



**Lived  
Experience**  
AUSTRALIA

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

Submitted Online to:

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For:

The National Health and Medical Research Council (NHMRC)

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## Introduction

Lived Experience Australia Ltd (LEA) is a national representative organisation for Australian mental health consumers and carers, families and kin, formed in 2002. Our 'friends' include approximately 9000 people with lived experience of mental health concerns, including suicide and suicidality, across Australia.

All members of our Board and staff have mental health lived experience as either a consumer, family/carer/kin/supporter, or both. This includes lived experiences with all parts of the mental health care system, NDIS, psychosocial disability support outside the NDIS, public and private service options, and service provision across urban, regional, rural and remote Australia.

Lived Experience is core to our advocacy, recognising that the impacts of policy and practice are felt not only by individuals, but also by families and whole communities. Our core business is to advocate for effective policies and systemic change to improve mental health care and psychosocial disability support services and support across the lifespan, across the whole Australian health and social care system, including within State and Territory jurisdictions.

**Elevating lived experience voices within research underpins one of our four Key Pillars. We achieve this by undertaking research from a lived experience perspective with our communities and partnering with research groups to support equity of inclusion of lived experience perspectives across the continuum of research. We use research as evidence to support advocacy for policy, system and service improvement for consumers and their families/carers/kin and communities. Our goal is to elevate lived experience evidence and knowledge; this is a social justice issue that is fundamental.**

We welcome the opportunity to provide our feedback to this crucially important issue for people with mental health challenges and psychosocial disability, and their families, carers and kin in the Australian community.

## Purpose of this Consultation

The National Health and Medical Research Council (NHMRC) and the Consumers Health Forum of Australia Ltd (CHF) are collaborating to review the [2016 Statement on Consumer and Community Involvement in Health and Medical Research](#) (the Statement). The Statement aims to support consumer and community involvement across all types and levels of health and medical research. It articulates the importance and benefits of consumer and community involvement in research and discusses a series of implementation issues. Since its publication in 2016, a variety of material addressing implementation of consumer and community involvement in research has been developed and made available in a variety of formats. Examples include:

- The NHMRC Toolkit for consumer and community involvement in health and medical research <https://www.nhmrc.gov.au/about-us/consumer-and-community-involvement/consumer-and-community-engagement>
- The Western Australian Health Translation Network handbook - Involving consumers in health and medical research <https://wahtn.org/platforms/consumer-and-community-involvement/cci-handbook/>
- The Department of Health and Aged Care Principles for Consumer Involvement in Research Funded by the Medical Research Future Fund. <https://www.health.gov.au/resources/publications/principles-for-consumer-involvement-in-research-funded-by-the-medical-research-future-fund?language=en>

With the increasing availability of practical implementation toolkits and other resources, published by a variety of organisations, it is proposed to remove implementation focussed information from a revised Statement. A review of the Statement will maintain its relevance and currency, and reframe it as a high-level, overarching statement, focusing on principles, values, and roles and responsibilities of those involved. NHMRC has developed a position paper with advice from CHF and the Consumer Statement Advisory Committee (CSAC) to guide input on what should be included in the revised Statement.

## Our Response to the Review

### 1. What parts of the current statement have or have not worked well?

#### Discussion questions:

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

The current Statement has good intentions, and the rhetoric of inclusion and partnership is apparent. What has worked less well is the translation of the values and principles to research practice. Accountability needs to be strengthened so that consumer-focused processes (such as 'co-design') are not simply colonised, which then fails to shift the fundamental structures of expertise and power sharing inherent in the values and principles.

- Why is consumer and community involvement in research valuable? Why does it matter to you?

Consumer and community involvement is crucial because they are the ultimate end-users of evidence produced from research, either directly or through the consequences of how it is translated into policy and practice by governments and services. Their involvement ensures that research and its outcomes reflect what matters to and has relevance to the lives of consumers and communities. Research involvement is fundamentally linked to human rights because the holding of expertise and knowledge is about power. So much research has involved interventions done to rather than done with people with mental health challenges and their families. Knowledge has been defined by others which has arguably maintained structures of power, control and discrimination. This has meant that research evidence has been produced that has failed to translate to the real world of practice and people's lives. In some cases, it has perpetuated stigma and discrimination towards some marginalised groups and communities.

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

Accountability across the full spectrum of research conduct  
Translation to minimise waste of valuable research effort.  
How impact is measured and by whom needs to be strengthened.

### 2. What overarching values are essential to include in the value statement of the revised Consumer Statement?

#### Discussion questions:

- The values that underpin the 2016 Statement are 'shared understanding, respect and commitment' (2016 NHMRC-CHF Consumer Statement). How might this be strengthened and improved in the revised Consumer Statement?

There is an opportunity to highlight and strengthen core values about the nature of knowledge and expertise. Shared understanding, respect and commitment are easy words to say but not always apparent in practice, and can become token, because there remains a traditional hierarchy of what counts as 'knowledge', and who holds power to determine that.

- Should values such as accountability, transparency, collaboration and partnership, equity, diversity and inclusiveness be included in the Statement? What others would you like to see, and why?

Yes, these are fundamental values. Human rights should also be an underpinning structure, as stated above.

- What overarching values are essential to include in the value statement of the revised Consumer Statement?

Equity, power-sharing, human rights, and social justice would be essential to include.

### 3. What are the most important practice principles to include in the revised consumer statement?

The following is a list of principles taken and adapted from existing documentation. They are provided as an example of the kinds of principles that could be included in the revised Statement. All principles included in this section should be broad in scope rather than directed at implementation.

- *Consumers and community members should be involved at all stages of research (source: MRFF Principles)*
- *Consumers and community members should be in partnership with researchers (source: MRFF Principles)*
- *Consumers and community members should be involved with broad diversity and equity (source: MRFF Principles)*
- *Mutually respectful relationships (source: UK Standards for Public Involvement: Better public involvement for better health and social care research)*
- *Respect for lived experience and community expertise (source: Principles of Community Engagement – CDC US Publication)*
- *Honesty in the development, undertaking and reporting of research, including presenting information truthfully and accurately in proposing, conducting and reporting research. (source: Australian Code for the Responsible Conduct of Research)*
- *Respect for research participants, the wider community and the environment (source: Australian Code for the Responsible Conduct of Research).*

#### **Discussion questions:**

What are the most important practice principles to include in the revised consumer statement?

All the above practice principles are important to include in the revised consumer statement.

### 4. What roles and responsibilities should be included in the revised consumer statement for consumers and communities; researchers; research institutions; and funders?

#### **Roles, expectations and responsibilities of consumers and community members**

The following are examples taken and adapted from existing documentation. They are provided as an example of the kinds of roles and responsibilities that could be included in the revised Statement.

- *Research institutions, researchers, consumers and community members all have a responsibility to consider the best person(s) for a particular role or task, taking into consideration issues such as age, gender, disability, cultural background and experience, health system experience and availability (source: 2016 NHMRC-CHF Statement).*
- *Consumers and community members can be involved at various levels of research activity and the institutions in which research is conducted. 'Levels of research activity' include planning and co-deciding, governance, developing research design and questions, recruitment, seeking funding, conducting the research, communicating the outcomes and evaluation (2016 NHMRC-CHF Statement).*
- *Consumers and community members should advise research institutions and researchers on their consumer and community perspectives and lived experiences (2016 NHMRC-CHF Statement).*
- *Consumers and community members may need skills, information and support in order to add value to the development, conduct and communication of research (2016 NHMRC-CHF Statement).*

## Discussion questions:

What roles and responsibilities for consumers and communities should be included in the revised Consumer Statement?

For the Statement to move beyond rhetoric, consumers and communities should be involved in all roles and responsibilities, for the reasons already stated. Research does not exist in a vacuum; its conduct and outcomes ultimately impact the lives of consumers and communities.

## Roles and responsibilities of researchers

The following are examples taken and adapted from existing documentation. They are provided as an example of the kinds of roles and responsibilities that could be included in the revised Statement.

- *Research institutions, researchers, consumers and community members all have a responsibility to consider the best person(s) for a particular role or task, taking into consideration issues such as age, gender, disability, cultural background and experience, health system experience and availability (source: 2016 NHMRC-CHF Statement).*
- *Champions: researchers elect to champion the benefits of consumer engagement. Key leaders with experience in consumer involvement advocate to improve the level of understanding among peers. (National Framework for Consumer Involvement in Cancer Control)*
- *Combined professional development: researchers and consumers are encouraged to undertake professional development together to learn from each other's knowledge and experience. (National Framework for Consumer Involvement in Cancer Control)*
- *Equality: consumers are considered equal members of the group or team (National Framework for Consumer Involvement in Cancer Control)*
- *Researchers should consider how they will involve consumers and community members in the development, conduct and communication of their research (2016 NHMRC-CHF Statement).*

## Discussion questions:

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

All of the above should be considered by researchers.

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

The structure of this questions is underpinned by assumptions that establish researchers is the predominant holders and owners of research knowledge and consumers and community representatives being invited in afterwards. A revised Statement must address this fundamental assumption if the new statement is to move beyond being just more rhetoric.

- Should involvement be an expectation of research and is there an ethical imperative to do so?

Involvement of consumers and communities is possible from its inception across any and every research type and design, whether it is quantitative or qualitative, purely lab-based research to research that is led or co-led by communities. The wider community has a vested interest fundamentally in the ethics of how research questions are understood and prioritized, how research is conducted and with whom (and who is excluded), in how research monies are used and distributed, and in the outcomes of research.

## Roles and responsibilities of research institutions

The following are examples taken and adapted from existing documentation. They are provided as an example of the kinds of roles and responsibilities that could be included in the revised Statement.

- Research institutions, researchers, consumers and community members all have a responsibility to consider the best person(s) for a particular role or task, taking into consideration issues such as age,

gender, disability, cultural background and experience, health system experience and availability (source: 2016 NHMRC-CHF Statement).

- Research institutions should commit to the involvement of consumers and community members in various levels of research activity (source: 2016 NHMRC-CHF Statement).
- Governance: governance structures, including boards and committees, policies and procedures, incorporate the principles, values and elements for effective consumer participation (source: National Framework for Consumer Involvement in Cancer Control)
- Seek feedback from researchers and consumer and community members involved in research and evaluate processes and outcomes (source: NIHR Cambridge Public and Patient Involvement Public Engagement Strategy 2021/2022)
- Education and training (source: National Framework for Consumer Involvement in Cancer Control)

**Discussion question:**

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

All of the above seem relevant to consider in the revised Statement. Research institutions also have significant opportunities to embed Lived Experience researchers as core to their vision and strategic planning and directions. They develop RAP statements, for example, to acknowledge Aboriginal and Torres Strait Islander communities. They could drive a shift in research and consumer involvement by modelling a culture that has this is core to their research strategies, for higher degree research student structures and so forth.

**Roles and responsibilities of funders**

The following are examples taken and adapted from existing documentation. They are provided as an example of the kinds of roles and responsibilities that could be included in the revised Statement.

- Governance: governance structures, including boards and committees, policies and procedures, incorporate the principles, values and elements for effective consumer participation (source: National Framework for Consumer Involvement in Cancer Control)
- Policy and Processes: Through policy guidance and other processes, set expectations for how people with lived experience (PWLE) and consumers should be involved in research projects. (Adapted from: Lived Experience Involvement in Research Funding: Taking a more systematic approach)
- Research Funding Programs: Research funders can involve consumers in reviewing funding applications, setting priorities, identifying research topics, designing and developing programs, and supporting funded projects (Adapted from: Lived Experience Involvement in Research Funding: Taking a more systematic approach)

**Discussion question:**

- What roles and responsibilities for funders should be included in the revised Consumer Statement?

All of the above seem relevant to consider in the revised Statement. Modelling the intent of the revised Statement begins with funders' and how they demonstrate the values and principles in their actions, and in the requirements and expectations that are then established for researchers.

- Should funders of research mandate the involvement of consumer and community representatives in the research they fund?

Yes. Absolutely. As stated above, even research that doesn't have direct involvement of consumers and communities as participants (eg. some lab-based research that does not involve humans) is relevant for consumers and communities to have input into determining the questions being asked and how they might eventually lead to discoveries that have relevance to people's lives. Consumers and communities may not have technical skills and expertise required for some research endeavours, but they can potentially offer insights that researchers may not have considered; they can be of crucial importance.

## Contact

We thank the NHMRC and the CHF for the opportunity to put our views forward. We wish you well with the next steps and would be pleased to contribute our lived experience perspectives to any future discussions about this important topic.

Your sincerely

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