

# Report to the National Health and Medical Research Council and the Consumers Health Forum of Australia

National engagement in response to the Review of the Statement on Consumer and Community Involvement in Health and Medical Research 2016 Position Paper

June 2024



## Project Leads

# Contents

EXECUTIVE SUMMARY	5-7
BACKGROUND	8
ABOUT AHRA	8
METHODOLOGY	9-11
DATA ANALYSIS	12-13
QUESTION 1: WHAT PARTS OF THE CURRENT STATEMENT HAVE OR HAVE NOT WORKED WELL?	14-19
QUESTION 2: WHAT OVERARCHING VALUES ARE ESSENTIAL TO INCLUDE IN THE VALUE STATEMENT OF THE REVISED STATEMENT AND QUESTION 3: WHAT ARE THE MOST IMPORTANT PRACTICE PRINCIPLES TO INCLUDE?	20-21
QUESTION 4: ROLES, EXPECTATIONS AND RESPONSIBILITIES OF CONSUMERS AND COMMUNITY MEMBERS, RESEARCHERS, RESEARCH INSTITUTIONS AND FUNDERS	22-28
QUESTION 5: SHOULD FUNDERS OF RESEARCH MANDATE THE INVOLVEMENT OF CONSUMER AND COMMUNITY REPRESENTATIVES IN THE RESEARCH THEY FUND?	29
REFERENCES	30

## About AHRA

The Australian Health Research Alliance (AHRA) is the voice of the 14 Research Translation Centres accredited by the National Health and Medical Research Council.

Each centre is a partnership of multiple health services, connected to research centres and universities. Collectively AHRA's members encompass over 90% of researchers and 86% of acute health care services across Australia.

AHRA's priorities are the systematic embedding of research in Australian health care; better alignment of research capacity with clinical priorities and more, better and faster research translation to deliver patient, public and economic benefit.

The Australian Health Research Alliance, together with its member Centres, acknowledges the Aboriginal and Torres Strait Islander nations of Australia as the traditional owners of our country. We pay respect to ancestors and Elders past, present and emerging.





## Executive Summary

The community are the funders and beneficiaries of both research and healthcare in Australia and deserve to be front and centre in driving a health system fully informed by research that meets their needs<sup>1</sup>. The National Health and Medical Research Council (NHMRC) and the Consumers Health Forum of Australia (CHF) joint *Statement on Consumer and Community Involvement in Health and Medical Research* (the Statement)<sup>2</sup> is a high-level national Statement that provides leadership and guidance in consumer and community involvement across all types and levels of health and medical research. Almost 10 years old, revision is required to maintain its relevance and accuracy now and into the future.

The Australian Health Research Alliance (AHRA) is a national partnership of 14 Research Translation Centres accredited or recognised as emerging by the NHMRC to embed research into health care. The Centre Partners have extensive breadth, with 367 hospitals, 33 First Nations and community groups, 53 Medical Research Institutes, 28 Universities and significant primary care reach. This highly collaborative, national network, with established governance and broad reach was commissioned to engage stakeholders in the national consultation process to revise the Statement. Additionally, we leveraged a Medical Research Future Fund investment in AHRA for a national consumer and community involvement project (MRFF2019278) to assist with diverse consultation.

Thirteen Centres, as well as the Australian National University, actively participated in a nationally coordinated program of 11 in-person and 11 online workshops, with central support provided by the Monash Partners team. Overall, 22 workshops were conducted across Australia between February 13th and May 23rd 2024. A total of 440 people attended the 22 workshops, with almost equal numbers of consumers and researchers participating and all states and territories of Australia represented. Most participants resided in urban areas (71%, n=310), were born in Australia (68%, n=292), spoke English only (78%, n=344) and spoke English either well or very well (98%, n=288). Sixteen participants identified as Aboriginal or Torres Strait Islander.

The aim of the workshops was to seek stakeholder views on the questions posed in the *Review of the Statement on*

*Consumer and Community Involvement in Health and Medical Research 2016 Position Paper*<sup>3</sup>. The workshop questions were codesigned with the NHMRC with expert input on best practice consumer and community involvement.

Participants provided general feedback about the Statement related to its purpose, function, use, accessibility and intended audience. This included an expectation that the revised Statement would: strengthen the uptake and implementation of meaningful consumer and community involvement; have a stronger profile across the health and medical research sector; be more accessible to readers with varying health literacy; include evidence-based and other high-quality resources; and, clearly identify the intended audience.

Overall, participants voiced their concern about the exclusion of implementation detail in the revised Statement. Many wanted implementation information included and strengthened, stating they looked to the NHMRC for guidance on how to do genuine consumer and community involvement in research. Further, retaining these details was recommended to ensure people knew how to practically apply information in the revised Statement. In the absence of guidance on how to undertake meaningful consumer and community involvement, participants were concerned tokenistic engagement would go unrecognised and persist.

Themes identified from the discussion are summarised below:

**• What parts of the current Statement have or have not worked well? Is the value of consumer and community involvement clear/communicated in the Statement as a whole?**

Perspectives on the value of the current Statement were varied; most participants did not find it particularly useful in its current form, others were unaware the Statement existed. Many were aware but rarely used it or referred to it in the course of their work. The definitions, rationale for consumer involvement, and described benefits were considered useful.



Participants suggested a range of improvements in the revised Statement including: incorporate the work completed with Aboriginal and Torres Strait Islander communities; emphasise involving consumers and community in research design and problem ideation; reword the phrasing around consumer and community involvement 'across all stages of research'; add guidance to operationalise the Statement; and, update language to strengthen wording and messaging.

**• Do the current values, 'shared understanding, respect and commitment' need to be strengthened and, if so, in what way? Should values such as accountability, transparency, collaboration and partnership, equity, diversity and inclusiveness be included in the Statement? Are there any others you would like to see, and why? What are the most important practice principles to include in the revised Consumer Statement?**

There was clear agreement between participants that the values and practice principles required strengthening. The workshops generated some consensus on the most important or "essential" values and practice principles as well as suggested additions. Essential values to retain included 'respect', and 'shared understanding'. 'Commitment' was not considered an essential value. Additional values and principles noted as essential were 'transparency', 'honesty', 'safety', 'accountability', 'partnership', 'reciprocity', 'equity', 'diversity', 'inclusive/inclusiveness', and 'culturally appropriate'. Others, raised by participants, but not ranked as essential were 'mutuality', 'authenticity', 'co-ownership', and 'connection'.

**• What roles and responsibilities should be included for: consumers and community members, researchers, research institutions, and funders?**

Overall, there was consistent alignment and support from participants for the roles and responsibilities outlined in the Position Paper. Suggested modifications and additions for the revised Statement around new roles and responsibilities are described below.

Recommended roles and responsibilities for consumers and community members to include in the revised Statement were: engage in activities to develop skills,

make contributions to research projects, intentionally utilise connections and networks, and be reflexive about motivations, limitations and responsibilities as a consumer.

Participants recommended the inclusion of multiple roles and responsibilities for **researchers** in the revised Statement. These included: consider the best person for a particular role or task; work ethically; maintain clear and regular communication with consumers; identify and respond to consumer training needs; learn together; champion the benefits of consumer and community involvement; consider reciprocity; build relationships and connections; and, appoint a dedicated person to support consumers.

Multiple roles and responsibilities for **research institutions** or inner organisational settings where research occurs, were also recommended to support individuals in consumer and community involvement. Specifically, the following were identified for inclusion in the revised Statement: lead cultural change; build the appropriate infrastructure (governance, systems, processes); show accountability; evaluate processes and outcomes; provide resources, education and training to capacity build researchers and consumers; prioritise and allocate funding; develop policies; connect researchers and community members; and establish dedicated and specialist consumer and community involvement roles.

While participants noted these recommendations had resource implications for research institutions, they were considered part of showing commitment and accountability to researchers and consumers to undertake meaningful consumer and community involvement. Participants from smaller research entities (such as health services) highlighted that some of the suggested roles and responsibilities may not be feasible without extra resourcing, and here partnerships such as the AHRA Centres could be considered.

Suggested roles and responsibilities for external stakeholders such as **funders** included: facilitate consumer involvement activities; articulate standards and expectations; ensure transparency around assessment and scoring of consumer and community involvement in grant applications; show accountability; provide guiding principles on consumer remuneration; and incorporate

and operationalise their consumer and community involvement recommendations.

**• Should consumer and community involvement be mandated by funding agencies – why and why not?**

Across the workshops conducted, most participants responded that funders should mandate consumer and community involvement in the research they fund. Participants justified their recommendations, noting they expected: better health and research outcomes; better value for money; increased accountability for how researchers conduct consumer and community involvement; improved opportunities to advance consumer and community involvement; and better recognition of the rights of consumers and their value.

Participants outlined a number of recommended conditions if consumer and community involvement was mandated in health and medical research. These conditions included: research institutions having appropriate infrastructure in place; making seed [pre-award] funding available; training for researchers and consumers; and, flexibility to accommodate circumstances when it's not possible to involve consumers.

Where participants responded 'no', the main reason provided was the high risk of consumer and community involvement becoming tokenistic (i.e. a tick box exercise) and a compliance task. It was noted that consumer and community involvement is not considered suitable for all research and there is a need to recognise that the nature of involvement may vary (one size does not fit all) and sometimes it not possible to achieve despite best efforts.

This project was led by Dr Angela Jones, Dr Sandra Reeder, Professor Helena Teede, Ainslie Cahill, Debra Langridge, Associate Professor Nicolette Hodyl and Cathie Pigott on behalf of AHRA.





# Background

The community are the funders and beneficiaries of research and healthcare in Australia and deserve to be front and centre in driving a health system fully informed by research that meets their needs<sup>1</sup>. The *Statement on Consumer and Community Involvement in Health and Medical Research* (the Statement)<sup>2</sup>, co-authored by the National Health and Medical Research Council (NHMRC) and the Consumers Health Forum of Australia (CHF), was published in 2016 with the aim of guiding research institutions, researchers, consumers and community members in the active involvement of consumers and community members in all aspects of health and medical research. It outlines the benefits of consumer and community involvement in health research to the public, researchers and research institutions; describes methods and models for involving consumers; provides definitions associated with consumer involvement in health research; as well as strategies for implementation.

The current review process is timely to ensure the Statement maintains its relevance and currency. A consultation paper, prepared by the NHMRC with input from the NHMRC Consumer Statement Advisory Committee and CHF, provided the framework for seeking views from consumers and community members, researchers, research institutions and funders about what should be included in the revised Statement - *Review of the Statement on Consumer and Community Involvement in Health and Medical Research 2016 Position Paper* (Position Paper)<sup>3</sup>.

In December 2023, AHRA was appointed by the NHMRC to convene a series of face-to-face and online workshops across Australia to facilitate robust discussion and gather input on the questions posed in the Position Paper.

# About AHRA

AHRA is a national partnership of 14 Research Translation Centres accredited or recognised as emerging by NHMRC to embed research into health care. The Centre Partners have significant breadth and partnership, with 367 hospitals, 33 First Nations and community groups, 53 Medical Research Institutes, 28 Universities and significant primary care reach.

The vision of the AHRA Centres is to see consumer and community involvement as intrinsic to and embedded in the operations of all research bodies, reflecting genuine

sharing of power, mutual trust and shared belief in its value. The Centres actively prioritise involving consumers as active and equal partners in co-design, implementation and dissemination of research. This work has provided a National AHRA framework and principles for consumer and community involvement in research, and nationally leading resources such as a co-developed handbook, new knowledge generation on best practice consumer and community involvement, and a national online knowledge hub funded by MRFF (MRFF2019278), to be launched in late 2024.



# Methodology

## Engaging stakeholders

Stakeholders were identified by applying a codesigned stakeholder matrix. Utilising our existing national networks of consumer and community representatives, researchers, research institutions, health services and research funders, across urban, regional, rural and remote areas of Australia we purposively engaged stakeholder groups (consumer and community representatives, researchers, research institutions and research funders) to conduct a series of online and in-person workshops. We leveraged existing consumer and community networks/advisory groups and theme structures/groupings of senior researchers as well as early and mid-career researchers within the Centres. The workshops were promoted via Centre communications channels (newsletters, updates at key meetings etc) and the AHRA website, which listed scheduled workshops, as well as the NHMRC website.

AHRA endorses best practice approaches to consumer and community involvement in research, including remuneration of consumers. It is noted that there was no dedicated NHMRC budget to accommodate honorariums for the engagement of people with lived experience, acknowledging this may have also impacted equity of representation in the workshops.

The requirement to complete this project by 15th June 2024 as well as budget implications excluded targeted, focussed consultation with Aboriginal and Torres Strait Islander community members on country and for this reason is beyond the scope of this report. However, we were able to engage First Nations partners and networks within the Centres, and build on the platform of work that commenced in 2018 with establishment of the Indigenous Research Capacity Building Network (IRNet) initiative and

informed the NHMRC funded Our Collaboration in Health Research (OCHRe) Network. Aboriginal and Torres Strait Islander community members were engaged through events hosted by the Central Australian Academic Health Science Network; Health Translation South Australia; Maridulu Budyari Gumal, the Sydney Partnership for Health, Education, Research and Enterprise (SPHERE) Western Australian Health Translation Network, Tropical Australian Academic Health Centre, Tasmanian Collaboration for Health Improvement and Top End Academic Health Partners.

## Workplan and timeline

In consultation with the office of the NHMRC, Monash Partners, on behalf of AHRA developed a workshop plan for stakeholder consultation. Thirteen Centres as well as The Australian National University actively participated in a nationally coordinated program of 11 in-person and 11 online workshops, with central support provided by the Monash Partners team. In total, 22 workshops were conducted across Australia between March 19th and May 23rd 2024 (See Table 1 overleaf). In person workshops were held at Centre partner venues to minimise room charges, for example, seminar/conference rooms, community centres within academic, research and health service member organisations. Online workshops enabled engagement of stakeholders unable to attend in-person events. Promoting the workshops through the AHRA website meant that stakeholders could access virtual workshops in other states.





Table 1: Workshop schedule.

Centre and state	Number of workshops in person and online	Target stakeholders			
		Consumer and community	Researchers	Research institutions	Funders
Monash Partners, Melbourne and South East, VIC	1 in-person 2 online Central coordination	√	√	√	√
Western Australian Health Translation Centre, WA	1 in-person 1 online	√	√	√	√
New South Wales Regional Health Partners, Regional NSW	2 online	√	√	√	
Tropical Australian Academic Health Centre, Northern QLD	2 in-person 1 online	√	√	√	
Health Translation South Australia	1 in-person	√	√	√	√
Health Translation Queensland, Metro QLD	1 in-person 1 online	√	√	√	√
Tasmanian Collaboration for Health Improvement, Tasmania	1 online	√	√		
Sydney Health Partners, Metro Sydney, NSW	1 in-person 1 online	√	√	√	√
Maridulu Budyari Gumal, SPHERE, Metro Sydney, NSW	1 online	√	√	√	
Western Alliance Academic Health Science Centre, Regional and rural, VIC	1 online	√	√	√	
Central Australian Academic Health Science Network, Alice Springs, NT	1 in-person	√	√	√	
Melbourne Academic Centre for Health, Metro Melbourne, VIC	1 in-person	√	√	√	√
Top End Academic Health Partners	1 Hybrid	√	√	√	√
The Australian National University, Canberra	1 in-person and other round table discussions and interviews	√	√	√	√

#### Communication with stakeholders

Each Centre utilised their extensive and established communication channels (e.g. newsletters, webpages) and centralised local networks to advertise the workshops. Relevant stakeholders were also approached directly through email or telephone or kitchen table discussions. In addition, AHRA, through their MRFF funded work on the *Consumer and Community Involvement: Implementation Research for Impact* project engaged national research funders through existing contacts. Standard information was created by the coordinating team and used by the Centres to promote the workshops.

#### Collection of participant demographic data

The participant demographic data fields were agreed with the NHMRC and collected via a standardised template at workshop registration. The demographic data included: self-identified role in consumer and community involvement; State/Territory of residence; country of birth; main language spoken at home; and if participants identified as Aboriginal and/or Torres Strait Islander.

#### Workshop format

Workshops formats were based on local facilitation expertise, stakeholder and setting context and included methods that encouraged open discussion between stakeholders such as roundtable and small group discussions through breakout groups. A standard workshop agenda and slide presentation was prepared for use at all workshops, containing information such as the objectives and workshop questions. The Monash Partners team facilitated a series of planning sessions, where the Centres brainstormed workshop methods, engagement and communication strategies, and framing of the questions to attendees. They also provided support with workshop facilitation where Centres lacked capacity. The workshop questions (drawn from the Position Paper) and agreed with the NHMRC were:

#### Question 1

- What parts of the current statement have or have not worked well?
- Is the value of consumer and community involvement clear/communicated in the Statement as a whole?

#### Question 2

- Do the current values, 'shared understanding, respect and commitment' need to be strengthened and, if so, in what way?
- Should values such as accountability, transparency, collaboration and partnership, equity, diversity and inclusiveness be included in the Statement? Are there any others you would you like to see, and why?

#### Question 3

- What are the most important practice principles to include in the revised Consumer Statement?

#### Question 4

- What roles and responsibilities should be included for:
  - a. Consumers and community members
  - b. Researchers
  - c. Research institutions
  - d. Funders

#### Question 5

- Should consumer and community involvement be mandated by funding agencies – why and why not?

#### Thematic summary

A summary of workshop discussions by theme domains was captured using a standardised template and provided to all Centres to complete and return to Monash Partners for central collation and finalisation of the summary report. Using a deductive framework, an overall summary of the workshops has been generated by the Monash Partners team and is presented here.



# Data analysis

## Demographic data

The demographic data collected from the workshop attendees is presented here. A total of 440 people attended the 22 workshops across Australia, with almost equal numbers of consumers (135, 31%) and researchers (154, 35%) (see Figure 1).

The participants resided in all states and territories of

Australia with NSW (125, 28%), Queensland (83, 19%) and Victoria (69, 16%) with the largest representation (see Figure 2).

As expected, most participants resided in urban areas 71% (n=310) (see Figure 3), were born in Australia 68% (n=292), spoke English only 78% (n=344) and spoke English either well or very well 98% (n=288). Sixteen participants identified as Aboriginal or Torres Strait Islander.

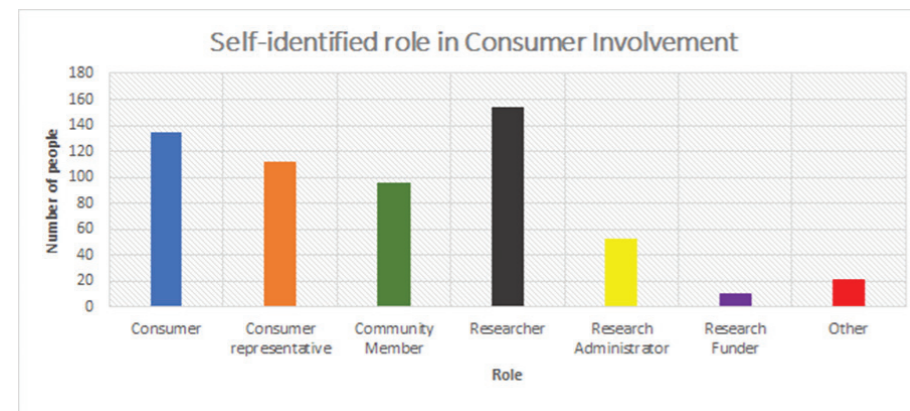


Figure 1: Self-identified role of participants in consumer and community involvement.

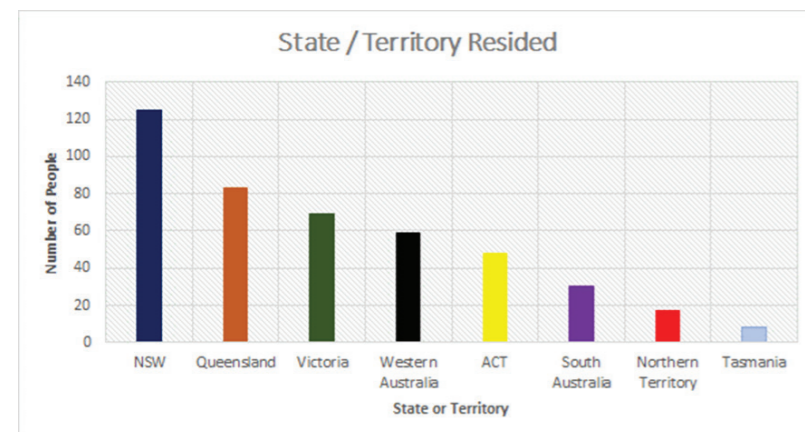


Figure 2: State/Territory where participants resided.

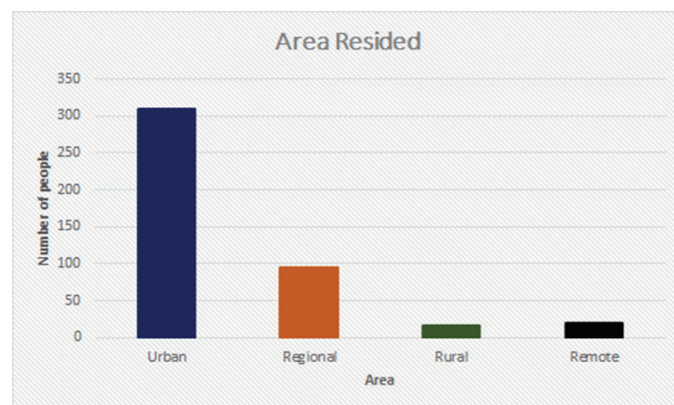


Figure 3: Location of workshop participants.

## Considerations during data analysis

Data were analysed thematically for each of the five main questions posed at the workshops. As the discussion at many workshops extended beyond what was specifically asked for in each question, a section on general feedback regarding the purpose, accessibility and audience of the Statement has been added. Additionally, responses to questions two and three in many workshops contained integrated information about both values and practice principles. To reduce the risk of altering participants' intended meaning, the methodological decision was made to integrate the responses to these questions.

## Feedback about the Statement

Workshop participants provided feedback about the Statement that was related to its purpose, function, use, accessibility and intended audience.

## Purpose and function

During workshop discussions, participants reported their expectations regarding the purpose of the revised Statement. Participants expressed their hope that it would serve to educate others about meaningful consumer and community involvement, provide expected standards of consumer and community involvement practice, and support consumer and community involvement uptake and implementation. They also hoped it would drive improved integration of consumers into research funding, provide references to other quality resources, and motivate research institutions to develop infrastructure to support consumer and community involvement. Some participants indicated that the Vision is something to be achieved in future, whereas a Mission statement is something for now.

## Include evidence, references and links

Several workshop participants suggested that evidence-based references and other high-quality references are added to the revised Statement to strengthen its position. For example, links to toolkits and consumer and community involvement training information would be helpful additions for consumers and researchers.

## Profile of the Statement

Participants recommended raising the profile of the revised Statement so there was greater awareness about it among undergraduate and PhD students in health and medical courses, consumers and community organisations, and researchers working in health and medical research. They highlighted the potential for "the NHMRC... to lead in this space and make the changes needed to show the evolution of consumer and community involvement".

## Improve Statement accessibility

Many participants described the need to consider the health literacy of readers of the Statement and for it to incorporate accessible language. The current Statement was perceived as "not that accessible for consumers in terms of length, language, assumption of research knowledge". Many concurred with the view that "language matters. [The revised Statement] should be straightforward and easy to understand. [Use] plain language". Some suggested that a separate plain language document could be produced as a public version, or a plain language summary Statement added. To make the revised Statement more "engaging" and accessible, there was significant support for the use of "graphics, videos, or other tools to ensure the Statement is understandable by, and meaningful to, all potential stakeholders". It was suggested that:

*Revised document needs greater involvement of consumers in the writing stage to ensure a stronger consumer voice and a document that speaks to consumers as well as researchers.*

## Clarify the audience for the Statement

A question raised by several participants was in regard to "who is the audience?" for the Statement. This feedback stemmed from the language used in the document ("not plain English") and that the Statement appeared to be "targeted at researchers" and not consumers. Several people suggested that "the Statement needs to speak to everyone – rural and urban, all demographics, genders, cultures and socio-economic groups" and "include clear Statement of [the] intended audience. [There] needs to be a single document that is meaningful for all audiences".



# Question 1: What parts of the current Statement have or have not worked well?

## Perceived value of the Statement

Workshop participants had varied perspectives about the value of the Statement. Most commented they did not find it particularly useful in its current form while others declared they were unaware the Statement existed. Many were aware but rarely used it or referred to it in the course of their work. The reasons provided for this included that it lacked specificity (written in “too high-level language”), was “vague” and “repetitive”, and “it’s not a policy, procedure or guideline”.

Participants explained that the broad coverage and content of the Statement “changes nothing” and there is no clear responsibility in it which “limit[s] accountability” for the delivery of meaningful consumer and community involvement. Others emphasised that the absence of detail and references in the Statement meant people were left with the challenge of finding other high-quality resources. Participants explained:

*The current Statement is very high level and has limited usefulness as people who want information about consumer and community involvement have to find other resources to actually implement consumer and community involvement.*

Aligned with overall feedback, one group of workshop participants offered the following advice:

*The Statement needs to ‘evolve’ as it is ‘quite theoretical’, ‘vague’ and ‘lacks practicality’, and ‘now is the opportunity to make this document the benchmark’, but it requires change, just as consumer and community involvement has evolved.*

## Useful components

A small number of people reported the Statement was useful. Some found the definitions to be helpful, while others liked the stated rationale for consumer involvement in health and medical research. The described benefits and types of involvement were also noted to be informative.

## Suggested additions and changes

### Incorporate the work completed with Aboriginal and Torres Strait Islander communities

Several participants suggested that the *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders*<sup>4</sup> should be referenced in the revised Statement, while others recommended the integration of its values and principles. One group of workshop participants explained that the values and principles:

*have been developed through extensive consultation and consideration, [and] demonstrate best practice in consumer and community involvement, and should be a reference point for general consumer and community involvement.*

Participants suggested that the terminology in the revised Statement be made consistent with the guidelines for research with Aboriginal and Torres Strait Islander Peoples and communities. Indeed, several participants advised that “there should be alignment across the NHMRC suite of documents especially at HREC [Human Research Ethics Committee] level.”

### Involve consumers and community in research design and problem ideation

Throughout workshop discussions, significant support was expressed for the involvement of consumers and community in early problem ideation, research priority setting and research design. Expressing the sentiment of many, participants from one workshop stated:

*Glaring omission [in the Statement]– research prioritisation and involvement of consumers in prioritisation. Doesn’t discuss co-design. Not addressed [in] the Statement – how do we drive forward consumers choosing research agendas, being part of conversations. [This is an] important piece in prioritising what research occurs under public funding.*

Participants suggested adding a “commitment to engaging with the public and informing the public about research opportunities from the outset” to the revised Statement. To support consumer involvement in the early stages of research processes, participants were clear that funding must be provided to support consumer and researcher collaborations. The provision of seed funding to enable early consumer involvement was viewed as a role and responsibility of research funders.

### Change the phrasing of ‘across all stages of research’

Participants noted inconsistency in the term “all stages of research” throughout the Position Paper. Strong support was evident to reword phrases such as “at all stages of the research” and “across all stages of the research cycle”. Participants considered that consumer and community involvement at “all” stages of research was an “unattainable goal” and may not always be appropriate. Further, concerns were raised about the practical application of consumer and community involvement at “all stages of research” due to funding constraints, insufficient support, questions around the value added, and inconsistent consumer interest and expertise. The following participants captured the concerns of many:

*It may be idealistic to involve consumers at every stage – [if there is] no funding to support. Maybe include ‘appropriate’ stages versus ‘all stages’. Researchers need funding to properly engage with consumers – ‘all stages’ requires a lot of funding and time.*

*Change [the wording] ‘All aspects...’ – as consumers don’t want to be involved in all aspects/stages they have no expertise in.*

Participants cautioned that it would be unlikely consumers knew what “all stages of research” meant, and that the word ‘stages’ could be replaced with more accessible wording such as ‘aspects’. Others felt it should be “acknowledge[d] there may be project stages and topics where there is no added benefit of incorporating consumer and community involvement” and offered suggestions for more “practical”

language. These included adding “...when able” or “...in a way that works for them” or “... where it will add value”. Further, it was recommended the sentence should commence with “consumers and community should be provided the opportunity to be involved...”.

### Implementing the values and principles

Some workshop participants suggested the current Statement “has not translated well” and voiced their concern about implementation information not being included in the revised Statement. Many participants noted that they wanted guidance on how to “operationalise” the information contained in the Statement as it did “not [have] enough detail for researchers on HOW to engage or WHO to engage with”. The absence of information about “how to engage” left researchers and consumers wondering “how does it all play out in practice?” Case studies or examples might make the principles easier to understand. The following comments summarised the sentiment expressed and shared by many:

*It was mentioned that [implementation] was proposed to be removed from the future Statement. The group did not agree, and consensus was that it should be strengthened, or a separate practical document developed.*

*The Statement doesn’t make consumer and community involvement be done well- people want information and models that help them put consumer and community involvement into practice – these would be the most useful to researchers.*

While some proposed that “high quality resources are needed to support any Statement to support quality consumer and community involvement implementation”, others questioned “is a Statement the most effective tool? Is a guideline or something with more substance better (with steps and directions)?” Some participants wanted the revised Statement to contain “goals and outcomes for consumer involvement, and a framework for how to get there”. Many people thought “it [the Statement] should be



explicit about what consumer involvement actually looks like” and requested the addition of examples and case studies to support operationalising meaningful consumer and community involvement. They also suggested, “the word ‘involved’ may need to be operationalised to include activities such as ‘read’, ‘attend meetings’ or ‘actively participate”.

Many participants expressed significant concern about the removal of consumer and community involvement implementation information as there would be no guidance on how to do meaningful and genuine consumer and community involvement. As a result, tokenistic consumer and community involvement may persist where “people can think they are implementing consumer and community involvement and the values stated, but still not share power”. Other participants reported frustration at the intention to remove implementation information as “people look to the NHMRC on how to do consumer and community involvement and do it well”. Without consumer and community involvement implementation information, participants would have to navigate through the myriad of consumer and community involvement toolkits and assess the quality of each one prior to use. Additionally, participants reported it would be more difficult for them to justify and inform research institutions about what is really required in conducting consumer and community involvement in research.

### Language and messaging

Workshop participants provided detailed feedback about the language and terms used and proposed in the Position Paper. Feedback was provided in many areas including using “stronger wording” and “strengthening statements” to improve clarity around expectations. Further, rewording, updating language, and defining terms were all recommended in the revised Statement. A common view expressed across many workshops was that the revised Statement “language needs to elevate beyond transactional consumer and community involvement and consumer and community involvement tokenism and foster authentic engagement”. Additionally, people wanted to see the revised Statement align with information and terms used in other NHMRC documents. Some participants also took the opportunity to advocate for a change to the term ‘consumer’.

### Reword and update language

Workshop participants noted that some words and terms were “unclear”, “abstract”, “generic”, and “inappropriate”. Overall, many agreed that “language needs to be more explicit” in the revised Statement. For example, some participants did not like the language “all Australians”:

*All Australians’ is too broad and could be reworded to ‘people from all communities’. ‘All Australians’ could also be considered limiting, as research often involves international collaborations or global outcomes, and not everyone who lives in Australia considers themselves Australian. There was a suggestion that simply deleting the reference to ‘all Australians’ would resolve this tension.*

Other participants perceived that there were “elements of paternalism” in the Position Paper language, citing the example that consumers “can ‘co-present’, but nothing on co-authoring peer reviewed publications”. Some participants felt the language was “culturally inappropriate”, and suggested “caution around use of the language, for example the terms ‘vulnerable; and ‘at risk’ groups which can disengage members of the community”. Furthermore, some participants noted “that the terminology of “participation” and “involvement” changes throughout the current Position Paper”, when “involvement” is the preferred term.

Some felt the language in the Statement was outdated and that it had “served purpose for an era, [and now we have] moved on. The language is so high level it isn’t a road map”. Participants also commented on terms used such as “appropriate” and “active” and questioned what was actually meant by these terms. Stating the difference between consumers and stakeholders, and removing the word “patient” were both recommended. Further, suggestions were made for the revised Statement to use “language such as ‘working alongside’ [as it] shifts the power balance”.

### Definitions

Many workshop participants requested that terms used in the revised Statement be consistently and clearly defined throughout. Several participants endorsed the addition of a glossary of terms noting that:

*Definitions in the document need to be extended to ensure common understanding of terms used throughout - language matters.*

Some suggested that the “NHMRC and MRFF need [to] align their definitions and share a common glossary.” Summarising the sentiment of several other workshop participants, one group proposed that the revised Statement:

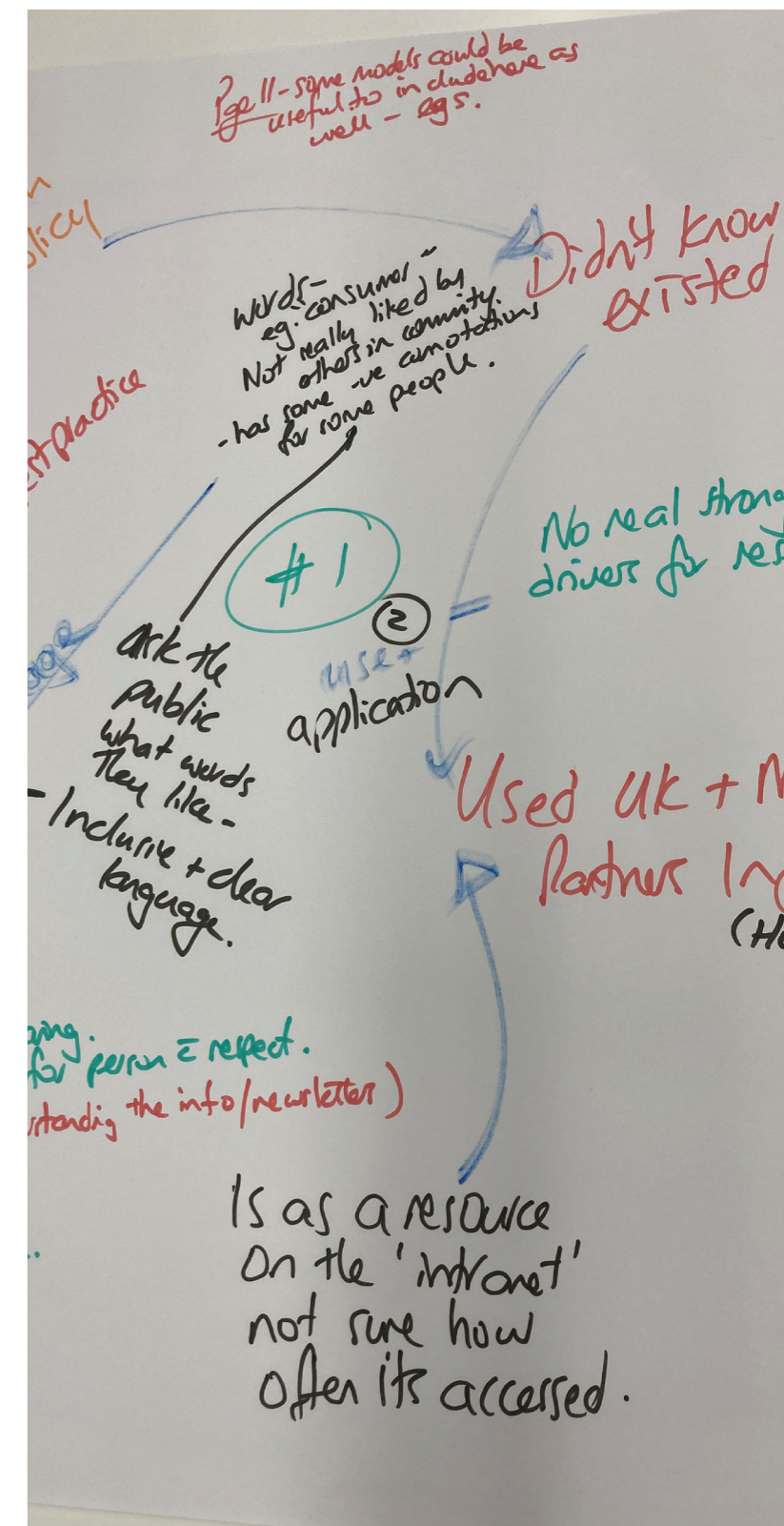
*should start with most important paragraphs (1) definition of consumer, (2) rationale of including consumers. Provide good definitions of consumers including lived experience, community member etc. Generic consumer is often substituted for lived-experience which often is not good enough.*

Some participants noted the term “partnerships” required a clear definition as it appeared “aspirational” rather than achievable in the current Statement. The inclusion of examples was recommended to clarify and help operationalise “partnerships” and other Statements.

### Additions to the Statement

Participants highlighted that the Statement was lacking references to some important literature and stakeholders. They suggested adding references to clinicians and practitioners to acknowledge that they also had an important role in research conduct. Additionally, there was a view that the Statement was “totally missing the inclusion of rural communities” and that it needed to “speak to regional, rural and remote” communities.

Participants further advised there should be greater emphasis on the value and benefits that consumers bring to health and medical research. In its current form the Statement “doesn’t have a great value proposition for involving consumers”, and the revised Statement should be “framed around the benefits of consumer and community involvement and how it leads to better (health) outcome and better experiences”. One group of participants echoed the perspective of many, stating:





*Value [is] not articulated in any detail. The Statement says consumer and community involvement can add value [but with] no indication of where and how contribution is valued. Talks about reinforcing health care decisions, acknowledges consumers potential beneficiaries, [but] doesn't talk about how that can contribute and at what timepoints along research journey.*

Additionally, some participants noted the value of involvement to the consumer was not clearly articulated in the Statement, and neither was information about the sustainability of consumer and community involvement. A group of participants questioned:

*Is there room for stating that consumer engagement be sustainable? Ideally, refer to consumer 'partnership' (rather than 'involvement') as being accountable, systematically embedded, and sustainable in the long term.*

#### Stronger wording and messaging

There was a clear consensus across workshops that "the Statement needs gravitas" and that "the purpose statement is too soft". To strengthen the revised Statement and align it with the importance of consumer

and community involvement, participants emphasised that the language needed to shift from suggesting "consumer and community involvement was 'nice to have' when it should be saying it is 'essential'. Numerous participants noted that "the word 'should' needs to be changed to 'must'. MUST be involved". Others felt the wording, "applicants should consider the benefits of including the consumer", read "like an optional message up the back... it hasn't been communicated well and comes across as an optional extra."

#### Use of the term 'consumer'

A number of workshop participants used the opportunity to express their dislike of the term "consumer". Summarising the overall sentiment of the people who commented on the term, one group of participants reported:

*People look to the NHMRC on how to do consumer and community involvement and do it well, but they must lead to do this by addressing the terminology issues - change the word 'consumer' and make consumer and community involvement in research 'essential'.*





# Question 2: What overarching values are essential to include in the value statement of the revised Statement? and Question 3: What are the most important practice principles to include?

While questions about overarching values and the most important practice principles were asked separately at each workshop, most participants integrated their discussion about values and principles. Very few participants were concerned with delineating the difference, with many noting “values inform the practice principles” and that it was important to make clear “how principles and values apply across many settings, projects and populations”. Accordingly, we have reported the results of both questions below.

There was clear consensus from the workshop participants that values and practice principles needed strengthening. Many recommended providing definitions and “including ideas on tangible outcomes and processes to support principles”. Similarly, other workshop participants stated:

*Rather than just list values, make it clear what NHMRC is going to do about integrating values into action.*

Furthermore, some participants suggested that “values should each have a partnership basis e.g. mutual respect, goal focused commitment”.

The workshops generated some consensus on the most important or “essential” values and practice principles as well as suggestions for additions.

## Values and practice principles

Participants recommended that it was essential to retain the values ‘respect’ and “respect for lived experience and community expertise”, and ‘shared understanding’. Although some pointed out there were “different perspectives on what ‘shared understanding’ could mean”, and suggested this should be clarified. ‘Commitment’, however, was not considered an essential value as participants commented that “commitment on its own is meaningless. What are we committing to? – it’s ambiguous”, and similarly, “without the context, the word ‘commitment’ was considered bereft of meaning”.

Other values perceived as essential to include in the revised Statement were ‘transparency’, ‘honesty’, ‘safety’, ‘accountability’, ‘partnership’ and ‘reciprocity’. With respect

to ‘honesty’, several participants preferred the term ‘transparency’. Strong support was voiced for the addition of ‘safety’ as an essential value as it was interrelated with principles of ‘do no harm’ and ‘duty of care’. Similarly, the value of ‘accountability’ was clearly endorsed for inclusion.

Some suggested that “mutual accountability” should be considered, as should the addition that “researchers, research institutions, funders need to be accountable for genuine and meaningful consumer and community involvement”. When discussing the value of ‘partnership’, participants provided a range of suggested prefix terms such as “equal”, “authentic”, “genuine”, and “mutually respectful”, indicating that researchers and consumers were “collaborating” and “sharing power”. Further, the addition of the value ‘reciprocity’ was suggested and well supported by workshop participants, provided that the revised Statement “spells out what reciprocity looks like”. A group of workshop participants explained their perspective:

*Reciprocity – ensuring consumers are getting something out of their engagement (funding, support, skills, knowledge, training...). Worth trying to understand what reciprocity may look like in practice. Want to make sure engagement is not tokenistic, rather a valuable experience for both parties.*

Other values and principles considered essential by participants were ‘equity’, ‘diversity’, ‘inclusive/inclusiveness’, and ‘culturally appropriate’. Participants from one workshop noted the Statement was “completely and utterly missing inclusiveness - change that”. Most participants agreed and indicated strong support for the addition of ‘inclusiveness’. Regarding the inclusion of ‘diversity’ and ‘equity’, participants offered suggested language to use in the revised Statement. They suggested including “respect for different identities” in the practice principle related to ‘equity’ and ensuring “fair access to consumer and community involvement opportunities”.

With respect to the proposed practice principle around “broad diversity”, participants across many workshops expressed the view this principle needed to be strengthened and more clearly and appropriately

expressed. They outlined multiple potential issues and suggested language to consider in the revised Statement:

*Diversity and equity needed further clarification. Broad representation was considered as not always best practice. There was a sense that this was an overarching Statement that could not be applied to all research projects (e.g., disease profile, working in discreet cultures etc). If this is pursued as an overarching principle – particularly in smaller communities – you run the risk of coercing community members to be involved in your research rather than partner. Smaller communities have smaller pools of people from which to draw. This principle should be more targeted e.g., “appropriate to the audience for the research” or “participant groups included in the research.” Consider providing consumers/community members with “equal opportunity” to be involved in research.*

*To ensure genuine diversity and equity, we suggest wording along the following lines: ‘consumer and community involvement must be drawn from the communities or population groups who are going to be impacted by the proposed research’.*

Participants suggested the terms ‘building relationships’ and ‘building capacity’ should be considered and noted that “building mutually respectful relationships” is an important principle and separate from other values and principles such as partnership and collaboration. While not necessarily a value or principle, many workshop participants raised ‘building capacity’ as important to mention in the revised Statement. The addition of ‘building capacity’ was rationalised as an enabler for empowering consumers and communities and for fostering meaningful and genuine partnerships and relationships. Furthermore, it was acknowledged that “you need quite skilled researchers for inclusive research, particularly [consumers] with additional support needs, so training is needed”.

Other values raised by participants, but not ranked as ‘essential’ included ‘mutuality’, ‘authenticity’, ‘co-ownership’, and ‘connection’. The values of ‘integrity’ and ‘collaboration’ were also mentioned but thought to be encompassed by, or enablers of, the values noted as essential. For

example, participants noted “integrity involves working with respect, upholding values, being open, transparent and accountable”. However, it was suggested that: “Too many values becomes meaningless, and then difficult to operationalise.”

In addition to the ‘essential’ values and practice principles reported above, a number of other practice principles were recommended by participants. These included ‘working ethically’, ‘working to empower consumers’, ‘ensuring consumers have access to research results and project publications’, ‘learning together’ and ‘effective communication’. ‘Tailoring approaches’ was also suggested as it “needs to be clear that there are segments of the community that need different approaches”, as well as shared decision-making, which “should be a key principle from the beginning”. Furthermore, some participants proposed that a practice principle around “use a community request approach for research in priority populations”, described as seeking out community groups with existing links and expertise with particular communities to conduct the involvement work on behalf of researchers or others.

Comments regarding the practice principle “involved at all stages of research” have been noted under Question 1 in this report as this language or similar language was used in multiple places throughout the Position Paper.





# Question 4: Roles, expectations and responsibilities of consumers and community members, researchers, research institutions and funders

Overall, there was consistent alignment and support from workshop participants for the roles and responsibilities articulated in the Position Paper. Suggestions around modifications and the addition of new roles and responsibilities are described below.

## Roles and responsibilities of consumers and community members

The most frequently identified roles and responsibilities for consumers and community members, for inclusion in the revised Statement were: engage in activities to develop skills, contribute to research projects, intentionally utilise connections and networks, and, be reflexive about motivations, limitations and responsibilities as a consumer. Participants agreed that consumers should **build their capacity**, if needed, to ensure they understood research processes and 'stages of research', were able to clearly communicate their perspective, and "deliver lived experience with impact so it is heard". Building consumer capacity was reported as important "in order to add value to the development, conduct and communication of research". Participants also concurred that areas of capacity building were likely to be specific to the individual and research project, and that "the researcher and research institution have the responsibility to facilitate these [training] opportunities".

Workshop participants explained that **contributing to research projects** encompassed being prepared, open to opportunities and ideas, and "ask[ing] lots of questions". **Intentionally utilising connections and networks** was described as communicating with others in their network/s and intentionally seeking out discussion with relevant consumer groups. Overall, many participants supported the view that:

*consumers feel they have a larger role to play especially in research projects being conducted in minority/disadvantaged populations where their community connections could be utilised to strengthen the success of the project.*

Participants suggested that in **being reflexive** about motivations, limitations, and responsibilities, consumers and community members should disclose personal interests, respond honestly and with integrity about their experience, and maintain an awareness of their own scope

and potential bias as a consumer 'representative':

*The responsibility [of consumers] should be strengthened with words such as 'honestly' or 'truthfully' particularly when providing feedback from their lived experiences.*

Other roles and responsibilities included being an **advocate** for consumer and community involvement. For example, advocating for more consumer involvement in research projects (generally and at the project level), and "for investment in resources to involve diverse people and to communicate results to consumer and community stakeholders". Being a consumer and community involvement "champion" was suggested by some to overlap with advocacy, however participants noted that a **champion** could "provide advice on consumer and community involvement", seek support to champion consumer and community involvement to researchers, research organisations and funders, "champion for more diverse consumer voices at every level", and call out tokenistic consumer and community involvement when encountered. Other roles mentioned included **seeking support** as needed and "taking ownership of clarifying unclear information".

One group of workshop participants felt that the roles and responsibilities for consumers and community members outlined in the Position Paper were "very general statements [and that] responsibilities need to be negotiated on each project/for each situation". Some supported the inclusion of "**tailored**" roles as a shared responsibility for consumer and community members and researchers while several others suggested that it was not a shared responsibility 'to consider the best person(s) for a particular role or task', and that this should be reworded as:

*Research institutions and researchers have a responsibility to consider the best person(s) for a particular role or task..."*

## Roles and responsibilities of researchers

Participants recommended the inclusion of multiple roles and responsibilities for researchers in the revised Statement.

Numerous participants from many workshops raised

that researchers had a responsibility to **consider the best person for a particular role or task** and not simply involve the 'easiest to access' consumers. They also suggested "working with consumers to identify other appropriate consumers to partner on [a] project" and highlighted that researchers have a responsibility to **work ethically** and be accountable for their work with consumers and communities. This was described as showing a duty of care, using trauma-informed principles and practice, planning and preparing for consumer and community involvement, seeking and being open to consumer feedback as well as responsive to it, and ensuring confidentiality for consumers.

Researchers maintaining **clear and regular communication** with consumers was also strongly supported with participants noting that all communication should reflect the values of honesty and transparency. Others added that it was important for researchers to understand consumer communication preferences, and communicate regularly using "accessible language". Clear communication from researchers should entail following up with consumers who have been involved in a project to inform them about the project results.

Participants revealed that meaningful consumer and community involvement was achieved when researchers **identify their consumer training needs and complete training** and are aware of best practice consumer and community involvement values, principles, and guidelines. While many participants endorsed that researchers and consumers should **learn together**, the addition of a responsibility for researchers and consumers to undertake professional development together was not as well supported. Some participants raised that there was no evidence to support this responsibility and proposed alternative wording:

*Researchers should build strong relationships with consumers and communities to learn from each other's knowledge and experience.*

Including a role and responsibility for research related to **equality** was strongly supported for inclusion in the revised Statement. Some participants, however, suggested rewording to the following:

*Researchers must establish the parameters of the relationship between the researcher and the consumer/*

*community member. Consumers/community members are considered equal contributors to the group or team based on their experiences and skills.*

Participant feedback was varied around the responsibility of researchers to **champion** the benefits of consumer involvement. Some supported this addition, while others cautioned it can "overburden researchers" and that "maybe [its] the responsibility of institutions – [as it's] a bit tough to expect everyone to do this".

Several participants recommended adding reciprocity and building relationships to the revised Statement. Examples of **reciprocity** included ensuring that consumer involvement activities were appropriately budgeted for in grants so that consumers were reimbursed, and inviting consumers to contribute to publications and the dissemination of results. Additionally, it was proposed that researchers should ensure consumers involved in a project have free access to all project outputs (such as project publications).

Workshop discussions also revealed that an expected role and responsibility for researchers was to **build relationships** and connections. One group of participants recommended adding to the revised Statement that "researchers need to have authentic connections with the consumers they are doing research about". The outcomes from researchers building relationships with consumers were anticipated to be shared understandings about the research project and the importance of consumer and community involvement, opportunities to learn from each other, and assurance that planned research will meet community needs.

Participants also suggested including that researchers must **appoint a dedicated project person** for consumers to contact. Such a role was expected to address the many consumer needs for consumer and community involvement reported by participants, for example, "onboarding for consumers so they were orientated to projects and processes". Additionally, a dedicated project person could regularly communicate and check in with consumers, and streamline processes for consumers to ask questions, direct feedback, discuss problems, and manage payments.

Several participants further raised in workshop discussions that a researcher role and responsibility was to engage with

consumers in all types of research, including laboratory-based research.

### Roles and responsibilities of Research Institutions

#### Lead cultural change

Participants clearly articulated that it is the role and responsibility of research institutions to **lead cultural change** by “building the culture of involving consumers” in health and medical research. There was a strong view the revised Statement should send a “clear message” of “step up to universities”. Participants indicated they expect research institutions to invest in, commit to, and expect best practice consumer and community involvement in their organisations. The strength of the message was conveyed through suggested changes to the wording in the Position Paper examples. Participants were dissatisfied with the language that ‘research institutions should commit to the involvement of consumers and community members...’, questioning:

*What does ‘commit’ mean? What does that actually look like? What are the responsibilities of ‘commit’ and at ‘various levels’? What resources are going to be ‘committed’? This responsibility is so broad it has lost meaning.*

Participants advised using stronger and more explicit wording such as “research institutions will provide...”. Leadership by research institutions should encompass embedding consumer and community involvement in organisational structures and processes “to walk the talk and demonstrate how to involve consumers”.

Workshop discussions revealed concerns about researchers being “overburdened” with conducting consumer and community involvement and that this was “not sustainable”. The following workshop participants echoed the perspective of many, noting:

*There is a lot of onus on researchers to do all the work in this partnership (ethics, governance, engagement) and little responsibility from the institutions.*

*Too many research institutions [are] not supporting consumer and community involvement in systematic and practical ways, leaving all of the responsibility with researchers.*

Other workshop participants emphasised their concern that:

*We have to make sure that research is still doable and that we’re not putting so much additional onus on our researchers that it all just gets too hard and they just stop [...] we’re expecting them to be experts in data security, in budgeting and all of the governance and ethics stuff, and that’s before they even start doing their research.*

In response, most participants called for the revised Statement to highlight the role and responsibility of research institutions to develop and implement:

*an organisational infrastructure with systems, policies, and processes that give structure to consumer and community involvement activity, support, its key activities (funding), and embed in routine practice.*

#### Build the appropriate infrastructure

To build the **appropriate infrastructure** for consumer and community involvement uptake and growth in health and medical research, participants noted that both large and small research institutions have a role and responsibility to **prioritise and allocate money and resources** to support implementation and sustainability. Some suggested commencing with “institutions ... provid[ing] leaders with expertise in consumer and community involvement”. Many participants proposed that research institutions demonstrate their commitment to and leadership in consumer and community involvement by **developing policies**.



Participants stated that “funders and research organisations need clear policies and procedures to guide consumer and community involvement in research” including, for example, policies about remuneration, co-authorship, and open access for consumers to project results. Furthermore, research institutions were advised by participants to co-produce policy and strategy documents and resources with consumers, such as developing an organisational “Consumer Engagement Strategy”. Participants explained:

*Research institutions must demonstrate a tangible commitment to continuous quality improvement, for instance, by developing a resource such as a Consumer Engagement Strategy, to ensure that relevant governance systems are fit for purpose and articulated in specific mechanisms.*

Participants suggested that **establishing governance** was a key part of the recommended consumer and community involvement infrastructure and role of research institutions. Governance was expected to include “consumer and community involvement at all levels”, and ensure processes that “seek feedback through continuous quality improvement” and “confidentiality [for] consumers”. Some workshop participants recommended strengthening the language in the example role and responsibility by the addition of the word “will”:

*Governance structures, including boards and committees, policies and procedures, will incorporate the principles, values and elements for effective consumer participation.*

Research institutions were also expected to provide **systems and processes** that supported the administration and delivery of meaningful consumer and community involvement. Participants stated that research institutions should develop “simplified payment practices, publicised engagement opportunities, dedicated community research feedback/engagement events” and “ensure all technical obstacles for consumer and community engagement are meaningfully considered and removed as appropriate”. Participants suggested that research institution systems and processes should contain consumer databases, measure outcomes of consumer and community involvement, and have “clear and transparent processes for consumers to make complaints and to leave a project”. Additionally, research institutions were

perceived to have a responsibility to provide resources such as selected standardised documentation (e.g. non-disclosure agreements and template position descriptions) to support researchers with undertaking best consumer and community involvement practice.

#### Evaluate processes and outcomes

Many participants advised adding that “research Institutions will **evaluate** the processes and outcomes from researchers and consumer and community members involved in research” to their roles and responsibilities. Participants elaborated, suggesting that research institutions should collaborate nationally to drive improvement through shared learnings, and developing national standards and benchmarks for consumer and community involvement performance.

#### Provide education and training to capacity-build researchers and consumers

They agreed it was the role and responsibility of research organisations to provide education and training to capacity-build researchers and consumers to design and undertake meaningful consumer and community involvement and deliver best practice principles. Multiple workshop participants advocated for the revised Statement to include the following language for research institutions:

*Research institutions need to provide a structure for supporting consumer reps to be trained and improve their skills and knowledge. That responsibility can’t sit with individual researchers.*

*It is the responsibility of research institutions to build capacity of researchers to empower consumers. The participants considered it was incumbent on research institutions to provide access to education and training for consumers ‘to feel prepared to undertake their role as consumer and community representatives in whatever position they’re taking it on, whether it’s on a research board or a project steering committee or a key community Research liaison person’.*

*Research Institutions will provide researchers and consumers/community members with opportunities for relevant education and training.*



Some participants noted that ethics committees should be included in the consumer and community involvement training and education provided by research institutions, emphasising the need to “train ethics committee to understand consumer and community involvement and embed consumers”.

#### Connect researchers and community members

They agreed that “consumer and community engagement needs institutional support to **connect researchers and community members**”. Some suggested that organisational leadership and investment in consumer and community involvement should be demonstrated by “establish[ing] a bank of consumers” and “develop[ing] meaningful partnerships with existing national consumer advocacy groups”. Connecting and building relationships with consumers and communities was proposed as an enabler for researchers commencing and conducting meaningful consumer and community involvement. Suggested wording was:

*Research institutions are responsible for establishing ongoing relationships with relevant consumer groups, that exist and continue beyond the life of any single project. This would ensure consumers are involved not only in research, but in the setting of strategic and research priorities.*

A further research institution responsibility was to establish a **dedicated and specialised consumer and community involvement role** to support consumers and researchers. The creation of such a role as part of consumer and community involvement infrastructure was to:

*bridge researchers and consumers [by] act[ing] as a liaison to ensure the relationship is maintained and support [was available for] both researchers and consumers during the process.*

Several participants agreed that such a specialised role could involve coordinating consumer and community involvement support across the organisation by developing opportunities for mentoring, establishing organisational systems for reporting and sharing successful and challenging experiences. Further, a dedicated consumer and community involvement role could include

facilitating communities of practice and providing tailored advice such as budgeting appropriately for consumers in projects.

#### Showing accountability

An important role and responsibility for research institutions was recognised by participants as **showing accountability** for the “implementation and conduct of authentic, genuine and meaningful consumer and community involvement”. Examples included, leading and driving consumer and community involvement culture change, instituting the consumer and community involvement infrastructure described above, and “report[ing] on consumer and community involvement metrics in annual reports”.

It was discussed by participants that many of the recommendations would have resourcing implications for research institutions, but investment in consumer and community involvement within the institution was considered part of showing commitment and accountability to researchers and consumers to undertake meaningful consumer and community involvement. Some participants from smaller research institutions however noted that without extra resourcing to build the appropriate infrastructure first, some recommendations such as having a dedicated and specialised consumer and community involvement role would be difficult to implement.

#### Roles and responsibilities of funders

Many workshop participants agreed with the example roles and responsibilities for funders outlined in the Position Paper, but some suggested they were “*hard to read and too complicated... with no definitions*”. Many additions were recommended for inclusion in the revised Statement.

These included that funders should have a role in **facilitating consumer opportunities** to be involved in health and medical research. It was noted that existing systems for consumer involvement advertisements are inefficient and ineffective, limiting broader involvement:

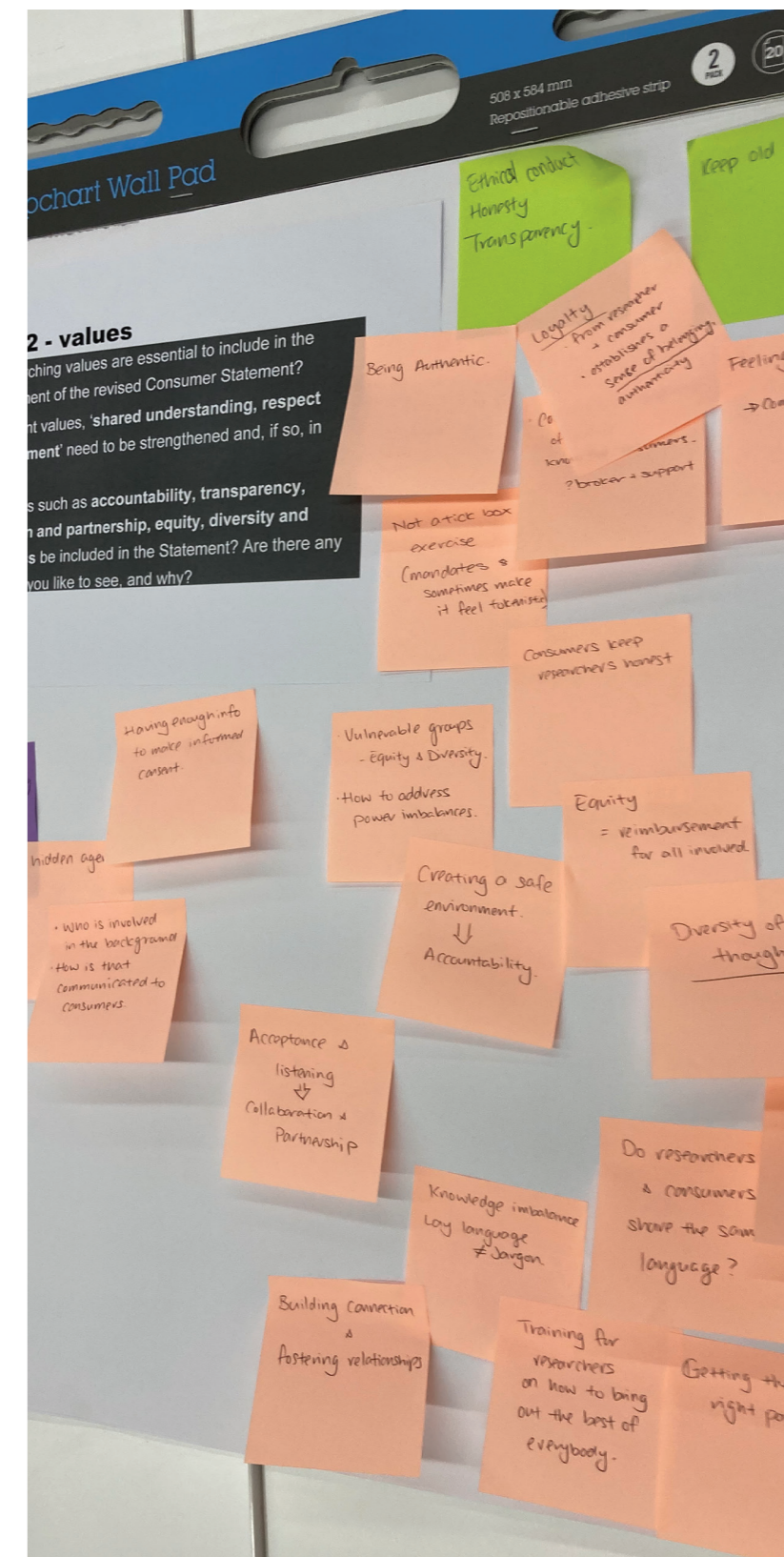
*only specific consumers with a particular agenda may know of engagements. Potentially a large number of*

*consumers never hear what's out there.*

Many participants wanted the revised Statement to contain a role and responsibility for funders to clearly articulate **standards and expectations for consumer and community involvement practice**. Concern was raised about the prevalence of tokenistic consumer and community involvement, including examples such as “a sole consumer representative is common and it’s ‘good on them if they can have any impact’”. Furthermore, it can be difficult to drive behaviour change without clear guidance on what are acceptable and appropriate “standards [for consumer and community involvement] that researchers need to meet”. A perspective shared by many was that the revised Statement “needs to outline a measurement of consumer involvement [otherwise] it’s too easy to take a tokenistic approach”.

Similarly, participants recommended that funders **be transparent** about consumer and community involvement assessment and scoring in grant applications. Many people wanted to see “clear guidelines for consumer and community involvement activity and how it will be scored” and “development of these guidelines with consumer panellist who also score applications”. Funders were advised it is their role to “be explicit about criteria [for] consumer and community involvement to be successful in receiving funding”.

Workshop discussions highlighted that funding and resources are required to embed enabling systems and processes to conduct genuine and meaningful consumer and community involvement and that funders should be responsible for ensuring this is sufficiently resourced in research institutions and for researchers. With respect to research, funding was required for reimbursing consumers for their time, skills, knowledge, and lived experience, conducting engagement activities (such as obtaining broad consensus from appropriate communities), training for researchers and consumers, and having time to build relationships with consumers and communities. Additionally, many participants advised that the revised Statement contain the responsibility that “funders should provide guiding principles on consumer remuneration”. Funders were advised to connect and collaborate with other funders to produce policy for all Australian researchers and consumers that enables them to fairly and consistently provide or receive consumer remuneration.





## Question 5: Should funders of research mandate the involvement of consumer and community representatives in the research they fund?

Similar to the stated researcher role and responsibility, participants wanted to see “**greater accountability** from a funder perspective”. They indicated that funders show accountability by requiring that all funding applications explain how genuine consumer and community involvement would be conducted and how consumers would be involved in the research design and instituting “mandat[ory] reporting of how consumer and community involvement has played out through the life of a project”. If consumers were not involved, a clear justification was recommended.

This accountability included ensuring that established systems, processes and rules were conducive to consumer and community involvement. Participants reported tension with funders encouraging consumer and community involvement yet having unfriendly administration processes to support involvement. Examples included researchers having no flexibility in how grant money was spent in projects that involved consumers, and consumers facing challenges in grant application processes:

*Funding guidelines are often rigid. [Funders] need to consider a level of time flexibility to ensure quality consumer engagement can be implemented.*

*Make it easier for consumers to be included in funding applications. The NHMRC Sapphire system is terrible for consumers, the application forms very consumer-unfriendly.*

Participants advised that funders should be responsible for adopting more accountable approaches by incorporating and operationalising their own consumer and community involvement recommendations. Numerous workshop discussions reflected the sentiment expressed by the following participants:

*What is the point of the document when it is not translated through the grant application and award process? There is no money to support early grant ideas with consumers, there are grant schemes without consumer and community involvement requirements when it should be in all, there is no reporting of how consumer and community involvement is conducted for successful grants, there is no national support for education and training, no grants specific for consumers to lead research.*

Many participants agreed that funders were expected to show leadership and commitment by integrating consumer and community involvement requirements into all funding streams, and consumers into grant administration structures and processes (including “consumer roles in governance and committees at all levels of the funder organisation”). A funder responsibility would subsequently include capacity-building consumers and people in funding organisations to ensure their policy for conducting meaningful consumer and community involvement aligned with the organisational work carried out. Many participants supported more meaningful roles for consumers in research funding organisations and that this be a responsibility for funders in the revised Statement:

*Research funders can involve consumers in reviewing funding applications, setting priorities, identifying research topics, designing and developing programs, and supporting funded projects.*

Some workshop participants also highlighted that, to reflect genuine consumer and community involvement, the NHMRC needed to incorporate consumers in scoring funding applications. This process was noted to be in place at selected funding institutions such as the “Cancer Council for example -30% of scoring [was by a consumer reviewer]. [It’s] fantastic!”. Consistent with this recommendation, participants advised that funders be responsible for ensuring all grant “reviewers assess consumer involvement in consistent ways, and that they understand meaningful involvement versus tokenism”.

Another funder role and responsibility discussed for inclusion in the revised Statement was for funders to make money available for consumers to be involved in problem ideation and early research designs. This recommendation was reported under Question 1 as its inclusion in the revised Statement crossed over many questions.

Across the workshops conducted, most participants responded that funders should mandate consumer and community involvement for the research they fund. While not all participants provided a rationale for their perspective, of the people who responded ‘yes’, multiple reasons were provided. These included that a consumer and community involvement mandate could lead to better health and research outcomes demonstrating value for money, and “increase accountability of researchers” for how they conducted consumer and community involvement. Others felt that a mandate would “advance consumer and community involvement” through increased uptake and “ensure that consumer and community involvement is embedded into research”. Additionally, a mandate was perceived by many as appropriate because it “respects rights of consumers and their value” and “will have an impact [on] how consumers and community experience or live their life with connection to the health services they use.”

While many people agreed funders should mandate consumer and community involvement, they also stipulated conditions. One condition involved research institutions having appropriate infrastructure in place to support researchers and consumers with meaningful consumer and community involvement. Many acknowledged that “it takes time to put in place all the pre-work to create an environment where we could mandate consumer and community involvement” and therefore suggested a “good approach [is] to take the time to assess the funding/consumer and community involvement landscapes at points in the future, and then re-assess if mandating is appropriate”. Others supported a mandate for consumer and community involvement in funded research on the conditions that “seed [pre-award] funding is made available”, “researchers and consumers are trained in consumer and community involvement” or that the mandate policy was flexible. Flexibility was suggested to accommodate circumstances when:

*[It is] not always possible to involve consumers (noting imbalances between supply and demand for consumers... internal capacity issues within research organisations, etc).*

Some workshop participants recommended alternatives to a general consumer and community involvement mandate for funded research. Several recommended

requiring “mandatory justification of why consumer and community involvement is not required” in funding applications. One group of participants explained, “embed consumer involvement component in grant applications [but] put the onus on researchers to justify why they are not involving consumers”. Alternatively, others suggested to “mandate consumer and community involvement in the development of a research question”.

Of the participants who responded ‘no’ to funders mandating consumer and community involvement in the research they fund, one of the main reasons provided was that “there is a high risk [consumer and community involvement] will be treated tokenistically (as a box ticking exercise)” and will become simply a “compliance task”. Others cited that consumer and community involvement is “not considered suitable for all research” and there was a “need to recognise [that the] nature of involvement may vary (one size does not fit all) and sometimes [it is] not possible to achieve despite best efforts”.





# References

1. Teede, H & Wesselingh, S 2018. Turning research push into implementation pull for health benefit, MJA InSight Plus. Accessed 13 June 2024, <https://insightplus.mja.com.au/2018/40/turning-research-push-into-implementation-pull-for-health-benefit/>
2. National Health and Medical Research Council 2016. Statement on Consumer and Community Involvement in Health and Medical Research. National Health and Medical Research Council, Consumers Health Forum of Australia.
3. National Health and Medical Research Council 2023. Review of the Statement on Consumer and Community Involvement in Health and Medical Research 2016 Position Paper, National Health and Medical Research Council.
4. National Health and Medical Research Council, 2018. Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders. Commonwealth of Australia: Canberra.







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