



Improving Dementia Mate Wareware Services in Aotearoa New Zealand

Action Plan

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Table of Contents

Why we need a Dementia Mate Wareware Action Plan.....	3
Kaupapa Māori	6
Links to other Strategies/Plans	6
Dementia mate wareware is a major challenge to Aotearoa New Zealand - it's time for action	9
Dementia Mate Wareware Action Plan	13
Vision	13
Goal.....	13
Equity.....	13
Principles.....	14
Action areas.....	16
Enablers	25
What is this Plan based on?.....	27
Appendix 1 - Who developed this Dementia Action Plan?	29

Aotearoa New Zealand Strategies and Plans

The Dementia Mate Wareware Action Plan is closely aligned with the current health sector reforms and will help to create a health and disability system that:

- places the voice of the people, family and whānau using the system at its centre, with services that are needs-based, improve equity and address high need populations
- places Te Tiriti o Waitangi and Te Ao Māori at the centre of systems and services for Māori
- delivers services that are more connected, supported by care coordination and navigation
- is structured around a single integrated system with national consistency, balanced with services that address local need - supported by stronger relationships, communication and commissioning arrangements
- ensures community, home-based services, and primary care (Tier 1) carry equal weight to secondary/tertiary (Tier 2) services, both with a focus on wellbeing
- relies on stronger population health systems
- has focussed and active leadership and stewardship.

The actions from this Dementia Mate Wareware Action Plan also support the [Healthy Ageing Strategy 2016](#) which sets out the strategic direction for the delivery of services so that older people live well, age well and have a respectful end of life in age-friendly communities. The current focus for that strategy is on the priority actions for 2019 to 2022.

This Plan also has links to, and supports, other strategies and plans, including:

- [Better Later Life – He Oranga Kaumātua 2019-2034](#) which sets out the actions needed for Aotearoa New Zealand to embrace the opportunities that an ageing population and longevity brings.

- The Carers' Strategy 2008 and the Carers' Strategy Action Plan 2019 to 2023 which is intended to provide resources and support to support care partners.
- The Aotearoa New Zealand Disability Strategy 2016 which has a vision for Aotearoa New Zealand as "a non-disabling society – a place where disabled people have an equal opportunity to achieve their goals and aspirations, and all of Aotearoa New Zealand works together to make this happen".
- He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction 2018 which provided advice to Government about changes needed to the system.
- The Health and Disability Kaiāwhina Workforce Action Plan 2015-2020 which is a five-year action plan with a 20-year vision for the Aotearoa New Zealand health and disability Kaiāwhina (non-regulated) workforce.

"I strongly agree with this action plan from the vision, goal, principals, objectives and enablers. There are systems that you have addressed that need to be put in place. There needs to be investment and financial resources to support the workforce and therefore making the process supportive, available for people with dementia and families

Having experienced difficulties going through this journey I strongly believe government needs to invest in the time to support a growing number of individuals and families affected by dementia."

Feedback on draft Dementia Action Plan

Dementia mate wareware is a major challenge to Aotearoa New Zealand - it's time for action

What's needed to improve the lives of people living with dementia mate wareware and reduce the impact on the health system is well known and accepted and has been for some time.

A best practice-based guide for District Health Boards - the *Aotearoa New Zealand Framework for Dementia Care* - was developed in 2013.

In 2015 a summit co-hosted by NZ Dementia Cooperative, Carers NZ and Alzheimers NZ identified a national dementia mate wareware Plan as the most important first action for Government to take.

Internationally, in 2017 the World Health Assembly (Aotearoa New Zealand is a member) adopted the *Global Action Plan on the Public Health Response to Dementia 2017 -2025*. Later that year the Lancet Commission published a comprehensive metanalysis of the research into what works for dementia (*Lancet Commission on the Prevention, Intervention and Care*) which was updated in 2020 (*Dementia Prevention, Intervention and Care: 2020 Report of the Lancet Commission*).

In 2021 the first Aotearoa New Zealand data on the prevalence of known risk factors for dementia mate wareware was published (*Ma'u et al, The Lancet Regional Health – Western Pacific (2021)*) which indicated that Aotearoa New Zealand has a higher estimated dementia mate wareware risk than comparator countries, and that the risk is likely to be higher for Māori and Pasifika people, mainly due to high prevalence of untreated hearing loss and obesity.

However, New Zealanders living with dementia mate wareware are still being let down by inadequate services of variable quality, and the current services are not capable of meeting the growing demand, therefore the system is under increasing pressure:

- **Current gaps make service improvement urgent-** Services exist but there are gaps across the whole dementia mate wareware journey:

- *Pre-diagnosis*: poor health literacy remains a significant issue and there is no plan or national activity focussed on dementia/mate wareware prevention.
- *Timely diagnosis*: there is inadequate workforce capability to deliver timely and accurate diagnoses, as well as inadequate support and limited care planning for those who are newly diagnosed.
- *Living well*: the system is complex and difficult to navigate, care planning is inadequate, community-based “living well” programmes are hard to access, limited in availability and underfunded, and families and whānau are overwhelmed, yet respite care is limited and inflexible.
- *Dying with dementia/mate wareware*: palliative care services for people living with dementia/mate wareware are poorly developed.
- ***Access to and availability of services is inequitable:***
 - access to services is inequitable across urban-rural and (pre-2022) District Health Board (DHB) boundaries.
 - access to services is also inequitable depending on which specialty people present to (e.g.: general practice versus neurology versus older persons mental health).
 - there are limited ‘by and for Māori services’ for kaumātua based on Te Ao Māori, and other providers are too often unable to deliver services that fully meet their needs.
 - limited services exist for specific groups such as Pasifika, Asian people, the Deaf community and people who have become hearing impaired, refugees, people living alone, LGBTIQ people, people with intellectual and developmental disabilities, people with young-onset dementia/mate wareware, people living with chronic and severe neurological and/or psychiatric conditions, those with addictions, homeless older people and people housed in corrections facilities, and the digitally excluded.

The quality of services is variable:

- services are not quality assured against ‘dementia/mate wareware friendly’ criteria.
- services are often task-centred rather than person-centred and often limited to medical solutions and/or to disability support services.

- opportunities for meaningful connection, activity and stimulation are limited or non-existent.
- psychotropic drugs continue to be used too often despite evidence that they are not as effective as and/or more harmful than non-pharmacological responses to behaviours associated with dementia/mate wareware.
- ***Human rights are ignored or overlooked*** - Stigma and discrimination create barriers to accessing services and support, decision-making authority is often denied to people living with dementia/mate wareware or their decisions are not respected, and the statutory model provides for substituted and not supported decision making.
- ***Population growth makes service development urgent*** - The number of people in Aotearoa New Zealand living with dementia/mate wareware is growing rapidly. There are estimated to be around 70,000 Aotearoa New Zealanders living with dementia/mate wareware in 2020. This is expected to rise to 100,000 by 2030 and by 2050 the number of people living with dementia/mate wareware is expected to have increased to almost 170,000. Most have family and whānau who are therefore also affected by the diagnosis.
- ***Dementia/mate wareware is an important hidden player in the wider health system*** - Dementia/mate wareware has multiple impacts in terms of lower thresholds for acute hospital presentations, increased lengths of stay, failed discharges, increased need for aged residential care and for higher levels of that care, and health system harms, especially falls and medication harms. Hospitals struggle to treat people with dementia/mate wareware who often emerge with worsened ability to function than when they were admitted.
- ***Dementia/mate wareware is a major cause of disability and dependency among older adults*** – Dementia/mate wareware has been estimated to account for 11.9% of the population’s years lived with disability due to a noncommunicable disease (WHO 2017), and has a significant impact not only on individuals but also on family and whānau, communities and societies. Most people with dementia/mate wareware have other

significant conditions affecting their health and wellbeing, adding to the disability and dependency they experience.

- ***Dementia/mate wareware leads to increased costs*** - The economic cost of dementia/mate wareware to Aotearoa New Zealand increased by 75% between 2011 and 2016, with the total cost of dementia/mate wareware to Aotearoa New Zealand in 2016 estimated to be \$2.4b, increasing to \$6b by 2050. People with dementia/mate wareware and their families/whānau face significant financial impact from the cost of health and social care and from reduction or loss of income.
- ***Workforce issues are worsening*** – Significant numbers of additional staff will be needed as the numbers of people living with dementia/mate wareware increase. Recruitment and retention is already a problem given current remuneration levels, poor access to education opportunities, and an ageing workforce. There is no workforce strategy to make sure there are adequate numbers of people with the right training to deliver quality services for this rapidly growing population.
- ***Future community expectations will increase, perhaps suddenly*** – When a disease modifying treatment for dementia/mate wareware becomes available there will be huge demand for it. Any such treatment will be expensive and the system is not geared to respond.

Dementia/Mate Wareware Action Plan

“We live our best possible lives when:... We have consistent quality support, care and information which is timely and appropriate to us; it is provided with kindness by compassionate people who have the right skills and knowledge, our interests as a focus, and with whom we are comfortable” The Dementia Declaration, developed by people living with dementia on Alzheimers New Zealand’s Advisory Group in 2019

Vision

An Aotearoa New Zealand in which dementia/mate wareware is prevented as much as possible; and where people living with dementia/mate wareware, their family and whānau, and care partners receive the support they need to live their best possible lives, with autonomy, meaning and dignity.

Goal

To improve the wellbeing of people living with dementia/mate wareware while decreasing the impact of dementia/mate wareware on them, as well as on Aotearoa New Zealand, family and whānau, communities, the health system, and the economy.

Equity

People living with dementia/mate wareware who are poor, have other chronic conditions/diseases, live with disabilities, live rurally and are of different ethnicities will have poorer health, greater exposure to health risks and poorer access to health services. These variables are unlikely to exist in isolation; they are deeply interwoven. The concept of intersectionality¹ is critical when exploring actions to address the fundamental causes of inequity.

Services, solutions and resources must be grounded in Te Ao Māori, recognising and responding to the unique needs of tangata whenua.

¹ Intersectionality is the complex, cumulative way in which the effects of multiple forms of discrimination combine, overlap, or intersect especially in the experiences of marginalised individuals or groups.

Services must also acknowledge and respond to the unique needs of other special groups within Aotearoa New Zealand's population including: Pasifika, Asian people, the deaf community and people who have become hearing impaired, refugees, people living alone, LGBTIQ people, people with intellectual and developmental disabilities, people with young-onset dementia/mate wareware, people living with chronic and severe neurological and/or psychiatric conditions, those with addictions, homeless older people and people housed in corrections facilities, and the digitally excluded.

Principles

The Plan is underpinned by seven interlinked principles:

- **Rangatiratanga and human rights** – people living with dementia/mate wareware are self-determining citizens whose lives matter and who have the same human rights as everyone else, including those in the *Convention on the Rights Persons with a Disability*.
- **Manaakitanga, wellbeing focussed and person-centred** – extending aroha (love and compassion) to people with dementia/mate wareware and their family, whānau and care partners putting them at the forefront of decision-making about their care and support so they thrive; living with autonomy, meaning and dignity; participating in and contributing to their family, whānau and communities for as long as possible.
- **Whanaungatanga** – underpins the social organisation of whānau, hapū and iwi, and includes rights and reciprocal obligations consistent with being part of a collective. It is the principle which binds individuals to the wider group and affirms the value of the collective.
- **Wairuatanga** – recognition that all aspects of Te Ao Māori have an ever-present spiritual dimension which pervades all Māori values.
- **Comprehensive and integrated** – services cover the whole life-course of dementia/mate wareware, from developing dementia/mate wareware to the end of life, with all parts of the sector working together to support people living with dementia/mate wareware and to implement the plan.
- **Kaitiakitanga** – guidance and protection to enable provision of compassionate and loving caregiving.

- **Evidence-based and consistent** – services are grounded in evidence and best practice, incorporating person-centred care with traditional health and disability support care, to deliver solutions that are nationally consistent, effective, sustainable, and affordable.
- **Kotahitanga** – unity of purpose, and collective action.

“[Support groups] give networking, sharing stories and ideas. We talk about medication, diet, funny happenings. We talk about all sorts of things. I find them very therapeutic just to discuss things.” Quote from This is our Story, 2019)

Actions areas

The Plan for 2020 to 2025 is to focus on four objectives:

1. **Reducing the incidence of dementia/mate wareware** - The diseases that cause dementia/mate wareware share many risk factors with other non-communicable diseases, including heart disease, stroke, diabetes, and cancer. Research suggests that proactive evidence-based interventions focused on modifiable risk factors could significantly reduce the population risk of developing dementia/mate wareware and/or slow progression.
2. **Supporting people living with dementia/mate wareware and their family and whānau, and care partners/supporters to live their best possible lives** - People with dementia/mate wareware and their family and whānau, and care partners/supporters can enjoy more full, active, and meaningful lives when they have access to a timely, accurate diagnosis as well as to the right support and assistance. Doing so will improve quality of life, reduce the impact on the health system and reduce the costs caused by higher levels of care and emergency care. These services must be equitable in terms of access and outcomes, tailored to individual needs, and their quality must be assured.
3. **Building accepting and understanding communities** - Stigma and a lack of awareness, poor understanding and barriers to inclusion are among the most devastating things that people living with dementia/mate wareware and their support people experience – making it harder to get the help and support they need and increasing their isolation.
4. **Strengthening leadership and capability across the sector** - The dementia/mate wareware sector is complex and fragmented, so services are provided inconsistently across the country. Making the changes needed to implement this Plan is a major programme of work, requiring leadership from Government and a strong focus on capability across the sector.

Actions for each objective are set out in the following table. For each action a government agency has been suggested to lead the collaborative work

required including drawing together those that will need to be involved, including tangata whenua, people living with dementia/mate wareware, community groups, service providers, professional colleges, and guilds.

Because this Plan covers a five year period which is expected to include the structural changes underway in the health sector, reference to Health NZ/Māori Health Authority includes the DHBs and reference to the Public Health Agency includes the Health Promotion Agency.

Objectives	Actions
<p>Reduce the incidence of dementia/mate wareware</p>	<p>Work with colleagues involved with other key non-communicable diseases and population health to design and implement a health promotion programme that is tailored to each ethnic group, delivered in a culturally appropriate way, addresses the unequal social determinants to health and promotes brain health for all people in Aotearoa</p> <p><i>Suggested lead organisation: Public Health Agency</i></p>
	<p>Invest in whānau ora approaches, recognising the importance of the life course approach in the prevention of mate wareware</p> <p><i>Suggested lead organisation: Māori Health Authority</i></p>
<p>Support people living with dementia/mate wareware and their family /whānau supporters/care partners to live their best possible lives</p>	<p>Investigate and implement options to improve the provision of timely and accurate diagnosis and comprehensive management planning in primary care/localities</p> <p><i>Suggested lead organisation: Health NZ/Māori Health Authority</i></p>
	<p>Design and implement initiatives to improve equity of access to culturally appropriate diagnosis and management planning for Māori and measure the impact of those initiatives</p> <p><i>Suggested lead organisation: Māori Health Authority</i></p>
	<p>Align core features of DHB Cognitive Impairment Pathways to reinforce a national approach, including integrating the Māori Assessment of Neuropsychological Abilities (MANA) tool in the assessment process and investigating health technology options for cognitive testing to arrive at a recommendation for national adoption</p> <p><i>Suggested lead organisation: Health NZ/Māori Health Authority</i></p>

Objectives	Actions
	<p>Commission and/or deliver equitable, tailored, person-directed, culturally appropriate and quality assured support services for people with dementia/mate wareware, family and whānau, and care partners based on holistic health models such as Te Whare Tapa Whā, including as the first priorities for improvement:</p> <ul style="list-style-type: none"> • at least 12 months’ post-diagnosis support to equip people to live their best possible lives, including but not limited to: <ul style="list-style-type: none"> ○ information on what to expect, the services available and their rights ○ tools and support to plan and prepare for the future ○ support services to strengthen resilience and wellbeing ○ Cognitive Stimulation Therapy and other proven interventions to maximise function ○ a long-term plan including referrals to ongoing services and supports • improve the design, quality and availability of the existing community and home-based services so they support people living with dementia/mate wareware to remain at home with autonomy, dignity, and independence • dementia/mate wareware navigation services to coordinate and support access to needed services including emergency support, so people have as smooth as possible a journey through the course of their dementia/mate wareware and get the services they need and that are right for them • support for family, whānau and care partners including information, education, support, and flexible, available and accessible respite services, including but not limited to: <ul style="list-style-type: none"> ○ In home

Objectives	Actions
	<ul style="list-style-type: none"> ○ Small group ○ Rural ○ Part and full day activities ○ Residential ○ Planned and urgent/as required <ul style="list-style-type: none"> ● Dementia/mate wareware information that is freely available, in accessible formats, and available in te reo Māori <p><i>Suggested lead organisation: Health NZ/Māori Health Authority</i></p> <p>Invest in a Māori mate wareware provider sector, and validate Māori models, tools and applications that are focused on:</p> <ul style="list-style-type: none"> ● improving health literacy ● assessment and management ● information in te reo ● Rongoā Māori ● Rongoā Mate Wareware (Māori adapted Cognitive Stimulation Therapy) ● nourishing wairua ● mate wareware navigation services ● support for tangata in adjusting to their changing roles

Objectives	Actions
	<ul style="list-style-type: none"> • invest in Māori mate wareware support groups • support for Māori dying with mate wareware <p><i>Suggested lead organisation: Māori Health Authority</i></p>
	<p>Work with palliative care and related partners in accordance with the Palliative Care and Healthy Ageing Strategy Action Plans to build capability and capacity in the health sector to better assist people dying with dementia/mate wareware</p> <p><i>Suggested lead organisation: Health NZ/ Māori Health Authority</i></p>
	<p>Work with mental health and related partners as part of the implementation of the recommendations from the He Ara Oranga: the Report of the <i>Government Inquiry into Mental Health and Addiction 2018</i>, so people with dementia/mate wareware and care partners do not miss out on the mental health services and support they need.</p> <p><i>Suggested lead organisations: Ministry of Health</i></p>
	<p>Start work with specific populations (for example, Pasifika/those living alone) to identify unique needs and develop solutions for each</p> <p><i>Suggested lead organisation: Health NZ</i></p>
<p>Build accepting and understanding communities</p>	<p>Support planned work by MSD and the Law Commission to review statutory mechanisms for decision making and consent with a view to shifting toward a supported decision-making model, with appropriate partnerships to explicitly identify and address the equity issues that arise for Māori whānau</p> <p><i>Suggested lead organisation – Ministry of Social Development</i></p>

Objectives	Actions
	<p>Improve understanding of dementia/mate wareware and ageing within Aotearoa New Zealand communities by promoting and supporting age and dementia/mate wareware friendly initiatives and programmes</p> <p><i>Suggested lead organisation: Health NZ</i></p>
	<p>Improve understanding of mate wareware and ageing in Māori communities supporting new Māori initiatives that:</p> <ul style="list-style-type: none"> • promote and link Māori whānau with the Mate Wareware App and link Māori whānau with the App • address negative stereotypes and stigma • provide people with the knowledge on how to care for their whānau member with mate wareware <p><i>Suggested lead organisation: Māori Health Authority</i></p>
	<p>Design and implement a multi-level, multi-channel campaign to raise awareness, increase understanding of dementia/mate wareware and tackle stigma and discrimination</p> <p><i>Suggested lead organisation: Health NZ</i></p>
	<p>Develop and implement a multi-channel campaign, purpose built to address Māori needs and thinking</p> <p><i>Suggested lead organisation: Māori Health Authority</i></p>
<p>Strengthen leadership and capability across the sector</p>	<p>Establish a national cross sector stewardship and leadership group that includes people living with dementia/mate wareware, sector NGOs, and the Mate Wareware Advisory Rōpū, with clear lines of accountability at locality, regional, and national levels to lead implementation of this Plan and monitor implementation</p> <p><i>Suggested lead organisation: Ministry of Health</i></p>

Objectives	Actions
	<p>Design agreed national indicators, measures, and standards for the dementia/mate wareware sector and roll out this process as part of the outcome measures work within the Healthy Ageing Strategy</p> <p><i>Suggested lead organisation: Health NZ/Māori Health Authority</i></p>
	<p>Establish human rights-based dementia/mate wareware and age friendly standards for delivering high-quality services for people living with dementia/mate wareware for primary care, home and community services, residential care and hospital, and other secondary care services in which providers demonstrate that they deliver best practice services and support for people living with dementia/mate wareware that:</p> <ul style="list-style-type: none"> • are human rights based and person-directed • are based on holistic frameworks such as Te Whare Tapa Whā • are culturally safe for Māori whānau, and for other ethnicities • reduce the use of antipsychotics and restraints in residential care <p><i>Suggested lead organisations Health Quality and Safety Commission</i></p>
	<p>Develop and implement a workforce strategy that addresses both the immediate capacity and capability issues and the long-term growth needs of the dementia/mate wareware and aged care sector, recognising the impact of the ageing workforce, so there are enough appropriately skilled and qualified people available when needed</p> <p><i>Suggested lead organisation: Ministry of Health (Workforce)</i></p>
	<p>Develop and implement a workforce strategy that increases and retains the number of Māori health practitioners working in the mate wareware sector, and increases the capacity and capability of Māori health providers to deliver mate wareware services</p>

Objectives	Actions
	<i>Suggested lead organisation: Māori Health Authority</i>
	<p>Improve training support for best-practice medical care, disability and social support services and make this education more available across all parts of the dementia/mate wareware and aged care sector, home and community care, primary care, and within the core health service so all health sector practitioners and providers can deliver informed, best practice, tailored, culturally safe, and person-centred services and support</p>
	<i>Suggested lead organisation: Ministry of Health (Workforce)</i>
	<p>Increase investment in research on dementia/mate wareware, in particular on the epidemiology of dementia/mate wareware, on culturally appropriate ways of describing and approaching dementia/mate wareware for tangata whenua and within Aotearoa New Zealand, on what works to support people living with dementia/mate wareware</p>
	<i>Suggested lead organisation: Ministry of Health/Health Research Council</i>
<p>Increase investment to grow the number of Māori researchers working in mate wareware</p>	
<i>Suggested lead organisations: Ministry of Health/Health Research Council</i>	

Enablers

Successful implementation of this plan relies on:

- **Government allocating sufficient financial resources** that meet the identified service needs and are allocated equitably across the whole continuum of care, including prevention, primary care, community and home support, residential care, and end of life care, together with better and more flexible funding options to support family, whānau and care partners.
- **Partnership with tangata whenua** including participation of Māori in the national leadership group and strengthened links with the Māori health provider sector, Māori health practitioners and Māori researchers.
- **A knowledgeable, skilled, valued, and supported workforce** across the sector and health system as a whole – significant investment across the whole workforce is needed to achieve this. A strategy is also needed to recruit and retain the growing workforce of appropriately skilled and qualified people the sector will need as the number of people living with dementia/mate wareware grows.
- **Stronger links across the dementia/mate wareware sector**, including primary care, secondary care and specialist care, community and home-based care, residential care, palliative care, mental health and first responders – to improve quality, and support comprehensive and integrated services throughout the course of the dementia/mate wareware journey.
- **A partnership-focussed commissioning model** that recognises the differing requirements of the very diverse dementia/mate wareware sector combined with flexible funding arrangements for individuals, family whānau to support choice and person-centred care.
- **Systematic, routine tracking and population-level monitoring of a core set of dementia/mate wareware indicators** to guide evidence-based actions to improve services, drawing on both international research and Aotearoa New Zealand specific research, and to measure progress towards implementing the actions in this Plan.

- **Related work in other sectors proceeding,** including:
 - flexible funding options for care partners under the Carers Strategy Action Plan
 - implementation of the recommendations from the Welfare Expert Advisory Group in relation to benefit levels
 - review of the Protection of Personal and Property Rights Act relating to consent and decision making.

What is this Plan based on?

This Plan is based on the information, evidence and research outlined in:

- *Convention on the Rights of Persons with a Disability (2008)*, United Nations
- *Declaration on the Rights of Indigenous People (2007)*, United Nations
- *Aotearoa New Zealand Framework for Dementia Care (2013)*, Ministry of Health
- *Aotearoa New Zealand Dementia Summit, Final Report (2016)*, NZ Dementia Cooperative, Carers NZ and Alzheimers NZ
- *Dementia Economic Impact Report (2021)*, University of Auckland for Alzheimers NZ
- *Dementia prevention, intervention, and care (2017)*, Lancet Commission
- *Dementia Prevention, Intervention and Care: 2020 Report of the Lancet Commission*, Lancet Commission
- *Differences in the potential for dementia prevention between major ethnic groups within one country: A cross sectional analysis of population attributable fraction of potentially modifiable risk factors in New Zealand (2021)*, The Lancet Regional Health – Western Pacific
- *HAUORA: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry (2019)*, Ministry of Health
- *Whakamaua Māori Health Action plan 2020-2025 (2020)*, Ministry of Health
- *Mate Wareware: Understanding 'dementia' from a Māori perspective (2019)*, Dudley, M., Menzies, O., Elder, H., Nathan, L., Garrett, & Wilson, D.
- *Global Action Plan on the Public Health Response to Dementia (2017)*, World Health Organization
- *Awareness and perceptions of dementia (2018)*, Summerset and *Awareness and understanding of dementia in Aotearoa New Zealand (2017)*, Alzheimers NZ
- *Care Needed: Improving the Lives of People with Dementia (2018)*, OECD
- *Dementia Declaration: Our Lives Matters (2019)*, Alzheimers NZ Advisory Group

- *This is our Story: A qualitative research report on living with dementia (2019)*, Litmus Research for Alzheimers NZ
- *InterRAI (various)*: aggregate published data from the interRai assessments
- *National Dementia Stocktake Report (2020)*, District Health Boards
- *The New Zealand Health and Disability Services (General) Standard (2007)*, Standards NZ.

The Plan was also refined and improved based on the feedback received during the consultation on a draft of the Plan released for comment in late 2019 (see Appendix 1).

Appendix 1 - Who developed this Dementia/Mate Wareware Action Plan?

Alzheimers NZ and the NZ Dementia Foundation facilitated a workshop in May 2019 to develop the draft Dementia Plan and invited:

- Alister Robertson – Alzheimers NZ Advisory Group member and person with dementia
- Matthew Croucher and Shereen Moloney, NZ Dementia Foundation
- Paul Sullivan and Anne Schumacher, Dementia New Zealand
- Sarah Cullum, University of Auckland
- Jane Large, Andrea Bunn, Elaine Plesner and Lesley Maskery, District Health Boards
- Maria Scott-Multani, Arvida Group
- Catherine Hall and Jean Gilmour, Alzheimers NZ

This group then worked together to develop the Dementia Plan seeking input from their respective communities of interest and working alongside the Ministry of Health.

The Draft Dementia Action Plan was circulated for comments within the dementia/mate wareware sector in early November 2019, with comments closing at the end of January 2020.

The consultation incorporated a broad range of stakeholders through recruitment networks, including people living with dementia/mate wareware and their care partners, health, allied health and other professionals with an interest in dementia/mate wareware, District Health Boards, national professional organisations and networks, and local and national community networks and groups. There were 358 responses to the online consultation. An additional 14 individuals or organisations provided feedback outside this channel, and a further 25 individuals provided feedback specifically on their experience with Cognitive Stimulation Therapy.

In mid-2020 Alzheimers NZ, Dementia NZ and the NZ Dementia Foundation partnered with tangata whenua to establish the Mate Wareware Advisory Rōpū to provide insight into the experience, needs and expectations of whānau living with mate wareware. The Rōpū developed a Mate Wareware Action Plan in 2021 and suggested that it be incorporated into the existing Dementia

Action Plan. The Dementia NGOs and the Rōpū worked together to produce this integrated Plan.

Members of the Mate Wareware Advisory Rōpū are:

- Waiora Port
- Makarena Dudley
- Oliver Menzies
- Cheryl Collier
- Beryl Kaa
- Pare Meha
- Lesley Morrison
- Bobby Nepia
- Treasure Thomas-Egglestone
- Susan Turner
- Ngāwai Herewini

Teresa Wall was co-opted onto the rōpū pending full membership, to assist in the development of the Mate Wareware Action Plan