Response ID ANON-X7CA-72AS-G

Submitted to Improving alignment and coordination between the Medical Research Future Fund and Medical Research Endowment Account
Submitted on 2023-07-14 15:42:27

Introduction

1 What is your name?

Name:
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2 What is your email address?

Email:
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3 Are you providing feedback as an individual or an organisation?

Organisation

Organisation

11 What is the name of your organisation?

Organisation name:
Rare Voices Australia

12 Where is your organisation based?

Other

13 If you chose ‘other’, please specify the location(s).

Organisation location (other):
National

14 What sector(s) does your organisation operate in?

Other

15 If you chose 'other', please identify the sector(s).

Organisation sector (other):
Peak body - rare disease policy

16 Please choose the description that correctly describes funding received by your organisation to date.

MRFF and MREA funding

17 Does your organisation represent one or more of the below priority populations?

People with rare or currently untreatable diseases/conditions

Guiding questions

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

Please provide your views. Maximum of 400 words.:

RVA’s responses are guided by the National Strategic Action Plan for Rare Diseases & centred around addressing the HMR needs of people living with a rare disease. RVA supports streamlining processes for HMR funding that ensure equity of research across the pipeline from fundamental discovery research right the way through to clinical translation, including equity of access to new knowledge delivered through research & embedded through policy. Efforts to better align & coordinate the MRFF & MREA should not dismantle existing established structures. Rather they should leverage from & strengthen accountability, integrity, transparency, consistency, multistakeholder partnerships & diversity of existing systems & approaches. Alignment should promote a person-centred, fit-for-purpose approach that responds to unmet need & is truly translational—embedding research into clinical care. In addition to increased alignment, the roles of both funds need to be more clearly differentiated, to enhance complementarity & encourage better collaboration across the research pipeline. The new governance model should:
• be fit-for-purpose to maximise impact of funding;

• be person-centred;
• strengthen partnerships—effectively engage all stakeholders in decision making;
• strengthen & clearly demonstrate links between health, research, & health policy for equitable implementation of new knowledge
• minimise duplication;
• decrease burden on applicants,
• increase equity across the research pipeline & across health disciplines;
• value the importance of health policy as a driver of equity;
• value & resource the involvement of consumer & health policy expertise in decision making; &
• support effective policy for equitable research to healthcare translation, including reimbursed health technologies.

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

Please provide your views. Maximum of 400 words.:

Rare disease care must embed research in clinical care delivery. This is vital for timely access to clinical trials, which is the only way to access treatment for many PLWRD. RVA was pleased to see this need highlighted in the Discussion Paper.
For consistency & equity, the new governance model must enable clear links between research, clinical care & health policy. With this in mind, features in proposed model 1, which maintain involvement of DoH as part of governance-accountability, are a vital inclusion. The DoH is an important link between HMR & policy-driven equitable healthcare. Reducing the governance role of DoH, as recommended under models 2 and 3, risks reducing this link to health policymakers, leading to fragmented systems that prevent equitable delivery of innovative solutions & research translation. Research translation to policy-driven equitable healthcare is vital for PLWRD who are inherently few & geographical spread. Without national health policies, access to innovative health technologies & models of care will remain reliant on patient postcodes.
RVA has concerns about imparting all accountability on only 2 parties, as proposed in models 2 & 3. RVA acknowledges more layers of accountability, outlined in model 1, require better coordination, but greater accountability will increase transparency, partnerships & streamlined implementation of new knowledge. The new governance structure should enable advice/input from every possible stakeholder group, including consumers & peak bodies, policymakers, federal, state & territory hospitals & health administrators, early, mid & late career researchers, clinicians & clinician-researchers.
RVA supports streamlined administration to reduce the burden of grant applications. Most rare disease specialists are time-poor clinician-researchers uniquely positioned to highlight gaps in rare disease & work on solutions. Recognising, supporting & promoting rare disease clinician-researchers through governance & administration will ensure research translates into clinical care & clinical care informs research.

20 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)

Please provide your views. Maximum of 400 words.:

The National Strategic Action Plan for Rare Diseases (the Action Plan) & RVA's strong relationships with policymakers & health departments have enabled greater investment in rare disease research, particularly through the MRFF. Until the launch of the MRFF, many rare disease researchers expressed difficultly securing government funding. The MRFF's commitment to priority driven research has been transformative for rare disease. This is partly due to the inherent high levels of unmet need & high burden in rare disease, where knowledge is limited and treatments are few. RVA strongly advises that the benefits for rare disease in this fund are preserved & strengthened through any new governance model.
The MREA has not been as evidently effective in responding to rare disease. Whilst the MREA may be funding rare disease research, it is difficult to measure. Based on RVA's experience formally partnering with researchers, the MRFF tends to attract, & fund, most rare disease research in Australia. This is likely contributing to inequity in the types of rare disease research being conducted, with the balance tipped more to translational research. The Action Plan & international rare disease consortia have highlighted the need for rare disease research across the entire pipeline, but the current system for funding is not adequately or consistently supporting this.
RVA has been pleased to see MRFF initiatives that recognise the value of building evidence for policy reform. This was notable in the recent call for high-cost therapies enabled research, which will drive policy around health technology assessments for rapidly emerging novel health technologies for PLWRD. Based on these observations, RVA recommends retaining & strengthening this current approach & focus of the MRFF & would like to see these links to building evidence for policy strengthened in the MREA.
The original principles of the MREA and the MRFF are well intentioned, but more needs to be done to increase accountability, transparency, objectivity & robustness around how the funds are delivered.

21 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)

Please provide your views. Maximum of 400 words.:

MRFF success for rare disease should be leveraged to improve the response of the MREA, which funds most fundamental discovery research in Australia. Without access to this funding, the causes of rare diseases will remain elusive, & Australia will not be competitive internationally.
RVA recommends keeping the 2 funding streams separate & strengthening existing principles to more clearly delineate their different but complimentary focuses. If instead, the MRFF & the MREA are merged, existing effective principles should be incorporated & strengthened, with robust governance for more transparent reporting & accountability.
The roles of consumer & peak body expertise should be explicitly included & adequately resourced in the new governance advisory structure. Peak bodies add value in an advisory role with their broad-brush knowledge base of issues affecting large groups of Australians. Peak bodies including, RVA, Research Australia, Consumers Health Forum of Australia, National Aboriginal Community Controlled Health Organisation, & the recently formed Australian Multicultural Health Collaborative under the Federation of Ethnic Communities' Council of Australia should be invited to these structures.
There should be ongoing commitment to improving governance & administration of HMR funding in response to feedback, change & new knowledge. RVA recommends aligning regular reviews of priorities & strategy for consistent & coherent delivery of the MREA and MRFF. Coordinating & following the MRFF's approach for 2 & 5 yearly reviews may improve alignment & delivery of the 2 funds to ensure maximal impact on health & wellbeing outcomes.
Due to lack of transparency around rare disease research funding supported by MREA, RVA recommends strengthening data collection, evaluation and

reporting as part of the new governance framework. This will support continuous improvements & increase accountability for an effective, fair & equitable approach to distributing HMR investments.

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

Please provide your views. Maximum of 400 words.:

Investment in all types of rare disease research is vital. For many rare diseases, there are several barriers to effective research & no active research programs. RVA advocacy was critical in highlighting the need for a greater rare disease research focus in Australia, which led to the MRFF's Rare Cancers, Rare Diseases and Unmet Need competitive grant program. The National Strategic Action Plan for Rare Diseases further highlighted the need for more coordinated investment in rare disease research.
Through RVA's formal research partnerships program, RVA is increasingly involved in research projects led by Australian rare disease experts. RVA's research roles range from in-kind support to develop grant applications & attend expert advisory groups, to budgeted roles, including full-time equivalent allocations for facilitating workshops & focus groups, co-designing project deliverables & plain language document reviews.
Academic researchers are increasingly recognising the value of RVA's peak body perspective & rare disease policy expertise in their work. During 2022 alone, RVA engaged in research partnerships with 17 multidisciplinary research teams on MRFF grants & one NHMRC Partnership grant. Over 44 per cent of these grants were chosen for funding. Up to June 2023, RVA has received over 10 requests to partner on proposals for MRFF funding.
The vital role of consumer expertise is increasingly being recognised & embedded in research (e.g. through consumer representation & consultation), supported by formal involvement & remuneration guidelines. Similarly, there is a need to incorporate policy expertise. RVA would like to see formal recognition and support for policy expertise in research through development of guidelines & recommendations to researchers. Organisations with strong policy links & expertise, like RVA, should be embedded at the grassroots level in governance advisory structures of the MRFF & MREA. This foundation will enable more meaningful, valued & formally resourced involvement of policy expertise in HMR.

How did you first hear about the consultation?

23 How did you first hear about the consultation?

Email

24 If you chose 'other', please state the other channel.

How did you hear about the consultation:

Consent to publish

25 Can we publish your response?

Yes