



Consultation:

Improving alignment and coordination between the Medical Research Future Fund and the NHMRC's Medical Research Endowment Account

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The Department of Health and Aged Care Consultation Hub

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Introduction

Lived Experience Australia Ltd (LEA) is a national representative organisation for Australian mental health consumers and carers, families and kin, formed in 2002 with a focus on the private sector. All members of our Board and staff have mental health lived experience as either a consumer, family carer or both. This is core to our advocacy, recognising that the impacts of policy and practice are felt not only by individuals, but also by families and whole communities.

Our core business is to advocate for systemic change to improve mental health care and support (including psychosocial disability) across the whole Australian health system, including within State and Territory jurisdictions, and improving understanding and inclusion in the community. This includes advocating for empowerment of people with mental health lived experience (people with mental health conditions and their family, carers and kin) in the broad range of issues that impact their mental and physical health, and their lives more broadly. It includes empowering them in their own care and contact with health and social services, promoting their engagement and inclusion within system design, planning, evaluation and research.

Our feedback the current Discussion Paper and models proposed therein comes from the perspectives and experiences of consumers with mental health lived experience, and from the perspectives of their families, carers and supporters. We draw on our experience and expertise in:

- Undertaking lived experience informed research
- Hearing the perspectives of the people we represent who have been involved in research as participants;
- Being community collaborators or community organisation partners with academic researchers on NHMRC and MRFF applications and funded projects; and
- Being the recipients of the outcomes of research.

Purpose of this Consultation

As stated in the Discussion Paper, this consultation is focused on seeking views from all stakeholders on the effective operation of the MRFF and MREA (NHMRC). The discussion paper notes a range of concerns that have prompted this consultation: limited alignment between the MREA and MRFF; need for greater clarity of purpose of each fund; varied consumer involvement; and the need for greater support for translation of research. The MREA is described as ‘bottom-up’ because research topics arise from researchers; whereas, MRFF is described as ‘top-down’ because research topics arise from priorities set by the Department of Health (though we note that this is following extensive consultation with the community and research sector). Each arrangement involves lived experience input to the process of assessing grants for funding.

The Discussion Paper lays out three potential Models, indicating that a combination of these could also be considered, and providing potential pros and cons of each, particularly related to implementation complexity:

Model 1: Better alignment through coordination

Model 2: Management of both funds by NHMRC

Model 3: Merge the two funds with new governance arrangements

The information will be used to provide advice to the Minister for Health and Aged Care on options for improving alignment and coordination between the two funds. There will be future opportunities to contribute to the development of a national strategy.

This consultation is focused on the following questions:

1. What benefits should be achieved through improving the alignment and coordination of the MRFF and MREA?
2. Which feature/s of the models will deliver these benefits?
3. What elements of the existing arrangements for the MRFF and the MREA work well and should be retained? Which feature/s of the models will help ensure these elements are preserved?
4. Which aspects of the current arrangements could be changed to deliver the most appropriate and effective change, and why? Which feature/s of the models will help deliver this change?
5. Is there anything you would like to raise that is not otherwise captured by these questions?

Our Response

We welcome this review and the opportunity to provide feedback and wish the committee well in its deliberations. It provides an opportunity for people with lived experience to reshape the narrative on how research funding is allocated to health and medical research.

We are pleased that the review of the structures and governance aspects of these research funds, and consumer engagement in the process, is being reviewed. We are particularly pleased that all five features are being addressed in the review: governance, accountability, strategy development, administration and implementation complexity.

1. What benefits should be achieved through improving the alignment and coordination of the MRFF and MREA?

Greater equity for the whole continuum of research community members, across the whole career trajectory.

Greater translation of research to practice and to address community needs.

Greater equity of the populations served and issues addressed by research – the research being funded must meet 'the pub test'.

Improved alignment and accountability for the use of research funding.

Improved mechanisms to support Early Career and Lived Experience Researcher development.

2. Which feature/s of the models will deliver these benefits?

Model 1:

Retaining the priority-setting currently present within the MRFF will ensure the community consultation underpinning the MRFF focus on community driven research, with a strong focus on translation is maintained.

Having an independent Chair, working with CEOs and senior executives of each fund, will help ensure greater equity in the range of research being undertaken and limit the dominance or privileging of more traditional approaches and designs.

Retaining of Consumer Involvement.

Model 2:

Consolidation and streamlining of decision-making, governance, resourcing, etc is suggested. Harmonisation of grant timelines, application requirement and processes would also be of clear benefit to research applicants, Universities and other authorising institutions. However, there may then be a disconnect with government policy and reform needs which are contingent of research to help address complex problems. The MRFF criteria and focus on translation should not be lost; specific applications requirements are useful.

Concerns that we note below may well arise with this model. The breadth of research being conducted may become more restricted, resulting in loss of current and future capability and skills within Australia in certain fields and increased reliance on overseas research which may or may not have relevance to Australian contexts, populations, and communities.

Retaining of Consumer Involvement and could provide an opportunity to review and strengthen Consumer Involvement beyond current arrangements.

Model 3:

There are many 'unknowns' about what the new governance arrangements would look like under this model, and the time required to develop such arrangements would be potentially very disruptive to the research community which already must deal with what is a complex and lengthy process of applying for funding. Also, it is unclear how equity would be ensured with this model, and protection from vested interests being dominant in decisions about what research is funded. For example, mental health research may be less likely to be funded within this model.

A lesser role for the Department of Health may lead to a disconnect between research and policy.

Could provide an opportunity to strengthen Consumer Involvement beyond current arrangements.

3. What elements of the existing arrangements for the MRFF and the MREA work well and should be retained? Which feature/s of the models will help ensure these elements are preserved?

Currently, it seems that NHMRC applications are 'stacked' with chief investigators who may or may not then have very much actual involvement in the delivery and work of the project. They are simply there to add their CV weight to win the grant. The MRFF seems less likely to experience this problem because there is a greater focus on research translation and the need to demonstrate what each chief investigator will tangibly bring to that process. Chief investigators who are Early Career Researchers can stand more equitably amongst the CI line-up, rather than be often relegated to the end of the list, deemed as Associate Investigators, or listed as research officers (potentially restricting their CV and career, doing the work that others take credit for in future applications and publication order). Lived Experience researchers can be elevated on the strength of their lived expertise and engagement in the field; they don't seem to experience as much disadvantage in cases where their academic CV may be less extensive.

4. Which aspects of the current arrangements could be changed to deliver the most appropriate and effective change, and why? Which feature/s of the models will help deliver this change?

We believe that the consumer committee needs to be elevated to be a principal committee. This would help to translate the rhetoric of consumer engagement and consultation into more meaningful cultural practice, both within the deliberations of the two structures (MRFF and MREA) and with the research community submitted funding proposals to these funding schemes.

We are also aware that the two schemes have had different histories that arguably impact some key areas of concern. The MREA has arguably traditionally favoured gold standard clinical trials, bench/laboratory-based research. This has created inherent disadvantages for health services research and more holistic public health research, and potentially reinforce the very silos in systems and the delivery of care that exacerbate health reform efforts and health for communities. Studies that aim to investigate complex 'real-world' concerns (e.g., mental health, addiction, physical health) have been less successful in receiving funding than studies dealing with more defined health areas, single diagnosis issues, etc. In our area of interest and advocacy (understanding and solving complex mental health related concerns in services and communities), RCTs may not be feasible or indeed ethical. Millions of research dollars have been spent on measure the shape and size of problems (e.g., to arrive at a % of people with X issue), with far less financial investment in understand how to fix the problem. There has been a clear traditional bias towards quantitative research, with qualitative methods arguably perceived as less rigorous and less important, as secondary to quantitative measures.

Added to this is the failure to include lived experience perspectives in determining what gets measured in the first place, or placing equal value on this when it is present. We have had enough trials in mental health (e.g., that measure impacts on hospital admission rates, improvements in medical compliance, etc) but don't also measure and given equal weight to things that may be more meaningful and impactful to consumers and their families (e.g., hope, relationships, connectedness, citizenship, etc). Of concern, this means that the services and workforces that are recipients of 'the evidence' are likely receiving limited and potentially biased 'evidence' that continues to privilege clinical expertise and does little to shift stigma and discriminatory cultures of service and fail to consider lived experience expertise.¹

5. Is there anything you would like to raise that is not otherwise captured by these questions?

One clear issue that is currently problematic is that research teams need to demonstrate strong community engagement or partnership in the development of proposals; they are assessed on the strength of this. Where this can create potential disadvantage is in the assessment of methodological rigor for applications that are heavily grounded in co-design – the very thing that make translational research strong. Traditionally, in order to rank highly in assessment of proposals in these schemes, researchers need to have the design and methods clearly and fully mapped out in the proposal.

Research teams that have capacity to fund the building and integration of these relationships and do important authentic co-design work prior to submission (e.g., in determining the research questions and most appropriate recruitment methods and outcomes of importance with communities) have a clear advantage. Otherwise, much of this work must occur in-kind or draw on other resources of all concerned. This is potentially problematic for researchers and community stakeholders who may be resource poor. There is no mechanism for supporting this vital work and it is not in the remit of MRFF or MREA to fund activities at this pre-submission staff. Therefore, one solution would seem to lie in how applications with designs that include formative co-design elements are assessed.

One clear example where the above conundrum was played out was the 'fallout' that arose from the announcement of successful funding to the ALIVE National Centre. Sectors of the lived experience mental health consumer community across the country were outraged that there was significant written detail about co-design and lived experience researcher capacity building in the proposal but that the consultation and engagement with lived experience mental health consumer researchers prior to submission had not occurred. They perceived this as a case of the proposed work being 'about them' but not 'with them'.

Another concern that we have with Model 2 is: How will it ensure that the biomedical focus doesn't push out more grassroots, co-designed community, public health and consumer-focused applications? With

¹ Isaacs, A.N., Brooks, H., Lawn, S., Mohammadi, L., Vicary, E., Sutton, K. (2022) Effectiveness of personal recovery facilitators in adults with schizophrenia and psychosis: a systematic review of reviews and narrative synthesis. *Schizophrenia Research*, 246, 132-147.

current structures, and potentially with Model 2, it may be difficult for smaller communities to have influence over what is researched and to have their priorities better understood. Also, any new processes need to be flexible and open enough to enable equity in hearing from individuals and communities where they may be less policy sophisticated or deep understanding of research, as is often seen in other areas.

Funding can often prohibit community organisations from being involved in research, especially where they have limited capacity to provide in-kind contributions due to their own funding arrangements, short-term contracts, or staffing, or already doing a great deal with little resource. There are limitations of the current systems of engagement and funding arrangements, with community organisations often deluged with requests to be involved as partner organisations. Organisations like Lived Experience Australia are routinely approached in this way because we can support meaningful and authentic recruitment, access to the field for 'hard-to-reach' populations, effective dissemination, etc. However, like others, we are expected and must resort to providing 'in-kind' contributions which may not then reflect the often larger actual load on input once the research commences.

Contact

We thank the Australian Government for the opportunity to put our views on the effective operation of the MRFF and MREA. We wish you every success with the next steps and would be keen to contribute our lived experience perspectives to any future discussions about this important topic.

Your sincerely

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