Feedback on the draft Priorities and Strategy of the Medical Research Future Fund

Comments from Multiple Sclerosis Research Australia, JDRF Australia and Asthma Australia

Introduction

Thank you for the opportunity to comment on the draft proposed strategy and priorities of the Medical Research Future Fund (MRFF), which was presented as part of the recent consultation days held around the country.

While we recognise and applaud the important issues, strategies and priorities covered by the draft document, as a group of organisations with a common interest, we would like to provide some specific further comment below that builds on our original submissions made during the written consultation phase.

Summary

The key messages of this feedback document are as follows:

1. **Areas of priority should include groups of diseases with common underlying mechanisms or risk factors, such as autoimmune diseases**
2. **Partnership models for funding should be specifically recognised in MRFF funding structures**
3. **Support for translation should be a key area of MRFF investment**
4. **Consumer input and participation should be a critical element in planning and research agenda setting for the MRFF**
5. **The role and relative position of the MRFF in the overall Australian funding environment should be clearly communicated**

These are outlined in further detail below

Detailed information

1. **Areas of priority should include groups of diseases with common underlying mechanisms or risk factors, such as autoimmune diseases**

The draft document identifies the priority areas of 'disadvantage and disparity', 'challenges and threats', 'burden of disease' and 'capacity and collaboration'. These priority themes, and the items listed under them, are quite rightly important and we welcome their inclusion. However the simplistic concept of 'burden of disease' omits a range of conditions and disorders with major impact on quality of life and considerable societal and health system burden. This method misses the opportunity to fund a range of diseases of significant impact to the individual, and to the Australian community, with common underlying mechanisms or risk factors, as is the case with autoimmune diseases.

As a group, autoimmune diseases affect approximately 8.5% of individuals world-wide. The severity of autoimmune and inflammatory diseases can vary widely, but for most, they bring with them an unpredictable and uncertain future and a reduced quality of life. For example:

- For people with advanced MS, the impact on overall quality of life, or utility, is equivalent to those with end stage cancer or stroke (please see the report on the Economic Impact of MS in Australia in 2010 for further details). For the Australian community as whole the cost of MS is over $1 billion with over 50% of that due to reduced employment opportunities for people with MS and their families and carers. A new generation of biologic treatments available for several of the autoimmune diseases, such as rheumatoid arthritis and MS, has brought great advances in care and greatly improved the long-term outcomes for many people with these conditions. However, it has also seen government spending on autoimmune conditions via the Pharmaceutical Benefit Scheme increase considerably.

- In type 1 diabetes affects over 120,000 Australian children and adults, with six new diagnoses every day. It is the most commonly diagnosed chronic disease in childhood. The burden of the disease is significant – medically, financially, and emotionally. The cost of type 1 diabetes to the Australian economy is over $400m a year, even before the costs of complications are taken in to consideration.

- Asthma remains a significant cause of ill health, disability and poor quality of life in Australia. It is estimated that 2.3 million Australians have asthma, and poor control of this widespread chronic condition is common. The prevalence of asthma is high by international standards with 1 in 10 Australians (10%) suffering from asthma and in 2013 there were 389 deaths due to asthma. The costs of asthma comprise both economic costs, as well as burden of disease costs. In 2015 the estimated cost of asthma in Australia was $28 billion (Hidden Cost of Asthma Report, 2015). Asthma is associated with a poorer quality of life, with Australians with asthma reporting worse psychological health than those without asthma, including more anxiety and depression. The biggest gaps between evidence and practice lie in asthma diagnosis and management; closing this gap will improve asthma control and patient quality of life and reduce asthma morbidity and its associated costs.

Research to better understand, more efficiently and effectively treat, and better still prevent autoimmune and conditions as a group would provide considerable impact not only to individuals and their families, but also for the health system. One way to provide funding to these diseases should be to prioritise MRFF funding based on risk factors or common underlying mechanisms of disease. Autoimmune diseases, and indeed other disease groups, often result from shared risk factors and common mechanisms. As an example, there is heightened risk of both MS and type 1 diabetes due to inadequate vitamin D and latitudinal gradient of incidence seen in both of these diseases. These two diseases, and several of the other autoimmune diseases, also share genetic risk factors.

The MRFF funding model should consider the impact of supporting groups of diseases to drive collaboration and knowledge sharing through the provision of collaborative awards which are given

to **multi-disciplinary, multi-disease networks of researchers and clinicians in a specific linked area**, such as autoimmunity. A funding gap also exists for direct funding of **national collaborations between researchers and clinicians with a common interest**. Collaborative funding ensures outcomes that could not be achieved by researchers acting in isolation and increases the likelihood of research progressing along the translational pathway.

Funding for **common risk factors or pathways** such as exists for autoimmune diseases would ensure the maximum number of people benefit from this research and mitigate any perceived risk of funding research into isolated disease groups. This is eminently achievable by collaboration between relevant research organisations, disease networks and not-for-profit and patient groups.

MS Research Australia, JDRF Australia, Asthma Australia and others are also collaborating on the concept of an Autoimmune Alliance to develop strategy to learn from one another and accelerate outcomes for patients across these disorders. **We would like to propose the inclusion of groups of diseases, such as autoimmune disorders, into the list of priorities for the MRFF.**

We believe that the MRFF has enormous potential to fund this type of cross-disciplinary research that involves researchers from different disease fields and brings together both laboratory researchers and clinicians. This approach will focus the best minds on the priorities for people living with autoimmune diseases and address the key unanswered scientific questions that are common to all autoimmune disorders.

This list, as presented at the consultation, also misses the vital opportunity to address the health outcome of the 'whole person' by omitting the possibility of comorbidities. There is strong evidence for example that having co-morbidities in addition to MS can adversely influence the course and severity of MS. Additionally, living with a chronic health condition, particularly one that affects mobility, can also increase the risk and burden of co-morbidities associated with low physical activity. As you know, people with multiple health issues are often excluded from research studies and denied the prospect of taking part in clinical trials. As the population ages and treatment options improve in a range of areas, this reality of an Australian population with many comorbidities, all of which may influence each other and influence the treatment options, are only increasing. This also impacts on any translational aspects of basic research, discussed below. We would suggest that a cross-disciplinary approach to comorbidities is also carefully considered in the final priorities of the MRFF.

2. **Partnership models for funding should be specifically recognised in MRFF funding structures**

In the information presented at the public consultations, the detail or even a conceptual framework of how the MRFF is to be managed and dispersed remains unclear. We would like to underline our support for **partnership funding models** to be included in the MRFF scheme, between academia, industry and independent research funding organisations such as ourselves. Investment in unifying coordinating bodies, or in partnership with such bodies, is a gap in the current funding landscape and encourages participation and judicious use of funds. Not-for-profit disease-specific organisations are already well positioned to bring together multiple stakeholders, identify patient-centred priorities,

and assemble expert collaborators around a common goal. They are also adept at collaborating with other not-for-profits within and across disease areas.

3. **Support for translation should be a key area of MRFF investment**

Funding to **bridge the gap between proof-of-concept research and full commercial development** is noted as a small component under the theme of 'capacity and collaboration' in the draft document, however it is a priority deserving of much greater attention if investment in research is to be fully realised into health benefits and economic benefits for the Australian community.

A notable challenge in the translation of research is the complexity which exists in a real world population of patients. Up until the translational stage research studies have carefully and deliberately controlled for (or excluded), including clinical trials controls complexity in their design. Funding for research which more closely resembles the real world situation of patients, such as through registries and registry-based clinical trials, and including co-morbidities as mentioned above, would significantly enhance success in translating research in Australia.

Support for pre-clinical work-up of promising compounds and devices would also greatly increase translational research activities and the up-take of potential new therapies by industry partners. This can be done by supporting collaborations in which basic researchers, clinicians, and individuals with expertise in regulatory affairs and clinical trials are brought together from the earliest phases of research. A specific solution would be for the MRFF to provide direct funding for the early translational efforts (for example over two years) of NHMRC funded research with promising findings in the clinical sphere.

Clinician researchers are key to ensure that translational goals of research are achieved effectively. The MRFF needs to focus on the need to embed research into the health system through encouraging clinician involvement in all stages of research from concept and discovery phases, to translation and implementation. This would greatly improve the probability of achieving practical and needed interventions. Examples, to achieve this, include the McKeon review suggestion for **clinical research fellowships and researcher-clinicians pairings**. As an example, MS Research Australia is in the planning stages of a scheme which will provide funding for a researcher and clinician, to allow the pair to collaborate on research and implement findings at a clinical level. Also, JDRF Australia supports a Mentored Clinician Research Fellowship to provide funding to free up the time of clinicians to work on research with the guidance of expert mentors.

4. **Consumer input and participation should be a critical element in planning and research agenda setting for the MRFF**

We would also like to highlight the importance of the voice of consumers and the organisations which represent consumers within this consultation process. As the end users of the healthcare system, this group is in a unique position to identify the research priorities that will bring them not only enhanced health but also enhanced quality of life. They can assist in identifying the gaps and shortfalls within the current system, which can then be realised as priorities for the MRFF.

Additionally, the role of consumers within research, both in priority setting and actual participation in clinical research, is vital to ensure research is relevant, feasible and effective for patients. MS Research Australia is currently conducting a research priority survey of the MS community to inform our research strategy moving forward. Clinical trial recruitment and consumer engagement is a key barrier to research progress. We would encourage the MRFF to find ways to more deeply engage consumers during this consultation phase, to gain an important perspective on the MRFF framework.

5. **The role and relative position of the MRFF in the overall Australian funding environment should be clearly communicated**

Government funding for medical research, while still not optimal in amount, is available through a number of sources. These include but are not limited to: the NHMRC, the Australian Research Council, the Biomedical Translation Fund, the Department of Industry, Innovation and Science and the newly formed body of Innovation and Science Australia. There are further micro-schemes that have the potential to overlap with the strategy and priorities of MRFF. It is key that the way that the MRFF will interact and/or complement these schemes is elucidated as part of the current consultation process.