

SUBMISSION TO

DEVELOPMENT OF THE MISSION ROADMAP

MEDICAL RESEARCH FUTURE FUND: MISSION FOR DEMENTIA, AGEING AND AGED CARE

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AAMRI Response to Consultation Questions

Is the Mission Statement appropriate for the vision and goals of the Mission?

No.

The mission statement could be strengthened by changing to the aim to "enable healthy ageing", where healthy ageing is defined by the World Health Organisation (WHO). WHO defines healthy ageing as the process of developing and maintaining the **functional ability** that enables **wellbeing** in older age (https://www.who.int/ageing/healthy-ageing/en/).

This would be a definable and measurable mission statement.

Is the Vision statement appropriate for the investment being made towards the Mission?

No.

The proposed vision statement does not fully capture the scope and mission statement of this MRFF Mission as it is focussed on delaying the onset of symptoms. As it is currently written, the statement implies that delaying the onset of symptoms is the only factor in enabling older people to make contributions socially, culturally and economically to the community. The vision should be reworded to separate the two sentiments and include improving aged care and improving quality of life by enabling healthy ageing.

Do the goals appropriately capture the aim of the Mission?

Yes.

The goals of the Mission could be strengthened by:

- Modifying the wording of Goal 1 to specify key issues of ageism that need to be addressed. This could be done as follows "Address the issues of ageism and their impact on quality of care and quality of life for older people. Key issues of ageism include attitudes and beliefs, behavioural discrimination and policies and practices."
- Refining the goals for dementia research. Goals 4 and 5 are very specific compared to the others and could be broadened or expanded to include additional goals such as understanding causes and risk factors of dementia and causes of cognitive decline, as well as developing new ways to slow the progress of decline. The goals should invite innovative research into dementia that considers "whole of person" and not exclusively focus on neuropathology (includes consideration of accumulated risk factors, mental health and sensory impairments such as hearing and sight). This goal should be supported by the Mission's investment priorities. The fifth goal should be expanded to acknowledge that it might not be beneficial to have diagnosis of dementia without appropriate interventions being available.
- Adding an additional goal, "Provide accurate, up to date, centralised information on ageing, health, dementia and treatments for an ageing population."

Will the guiding principles provide sufficient guidance to facilitate optimal research outcomes with the Mission's funds?

Yes.

The guiding principles align well with the vision and mission statement and provide a strong foundation for funding research that will help achieve the Mission's goals.

The guiding principles could be strengthened by:

- Recognition of the need to help older persons and those with dementia to adapt to a changing Australian climate, especially in regional Australia.
- Explicitly stating that research under the mission should be inclusive of all backgrounds and life experience, including Aboriginal and Torres Strait Islander people and people from vulnerable and hard-to-reach groups.
- Explicitly stating that inclusive research for older people refers to all older people, regardless of age, cognitive ability and other common problems. Inclusion of all older people is essential for effective research into ageing and aged care, particularly implementation science.
- Include "older people" in the list of end users to be considered when embedding a codesign approach. This is essential for implementation research.
- Recognising that research talent and skills are essential to the success of the
 mission and should be prioritised for investment. The principles should include
 support for increasing capacity in aged care research and research training for aged
 care workers, including implementation research into the most effective ways to
 inform and educate aged care workers in evidence-based practice. For example,
 investments could support research scholarships for aged care professionals.

Are there key barriers in the Australian research context that should be considered in framing these guiding principles to maximise the success of their achievement?

Yes. These barriers are:

- Insufficient recognition of the legitimacy, validity and rigour of implementation science, co-design methods, participatory action research and other methods that should be used in translational research.
- Focus on single disease research rather than research on the whole older person
 encompassing the complexity of clinical and social issues they face. Clinical issues
 include both physical and mental health issues.
- Systematic exclusion of groups of people from research including people with low English proficiency and people with cognitive impairment.
- Challenges associated with engaging people living with dementia and their family carers in research
- Ageism, which is reflected in the idea that research related to older people is a less valuable investment than that relating to younger people.

In your view, do the six funding priorities and sub-questions (extract below) identify the top priorities during the life of the Mission?

The six priorities identify the top priority areas to address under the mission, however, we recommend that there should be additional sub-points included to prioritise research that will address important gaps in understanding, policy and practice for dementia, ageing and aged care.

Priority 1

This priority is essential as it is the only one of six priorities that addresses dementia specifically and should be broadened to include research that considers and innovative directions and new paradigms of causes of dementia. This should invite left of field research that considers "whole of person" approach to understanding causes of dementia rather than limiting to neuropathologies. This priority should include research into:

- development of drugs and new interventions for dementia, as well as underlying causes and risk factors in older people.
- Sensory impairment including both hearing loss and vision loss. Hearing loss has been reported by the Lancet Commission as the largest potentially modifiable risk factor in mid-life for dementia. Vision loss has been identified as a risk factor for cognitive decline and increases risk of falls.
- Fall prevention caused by numerous factors
- Mental ill-health as a risk factor

It should be noted that given that there is no treatment currently available, early diagnosis of dementia needs to be supported by evidence of benefit in diagnosing the condition early.

Priority 2

This priority is essential to the mission as ageism is an issue that affects health of older people in many ways. This priority should include environmental and community aspects of how to address ageism, including how to engage in intergenerational discussions on ageism and promote public awareness on the issues.

Priority 3

We support research into developing and maintaining purpose as a high priority for the mission.

Priority 4

This priority is of high importance and we support the focus on healthy ageing starting earlier in life (middle-age). This priority should also include an emphasis on prevention and support for translational research in this field. This includes both communicable and non-communicable diseases - cancer, cardiovascular disease and infectious disease, and other risk factors such as mental ill health and increasing impairment of senses (hearing, vision). There are distinct challenges for older populations with declining immunity that should be a priority for research investment, including low efficacy of vaccines and low coverage of vaccines in the population.

This priority should include research into implementation of evidence-based interventions for older people that can improve health outcomes. For example, exercise has been shown to reduce risk of falls, cardiovascular conditions, and improve mental health. Studies into new interventions supporting this priority need to be inclusive of all older people, involve older people in co-design of research and fund long-term trials that can be run over 5-10 years.

Priority 5

This priority addresses a high priority issue raised by older people and is of high importance for the mission. This priority should include research into preventing 'falls' which can result in fractures and disability and are a serious threat to the quality of life and independence of older people. There is a need for research into the mechanisms of falls to better design effective interventions (e.g. reactive balance in responding to trips and, slips) and implementation research for known risk factors that have not yet been integrated into practice.

Priority 6

Health of the frailest of the frail in Aged Care Facilities should be a top priority of the Mission. This priority represents an opportunity to take up the challenges and recommendations highlighted by the current Royal Commission into Aged Care Quality and Safety through high quality research into aged care provision. It is also an opportunity to ensure aged care is visible and integrated into the local community and broader society.

Are there any specific areas of research that you would prefer to see funded under any of the priorities?

Investments should be in research that:

- Includes diverse communities such as culturally and linguistically diverse (CALD) communities (30% older Australians are from CALD background) and the needs of Aboriginal and Torres Strait Islander communities.
- Has an implementation science focus to advance health and care as well as advance methods and science on implementation. This includes diverse methods and approaches combining arts, design, technology and clinical interventions.
- Takes a systems-based approach that includes older people, their families, carers and communities.

Considers multi-morbidity and medication management for older people. Many older people have 5-10 conditions simultaneously which presents challenges for choosing treatment options as each condition cannot be treated separately. Most (95%) people over 65yo are on at least 1 medication and two thirds are taking five or more medications. Management (and reduction) of medications for older people as well as how to effectively manage multiple conditions is essential to enabling healthy ageing.

What should be the high priorities for the Mission?

- Research that considers new paradigms of research into underlying causes of dementia
- Research that is inclusive of diverse communities
- Prevention and care, not just cure, to enable older people to contribute socially, culturally and economically to the wider community.
- Improving health and aged care systems to promote the health and wellbeing of older people.
- Developing approaches that consider multiple morbidities for treatment and prevention strategies.
- Pragmatic and realistic implementation in daily life.

Is there anything that you would like to raise for consideration in the context of finalising the Mission Roadmap?

Wherever feasible competitive and transparent processes should be used to make MRFF funding decisions, including for research funded under this Mission.

These processes should include:

- A 4 to 6-week lead time in advertising competitive grant opportunities before they open for applications, including publishing grant guidelines.
- Transparency in the grant review process for competitive opportunities
- Publishing grant outcomes for each opportunity