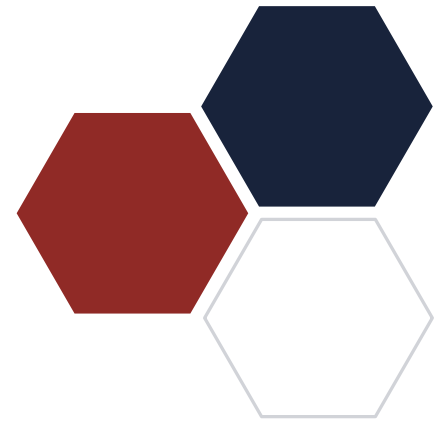




Australian Government

Department of Health

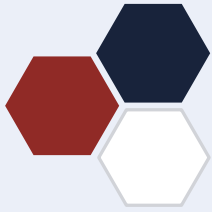


Medical Research Future Fund

Dementia, Ageing and Aged
Care Mission

International review
of the Roadmap and
Implementation Plan

5 November 2020



Introduction

Our mission

To generate measurable improvements in the:

- detection, prevention, assessment and treatment of dementia, and care and support for people living with dementia
- average healthy lifespan experienced by older Australians
- consistency and quality of care for older Australians across all care settings

Our goal

To improve quality of life for Australians as they age.


The Medical Research Future Fund (MRFF) is a \$20 billion long-term investment supporting Australian health and medical research. The MRFF aims to transform health and medical research and innovation to improve lives, build the economy and contribute to health system sustainability.

The Dementia, Ageing and Aged Care (DAAC) Mission will provide AUD\$185 million over 9 years under the MRFF to improve outcomes for people living with dementia and for older Australians.

DAAC Mission Expert Advisory Panel

A DAAC Expert Advisory Panel (EAP) was established to advise the Australian Minister for Health on the strategic priorities for research investment through the DAAC Mission.

The DAAC EAP's role is to define evidence and knowledge gaps that should be addressed through mission research funding, to help transform health care and health outcomes for individuals and communities. This role includes defining key research questions that – if answered – will deliver meaningful change to older people through the translation of research.



The DAAC EAP developed a Roadmap and Implementation Plan to advise about priorities for research investment through the DAAC Mission.

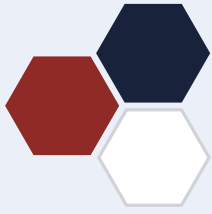
The Roadmap includes:

- the mission statement and goal
- possible themes and priorities for investment

The Implementation Plan includes:

- 3 aims that outline how the DAAC Mission will benefit Australians
- priorities for investment in the short, medium and long term
- opportunities for leveraging additional investment
- activities needed to support the DAAC Mission's outcomes and facilitate their implementation

DAAC EAP members will consult and engage with other researchers, industry, and consumer and patient groups, and participate in media and public activities to build awareness of, and facilitate interaction with, the mission and with other MRFF-funded research.



DAAC Mission International Review Panel

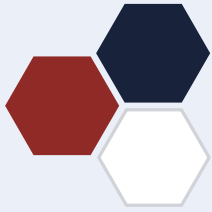
The DAAC Mission International Review Panel's (the DAAC Panel's) role was to provide expert feedback and experiential advice in the context of relevant activities occurring internationally, which can inform the strategic direction of the mission's Roadmap and Implementation Plan.

The DAAC Panel members were asked to:

- a. Advise on the applicability of the DAAC Mission's goal to the international context; specifically, whether the goal duplicates or contributes to international research activities
- b. Advise on the likely effectiveness of the research priorities (including their sequencing) to achieve the goal
- c. Provide learnings from international research activities in the field
- d. Identify opportunities for leveraging and complementing international research activities to achieve the goal
- e. Advise on the appropriateness of the proposed measures for evaluating progress towards meeting the goal

The DAAC Panel comprised 6 members representing expertise in a variety of clinical and scientific research areas:

- Prof Carol Brayne CBE – Professor of Public Health Medicine, Co-Chair of Cambridge Institute Public Health; University of Cambridge, UK
- A/Prof Abraham Brody – Associate Professor, Nursing & Medicine; Associate Director, Hartford Institute for Geriatric Nursing; New York University, USA
- Prof Carole Estabrooks – Faculty of Nursing, University of Alberta, Canada
- Prof Joseph Gaugler – Professor and Robert L. Kane Endowed Chair in Long-Term Care and Aging, School of Public Health; Director, Center of Healthy Aging and Innovation, School of Public Health; Emeritus Long-Term Care Professor, School of Nursing; University of Minnesota, USA
- Prof Ann Kolanowski – Professor Emerita of Nursing; Professor Emerita of Psychiatry; College of Nursing and College of Medicine; Penn State University, USA
- Prof Vincent Mor – Florence Pirce Grant University Professor, Professor of Health Services, Policy and Practice; Brown University, USA



Consultation discussion

The DAAC Panel met on Thursday 5 November 2020 to discuss the DAAC Mission's Roadmap and Implementation Plan.

Participants at the meeting were required to declare any conflicts of interest and relevant collaborations. None of the declared interests were considered material to the meeting.

Key points

- The DAAC Panel broadly supported the Roadmap and Implementation Plan, but suggested that some refinements could improve it even more
- The mission's goals broadly align with international goals
- Consider outcomes across different care settings for people living with dementia and their carers
- Data collection and infrastructure must be enhanced to support improved health outcomes
- The effects of early diagnosis need to be explored, as the advantages and disadvantages are not yet fully understood
- To improve models of care and produce better outcomes for older people, an upskilled workforce must have a well-functioning system to work in
- Marginalised and minority populations need to be considered carefully, to ensure they are receiving care that produces the best possible outcomes for them
- A stage-gating funding process could be used to ensure that only the successful research programs proceed to later stages
- A robust, stakeholder-engaged approach to research is required to achieve the DAAC Mission



Align goals with international aims

The DAAC Panel highlighted several other sources that could contribute to refining the DAAC's goals:

- the National Institute on Aging's (NIA's) **Strategic directions for research, 2020–2025** (USA)
- NIA research summit report (not yet available)
- the National Academies of Science, Engineering and Medicine report on nursing home quality, to be released in February 2021, which includes a summary review, mission statement and recommendations relating to dementia and ageing (USA)
- Health ageing report (Canada)
- The Centers for Disease Control and Prevention Healthy Brain Initiative Roadmap
- The European Union Joint Programme of Neurodegenerative Disease
- Interdem, a pan-European research network on detection and timely INTERvention in DEMentia

The DAAC Panel recommended consideration of research that considers the adaption and/or implementation of existing international research outcomes (eg models of care) into Australian settings.

Consider patient care and outcomes across all settings

The DAAC Panel highlighted that older people move across different care settings and that their care and outcomes as they transition through these settings should be considered. While research projects may focus on one setting or another, understanding transitions between care settings within community contexts may improve understanding of outcomes for older people. The panel noted that there would be merit in better understanding outcomes of whole-of-system approaches, particularly clinical outcomes.

Use a systems approach to improve models of care and patient outcomes

The DAAC Panel noted that, for the aims in Priority area 3.1 (effective models of care) to be achieved, a whole-of- systems approach is required, including the context of those systems in community. The panel highlighted that even a highly trained workforce cannot be effective if the system it works in does not support their level of skill. The system itself must be improved alongside upskilling the workforce.

In addition, the DAAC Panel noted that the research outcomes should transform the whole system and not be disease-specific. In Canada, for example, national priorities are quite general, and focus on social care and quality of life. The DAAC Panel applauded how dementia and ageing research are considered together in the roadmap and plan, as some patients with comorbidities have complex needs and dementia is only one aspect of their health and wellbeing.

In the context of the COVID-19 crisis, the DAAC Panel raised the importance of infection control practices and the need for research to address the barriers to their effective implementation, in aged care settings and during transitions.

Implementation and sustainability of any dementia care innovation should be considered at the outset of intervention design and evaluation.


Ensure strong data infrastructure and consistent data collection

The DAAC Panel noted that high-quality, consistent data are key to achieving the mission's goals, and ensuring that measurements are comparable across all settings and projects, such as how 'function' is measured. Collecting core data elements needs to be a part of all projects. This will allow projects to measure improvements across all settings.

The DAAC Panel suggested that the mission could fund research that gathered nationally representative data to establish feasible, evidence-based approaches to improve care for older Australians.

It was also stated that it would be valuable to record an individual's journey across the care continuum, and an individual's reported wellbeing across different care settings.

The DAAC Panel also recommended pushing for stronger data-sharing among states and territories to help researchers access data to achieve the mission's goals.



The DAAC Panel advised that, if data-sharing among jurisdictions is not possible, then researchers should have open access to data from all projects.

Consider all effects of early diagnosis

The DAAC Panel noted that there are advantages and disadvantages of early dementia diagnoses. Early diagnosis can lead to labelling, resulting in stigma. Although early diagnosis might be beneficial for some patients, the overall effects of early diagnosis are unknown. The panel believed it would be useful to consider exploring this more, especially in multicultural settings.

Address marginalised and minority populations

The DAAC Panel felt that researchers need to understand the distribution of care before they can fully understand disparity of care. For example, do minority groups receive suboptimal care because they are treated differently in the same place, or because they receive their care in suboptimal places?

The panel also emphasised that a multicultural approach is essential to improve models of care. In particular, all older people do not need to receive the same care; rather, all older people need to receive care that is right for them. This could be achieved, in part, by cross-cutting projects with the Indigenous Health Research Fund.

These issues can only be addressed if researchers have access to the right data (see 'Ensure strong data infrastructure and consistent data collection').

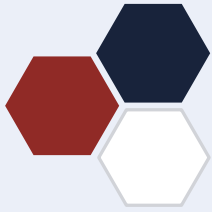
Focus on positive outcomes and strengths-based perspectives

The DAAC Panel advised that the research outcomes focus on positive aspects of wellness and resilience, not negative biomedical outcomes.



Use a stage-gating process for delivering funds

The DAAC Panel felt that a stage-gating process for delivering funds would optimise research direction and achieve the best results. This means that researchers could pace, present and adapt approaches with clear tracking of progress from one stage of research to the next. As an example, a first phase of research could be about tailoring solutions known to work internationally for the Australian context, followed by a second phase that investigates implementation of the model.



Recommendations

- Review materials (see above) to further align the DAAC Mission's goals with international research programs, and consider re-ordering the goals so they flow logically (prevention, early detection, care)
- Consider patients across all care settings together and in context of their population setting
- Upskill the workforce to ensure better patient care, but also ensure the workforce has an effective system in which to function
- Research and consider all effects of an early diagnosis of dementia
- Carefully consider the needs of marginalised and minority groups
- Use a stage-gating process to progress projects from early to later phase
- Engagement with stakeholders, particularly older people and their carers, should be embedded in all aspects of the mission