Advice for commissioners of the Budget 2022 Dementia Mate Wareware Action Plan projects

The Dementia Mate Wareware Leadership and Advisory Group
Te Whakaruruhau mō te Mate Wareware

17 February 2023

Introduction

The Dementia Mate Wareware Leadership and Advisory Group thanks Te Whatu Ora and Te Aka Whai Ora for the invitation to provide advice to government about the commissioning process for the Budget 2022 Dementia Mate Wareware Action Plan projects.

We hope that this response is useful in your deliberations. We ask that you provide timely feedback on how this advice had an impact on your decision making. This will help provide transparency, build trust across the Dementia Mate Wareware Network, and motivate future engagement for the Dementia Ecosystem.

The Dementia Mate Wareware Network is supported by:

Te Whatu Ora
Health New Zealand

Te Aka Whai Ora
Māori Health Authority

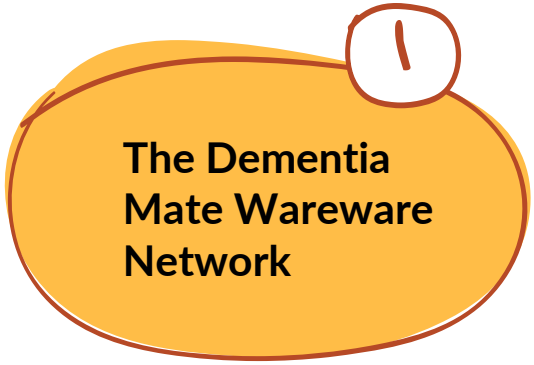
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The opinions expressed in this booklet are the Network and Dementia Mate Wareware Leadership and Advisory Group's own and do not necessarily reflect the views of Te Whatu Ora or Te Aka Whai Ora.

This document was produced by New Zealand Dementia Foundation as the secretariat of the Dementia Mate Wareware Ecosystem

The building blocks

It is important to involve people and whānau affected by dementia mate wareware and people who work to support them when the government makes decisions about the future. Te Whatu Ora and Te Aka Whai Ora have set up two new groups to make sure that this happens. These two groups work together to provide advice to government about how we can make the Dementia Mate Wareware Action Plan happen.



The Network provides the views and opinions of people who are involved with dementia mate wareware in Aotearoa New Zealand.



This group provides strategic advice to guide government. They listen to and work with the Network.

You can find out more about this governance system online at https://www.nzdementia.org/Dementia-Ecosystem

The projects

Budget 2022 set aside $12 million to support some Dementia Mate Wareware Action Plan projects. This money will be spent over four years. The government has indicated what the focus of the projects are:

Support

Some projects will focus on the community supports available for people who have recently been diagnosed with dementia mate wareware and their whānau. The Government has stated that priority will be given to meeting the needs of Māori, Pasifika, and rural people, as well as people and whānau affected by dementia mate wareware at a young age.

Navigation

People and whānau affected by dementia mate wareware may benefit from a guide to link them to the supports and services that can help them. Boosting effective navigation will be an important goal for some projects.

Respite

Some projects will focus on innovative respite care approaches that meet the needs of people living with dementia mate wareware and their whānau and family supporters.

How the advice was developed

First Network hui

The Network met online in November 2022. The participants talked about what was needed to commission services that meet needs and make a difference.

Network Survey

In January 2023 the Network were invited to read the draft advice and provide feedback through a survey.

Second Network hui

The Network came together for a online hui on the 16th of February. The Network were invited to discuss the revised advice.



Leaders' meetings

The Dementia Mate Wareware Leadership and Advisory Group read a summary of the Network's messages. The Group met in December and January and developed draft advice for commissioning process.

Chairs' meeting

The chairs of the Dementia Mate Wareware Leadership and Advisory Group met to discuss and respond to the survey feedback. They revised the advice for commissioners.

High priority recommendations

In response to feedback from the Network, the advice has been divided into high priority and general recommendations. There are six high priority recommendations.

	The Dementia Mate Wareware Leadership and Advisory Group recommends that:	This supports the messages from the first Network hui that they want:
1	Commissioners should ensure that the application process is accessible and minimises barriers to applying.	Simple everyday language (p.11)
2	Commissioners should prioritise projects that seek to address current challenges affecting service access for tangata whenua, Pasifika communities, rural communities, and people with young onset dementia and their support people / families / whānau.	Everyone has access to information and services, regardless of their cultural identity, where they live, or how old they are (p.15)
3	Commissioners should prioritise projects that show that the organisation has partnered with people with lived experience of dementia and their supporters in the planning.	Genuine partnership, commissioning led from the ground up, and co-design and co-production (p.14)

* Page numbers refer to the “Kōrero Mai: Let’s Talk” booklet bit.ly/koreromai

	The Dementia Mate Wareware Leadership and Advisory Group recommends that:	This supports the messages from the first Network hui that they want:
4	Commissioners should prioritise projects that show that they explicitly address each of the five principles of Te Tirirti o Waitangi.	A genuine commitment to Te Tiriti o Waitangi and older Māori and whānau are fully engaged (p.13)
5	Commissioners should prioritise projects that show that they will evaluate outcomes related to improvements in quality, well-being, and equity. Equity includes equity in eligibility, access, uptake, and outcomes.	Services help people to live well with dementia mate wareware, not just meet their basic needs (p.13) Measurement of impact (p.13)
6	Commissioners should prioritise projects that aim to confer direct benefits to people living with dementia mate wareware and to family and whānau, rather than one or the other.	A respite system that is more focused on the person living with dementia (p.15)

General recommendations

These are important principles for decision-making, but it is recognised that not all projects will meet all criteria.

The Dementia Mate Wareware Leadership and Advisory Group recommends that:	This supports the messages from the first Network hui that they want:
7 Commissioners should prioritise projects that cover more than one of the three budget priority areas if that means more worthwhile projects can be obtained from the small amount of money available.	One-stop shops (p15)
8 Commissioners should prioritise projects that show collaboration across providers.	Services connect and collaborate (p.14)
9 Commissioners should prioritise projects that show that they will lead to an increase in options open to people with dementia mate wareware / families / whanau. This is particularly important for respite service projects.	A respite system that is more flexible and has more capacity (p.15)

The Dementia Mate Wareware Leadership and Advisory Group recommends:	This supports the messages from the first Network hui:
10 Commissioners should prioritise projects that bundle support to navigate dementia services with other post-diagnostic support to whānau, families, and individuals, as this should be the model for the future. This is particularly important for service navigation projects.	People have a seamless experience across time and between services. (p13)
11 Commissioners should prioritise projects that involve GP-based primary care and seeks to strengthen its involvement with people affected by dementia mate wareware. This is particularly important for post-diagnostic support projects.	General practice professionals are confident, timely, and positive when making a diagnosis (p.14)

Attachment:

The summary of the messages of the first Network meeting on can be read at bit.ly/koreromai
At the second Dementia Mate Wareware Network meeting on 16 February 2023, communities of interest groups gave their 'headlines'. There will be ongoing mahi to articulate the current situation and priorities, but those initial messages are given here.

Māori Perspectives Community of Interest Group

So in terms of what works well for Māori, what clearly came through was the connection to whānau ... many whānau come together in times of adversity and this is one occasion when that happens. And so the advantage is whānau can pull resources, they can come together and support each other.

I guess it's a double edged sword. On the other hand, many of our Māori whānau are already struggling in terms of their financial situation. So there are socio economic issues that need addressing and need looking at. .. many of them, the housing situation is not adequate in order to cope [and] take care of the person living with mate wareware.

There are other issues that are more important and more salient … in a whānau living with mate wareware, such as providing kai - putting kai on the table, providing clothing, like really the basics of just living, which our whanau face day in and day out, day in and day out. So, how do we improve this? What can we do now? …a lot of the funding is not distributed equitably amongst our community and what we need … is further funding, equitable funding for Māori whānau in order to be able to provide … premium care for … any member living in the whānau living with mate wareware.

Tagata Moana Perspectives Group

…diagnosis is critical for Pasifika whanau. That isn't working because we don't often come to light until much later. And so we operate on a collectivism thinking before we get to that point where we just come straight to the NASC and to run all these other processes. So there's got to be a focus there...

.. with the funding that's coming, kei te pai, hopefully it's not just a tokenistic approach to doing things … we need real depth detail of what's going to happen from here.

What is working from now is that a presence, whether your leadership governance or kaimahi or whanau, actually a presence is working well … and actually seeing how whānau operate.. .. go into the space and actually seeing how whānau operate. That should be what's informing all this stuff that people are writing in Wellington or writing RFPs whatever.

… what connects Pasifika is the moana so preference is Tagata Moana and we alongside our Tangata Whenua absolutely agree that the mahi that's been done into Te Tiriti obligations also underpin the values of Pasifika. So that mahi has started. Well done. Keep it going.

Young Onset Dementia Perspectives Group

there's a strong awareness of the different needs of people living with young onset dementia and their supporters.

The feedback highlight was the day cares were not set up well for young onset of dementia people. One voiced their GP experience was a road block to specialist care.

Respite Perspectives Group

The overarching thing … was accessibility to respite care and in particular dementia level care.

We learned from our colleagues ..that they have the software available to manage any ring fenced respite beds … and they're able to actually pre book in advance and provide a care which just sounds amazing. ..From the point of view of a service user, family members expressed the angst in needing to … chase a bed yourself as an already burdened caregiver. And having some better form of booking system would be just truly amazing.

Community Service Perspectives Group

Two actions that we spoke about : whether daily activities respite, and that particular community help, is available for funding and to what level. And also … how families of loved ones living with dementia are supported given the impact dementia has on informal care and the wider community.

Dementia Friendly Communities Group

at the moment things that are working well are our Dementia Friends programme that people can learn more about dementia in the community.

Two things that we think should be improved is the city councils need to make their cities and towns more Age Friendly, which means that they'll also be more dementia friendly. And also, healthcare has to be more dementia friendly, particularly secondary care and people with dementia going into EDS and how very distressing that is, and also making primary care more dementia aware as well.

Navigation Group

…the critical path for navigation was actually around education of the workforce, and especially in the primary care sector so they can be actively supporting the person living with dementia for navigating early diagnosis.

And then ongoing access for support systems and the critical importance of navigation being fully resourced as part of an integral core national service model... the right funding through a national model would help to ensure addressing inequities and the current system postcode lottery, which sees some areas having no funding support for navigation and others being reasonably well supported for the navigation.

Therapeutic Perspectives Group

We had …people with an interest in CST, speech language therapy, voice arts diversional therapy, occupational therapy and biomedical therapeutics, so a wide range of different ways of thinking about therapeutic interventions... that just scratches the surface of what we already know about and what's possible.

The key, one thing that needs to happen is that those kinds of interventions and opportunities need to be available for everyone across the country wherever they live, and considered to be a core part of the service offering. And in order for that to happen, there needs to be money associated with that for the right capacity, right capability for the service delivery element, but also for the ongoing research to be able to demonstrate what works into the future, because there will be more developments in that space.

General Group

there should be much more attention given to people [with mild cognitive impairment] who are not yet diagnosed as dementia, because we have a threat hanging over the nation …

there should be more opportunities for peer to peer support in general….

there should be far more health improvement practitioners spread around primary care in the country, which would, among other things, relieve the load on GPs.

Aged Residential Care Perspectives Group

some of our highlights were around the funding structure not having a person centred approach and also not being consistent across different localities and areas of the country.

There was a concern about InterRAI not being client focused, being an imported system brought from Canada to Aotearoa, [yearly examinations] that do not focus on health outcomes and equity outcomes .. .[and] the very few … registered nurses being available, particularly at smaller age residential care facilities to actually do InterRAI and collect data.

…there was feedback about consistency and legal frameworks around enduring powers of attorney how to protect people to go into care, better support people, dealing with … the issue of bed blocking and hospitals … while people wait for enduring powers of attorney to come through, ... [and] the need for legal reform around …decision making

there was some feedback about home-based community-based model of care rather than an institutional model to support people needing person-centred [aged residential] care for dementia.

Ngā mihi nui



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