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Submitted to Draft Statement on Consumer and Community Involvement in Health and Medical Research
Submitted on 2025-09-16 15:07:57

Introduction

Privacy Collection Notice

I have read the security warning/disclaimer in the Privacy Collection Notice and accept the risks and conditions outlined.:
Yes

What is your name?

Name:
Falak Helwani

What is your email address?

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Have you, or has someone from your organisation attended a roundtable for the draft Statement?

Yes

If you selected "yes" or "no, but I have submitted an EoI", please select the roundtables you attended or have submitted an EoI to attend from the list below.

Thurs 7 Aug, Translational Research Institute Woolloongabba, Brisbane

Are you providing a submission to this survey as an individual or on behalf of an organisation?

On behalf of an organisation

About your Organisation

What is the name of your organisation?

Organisation name:
Rare Voices Australia

What is the postcode your organisation is located in?

Postcode::
National

If outside of Australia, please specify below::

What sector(s) does your organisation operate in? (select all that apply)

Consumer/Community, Other

If other, please specify below::
RVA is the national peak body for Australians living with a rare disease

The Consumer Statement and importance of Consumer and Community Involvement in research

Expectation of Consumer and Community Involvement in health and medical research

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

Yes

Would you like to make further comments?:

From RVA's perspective, it would be helpful if the Statement included more tangible examples of how consumers can be meaningfully involved at every stage of the research cycle. We acknowledge that consumer involvement can sometimes be more challenging in highly technical, basic research programs compared with qualitative research that is closer to the translation end of the pipeline. However, it is vital to ensure the Statement calls out the need for a genuine cycle of early and continuous consumer involvement—from conceptualisation through to outcomes and back again—across the entire research pipeline

An obvious gap in the Statement that may prevent early and continuous involvement of consumers in research is the need to involve consumers in planning for next steps once a research program ends. While this may be implied by ‘all stages’, it is important to make it explicit, as this can easily be overlooked when a project is completed. RVA notes that this expectation is already outlined in the Toolkit and recommends that it also be included in the Statement.

Values and Principles of Consumer and Community Involvement

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

No

Would you like to make further comments?:

RVA welcomes the inclusion of the values of accountability, transparency, equity, respect and diversity. Based on our experience partnering formally with rare disease researchers across Australia, we view accountability as an essential overarching value to ensure meaningful involvement of consumers and community in research.

We would encourage the Statement to reconsider the inclusion of “mutual benefit.” From RVA’s perspective, this wording is individualistic and requires clarification or additional context. In rare disease research, involvement is fundamentally about moving towards collective solutions that benefit everyone. As such, RVA recommends replacing “mutual benefit” with language such as “solutions-focused” or “strengths-based partnerships.” This framing emphasises the tangible benefits of involving consumers and all relevant stakeholders in research—that is improved outcomes, which manifest from designing collective solutions and leveraging strengths across systems and expertise.

Importantly, this alternative to 'mutual benefits' also highlights that consumer involvement should extend beyond identifying issues and gaps, to actively shaping research questions, outcomes and outputs. Embedding this expectation in the Statement will help support genuine research partnerships and ensure more impactful outcomes.

Principle 1:
RVA strongly recommends strengthening the concept of “active involvement," in principle 1. This ensures consumer and community involvement always has a clear function and purpose, preventing tokenism. Revise Principle 1 to read: “Consumers and communities are actively involved in all stages, levels, and types of health and medical research.” Consider adding emphasis on early and continuous involvement to reinforce meaningful engagement across the research lifecycle.

Principle 2:
Emphasise trust and relationship-building under Principle 2. RVA suggests addition of the word trust to this principle. In addition, this section should highlight the importance of long-term relationship building, respectful and effective communication, and recognition of the time required to establish trust for genuine involvement. This is particularly critical when involving First Nations peoples, with explicit acknowledgment of historical harms and barriers that must be addressed to enable meaningful engagement.

Principle 3:
RVA recommends, removal of 'medical condition' as this is very limiting. The Statement should recognise health consumers more broadly. Being a health consumer does not always require a diagnosed medical condition. Rather it encompasses, people with disability who may not have a specific diagnosis, people with traumatic injury, people engaging with routine check-ups, public health testing, or seeking general health advice. Therefore RVA suggests revising this to a more inclusive definition, e.g.: “...caring for someone accessing health care.”

In line with RVA's recommendation to change value 'mutual benefits'. RVA recommends revising the wording of Principle 3 from “Working in partnership for mutual benefit,” to either “Working in partnership towards solutions” or “Strengths-based, solution-focused partnerships.” This shifts the emphasis to collaboration that delivers tangible outcomes.

RVA strongly recommends strengthening the policy dimension under Principle 3. The current context omits the value of partnering with policy expertise. Alignment of research with policy—or research that addresses policy gaps—is vital for equitable translation. Therefore, researchers should involve policy experts and community peak bodies with strong advocacy expertise. This would ensure new evidence informs policy reform and supports real-world impact. Peak health bodies, like RVA, bring broad consumer knowledge of systemic challenges and policy barriers and enables providing critical insights that are often overlooked by researchers. Including this emphasis will also strengthen the Consumer Statement’s acknowledgement of the need for greater alignment between research and policy.

Principle 4:
RVA was pleased to see mention of the need to provide consumers and community with appropriate training, support and remuneration so they can be equitably involved. However, RVA would also like to see mention of the need to provide researchers with training in how to effectively involve consumers. Under the section about diversity, in line with RVA's previous later recommendations, RVA would like to see emphasis, and explicit mention, of the need for representative involvement. Researchers should be clear about the type of input that will add the most value to their project—whether they are seeking an individual perspective or a representative voice. Where representative involvement is required, researchers must also explain how they will ensure that the person brings a representative perspective rather than solely their own experience.

Principle 5:
This section should explicitly include the need to set expectations for consumer involvement—with clear objectives, defined roles, and transparency

about what contributions will add the most value. Consumers often “wear many hats,” so researchers must be clear about which role they are being asked to bring. Roles should be realistic, purposeful, and thoughtfully designed.

The context should also highlight the importance of ensuring that researchers are confident about the representativeness of consumer views. Researchers must consider whether they are seeking individual perspectives or representative knowledge, and how they can be confident that the involvement reflects the broader community.

The principle should emphasise the importance of acknowledging consumer contributions, including recognition in reporting, publications and other outputs.

Accountability should include a requirement for researchers to reflect on the value and impact of consumer involvement as part of continuous improvement. This reflective practice is essential to upholding integrity.

Principle 6:
RVA recommends restructuring this section to avoid opening with a deficit view, as this framing is unhelpful and risks discouraging consumer involvement. Instead, the section should begin by emphasising that consumers must be given the time and space to ask questions, and they should feel supported and safe to do so. Only after establishing this supportive framing should the section outline the challenges and barriers, ensuring the overall message remains empowering and solutions-focused.

Roles and Responsibilities for Consumer and Community Involvement

Roles and Responsibilities for Consumer and Community Involvement

Yes

Would you like to make further comments?:

In Table 1, the section on shared roles should explicitly include accountability to ensure the Statement’s overarching value of accountability is upheld. In RVA’s previous submission to the National Statement, we emphasised the need for practical guidance and clear steps to hold researchers accountable for their commitment to consumer involvement, in whatever form is agreed with consumers.

Such guidance should:
*Encourage researchers to carefully consider which types of consumer expertise will add the most value to their project.
*Highlight the importance of involving consumers in defining their own contribution.
*Require consumers to be transparent about the expertise they bring to a project.

The scope of roles and responsibilities for both researchers and consumers should be defined upfront, with mutual accountability to ensure each party delivers on their commitments.

Under 'Resourcing, Networking and Recruitment', RVA welcomes the call to adequately resource and fund consumer and community involvement. However, there are well-known gaps in resourcing consumer involvement at the early conceptualisation stages of research—for example, during grant proposal development. RVA recommends that this be called out explicitly as a critical area requiring investment. In addition, RVA strongly recommends highlighting the need for researchers and institutions to ensure not only that consumer involvement occurs, but that it is representative involvement, reflecting the diversity of the community and the lived experiences most relevant to the project.

Yes

Would you like to make further comments?:

RVA suggests inclusion of a more detailed list of practical examples of how consumers and community can be involved in research - the final bullet point in this section only mentions peer review of grant applications.

Yes

Would you like to make further comments?:

RVA would like to see explicit mention of researchers’ responsibility to disseminate findings, opportunities and reports in accessible formats. This should include plain language summaries, easy-read versions, and, as much as possible, free public access to research outputs (e.g. journal articles and reports) to ensure transparency and equity of access.

From RVA’s perspective, the roles and responsibilities of researchers should explicitly include mention of a commitment of researchers to clear and transparent communication and expectation setting. Researchers must:
*Articulate anticipated outcomes of their research and the ways consumer involvement can strengthen these outcomes.
*Define the scope of the project upfront, including identifying potential roles and responsibilities for consumers on the project.
*Ensure representative consumer perspectives are incorporated into research design and delivery.
*Consider carefully the type of consumer expertise that will add the most value before approaching consumers.
*Manage expectations respectfully—setting clear boundaries around consumer roles and likely outcomes, while also creating space for consumers to share aspirational goals safely. Researchers should be prepared to acknowledge these aspirations, even if they may not be achievable or within the project scope. This should be added under bullet point 'maintaining ethics and integrity'.

Without this scaffolding, consumers may find it difficult to understand what is expected of them, which can create barriers to effective engagement and challenges in managing their capacity. Researchers may also support consumers to undertake an informal capacity assessment before committing their time, and make accommodations/adjustments to enable consumer input.

Yes

Would you like to make further comments?:

Research institutions must ensure that all researchers—across disciplines and career stages—are aware of the Statement and understand the importance of implementing it.

Not Answered

Would you like to make further comments?:

From RVA's perspective and experience partnering with researchers:
*Research funders, and all stakeholders, should be responsible for ensuring the Statement is disseminated to researchers and institutions.
*Research funders must also hold researchers accountable for their commitments to consumer and community involvement. If this is not strengthened in the Statement there is a risk that the Statement's vision for accountability will not be realised. This could be done through mandatory reporting on consumer and community involvement and mechanisms for consumers to report on their involvement in research and whether intentions/plans match involvement activities.

Implementing the Statement

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

Please specify below::

RVA welcomes the acknowledgement of the need to have a plan for implementing consumer and community involvement in research. This should include a commitment to building capability through training for both researchers and consumers; a national approach to resourcing involvement from the earliest stages considering remuneration and accessible research opportunities; clarifying roles and representation by defining expectations and ensuring diverse voices; ensuring accountability through mandatory reporting and consumer feedback mechanisms; and fostering respect and alignment by recognising contributions, creating safe spaces, and aligning research with policy priorities. Importantly, all stakeholders should be made more aware of the Statement, with its principles embedded into undergraduate education and early career researcher development to strengthen cultural change from the ground up.

Additional comments

Do you have any additional comments on the Statement?

Additional comments::

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