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Dementia, Ageing and Aged Care Mission Roadmap

Dementia Australia's response

February 2020

About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We represent the more than 459,000 Australians living with dementia and the estimated 1.6 million Australians involved in their care.

Dementia Australia works with people of all ages impacted by dementia, all governments, and other key stakeholders to ensure that people with all forms of dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with individuals and communities means that we can advocate for those impacted by dementia and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people of all ages living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.



Dementia, Ageing and Aged Care Mission

The Dementia, Ageing and Aged Care Mission is a research program that is investing \$185 million from 2018-19 to 2028-29. It aims to support older Australians to maintain their health and quality of life as they age, live independently for longer, and access quality care when they need it.

The Dementia, Ageing and Aged Care Mission has released the draft Roadmap for public consultation. The consultation will present the Australian public with an opportunity to assess the draft Roadmap, and offer feedback on the current strategy. It will ultimately assist the Government as it seeks to prioritise funding for critical dementia and aged care research.

Funding for the Mission is made available through the Medical Research Future Fund (MRFF).

Dementia Australia's response to the online survey consultation on the Dementia, Ageing and Aged Care Mission's Roadmap

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

Mission Statement: *Through health and medical research, the Dementia, Ageing and Aged Care Mission aims to improve the quality of life for people as they age.*

The mission statement, while appropriate to the vision and goals of the Medical Research Future Fund, does not overtly address research translation. Dementia Australia recommends that the Mission refer to the implementation of research into practice, as research on its own will not achieve the vision and the goals of the Mission. Dementia Australia suggests that the Mission Statement be changed to "Through health and medical research, **as well as demonstrated translation into practice**, the Dementia, Ageing and Aged Care Mission aims to improve the quality of life for **all** people as they age."

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

Vision:

Healthy ageing will enable older people to contribute socially, culturally and economically to the wider community and reduce the cost burden of disease by delaying the onset of symptoms, particularly those associated with more resource intensive health and aged care services.

Dementia Australia suggests that the following aspects need to be considered to ensure that the Vision statement is appropriate to the level of investment being made towards the Mission:

- The Vision needs to balance healthy ageing in the population with research and interventions that are targeted to specific conditions/diseases.
- The Vision needs to appropriately articulate how government arrangements for the fund will ensure appropriate levels of engagement with consumers and aged care and/or health providers so that they are informing the research priorities and agenda to ensure translation of knowledge and implementation of research into practice.

Grouping dementia, ageing and aged care under the one research umbrella may prove too ambitious a goal to the overall envelope of funding allocated. The Boosting Dementia Initiative allocated \$200 million to dementia research over a five year period (2014-2019). By comparison, this current allocation is \$185 million over 10 years and targets three broad areas of health and healthcare (dementia, ageing, and aged care). While there are some cross-cutting themes, an ongoing investment in dementia-specific research is imperative to addressing the impacts of the disease on hundreds of thousands of Australians. While the full gamut of dementia research – from prevention to cure – is urgently required, the more immediate quality of life improvement for people impacted by dementia is likely to arise from behavioural and social research. There is also an urgent need that Australia retains and builds on this new research capacity so as to allow us to participate in international clinical trials aimed at delaying the onset of dementia, and offering new forms of treatment.

Dementia Australia is also concerned that funding for dementia research will be limited in comparison to other health priorities such as cancer and cardiovascular research, despite the prevalence of dementia in our communities and its significant influence over cause of death data (it is the second leading cause of death of all Australians and the leading cause of death of women).

Do the goals appropriately capture the aim of the Mission?

Goals:

- Address the issues of ageism and its impacts on quality of care and quality of life for older people.
- Increase the number of years a person could expect to live in optimal health as they age.
- Deliver care and services that are of high quality, takes a human rights based approach and supports an individual's wellbeing.
- Slow the progression of cognitive decline.
- Achieve timely diagnosis of dementia.

These outcomes would be facilitated through the following elements:

- Develop innovative care models, interventions and technologies to improve health and wellbeing.
- Inform health and aged care system change to deliver improved quality of life and care.

- Retain and build research capacity, excellence and collaboration on these topics that is integrated into care settings across the health and aged care sector.

Dementia Australia suggests that each of the goals might benefit from being specifically aligned to one of the three themes of the Mission – ageing, aged care or dementia – in order to ensure equity of focus. While there are some cross-cutting synergies across the priority areas, such as addressing ageism and discrimination, improving education and making cultural shifts towards more empathy and respect, there are nuances in, for example, approaches to ageing compared with dementia that need to be taken into consideration. Specifically, in relation to dementia, the Mission would benefit from targeted goals around timely diagnosis and risk reduction; the involvement of families and carers as partners in care; and creating supportive environments that facilitate meaningful engagement for people living with dementia.

The goals should also have a clear, measurable focus on the provision of a holistic and person-centred approach to care, including high-quality communication, particularly for people living with dementia.

For example the goal: ***"Retain and build research capacity, excellence and collaboration on these topics that is integrated into care settings across the health and aged care sector"*** would be strengthened by an elaboration of what is meant by excellence and collaboration.

The goal: ***"Develop innovative care models, interventions and technologies to improve health and wellbeing"*** would be more powerful if it includes specific reference to the involvement of providers and consumers.

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

Guiding Principles:

- Research priorities and projects should be designed to have an impact on policy and practice, and identify and measure a targeted improvement for the end user.
- The investment will span the research pipeline from discovery through to implementation and improve the current experience of ageing, aged care and outcomes for people living with dementia.
- Consider all older people, inclusive of all backgrounds and life experience.
- Embed a co-design approach with end-users (consumers/patients, peak bodies and philanthropic organisations, carers and the public, industry, other levels of government) in priority setting, in conducting and in translating research. Encourage and facilitate domestic and international collaboration, including collaboration with other MRFF missions and across industry sectors. Good to see and the question is how that will be achieved
- Address the gaps in the current evidence base on supporting people with dementia and their carers across their period of living with dementia (from pre-diagnosis through to end of life).

- Foster a culture of research excellence in dementia, ageing and aged care, including through research training.
- Consider new and emerging trends in dementia, ageing and aged care.
- Seek co-investment, through partnerships and appropriate governance, from the private sector, philanthropic organisations and government.

The guiding principle: ***“The investment will span the research pipeline from discovery through to implementation and improve the current experience of ageing, aged care and outcomes for people living with dementia”*** is supported by Dementia Australia, but the impact of the principle would be heightened if it could reference the importance of research translation and evaluation, given these aspects have undermined the effectiveness of existing research.

The guiding principle: ***“Consider all older people, inclusive of all backgrounds and life experience”*** seems to imply that dementia is an older person’s disease rather than recognising that younger people can be diagnosed with dementia too. Younger people in their 50s, 40s and even their 30s can receive a diagnosis of dementia, so it is important to ensure the needs of people with younger onset dementia are included within the mission.

The guiding principle ***“Embed a co-design approach with end-users (consumers/patients, peak bodies and philanthropic organisations, carers and the public, industry, other levels of government) in priority setting, in conducting and in translating research. Encourage and facilitate domestic and international collaboration, including collaboration with other MRFF missions and across industry sectors”*** is strongly supported by Dementia Australia, since we advocate for the involvement of people living with dementia, their families and carers in research priority setting from the outset through to the implementation, evaluation and translation of the research into practice. Dementia Australia advocates (people living with dementia, their carers, and former carers) have shared their concerns of being ‘an afterthought’ and feeling as though their insights are interpreted rather than fully understood and respected, so addressing this engagement overtly will go some way to ameliorating these issues.

It would also be useful to specifically identify which other MRFF missions may intersect. This will help establish targets and build strategic plans around where the funding is being allocated.

The guiding principle: ***“Address the gaps in the current evidence base on supporting people with dementia and their carers across their period of living with dementia (from pre-diagnosis through to end of life)”*** would also benefit from including reference to the ‘post bereavement phase’ and the impact this has on family and carers.

Moreover, it is important to address translation of existing research into practice as this is a key barrier – especially addressing the challenge of low understanding and awareness of dementia among the health workforce, particularly in the palliative and end of life stages.

The guiding principle ***“Seek co-investment, through partnerships and appropriate governance, from the private sector, philanthropic organisations and government”*** would be stronger if it is able to specify how systemic capacity building will be balanced by commercialisation and market differentiation.

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?

A key barrier in the Australian research context is the lack of foundational data on dementia in the health, disability and aged care systems. This lack of data currently makes it difficult to quantify the problem research is trying to solve, as well as informing what a successful outcome would look like. Government investment in foundational data collection and analysis at a systemic level is required to complement the Dementia, Ageing and Aged Care Mission.

Another barrier is the lack of collaboration between researchers and service providers, and the lack of engagement with consumers by researchers. This needs to go beyond having people register their interest in trials, and requires a support system that consciously enables informed involvement over time, as appropriate to the circumstances of each individual

There is also still a significant delay between research being funded and the translation of research findings to practice. It is estimated that it can take up to 25 years for research evidence to reach clinical practice. This delay manifests itself as poor outcomes for people living with dementia. Investment that supports the translation of research into practice, will ensure that people with dementia, their families and carers will benefit from improved care and services. Dementia Australia suggests that, in order to maximise the success of the guiding principles of this research mission, the following also need to be taken into consideration:

- How the Mission will facilitate the translation of research into practice across different care settings.
- The alignment of the Mission with other dementia, health and ageing policies and frameworks, so as to include social/policy research as well as medical research.
- The level of collaboration across health care, aged care and the disability sector in order to avoid duplication or contradiction of activities and priorities.
- The inclusion of effective education campaigns on the translation and dissemination of research evidence into practice.
- The application of a governance model that ensures the research agenda and priorities are informed by both consumers and industry.
- Research that aims to study and address the root causes, and the flow on effects of emerging evidence on dementia, ageing and aged care.

Are there other principles that should guide the Mission's research that you feel are missing from the draft Roadmap?

As already outlined above, additional principles that may be considered include:

- The important role of research translation;
- The fundamental importance of a demonstrated partnership between researchers and consumers, both at an advisory and participant level;
- The alignment of specific priority areas (ageing, aged care and dementia) with individual principles (as one person living with dementia articulates, *“while there are*

similarities, there are also nuances and specialist care needs of people living with dementia”);

- The focus on multiple types of dementia, including younger onset dementia;
- An equitable investment in dementia research, compared with ageing or aged care research.

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

Investment Priorities:

- 1. Research into the causes, treatment, management and potential cure of dementia.**
 - What interventions could be taken up that could prevent or delay onset of dementia symptoms?
 - What care pathways and interventions could help to diagnose dementia earlier in the disease process?
 - How can we achieve cost-effective care continuity for those living with dementia and carers from the time of diagnosis until death and the post bereavement phase?

The number one priority for people with a lived experience of dementia with whom we consulted is research into causes, treatment, management and a potential cure for dementia.

When it comes to dementia prevention, multi-disease prevention campaigns that include dementia would appear to be the most cost-effective and sustainable approach, to ensure that there is. We need greater awareness of the modifiable risk factors for dementia.

Arguably, there is a pressing need for research focusing on the feasibility/effectiveness of a nationally consistent approach to dementia diagnosis (such as a national screening program) and the impact of early intervention access and supports.

Regarding continuity of care, the focus of the Priority would be improved through inclusion of a reference to ‘quality care’ that is distinct from cost effectiveness.

- 2. What interventions or initiatives could be implemented to address ageism and improve quality of life for older people?**
 - How can we reduce societal stigma around ageing?
 - How do we ensure age friendly and inclusive communities?

Dementia Australia is currently undertaking work to explore the discrimination experienced by people living with dementia, families and carers. This work has highlighted that is important to tackle both stigma – which equates to thought – and discrimination – which relates to behaviour and this dual focus may warrant inclusion in research initiatives funded through the Mission.

Dementia Australia is also supportive of the focus on ageism and improving quality of life. Age friendly and dementia friendly initiatives in turn, should be shaped by clear outcomes, deliverables and thorough evaluation of impact.

3. How do we ensure that people develop and/or maintain a sense of purpose as they age?

- How do we support and maintain meaningful engagement, participation, contribution and social inclusion to benefit people as they age?

Dementia Australia recommends that the focus must not only be on physical care, but that further consideration into of the psychological, social and spiritual aspects of ageing, aged care and dementia are addressed. This should include a holistic, person-centred exploration of what meaningful engagement looks like and the benefits of contribution, social inclusion and participation, particularly for people living with dementia, their families and carers.

4. How do we extend healthy, active years of life for all Australians?

- What health and medical interventions in mid-life will extend healthy, active years of life and compress the period of morbidity?
- How do we encourage more proactive health management, including health literacy for older people?

It would be useful to explore under this priority area the effectiveness of public health campaigns and behaviour change initiatives on people's health choices and behaviours.

5. How can we support older people who wish to live in their own homes for as long as they prefer to do so?

- What lifestyle, medical, technological and psychosocial supports are most effective to support those ageing at home and their carers?
- What care models/support/direct provision of services and carer support options are most effective for older people as well as their carers?

In addition to the questions offered above, Dementia Australia recommends the following areas be included or referenced:

- Community social connectedness and support groups, involving local government programs and initiatives.
- Aged care planning supports to assist people to plan for their future needs for housing, medical and social support, at a time when they have capacity.
- Technological enhancement and assistive technologies.
- New ways of considering aged care supports – such as smaller group homes rather than larger 'institutions' to bridge the gap between home and residential care, and exploring supported accommodation models.

6. What approaches to care provision need to be developed or adapted to ensure support and improvements in quality of care and quality of life for people as they age?

- What adaptations, including technological innovations, are required across health and aged care systems to ensure all older Australians, particularly the most vulnerable and disadvantaged can access high quality, culturally appropriate, trauma-informed care?
- How can we ensure equitable and appropriate access to quality clinical care and minimise avoidable transitions between settings (particularly avoidable

hospitalisations)? As above, improve the training and expertise of those caring for people with dementia in the community.

- How can we maximise social inclusion and multi-generational engagement in all long-term care settings?

Dementia Australia recommends consideration of:

- Expanding research on dementia learning programs and ensuring that people caring for people with dementia are adequately trained to support them and meet their care needs.
- Further research into the positive impact of intergenerational connectedness, and the positive role children play on older people's wellbeing in residential aged care.
- Exploring streamlined access to services and supports – effective models and ways of working that support people living with dementia, their families and carers throughout the care journey.
- Research into the economic impact of shortages in basic home care and supports, which can lead to preventable hospitalisation and premature entry into residential aged care.

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

Dementia Australia is concerned that there is no specific mention of younger onset dementia and where this fits within the research priorities of the Mission. By including dementia research with the ageing and aged care priorities, there is a risk that the needs of people with younger onset dementia, their families and carers will be overlooked. Dementia Australia suggests that support for research into best practice approaches to meeting the care needs of people living with younger onset dementia, their families and carers, as well as how they can remain engaged in the community and live meaningful and quality lives, would be beneficial.

Dementia Australia recommends that the priorities could be expanded to include reference to other issues, including:

- Alternative therapies to mainstream medical management of dementia, particularly in residential aged care, for example music therapies, and art therapies.
- The effectiveness of community based and psychological interventions for people with dementia, such as exploring the impact of peer support and carer support groups, and dementia care navigation.
- Human rights based approaches to care for people living with dementia and what can be done to achieve recognition of these rights.
- Effective reablement and tailored person-centred care.

What should be the high priorities for the Mission?

After extensive consultation with people impacted by dementia, government and other stakeholders, Dementia Australia's strategic priorities are:

1. Timely diagnosis of dementia
2. Quality care for people living with dementia
3. Discrimination reduction

Alignment of research priorities to these themes will ensure that the perspectives of people with a lived experience of dementia are aligned with the focus of the Mission.

Dementia Australia also notes that the individuals with whom we consulted about this Mission expressed a preference for prioritising the causes, treatment, management and potential cure for dementia. Increasing the focus on quality of care to maintain, support or improve quality of life was also flagged as a priority, as well as being fundamental to helping people maintain a sense of purpose as they age.

Dementia Australia shares the perspective of the NHMRC National Institute for Dementia Research that mechanisms for setting key performance indicators, the ongoing facilitation of coordination and collaboration across the sector, and the continued monitoring of progress and review of strategic priorities, will elevate the research sector.

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

Dementia Australia believes it is important that the Mission Roadmap has some clearly defined, cross-cutting streams but that it also supports research that specifically targets each stream (dementia, ageing and aged care). The outcomes from the \$200 million Boosting Dementia Research Initiative, combined with evidence from the Royal Commission into Ageing Care Quality and Safety and feedback from people with dementia, families and carers, highlight the vital and ongoing importance of targeted dementia research.

As mentioned above, we also urge the inclusion of younger people living with dementia within the focus of the Mission, and strengthening of the role of people living with dementia, their families and carers in all aspects of research.

We would welcome further opportunities to provide feedback and support to the Department as work on the Mission progresses.