



Submission to the consultation on improving alignment and coordination between the Medical Research Future Fund and Medical Research Endowment Account

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***The Neurological Alliance Australia is** an alliance of 18 not-for-profit peak or national patient organisations representing adults and children living with progressive neurological or neuromuscular diseases or neurological disorders in Australia. The Alliance was established to promote improved quality of life for people living with these conditions and increased funding to support research. Members of the Alliance are: Dementia Australia, Brain Injury Australia, Emerge Australia, Huntington's Australia, Motor Neurone Disease (MND) Australia, MJD Foundation, MS Australia, Muscular Dystrophy Australia, Muscular Dystrophy Foundation Australia, Parkinson's Australia, Spinal Muscular Atrophy Australia, Leukodystrophy Australia, the Childhood Dementia Initiative, the Mito Foundation, Polio Australia, the Fragile X Association of Australia Inc, the Brain Foundation and Migraine Australia.*

***The Neurological Alliance Australia represents** over 6.5 million Australians living with the conditions represented by the members of the Alliance with an annual impact on the Australian economy of over \$90 billion.*

Introduction

The Neurological Alliance Australia is pleased to provide a submission to the consultation on improving alignment and coordination between the Medical Research Future Fund and Medical Research Endowment Account.

The focus of the comments provided in this submission are on key areas that will impact on those conducting research into neurological disorders or progressive neurological and neuromuscular conditions represented by our member organisations and ultimately on those people living with these incurable conditions and disorders.

The [Neurological Alliance Australia](#) is an alliance of national not-for-profit peak or national patient organisations representing adults and children living with neurological disorders or progressive neurological and neuromuscular diseases in Australia. The Alliance was established in 2010 to promote improved quality of life, coordinated services and greater research investment in these diseases.

The Alliance represents nearly over 6.5 million Australians¹ living with these conditions that have no cure, with an estimated annual cost to the Australian economy of over \$90 billion². This group includes adults and children, carers, families, friends and workmates whose lives have been affected by a progressive neurological or neuromuscular condition or a neurological disorder. The impact of neurological disorders and progressive neurological and neuromuscular conditions on individuals and families can undermine their resilience, which is a vital element of their ability to remain purposeful and in control of their lives in addition to preventing or minimising financial and emotional burden.

While this broad group contains conditions with various characteristics, different disease trajectories and life expectancy, nearly all are degenerative, all are incurable and few have proven treatments. This results in significant disability and the need for expert information, specialised care and personal assistance which is responsive to individual needs.

The Alliance works collaboratively to identify and advocate for opportunities that will drive improved quality of life for people living with these conditions and funding to support research.

¹ Based on an aggregation of data from those NAA members who have commissioned prevalence studies

² Based on an aggregation of data from those NAA members who have commissioned economic impact studies

Summary of issues

The NAA recommends that, in considering the alignment and coordination of the MRFF and MREA, that the following benefits be achieved:

- **Fiscal efficiency, releasing more funds for research activities**
- **Areas of unmet need, such as research into neurological and neuromuscular conditions**
- **Incentives for collaboration**
- **Administrative processes – to be simplified and streamlined**
- **Confidence in MRFF decision-making processes**
- **MRFF performance measures and their publication**
- **Long-term funding stability alongside flexibility**
- **Translation and implementation of research outcomes**
- **Enhanced consumer involvement**
- **Rigorous peer review**
- **Retain both priority-driven and investigator-led research**

These matters are set out in more detail below.

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

Members of the NAA would like to see the following benefits achieved:

Fiscal efficiency

A commitment that an improvement in alignment and coordination of governance and administrative arrangements will be fiscally more efficient and result in the release of more funds for research grants.

Address areas of unmet need

A broader focus on/address areas of unmet need, such as research into neurological and neuromuscular conditions, as identified by the Auditor-General's Report of the Department of Health's Management of Financial Assistance under the Medical Research Future Fund, dated 9 September 2021, section 3.15³, that stated:

³ https://www.anao.gov.au/sites/default/files/Auditor-General_Report_2021-22_3.pdf, page 37

Paragraph 32E(3)(a) of the MRFF Act requires AMRAB⁴ to take into account 'the burden of disease on the Australian community' in determining the MRFF Priorities. Sixteen of the 33 submissions received by the ANAO⁵ considered that diseases with a high disability burden, such as asthma, **musculoskeletal diseases and neurological and psychiatric disorders, had been overlooked or had received limited coverage.**

These submissions referred to an article by Gilbert et al, which found that, for grants awarded between 2016 and September 2019, there was a strong association between MRFF funding and death burden, with many non-fatal conditions receiving comparatively little funding⁶.

Improved incentives for collaboration

Improved incentives for collaborative partnerships between research institutions, government agencies, industry, and community organisations should be a valuable aspect of the new model. By actively promoting collaboration, both the MRFF and NH&MRC can leverage diverse expertise, resources and perspectives to address complex health challenges more effectively.

Process improvements

Simplifying and streamlining administrative processes can improve the efficiency of both the MRFF and the NH&MRC. Reducing bureaucracy, minimising paperwork, and leveraging technology for smoother application processes and reporting requirements can save time and resources for researchers and institutions. This allows them to focus more on their research activities.

Improvements could include:

- A streamlining of grant deadlines
- A streamlining of the applications processes (rather than currently having to use two portals)
- A streamlining of post award processes
- An improvement in feedback mechanisms, especially providing more detailed feedback to unsuccessful MRFF grant applicants

Improve confidence in MRFF funding outcomes

Enhancing the transparency of decision-making processes within the MRFF can contribute to more appropriate and effective outcomes. Implementing clear guidelines, criteria, and evaluation mechanisms for research funding allocation can ensure that decisions are based on rigorous scientific merit, alignment with national health priorities, and potential impact on health outcomes.

⁴ The Australian Medical Research Advisory Board (AMRAB) advises the Minister for Health and Aged Care on prioritising spending from the Medical Research Future Fund (MRFF)

⁵ The Australian National Audit Office (ANAO) is a specialist public sector practice providing a range of audit and assurance services to the Parliament and Commonwealth entities

⁶ Stephen E Gilbert, Rachelle Buchbinder, Ian A Harris and Christopher G Maher, A comparison of the distribution of Medical Research Future Fund grant with disease burden in Australia, Medical Journal of Australia, 2021.

Improving decision-making transparency and accountability will restore confidence and dispel the current feeling in the sector that MRFF grants represent “captain’s picks”^{7,8}. The Auditor-General’s Report of the Department of Health’s Management of Financial Assistance under the Medical Research Future Fund, dated 9 September 2021, section 3.14⁹, stated:

Health has not published an explanation of how grant opportunities are identified or a list of priorities for future research and innovation, particularly for non-mission initiatives. Nineteen of the 33 submissions received by the ANAO considered that it is unclear how grant opportunities are selected and seven submissions said that this gave rise to perceptions of bias.

Improve MRFF performance measures

An improvement in MRFF performance measures and their publication.

The Auditor-General’s Report of the Department of Health’s Management of Financial Assistance under the Medical Research Future Fund, dated 9 September 2021, summary section¹⁰, stated:

Health does not have adequate performance measures for MRFF and has not effectively measured and reported on the performance of MRFF financial assistance in its annual performance statements. Health published a monitoring and evaluation strategy in November 2020, with most of the activities yet to occur. It has also made a number of improvements to the operation of the program.

Ensure long-term funding stability alongside flexibility

Ensuring long-term funding stability is crucial for sustained research progress and the development of innovative solutions. Providing multi-year funding commitments and minimizing uncertainties in budget allocations can allow researchers to plan and undertake longer-term projects. This stability facilitates continuity and promotes impactful research outcomes.

Alongside the need for funding stability, any future model should be designed to accommodate emerging research priorities and evolving healthcare needs. Flexibility in funding mechanisms, such as responsive funding rounds and strategic investments, should enable the MRFF and the NH&MRC to address emerging health challenges promptly. Additionally, the ability to adapt the funding model based on evaluation and feedback mechanisms helps optimise its effectiveness over time.

Focus on translation and implementation

Emphasising the translation and implementation of research outcomes into clinical practice and healthcare policies is crucial for improving health outcomes.

⁷ <https://www.timeshighereducation.com/news/australian-pre-election-spending-splurge-sparks-political-interference-fears>

⁸ <https://theconversation.com/covid-has-left-australias-biomedical-research-sector-gasping-for-air-145022>

⁹ https://www.anao.gov.au/sites/default/files/Auditor-General_Report_2021-22_3.pdf, page 37

¹⁰ https://www.anao.gov.au/sites/default/files/Auditor-General_Report_2021-22_3.pdf, page 8

The new model should incorporate mechanisms that support the effective translation of research findings, including targeted funding for clinical trials, health system integration, and knowledge exchange platforms.

Improve consumer involvement

Improving consumer involvement will be beneficial for ensuring that research initiatives align with the needs and perspectives of health consumers. This could be achieved through:

1. Ensuring that information about the MRFF and the MREA objectives, arrangements, funding opportunities and decision-making processes are easily accessible and understandable to health consumers and the general public.
2. Strengthen the work of and actively communicate and promote existing consumer advisory bodies such as the MRFF Consumer Reference Panel¹¹ and the NH&MRC's Consumer and Community Advisory Group¹² through more regular public consultations to gather input and feedback on research priorities, funding guidelines and the allocation of funds.
3. Regularly evaluate the effectiveness of consumer involvement initiatives in the MRFF and NH&MRC and solicit feedback from consumers on their experiences and the impact of their contributions. Use this feedback to refine and improve consumer engagement strategies over time.

2. 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?

Rigorous peer review

Rigorous peer review is arguably one of the major cornerstones of the academic process and critical to maintaining rigorous quality standards for research grants and publications.

As stated on the NH&MRC website, "peer review helps NHMRC make decisions on funding based on impartiality and expert advice"¹³. Further, this website states that, "The ongoing voluntary participation of the research community in the peer review process ensures that NHMRC continues to fund the best health and medical research and researchers."

It is essential that this process is retained.

¹¹ <https://www.health.gov.au/resources/publications/principles-for-consumer-involvement-in-research-funded-by-the-medical-research-future-fund?language=en>

¹² <https://www.nhmrc.gov.au/about-us/leadership-and-governance/committees/consumer-and-community-advisory-group>

¹³ <https://www.nhmrc.gov.au/funding/peer-review>

Retain both priority-driven and investigator-led research

It is well understood within the health and medical research community that the MRFF funds **priority-driven research** with a focus on research translation and impact, whereas the NH&MRC focuses on **investigator-led research**.

The NAA encourages an ongoing commitment to retaining both investigator-led *and* priority-driven research.

There is a perception amongst researchers (either real or imagined) that the MRFF may lose its strategic benefits and uniqueness if fully merged into the NH&MRC system. For example, in the dementia research space, there is a perception that under NH&MRC direction, it may become more difficult for psychosocial and translational work to be awarded funding as NH&MRC is perceived to be far more focused on biomedical research. There is also a perception that over time, the eligibility criteria for applying for an MRFF grant will be absorbed by NH&MRC and, if so, some organisations who are able to apply for MRFF funding would no longer be eligible under an NH&MRC framework.

Therefore, Model option 3 would require careful design of governance arrangements, as suggested in the Discussion Paper. Given it would involve a “merged MRFF-MREA fund with the NH&MRC disbursing funds as part of a single grant program”, the above perceptions would need to be addressed and managed appropriately.
