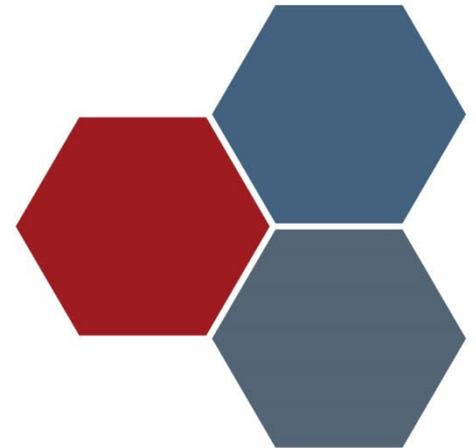
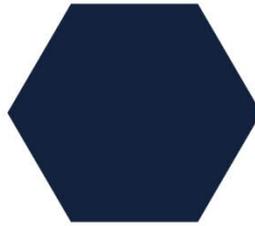
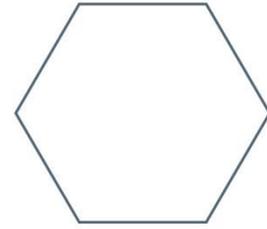




Australian Government



Medical Research **Future Fund**



Principles for Consumer Involvement in Research
Funded by the Medical Research Future Fund

*Advice from the Medical Research Future Fund
Consumer Reference Panel – March 2023*

Minister's Foreword

*I feel privileged to support the work of the Medical Research Future Fund (MRFF)'s new Consumer Reference Panel, and present their **Principles for Consumer Involvement in Research Funded by the Medical Research Future Fund (the Principles)**.*

Putting people at the centre of Medicare and medical research is a core focus for this Government. The Principles reflect that effective consumer involvement, and in particular safe, diverse, and effective consumer involvement, will promote and support the success of MRFF-funded research. The different perspectives and lived experiences that consumers bring to research improves its quality, relevance and impact.



The MRFF Consumer Reference Panel is an enthusiastic, knowledgeable and diverse group of consumers. The diversity they bring is so important – Australians encompass a mix of socially, ethnically, culturally, linguistically and geographically diverse populations, who have a range of different health needs.

Almost half (48.2%) of Australians have a parent born overseas¹. Therefore, it is important that researchers work in partnership with Australians from culturally and linguistically diverse communities to understand their varied perspectives and incorporate their life experiences, values and cultures into research questions, processes and outputs.

Similarly, it is important that the priorities of and input from other priority populations is sought, heard and influences research. This includes Aboriginal and Torres Strait Islander people, older people experiencing diseases of ageing, people with rare or currently untreatable diseases/conditions, people in remote/rural communities, people with a disability, LGBTIQ+ people, and youth.

I appreciate that structural and cultural change, time, and resources are all required to achieve 'best practice' consumer involvement across all research projects and all stages of research. But I strongly encourage researchers to start doing what they can now, to involve consumers in their research. It is only through effective partnership that we give ourselves the best opportunity to improve the lives of all Australians.

I look forward to continuing to work with the Consumer Reference Panel, my Government colleagues, consumers, researchers, research organisations and other players in the health and medical research sector on this important work.

The Hon Mark Butler MP
Minister for Health and Aged Care

¹ <https://www.abs.gov.au/media-centre/media-releases/2021-census-nearly-half-australians-have-parent-born-overseas>

Introduction

Consumers are the ultimate funders, users and beneficiaries of health and medical research and innovation. They have valuable contributions to make to research and a right to be involved. Many consumers want to be involved in health and medical research and to be involved beyond a role of ‘participant’ or ‘subject’.

The object of the Medical Research Future Fund (MRFF) is to improve the health and wellbeing of Australians. Our collective ability to achieve this is enhanced by effectively involving consumers in the prioritisation, design, conduct, translation and evaluation of research funded by the MRFF as well as in the selection of funded research projects.

Consumers bring a broad range of valuable perspectives and experiences, such as diversity in culture, linguistics, gender and ability, that can improve the quality, relevance and impact of research.

There is evidence that involving consumers can build trust between researchers and consumers², increase recruitment of participants³ and improve the quality, outcomes, relevance and impact of the research.^{2,4}

Strengthening consumer involvement in MRFF-funded research is important to align Australia’s health and medical research conduct with international best practice, and to further build the quality and international competitiveness of Australian research.

Strong and effective consumer involvement requires strong consumer engagement skills and approaches by research teams, adapted to each unique project. It also requires engagement from, encouragement by, and facilitation through, all areas of the health and medical research sector – including but not limited to research funders, research organisations, researchers, professional bodies, industry, consumer organisations, consumers, and community members.

MRFF Consumer Reference Panel

To enhance the involvement of consumers in implementation of MRFF, the inaugural [MRFF Consumer Reference Panel](#) was established in 2022. The role of the Consumer Reference Panel is *“to provide advice to the Chief Executive Officer of the Health and Medical Research Office [office responsible for implementation of the MRFF] on strategies for strengthening consumer involvement in the Medical Research Future Fund’s implementation”*.

Consumer Reference Panel members bring a broad spectrum of perspectives on consumer involvement. They represent a wide cross-section of the Australian community, including lived experiences as patients, service users and carers, and culturally and linguistically

² A Anderst et al, ‘Engaging consumers in health research: a narrative review’, *Australian Health Review*, 2020, 44(5): 806-813, doi.org/10.1071/AH19202.

³ J Crocker et al, ‘Impact of patient and public involvement on enrolment and retention in clinical trials: systematic review and meta-analysis’, *BMJ*, 2018, Nov 28;363:k4738, [doi: 10.1136/bmj.k4738](https://doi.org/10.1136/bmj.k4738).

⁴ J Brett et al, ‘Mapping the impact of patient and public involvement on health and social care research: a systematic review’, *Health Expectations*, 2012, 17: 637–650, doi.org/10.1111/j.1369-7625.2012.00795.x.

diverse backgrounds. Many Consumer Reference Panel members are experienced consumer representatives and have existing or previous involvement in health and medical research. On the Consumer Reference Panel, members act as individuals and aim to speak for the whole community, not just on issues of concern to particular organisations.

The Consumer Reference Panel is passionate about the importance of health and medical research and the value that consumers can add across the whole research journey from idea to implementation. The Consumer Reference Panel wants to empower the consumer voice and identified developing principles to promote consumer involvement in research funded by the MRFF as a high priority for their panel.

Principles and associated guidance

Together, the Consumer Reference Panel has developed their **Principles for Consumer Involvement in Research Funded by the Medical Research Future Fund** (the Principles), providing advice on how to promote and strengthen consumer involvement in MRFF-funded research.

This document sets out the Consumer Reference Panel's advice on best practice principles as well as implementation guidance for consumer involvement in research (Attachment 1). It is expected that as the MRFF matures and MRFF implementation develops, and as culture and practices change within the research sector, the scope and strength of these Principles may change.

Many researchers and consumers are seeking guidance to help navigate this challenging area. It is intended that these written principles and implementation guidance will help researchers, research organisations, other relevant stakeholders and consumers by deepening their understanding of what 'good' consumer involvement looks like and will offer teams new approaches for involving consumers in research projects.

This document is intended to complement existing overarching MRFF guidance documents, including the independent Australian Medical Research Advisory Board (AMRAB)'s [Australian Medical Research and Innovation Strategy](#) and the [Australian Medical Research and Innovation Priorities](#), the MRFF's [\\$6.3 billion 2nd 10-year Investment Plan](#), and the [MRFF Monitoring, Evaluation and Learning Strategy](#).

This document is also intended to align with key sector guidance, including the National Health and Medical Research Council and Consumer Health Forum of Australia's [Statement on consumer and community involvement in health and medical research](#) and the [Australian Code for the Responsible Conduct of Research](#).

Timeline for implementation

The principles and implementation guidance are a signal of intent and future direction for research funded by the MRFF. The Consumer Reference Panel's vision is that, in line with international best practice, effective consumer involvement would ultimately be required in all MRFF-funded research. These principles reflect that ultimate, best practice end goal.

The Consumer Reference Panel acknowledges that the full and consistent implementation of these principles will require both structural and cultural change, time and resources to build the capacity and capability of researchers and consumers, and additional time and funding for researchers to deliver their projects within this new framework.

In the meantime, the Australian Government's Health and Medical Research Office will work with researchers, research organisations and other relevant stakeholders towards implementation of the Consumer Reference Panel's advice, including consulting with the sector on strategies and approaches for doing so.

While consumer involvement is not a requirement of MRFF funding **at this time**, it is nonetheless expected and viewed favourably in the assessment of MRFF grant applications (see for example the [recent changes to the MRFF's assessment criteria](#)). The costs of supporting consumer involvement will continue to be considered eligible expenditure for MRFF funded grants.

The establishment of the Consumer Reference Panel and their development of these Principles is the first phase of work promoting stronger consumer involvement in MRFF implementation. In partnership with the Health and Medical Research Office, the Consumer Reference Panel will now review MRFF processes more broadly with a view to strengthening consumer engagement throughout the grant life cycle from priority setting to designing grant opportunities, selecting projects for funding and monitoring project progress and outcomes (see Attachment 2).

It is also acknowledged that the National Health and Medical Research Council and Consumer Health Forum of Australia's Statement on consumer and community involvement in health and medical research is [currently under review](#). The progress and outcomes of that review will be monitored with the goal of achieving complementarity and providing a consistent approach for the health and medical research sector.

Principles for Consumer Involvement in Research Funded by the Medical Research Future Fund

Advice from the Medical Research Future Fund Consumer Reference Panel

A consumer is a person with lived experience as a patient, client, potential patient, user of health services, and/or providing support as a carer, family or community member.

It is the view of the Consumer Reference Panel that to achieve the best quality, outcomes and value for money in MRFF funded research, consumers should be involved:

- **In every type of research**, including basic science, public health, preventive health, translation and clinical research.
- **At all stages of research**, from defining the need/priority of a research question, refining the research question and research design through to conduct of the research and sharing and translation of results.
- **In partnership with researchers**, with consumers respected and recognised for the valuable and complementary knowledge, expertise and perspectives they bring to the research.
- **Effectively**, with sufficient time, resources and depth of relationships to enable consumers to understand and actively engage with and contribute to the research.
- **Sensitively and safely**, through research teams with strong and broad capacity and capabilities in consumer involvement, appropriate training and a supportive environment for consumers, and clearly defined and agreed roles.
- **With broad diversity and equity**, with the goal of increasing involvement of priority populations through culturally safe and appropriate engagement.

The form and level of consumer involvement should be appropriate to the specific project and to that cohort of consumers.

The Consumer Reference Panel has also put together guidance for researchers on what these Principles could look like in practice. This guidance is provided at [Attachment 1](#).

Attachment 1 - Implementation Guidance

The Consumer Reference Panel has provided the following advice to support researchers, research organisations, other relevant stakeholders and consumers to achieve best practice consumer involvement as a strategy for supporting the best possible outcomes from MRFF funded research.

While expected across all research projects, it is noted that addressing every dot point below in every research project is aspirational. Also, the form and level of consumer involvement should be appropriate to the specific project and to that cohort of consumers.

To achieve best practice consumer involvement, MRFF grant applicants and prospective grant applicants would:

- Build ongoing, productive, two-way relationships with consumers, consumer representatives, consumer advocates and consumer organisations, as appropriate to their area of research
- Engage with diverse communities as relevant to their area of research, including Aboriginal and/or Torres Strait Islander people, culturally and linguistically diverse people, older people experiencing diseases of ageing, people with rare or currently untreatable diseases/conditions, people in remote/rural communities, people with a disability, LGBTIQ+ people, and youth
- Work with consumers to understand consumer priorities
- Involve consumers in defining the need, priority and framing of the research question
- Regularly consult with consumers to understand how consumers want to be involved in the research project through design, conduct, dissemination and translation
- Work with consumers to co-design the research project

To achieve best practice consumer involvement, within an MRFF grant application, applicants would:

- Describe how their project aligns with consumer needs, values and priorities and benefits consumers and how this alignment has been achieved
- Describe how, when and in what roles consumers have been and will be involved in the ongoing conduct and dissemination of the research (e.g., governance, oversight, recruitment, consent, ethics, communications, publications, translation, as a chief/associate investigator)
- Describe how consumer involvement is embedded across various project governance levels, and ensures sufficient peer support for consumers (e.g., more than one consumer on each committee)
- Describe how consumer involvement is inclusive and diverse, as appropriate to the project (e.g., age, gender, geographic association, socio-economic status, cultural and linguistic diversity). If they have excluded groups from their research population, explain why

- Describe how effective support, training and information will be provided to consumers to allow consumers to contribute to their full potential
- Describe how an environment where consumer involvement is safe, sensitive and respectful will be provided
- Outline how their research team has the appropriate skills, capability and resources to effectively engage consumers, including as appropriate, the inclusion of lived experience team members
- Ensure their research plan includes appropriate timelines to plan and support consumer involvement activities
- Ensure their research budget includes costs associated with supporting consumers (e.g., consumer engagement managers, translators, interpreters), supporting consumer involvement (e.g., travel costs/regional trial sites for rural and remote populations), consulting with consumers (e.g., events) and appropriately remunerating consumers for their time and contribution
- Ensure their risk management plan addresses consumer involvement in their planned project, including provision of effective support

To achieve best practice consumer involvement, MRFF-funded projects/grantees and their supporting research organisations would:

- Build and maintain ongoing relationships and partnerships with consumers and consumer organisations
- Ensure consumers are involved in the project at least as effectively as outlined in the grant application
- Ensure researchers and consumers are clear on their roles and responsibilities
- Provide effective support, training and information to consumers, including using plain language, culturally appropriate concepts and with awareness of any sensitivities particular to that consumer group, to allow consumers to contribute to their full potential
- Provide an environment where consumer involvement is safe, sensitive and respectful
- Ensure sufficient consumer numbers to facilitate multiple voices and peer support amongst consumers
- Maximise return on investment by ensuring outcomes of research are shared (including through publication, but also through feedback to the community, health services and policy makers), and (where appropriate) translated into practice
- Ensure all consumers involved in the project receive regular feedback and updates on the results and outcomes of the project, including the value they have added
- Appropriately compensate and recognise consumers and community members for their involvement
- Ensure consumers are appropriately acknowledged in reports, presentations, etc
- Reflect and evaluate with consumers to inform continuous improvement
- Use progress and final reports to report on consumer involvement in their project

Attachment 2 – Future Work Program

The Health and Medical Research Office (responsible for MRFF implementation) and the Consumer Reference Panel are committed to strengthening consumer involvement in MRFF implementation and aligning with international best practice. Areas of current and future consideration include, but are not limited to:

- Research priority and question setting at the MRFF program level
 - E.g., improving the numbers and diversity of consumers involved in consultation processes, direct channels for consumers to put forward research questions
- Application processes
 - E.g., strengthening consumer involvement requirements in Grant Opportunity Guidelines and application templates, reviewing application timelines to allow for relationship building between researchers and consumers
- Assessment processes
 - E.g., strengthening consumer involvement in the selection of research projects for funding, introducing specific assessment criteria for assessing involvement of consumers in research projects, training of Grant Assessment Committee members on how to score consumer involvement
- Post award processes
 - E.g., defining and requiring adherence to specific consumer engagement standards, requiring reporting on consumer involvement over the life of a research project
- Supports consumers and researchers
 - E.g., consumer capacity/capability/skill building, research team capacity/capability/skill building, promoting best practice examples of consumer involvement, aiding collaboration and partnerships between researchers and consumers