



SCIENCE FOR ALL

Science for All response to NHMRC Consultation on the 'Review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research'

About this document

This document is being shared so that Science for All can invite feedback on our response to the consultation on the 'Review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research'

<https://consultations.nhmrc.gov.au/research-partnerships/review-of-the-statement-on-consumer-and-community/consultation/intro/>

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Response

Context: Statements from the the National Health and Medical Research Council (NHMRC) Corporate Plan 2022–23

We highlight these three key statements from the Corporate Plan (<https://www.nhmrc.gov.au/about-us/publications/nhmrc-corporate-plan-2022-23>):

1. ‘Community involvement is essential to, and underpins, NHMRC’s strategy for health and medical research...All three strategic themes draw on the lived experience of consumers and the community’
2. “NHMRC will engage with health consumers and the Australian community on health and medical research, and work to increase community involvement in research and access to the results of research.”
3. “Risks: Needs and feedback of stakeholders, including researchers and consumers, are not adequately taken into account which adversely impacts achieving the end goals for the community”

Noting the above statements, Science for All acknowledges and welcomes an update to the ‘2016 Statement on Consumer and Community Involvement in Health and Medical Research’, but notes that we advocate that the Australian public requires more than a ‘Statement’. The public requires a commitment to funding and resourcing. We welcome codified values which underpin any future Statement, but note that without resourcing, it may imply to some that the values are not valued by NHMRC. In summary, we advocate for appropriate resourcing to accompany any statement, otherwise the Statement cannot and will not be implemented effectively across Australia.

Summary of response

The three key areas for consideration in relation to involvement can be summarised as ‘understand’, ‘support’ and ‘evaluate’.

1: Understand - improve understanding of the importance and benefits of public involvement in research, and develop practical skills

2: Support - improve practical support for involving the public in research

3: Evaluate - improve reporting and evaluation of how different stakeholders (including the public) are involved in research

Key areas for consideration

1: Understanding

1.1 Improve understanding of concepts such as 'involvement' and 'engagement'

- a. Standardise words and concepts internally within NHMRC, in order to demonstrate and inform external stakeholders on appropriate language used (and inform reporting and evaluation). Example: Australian Genomics ['Guidelines for Community Involvement in Genomic Research'](#) defines concepts at the start of the document
- b. We support the Australian Genomics' community-led project 'Involve Australia' and their Guidelines for Community Involvement in Genomic Research
- c. We would encourage the use of the open access tool 'Standardised Data on Initiatives (STARDIT)', hosted by Wikimedia Australia, and such reporting could be included in grant applications and acquittal. Further information: ScienceForAll.World/STARDIT Peer reviewed article: <https://doi.org/10.1186/s40900-022-00363-9>
- d. Consider international alignment of terminology with existing standards and commitments. For example, the ['UK Standards for Public Involvement'](#) and the ['Health Research Authority UK 'Shared Commitment to public involvement''](#)
- e. Ensure multiple stakeholders, including the public, are involved in co-creating and defining language used to describe them and other stakeholders involved (such as 'public', the public, patients, carers, mental health service users, consumers of services or health technology). We note that while some people self-identify with the word 'consumer' in the context of a person involved in research, we also note that some people also consider it inappropriate, and in some cases, offensive. We encourage careful consideration of a continuation of usage this term by NHMRC, noting other countries in English-speaking countries (including the UK, USA and Canada) have transitioned away from using this out-dated term. NHMRC should be seen to lead a change in tone and terminology which is informed by genuine and transparent co-creation.

1.2 Improve federal resourcing for learning and development relating to involvement and engagement, including but not limited to:

- f. Training resources - we note that there is a wealth of content available in the English language and encourage NHMRC to consider if creation or curation is the best route. If funding the creation of resources, NHMRC will need to have consistent terminology and a commitment to updating resources in line with ongoing feedback
- g. Development of people's skills is crucial (particularly in the peer-review and grant assessment) - consider facilitating longer term buddying and mentoring

(resourcing it in a way that facilitates people learning from each other and building capacity)

- h. Evaluation and impact assessment - ensuring that evaluation of learning and development is built into any plans and is resourced appropriately. For example, ensuring data is collected about it relating to whether it is culturally safe, appropriate, inclusive and accessible
- i. Consider multiple delivery modes for learning and development and the respective resourcing required for online resources, webinars, in person events, online courses and asynchronous facilitated and moderated text-based forums

2: Support

2.1: Improve inclusive and equitable ways of involving people

We would like to share the following questions for consideration – specifically relating to ensuring involvement in research is inclusive (including providing adequate resourcing for involving the public, patients, carers, mental health service users, consumers of services or health technology, Indigenous peoples and other stakeholders):

Question 1: Will extra funding be provided, ring-fenced - or will ‘seed/incubator’ grants be set up to fund involvement activity; or alternatively, will this be expected to come from the existing funding allocations or research institutions?

Question 2: Will the Federal Government provide non-financial support for involvement? For example, providing practical support related to planning and doing involvement (as England’s National Institute for Health Research has in the form of a Research Design Service)?

Consideration 1: If mandating, will resourcing come from existing grant streams and need explicit allocation in budget lines (for example, resourcing for patient/public/consumer investigators to be paid equally alongside other researchers)

Consideration 2: Federally funded seed-funding for involvement activities (for example, funding involvement activities in order to inform grant applications and allows researchers to start building long term relationships with communities, such as capacity building grants).

2.2: Consider **Ethics** and ‘**Integrity**’.

The Corporate Strategy 2022-23 states “Maintain a strong integrity framework underpinning rigorous and ethical research and promoting community trust”

Consider: While there are some methods of involving people in research which require ethical approval (for example, from Human Research Ethics Committees) - more broadly there’s the concept of ‘ethical involvement in research’, which is more of a moral concept, and requires codified values. This encompasses concepts such as inclusion and accessibility (for example not exploiting people or excluding people based on income or language, paying people, and

ensuring ways of working are accessible). These concepts are best outlined in the document [‘Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities’](#), which Science for All considers to be international best-practice, and provides a guide for how all research could be conducted (for example, including concepts such as reciprocity).

3. Evaluate

With a goal to moving towards evidence informed methods (and therefore the most cost-effective methods) the following should be considered:

3.1: Encouraging (and by 2030, mandating) standardised ways of publicly reporting proposed, ongoing and completed research, including how different stakeholders were involved.

Science for All supports Australian Genomics when they “suggest the use of ‘Standardised Data on Initiatives’ (STARDIT) reporting tool” and note “Community members can also be involved in updating STARDIT reports, including reporting impacts and outcomes. This ensures that the community are empowered alongside researchers to be involved in such reporting” ([see page 48 of the guidelines](#))

A peer reviewed article about STARDIT can be found here: <https://doi.org/10.1186/s40900-022-00363-9>

3.2: Consider alignment with United Nations reporting methods:

Consideration 1: how can NHMRC encourage reporting of research to align with United Nations Sustainable Development Goals?

Consideration 2: How can NHMRC align with the [‘UNESCO Recommendation on Open Science’](#)

Closing statement

Without an increase in funding and resourcing from the Federal Government (via tax payers) for involving people in research, there is a risk that a majority of the resourcing for involving people (including financial resourcing and staff time) will instead be covered by respective research organisations, or by the charity sector, with a considerable proportion of this resourcing being pro bono. There is a risk that the better resourced (richer) organisations and institutions will be more likely to be able to afford effective involvement, and therefore succeed in a greater proportion of grant applications. There is a potential that this could perpetuate inequity in the funding of some research areas over others, including perpetuating neglected areas of research and widening the gap in health outcomes in Aboriginal communities.

We also note that the expertise required to plan, do, report and evaluate involvement activities ‘well’ can be a perceived barrier for many researchers, where researchers may avoid even

trying to do research in partnership with communities, at the risk of doing ‘bad’ research in relation to stakeholder involvement.

A lack of NHMRC funding can thus widen the gap in rural, remote and Aboriginal communities. Improved practical and financial support for both researchers and the public will ensure involvement is more inclusive, and any commitment to this should be consistent across Government funded research.

We encourage any future Statement to be accompanied by a plan for evaluation, impact assessment and regular updates, with transparent methodologies informed by international best-practice.

Finally, we encourage the Federal Government to consider a longer-term aspiration of a parity of terminology, standards and requirements (mandates) for public involvement across all taxpayer funded research, not limited to health and medical research - but including other areas, such as social, environmental and educational research. This will allow a parity in reporting and evaluating methodologies associated with involving people in research, providing improved evidence on the most effective ways of involving people.

About this response

This response has been created by the charity Science for All (ABN: 37636063351 ACN: 636063351). Members of the public were invited to give feedback on this response. Science for All receives no money or in-kind support from industry or for-profit organisations.

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Author information

For transparency, we note that:

1. This response has been coordinated by our Director, Dr Jack Nunn, who is also a member of the the 'Consumer Statement Advisory Committee' (CSAC), which 'provides advice to the National Health and Medical Research Council (NHMRC) and Consumers Health Forum of Australia (CHF) on a revision of and update to the joint Statement' (<https://www.nhmrc.gov.au/about-us/consumer-and-community-involvement/consumer-statement-advisory-committee>). This response contains no data, views or is in any way influenced by discussions within CSAC, and represents only the position of the charity Science for All.
2. Dr Jack Nunn is paid sitting fees by Australian Genomics to be on the working group for the 'Involve Australia' guideline development (Guidelines for Community Involvement in Genomic Research)
3. Dr Jack Nunn is volunteer Chair of the Steering Committee for the co-creation process of Standardised Data on Initiatives (STARDIT)
4. Dr Jack Nunn is a volunteer co-chair of the 'Citizen Science & Open Science Community of Practice', which provided input into the 'UNESCO Recommendation on Open Science'

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