Australian Government
National Health and Medical Research Council

Consumers Health Forum of Australia

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

2025 Consultation Report

Contents

Executive Summary

The 2025 Consultation Report presents the findings of the national consultation on the draft revised *Statement on Consumer and Community Involvement in Health and Medical Research*[1] (the Statement). The Statement was co-authored by the National Health and Medical Research Council (NHMRC) and the Consumers Health Forum of Australia (CHF). The NHMRC-Medical Research Future Fund (MRFF) Interim Consumer Advisory Network (ICAN) and the NHMRC-MRFF Consumer Advisory Group (CAG) provided advice to NHMRC and CHF throughout the drafting process.

The 2025 consultation was facilitated by The Kids Research Institute Australia (The Kids) and consisted of Australia-wide in-person and online roundtables. Stakeholders were also welcome to provide written submissions. The consultation gathered feedback about how clear and appropriate the Statement was and how it could be improved. Stakeholders also shared what support and resources they need for consumer and community involvement (CCI) to be effectively implemented in research.

Overall clarity and suitability

Stakeholders agreed that Principle 1 and the Purpose section of the Statement set an expectation that consumers and communities should be involved in all stages of health and medical research. However, many felt the Statement's overall clarity could be improved. Suggestions included adding a short mission statement to declare the Statement's purpose upfront, providing background information on the different stages and types of research and levels of CCI, and defining the Statement's intended audience.

Views on suitability were mixed. Some stakeholders thought the expectation that CCI is embedded in all research was appropriate, while others argued that basic science research should be exempt. There were also differences in opinion on the language. Some stakeholders preferred the use of flexible language in the Statement to allow appropriate involvement for each project. Others recommended strengthening the language to make CCI a requirement, not an option.

Values and principles

Stakeholders generally agreed that the Statement's values and principles were appropriate, but felt their presentation could be improved. Suggestions included using visual diagrams to explain how the values and principles are linked, and providing examples of them in action. Several stakeholders recommended shortening this section by combining similar values such as equity and inclusion. Others suggested adding values and principles, particularly trust and power-sharing.

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[1] National Health and Medical Research Council and Consumers Health Forum of Australia. Draft Statement on Consumer and Community Involvement in Health and Medical Research. https://www.nhmrc.gov.au/about-us/publications/draft-statement-consumer-and-community-involvement-health-and-medical-research (accessed 6 October 2025).

Roles and responsibilities

Stakeholders suggested some changes to the roles and responsibilities and called for the Statement to specify how they will be enforced. A key theme was the need for the Statement to recognise the full scope of roles consumers, communities, and consumer organisations can play in research. These include leading research and being involved in research governance, evaluation, and monitoring. Some stakeholders found the shared roles and responsibilities section confusing and made suggestions to improve its formatting. Stakeholders called for greater emphasis on researchers' responsibility to ensure CCI is accessible and remunerated, and how research institutions can support this. Funders were seen as key drivers of accountability, with some stakeholders suggesting compliance with the Statement could be linked to grant funding eligibility.

Implementation and additional comments

Stakeholders argued that the expectations set by the Statement must be supported by funding and resources. Many noted the difficulties of involving consumers and communities in the pre-grant planning phases of research, and called for dedicated funding to enable this. Stakeholders also called for the final Statement to be published in accessible formats, such as Easy Read and in languages other than English, to maximise its use. They also suggested that the final Statement be accompanied by an implementation roadmap, practical guidance material, and monitoring and evaluation frameworks.

Additional comments highlighted several new themes, particularly the role of science communication professionals in research translation and building public trust. Stakeholders also discussed language, particularly the definition of *consumer*, and distinguishing between CCI and participation in clinical trials. There were calls to address persistent inequities in regional, rural, and remote areas with dedicated research funding. Stakeholders also advocated for a future-focused final Statement that is aligned with the National Health and Medical Research Strategy.

Introduction

This report was jointly developed by the National Health and Medical Research Council (NHMRC) and the Consumers Health Forum of Australia (CHF). It provides a summary and analysis of feedback received on the draft *Statement on Consumer and Community Involvement in Health and Medical Research* (the Statement). More information on the Statement is available at Appendix A.

Consultation approach

In 2024, NHMRC and CHF drafted a revised Statement using feedback from a national consultation run by the Australian Health Research Alliance (AHRA). The Statement was released for a second round of public consultation in June 2025, which was facilitated by The Kids Research Institute Australia (The Kids). Between July and September 2025, The Kids ran 18 in-person and 7 online roundtables to discuss the Statement. Stakeholders provided feedback on whether it was clear and suitable, and how it could be implemented in research. A total of 497 people attended the roundtables. More information about the roundtables is available in The Kids National Roundtable Report[2].

At the same time, NHMRC ran an online survey on the Consultation Hub[3] to collect written feedback on the Statement. The survey closed on 21 September 2025 and received 117 responses. Fifty-nine responses were from individuals and 58 were from organisations. More information about the survey responses is available at Appendix B and Appendix C.

NHMRC and CHF staff used the summaries of each roundtable and the online survey responses to write this report.

Methodology

The roundtable and survey feedback was analysed for recurring themes using Nvivo[4], Citizenspace,[5] and Microsoft Excel software. All analysis was done manually, except for Question 9, which includes automated analysis of commonly occurring phrases.

The What we heard section presents the qualitative analysis of responses to each question. Similar feedback was received in the roundtables and the survey, so the results have been reported together. Questions 1-7 in the online survey also included yes/no components that have been quantified (refer Figures 1-7).

People who participated in the roundtables and the survey will be referred to as "stakeholders" throughout this report.

What we heard

In the online survey, stakeholders selected "yes" or "no" to questions 1-7 and could also provide free text comments. While most stakeholders selected "yes" to each question (refer Figures 1-7), most of the free text comments highlighted areas for improvement. This trend was consistent across all questions. Stakeholders could only provide free text responses to questions 8 and 9, but again, the feedback focused on improvements.

At the roundtables, stakeholders discussed the same questions, but without the "yes" or "no" component. Like the survey, stakeholders at the roundtables suggested how the Statement could be improved, therefore these suggestions make up most of this report.

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[2] The Kids Research Institute Australia. National Roundtable Executive Summary: NHMRC Draft Statement on Consumer and Community Involvement in Health and Medical Research. https://www.thekids.org.au/events/shape-the-future-of-health-and-medical-research/ (accessed 4 November 2025).

[3] NHMRC Consultation Hub. https://consultations.nhmrc.gov.au/ (accessed 6 October 2025).

[4] NVivo. https://lumivero.com/products/nvivo/ (accessed 6 October 2025).

[5] Delib: Citizen Space. https://www.delib.net/citizen_space (accessed 6 October 2025).

Question 1: Does the Statement set clear and suitable expectations that consumers and communities will be involved in all stages of research?

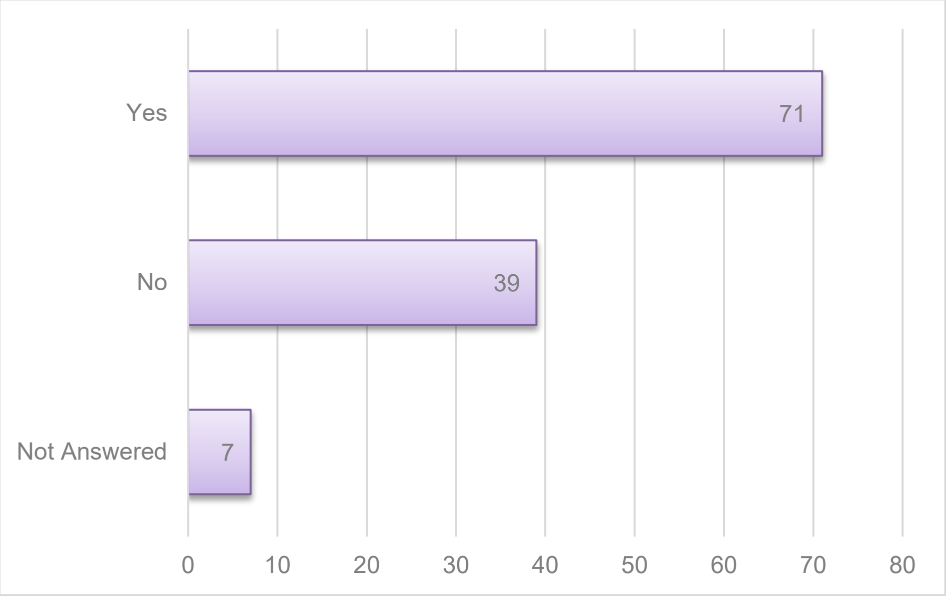

Figure 1. **Quantitative responses to Question 1 (source: Consultation Hub survey)**

Summary of Findings

Stakeholders generally supported the Statement's goal to embed consumer and community involvement (CCI) in every stage of health and medical research. However, feedback from both the roundtables and online survey showed how the Statement could be made clearer, more accessible, and easier to use. This feedback was grouped into 5 key themes:

Theme 1: Clarity and definitions

Some stakeholders thought the Statement was well-written and explained the expectations clearly. They appreciated that the Statement presents CCI as a shared responsibility. Several commented that Principle 1 and the Purpose section set a clear upfront expectation:

Representative stakeholder quotes[6]

"The draft Statement does spell out an expectation that consumers and community members should be present at all stages, levels and types of health and medical research. That intent comes through most clearly in Principle 1, which opens with exactly that wording and lists the key steps where we have a role: early planning, doing the research, interpreting and sharing findings, and evaluation/peer review."

– Consultation Hub survey response

"The purpose clearly articulates the importance of consumer and community involvement, highlighting its transformative potential in research."

– Consultation Hub survey response

Despite this, many stakeholders thought the introduction needed to be clearer. They felt the purpose section provided background information but did not clearly articulate the Statement's goals.

Suggestions to improve this included:

- Adding a short vision or mission statement to explain the Statement's purpose.
- Including a preamble that explains how the Statement was developed.
- Providing a logic model or roadmap showing how the Statement's values, principles, roles, and responsibilities are connected to each other.

"The document needs to clarify who this is for, and what it's for. Potentially background, scope, then purpose."

- AAMRI workshop on Zoom (Online) on 19 Aug 2025

"Some sub-headings in the purpose may help the reader, it is not until the final paragraph of this section that the purpose/goal is actually stated. Might need to highlight this goal/purpose a little more."

– Consultation Hub survey response

"Our group felt that the length of the 'Purpose' section meant the core purpose was easily missed. Propose highlighting a single clear, bold mission statement that drives the entire Statement."

– Consultation Hub survey response

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[6] Some quotes have been paraphrased for readability.

Stakeholders also felt that the Statement could provide a stronger explanation of the value of CCI in research.

Suggestions included:

- Framing CCI as a sign of high-quality research.
- Explaining how lived experience can shape research and benefit everyone involved.
- Providing data and examples to support the Statement's claim that CCI leads to better research.

> *"Consumers bring a unique literacy to research due to their experience. Their contributions should be valued as we value researcher expertise."*
>
> - VCCC Alliance workshop, in Melbourne, on 17 Jul 2025

The Statement does not include guidance on how to put CCI into practice, because this information is widely available elsewhere. Some stakeholders were concerned by this, noting the Statement assumes its readers already know about and understand CCI. They suggested adding:

- A list of the stages that make up the research lifecycle, such as ideation, priority setting, design, ethics, data analysis, communicating the results, and evaluation.
- Showing what effective involvement looks like in each research stage with examples, case studies, diagrams, or infographics.

> *"The Statement outlines involvement well but lacks clarity on how often and to what extent consumers are engaged across all stages."*
>
> - The Kids Research Institute Australia workshop, on Zoom (Online), on 05 Sep 2025

Theme 2: Suitability

Stakeholders strongly supported the Statement's expectation that consumers and communities should be involved in all stages of research. However, many felt the language in the Statement was too broad. Some suggested that different types of research may need different expectations.

Key suggestions included:

- Instead of applying broad expectations to all research, the Statement should encourage co-design methods and consumer and community-led research.
- Making CCI a requirement of receiving grant funding, instead of an expectation. Some stakeholders thought CCI should be required in all health and medical research, while others said it should only be mandatory in clinical and translational fields.
- Explaining whether the Statement's expectations apply to basic science (laboratory-based) research. Some suggested the Statement should explain how to involve consumers and communities in basic science research and why it is beneficial.

- Allowing flexibility. Stakeholders noted that some consumers might not have the capacity or the interest to be involved in every stage. They also acknowledged it can be challenging to involve consumers and communities in rare disease research and sensitive topic areas.
- Making the Statement more relevant by adding roles of other key groups in research. Suggestions included healthcare professionals, peak bodies, and policymakers.

> *"We strongly recommend that the Statement explicitly recognises co-design as the gold standard for meaningful consumer involvement."*
>
> – Consultation Hub survey response
>
> *"The risk in the current wording in the Statement is that it positions consumer and community engagement as a "nice to have" rather than being mandatory and a requirement for all research that is undertaken."*
>
> – Consultation Hub survey response
>
> *"My only concern is that people in discovery research may feel pressured to involve consumers beyond what is reasonably suitable. Different types of research lend themselves to deeper engagement. Much of the discovery or lab-based research can be very challenging in involving consumers at every stage and this could lead to tokenistic engagement which is off-putting for all."*
>
> – Consultation Hub survey response

Stakeholders also noted that the Statement's intended audience is unclear. Some felt it was more relevant to researchers than consumers and communities.

Suggestions to address this included:

- Clearly stating the target audience early in the document.
- Creating different versions of the Statement for different groups, such as researchers, consumers, culturally and linguistically diverse (CALD) communities, and Aboriginal and Torres Strait Islander Peoples.

Theme 3: Equity and inclusion

Stakeholders emphasised that CCI must be equitable and suggested that the Statement include strategies to reduce barriers to involvement. The Statement does discuss equity and inclusion, but many stakeholders thought more detail was needed.

Suggestions included:

- Providing guidance on how to protect the identities, values, and lived experiences of consumers and communities from diverse backgrounds. For example, when working with Aboriginal and Torres Strait Islander Peoples, consumers with lived experience of mental illness, or survivors of violence, stakeholders highlighted the need to:
    - Offer emotional support
    - Avoid language that could be upsetting
    - Revisit informed consent throughout the research process.
- Making it clear that research must be communicated in accessible formats and language. This ensures that people with disabilities, and varying literacy levels and language backgrounds can be involved. For example:
    - Using plain language summaries
    - Avoiding jargon and technical terms
    - Using audio-visual aids
    - Ensuring websites and documents meet accessibility standards.
- The Statement should expect researchers and institutions to provide tailored support. For example:
    - Covering costs for travel, childcare, and interpreters
    - Offering evening or weekend sessions
    - Allowing flexible involvement, such as a consumer providing input via email instead of an in-person meeting.
- Making it clear that consumer and community members must be treated as equal partners in research.
- Acknowledging that while involvement in research can be rewarding for consumers and communities, it can also be emotionally difficult. Stakeholders suggested the Statement include guidance on trauma-informed practices.
- Ensuring that the Statement's expectations of CCI are supported by adequate funding, resources, and training.

"While the Statement promotes values such as inclusivity, respect, and mutual benefit, it could go further in recognising the power imbalances that continue to shape research spaces. Consumers are too often invited in once priorities are set or ethics applications are submitted, limiting their influence over the research questions, design, and intended impact."

– Consultation Hub survey response

"If we are truly to be partners in research—not tokens—then the Statement needs to better clarify how structural barriers will be addressed and what safeguards will ensure that consumer voices are not just included, but carry weight."

– Consultation Hub survey response

"Expectations for consumer and community involvement must be accompanied by adequate and sustained investment. Funding, training, and organisational support are essential to ensure that involvement is feasible, equitable, and sustainable over time."

– Consultation Hub survey response

Theme 4: Language and terminology

Many stakeholders felt the Statement's language was not clear or strong enough. They thought that more direct wording would set clearer expectations.

Key suggestions included:

- Replacing words like "can," "may," and "should" with stronger terms like "must," "require," and "expect."
- Using plain language and avoiding jargon or corporate terms.
- Explaining the difference between CCI and participation in a clinical trial. Some stakeholders noted that this is a common area of confusion.

"There isn't enough strong language to build a long-term relationship to be engaged throughout the planning through to when the research finishes. Sounds like a nice to have, doesn't emphasise the longevity of the relationship."

- The Kids Research Institute Australia workshop, on Zoom (Online), on 05 Sep 2025

However, not everyone agreed with using stronger language. Some stakeholders said the Statement's language needed to be more flexible to avoid putting too much pressure on consumers and communities.

Examples of circumstances where flexibility is needed include:

- Where consumers and communities do not have the capacity to be involved in every research stage due to health, caring responsibilities, or trauma.

- In basic science and laboratory-based research, where it may not be practical to involve consumers and communities in every stage.
- In small populations, where finding consumers to involve is difficult.

Stakeholders suggested flexible language that could be used, including:

- Saying that consumers and communities "can be involved" or "may participate."
- Letting consumers and communities choose how much they are involved. For example, when producing information about the research, some may wish to check that plain language documents are accessible. Others may want to take a more active role, such as co-authoring publications about the research.
- Recognising that not all research needs the same level of involvement. Some stakeholders were concerned that inflexible expectations could lead to tokenism.

"Flexibility is key… sometimes researchers cannot get consumers involved in all stages because there might not be the number of people who can get involved."

- AAMRI workshop, on Zoom (Online), on 19 Aug 2025

"They [consumers] want to be offered to be part of every level, stage and type of health and medical research but they want the choice as to what level, stage and type of health and medical research they take part in. There is danger in making researchers think that they must engage consumers in every level, stage and type of health and medical research - this is not what every consumer wants."

Consultation Hub survey response

Some stakeholders suggested that only consumers and communities should be offered flexibility. They noted that researchers, institutions, and funders hold more power in research and should be held to higher standards.

Examples of higher standards include:

- Researchers showing how consumers and communities were involved in research planning when submitting grant applications.
- Institutions providing training, infrastructure, and funding to support CCI.
- Funders requiring evidence of CCI from researchers and institutions when they report on grant progress.
- Institutions and funders showing accountability by monitoring and evaluating the quality and impact of CCI.

Stakeholders also recommended supporting these expectations with checklists, minimum standards, and examples of good practice.

> *"We cannot expect what we do not demonstrate. More onus needs to be put on systems and structures that are governing consumer engagement."*
>
> – AAMRI workshop, on Zoom (Online), on 12 Aug 2025

Stakeholders felt that some terms used in the Statement were clinical, transactional, or othering. For example:

- Some stakeholders found the term "consumer" limiting or stigmatising. They felt that the term implies a passive role instead of active partnership. Alternatives included "people with lived experience," "community members," or "partners." At a minimum, they suggested using alternate terms alongside "consumer."
- Replacing "vulnerable" with "underserved," "marginalised," or "priority populations."
- Replacing "hard-to-reach" with "traditionally excluded."
- Replacing "involvement" with "shared decision-making," "co-design," or "collaboration."

> *"The term 'consumer' may not be sufficient to capture all involved, such as carers, family, kin and significant others."*
>
> - AAMRI workshop, on Zoom (Online), on 12 Aug 2025
>
> *"We prefer talking about people with lived experience – not consumers."*
>
> - The Kids Research Institute Australia workshop, on Zoom (Online), on 28 May 2025
>
> *"The term 'vulnerable' feels passive and paternalistic. Better to say, 'populations that experience marginalisation'."*
>
> - The Kids Research Institute Australia workshop, on Zoom (Online), on 28 May 2025

Theme 5: Accessibility and guidance

Stakeholders were concerned that the Statement may not be accessible to everyone, particularly people who are new to research. Suggestions to fix this included:

- Adding more definitions, such as the different levels of involvement and stages of research. Some stakeholders said the definition of "consumer" should appear earlier in the document, either by moving the glossary to the beginning, or including it in the Purpose section.
- Publishing the final Statement in multiple formats, such as Easy Read, languages other than English, audio, and video.
- Providing guidance on CCI in different types of research. Some stakeholders suggested adding links to existing guidance material.

- Several stakeholders reported that payment practices are inconsistent between institutions. They suggested including advice on consumer remuneration with set payment rates.
- Developing performance indicators or minimum standards for CCI. These would allow people using the Statement to make sure they are following the principles, roles, and responsibilities.

> *"Without examples of what good consumer involvement looks like, the Statement will lose its impact and purpose."*
>
> - The Kids Research Institute Australia workshop, on Zoom (Online), on 28 May 2025

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

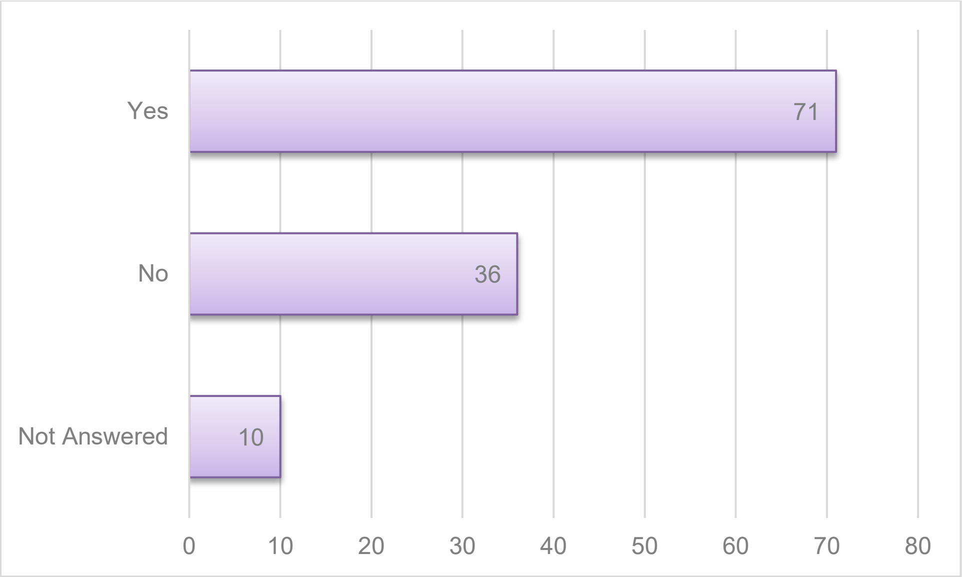

Figure 2. **Quantitative responses to Question 2 (source: Consultation Hub survey).**

Summary of Findings

Stakeholders generally agreed that the values and principles in the Statement support effective CCI. However, some said they could be clearer and better explained with examples. Three key themes emerged:

Theme 1: Values & Principles Integration

Stakeholders provided mixed feedback on whether the values and principles were clear. Some felt that the values were not sufficiently explained, or clearly linked to the principles, roles, and responsibilities.

Key suggestions included:

- Defining each value and mapping it to its related principle to show what it looks like in practice.
- Simplifying this section of the Statement by reducing the number of values. A common suggestion was to merge similar values, like equity and inclusion, or partnership and mutual benefit. A few stakeholders suggested removing the values altogether and focusing only on the principles.

- Using visual aids such as diagrams, colour coding, or tables to show how the values and principles are linked.

"I like the illustration that talks about values. They are good, very distinct to each other. Not overlapping. But it would be good to put a couple of examples."

- The Kids Research Institute Australia workshop, on Zoom (Online), on 28 May 2025

"We feel the values diagram could be strengthened, as well as providing baseline definitions. It would be great to highlight how the values and principles link."

– Consultation Hub survey response

Theme 2: Power, Equality, and Safety

A recurring theme in the feedback was the need to address power imbalances between researchers and consumers. Many stakeholders noted the values and principles mention equality and safety of consumers, but felt the explanation was underdone.

Recommendations included:

- Adding power-sharing as a value or principle. This should be accompanied with guidance on how to implement it, especially when working with priority populations.[7]
- Recognising that lived experience is a form of expertise in Principle 2.
- Using language that better reflects power-sharing, for example "shared benefit" instead of "mutual benefit" in Principle 3.
- Adding "trust" as a value. Stakeholders pointed out that equal partnerships (mentioned in Principle 3) require trust to be built first.
- Adding clearer guidance to Principle 6 (safety of consumers and communities). For example:
    - Explaining informed consent, confidentiality, and data protection.
    - Defining the role that human research ethics committees (HRECs) play in overseeing the ethics of research.
    - Emphasising the need for trauma-informed practices in research and offering aftercare to consumers.
- Aligning the values and principles with Aboriginal and Torres Strait Islander ways of knowing, being, and doing. Stakeholders suggested explaining how the Statement's values and principles interact with existing resources, particularly NHMRC's *Ethical conduct in*

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[7] Australian Government Department of Health, Disability and Ageing. Australian Medical Research and Innovation Priorities 2024-2026. https://www.health.gov.au/resources/publications/australian-medical-research-and-innovation-priorities-2024-2026 (accessed 28 October 2025).

research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders[8]*.*

> *"Consumers are often invited in; they don't have a say. The power is with the researchers."*
>
> - Health Consumers' Council WA workshop, in Perth, on 23 Aug 2025
>
> *"Participating is a privilege, but it has an emotional and financial toll."*
>
> - AAMRI workshop, on Zoom (Online), on 12 Aug 2025

Theme 3: Authentic Involvement vs Tokenism

Some stakeholders liked the Statement's concise format, while others thought it was not detailed enough to provide guidance. Many were concerned that the high-level values and principles would not prevent tokenistic involvement. Stakeholders suggested including accountability mechanisms, safeguards, and examples of the values and principles to prevent them being used as a "tick-box" exercise.

Suggestions included:

- Linking the principles to grant funding. This would mean researchers must follow the principles for their research to be eligible for funding.
- Adding examples, case studies, or measurable indicators to each principle to show what authentic involvement looks like.
- Developing companion resources, such as checklists, templates, training materials, and implementation guides.
- Creating accountability mechanisms. For example, funders, HRECs, and governance bodies could be required to report on how they support CCI.
- Safeguards to protect consumers and communities from exploitation and ensure their voices are heard. For example:
    - **Feedback Loops -** Mandatory reporting back to consumers and communities on how their input shaped research decisions, and an explanation if their suggestions were not used.
    - **Confidentiality and Data Protection -** Clear consent processes for how personal stories and data will be used, with the option to withdraw at any stage.
    - **Escalation Pathways -** A named contact or independent body for consumers and communities to speak to if they feel exploited or ignored.

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[8] National Health and Medical Research Council. Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders. https://www.nhmrc.gov.au/about-us/publications/ethical-conduct-research-aboriginal-and-torres-strait-islander-peoples-and-communities (accessed 28 October 2025).

"If accountability is unclear, involvement risks becoming tokenistic."

- AAMRI workshop, on Zoom (Online), on 12 Aug 2025

"How do we ensure that consumers are being involved and represented appropriately, and does this require funding, incentives or some type of enforcement to ensure consumer organisations are being consulted?"

- The Kids Research Institute Australia workshop, on Zoom (Online) on 03 Sep 2025

"While the values and principles are strong in intent, the Statement could be strengthened by linking principles directly to funding or compliance mechanisms to ensure they move beyond aspirational statements into consistent practice."

– Consultation Hub survey response

Stakeholders also emphasised the importance of reciprocity. Some felt the Statement (particularly Principle 3) explains how CCI improves research, but it could better articulate how it benefits consumers and communities.

Suggestions included:

- Recognising that consumers and communities are essential members of the research team.
- Clearly stating how involvement can benefit consumers and communities. Examples include skill development, career opportunities, improved mental health, and community empowerment.
- Emphasising that CCI must be an equal partnership where everyone contributes and benefits. Some stakeholders suggested replacing the term "mutual benefit" with "reciprocity" or "shared benefit" to better reflect shared ownership and goals.

"Mutual benefit is undersold. It lacks guidance on how to achieve reciprocal value."

- The Kids Research Institute Australia workshop, on Zoom (Online) on 05 Sep 2025

Roles and responsibilities

Stakeholders generally supported the roles and responsibilities listed in the Statement. However, some thought they could be presented more clearly, and with an explanation of whether they will be enforced.

Stakeholder feedback about the roles and responsibilities will be presented in 2 sections:

1. **Cross-cutting themes.** These are ideas that are relevant to the overall roles and responsibilities section. For example, some stakeholders thought that all the roles and responsibilities should be supported with case studies and examples.
2. **Section-specific themes.** These are themes that apply to a specific part of the roles and responsibilities section. These themes are presented in questions 3-7.

Cross-cutting themes

Theme 1: Consumer and community-led research

Stakeholders felt that the roles and responsibilities section could better recognise consumers and communities as leaders of research.

Recommendations included:

- Explaining that consumers and communities do not only contribute to research. They can initiate, lead, and make decisions about it.
- Emphasising research co-design, and explaining that consumers can be paid investigators on grants and co-authors on publications.
- Describing the distinct roles and responsibilities of consumers, communities, consumer organisations, and lived experience researchers.

"The Statement needs to be flipped - consumers should be directing the research."

- VCCC Alliance workshop, in Melbourne, on 17 Jul 2025

"The Statement should clarify that researchers can also support and enable consumer-led projects, recognising that not all research is researcher-initiated."

– Consultation Hub survey response

"Consumers should be involved from the beginning and research should be consumer-led."

- Health Consumers' Council WA workshop, in Perth, on 23 Aug 2025

Theme 2: Guidance & accessibility

Some stakeholders felt the roles and responsibilities section lacked detail on how and when to involve consumers and communities.

Key suggestions included:

- Clear role definitions with examples of activities.
- Setting clear standards by using direct language, like "must," "will," or "is expected to."
- Avoiding jargon and buzzwords like "championing" or "effective," or defining them if they must be used.
- Clear definitions and examples of co-design, co-production, and participatory research.
- Toolkits, guidance materials, and implementation strategies.
- Visual representation of everyone's roles and responsibilities across the research lifecycle.

> *"The Statement provides general recommendations, but many research organisations would benefit from more detailed and actionable guidance tailored to their operational contexts."*
>
> – Consultation Hub survey response

Theme 3: Adherence and accountability

While stakeholders generally supported the included roles and responsibilities, many questioned how they would be implemented and enforced.

Key concerns included:

- The Statement does not say if compliance with the roles and responsibilities will be monitored.
- If the roles and responsibilities are not enforced, the Statement may not prevent tokenistic CCI.
- It is unclear how the Statement's impact on quality CCI will be measured.

Key recommendations included:

- Accountability mechanisms for researchers and research institutions. For example:
    - Integrating CCI into research ethics processes. For example, HRECs could require researchers to explain how consumers were involved in the study design and how they will be supported throughout the research.
    - Making CCI a mandatory discussion point in research governance meetings.
    - Funders requiring CCI updates as part of grant milestone reporting.
- Feedback loops to support continuous improvement.
- Reporting by institutions and funders on the CCI they support. This could include:

    - The percentage of projects that involved consumers and communities.
    - Whether consumers and communities were remunerated for their involvement.
    - How satisfied consumers and communities were with their involvement.
- Developing a standardised framework to monitor and evaluate CCI.

"Without clear expectations or accountability, researchers may continue involving consumers in tokenistic ways. The burden often falls on consumers to make the process meaningful, when it's researchers who hold the structural power to do so."

– Consultation Hub survey response

"Where consumer and community involvement has not taken place, the researcher should also have a joint responsibility with the research institution to report or explain non-involvement in a specific scheme or project."

– Consultation Hub survey response

Theme 4: Supporting consumers, communities, consumer organisations, and researchers

Stakeholders agreed that consumers, communities, consumer organisations, and researchers all require training and support to ensure safe and effective CCI.

Key recommendations included:

- Mandating training in cultural safety, trauma-informed practice, and relationship-building. Some stakeholders suggested that consumers and researchers should attend training together to ensure mutual understanding.
- Support for researchers at all career stages, especially early-career and basic science researchers.
- Funding for early-stage involvement, including seed funding grants and support for consumer organisations.
- Professional development pathways for researchers and consumers, including:
    - CCI training in university courses.
    - Supporting consumers to become co-researchers, educators, and mentors.
    - Nationally accredited training that is recognised across institutions.

"Researchers need training and support for true co-design and equity."

- Health Consumers' Council WA workshop, in Perth, on 19 Aug 2025

The feedback highlighted some tension about who should be responsible for providing support to consumers, communities, consumer organisations, and researchers.

- Some stakeholders thought that researchers are responsible for seeking training for themselves and consumers.
- Others thought that institutions should fund and provide training, seed funding, and remuneration, potentially through a dedicated consumer involvement manager. Some stakeholders thought these responsibilities sit with funders, not institutions.
- Many stakeholders recognise that consumer organisations have the expertise to provide researchers and consumers with training. However, they often lack funding and resources. There were calls for institutions and funders to support consumer organisations to provide training.

> *"Consumer organisations reported that with appropriate funding and resourcing they can mentor, support and guide research institutes and universities to develop ongoing and sustainable consumer involvement infrastructure."*
>
> – Consultation Hub survey response

Theme 5: Equity

Stakeholders emphasised that CCI must be inclusive, representative, and culturally safe. Stakeholders noted the strong focus on equity in the values and principles, but thought it was not adequately addressed in the roles and responsibilities section.

Key feedback included:

- Lack of clarity on what is considered a "diverse" or "vulnerable" population.
- Barriers to inclusion, such as language, literacy, location, and lack of trust.
- Over-reliance on the same voices, meaning that research may not fully represent communities.

> *"We need to be realistic in giving voices to the most voiceless, vulnerable groups."*
> - Health Consumers' Council WA workshop, in Perth, on 23 Aug 2025
>
> *"Without equitable access to resources, the Statement risks becoming a theoretical ideal rather than a practical framework, leading to superficial or unsustainable engagement."*
>
> – Consultation Hub survey response

Recommendations included:

- Defining priority populations in the Statement.
- Providing guidance for researchers working with specific priority populations.

- Recognising that people may face intersections of disadvantage, for example, being part of more than one priority population.
- Explaining how to overcome barriers to involvement, such as time and funding.
- Using recruitment strategies and quotas to reach underrepresented groups.
- Allowing flexible involvement to accommodate diverse needs, life stages, and capacities.
- Creating national guidelines for consumer remuneration and reimbursement. Funders should make it clear whether CCI costs can be included in grant budgets.

Theme 6: Incentivising consumer and community involvement

Many felt the Statement should do more than encourage CCI. They called for making CCI easier and rewarding good practice.

Recommendations included:

- Creating an online platform to provide guidance and connect consumers and communities with research opportunities.
- Recognising consumers and researchers who demonstrate good practice through awards, testimonials, and support for publishing their work.
- Including CCI in promotion criteria for researchers. This ensures CCI is considered alongside traditional measures of research excellence, such as publications and grants.

> *“We need everyone to get on board - institutions need to really support this, funding bodies and public groups need to back it up and recognise good work, and consumers and researchers need to actively take part. This is really about changing how we do things: long-term culture change across the whole research world.”*
>
> - The Kids Research Institute Australia workshop, on Zoom (Online), on 28 May 2025

Section-specific themes

Question 3: Does the Statement clearly explain the shared roles and responsibilities of all involved to ensure effective consumer and community involvement?

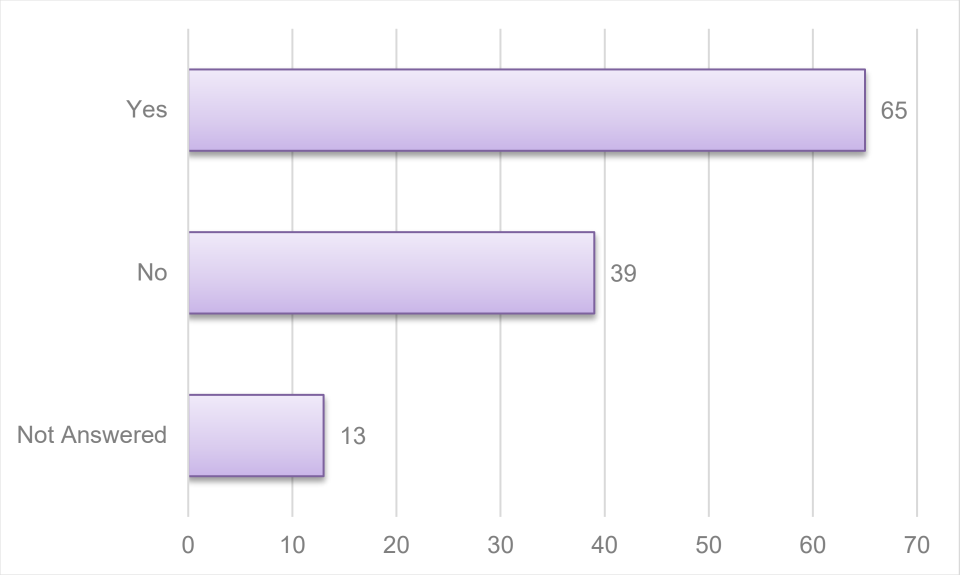

Figure 3. Quantitative responses to Question 3 (source: Consultation Hub survey).

Summary of Findings

Theme 1: Clarity

Stakeholders liked the shared roles and responsibilities section because it made it clear that CCI is everyone's responsibility. However, many found the format confusing, particularly the shared roles and responsibilities table.

Key concerns included:

- Some of the roles were vague, especially those of consumers, communities, and consumer organisations.
- It was unclear who is responsible for implementation, monitoring, and compliance.
- The shared roles and responsibilities table overlapped with later sections of the Statement.

> *"The roles and responsibilities table is very unclear. It suggests it's for everyone, but the roles within it are specific to individuals."*
>
> - The Kids Research Institute Australia workshop, in Adelaide, on 03 Sep 2025

Stakeholders recommended:

- Using clearer language and examples to explain the roles and responsibilities.
- Using visual tools to show how roles and responsibilities apply in different research stages.
- Reformatting suggestions, for example:
    - Listing the stages of research in the table and explaining who is responsible for tasks within each stage.
    - Listing shared roles and responsibilities, with tick boxes showing which stakeholder group/s are responsible for them.
    - Some stakeholders suggested removing the shared roles and responsibilities section altogether. This would address the overlap with other parts of the Statement.

Theme 2: Amendments and additional stakeholders

Stakeholders suggesting changing some of the shared roles and responsibilities, and including more stakeholders.

Suggestions included:

- Adding roles and responsibilities of groups not currently mentioned in the Statement. These include HRECs, carers, health services, policymakers, government, consumer engagement facilitators, and research translators.
- Expanding on the roles that consumers and communities can play in governance, evaluation, and monitoring.
- Stakeholders had mixed views on the shared role of championing:
    - Some said that the Statement should acknowledge that consumers and communities can be champions.
    - Others felt that individual researchers should not be responsible for championing. Instead, they suggested that institutions should appoint experienced researchers as CCI champions.
    - Some stakeholders disliked the word "championing" and suggested removing it or using a different term such as "advocacy".

> *"Every research institution needs CCI champions to ensure adequate representation, implementation and allocation of funding and resources."*
>
> - Translational Research Institute & The University of Queensland workshop, in Brisbane, on 07 Aug 2025

Question 4: Does the Statement clearly explain the roles and responsibilities of consumers, communities and consumer organisations that ensure effective consumer and community involvement?

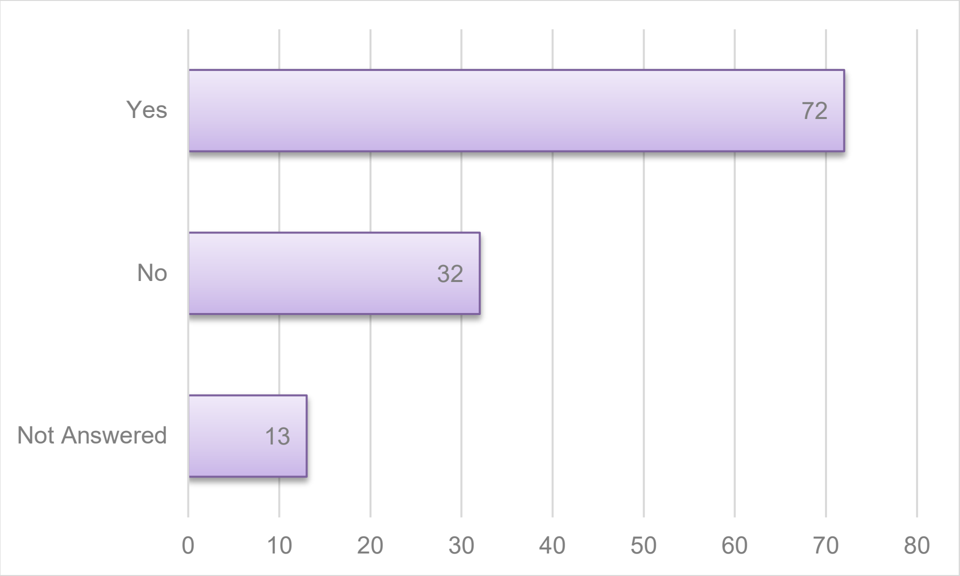

Figure 4. **Quantitative responses to Question 4 (source: Consultation Hub survey).**

Summary of Findings

Stakeholders welcomed the inclusion of consumer, community, and organisational roles in the Statement. However, many felt this section did not capture the full scope of roles consumers, communities, and consumer organisations can play. Two key themes emerged:

Theme 1: Language & Framing

Key concerns included:

- Use of the term “consumer.” Some stakeholders felt this term sounded transactional, rather than reflecting an equal partnership.
- The Statement often reads as researcher-led and does not adequately explain that research can be co-designed or community-driven.
- Grouping consumers, communities, and consumer organisations together caused confusion.

> *"The word 'consumer' is hard to connect with and feels like a transaction will take place rather than a relationship."*
>
> - The Kids Research Institute Australia workshop, in Adelaide, on 03 Sep 2025

Recommendations included:

- Replacing "consumer" with terms like "person with lived experience" or "community member".
- Listing consumers, communities, and consumer organisations as distinct stakeholder groups with their own roles and responsibilities. Stakeholders also suggested including specific roles and responsibilities of lived experience researchers.
- Emphasising that consumers and communities must be equal partners in research. Stakeholders felt this could be made clearer by stating that consumers and communities can be involved in writing publications, research governance, and decision-making.

> *"The Statement does not differentiate between the role of an individual consumer sharing lived experience, a community group advocating for specific needs, or a consumer organisation with existing expertise in research collaboration. These groups have different capacities and responsibilities."*
>
> – Consultation Hub survey response

Theme 2: Missing roles, responsibilities, and stakeholders

Stakeholders identified several additions that could improve this section of the Statement. These included:

- Acknowledging the unique expertise of consumer organisations. Stakeholders felt that consumer organisations should be given the responsibility of training consumers and researchers, rather than research institutions. However, many thought that institutions and funders must fund the training.
- Including roles and responsibilities for consumers under the age of 18, carers, and consumer representatives.

Question 5: Does the Statement clearly explain the roles and responsibilities of researchers that ensure effective consumer and community involvement?

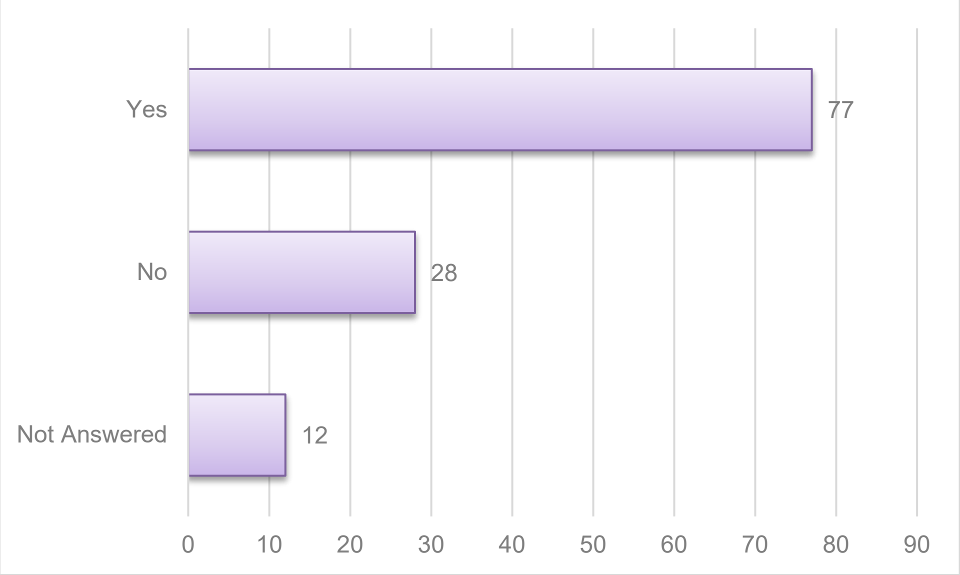

Figure 5. **Qualitative responses to Question 5 (source: Consultation Hub survey).**

Summary of Findings

Stakeholders agreed that researchers play a central role in CCI and that they require support from their institutions. This feedback is captured in the cross-cutting themes section. Two key additional themes emerged:

Theme 1: Health Literacy & Accessibility

Stakeholders emphasised that researchers must take responsibility for making research accessible.

Key concerns included:

- Complex or clinical language can create barriers to involvement, especially for consumers with disability or varying levels of health literacy, and CALD communities.
- Technology can create involvement opportunities, but it can also exclude people. For example, virtual meetings can allow involvement of consumers in remote areas, but may also exclude those without internet access. Stakeholders emphasised that flexibility is essential.

> *"Health literacy must be considered - language should be clear, accessible, and easy to understand."*
>
> - Menzies Institute for Medical Research workshop, in Hobart, on 26 Jul 2025

Stakeholders identified ways for the Statement to strengthen its expectation of accessibility.

Recommendations included:

- Providing examples of accessible documents, such as plain language summaries, translated documents, and visual aids.
- Training for researchers in communication and accessibility.
- Emphasising that research outcomes must be reported in accessible language and formats.

Theme 2: Facilitating high-quality involvement

Stakeholders suggested researchers could ensure high-quality CCI by:

- Planning for the highest possible level of CCI, with an emphasis on co-design as best practice.
- Including adequate budget in grant applications for:
    - Consumer remuneration
    - Wellbeing support (particularly cultural and psychological safety)
    - Consumer training.
- Creating ways for consumers to give feedback that is used to improve CCI.

> *"I suggest an annual check-in where researchers report back to consumer partners on how involvement shaped the project and what could be different next time."*
>
> – Consultation Hub survey response

Question 6: Does the Statement clearly explain the roles and responsibilities of research institutions that ensure effective consumer and community involvement?

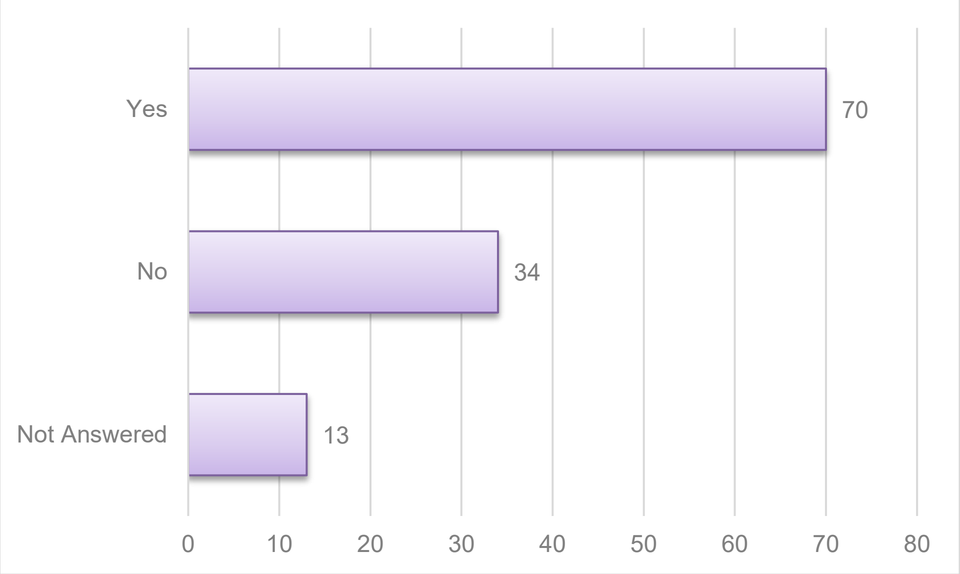

Figure 6. **Online responses to Question 6 (source: Consultation Hub survey).**

Summary of Findings

Stakeholders agreed that research institutions play a critical role in enabling CCI. Some felt the Statement could more clearly define their responsibilities and provide practical guidance. Four key themes emerged:

Theme 1: Organisational Structures

Stakeholders noted that institutions must create support structures for CCI.

Recommendations included:

- Dedicated staff to coordinate CCI, training, and support.
- Including clear CCI expectations in role descriptions of institutional staff.
- Creating accountability mechanisms to ensure CCI responsibilities are met.

> "Institutions could consider creating pathways and resources for embedding lived experience researchers within research teams, research units, centres and institutes."
>
> - Consultation Hub survey response

Theme 2: Accountability and Leadership

Stakeholders felt the Statement could better explain who is responsible for ensuring CCI is effective.

Key concerns included:

- Supporting CCI must be clearly identified as an institutional responsibility. Otherwise, there may be an over-reliance on individual researchers.
- Small and regional institutions often lack systems to monitor and evaluate CCI.
- A need for cultural change to improve CCI practice across the research sector.

> "Involve support and leadership from within research institutions, including senior leadership, to help drive cultural change - this will also support funding mechanisms."
>
> - Menzies Institute for Medical Research workshop, in Hobart, on 26 Jul 2025

Suggested responsibilities for institutions included:

- Mandating CCI in grant applications.
- Creating feedback and reporting loops to track CCI impact.
- Driving cultural change by integrating CCI values and principles into institutional policies and activities.

Theme 3: Integration into Strategy and Governance

Stakeholders noted that sometimes CCI is treated as an add-on or optional activity. They called for CCI to be embedded within institutions and across the research lifecycle.

Recommended responsibilities of institutions included:

- Involving consumers and community in strategy development, priority setting, and research planning.
- Supporting researchers to undertake co-design and co-production of research.

> "Institutions need to really support this... This is about long-term culture change across the whole research world."
>
> - The Kids Research Institute Australia workshop, on Zoom (Online), on 28 May 2025
>
> "I would like to see research institutions take steps to involve consumers in activities such as co-designing policies and procedures, providing advice on what constitutes a 'safe environment,' and being central to the process of promoting an institutional culture that is conducive to consumer involvement in all aspects."
>
> – Consultation Hub survey response

Theme 4: Addressing Systemic Barriers

Stakeholders highlighted barriers that institutions must address for CCI to be equitable.

Key issues included:

- Funding gaps. Stakeholders emphasised that it is difficult to pay consumers for their involvement early in a project, before grant funding is awarded.
- Lack of training, resources, and administrative support.
- Accessibility challenges, particularly for rural, remote, and marginalised communities.
- Emotional toll on consumers and communities if they are not adequately supported.

> “There needs to be appropriate funding of the infrastructure to support consumers to be actively involved in all stages of research.”
>
> - The Kids Research Institute Australia workshop, on Zoom (Online), on 05 Sep 2025

Recommended responsibilities for institutions included:

- Providing seed funding to pay for CCI outside of a grant.
- Supporting researchers to use diverse involvement models, like flexible timing and formats.
- Providing training on trauma-informed, culturally safe, and co-design practices.
- Developing mentorship programs. These would pair an experienced researcher or consumer with someone new to CCI in research.
- Building accessibility into all research processes. This would help ensure CCI is possible at every stage.

> “It [the Statement] does not address the need for institutions to remove organisational barriers that prevent purposeful engagement and to provide the resources and environment needed for researchers to do so.”
>
> – Consultation Hub survey response

Question 7: Does the Statement clearly explain the roles and responsibilities of research funders that ensure effective consumer and community involvement?

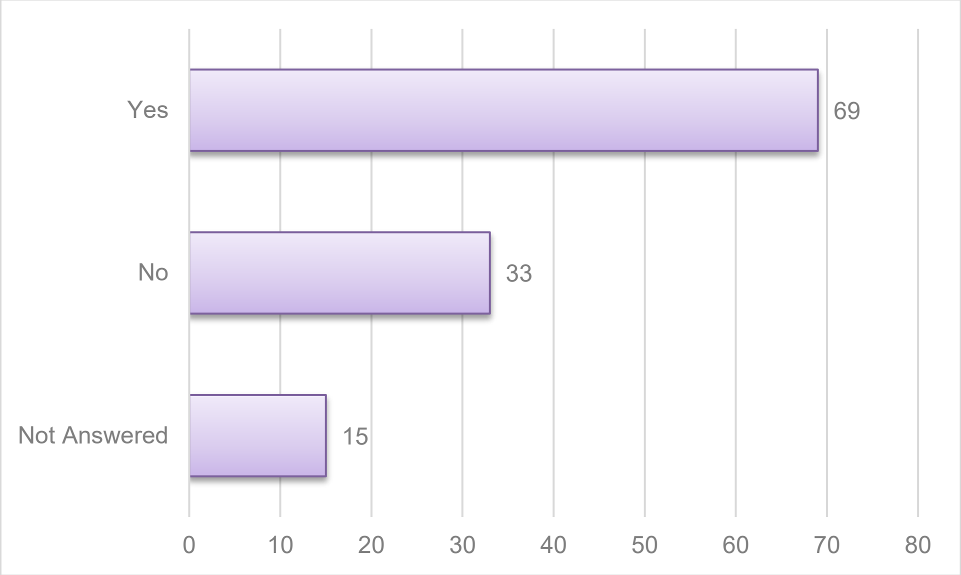

Figure 7. Qualitative responses to Question 7 (source: Consultation Hub survey).

Summary of Findings

Stakeholders agreed that research funders play a key role in sustaining CCI. Some felt the Statement could more clearly explain funder responsibilities and provide guidance. Three key themes emerged:

Theme 1: Pre-Award Support and Dedicated Funding

Stakeholders consistently raised concerns about the lack of funding available before grants are awarded. This makes it difficult for researchers to involve consumers and communities effectively in early research stages.

Stakeholders recommended that the Statement should recommend flexible funding models that accommodate diverse needs and timelines.

They also suggested that funders should provide dedicated funding for:

- Early involvement (seed funding).
- Consumer and community capacity building.
- Consumer and community-led research.

- Relationship-building between consumers and researchers, especially in rural, remote, and marginalised communities.

> "Researchers need funding for CCI but find it hard to obtain grants without CCI. We need pre-award funding to allow researchers to engage in CCI when applying for grants."
>
> - Translational Research Institute & The University of Queensland workshop, in Brisbane, on 07 Aug 2025

Theme 2: Remuneration and Budgeting

Stakeholders generally agreed that consumers must be paid for all contributions. They suggested that funders have a responsibility to ensure CCI is built into research budgets.

Key concerns included:

- Inconsistent remuneration practices between institutions.
- Barriers to payment, such as remuneration impacting Centrelink payments. Some stakeholders also reported institutional constraints causing delayed or missed payments.

> "If we are not paid then we are not valued."
>
> - The Kids Research Institute Australia workshop, on Zoom (Online), on 05 Sep 2025

Recommended funder responsibilities included:

- National remuneration and recognition guidelines, ideally led by NHMRC or a national peak body.
- Producing guidance on how to budget for CCI. Stakeholders noted that some grant guidelines do not clearly state whether CCI can be included in the grant application budget.
- Allowing Associate Investigators to draw a salary from NHMRC and Medical Research Future Fund (MRFF)-funded research.

> "Ongoing funding support for long-term relationships with consumer organisations, community liaisons, and remuneration frameworks will be essential for the Statement's implementation."
>
> – Consultation Hub survey response

Theme 3: National Guidelines and Funder Accountability

Stakeholders called for the Statement to include stronger accountability mechanisms to ensure it is implemented.

Suggested funder responsibilities included:

- Mandating CCI in funded research. Some stakeholders felt that CCI should be mandated in all health and medical research. Others suggested that CCI is less relevant to basic science research, and it should be exempt from a mandate.
    - One suggested way to mandate is by funders requiring CCI plans and budgets in all funding applications.
    - Mandating CCI is explored in greater detail in question 8, and in NHMRC's report on the 2024 Consumer Statement consultation[9] (refer question 14).
- Public reporting and evaluation of CCI in funded research.
- Providing support for consumer organisations, including infrastructure and capacity-building grants.
- Requiring researchers and institutions to report on consumer and community involvement in order to receive continued funding. This could include metrics such as:
    - Number of consumers involved.
    - Diversity of representation.
    - The amount of remuneration provided.
- Including consumers in funding decisions, such as on grant review panels.
- Improving transparency around funder conflict of interests, especially in industry-funded research. Stakeholders noted that industry may have interests in the commercial outcomes of research. Stakeholders explained they were less likely to trust research if they suspected these interests influenced funding decisions.

"NHMRC could work this into their funding criteria a lot more - add weighting to scoring matrix."

- University of NSW workshop, in Wagga Wagga, on 13 Aug 2025

"Mandating/making compulsory that CCI must be evident in grant applications – from prioritisation, ideation, design, implementation to translation. This can be done and is being done in different parts of the funding sector, so needs to be made a deliverable."

– Consultation Hub survey response

"Transparency around partners in funding. Some members of public might be fine with whatever, but for others could be a critical issue."

Flinders University workshop, in Adelaide, on 06 Aug 2025

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[9] National Health and Medical Research Council. Review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research - Online engagement report. https://www.nhmrc.gov.au/research-policy/consumer-and-community-involvement/review-statement-consumer-and-community-involvement-health-and-medical-research/online-engagement-report (accessed 28 October 2025).

Question 8: What else is needed to support the effective implementation of consumer and community involvement?

Summary of Findings

Stakeholders identified a range of structural, cultural, and practical enablers to support the effective implementation of CCI. Four key themes emerged:

Theme 1: Implementation Roadmap

Stakeholders said the Statement needs a clear, visual roadmap to show how it can be implemented by everyone involved in research.

Suggestions for what could make up the roadmap included:

- Guidance on involving consumers and communities in each stage of the research cycle, supported by examples and case studies.
- Clear explanation of the roles that consumers, researchers, institutions, and funders play in implementing CCI.
- Calls for a peak body to lead national implementation and evaluation of the Statement.
- A commitment by funders and institutions to provide funding and infrastructure that enables the level of involvement expected in the Statement.
- Explanation of what mechanisms will be used to monitor and evaluate implementation. Suggestions included:
    - An evaluation framework that consumers, researchers, and institutions can use to measure the impact of CCI.
    - Public reporting that tracks the amount and quality of CCI in funded research.
    - Clear, measurable indicators for CCI, and timelines for when researchers and institutions are expected meet these standards. Stakeholders felt that these standards will simplify implementation and ensure consistency across the research sector.

> “We need a national roadmap so that each institute doesn’t have to figure out their approach from scratch.”
>
> - Health Consumers’ Council WA workshop, in Perth, on 23 Aug 2025
>
> “We need mechanisms to make involvement visible and measurable - for example, annual reporting requirements or a public dashboard.”
>
> - AAMRI workshop, on Zoom (Online), on 12 Aug 2025

Theme 2: Feedback & Communication

Stakeholders identified poor communication as a barrier to implementing CCI. Key areas of concern were:

- Some consumers and communities feel forgotten in the later stages of research. They noted that sometimes they are not informed of the outcomes of the research they have been involved in, for example, whether it has led to a change in policy or practice.
- There is little public awareness of the Statement and of opportunities to be involved in research.
- Barriers to communicating research to the public, including paywalls and jargon.

Recommendations included:

- Creating clear expectations of researchers to report back to consumers and communities throughout all research stages and acknowledge their contributions.
- Institutions could provide regular updates to consumers and communities. These could include newsletters, social media, and community events.
- Coordinating a public awareness campaign to increase uptake of the Statement and knowledge of research opportunities.
- Ensuring research publications are open access and available in plain language.

> "Closing the loop - consumers need to be provided feedback on the outcomes of research and if it has been translated into a health system change."
>
> - Translational Research Institute & The University of Queensland workshop, in Brisbane, on 15 Aug 2025
>
> "There needs to be public recognition of the benefits of consumer input. This could be achieved through a public awareness strategy to include demystification of research to encourage consumer involvement."
>
> – Consultation Hub survey response

Theme 3: Equity of opportunity

Stakeholders noted that priority populations are often excluded from CCI, despite having valuable perspectives. Their feedback largely focused on barriers to involvement for young people, CALD communities, and people living in regional, rural, and remote (RRR) areas.

Key issues included:

- Needing time to build relationships with underserved communities.
- Legal constraints and a lack of guidance that prevents involvement of people aged under 18 years.
- Higher costs of involving consumers and communities in RRR areas.
- Language barriers.

Recommendations included:

- Dedicated youth engagement strategies. These could include mentorship and advocacy to support involvement. Stakeholders noted that young carers are particularly in need of support.
- Legal and ethical guidance for involving youth in research.
- Dedicated funding and capacity building opportunities for underserved communities, including CALD and RRR populations.

> "Young people want to use their voices but don't see themselves as being listened to. We need to know how our impact will be seen and valued."
>
> - AAMRI workshop, on Zoom (Online), on 05 Aug 2025
>
> "Effective implementation will require dedicated funding and infrastructure to support inclusive engagement methods (translations, interpreters, culturally safe spaces)."
>
> – Consultation Hub survey response
>
> "Funding streams dedicated to consumer involvement activities, including rural travel, digital access, and training."
>
> – Consultation Hub survey response

Theme 4: Flexibility & Research Context

Stakeholders agreed that one-size-fits-all approaches do not work across diverse research settings.

Key concerns included:

- Mandating CCI may not suit basic science, rare disease, or small population research.
- The Statement lacks contextual guidance, especially for laboratory-based or data-driven research.
- Some researchers were unsure how to apply the Statement in their field.

> "Instructions to applicants and reviewers should highlight the level of expectations of consumer and community involvement and include explicit guidance on how consumers and community could be involved in discovery (basic) research, if this is indeed an expectation."
>
> – Consultation Hub survey response

Recommended implementation material included:

- Models that illustrate different levels of involvement.
- Fit-for-purpose frameworks. These would allow CCI to be tailored to the research type, population, and context.
- Examples and case studies to illustrate best practice across disciplines.

> "Flexibility is the key for the whole statement. Both perspectives, evaluate how to incorporate the involvement. Not just throughout but after as well. How it's reported back to the consumers and researchers, not sure how to implement that in practice. Shouldn't be a one-time thing, not a one size fits all, but should reflect community engagement in the process."
>
> - AAMRI workshop, on Zoom (Online), on 19 Aug 2025

Question 9: Do you have any additional comments on the Statement?

Participants in both the roundtables and online survey were invited to provide any additional comments not captured by the previous 8 questions. Automated text software analysis[10] was used to generate a word cloud that identified the most common phrases mentioned in the responses (refer Figure 8). The font size is larger for the phrases that were mentioned most frequently. Phrases such as “consumer and community involvement”, “draft Statement” and “health and medical research” were excluded from the word cloud because their frequency obscured other terms.

Figure 8. **Word cloud for responses to question 9.**

Much of the feedback overlapped with other questions, for example suggested additional roles and responsibilities, or implementation concerns. This feedback has been captured under the relevant previous questions. The most common phrases that have not already been discussed in detail are expanded on below.

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[10] Provalis Research. Wordstat. https://provalisresearch.com/products/content-analysis-software/ (accessed 30 October 2025).

Phrase 1: Science communication/science communicators

The role that science communication professionals can play in strengthening CCI was described. It was noted that like consumer organisations, science communicators can enhance or facilitate collaborations between consumers, communities, and researchers.

Examples included:

- Advising researchers on best-practice engagement with consumers and communities.
- Translating complex scientific research into accessible language.
- Raising public awareness of research opportunities for consumers and communities.
- Improving public trust in research.

Phrase 2: Term "consumer"

Some stakeholders reiterated their preferred terminology to "consumer" in this section. This is discussed in more detail in question 1. Some noted that the Statement's current definition of "consumer" excludes people who may benefit from knowledge gain in basic science research. They suggested the definition of "consumer" be expanded to include undergraduate and/or postgraduate students, other basic science researchers, clinicians, and industry partners.

Phrase 3: Mental health

The mentions of mental health in this section included:

- Reconsidering some of the language in the Statement. For example, "compliance" may have negative connotations for people with lived experience of mental ill health.
- A suggested definition of "consumer": A person who uses their lived or living experience of disability, mental health or any other health condition to inform the planning, conduct and interpretation of research and health services.

Phrase 4: Clinical trials

Suggestions included aligning the Statement with clinical trials frameworks and health service strategies. It was also noted that the difference between consumer involvement and participation in clinical trials could be better explained in the Statement.

Phrase 5: Rural and remote

Stakeholders noted the health inequities that persist in rural and remote parts of Australia, and the difficulties of effectively involving consumers in research to address these. There were calls for increased funding for RRR research to help overcome these barriers. It was also suggested that the Statement's definition of "community" be amended, as this often refers to a geographic association in RRR areas.

Phrase 6: Opportunity to provide

Stakeholders expressed that the consultation was an important opportunity to share their thoughts, set national expectations for CCI, and ultimately drive better health outcomes. As noted in one Consultation Hub submission: “We see this statement as an incredible opportunity to model genuine partnership, not just guidance, but a cultural shift in research practice.”

Phrase 7: Final Statement

Stakeholders expressed they were looking forward to the Statement being finalised and implemented. Noting that CCI is evolving rapidly, there were calls for the final Statement to be future-focused and aligned with the National Health and Medical Research Strategy.

Appendix A – Background to the Consumer Statement and review

NHMRC and the CHF have partnered on driving CCI policy for decades. The Statement was first published in 2002 and last updated in 2016. The 2016 Statement aimed to support CCI in all health and medical research, through highlighting the benefits of involvement and discussing a series of implementation issues.

Much has changed in the health and medical research sector since the 2016 Statement was published. The benefits of CCI are now widely recognised, and many organisations are producing their own implementation guidance. It was clear that the 2016 Statement was outdated, so NHMRC and CHF decided to revise it.

The intentions of revising the Statement included:

- Creating a national document applicable to all health and medical research, which sets an expectation that consumers and community are always involved.
- Outlining the values and principles that underlie effective CCI.
- Defining the roles and responsibilities of consumers, communities, consumer organisations, research institutions and research funders in ensuring effective CCI.

2024 consultation

The 2024 consultation, facilitated by AHRA, sought stakeholder views on what content should be included in a revised Statement. Between March and June 2024, AHRA held 22 workshops in all Australian states and territories, and online. The workshops were attended by a total of 440 people. In parallel, NHMRC and CHF hosted an online survey on NHMRC's Consultation Hub. The survey collected stakeholder views using the same discussion questions as the workshops and received 102 responses. The results of this consultation were used to draft the revised Statement and are available in the AHRA Workshop Report[11] and NHMRC Online Engagement Report[9].

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[11] Australian Health Research Alliance. 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. https://ahra.org.au/wp-content/uploads/2024/12/AHRA-CCI-Report-Web_Final-updated_V268.pdf (accessed 28 October 2025).

Appendix B – Demographic data analysis (individual survey respondents)

There were 59 responses from individuals to the 2025 Consultation Hub survey. The following section presents responses from individuals to the demographic questions. Demographic statistics from the roundtables are available in the Kids Institute National Roundtable Report[2].

Question 1: Do you have any previous experience in consumer and community involvement?

Respondents could select one or more of the following options:

- Consumer/community member
- Representative from a consumer organisation
- Researcher
- Representative from a research institution
- Representative from a research funder
- Other
- I have no experience but am interested.

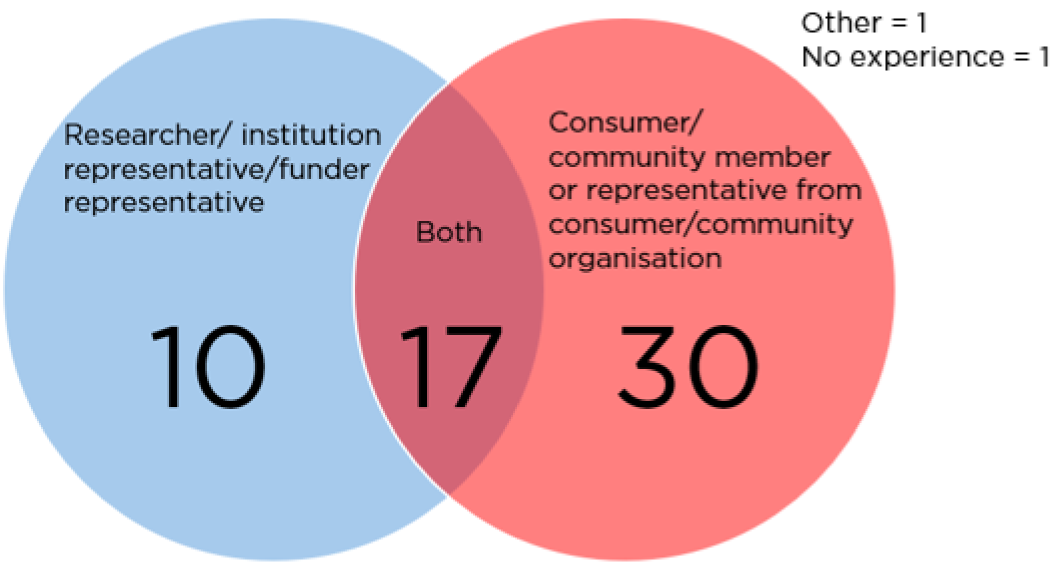

Figure 9. **Experience in consumer and community involvement (individual survey respondents). The shaded part of the diagram indicates respondents with experience in both consumer/community and research, for example, lived experience researchers.**

Question 2: What is the postcode where you live?

Postcodes provided by individual respondents were used to map Figures 10 and 11. Individual respondents resided in all Australian states and territories. The greatest representation was from New South Wales and Queensland (refer Figure 10) and from metropolitan, Modified Monash Model 1 locations[12] (refer Figure 11).

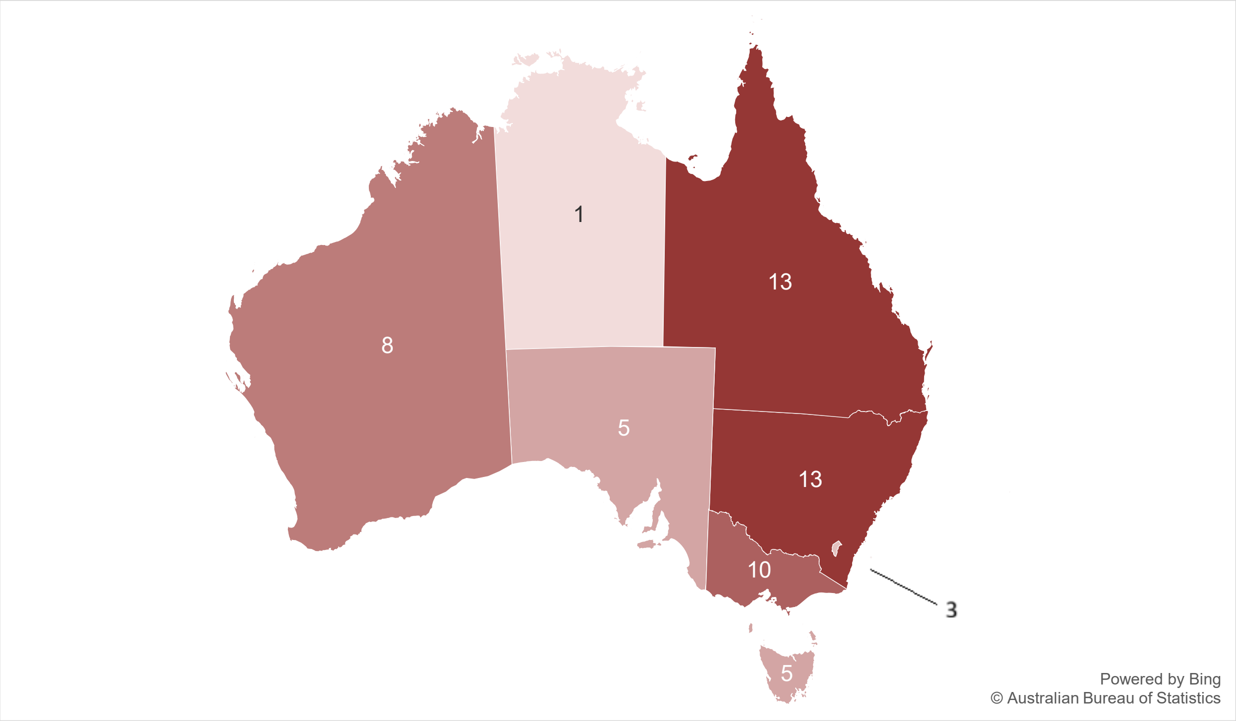

Figure 10. **State/territory of residence (individual survey respondents)[13].**

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[12] Australian Government Department of Health, Disability and Ageing. Modified Monash Model. https://www.health.gov.au/topics/rural-health-workforce/classifications/mmm (accessed 28 October 2025).

[13] One respondent provided an invalid postcode and has not been included in Figure 10 and Figure 11 analysis.

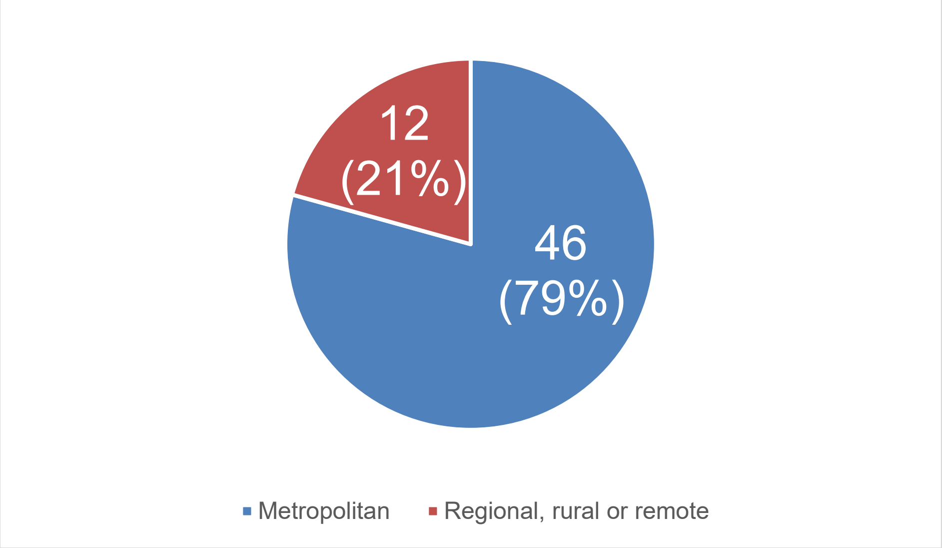

Figure 11. City vs regional, rural or remote residents (individual survey respondents)[13].

Question 3: What is your gender?

Respondents could select from 5 options. The final option, *I describe my gender as,* was followed by a free-text box, however no respondents selected this option.

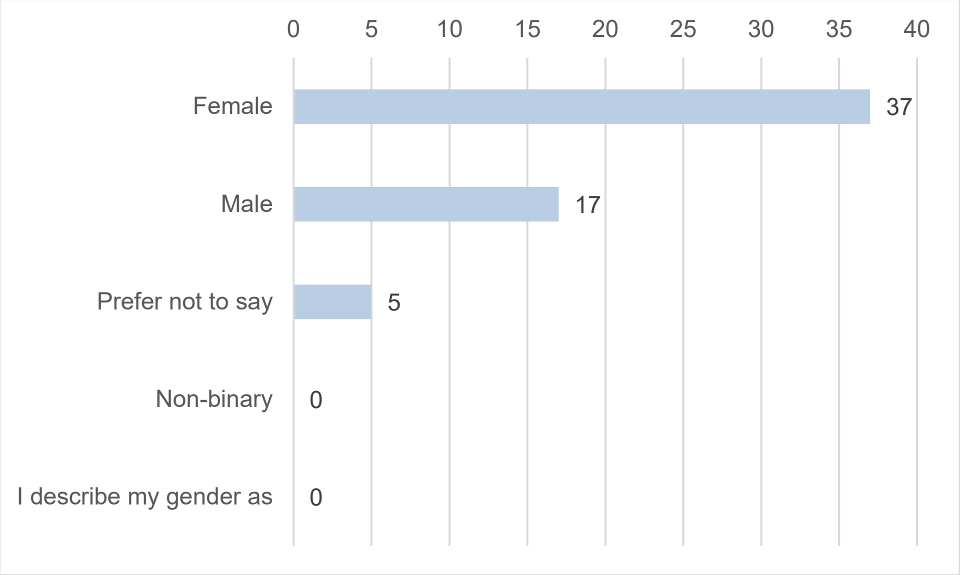

Figure 12. Gender identity (individual survey respondents).

Question 4: Do you identify as Aboriginal and/or Torres Strait Islander?

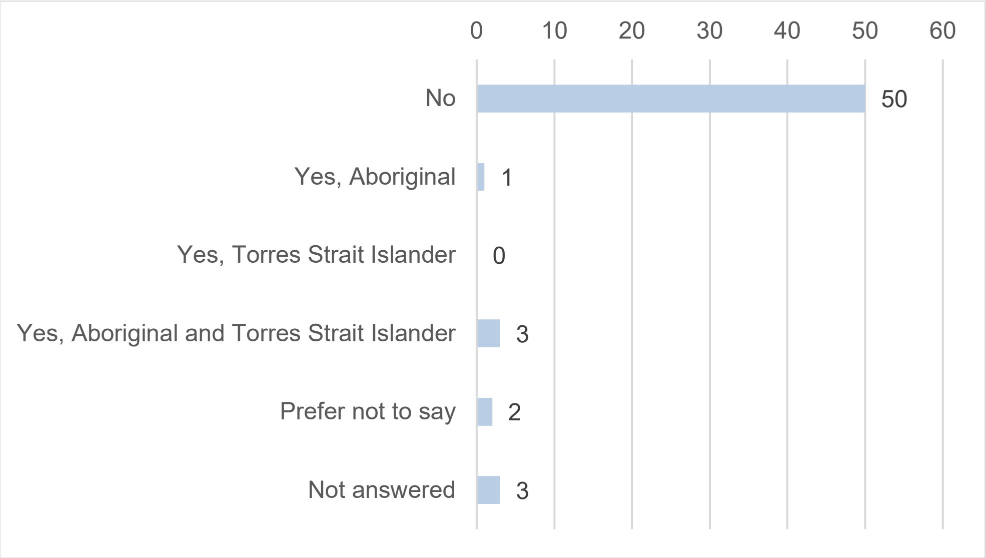

Figure 13. Indigenous status (individual survey respondents)

Question 5: What country were you born in?

Approximately two-thirds of respondents were born in Australia. The next most common countries of birth were the United States of America (8%, n=5) and Pakistan (7%, n=4).

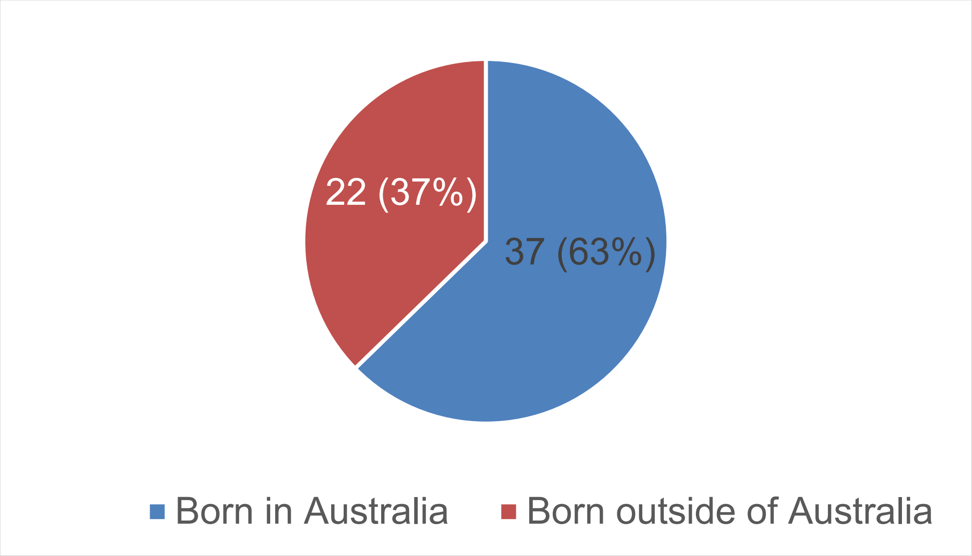

Figure 14. Country of birth (individual survey respondents)

Comparison of survey and roundtable demographics

The survey and roundtables demonstrated diverse and complementary representation. Participants from all states and territories were involved in both consultation activities. Holding roundtables throughout Australia (including regional areas) helped to balance the state and territory representation. This ensured voices from NT, SA, ACT and Tasmania were heard. Australia's multicultural reality was also well-reflected, with greater than one-third of survey respondents and roundtable participants born outside of Australia.

There was good representation of both professional (researcher, institution and funder) and consumer/community perspectives, as well as a significant number of participants who identified with both. Areas that could be improved on include gender balance, with far greater representation of females in both consultation activities, and Aboriginal and Torres Strait Islander participation.

Appendix C – Demographic data analysis (organisational survey respondents)

Organisations were asked to provide the postcode they were located in, which were used to create the below state and territory map. Of the 53 organisations that provided a response through the Consultation Hub[14], 50 were located in a single state or territory, while 3 were located nationally or in multiple states or territories. All organisations except one were located in an MM1[12] area. The below figure shows how many organisations were located in each state and territory.

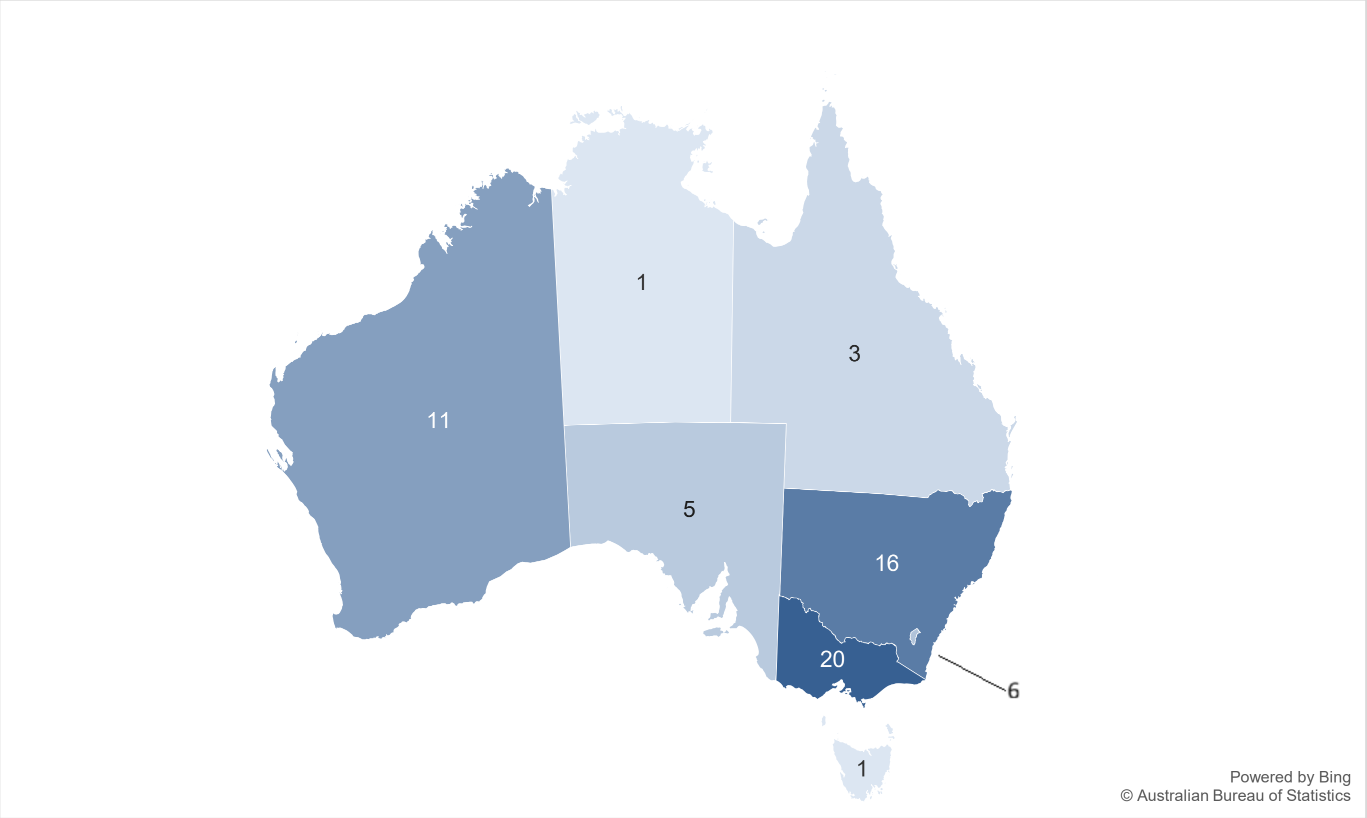

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Figure 15. State and territory representation (organisational survey respondents).

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[14] Five organisations provided email submissions and did not complete the demographic questions.

Organisations were asked to select the sector/s they operated in. Of the 53 responses, 23 (43%) represented one sector only, while 30 (57%) operated in multiple sectors.

“Other” sectors included peak bodies, advocacy, and not-for-profit organisations.

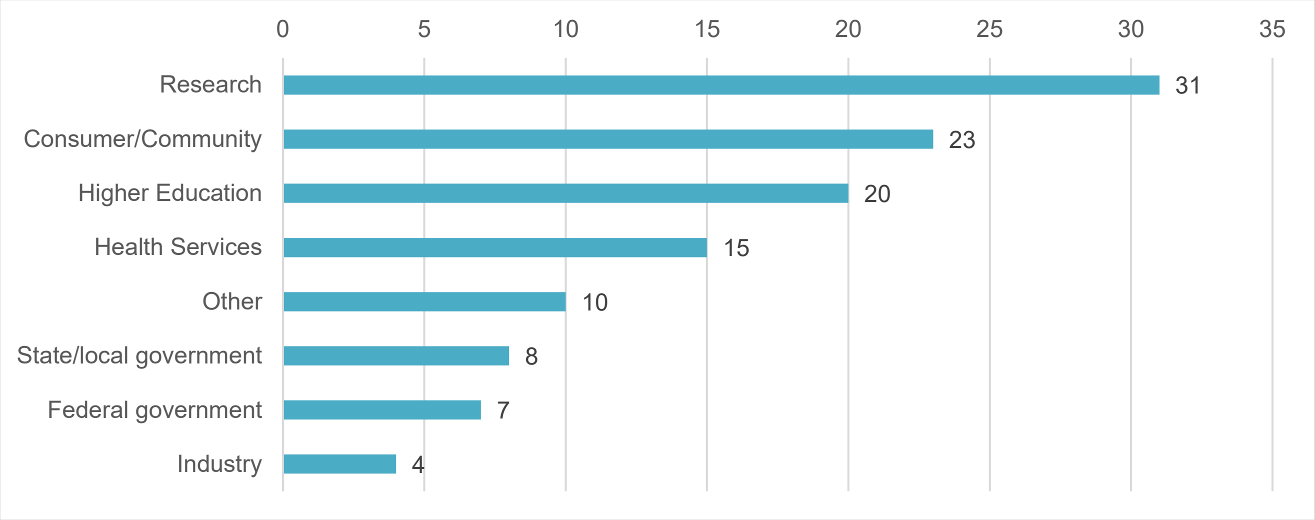

Figure 16. **Sector/s of operation (organisational survey respondents).**