champions for early diagnosis and a cure

Hepatitis NSW

swop

Consumer Organisations in Research

Submission for review of the National Health and Medical Research Council (NHMRC) and Consumers Health Forum (CHF) of Australia Statement on Consumer and Community Involvement (CCI) in health and medical research

14 June 2024

Prepared by Health Consumers NSW.

1. Why this submission

On 23 May 2024, Health Consumers NSW (HCNSW) and the NSW Users and AIDS Association (NUAA) co-facilitated a workshop with 15 Consumer Organisations to explore their experience of being involved in health research (see Appendix 1). The workshop also aimed to explore the principles that should underpin Consumer Organisations involvement in health research. Health Consumers NSW initiated this workshop, as a member-based organisation who has over 60 consumer organisation members, many of whom have been actively involved in health research.

We recognize that language matters and for the purpose of this submission we use the following terms[1]:

Co-design - Co-design is an approach to designing with, rather than for, people. There are four key principles for co-design: share power (with researchers, consumers and the community); prioritise relationships that build trust and connection; use participatory means (that facilitate self-discovery and move people from participants to active partners); and build capacity (to support people to teach and learn from each other).

Consumer - a person who uses, has used, or is a potential user of, health services. Consumers may participate as individuals, groups, organisations of consumers, consumer representatives or communities.

Consumer Organisation – 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.

Involvement -Involvement refers to a partnership between consumers and researchers, where consumers are actively involved in the research process It has been described as doing research 'with' or 'by' people who use health services, rather than 'to', 'about' or 'for' them.

People with lived and living experience - 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.

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[1] 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/

Health consumer organisations are partners in a number of NHMRC funded research. These partnerships and the unique role consumer organisations play in research are not mentioned in the 2016 CCI statement. We write this submission to, firstly, redress this exclusion, and secondly to express concerns about the current NHMRC CCI review process which has not acknowledged or considered the critical role of Consumer Organisations in health research. Consumer organisations (when adequately funded) can support the involvement of consumers and people with lived and living experience across all types of health and medical research in Australia. Consumer organisations across NSW and Australia are currently not effectively funded to support the ongoing involvement of consumers in health and medical research.

2. Consumer organisation's experience of being involved in health research

Consumer organisations represent a diverse range of consumers and work to improve the experiences of consumers in health services, health research, and health systems and provide peer to peer support for people with lived and living experience. For example, NUAA is a peer-based drug user organisation, that strives to improve advocacy for, and services supporting, the diversity of people impacted by stigma and discrimination caused by the criminalisation of drug use across NSW. In contrast, Health Consumers NSW represents the interests of health consumers in health services and health research to inspire, lead and drive change in policy, research and practice. The diversity of consumer organisations that work to amplify the voices and perspectives of people with living experience in research is a strength, however, they need to be funded to be involved in research.

Consumer organisations described a range of experiences of being involved in research. Some described positive experiences of partnering with researchers (such as Positive Life NSW and Hepatitis NSW) who have been active in advocacy and health research for over a decade. Furthermore, they described the importance of amplifying the perspectives of people with lived and living experience to ensure meaningful and relevant research. Furthermore, some consumer organisations had developed trusted and respectful relationships with specific researchers to foster and develop research agendas for the people with lived and living experience that they represented.

In contrast, most consumer organisations described being 'under pressure' from researchers and research organisations to meet researchers' requests for consumer involvement. Often these requests are made without specific funding to consumer organisations to support consumer involvement. This created significant challenges because the consumer organisation did not have the resources to support consumers to be actively involved in research and had to educate researchers about key principles of consumer and community involvement. This led to many organisations feeling like they were 'stuck in the middle', between researchers and consumers or people with lived and living experience. Some also described feeling like they were 'steam rolled' by researchers whereby they agreed to be involved in research projects, however, the researchers progressed their agenda without effective involvement of consumers and people with lived and living experience in the research project.

The structures and expectations of some NHMRC research grants further entrench some of these inequities. To be a partner on an NHMRC Partnership Grants requires consumer organisations to give financial or in-kind support to the research. There are times when consumer organisations are asked to give support for research projects which have a budget many times the entire annual income of the consumer organisation. This is a structural barrier to Consumer Organisations involvement, which is not neither sustainable nor equitable.

Another key theme was the lack of meaningful co-design of consumers, people with living and lived experience and consumer organisations throughout the research cycle. Consumer organisations reiterated the importance of being engaged from the beginning of any research and throughout the research cycle from the planning, execution and translation of the research into practice.

Many of the consumer organisations who participated in this workshop, work alongside consumers and people with lived experience from marginalised groups. Ensuring that the proposed research was ethical and 'safe' for consumers and people with living and lived experience was extremely important. This included whether the research aims and priorities aligned to the priorities of consumers and the consumer organisations and were in the best interests of people with living experience. Many consumers organisations described developing screening processes for research projects to ensure that the research proposed had effective processes for ensuring that consumers and people with living and lived experience were not retraumatized or stigmatized by the research. Some consumer organisations described having to withdraw from research projects because researchers had not followed their advice in terms of how to involve people with lived and living experience in a non-stigmatising and safe way.

3. What principles should underpin Consumer Organisations involvement in health research?

Consumer organisations described the following key principles that should underpin their involvement in health research.

i. Co-design and Collaboration

Consumer organisations should be designing research with consumers and researchers from the beginning of the research process. Researchers and research organisations should be sharing power with consumer organisations to build trust and relationships over time, to play an active role throughout the research cycle.

ii. Respect and Humility

Consumer organisations, consumers and people with living experience should be treated with respect and humility throughout the research process by researchers and research organisations. This includes researchers and research organisations understanding and working with the constraints of consumer organisations and taking on the advice provided by consumer organisations on how to involve consumers and people with lived experience in their research. As well as researchers' recognising the expert knowledge consumer organisations bring around what is important to their members, and their experience in engaging consumers.

iii. Equity

Consumer organisations do not have access to the same level of resources as researchers, research organisations, and research funders. Providing appropriate resourcing and funding to consumer organisations to ensure equity between consumer organisations and research organisations is critical for equity of outcomes.

iv. Recognition and Resourcing

Consumer organisations and consumers involved in research need time and to be recognised and appropriately remunerated for their active involvement in research. Consumer organisations need to have the opportunity to be involved where appropriate in the communication of research findings, for example in publications, joint conference presentations and/or public events.

v. Ethical Involvement

Research involving consumer organisations and people with lived and living experience should be ethical. Ethical research is working with consumer organisations to conduct research; clear roles between researcher/s and consumer organisations and consumers/ people with lived and living experience, and enabling shared decision making powers throughout the research process. Researchers need to listen and take on the advice of the consumer organisations in terms of how to engage specific consumers and communities.

vi. Transparency and Accountability

Communication and involvement between consumer organisations and research organisations, funders and researchers should be transparent and throughout the research cycle. The findings of the research should be communicated to the consumer organisations and the community. The roles of consumer organisations and research organisations should be clearly communicated.

4. What do consumer organisations need to be active partners or lead health research?

To be actively involved in research, consumer organisations need time, funding and resources to provide training and mentoring to consumers to support their involvement in health research.

Consumer organisations would like to work with the NHMRC to explore how we can effectively support and foster the involvement of consumers and people with living experience across health and medical research.

We welcome the opportunity to meet with the NHMRC and to host a national workshop to continue the work to actively involve consumer organisations in research.

Appendix 1 – Consumer Organisations who participated in the workshop

- Carers NSW
- Cancer Voices NSW
- BEING Mental Health Consumers
- The Association for the Wellbeing of Children in Healthcare
- Hepatitis NSW
- Neuroendocrine Cancer Australia
- Sex Workers Outreach Project NSW
- Positive Life NSW
- Health Consumers Tasmania
- Health Care Consumers Association (ACT)
- Mental Health Carers NSW
- Australian Breastfeeding Association NSW Branch