Involve Australia’s response to NHMRC Consumer Statement Review Public Consultation

Involve Australia believes that a Consumer Statement is valuable and a good first step in consumer and community involvement. The NHMRC now has an opportunity to take the next step forward to further support involvement and demonstrate their own commitment to this essential part of research. We also suggest the NHMRC make consumer and community involvement a requirement in all health and medical research.

The NHMRC states that “the revised Statement is intended to be a high-level, overarching document that does not focus on issues related to implementation of consumer and community involvement in health and medical research”. Involve Australia, however, believes that the NHMRC has a responsibility to standardise and actively support implementation of involvement, and provide specific guidance for all stakeholders.

This revision presents an occasion for the NHMRC to assess the integration of consumer and community involvement within its own funding processes. This can be done via consumer and community involvement having significant weighting in funding applications and co-designing criteria to assess involvement with consumers and community members. Consumers and community members assessing grant applications should be considered ‘full panel members’.

Involve Australia would also like to request that the NHMRC consider implementing the strategies recently published in the *Recommendations to Health and Medical Research Funders*, which outlines how funders can further support consumer and community involvement across the entire research process. This includes more specific advice on embedding involvement in funding and grant application processes, as well as support that funders can provide to encourage researcher-community partnerships in their work.

A missed opportunity when developing the 2016 Statement was the lack of an implementation plan. The NHMRC should develop a plan to determine how the Revised Statement is being implemented, what its impact is on improving researcher-community partnerships and how consumer and community involvement will be administered.

Given their role in research, the NHMRC can demonstrate appropriate consumer and community involvement practices when conducting activities such as this and lead by example. Please refer to exemplary international guidance, including the *Canadian Institute of Health Research’s Frame for Citizen Engagement* which prioritises sustained citizen engagement in their own work as a national funder. Also see the *UK National Institute of Health Research Standards for Public Involvement*, which were developed over 3 years by a 4-nation partnership and tested by 40+ individuals, groups and organisations during a year-long pilot program.

Involve Australia

Involve Australia is a community-led project coordinated by Australian Genomics and began its work in mid-2021. It is informed by an expert working group which includes patient advocates, genetic patient support and advocacy group leaders, and researchers. This project aims to promote the effective involvement of consumers and community members in genomic research by developing and implementing evidence-informed policies of responsible and meaningful consumer and community involvement.

Involve Australia's Research

Involve Australia surveyed the Australian public on their perceptions of health research, interviewed consumers and community members, researchers, consumer and community involvement program coordinators and institute leads, and reviewed existing consumer and community involvement guidelines in 2022 and 2023.

This research informed the development of the *Guidelines for Community Involvement in Genomic Research*, published at the end of 2023. Alongside accompanying documents, these guidelines aim to assist researchers in their endeavour to involve consumers and community members in public-funded research.

In May 2024, Involve Australia released their *Recommendations to Health and Medical Research Funders and Institutes*, providing guidance on how to improve their consumer and community involvement processes and support researchers and consumers and communities to work collaboratively in a more effective and inclusive way. Many researchers want to involve consumers and community members in their projects, but come across several institutional, organisational and/or funding barriers that can limit their efforts.

Submission Summary

The primary purpose presented in the 2016 Statement is "building a healthy Australia". Research outcomes and their translation demonstrate the quality of research. These key indicators of success can be improved upon through effective consumer and community partnerships.

Including consumers and community members in research means research priorities and outcomes are more likely to align with consumer and community needs, wants, and expectations. Projects need to reflect consumers and community members' views so they can be more readily adopted and translated into clinical care and practice. This also lays a foundation for research that is more acceptable to the public.

Consumers and community members are experts in their lived experience. They are well positioned to convey what needs to be done to improve the patient outcomes and the healthcare journey as they have experienced the healthcare system themselves. As end-users of health research, consumers and the community have a right to be involved in all stages of research.

There is also a moral and ethical imperative to involve the Australian public in health and medical research as it is funded by taxpayer dollars, making consumers and the community key stakeholders. It is essential that there is accountability and transparency for the use of these funds.

Therefore, the NHMRC has a responsibility to ensure consumers and community members are being involved meaningfully. Australia will fall behind in health outcomes if this does not occur. The NHMRC can be an example to all funding bodies on how consumer and community involvement should be supported and prioritised in all research.

Key suggestions:

- Consumer and community involvement should **be made a requirement** for all health and medical research. The NHMRC should clearly outline to researchers that involvement activities are a spectrum and that different projects will have different levels of engagement and involvement, and involvement will often change at different points in the lifecycle of a project.
- The 2016 Statement was relevant at the time and continues to reflect important values and principles all research stakeholders should adhere to.

- The NHMRC **has a responsibility to actively support** researchers, research institutes and consumers and communities in their partnerships.
- Involve Australia has interviewed researchers, consumers and community members, and consumer and community involvement program coordinators at research institutes, who all said they **need more support from funding bodies** to begin and continue these partnerships.
- Developing researcher-community relationships is a long-term process that does not fall neatly into grant timelines. The NHMRC should support researchers and research institutes to **build these relationships over time**. This is particularly important when working with marginalised communities.
- The NHMRC should develop a **'Code of Conduct'**, outlining how they will support consumer and community involvement in their own processes and should also include the steps they will take to support researcher-community partnerships. This action plan should be informed by all relevant stakeholders, in particular consumers and community members currently involved in research.
- There are **several implementation issues** that researchers and consumers and community members experience. Suggestions on how funders can address some of these are present in Involve Australia's *Recommendations to Funders*.
- **Specific implementation guidance** accompanying the Revised Statement can further support researcher-community partnerships and provide a standard that researchers can adhere to and be evaluated on.
- **Specific guidance on remuneration** of consumers and community members is needed (e.g. standard rates of remuneration)
- Present the Revised Statement in a more **accessible** way (e.g. create an Easy Read version, use images and plain language where possible) so it is a *shared* resource.

General feedback:

- As the leading health and medical research funding organisation in Australia, the NHMRC has a responsibility to actively support researchers, research institutes and consumers and communities in their partnerships. Without support from leaders in the field, there are several implementation issues that researchers and consumers and community members experience when trying to collaborate.
- We suggest the NHMRC implement Involve Australia's *Recommendations to health and medical research funders*, published May 2024.

SURVEY RESPONSES:

The current Statement and importance of consumer and community involvement in research

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

Table 1: 2016 Statement – what has worked well

What has worked well?	How can this be used in the Revised Statement?
The 2016 Statement was appropriate when first published and reflected important values and the benefits of consumer and community involvement.	Researchers who champion consumer and community involvement are now more concerned with how to involve consumers and community members more effectively and maintain these partnerships in the long-term. Researchers are also concerned with how the NHMRC, as the leading funding body for health and medical research, will support this.
The 2016 Statement focussed on what individual research projects could do to involve consumers and community more effectively and meaningfully.	The Revised Statement should highlight the role all stakeholders should play in standardising consumer and community involvement as a requirement in all research. This should also include Human Ethics Research Committees, who have not been mentioned in the 2016 Statement or the Position Paper.
The 2016 Statement featured an appropriate vision statement for the research community to aspire to.	This should remain in the Revised Statement.
The 'Implementation issues that may need to be considered' section in the 2016 Statement is still relevant today.	According to Involve Australia's research, a lot of these barriers are still present. Outlining ways to resolve or work around these barriers are important at the project-level. However, researchers and consumers and community members, and consumer and community involvement program coordinators have stated that the nature of research itself is a big barrier. This should be considered in the Revised Statement.
The 2016 Statement features the section 'Putting the statement into practice', which contains many helpful recommendations for research institutes to consider.	This must remain available either in the Revised Statement or in a toolkit for referral. Please also see Involve Australia's *Recommendations to research institutes* or more suggestions to include.

Table 2: 2016 Statement – what hasn't worked well

What hasn't worked well?	How can this be improved in the Revised Statement?	Why should this be improved?
The language in the 2016 Statement was not strong enough and did not state consumer and community involvement as a requirement for researchers.	The Revised Statement should state consumer and community involvement as a requirement in all health and medical research. The inclusion of funds for consumer and community engagement and involvement within grant budgets should also be a requirement.	A Statement without a requirement for consumer and community involvement is not actionable. The NHMRC has a responsibility to support involvement as the leading funder in health and medical research.
The 2016 Statement does not consider the time it takes to build long-term, respectful partnerships between researchers and consumers and communities.	The Revised Statement should feature the NHMRC's commitment to consumer and community involvement and outline how the NHMRC will consider the process of relationship building in their various processes (e.g. capacity building grants, extra budget especially for relationship building).	Involve Australia's research found that researchers are keen to involve consumers and community members, but they often struggle with the practicalities due to no or limited budget, and the timeframes required for typical grant cycles. Relationship building is important to avoid tokenistic involvement, build trust and can further benefit research outcomes and health outcomes. This is particularly important in underrepresented populations whose voices have previously been overlooked.
The 2016 Statement was written for research audiences and could have been presented in plain language, so it is more accessible to consumers and communities.	Consider writing the Revised Statement in plain language or develop 'Easy Read' versions. For example, the University of NSW Disability Innovation Institute features Easy Read versions of their consumer and community involvement strategies.	A plain language Revised Statement can help to balance the power dynamic between researchers and consumers and communities and even equalise it. Shared resources will further support partnerships in research.
The 2016 Statement lacked an implementation plan for researchers and research institutes when involving consumers and the community.	More specific guidance outlined by the NHMRC can further support researchers in their consumer and community involvement endeavours and set a standard that can be adhered to and evaluated.	The lack of implementation guidance has led to researchers and research institutes separately developing their own practices and policies for consumer and community involvement and a duplication of efforts, thus wasting research funds and resourcing. Conversely, some researchers have avoided consumer and community

	It should also be clearly outlined what resourcing and funding will be provided for consumer and community involvement from the federal level. This should assist researchers and research institutes with nationally consistent implementation of consumer and community involvement.	involvement due to a lack of practical guidance. Without an implementation plan or a requirement for consumer and community involvement, its implementation is dependent on the goodwill of research institutes leaders. When leadership changes, consumer and community involvement may no longer be prominent on strategic plans and initiatives. Making consumer and community involvement a requirement with specific guidance on implementation can reduce wastage of research funds and promote nationally consistent consumer and community involvement.

Why is consumer and community involvement in research valuable?

- Research quality and research outcomes improve when researchers form partnerships with consumers and community members. Therefore, the NHMRC has a responsibility to ensure and support consumer and community involvement to improve Australian public health outcomes. The NHMRC can be an example to all funding bodies (both nationally and internationally) on how involvement should be supported and prioritised in all research.
- Consumer and community member involvement can also lead to improved translation of research findings into clinical practice and promote public acceptability.
- Empowering consumers and community members to have a say in their health and healthcare will promote better health outcomes.
- ‘High value healthcare’ considers the perspectives of patients and families, resourcing in the context of consumer and community benefit, and sound evidence-based practice – ‘high value research’ should mirror these priorities, especially in the public sector.

Why does consumer and community involvement in research matter to you?

- Involve Australia aims to promote consumer and community involvement in genomic research. Genomic research brings with it complex ethical, legal, and social implications, such as high levels of unmet need for people living with genetic conditions, including access to therapies and treatments such as precision medicine and gene therapy, and palliative care. Each of these areas will benefit from the lens of lived experience in the equitable and responsible implementation of research.
- Consumers and community members are experts in their lived experience. They are well positioned to convey what needs to be done to improve the patient outcomes and the healthcare journey. Although the NHMRC funds basic science research, consumer and community involvement is still

important in these projects. Knowing who the end-users are will keep translational outcomes in mind, and better align with NHMRC's mission of "building a healthy Australia".
- Involve Australia's public perceptions of health research survey demonstrated that the public would primarily like to be involved in research for altruistic reasons. Consumers' and community members' personal investment in research that impacts their lives, and the lives of those they provide care for holds research to high ethical standards
- Historical inadequate healthcare in marginalised communities needs to be addressed to ensure a healthier Australia for all Australians. This should involve and empower community voices.

Value Statement

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

Table 3: Values to consider adding to the Revised Statement

Value	Why?
Equity	• Two ways that equity should be addressed in involvement: 1. Researchers should individualise involvement so consumer and community member needs, capacity and availability are considered. Consumers and community members may be impacted by or care for someone impacted by a chronic condition. Therefore, researchers should factor this into their project plans and timelines and consider any additional needs for consumers and communities. E.g. providing extra time to review documents, allowing in-session and out-of-session review of research materials, online meetings. 2. Involving consumers and community members can promote equitable healthcare and healthcare services.
Respect	• Being respectful of consumer and community member experiences, and acknowledge that every consumer and community member is different and will have had different experiences. • Provide space for consumers and community members to give their perspectives without judgement. • Ensure consumers and community members are equally valued members of the research team. • Be mindful of the power dynamics present. • Keep communication channels open. • Value consumer's and community member's time and expertise ○ Consumers and community members provide researchers with insights that allow for meaningful and effective research. ○ Payment can be a factor that encourages participation and shows contribution is valued. Without offering payment, the risk is that research is only informed by the limited group of consumers and community members who have surplus time and energy, can take time off work, or have assistance with caring responsibilities. By offering payment, some of these

	barriers are removed, enabling a more diverse consumer and community member workforce. • Being transparent about why certain research decisions are made will promote shared understanding and respect between researchers and consumers and community members. It also allows consumers and community members to stay informed and therefore provide better advice.
Trusting, enduring relationships and resourcing	• Ideally, relationships between researchers and consumers and community members should not be limited to a single research project or a single aspect of a research project. Prioritising long-term relationships can enhance research outcomes over time, allow for identification of future avenues of involvement, and lead to lasting change in healthcare and healthcare service provision. • Developing and investing in long-term relationships with consumers and community members and patient support and advocacy groups can create trusted, valued interactions with one another. This has multiple benefits, such as a better understanding of each other's perspectives and values, and avenues for involvement. • In the healthcare system, people with a health condition may face many traumatic events due to poor healthcare experiences. These can have a cumulative impact and erode trust. Therefore, building mutual trust can take more time than anticipated. • Funders should provide resourcing that allows early career researchers to begin establishing long-term relationships with consumers and communities. • Research institutes should promote consumer and community involvement and contribute to resourcing. Please see our response to the 'Responsibilities and roles of research institutes' section. • Transparency can build stronger relationships and lead to improved consumer and community involvement processes in future.
Inclusion / diversity	• The Australian population is multicultural and diverse. Twenty-eight per cent of the Australian population was born overseas, according to the 2021 census. It is essential that research benefits all communities within Australia. • Historical medical research abuse and negative healthcare experiences have resulted in a lack of trust between researchers and underrepresented communities (for example, Aboriginal and Torres Strait Islander peoples, people with disability). Rebuilding trust between researchers and underrepresented communities is vital. Empowering these communities to be involved in health and medical research can prevent further gaps in health outcomes. • Underrepresented populations may have different experiences of the healthcare system that can lead to poorer health outcomes. Providing space for their voice in research can have a positive impact on their communities. These groups are also underrepresented in patient support and advocacy groups, so using multiple avenues for recruitment is essential.

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

- In the 2016 Statement, the above values were provided without explanation of what they mean in consumer and community involvement and why they are important. Including the 'why' will strengthen these.
- Providing values without further context also makes it difficult to understand 'who' these values should be upheld by. E.g. shared understanding is clear that all stakeholders should aim to understand one another's perspective, but respect and commitment are vaguer. It is all stakeholders' responsibilities to ensure consumer and community involvement occurs in a meaningful and effective manner. These values should remain in the Revised Statement however, context must be included.
- NHMRC should also state that they are committed to consumer and community involvement in health and medical research and what steps they will take to support researchers, research institutes and consumers and community members in their partnerships.

Should values such as accountability, transparency, collaboration and partnership, equity, diversity and inclusiveness be included in the revised Consumer Statement?

- Yes, see reasoning provided above for equity, diversity and inclusiveness.
- Also agree that accountability, and collaboration and partnership should be included as values. See 'trusting, enduring relationships' value in table above. Again, context needs to be provided for these values.
- It is noted that these values seem to be directed at researchers and the way they should act when involving consumers and communities. It may be worth thinking about whether shared values will be more useful – values that funders, research institutes, researchers and consumers and community members should all consider as a collective.

Better practice principles for consumer and community involvement in research

What do you regard as the most important principles that should be included in the revised Consumer Statement?

- Many of the principles provided in the position paper are from Australian Government reports. It is good to align with existing and approved government documentation, however there are many consumer and community involvement resources developed by Australian health consumer and community groups and championing research institutes that may also be worthwhile aligning with. Examples of these include:
    - Health Consumers Queensland (HCQ)'s *Consumer and Community Engagement Framework (For Health Organisations and Consumers)*
    - UNSW Disability Innovation Institute's *Doing Research Inclusively: Guidelines for Co-Producing Research with People with Disability*
- The UK NHS Health Research Authority provides four principles for meaningful involvement of patients and the public in health and social care research, which the NHMRC may also want to consider in their Revised Statement:
    - Principle 1: Involve the right people
    - Principle 2: Involve enough people

    - Principle 3: Involve those people enough
    - Principle 4: Describe how it helps
- Also see the *UK National Institute of Health Research Standards for Public Involvement*, which were developed over 3 years by a 4-nation partnership and tested by 40+ individuals, groups and organisations during a year-long pilot program.
- It may be worthwhile aligning principles with the *National Consumer Engagement Strategy for Health and Wellbeing* being developed by the Department of Health and Aged Care to ensure consistency across different government departments.

Table 4: Additional principles to consider including in the Revised Statement

Additional principles that should be included:	
Additional Principle	**Justification**
Involve consumers and community members early in the research process	While the Position Paper states that consumers and community members should be involved in all stages of research, we would like to emphasise that consumers and community members are involved as early as possible in a project. Involve Australia found when interviewing consumers and community members that they were often not involved early enough in a project to have sufficient impact.
All research should involve consumers and community members	Involve Australia asks the NHMRC to make consumer and community involvement a requirement for all health and medical research. Rather than a principle, this may be more suited as a 'requirement'.
Pay consumers and community members for their time, efforts and expertise	• Consumers and community members provide researchers with insights that allow for meaningful and effective research. • Payment can be a factor that encourages participation and shows contribution is valued. By offering payment, barriers such as consumer and community member work hours and caring responsibilities, are removed, enabling a more diverse consumer and community member workforce.

Table 5: Considerations for principles included in the Position Paper

Principles suggested in the Position Paper:	
Principle in Position Paper	**Suggestions for this principle**
Consumers and community members should be involved at all stages of research (source: MRFF Principles)	• Involve Australia research found that some researchers are concerned that mandating consumer and community involvement will lead to further tokenistic involvement. We suggest that if this were to remain a principle, the NHMRC highlights that they are aware that consumers and community members will be involved in different ways and at different times depending on the type of project.
Consumers and community members should be in partnership with researchers (source: MRFF Principles)	Researcher-community partnerships should lead to meaningful impact.
Mutually respectful relationships (source: UK Standards for Public Involvement: Better public involvement for better health and social care research)	• Build long-term partnerships that are meaningful and respectful. • Involvement should be individualised to the consumer and/or community being involved. • Support consumers and community members to share their experiences by providing a safe, inclusive and non-judgemental environment.
Respect for lived experience and community expertise (source: Principles of Community Engagement – CDC US Publication)	Suggest revising this principle to instead prioritise instead of only respecting experiential knowledge in research.
Honesty in the development, undertaking and reporting of research, including presenting information truthfully and accurately in proposing, conducting and reporting research. (source: Australian Code for the Responsible Conduct of Research)	‘Transparency’ may be a better word than ‘honesty’.

Roles and responsibilities

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

Table 6: Considerations for consumer and community member roles and responsibilities included in the Position Paper

Consumer and Community Member – Roles and responsibilities suggested in the Position Paper:	
Roles and responsibilities in Position Paper	**Suggestions for this role/responsibility**
Research institutions, researchers, consumers and community members all have a responsibility to consider the best person(s) for a particular role or task, taking into consideration issues such as age, gender, disability, cultural background and experience, health system experience and availability (source: 2016 NHMRC-CHF Statement).	• Revise the statement to remove "…issues such as…" • This statement should focus more on making sure the 'right' people are being involved, and align with the *UK NHS Health Research Authority principles* for meaningful involvement of patients and the public in health and social care research.
Consumers and community members can be involved at various levels of research activity and the institutions in which research is conducted. 'Levels of research activity' include planning and co-deciding, governance, developing research design and questions, recruitment, seeking funding, conducting the research, communicating the outcomes and evaluation (2016 NHMRC-CHF Statement).	• This somewhat contradicts the principle mentioned earlier in the Position Paper: 'Consumers and community members should be involved at all *stages* of research'. Through research conducted by Involve Australia, we found that consumers and community members can be involved in different ways at different points of the research cycle. When stating that consumer and community involvement is required, the NHMRC, as the leading funding body, should acknowledge that the way consumers and communities are involved will differ depending on the project and depending on the stage of the project. • Consumers and community members do not always have a choice about which parts of the research project they are involved in as power often lies with researchers. Therefore, including this under the consumer and community member 'roles and responsibilities' section does not sit well. This may be better as a shared role in researcher-community partnerships.
Consumers and community members should advise research institutions and researchers on their consumer and community perspectives and lived experiences (2016 NHMRC-CHF Statement).	• This is very vague. We assume it means that consumers and community members are being brought onto projects to provide their perspectives and therefore that is one of their roles as a

	consumer and community member. Reword to make this clearer.
Consumers and community members may need skills, information and support in order to add value to the development, conduct and communication of research (2016 NHMRC-CHF Statement).	• This is not a responsibility of consumers and community members – if they require additional information about the project they are involved in, this should be provided by the research team. Training for consumers and community members can be organised by research institutes and patient support and advocacy groups.
Additional roles and responsibilities to consider including in the Revised Statement:	
Roles and responsibilities	**Suggestions for this role/responsibility**
Joint responsibility with researchers to determine whether the consumer and/or community member is the right person for the role.	• One consumer or community member does not always represent a whole community. Every consumer and community member has had different experiences. • Important to consider whether the research needs a community perspective and if the consumer or community member involved can assist in providing this perspective. Consumers and community members may represent an organisation or just themselves.
Consumers and community members should provide input based on their lived experiences, which can be used to inform and support decision making. If needed, they should bring a wider community perspective either through their own networks or by helping researchers source suitable perspectives.	• Every consumer and community member brings their unique experiences, even if they are affected by the same genetic or rare condition. A decision needs to be made, preferably in collaboration with consumers and community members, on what is an appropriate strategy for consumer and community involvement and/or engagement.
Consumer and community members should contribute to the research team and its processes respectfully.	• Consumer and community members should: ○ be prepared for and contribute at meetings ○ be clear of any conflicts of interest that may arise ○ adhere to confidentiality requirements
Consumer and community members can ask for and access any support or training required.	• Training specifically for consumers and community members and researchers on partnering together can foster positive working relationships, help improve ways of working and promote mutual understanding of expectations. • It is the role of the researcher and research institute to provide training.
Consumer and community members should be clear about their roles and its expectations.	• Early in the project, team member roles and expectations should be co-defined. Considering how

	each person's role will impact the bigger picture is a way to promote team cohesion.

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

Table 7: Considerations for researcher roles and responsibilities included in the Position Paper

Researcher – Roles and responsibilities suggested in the Position Paper:	
Roles and responsibilities	**Suggestions for this role/responsibility**
Research institutions, researchers, consumers and community members all have a responsibility to consider the best person(s) for a particular role or task, taking into consideration issues such as age, gender, disability, cultural background and experience, health system experience and availability (source: 2016 NHMRC-CHF Statement).	• Revise the statement to remove "…issues such as…". • This statement should focus more on making sure the 'right' people are being involved – aligns with the *UK NHS Health Research Authority principles* for meaningful involvement of patients and the public in health and social care research.
Champions: researchers elect to champion the benefits of consumer engagement. Key leaders with experience in consumer involvement advocate to improve the level of understanding among peers. (National Framework for Consumer Involvement in Cancer Control).	• This is very important but will also require resourcing from research institutes.
Combined professional development: researchers and consumers are encouraged to undertake professional development together to learn from each other's knowledge and experience. (National Framework for Consumer Involvement in Cancer Control).	• This is something research institutes can facilitate and resource. Researchers should however also initiate conversations with their research institutes if needed.
Equality: consumers are considered equal members of the group or team (National Framework for Consumer Involvement in Cancer Control).	• This is important but feel it is missing the 'equity' lens. Researchers should also be accommodating of the needs of consumers and community members being involved. Consumers and community members working on a research project may be impacted by or care for someone impacted by a chronic condition. Therefore, researchers should factor this into their project plans and timelines, and consider any additional needs for consumers and community members E.g. providing extra time to review documents, allowing in-session and out-of-session review of research materials, online meetings i.e. individualise involvement so consumer

	and community member needs, capacity and availability are considered.
Researchers should consider how they will involve consumers and community members in the development, conduct and communication of their research (2016 NHMRC-CHF Statement).	• This statement does not add a new concept. Involving consumers and community members in all stages of the research process has already been stated in the principles section.
Additional roles and responsibilities to consider including in the Revised Statement:	
Roles and responsibilities	**Suggestions for this role/responsibility**
Researchers should always offer payment to consumers and community members being involved.	• Consumers and community members provide researchers with insights that allow for meaningful and effective research. • Payment can be a factor that encourages participation and shows contribution is valued. By offering payment, barriers such as consumer and community member work hours and caring responsibilities, are removed, enabling a more diverse consumer and community member workforce. • While it’s important to pay consumers and community members for their involvement, you do not need funding to begin having conversations and building positive relationships with consumers and community members.
Researchers should be mindful of power imbalances present in researcher-community member relationships and make adjustments to equalise this.	• Researcher can hold informal meetings outside the clinic or research environment to equalise the power dynamic. • Explicitly acknowledging the presence of a power dynamic prior to discussions on patient experiences can make consumers and community members feel more comfortable.
Researchers should budget for consumer and community involvement in their grant applications.	• Consumers and community members provide time, effort and expertise to the research process and should be paid for their involvement. • Budgeting should also include reimbursements (e.g. car parking fees, childcare, transportation) and other resources (e.g. consumer and community involvement training).
Researchers should reach out to consumers and community members to co-create shared goals for the project.	• Researchers should reach out to consumers and community members well before grant application deadlines to collaborate on project priorities and goals before submission.

	• This will ensure research aligns with consumer and community needs and expectations.
Researchers should ensure they are providing consumers and community members involved in a research project relevant contextual information.	• This can help consumers and community members to make informed assessments and critiques of the research process.
Researchers have an obligation to evaluate their consumer and community involvement processes and report on their processes.	• Doing this can build an evidence-base for the positive impact consumer and community involvement can have on research outcomes and demonstrate to other researchers its benefits. • In line with the Involve Australia *Guidelines for Community Involvement in Genomic Research*, 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.
Researchers should consider how their research may eventually be translated into clinical practice.	• To truly improve the health of Australians, research should have implementable outcomes that consumers and community members will approve of. This should be discussed and deliberated with consumers and community members.

Should involvement of consumers and community members be an expectation of research?

Yes.

There is a moral and ethical imperative to involve the Australian public in health and medical research as it is funded by taxpayer dollars, making consumers and the community key stakeholders. It is imperative that there is accountability and transparency for the use of these funds.

Also see answers to:

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

Is there an ethical imperative to involve consumers and community representatives in research?

Yes.

See answers to:

- Why is consumer and community involvement in research valuable?
- Why does consumer and community involvement in research matter to you?
- Should involvement of consumers and community members be an expectation of research?

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

Involve Australia has recently released *Recommendations for health and medical research institutes to support community involvement in research.* These recommendations include:

- Set the **tone from the top**. Leaders of institutes, including all governing boards and committees, should **champion, model and prioritise** community involvement practices.
- Include community involvement in the institute's **strategic plan** to prioritise it in standard research practice.
- Create a mechanism for **seed funding** to embed community involvement early in projects, prior to the submission of grant applications. This allows projects to be **co-designed with community**.
- Provide appropriate resourcing such as **dedicated staff** to support researchers and community members in their involvement practices. Institute-wide community involvement programs should be **well-funded** by institutes.
- Facilitate **ongoing relationship building** between researchers and the community by creating **opportunities for connection**.
- Create and support **training opportunities** for researchers and community members to develop skills for **partnering in research**. Joint training sessions allow for a **collaborative learning environment** where all types of knowledge, including experiential, is valued.
- Create **streamlined** and **accessible** pathways for institute-wide processes such as community member orientation and payment. This reduces the **administrative burden** on researchers and community members.
- **Evaluate and report** on community involvement practices and processes alongside other academic metrics of success

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

- Funders have a responsibility to provide structure to build capacity of researchers and consumers and community members to work together – Australia lags behind other countries, including Canada and the UK where consumer and community involvement is a requirement from the main funding bodies.
- The Western Australian Health Translation Network (WAHTN) published a practical handbook in 2021 for all stakeholders in consumers and community involvement in health and medical research. This was funded by the MRFF and developed in partnership with the Australian Health Research Alliance (AHRA). Funders were included as a key stakeholder who play an influential role in the promotion of consumer and community involvement in health research.
    - Practical advice provided in the handbook to funders includes the following, which NHMRC may want to consider as an actionable step they can take:
        - a public communication to internal and external stakeholders on the funder's commitment to consumer and community involvement. While stating principles and values that researchers should adhere to is useful, the NHMRC has a responsibility to publicly state their own commitment to consumer and community involvement. This should include the actionable steps the NHMRC will take to ensure consumers and community members are involved in the various funding processes, and how grants applications will be revised to reduce researcher barriers to involving consumers and community members.

Involve Australia has recently released their *Recommendations for health and medical research funders to support community involvement in research*. These recommendations include:

- Involve community members in **setting targeted grant opportunities** and **prioritising grant opportunities**.
- Offer a **stream of funding** that promotes **community-led research**. This will lead to research that is more relevant to communities.
- Require **community involvement in all grant opportunities** and ensure it has significant weighting. Criteria to assess community involvement should be developed with consumers.
- Offer a **stream of funding** that allows researchers to start building long term relationships with communities, such as capacity building grants.
- Create a category for "**consumer investigators**" in grant applications and include a **budget line item** for remuneration. Review grant applications to ensure that appropriate funds are requested for the **payment of consumers and community members**. Payment acknowledges their contributions and shows their **expertise is valued**.
- Involve community members in the review of grant applications to ensure involvement is **effective, meaningful,** and **not tokenistic**. Significant weighting should be given to community review of applications.
- Provide **payment** for consumer and community involvement **evaluators** (who are usually consumers) for their review of grant applications.
- Provide grant application **feedback** to researchers on how community involvement strategies can be **improved** upon if not appropriate for the study.
- **Evaluate and report on funding provided** for consumer and community involvement in annual reports and other official documents.

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

'Mandating' consumer and community involvement may need to be clarified so researchers are aware that the NHMRC recognises that a justification for the type of consumer and community involvement or lack thereof is sufficient in grant applications. This will require a more in-depth analysis of grant applications and involving consumers and community members in the review process.

It is noted by stakeholders involved in Involve Australia interviews that involvement looks different depending on the research and the stage of the project. The NHMRC should reference a preferred involvement spectrum to demonstrate the different ways consumers and community members can be involved depending on the project and its various stages.

Involve Australia proposes the term '**requirement**' rather than 'mandate' to facilitate researcher acceptability with the above suggestions. Making consumer and community involvement a requirement in all areas of research can also demonstrate respect to the benefits that consumers and community will bring to research when their voice is included.

Without a requirement, consumer and community involvement is dependent on the goodwill of research organisations and institutes leaders as to whether it is a strategic initiative or goal. Leadership changes can then lead to reduced prioritisation of consumer and community involvement. Having a requirement in place will promote consistent implementation across different institutes over time.

The Involve Australia *Guidelines for Community Involvement in Genomic Research* have been endorsed by 18 different groups, including patient support and advocacy groups and research organisations and

institutes. This demonstrates the commitment researchers and consumers and community members have towards better researcher-community partnerships and suggests that many will perceive ‘requirement’ as the appropriate next step.

Implementing the revised Statement

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

- The Involve Australia *Guidelines for Community Involvement in Genomic Research* provide genomics researchers with practical, implementable advice on how to involve consumers and community members in their projects. The guidelines were written with the intention that other health and medical researchers can use this guide to aid their own consumer and community involvement processes. See a summary of the key domains here.

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

- It is not clear how the outcomes of the stakeholder workshop and research undertaken as part of the environmental scan has contributed to the Position Paper and will contribute to the Revised Statement. The activities undertaken to revise the statement are therefore disjointed.
- Additionally, the sources cited in the Position Paper under ‘roles and responsibilities’ of the stakeholders were usually the *MRFF Principles for Consumer Involvement* and the NHMRC’s 2016 Statement. There are many other guidelines created by and in partnership with consumer and
- community groups that can be drawn upon for all aspects of the Revised Statement.
- The NHMRC’s *National Statement on Ethical Conduct in Human Research (2023)* forms the basis of all Human Research Ethics Committee submissions for research projects in Australia – could the consumer and community involvement statement serve a similar purpose?
- Ensure toolkit resources are linked to clearly and easy for stakeholders to find on the website.