

CoMHWA



Consumers of Mental Health WA (Inc)

**Feedback to the Department of Health and Aged Care and National Health and
Medical Research Council**

***Consultation: Improving alignment and coordination between the Medical
Research Future Fund and Medical Research Endowment Account***

14 July 2023

Consumers of Mental Health WA

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1. Preliminaries

About the Respondents

Consumers of Mental Health WA (CoMHWA) is Western Australia's peak body for and by mental health consumers (people with a past or present lived experience of mental health issues, psychological or emotional distress). We are a not-for-profit, systemic advocacy group independent from mental health services that exists to listen to, understand and act upon the voices of consumers. We work collaboratively with other user-led organisations and a diversity of stakeholders to advance our rights, equality, recovery and wellbeing.

Language

CoMHWA uses the term mental health consumer throughout this submission. Mental health consumers to refer to people who identify as having a past or present lived experience of psychological or emotional distress, irrespective of whether they have received a diagnosis of mental illness or accessed services. Other ways people may choose to describe themselves include "peer", "survivor", "person with a lived experience" and "expert by experience".

This definition is based on consumers' call for respect, dignity and choice in how we choose to individually identify. As individuals we choose different ways to name and describe our experiences that may confirm or trouble ideas about 'mental illness'.

About the Consultation: 'Improving alignment and coordination between the Medical Research Future Fund and Medical Research Endowment Account'

The Australian Government is committed to ensuring health and medical research investment delivers the greatest benefit to the community while driving long-term economic sustainability.

To optimise the government's investment in health and medical research, the Department of Health and Aged Care and National Health and Medical Research Council (NHMRC) are undertaking national consultation to improve alignment and coordination between the Medical Research Future Fund (MRFF) and Medical Research Endowment Account (MREA).

This national consultation will help to identify ways to improve the strategic alignment and coordination between the two funds. Potential models for reform include:

- a coordination mechanism with broad representation to provide coordinated advice and oversight to ensure greater strategic alignment between the two funds
- the NHMRC to manage both funds separately, supporting both investigator-led and priority-led research
- the NHMRC to manage the merged funds; with research at every stage of the pipeline supported to meet the needs of Australia's increasingly complex health care system.

Close Date: 14th July 2023

Submissions to:

HMRconsultations@health.gov.au.

2. Introduction

CoMHWA welcomes the opportunity to make a submission ...

We base our submission on:

- Ongoing consultation with consumers in Western Australia on joint priorities for an improved mental health system
- Consumer representation in relevant settings, including but not limited to: Primary Health networks (WAPHA), WA regional equivalents of the Local Health Networks (regional mental health services under the WA Health Board structure), the Mental Health Commission and the health complaints agency, Health and Disability Services Complaints Office (HaDSCO)

Responses to Submission Questions

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

Response 1: Consumers of Mental Health Western Australian (CoMHWA

www.comhwa.org.au), as a peak body representing consumers of mental health, has a keen interest some of the potential benefits listed in the discussion paper 'Improving alignment

and coordination between the Medical Research Future Fund and NHMRC's Medical Research Endowment Account'. The key issue relevant to CoMHWA and our membership is described under the heading of 'How the models address stakeholder concerns' in the discussion paper, specifically the 'Limited avenues for consumer involvement in research'. While the paper makes clear that there are presently mechanisms in place to receive advice and consumer involvement in both the MRFF and MREA (the Consumer Reference Panel and Consumer and Community Advisory Group, respectively), this consumer involvement is attached to the process of research funding via consultation, rather than being meaningfully embedded throughout the governance mechanisms of these funds. Expanding and deepening the avenues for consumer involvement would be an excellent step towards developing better health research in Australia. In the context of the above groups, this could be achieved by ensuring that consumer input is not simply relegated to the checkbox practice of meeting with consumers in advisory groups to hear what they have to say about research. Instead, by employing consumers with relevant Lived Experience Expertise internally as permanent staff within these health research bodies, it would be possible to achieve a true redistribution of decision-making powers and responsibility between health researchers and consumers. If these steps are taken, the expertise of consumers could then help to collaboratively direct research funding towards key concerns held by consumers at large, and help ensure that future research supported by the MREA and MRFF makes space for consumer input throughout both design and implementation. Within the space of health research itself, extensive consumer involvement should provide concrete input into aspects of the research such as: setting the priorities of the research, helping to develop the research question, the choice of methodology adopted and any proposed translation of the research into health care proper.

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

Response 2: In relation to expanding the avenues for consumer involvement in medical research, CoMHWA is particularly interested in the opportunities that would emerge from the adoption of 'Model Three' as described in the discussion paper. Simply put, this model has the greatest potential to develop more comprehensive consumer engagement with health research—the new governance structures that would be developed for the NHMRC could be designed in such a fashion as to integrate consumer expertise at every level of the MRFF and MREA when organising health research. Furthermore, as noted in the briefing paper on page 25, there is an opportunity to develop the new governance process to ensure that a key requirement for research to be supported is the presence of co-design and meaningful engagement with consumers. Creating a standardised framework for consumer

engagement that is shared between the MREA and MRFF would streamline expectations about the extent to which consumers should be involved with both design and implementation, allowing those applying for grants to accommodate consumer involvement in their proposals in a clear and straightforward fashion.

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?

Response 3: Presently, the MRFF and MREA use two distinct consumer-led advisory groups, the Consumer Reference Panel and Consumer and Community Advisory Group, with the aim to facilitate increased consumer engagement with research and provide recommendations about particular projects. CoMHWA recommends that these advisory panels should be retained in their current composition but incorporated into the core staff of the NHMRC via the creation of new modes of governance required under 'Model Three'. By retaining these Lived Experience experts within the new governance model, they will be well placed to deliver on their current goal of expanding the scope of consumer involvement, and could even be utilised to help co-design the role of consumers in the new governance of 'Model Three'. Both the Consumer Reference Panel and Consumer and Community Advisory Group have released detailed and ambitious guidelines for the expansion of consumer involvement in their respective research groups. Specifically, the Consumer Reference Panel's 'Principles for Consumer Involvement in Research Funded by the Medical Research Future Fund' and the Consumer and Community Advisory Group 'Statement on Consumer and Community Involvement in Health and Medical Research' are both detailed resources with clear goals and rationale for increased consumer collaboration. By providing consumer advisory groups a place at the decision-making table for Model Three governance changes, the NHMRC would have the rare opportunity to enact systemic improvements to the process of funding health research.

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?

Response 4: While the present arrangements for the MREA and MHFF do provide a space for consumer input into the decision-making process for mental health research, there is an opportunity to expand this engagement to promote more meaningful consumer engagement with, and co-design of, research funded through these bodies. The movement towards

thorough and meaningful (that is to say, non-tokenistic) consumer collaboration is increasingly coming to be recognised as a hallmark of 'best practice' within the space of health governance. The World Health Organisation (WHO) through their "WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions" is a recent example of this. In this framework, the WHO calls upon member states to adopt a variety of practices that facilitate consumer engagement, including integrating consumers within all facets of healthcare and health research, and provides a list of benchmarks that give examples of what such meaningful engagement would look like. The present arrangements for consumer input in the MREA and MRFF could charitably be taken as conforming to the 'bronze' standard for 'institutionalising engagement', but by embracing the opportunities entailed by a governance restructure in 'Model Three' there is the possibility for Australia to lead the world through extending consumer involvement towards the WHO's silver, or ideally gold, standards in relation to medical research. In addition to the WHO, there is also recognition within Australia of the benefits of developing more thorough consumer engagement, outlined in documents such as the National Mental Health Commission's 'Consumer and Carer Engagement: a Practical Guide'. This resource discusses the benefits of ensuring dedicated funding for consumer engagement and redistributing some control and decision-making authority to consumers working in the mental health sector, which could potentially be implemented through the NHMRC's redesigned governance structure under Model Three. While the fundamental changes required by Model Three will invariably be more challenging to enact than the less drastic proposals of Models One and Two, the new governance processes that Model Three requires offer a chance to ensure comprehensive and meaningful consumer engagement when commissioning mental health research in Australia.

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

Response 5: CoMHWA's commitment to taking steps to expand consumer involvement with research is supported by an overarching principle that people with lived experience of mental health should be foundationally involved, from the ground up, with the research that will come to impact them in the future. Simply put, there should be nothing made or designed to help mental health consumers, including research, that is developed without the insights that emerge from people with lived experience of mental health challenges and healthcare. The involvement of consumers with lived experience within research grant bodies and research projects will help to develop a living connection and conversation between health researchers and the people who stand to benefit from this research. The input from the trauma-informed and recovery-orientated perspective of Lived Experience Experts will help to underscore the human dimension all health research should ultimately serve, and pre-emptively identify insensitive or problematic research methods and practices that may have been

unrecognised in the abstraction of the clinical design process. Furthermore, a commitment to including the Lived Experience Expertise of consumers should also promote diversity, ensuring that those consumers involved have relevant lived experience to the project and are not over-represented in the sector when others would be more suitable. While CoMHWA as an organisation is focused upon the specific promotion of consumer involvement in the mental health space, this does not impact our above recommendations as the benefits of including Lived Experience Expertise are applicable to the entire spectrum of healthcare.