21 July 2023

Joint submission from the **Lung Health Alliance** to the Department of Health and Aged Care consultation on: *Improving alignment and coordination between the Medical Research Future Fund and Medical Research Endowment Account*

This is a joint submission from the Lung Health Alliance.

The Lung Health Alliance is a collective of national respiratory not-for-profit organisations working together to improve the lung health of individuals and communities in Australia and to contribute to the global effort for lung health. The following organisations are members of the Alliance: Asthma Australia, Cystic Fibrosis Australia, National Asthma Council Australia, Lung Foundation Australia, The Thoracic Society of Australia and New Zealand.

About the Thoracic Society

The Thoracic Society of Australia and New Zealand (TSANZ) is a health promotion charity whose mission is to lead, support and enable all health workers and researchers who aim to prevent, cure, and relieve disability caused by lung disease. The TSANZ is the only Peak Body in both Australia and New Zealand that represents all health professionals working in all fields of respiratory health.

The TSANZ is a leading advocate and provider of evidence-based policy for the prevention and management of respiratory conditions in Australia and New Zealand, undertakes professional education and training, is responsible for significant research administration, and coordinates an accredited respiratory laboratory program.

As the leaders in lung health, we promote the:

- highest quality and standards of patient care
- development and application of knowledge about respiratory health and disease
- highest quality air standards including a tobacco smoke free society and effective regulation of novel nicotine delivery systems
- collaboration between all national organisations whose objects are to improve the wellbeing of individuals with lung disease and to promote better lung health for the community
- professional and collegiate needs of the Membership

About Lung Foundation Australia

Lung Foundation Australia is Australia's leading lung health peak body and national charity. Founded in 1990, we have become the trusted point-of-call for the 1 in 3 Australians living with a lung disease. We work to improve lung health and reduce the impact of lung disease and lung cancer. To do this, we: deliver information and support services; facilitate access to peer support and exercise programs; coordinate clinical improvement activities and education and training for health professionals; provide research grants; fundraise; and advocate for policy change.

About Asthma Australia

Asthma Australia is a for-purpose, consumer organisation with a history of improving the lives of people with asthma. We operate across New South Wales, Victoria, Queensland, Tasmania, South Australia, and the Australian Capital Territory to deliver evidence-based prevention and health strategies to more than half a million people each year. We work with people with asthma, their family and friends, health professionals, researchers, and governments. We find the best treatments and practices to make sure life with asthma is the best it can be.

About the National Asthma Council Australia

The National Asthma Council Australia is the national authority for asthma knowledge, setting the standard for asthma care. We build the capabilities for people to breathe well and facilitate best-practice care for people with asthma and allergies. We set and disseminate the standards of care through our responsive and evidence-based asthma guidelines, practice tools and resources and education programs. We actively work to assess and address the impacts of asthma through advocacy and collaboration with policy makers, stakeholders and Australian and international asthma and lung health organisations. For further information visit www.nationalasthma.org.au and www.asthmahandbook.org.au.

About Cystic Fibrosis Australia

Cystic Fibrosis Australia (CFA) are the peak consumer body for people living with cystic fibrosis (CF). We focus on collaborative programs and research, funding partnerships, and advocacy. Our members are known as the Federations, these are the State and Territory Offices providing support and services to people living with CF.

Our mission is to raise the profile of CF nationally, taking key messages to government, business, the health sector, and the community to ensure that challenges faced by people with CF and their families are understood. Our Vision is 'Lives Unaffected by CF', where every person born with CF will be able to reach their full potential, unburdened by the disease.

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

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

1. a coordination mechanism with broad representation to provide coordinated advice and oversight to ensure greater strategic alignment between the two funds
2. the NHMRC to manage both funds separately, supporting both investigator-led and priority-led research
3. 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.

Questions specified by the Consultation

What benefits should be achieved through improving the alignment and coordination of the MRFF and MREA? (Maximum 400 words)

The proposed alignment and coordination of the MRFF and MREA will offer a range of benefits which save resources and promote outcomes. We highlight the following benefits.

1. Independence and accountability

The alignment should result in research funding that sits outside, albeit funded by, the Department of Health and therefore free from political intervention. Improved and comprehensive strategic planning, coordination and reduced layers will ensure more funding is available for the benefits expected of our national research program.

2. Improved coordination and complementarity

The limited research dollar in Australia needs to be carefully allocated to foster a world class environment where the best individuals and teams lead the development and translation of world class skills and methods which are best enabled to make revolutionary discoveries that elevate health and wellbeing outcomes for people in Australia.

The programs currently supported by the MRFF and MREA are remarkable and effective, but their lack of coordination and complementarity is resulting in confusion, stress, and waste, where certain critical elements are falling through the cracks (research pipeline, consumer priorities, consistent and predictable governance), while others are excessively resourced.

3. Protection of and investment in the pipeline of health and medical research

The contraction of basic and discovery science investments noted during the recent NHRMC reform was not compensated for in the MRFF program. Basic and discovery research methods underpin most new medicine discoveries, deepen our understanding of disease mechanisms, and provide the building blocks for concepts of cure and prevention. Pure discovery research needs to be preserved and supported in order that it is allowed to make the unpredicted discoveries that have potential to lead to change and not just those we seek due to a priority we impose.

Similarly, we need to see investment in research infrastructure that enables the translation and implementation of discoveries, ideas, and solutions into tangible models of care, other practice outcomes, and policy settings.

4. Partnerships with industry, multi- and trans-disciplinary partnerships, clinical experts and consumers must be supported.

Australia's research investment process needs to be collaborative, within and across sector, involving all participants and end-users in program design, priority setting and research.

These collective changes will minimise duplication of administrative activities internally but also for researchers. This optimisation process will enable a streamlined process with better efficiency enhancing the program's impact and ultimately ensuring Australian medical health research priorities are addressed for societal benefit.

Which feature/s of the models will deliver these benefits? (Maximum 400 words)

Ideally there will be a single cohesive grant program governed by a single set of policies. This consolidation will facilitate ease of use and avoid duplication of effort.

- Centralised administration of the single strategy has the potential to result in better coordination of opportunities, making life easier for researchers and institutions and attracting high achievers to the sector.
- The consolidation of AMRAB and NHMRC council into one advisory council removes unnecessary layers and the risk of duplication and offers a streamlined approach.
- Strategic development will be centralised and more coherent to the contemporaneous needs and the proposed benefits, including strategic investment in the pipeline of health and medical research including but not limited to, discovery science and implementation research, engagement of people and peak organisations in research and equitable distribution of opportunities and benefits.

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? (Maximum 400 words)

Workforce: For decades, the NHMRC program has supported the development of world-class careers and delivered life changing research through the execution of its diverse grant portfolio. This must be maintained and enhanced to foster and retain talent in Australia.

Knowledge: The NHMRC and MRFF have supported the breadth of medical research from innovative new ideas and discovery science through to clinical translation and commercialisation.

The MRFF provided new opportunities to researchers who preferred to focus on impact around established priority areas and others whose innovations could benefit from the pathways offered towards commercialisation. It also provided opportunities for consumer driven research.

Engagement: The NHMRC and MRFF have both facilitated appropriate stakeholder engagement.

The development of a new governance model will eliminate overlap and ensure that all areas of the medical health research pipeline are supported. The governance and strategy features of a new model should be where these elements are preserved. The centralised NHMRC council terms of reference would include the definition of priorities, mechanisms, and processes to ensure benefits we acknowledge within the existing arrangements.

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? (Maximum 400 words)

The current arrangement is too convoluted, lacks coordination, appears administratively inefficient, and is poorly accountable. Researchers and stakeholders find it difficult to engage with the two models and are expending a lot of energy for disproportionately minimal reward. The new model needs to ensure improved coordination, clearer and transparent strategy, direction, and accountability, and embed more efficient and user-friendly processes.

A coordination layer around the current two funds (as proposed in model 1) is an unacceptable solution and will worsen the convoluted nature of the current arrangement. Maintenance of two funds within a centralised program is an improvement but seemingly a disingenuous idea to retain the proposed distinct characteristics of the two. If we agree that a national health and medical research program should support our comprehensive objectives, we should strive for a model which does that, unified, centralised, structured, and equipped to deliver results and accelerate Australia's standing as a world champion in health and medical research.

Whilst Model 2 is a satisfactory solution, a built for purpose program as per Model 3 appears to be the model best suited to achieve the benefits outlined above. This model has the potential to deliver a unified governance structure which will serve the medical health research sector in a more cost-effective and transparent manner. Further detail regarding the composition of the governance/advisory structure and stakeholder involvement is required. Although this model is the most underdeveloped of the three and would take more time to implement, it has the potential to provide the most flexibility in developing our research funding program to support the changing needs across our diverse medical research community.

Is there anything you would like to raise that is not otherwise captured by these questions? (Maximum 400 words)

The respiratory research community wants to see more encouraging detail within a centralised program that emphasises the key points of difference, and which is both visionary and adaptive.

As a coalition of peak bodies and representatives of both professional and consumer communities focused on lung health, we call on the Government to provide a cost-effective and user-centred model to manage research funds. We put to the Department the following principles as it considers potential models for reform of the alignment and coordination between the Medical Research Future Fund (MRFF) and Medical Research Endowment Account (MREA).

1. **Cost-effective administration and governance** - This is an opportunity to create a new fit-for-purpose version of the third model which minimises waste and maximises outcomes. There must be transparent detail on the administration and governance aspects of the model, including a timeline on how this can be achieved with minimal impact to the sector.
2. **Balance of representation of the full research pipeline –** With the coming together of the MREA and MRFF, the full research pipeline must be actively fostered at every step of the process. This will ensure that all areas, from discovery through to clinical translation and implementation, are considered during the program life cycle (e.g., during development, conduct, implementation, maintenance, evaluation, and future revision periods).
3. **Organic stakeholder engagement –** Genuine and consistent engagement with all stakeholders in the development process (co-design) and key decision-making steps (co-production). Stakeholders include all users, explicitly all and any consumers, patients, and carers, academics and researchers, industry, peak and representative bodies, health practitioners and policymakers. The inclusion of all stakeholders in the advancement of this model is important and representatives should be imbedded in the governance and priority setting, with contributions during key decision steps.
4. **Commitment to evaluate and adapt to the changing medical health landscape –** We need a fit-for-purpose and future-proofed program that is adaptable and responsive. This requires a commitment to review and evaluate the model and be prepared to revise the program as the medical health landscape changes. We suggest pre-determined review periods, explicit supporting mechanisms and evolving features be built into the program to provide confidence that the end model is progressive and expansive in its design. Adaptive features of the end model will give us the best prospect to be a research leader around health issues that are predominant in Australia.